Group Therapeutic Model on Family Needs of Children with Intellectual Disability

[1]Ms. Torsa Das, [2]Mrs. Rupa Chakraborty

[1]Psychiatric Social Worker, [2]Psychiatric Social Worker and Special Educator
Department of Psychiatry & De-addiction Centre
Base Hospital, Barrackpore, West Bengal, India

Abstract

Background- Intellectual Disability, formerly known as Mental Retardation, can be caused by a range of environmental and genetic factors that lead to a combination of cognitive and social impairments. In DSM-5 various levels of severity of intellectual disability are determined on the basis of adaptive functioning, not on IQ scores. Intellectual Disability does not improve, although the level of adaptation increases with age and can be influenced positively by an enriched and supportive environment.

Assessment & Management- 12 children with intellectual disability disorder and their both parents who were attending outpatient department in a tertiary mental health care set up in Kolkata, West Bengal for treatment were taken for the structured group therapy sessions through criteria based purposive sampling. Semi Structured Socio Demographic Performa and Clinical Data Sheet, NIMH family needs schedule were used for assessment before starting the management.

Outcome- After intervention through group therapy sessions inter-personal issues between parents, their family need along with children's individual needs were significantly minimized.

Conclusion- Positive interaction with parents and group facilitators is helpful to provide support and proper guidance to manage their children with intellectual disabilities and it also helpful for open up and discuss own feeling and problems which not only relieve their stress, group facilitators assist them to sort their interpersonal issues as well .

Keywords: **Group Therapy, Intellectual Disability, Family need, Parents.**

I. INTRODUCTION

According to **American Association on Intellectual and Developmental Disabilities** (formerly known as Mental Retardation), **Intellectual Disability** 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 severity of the disorder determined by the number and degree of functioning that are affected and impaired [3]. Types of category is seen in Mental Retardation based on the IQ level, mild mental retardation (IQ-50-69), moderate mental retardation (IQ-35-49), severe mental retardation (IQ-20-34), profound mental retardation (IQ-under 20), other mental retardation, unspecified mental retardation [2].

The term 'Mental Retardation" is replaced with 'Intellectual Disability' by federal statute in the United States (Public Law 111-256, Rosa's Law). According to DSM-5, diagnostic criteria for Intellectual Disability are as follows:

1. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience, confirmed by both clinical assessment and individulaised, standardized intelligence testing.
2. Deficits in adaptive functioning that result in failure to meet developmental and socio cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limits functioning in one or more activities of daily life, such as communication, social participation and independent living across multiple environments such as home, school, work and community.
3. Onset of intellectual and adaptive deficits during the developmental period. [10].

The skill of Intellectual Disability may improve, by adaptive skill training with proactive environment .

According to NSS report no 583, statistical profile of persons with intellectual disability in India is 0.2% male and 0.1% female in both rural and urban area. In West Bengal 0.2% male, 0.1% female in both rural and urban area [9].

Group therapy is the form of treatment practiced in which a group of people with same problems are treated together by trained professionals using therapeutic principles. Through involvement in group therapy session, children can learn how to interact with others in the society. Group therapy not only serve many people at a time but also helpful for treating child with conduct problems as caregivers gained skills to manage their children's disruptive behaviour and increase positive parenting skills (includes praises, reflections and behavioural description) and decrease negative parenting (include criticism, questions and commands) [8].

Family are the key teachers, socializing agents and care givers for their children during early years. Generally primary care givers refer to the **parents** who have the greatest responsivity for daily care and rearing of a child. The role of parents of a child with Intellectual Disability is not an easy job. They have variety of family needs present for every parent for fostering their children. Family needs includes Poor knowledge, medical needs of the child, and stress reaction or other behavioral problem of child with Intellectual Disability. Disability [4]. During 60s & 70s, some dedicated parents formed parents' associations in Bombay, Ahmedabad & Bangalore which working for the welfare of Mental Retardation and provide them with many facilities for their education, trained them to be independent as possible and including them in mainstream society [6]. Cultural beliefs, negligence, lack of sensitization and technical skills among parents are the major cause of low enrollment in school of intellectual Disable children [5]. **Family** of the intellectual disable perceived that support group beneficial for understanding and helping their child

rearing as well as acquire information and also fulfilled other family needs from group members which is valuable for them to ease their uncertainties and create productivity for child empowerment [4] . The present study conducted with the purpose to find out the effectiveness of group therapeutic model in tertiary mental health care set-up for reducing the individualized family needs of family of children with Intellectual Disability Disorder.

