



A STUDY ON THE PROBLEMS FACED BY THE PARENTS IN HANDLING THE MENTALLY CHALLENGED CHILDREN IN MANGALORE DISTRICT

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Abstract

The attitude of the people has taken a positive turn towards mentally retarded or the challenged, the new modern technical word 'Special Children' due to increased knowledge, awareness due to higher education and the societal initiatives. People with such disabilities are often not seen as full citizens of society. Person-centered planning and approaches are seen as methods of addressing the continued labeling and exclusion of socially devalued people, such as people with disabilities, encouraging a focus on the person as someone with capacities and gifts as well as support needs. The researchers aim at assessing the knowledge of the parents regarding the mental retardation and the psycho-social, economical problems they face.

Keywords: Attitude, Problems, Retardation.

1.0. Introduction

For an understanding of the behavioural and psychological problems of childhood, it is essential to know the normal patterns of child development. Every person born in this world is not similar to the other, although no two children are alike; there are general similarities in the mental and physical development of all normal children.

The attitude of the society towards mentally challenged has changed in the positive direction in this modern world where people are living with increased knowledge, higher education, awareness about the complications in the field of medicine and other technological development. People have become more sympathetic and considerate. There are various Organizations, private Institutions and Government initiatives to take care of the special children with special and utmost care. Recently, there have been vigorous changes in the attitude and of late several institutions and special schools have been opened for the training of the retarded. The first organized programme for the mentally challenged was started in 1837 by a French Psychiatrist named Seguin. The first schools for such children was opened in Massachusetts in 1848, followed shortly by another school in New York and then in Pennsylvania and the first professional organization now known as the American Association on Mental deficiency was started by Medical Officers of Institutions in 1876 (Girishbala Mohanty 2002). In India, the first institution for mentally challenged was started at Mumbai in 1941. Mangalore city in Karnataka has seen the developmental milestone in its history. St. Agnes Special School which was started in the year 1970 run by the sisters of Apostolic Carmel, has become a huge tree which shelters 300 special children and has brought crown to the city of South India. They have been working for the welfare of the special children and their families which are in distress due to the stigma of having a special child in the family. There are now many schools which are working for the welfare of the mentally challenged children.

There are thousands of agencies around the world that provide assistance for people with developmental disabilities. They include state-run, for-profit, and non-profit, privately run agencies. Within one agency there could be departments that include fully staffed residential homes, day rehabilitation programs that approximate schools, workshops wherein people with disabilities can obtain jobs, programs that assist people with developmental disabilities in obtaining jobs in the community, programs that provide support for people with developmental disabilities who have their own apartments, programs that assist them with raising their children, and many more. There are also many agencies and programs for parents of children with developmental disabilities.

1.1 Meaning of Mental Retardation

The American Association of Mental Retardation [AAMR] defines "Mental Retardation as a significantly sub average general intellectual functioning resulting in or associated with concurrent impairment in adaptive behaviour and manifested during the developmental period" (R. Sreevani 2010).

Mental retardation according to English law is a condition of arrested or incomplete development of mind existing before the age of 18 years whether arising from inherent causes or induced by disease or injury (Mental Deficiency Act 1929). According to Tredgold (1937) "it is state of incomplete mental development of such a kind and degree that the individual is not capable of adopting himself to the normal environment of his fellow in such a way to maintain existence independently of supervision, control or external support."

Page (1976) in his book *Abnormal Psychology* calls mental retardation as Mental deficiency. He writes that mental deficiency is a condition of subnormal mental development, present at birth or early childhood and characterized mainly by limited intelligence and social inadequacy.

S.K. Mangal in his book *Abnormal Psychology* reveals that:

1. Mental retardation is a condition or state of mind.
2. It is not a disease or illness of the mind
3. It is related to the subnormal development of the mind or brain.
4. It is also related to one's inadequate adjustment with the environment.
5. The deficiency may be observed at birth or in early childhood.
6. Both the inherent and external factors may cause mental retardation.

Being a parent has never been an easy task. It is 24 x 7 round the clock and has no reward for having this untiring job. Parenting is the job with no preparations and training. Have no leaves; either the casual or sick leave. No bonus or increment for the work and yet parents especially those who have mentally retarded or special child have to be like the machine. AKKOK (1996) reported that children with mentally challenged have special needs that require more attention, greater vigilance and effort from parents than normal children. Chronic illness in childhood has massive physical social and physiological effects on families who are expected to raise the social adaptive child with special needs. Psychosocial [how parents and children mentally adapt social situations] issues of parents and children with retardation can be very traumatic for most parents. Psychological aspects, influences parents and family factors all contribute to a healthy child with special needs.

