

EXCLUSION AMONGST MUSLIM PARENTS OF MENTALLY CHALLENGED CHILDREN IN HYDERABAD

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ABSTRACT

The proposed paper examines exclusion among Muslim parents of mentally challenged children in Hyderabad. Mental retardation is a serious problem affecting a large number of people. Amongst them the Muslim parents are worse off than average. Although in India Muslims constitute a largest minority but they are poorest of the poor because they are socially, educationally and economically excluded. Social exclusion also applies to some degree to parents of children with a disability, to minority men and women of all races, and to the elderly. Anyone who deviates in any perceived way from the norm of a population can become subject to coarse or subtle forms of social exclusion. Exclusion is the process and situation in which a section of a society is excluded from its general stream with regard to the requirements and necessities of normal life. There could be numerous determinants for this state of affairs the major one being nothing other than poverty. The proposed paper focusses on the excluded Muslim parents, how they are unable to send their children to special schools due to lack of awareness and money. So it can be concluded that if the government adopt some policy for these parents and their children like counselling, providing funds, strengthening preventive health programs, screening all children at a young age, empowering disabled young adults with employable skills, encouraging the private sector to employ people with disabilities. Then these parents would be able to overcome this stressful situation.

Keywords: Parents, Mental Retardation, Exclusion, Children, Muslims.

INTRODUCTION:

The proposed paper examines exclusion among Muslim parents of mentally challenged children in Hyderabad. All parents wish for a healthy baby, but some parents though not by their choice are forced into a situation of having a mentally challenged child. Parenting is a stressful job and requires great amount of skills and efforts on the part of the parents, however parenting a physically and mentally challenged child is not an easy task. There is abundant evidence that parents of disabled children undergo more than the average amount of psychological stress. Mostly, it is the negative definition of the situation that added to the psychological stress. The negative impact included difficulties in meeting extra demands with physical care of the child, experiencing health related problems, making career adjustments, experiencing loss of support from the spouses etc. Previous studies on similar topics showed that there can be a chance of having negative emotions like 'despair', 'blaming each other', 'comparing child with normal children', 'marked disruption in parental job activities', 'interpersonal relationships', etc. (Singh, Indla, & Indla 2008).

Mental retardation is a serious problem affecting a large number of people. If we consider it alone, its incidence in general population is about three percent (as per WHO surveys) and 2.5% per simple statistical probability. So it can be concluded that if the government adopt some policy for these parents and their children like counselling, providing funds, strengthening preventive health programs, screening all children at a young age, empowering disabled young adults with employable skills, encouraging the private sector to employ people with disabilities. Then these parents would be able to overcome this stressful situation.

PREVALENCE OF DISABILITY:

It is estimated that amongst 2 billion children in the world there are 100 millions have disabilities (www.unhcr.ch/html/menu2/6/crc/doc/days/disabled.pdf). Since India has a large population of persons with disabilities and according to the latest Census survey conducted in the year 2001, the population of persons with disabilities in India is 2.01 per cent of its total population. Therefore, in terms of numbers, the total population of persons with disabilities comes to 20 million. The Census did not record the population with multiple disabilities. As per survey conducted by the National Sample Survey Organization in 2002 a total of 1.8% population of the country suffers from one or the other disability. The population with multiple disabilities in India estimated to be of 10.63% of the total population with disabilities (www.nise.go.ip/PDF/JSEAP-3.pdf).

There are various causes of disabilities like heredity, health conditions or birth complications. Almost 70% of the causes of disabilities in India are due to communicable diseases, serious illness during childhood, pregnancy related, polio, ear discharge, eye diseases, cataract, accident, violence and untreated injuries/diseases. However, there is a strong link between poverty and disability. Poverty is the biggest cause of disability in India. The 360 million people in India who live below the poverty line are the most vulnerable to impairments. In addition to the above causes, malnutrition, disease, unsafe drinking water and poor sanitation also cause a large number of disabilities among children. There are many types of disabilities that affect children in very different ways. Development, learning processes and individual needs vary according to the nature of the disability. Children are differently affected by the extent, severity and multiplicity of the deficiencies. Children with disabilities are referred as intellectual disabilities (mental retardation), hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopaedic impairments, autism, traumatic brain injury, other health impairments or specific disabilities. Table 1.1 shows the prevalence of above disabilities in India.