II. METHODOLOGY

Design: One group pre test-post test quasi experimental study design.
Variables: Independent Variable- Group Therapeutic model
Dependent Variable- Individualized family needs
Population: All parents who are attending with their Intellectual Disable child for treatment in outpatient department in a tertiary mental health care set up in Kolkata, West Bengal.
Sample size: 12 children with intellectual disability disorder and their both parents.
Sampling method: Criteria Based Purposive Sampling
Details of the group:

- A group therapy session was held from April to Sept in a tertiary mental health care set up in Kolkata of West Bengal on working 4 days in a month.
- Duration- 1.5 hr.
- No age criteria followed for the parents of the children with Intellectual Development Disorder.
- Type of Group: Close group.
- Category: Mild to moderate

Participants & Procedure: Parents of Intellectual disable child who are attending the outpatient department in a tertiary mental health care set had taken up for study by using purposive sampling technique. 12 participants (both male and females were included in the study) aged between 8 years – 16 years, diagnosed by registered psychiatrist and also fulfilling the diagnostic criteria would be included in the study. Trainee researcher explained the norm and regulations, purpose of group therapy, socio demographic details and clinical data were taken by Semi structured socio demographic and clinical data sheet which were designed by the trainee researcher by using semi structured Performa. A scale (NIMH family needs schedule), after taking verbal and written consent, was administered for identification of problems and making session's plans. If the participants lived alone or had chronic physical, neurological illness or any other form of disability or psychiatric co morbidity were excluded and the parents should had the physical custody of the children and lived with them since childhood. If any caregiver or parents have any kind of physical and psychiatric disorder were excluded from the study. After treatment again the same scale administered for checking the progress and therapy sessions terminated accordingly. After data collection, appropriate coding and statistical analysis had done accordingly.
Hypothesis: There will be significant effect of group therapeutic model in reducing the individualized family needs of parents or family of children with intellectual disability disorder.
Questionnaire and measurement scales: We used Semi Structured Socio Demographic Performa and Clinical Data Sheet, NIMH family needs schedule.

1. **Semi Structured Socio Demographic Data Sheet:** Semi structured proforma was designed by the trainee researcher of general information about the responders such as age, sex, occupation and domicile of the persons with intellectual disabilities and other information according to the need of the need.
2. **Semi Structured Clinical Data Sheet***:* Semi structured proforma was designed by the trainee researcher including family history, name of the medicine if present etc.
3. **To identify the need of the parents (NIMH Family Needs Schedule):** The scale is developed by Reeta Peshawaria, D.K Menon, Rahul Ganguly, Sumit Roy, Rajam P.R.S Pillay, Asha Gupta. It consists of three schedules- for parents, siblings and grandparents. The scale has three-point rating- Very Much-2, Little-1 and No Need-0. We used the schedule of parents here which covers 15 areas with 45questions.

Statistical Analysis:

- In this study, descriptive statistics – mean, standard deviation was used.
- Single sample T-test was used to test the hypothesis.
- Collected data was coded and analyzed with the help of Statistical Package for Social Sciences (SPSS) version 25.

III. THERAPEUTIC DETAILS

Initial Phase (Session 1-3): All members were included in the group sessions after administering the scales individually. On the first session group members were introduced with each other and with the facilitators to make them ease so that they could share their problems in front of everyone. Purpose of the group was explained properly and provide orientation. To maintain the compliance group norms and regulations were explained. Initially group members were psycho educated about the disorder. Informative counseling about the disability certificate and its benefits. Parents were always encouraged to share their feelings, queries and feedback during the sessions. Initially child's problem behavior and skill behavior were explored and prioritized behaviors according to their severity and need for remediation. At the same time family dynamics, expressed emotion were explored. All the outcomes and findings were shared with the group members for safeguarding and promoting welfare of the child, boost self esteem and confidence in the parents and most important parents gain a sense of belonging and acceptance in the group.

Identified problem behaviour in children were
• Anger outburst
• Stubborn
• Beating others
• Poor academic skill
• Poor self help skill
• Restless
• Disobedient
• Poor socialization
• Poor attention and concentration

Middle Phase (Session 4-10): In this phase, group intervention was done according to the findings.