1.2 Problems Faced By Parents of Mentally Challenged Children

Whether the special needs of the child are minimal or complex, the parents are inevitably affected. They may receive assistance from family, friends and the community or the paid caregivers but it is difficult task of maintaining balance in the home. Parents with special children go through psychological, emotional, spiritual and physical trauma all throughout during their lifetime. There are various problems faced by parents of such special children.

1. *Acceptance*: When the parents are informed by the child specialist, doctor or a counsellor, they are not ready to accept that the child is special. It is too painful for most parents to accept. Since many of them find it difficult to accept, they live in a phase of denial and try to find solution or cure for this incurable problem by visiting many doctors or sometime they may also go to the black magicians or fortune tellers to find out why it has happened to them or whether they have any solution for the problem. Their dreams and aspiration for their child is shattered once they come to know that they cannot do anything rather they need to accept the fact that their child is a special child.
2. *Self-blame*: Most of the parents develop guilt and sometime they start thinking whether they have committed any mistake that their child has to suffer. They wonder if God is punishing them for their past sins. Sometime they may also get into depression if they think that their sins are the reason for their child to suffer.
3. *Social Stigma*: Having mentally retarded or special child in the family is something to be ashamed. Many parents do not go out for any public gathering or celebrations by the family as they fear that the neighbours, relatives and other known people might make cruel remarks about the child or may make them feel more with their sympathies targeting the condition of the child. This sometimes make the parents feel guilty about their past and might feel isolated and without any support from the family, relatives or the community.
4. *Behaviour Problems*: Special children are unable to concentrate, aggressive in nature and stubborn and parents of such children find it difficult to hand such behaviour problems of the children. Patience can wear thin for parents especially mothers who have to manage both household chores and outside jobs. Children of such intelligence will not know why the parents are angry with his/her behaviour.
5. *Physical exhaustion and stress*: Physical exhaustion can take a toll on the parents of a mentally retarded child. The child may be needed a close watch to avoid any inadvertent self-harm such as falling down from the stairs or walking on the street. Sometimes the child needs to be monitored closely for bathing, feeding, moving around in the house or around, or even changing of diaper and clothes. This is a difficult task for someone who is overweight and not in a position to handle himself /herself. These additional responsibilities can take a physical toll on a parent, leading to exhaustion. This can be a cause of burnout to the parents.
6. *Socio-Economic Problems*: Socio economic problem faced by the parents like low social status, stigma, social isolation negligence, lack of facilities, low financial status, lack of social contact, independence. Children with disabilities are often not seen as full citizens of society. They are unfit to do any jobs in the society and so they are considered as burden to the society or useless and unwanted persons in society. These problems bring down the coping ability of the parents. Raising a child with a mentally retarded may be more expensive than raising a typical child. These expenses can arise from medical equipment and supplies, medical care giving expenses, private education tutoring, adaptive learning equipment or specialized transports.
7. *Marital/Family Problems*: Having a child who is mentally retarded places greater strain on a family. Due to the extra tasks that have to be done to take care of the child, parents feel overworked, stressed out and unhappy. The marital relationship can become strained if the parents have different approaches in dealing with the child or if one parent has to take care of the child all the time. Sometimes the mothers might feel that they are not getting enough support from their husbands in taking care of the child and fathers might feel that the wives are unnecessarily worried and too protective of their child.

8. *Helplessness*: Helplessness of the parents comes both from a lack of knowledge regarding the retardation and a lack of information about the resources available for mentally retarded. Many parents find it difficult to take care of the child and they are not aware of the assistance by the Government and various NGO's for the welfare of the mentally retarded children. Helplessness also arises from insensitive handling of the case by the mental health professionals who might not have enough time to assistance the families and give them psycho-education.
9. *Emotional Problems*: Parents of mentally retarded children face lot of emotional problems like stress, fear of taking care of their children after their death, fear of losing them, fear of the people who make these children victim of abuse sexually or physically. Some of the parents commonly experience a gamut of emotions over the years. They often struggle with guilt and sometimes they may feel that they are reason for their child to be the victim of their selfishness. This guilt can harm the parents' emotional health if it is not dealt properly. Most of the parents have dreams of their child before it is born. They want their child to be a star in the competitive world but when they see the child with inabilities their dreams are shattered and they cannot compromise with the reality. Such parents either become protective of their child or develop a total neglect towards that child.
10. *Worry about the future*: one of the main concerns of parents with mentally retarded children is about how their child will be taken care of when they die. They feel that no one else can take care of their child with same love and care that they have and they are scared about how their child will be able to manage to survive in the world. Sometimes they try to accumulate the wealth in the name of the child but that does not take the worry they have about the future of the child.
11. *Unrealistic expectations*: many times, parents of mentally retarded child are dissatisfied with the slow progress their child is making in learning new things like any other normal child. They try to push harder to force the child to learn quicker and try to be on par with other children. However, the child can only learn to the best of his/her ability and not more than that. When parents have unrealistic expectations of what their child can achieve, it leads to disappointment not only for them but also in the child who does not understand what he/she is doing wrong.
12. *Societal attitude and responses*: Somewhat stereotyped view of mental retardation by the society makes vulnerable in the parents self perception. Parents often feel both misunderstood by the society at large and ashamed of themselves and so they try to be away from public in order to avoid the humiliation of tag that they have a mentally retarded child.