TABLE 1.1: ESTIMATED NUMBER OF PERSONS WITH DISABILITIES IN INDIA

NSSO 2002			Male		Female	
	Total	%	Nos.	%	Nos.	%
Locomotor Disability	10634000	58	6633900	36	4000100	22
Hearing Disability	3061700	17	1613300	9	1448400	8
Speech Disability	2154500	12	1291100	7	863400	5
Blindness	2013400	11	928700	5	1084700	6
Mental Illness	1101000	6	664500	4	436500	2
Mental Retardation	994700	5	625800	3	368900	2
Low vision	813300	4	369300	2	444000	2
Any disability	18491000	100	10891300	59	7599700	41

(Source: www.geocities.com/mahesh_mobility/pwd_india.htm).

MENTAL RETARDATION:

Mental retardation is more than a failure to behave appropriately (Baumeister, 1987, p. 800). The long-used term "mental retardation" has acquired an undesirable social stigma. Because of this stigma, doctors and health care practitioners have begun replacing it with the term "intellectual disability." Because this change is recent, the term "mental retardation/intellectual disability" (MR/ID) is used to mark the transition in terminology. Intellectual disability is the most prevalent handicapping condition throughout the world. Since 1992, with the significant paradigm shift in the concept of mental retardation proposed by the American Association on Mental Retardation (AAMR) (Luckasson, Coulte, Pollock, Reiss, Schalock, Snell, Spitalnik, & Stark, 1992) it has been considered that mental retardation refers to substantial limitations in present functioning. Actually, in order to be diagnosed as a person with mental retardation, the person has to have both significantly low IQ and considerable problems in everyday functioning. Most children with mental retardation can learn a great deal, and as adults can lead at least partially independent lives and most individuals with mental retardation have only the mild level of mental retardation. Mental retardation, mental deficiency, mental sub normality and mental handicapped are the terms used to refer to the same condition. According to the American Association of Mental Deficiency, Mental retardation refers to "significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behaviour, and manifested during the developmental period."

FOUR LEVELS OF MENTAL RETARDATION ARE RECOGNIZED BY DSM-IV-TR:

Mild Mental Retardation (50-55 to 70 IQ): About 85 percent of all those who have IQs less than 70 are classified as having mild mental retardation. These persons usually look and act normal and display no overt, obvious signs of retardation.

Moderate Mental Retardation (35-40 to 50-55 IQ): About 10 percent of those with IQs less than 70 are classified as having moderate mental retardation. Brain damage and other pathologies are frequent.

Severe Mental Retardation (20-25 to 35-40 IQ): Of those people with IQs less than 70, about 3 to 4 percent come under the category of severe mental retardation. These people commonly have congenital physical abnormalities and limited sensory motor control.

Profound Mental Retardation (below 20-25 IQ): Only 1 to 2 percent of people with profound mental retardation are classified as having profound mental retardation, requiring total supervision and often nursing cares all their lives. The probability of concomitant neurological damage is high and many are non ambulatory (Kring, Davison, Neale, & Johnson 2003: 500).

Mental retardation is caused by a number of factors. They can be broadly grouped into prenatal, perinatal and postnatal factors.

PRENATAL CAUSES:

- 1) Errors in chromosomes produce conditions with medical problems and most of these conditions cause mental retardation.
- 2) Genetic disorders: Defect in the genes, transmitted from the parent to the offspring can result in certain conditions with mental retardation.
- 3) Infection in the mother, especially those during the first three months of pregnancy can damage the developing brain of the fetus. Some of the infections that affect the fetus are rubella, herpes and cytomegalic inclusion disease: toxoplasmosis, syphilis and tuberculosis.
- 4) Maternal diseases such as diabetes, mellitus and high blood pressure; chronic problems in the kidneys and malnutrition in the mother can damage the growing fetus. Excess of thyroid in the mother (hyperthyroidism) can produce defects in the central nervous system of the growing fetus leading to mental retardation.
- 5) Exposure to X-ray in the early months of pregnancy, using harmful drugs and hormones can damage the growing fetus. Untreated fits in the mother and accidents from falls resulting in the injury to the abdomen can damage the growing fetus and lead to mental retardation.
- 6) Congenital defects of the central nervous system such as hydrocephalus, microcephaly and a number of defects of the brain and spinal cord are associated with mental retardation.

PERINATAL CAUSES:

- 1) Premature birth (being born between 28 weeks and 34 weeks) and low birth weight babies (less than 2 kg).
- 2) Lack of respiration immediately after birth.

- 3) Trauma to the head of the new born due to factors such as excessive moulding due to disproportion between fetal head and birth canal of prolonged labour of delivery by improper use of instruments and abnormal position of fetus in the uterus.
- 4) Excessive coiling of umbilical cord around the neck of the fetus and toxemia of pregnancy with high blood pressure and fits in the mother.
- 5) Bleeding in the brain and severe jaundice in the new born due to various causes.