Skill training were done including self help skill (brushing teeth**,** bathing, button and unbutton clothes and eat by himself, combing), communication skill (gestural communication, maintaining eye contact), motor activities (both gross motor and fine motor) through modeling, verbal prompting and physical prompting, gestural prompting with different task assignments. Along with explaining the tasks parents were oriented about positive reinforcement and negative reinforcement to reinforce the newly acquired behaviour and change the reinforcements with time so that they would not get bored with them as well as create awareness in the parents regarding their role in training of their children. Parents could reinforced the child's new behaviour step by step through shaping or broke a complex task into a no of small steps and each steps was taught to the child through chaining, these would be helpful in increasing their motivation. For decreasing the undesirable behaviour (Aggressive & Disruptive behaviour), facilitator introduced punishment. time out, hand lock, extinction, over correction. To improve their academic skills, identify colours and body parts, alphabets and numbers were introduced to the children and their parents. And suggest them to practice through the teaching strategies- matching, identification and naming after making two sets of flash cards. When the children properly mastered the given tasks, facilitators moved towards the functional academics which would be used by the children for the rest of their life like their name, address, survival words (danger, poison), identify coins and notes, road signals. After mastering the body parts trainee therapist introduced sex education including good touch and bad touch as children with intelletual disabilities were most vulnarable to the harrashment because some people took adavantage of them. In every session child's progress was monitored and it was also checked that the parents maintained a copy where they could write the instructions properly.

Targeted behaviour after prioritization of problem behaviors
• Poor self help skill
• Aggressive and disruptive behaviour
• Poor academic performance
• Poor socialization

Family assessment including exploring interactive patterns, burden, boundary, support system, expressed emotion of the child and his/her family members was done.

Common identified problem in family dynamics and expressed emotion were
• Role multiplicity in mothers of children with intellectual disability,
• Illness and emotional burden,
• Inadequate primary support,
• Negative expressed emotion in the form of critical comment and hostility due to inability of doing any work and over involvement as some parent did not allow their children to do any work and do all works on behalf of the children.

To improve interpersonal relationships within families and their parents, decrease role burden and improve the primary support system and expressed emotion facilitator applied some family therapy techniques like guided discovery, contracting and reinforcement technique. To decrease the illness burden, applied guidance technique. loving days applied to improve the cohesiveness in the family where pleasurable behaviors to other family members had to increase on specified days and eat food together at least for a one time in a day, contingency contract with those parents who did not follow the assigned home task in the previous sessions with the goal of positive interaction with other family members and also focused role structuring as children's responsibilities were equally divided to both parents and the children would also get the opportunity to spend time with both of his/her parent which also decrease the role burden of mothers. Group therapy techniques concentrates on every individual domain of family needs

Terminal Phase (Session 11-12): At this part, trainee therapist reevaluated parents or family needs and identified problems with the help of scale administration in group and summarized results of intervention and their previously discussed problems. Effective feedback was taken from the group member. parents were addressed and advised them to continue the techniques and works which they had learnt from the session. Group members were thanked for their good compliance & effort for the progress of the children. Good byes and appreciative remarks and reinforcements for children and their parents end the sessions.

IV. RESULTS:

TABLE: - 1

SOCIO DEMOGRAPHIC PROFILE OF CHILDREN WITH INTELLECTUAL DISABILITY DISORDER

VARIABLES	CATEGORIES	CHILDREN WITH INTELLECTUAL DISABILITY DISORDER Frequency (%) Mean ±SD [*n*=12]
Age (years)		10.58±3.02
Sex	Male	9(75%)
	Female	3(25%)
	Others	-
Age of parents (years)	Mother	32.91±5.01
	Father	39.25±4.35

TABLE: - 2

PRE-POST QUANTITATIVE MEASURES OF NIMH-FAMILY NEED SCHEDULE FOR PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY DISORDER

SL NO	DOMAINS	PRE TEST DATA Mean ±SD [*n*=12]	POST TEST DATA Mean ±SD [*n*=12]
1.	**Information Condition**	8.92±2.275	4.58±2.429
2.	**Child Management**	11.08±2.843	5.92±2.353
3.	**Facilitating Interaction**	2.58±2.843	1.00±2.892
4.	**Services**	7.58±2.678	.50±.798
5.	**Vocational Planning**	1.50±.674	1.25±.965
6.	**Sexuality**	1.50±.674	.75±1.545
7.	**Marriage**	.83±.937	1.83±1.992
8.	**Hostel**	1.08±1.676	1.58±.996
9.	**Personal Emotional**	4.92±2.778	.25±.622
10.	**Personal Social**	1.33±1.670	2.33±1.923
11.	**Support Physical**	1.42±1.881	1.08±.996
12.	**Financial**	4.83±3.950	1.75±1.288
13.	**Family Relationship**	2.42±1.881	3.67±.651
14.	**Future Planning**	2.92±1.165	3.00±2.089
15.	**Government Benefits And Legislation**	3.67±.778	1.58±.669