1.3 Methodology

Objectives of the Research Study

1. To assess the knowledge of the parents regarding mental retardation.
2. To study the psycho-social, economical problems faced by parents of mentally challenged children.
3. To suggest better way and means for the handling of mentally challenged children.

Universe of the Study

The study includes all the parents of mentally challenged children who are in different special schools in Mangalore District.

Sample Size and Techniques

The study included 50 parents of mentally challenged children in Mangalore district. Simple random method was selected by the researcher and samples were chosen through lottery method.

Method of Source of Data Collection

The data collection in the research was primary data. The researcher used interviews with interview schedules. Local languages were utilized to investigate and approximately an hour was utilized to interview samples.

Inclusive criteria: Respondent whose children are below 15 years are only taken in to consideration.

Exclusion criteria: Parents of children with co-morbiditory diseases are not considered.

1.4 Limitations of the Study

- Depth study with accuracy was constrained due to resources and time factor.
- Lack of rapport with respondents affected the quality of answers.
- Since the sample size is small the accurate conclusion could not be drawn.

1.5 Analysis & Interpretation

Assessment of parents regarding the knowledge on mental retardation: Parents of mentally challenged children commonly experience a gamut of emotions over the years. Most parents have aspirations for their child and their dreams get shattered when they realize that their child is special and they start examining their own conscience and start finding the reason for the condition of their child. Some parents struggle with the guilty conscience and they find no answer for their 'Why's in their mind.

The parents from rural area have different reason for the disability condition of their child and semi urban / urban have their own reasons and the answer for their queries. Among the children the cause is unknown but the parents attribute to various reasons because of which their children suffer.

Table 1.1 Parents perception about the various causes of mental retardation of their child.

Respondent	Evil eye	Mental Problem during pregnancy period	Hereditary	Birth injury	Stress during pregnancy	Any other	percentage
Rural	9(50%)	3(16.67%)	1(5.56%)	5(27.77%)			100%
Semi urban	3(9.67%)	11(35.40%)	10(32.42%)	7(22.50%)			100%
Urban	1(9.09%)	3(27.27%)	5(45.45%)	1(9.09%)			100%

The table displays that each individual will look differently at the causes of mental retardation. With multiple answers given by the individual from rural area the researchers feel that thinking and reasoning differs from the individual belonging to semi urban and urban areas. The above table clearly shows that 9 (50%) respondents from rural area believe that it is the evil eye that has caused their child to develop this condition and 3(16.67%) feel that it is the condition which the child developed during the pregnancy of mother some of them feel since they are educated that this has resulted when the foetus did not develop properly during pregnancy and 1(5.56%) feels that it is hereditary that is the genetic conditions sometimes it is caused by abnormal genes inherited from parents and 5 (27.77%) rural people feel that is the injury during birth that is the cause for this condition. But the semi urban have their own way of attributing this condition. Education plays an important role in the thinking pattern of the parents who have mentally retarded child.

Table 1.2: Awareness of the parents regarding Mental Retardation

Respondent	At birth	Below 6 month	6 month to 3 year	3 year to 7 year	Later
Uneducated		1(14.2%)	5(71.42%)	1(14.2%)	
Below 9 th	1(5.26%)	10(52.6%)	5(26.3%)	2(10.52%)	1(5.26%)
PUC/SSLC/ITI	6(28.57%)	4(19.04%)	6(28.57%)	4(19.04%)	1(4.76%)
Graduate	-	3(100%)		-	-

Table 1.2 clearly shows that uneducated parents of mentally children are not having any knowledge of retardation. They sometimes are not able to find the real condition of the child and are ignorant of the condition of the child and may not be able to take to the physician or a counsellor for guidance. Parents who are graduates know that their child is not like any other normal child below 6 months. They are ready to take the guidance of the physicians and psychologists in order to help their child and cope with the disabilities. 6(28.57%) parents who are qualified with High school, Pre University and other technical training know that their child is disabled at the time of birth, 4 (19.04%) of the respondents come to know about the condition when the child is below 6 months, . 6(28.57%) of the respondents know between the age of 6 months to 3 years and 4 (19.04%) come to know the condition of the child between the years 3 to 7. Identification of the problem is another aspect the researcher studied. The respondents from rural area mentioned that their parents though illiterate were first to identify the condition of the child. When they realized that the child was not like any other normal child they took the child to physician or other other relative who had some knowledge about the condition.