POSTNATAL CAUSES:

- 1) Malnutrition in the child, inadequate intake of proteins and carbohydrates during this period can lead to mental retardation.
- 2) Infections in the child such as meningitis or encephalitis and repeated fits in the child and any injury from accidents or falls can damage the brain.

RESEARCH DESIGN:

The study was designed to assess the stress and coping styles of parents of mentally challenged children. The major aim of the study is to understand the stressful effects the Muslim parents experience in raising a mentally challenged child and how they are unable to manage and to deal with this traumatic situation. The study was designed to answer the basic question: Why Muslim parents of mentally retarded children are unable to overcome with this painful situation due to their exclusion from the society? The study was designed by the author and based on the case studies which they gathered from Hyderabad.

CASE STUDIES:

The concern of the present paper centers around the level of parental stress associated with mental retardation in the Muslims parents of mentally challenged children and to analyse the perception of fathers and mothers with regard to rearing and managing the mentally challenged child. Another important direction of this paper is to explore the problem of exclusion with consideration of Muslim parents. This paper is based on facts gathered from primary sources. Following case studies are in favour of the above problem.

CASE: 1

Syed Jaweed who is just 12 years old at that time lived with his parents and 6 siblings in house no. 18-7-212/30/25/3 of Nogalpura area (Hyderabad). He has got admission in a normal school and studied upto 3rd standard. He is a mild mentally challenged child. His father's name is Syed A. Basha who is 54 years old and his mother's name is Syeda Shamim who is 46 years old. His father studied upto Intermediate and is now working as a building contractor. He earned 4000.Rs Per month approximately. His mother who was just a 7th standard passed is housewife only. His family history shows that it is a nuclear and intact family which maintains a good relationship. It was also found that there was a consanguineous marriage between his parents. Pedigree chart showed that his mother was the only daughter of her parents and his mother's mother died few years back that was mentally retarded. On the other hand no history of mental retardation is found from his paternal side. His father is having one sister whose children are normal. Jaweed had five elder sisters ranging from 30 years, 28 years, 26 years, 24 years and 22 years respectively. He was the 6th born and the only mentally challenged child in the family. His 3 years old younger brother is found normal at all.

His prenatal history shows that his mother didn't go for regular check-ups due to lack of money and also because she had to take care of her mother-in-law who was suffering from paralytic attack. Natal history shows that it was a full term normal delivery at the hospital. Mother was reported very weak and the birth cry was delayed but normal birth colour and weight were reported. During post natal period he was reported to have jaundice at the age of 3 years and had head injury 4 years back. His presenting complaints are that he forgets very soon, talks to himself and had fear of darkness. He hates black colour because of an incident which took place on Muharram. He find someone wearing black colour he gets irritated and also he hates studies. According to his development history showed that he started speaking sentences when he was 7 years old which was delayed. Toilet control was also delayed. Apart from this he didn't have any physical deformity, sensory impairments and fits. His occupational history showed that he fetches milk from the shop and also can be able to buy many things. He is able to wash his own clothes and can take bath himself. During case study session I found that he was very talkative, active and cooperative. He was well dressed and was physically age appropriate. He was very friendly and was fond of watching movies.

CASE: 2

Another case study related to a girl child of Hyderabad whose name was Zareena Begum she is just 11 years old. She is living in House no. - 18-8-233/71/A, Riyasat nagar, Dalga Bandasha; Hyderabad. Her father's name is Mohammad Haji Shareef who is just 5th class passed. Her mother's name is Zulekha Begum who is 6th class passed and is only a housewife. She wanted to work but due to her mentally challenged daughter she cannot leave her at home. That's why she is unable to work. She also admitted that due to lack of money she can't give her daughter a proper treatment. Zareena's father is an auto driver and can earn approximately 3000 per month. Zareena used to go to Child Guidance Centre and studied upto 4th class. Her father's age is 45 years and mother's age is 40 years. The I.Q. score of Zareena shows that she falls under the category of severe mental retardation. The family history shows that there is no consanguinity at all. It is a fully nuclear family. No history of mental retardation and mental illness is found. Her mother was having 2 brothers only and her father was having 1 brother and 1 sister. Zareena is the eldest one amongst 3 siblings.