TABLE: - 3

PRE-POST TREATMENT COMPARISON DETAILS OF FAMILY OF CHILDREN WITH INTELLECTUAL DISABILITY DISORDER

SL NO	DOMAINS	Mean	Std. Deviation	t	df	Sig(2-tailed)
1.	**Information Condition**	4.333	3.172	4.733	11	.001
2.	**Child Management**	5.167	3.157	5.668	11	.000
3.	**Facilitating Interaction**	1.583	4.542	1.208	11	.253
4.	**Services**	4.583	2.746	5.783	11	.000
5.	**Vocational Planning**	-.083	1.084	-.266	11	.795
6.	**Sexuality**	.250	1.215	.713	11	.491
7.	**Marriage**	.333	1.497	.771	11	.457
8.	**Hostel**	.333	2.188	.528	11	.608
9.	**Personal Emotional**	3.083	2.109	5.065	11	.000
10.	**Personal Social**	-.250	2.221	-.390	11	.704
11.	**Support Physical**	1.167	2.082	1.941	11	.078
12.	**Financial**	2.500	4.964	1.745	11	.109
13.	**Family Relationship**	1.333	2.103	2.196	11	.050
14.	**Future Planning**	1.167	2.082	1.941	11	.078
15.	**Government Benefits And Legislation**	.000	1.128	.000	11	1.000

TABLE: - 4
QUALITATIVE MEASURES OF GROUP THERAPY ACROSS THE GROUP

SL NO.	MEASURES	POST INTERVENTION
1.	Behavioual problem	Decreased
2.	Gross motor activity	Improved
3.	Fine motor activity	Improved
4.	Poor social skill	Improved
5.	Poor Academic performance	Improved
6.	Parent involvement	Increased
7.	Self Help skill	Improved
8.	Family problems	Decreased

V. DISCUSSION

Table 1 shows the socio demographic profile of children with intellectual disability disorder. It is seen that mean age of children attended group therapy is 10.58+3.02yrs and majority of them were male. In west Bengal males are more affected by this disorder than females [9].

Table 2 shows the pre-post quantitative measures of nimh-family need schedule for parents of children with intellectual disability disorder. Parents of mildly retarded children want more information about preventing and adjustment nature whereas parents of moderately retarded children were more concerned with lifelong adjustment and financial security including government help for their child [12]. It is seen from the table that before the group therapy session most of the parents stated the need of information condition, child management, government benefits and legislation for their children. In rural areas of West Bengal 15.5% children, in case of urban areas 11.0% children received any assistance aid or help from government, 1.6% children of rural area and 2.3% children of urban area received assistance from other organization [9].

Table 3 shows pre-post treatment comparison details of family of children with intellectual disability disorder. It can be seen that after group therapeutic session there is significant effect on individualized need of family of children with intellectual disabilities. So the hypothesis is accepted.

Government funding to schools for supporting educational program of learners with mental retardation was not adequate, majority of teachers and parents were not well trained in managing them [5].

Level of psychosocial problems faced by the parents of Mentally Retarded children increases with the level of intellectual disability [12]. Family Stress affected by child's challenging behavior and disruption of family routine as a result of the child's disability, therefore they need professional support to reduce the level of parental stress [11] in these group session behavioural management therapy along with parent management training and psychosocial intervention delivered as per the need of the parents and clients.

In table 4 shows qualitative measures of group therapy across the group. It can be seen that behavioural problem remarkably decreased along with family problems. Parents of children with intellectual disability need to both be understood and obtain information, parents in supports group with others parents facing similar challenges get an opportunity to learn from others and help others [4] improved children's behavioural problems as a result of gained skills over time after participating in group therapy. Caregivers demonstrated an improvement in their parenting skills from pre-post treatment such as decreased inappropriate behaviour such as negative or critical statements and increase of using prosocial behavior such as praise and positive attention [8]. Positive parenting program used for reducing behavioural problems in children and promoting the mother child relationship through offering information about various needs of mothers as well as children, mother-child interaction, family functionin and parenting styles. Parents of IDD need more intensive parenting program and family therapy. Interpersonal relationship are affected by challenging behaviour of their own children and low cooperation of fathers. Parents could better understand the children's problem by accessing new information and acquiring the behavioural management skills [1]. In some families having female mentally retarded child was more significantly more stressful than male child with the disorder [7].

VI. LIMITATION

- ✓ Only mild to moderate children were included which provides little basis for generalization.
- ✓ There was no control group.
- ✓ There was no homogenesis in case of domicile and educational qualification, economic status of the parents.
- ✓ The study was conducted for few months; therefore, it was not able to observe the complete recovery.
- ✓ Male female ratio was not equal.
- ✓ Purposive sampling limits the generalization of the study.
- ✓ Co morbidity in parents not assessed.
- ✓ The study was conducted in a population of a tertiary mental health care system, so it limits generalization in other culture or population.