Table 1.3: The first identification of the problem by the respondent

Problem Identification	Parents	Physician	Relative	Friends	Percentage
Rural	8(57.14%)	2(14.28%)	4(28.57%)		100%
Semi urban	8(32%)	10(40%)	5(20%)	2(8%)	100%
Urban	6(54.55%)	5(45.45%)			100%

The above table clearly shows that 8 respondents comprising of 57.14% said that their parents were the first to identify the problem and tried to find solution for thier problem in spite of being illiterate. Only 2 respondents comprising of 14.28% said that the condition was noticed by the physician and then the parents came to know about it and were really in shock when they came to know that their child was not able to be like any other normal child and 4 respondents comprising of 28.57% said that they came to know about the condition from their relatives who had visited them.

Families with disabled children perceived greater financial stress, frequent disruption of family routine and leisure, poor social interaction, and ill effects on their physical and mental health as compared to families of normal children.

Table 1.4: Opinion on Social Status.

Respondent	Yes	No	Percentage
Rural	6(54.45%)	5(45.45%)	100%
Semi urban	17(60.57%)	11(39.43%)	100%
Urban	5(45.45%)	6(54.45%)	100%

The above table clearly depicts that the social status of the parents is affected in one way or the other. They perceive that there is a greater disruption of family routine life and the leisure that they want to enjoy. Many times they find it difficult to go for social gatherings or to have any social interaction with any outsider or friends as they feel that it is

awkward or uncomfortable to have a child with disability. In rural set up the 6 respondents comprising of 54.45% say that they feel bad in the company of retarded child to go for social gatherings or get together. In a semi urban set up 17 (60.57%) respondents perceived that they found difficult to go out for social interaction or for family leisure outside having the retarded child and 5 respondents consisting of 45.45% from urban set up felt that they feel going out with a retarded child. They felt that their social status is affected much by taking the child out when compared with a normal child. But the other respondents from urban and semi urban, comprising of 6(54.45%) from urban and 11(39.43%) from semi urban felt that their life is not affected at all with the presence of the mentally retarded child in the family. They are able to cope with any stress in the family.

Parents will feel that their child is a burden to them in spite of having so many disabilities. They will never abandon their child only because of the mental retardation. The study shows the feelings of the respondents about the special child and whether they take the child as a burden or not.

Table 1.5: Special child is felt a Burden to the parent based on the monthly income

Respondent	Never	We don't mind it	Some times	Yes definitely	Percentage
Below Rs.10000	1(9.09%)	4(36.64%)	6(54.45%)	-	100%
Rs.10000 to Rs.19999	4(30.08%)	4(30.08%)	5(38.85%)	1(7.69%)	100%
Rs.20000 to Rs.35000	6(33.33%)	6(33.33%)	6(33.33%)	-	100%
Above Rs.35000	3(42.29%)	2(28.86%)	2(28.86%)	-	100%

The table 1.5 shows that 19 parents from all income groups feel that some times mentally retarded child becomes burden. With individual interviews the researcher comes to know that due to social stigma, growing price rate of every commodity and medical expenses of the child, emotional stress and job stress, all these make them feel that the special child sometimes is a burden to the family. 16 respondents don't mind having the child as they feel that the child is the God's gift. 14 respondents of different income groups feel that they are never a burden to them and they are able to cope with any psychological, emotional, financial stress that they undergo. One respondent was quite sure that the child is obviously burden to the family.

1.6. Suggestion & Conclusion

A). Suggestion:

- Parents should be made aware of problem related to Mental Retardation and their causes. Educating the parents with regard to welfare, care and treatment is very essential.
- They should gain suggestions from physician in time to time and also should inform behavioural changes of child to physician.
- Parents should create a good environment which may help the children to develop their mentality.
- Positive thinking about the problem and having optimistic attitude by the parents will help the children to grow in a positive way
- Parents should try to spend more time with their children.
- Always try to follow suggestions of physicians and child specialists.
- Provision of special education and training is very necessary. Even parents also should have the skills of taking care of special children. This helps the parents to train their special child to manage their personal affairs independently.

B). Conclusion:

Our society has developed at a faster rate. But the general attitude towards the mentally challenged needs to be changed. They are not to be sympathised, protected, ridiculed rather they need to be helped in growing and developing within their strengths and limitations. Their education or training should begin at home, thereafter special schools and institutions may be involved for their education and training. The society and the state, then should take responsibility for their rehabilitation and adjustment.

1.7. References

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