Her prenatal history shows that regular antenatal checkups were done and it was reported nothing significant. It was a full term normal delivery at home. Birth cry was also present and the weight and colour of the child were normal. During her post natal period it was seen that immunization was given. Child had high fever and got fits after 9 months so she got admitted to Nilofer hospital. It was found from her developmental history that there was some delay in her neck holding and walking. She started speaking sentences at the age of 6 years. She is unable in her toilet control and she didn't have a sense of money transaction. She faced some problems in school that's why she left from that school. She didn't have any sensory impairments and physical deformity. Her occupational history was nil. She throws objects on other people and have fits so doesn't listen to anyone. She also has an obsession for grass. During case history session she was not paying attention too much but was very active. She was physically age appropriate. She was wandering here and there in the room. She was able to follow two level instructions.

DISCUSSION AND ANALYSIS:

Becoming the parent of a child who has a disability is a time of great stress and change (Thompson, 2000). Muslim parents of mentally challenged children face problems and perceive considerable stress as their whole life-style get affected including their personal and psychological well-being. They used different coping styles to manage and deal with the stressful situation in order to avoid negative psychological, emotional and physical consequences.

In this context Dyson (1997), compared 30 mother-father pairs with a child who had a disability with 32 pairs who did not have a child with a disability. Both mothers and fathers of children with disabilities reported significantly more parental stress than mothers and fathers of children without disabilities. The parental stress for both fathers and mothers was influenced by family psychological resources such as appraisal of family functioning, social support, and personal growth. Tunali & Power (1993), also reviewed existing literature on stress and coping in families of children with disabilities and found that there were increased financial strains due to the need for medications, hospitalizations, intervention services, and specialized equipment. They also found that there was the potential for strained emotional relationships in the family due to less available time for other family members, overprotection of the child, and feelings of blame for possibly being genetically responsible for their child's disability. Finally, they found that families may feel socially isolated due to negative reactions from extended family, friends, and neighbours; potential embarrassment about how the child looks or acts; fear of accidents; and/or limited mobility (Smith 2007: 4-5).

Mc Dowell, Shea, & Bouer (1985), reported that parents of a disabled child progress through six emotional stages upon discovering their child's disability, these are disbelief, guilt, rejection, shame, denial, and a feeling of helplessness, but all these things may vary from parent to parent. Frequently, the parents' initial feelings are shock and numbness; parents may experience periods of panic, anxiety and helplessness, as well as periods of indifference and anger, at which time they face nearly overwhelming depression, apathy and bitterness (as cited in Vijesh & Sukumaran 2007: 76-77). (Hastings 2002; Konstantareas 1991; Scorgie, Wilgosh & McDonald: 1998) have found that parents of children with developmental disabilities experience greater stress than parents of children without developmental disabilities.

(Byrne & Cunningham 1985, Dykens 2000), found that outcomes of parents of children with developmental disabilities may experience additional stressors such as unmet service need and financial problems that may lead to pathology and maladaptation (Jones & Passey 2004: 31). Rogers (2007), reported the impact upon the parents of the diagnosis of a disability in the child and the process of possible denial, and the associated importance of feelings of being supported and socially accepted.

Studies have revealed that the unique stress experience by parents of these children may be different for

mothers and fathers due to differential role relationship. Kashyap & Tiwari (1996), reported that the presence of a disabled child changes the family roles, power, relationships and responsibilities.

It was found that more mothers have traditionally stayed home and have taken on greater responsibility for childcare. Only a few investigations have examined family experiences of both fathers and mothers and the results are conflicting. Some studies report that fathers experience more stress as they have fewer outlets for their stress than do mothers (Cummings, 1976). Others have reported that mothers and fathers experience similar amount of stress. Esdaile & Greenwood (2003), supported this by assessing parenting stress amongst the parents of children with disabilities. Having a child with a disability was associated with elevated scores for both mothers and fathers and this indicated the importance of considering stress management as an integral part of programs that involves parents of children with special needs.

Rosenthal, Biesecker, & Biesecker (2001), stated that both fathers and mothers reported the overall experience was stressful for them and rated the parental role and the child's behaviours and emotions as the most stressful dimension of their experience. "Parents may also experience intense anger at the unfairness of the situation, or they may feel socially isolated and stigmatized" (as cited in Saied 2006: 1). However, the stress associated with a child's disability can devastate some families. The parents are stressed because they may no longer be able to do things that are considered essential to the basic foundation of being parents. Parental stress changes over time and is affected by the nature and course of the illness. The additional stressors influence parent's level of stress, and how they cope and adjust to the situation. However, resources outside of the family may be equally important in managing a stressful situation (McCubbin & Patterson 1983; McCubbin, Thompson & McCubbin 1996). If parents become depressed from the strain and stress of care giving, then their own health will be impaired (Saied 2006: 7).