VII. FUTURE DIRECTION

✓ Through the group therapy session, parents were oriented towards their chilren's skills and performance, which will help them to take appropriate training decisions in future.

✓ Improvement in social skills will help the children to mix with their same age peer group.

✓ Parents are orieneted towars the evedence of some specific problem that require tratment, even they can psycho educate other parents and let them know about treatment procedures who have children with special needs..

✓ A good environment in home help the children to flourish and progress in future.

✓ Parents aware of their own strength as well as their chilren's strength and skill. So they have the motivation and realisation that they can take their children's responsibility and take care of them.

✓ The study can be taken further with larger sample size with random sampling method with equal number of male and female.

✓ Closer and longitudinal study may provide the closer and clear picture of the needs of the parents as well as the children.

✓ A comparative study will be conducted between any other developmental disorder.

✓ Cross sectional studies can be done with other population or culture to confirm the findings.

CONCLUSION

Family has the single most important in child's life. From their first moments of life, children depend on parents or care givers. Parents play a vital role in the training and development of the children with intellectual disabilities. They considered as leading mentor for the children in their early life as well as later life. So working with the parents or caregivers of the children and their need, we can indirectly intervein with the children as well. Through the group therapy sessions, family members enhanced their knowledge which helped them to cope better and increase the chance of wellbeing of the children with the intellectual disabilities which depend upon positive environment in home and proper behaviour with them.

VII. METHODOLOGICAL CONSIDERATION

They informed about the session structure of group therapy. They were assured about maintenance of their confidentiality of sharing intimate details. Verbal consent was taken from them for sessions and written consent were taken for administering scales.

VIII. FINANCIAL SUPPORT AND SPONSORESHIP

None.

IX. CONFLICT OF INTEREST

None

REFERENCES

[1] Ashori.M, Norouzi.G, and Jalil-Abkenar.S.S, "The effect of positive parenting program on mental health in mothers of children with intellectual disability", Journal of Intellectual Disabilities, pp.1-12, 2018, doi:10.1177/1744629518824899.

[2] "International Classification of mental and behavioural disorders: Criteria for Research" (10th ed.) Geneva: World Health Organization.pp.225-231.

[3] Jackson.J,B, and Roper.S,O, "Parental adaptation to out –of-home placement of children with severe or profound developmental disabilities", American Journal on Intellectual and Developmental Disabilities,pp.119,203-219, 2014, https://doi.org/10.1352/1944-7558-119.3.203.

[4] Jackson.J.B, Steward.S.R, Roper.S.O, and Muruthi.B.A, "Support group value and design for parents of children with severe or profound intellectual and developmental disabilities",Journal of Autism and Developmental Disorders, 2018, https://doi.org/10.1007/s10803-018-3665-z.

[5] Joseph.G, and Muthee.J, "Role of parents in education of mentally retarded learners in selected school in Madaraka zone, Kiambu country, Kenya", Journal of Education & Practice, vol.7, issue no.3, pp.19-24,2016.

[6] "Mental Retardation", Rehabilitation Council of India, Chapter.9, pp.278.

[7] Morya.M, Agarwal.A, Upadhyaye.S.K, and Sharma.D.K, "Stress and Coping Stratgies in Families of Mentally Retared Children", Journal of Evolution of Medical and Dental Sciences, vol.4, issue no.52, pp.8977-8985,2015, doi:10.14260/jemds/2015/1303.

[8] Nieter.L, Thornberry.T Jr, and Brestan-Knight.E, "The effectiveness of group parent-child interaction therapy with community families", Journal of Child and Family Studies, 2012, doi:10.1007/s10826-012-9601-5.

[9] "Persons with Disabilities (Divangjan) in India- A Statistical Profile: 2021", Government of India, Ministry of Statistics and Programme Implementation, pp.164-165, 225, www.mospi.gov.in .

[10] Sadock.B.J, Sadock.V.A, and Ruiz.P, (ed), "Synopsis of Psychiatry", (11th ed), Wolters Kluwer, pp.1120,2015.

[11] Sharma.D, Kumar.M, and Gunthey.R, "Family Efficacy of children with intellectual impairment", https://ejid.name/files/148/article-02-11.pdf .

[12] Upadhaye.S, "Psychosocial problems and needs of parents in caring mentally retarded children: The impact of level of intellectual disability of children", Indian Journal of Social Science Researches, vol.6, issue no.1, pp.103-112, 2009.

,