Mothers are at a greater risk of developing stress related illness such as migraine or tension headaches, body aches and pains, hypertension, anxiety, depression etc. Fathers are generally known to take longer to adjust with the situation of having a mentally challenged child. It could be because they tend to spend less time with the child and also their contact with the professional may also be less which gives them less chance to sort out their problems. They too are known to suffer from depression, though less than the mothers and develop problems in marital relationship and personality difficulties (Peshawaria, Menon, Ganguly, Roy, Pillay, Gupta, & Hora 1994: 26-27).

Cuskelly, Pulman, & Hayes (1998), conducted a study and found that a smaller percentage of mothers of disabled children work than do mothers of normal children, although the difference is not statistically significant. However, 100% of the working mothers of disabled children worked only part-time, whereas 50% of working mothers of normal children work part-time. In addition, 37.5% of the working mothers of disabled children worked out of their home. These statistics indicate that having a child with a disability restricts the ability for the mothers to work when otherwise they might have wanted to. Children with disabilities typically need costly health care and with only one full-time income, families with disabled children are at a financial disadvantage, adding stress to both parents. Social ramifications also exist for the parent who stays home to care for the children. Women, who leave the workforce to care for their children, disabled or not, often experience a sense of loss and social isolation. A reduction in their social network through work relations decreases the ability for the mother to cope with stress. In addition, the mother can feel further isolation from loss of friendships if the friends do not understand the parent's situation and may even feel discomfort in dealing with the disabled child. It can be said, however, that with the child's greater daily needs and without an increase in father's involvement, adding the responsibilities of a job would just increase the amount of stress experience by the mothers.

The term 'social exclusion' has been defined as a process of long term non-participation in the economic, civic and social norms that integrate and govern the society in which an individual resides (Burchardt et. Al. 1998). Exclusion is the process and situation in which a section of a society is excluded from its general stream with regard to the requirements and necessities of normal life. It is a multidimensional concept in which certain populations are excluded from the benefits of social, political, economic, cultural, educational and religious domains of societal life based on their race, gender, ethnicity or disability. For example, people may be excluded from livelihoods, employment, property, earnings, housings, minimum consumption, education, personal contacts or respect, the welfare state etc (Silver, 1995). Anyone who deviates in any perceived way from the norm of a population can become subject to coarse or subtle forms of social exclusion.

Getting insight of the above various concepts, it can be understood that parents having a child with disabilities experience a variety of stressors. Empirical and theoretical researches have also shown that disabilities in children make exceptional demands on the parents. Study of disability is an issue of vital importance, although many studies have been conducted around finding out which factors contributed to parental stress as a whole, but no study has touched the dimensions of parental stress and coping with

consideration of parents. These problems become double if the parents are Muslims because they are worse off than average. In India Muslims are the most excluded segment of the population although Muslims constituting a largest minority and highly noticeable in the entire length and breath of the country. But they are poorest of the poor because they are educationally most backward, economically poor and politically powerless community of the country. Not much improvement in the conditions of Muslims has taken place in the last 23 years. On the whole Muslims seen to be characteristically obscure due to social and physical distancing from the social, economic and political nucleus. They also have low personal esteem. Apparently, low dependency ratios because almost everyone has to work including children, relatively more nuclear and fractured families, high fertility and low health care utilization, low employment and wage stability are observed among Muslims (Mistry, 2005: 413).

CONCLUSION AND IMPLICATIONS:

The proposed paper focusses on the excluded Muslim parents, how they are unable to send their children to special schools due to lack of awareness and money. So it can be concluded that if the government adopt some policy for these parents and their children like counselling, providing funds, strengthening preventive health programs, screening all children at a young age, empowering disabled young adults with employable skills, encouraging the private sector to employ people with disabilities. Then these parents would be able to overcome this stressful situation. Hence, there is an urgent need to take meaningful steps for upliftment of Indian Muslims who are living in abject poverty, insecure condition and are under-represented in governmental services, educational institutions and in decision-making bodies.

Thus the perceptual differences of Muslim fathers and mothers about the stressful effects having mentally challenged children may assist interventionists and planning social support programmes for such muslim parents. The findings of the study also suggest the importance of counselling focussed specifically towards developing healthy parental attitudes which would in turn result in acceptance of the child's disability and facilitate therapeutic progress. A concerted effort must be made to prepare and train these Muslim parents of children with mental retardation in handling the needs of their children and this effort should start from the stage of identification of the disabilities of children. Thus, in order to reduce this gender disparity there is a need on the part of governmental and non-governmental agencies come forward and help the parents of such children living in Muslim families.

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