

Child with Intellectual Disability and Parental Response: A Comparative Study of Nuclear and Extended Family Structures in Khyber Pakhtunkhwa, Pakistan

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Abstract

The birth of a child with an intellectual disability puts varying amount of pressure on nuclear and extended families. The purpose of this research paper is to explore the experiences of parents having children with intellectual disability in nuclear and extended families in Khyber Pakhtunkhwa (KP). For this purpose, 12 parents for in-depth interviews and 24 parents for three focus group discussions were selected. Furthermore, in-charge from each center was also interviewed. It was found that parents belonging to extended family structure comparatively feel relax due to family support in managing the child's care and household activities. On the other hand, institutional support can reduce the burden of child care on parents resides in nuclear family structure.

Keywords

Intellectual disability, Social exclusion, Parents, Extended family, Nuclear family.

Introduction

The incidence of a child with an intellectual disability¹ puts significant pressure on families. Such a child needs 24 h of attention not only in early childhood, but also in his/her later years of development. A child with an intellectual disability is unable to properly recognize people, objects, or events. Such a child is also unable to perform a normative behavior or adapt to situations. Such a child may easily get himself/herself injured or put himself/herself in any other harmful situation. This condition demands 24 h care from those in charge of the child.

Besides this internal pressure, the incidence of such a child also puts a significant amount of social pressures on families. For example, Ahmad (1995) noted that in developing societies such as Pakistan, intellectual disability is concealed by families owing to fear of stigma (Ahmed, 1995). The families with an intellectually disabled child are perceived to have a genetic deficiency. Communities and neighborhoods abstain from establishing marital relations with such families owing to the fear of getting an intellectually disabled child in future.

As far as, the prevalence of intellectual disability is concerned, it is on the rise globally. A report of the World Health Organization (1994) reported 3% of global population (or 156 million) to have some form of mental retardation. However, it sharply increased in 2011 to 15% (or 785 million) globally. Moreover, it is not a phenomenon of the third world alone. Intellectual disability is prevalent throughout the developed and underdeveloped world. For example, in the UK 1,198,000 people have intellectual

disability that includes 298,000 children of age group 0-17 years (Emerson et al., 2010: 1). Likewise, in the US, there are about 6 million (or 3%) who are suffering from mental retardation (Xingyan, 1997: 3).

As far the exact prevalence of children with intellectual disability in Pakistan is concerned, it is not known due to delay in carrying out official censuses since 2008. The only official available statistics are more than 15 years old (National Census Statistics: 1998). As per 1998 census, there are 32, 93, 155 people who have some form of disability. Out of the total, 7% are hearing impaired, 8% are blind, 14% are intellectually disabled and insane, 19% are physically disabled, 8% are suffering from multiple disabilities while 43% are not categorized (Table 1).

In Khyber Pakhtunkhwa (KP)², the most common disease and disabilities among children are fits, mental backwardness³ and difficulty in speaking which constitute a significant part of population, i.e. 4% (Government of KP, 2008).

In normal situation, families expect a healthy child at birth. In case, a child is born with a defect it becomes a very disturbing event for the family. It shatters the expectations of the family. Their social reputation gets at stake. In such circumstances, people culturally associate it with a sin they might have committed. In addition to such perceptions, it become a problem for their families (Jamison, 1965) in terms of economic liabilities (Boyd, 2011), emotional disturbance (Gohel et al., 2011), psychological adjustment (Cohen, 2011), and relationship among the sibling as

¹The term intellectual disability is defined as "significant limitations both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18" (Schalock, 2007: 118). Intellectual functioning is the ability to learn about, learn from, understand, and interact with one's environment. This general ability consists of a number of specific abilities; like adaptability to a new environment or to changes in the current environment and capacity for knowledge and the ability to acquire it (Bainbridge, 2012).

²Khyber Pakhtunkhwa is a province of Pakistan located in the north-west of the country. It was previously known as North West Frontier Province (N.W.F.P). Extended family structure is predominant social feature in Khyber Pakhtunkhwa; however, nuclear structure also existed in the sub-urban areas of the province like Hayatabad in Peshawar district. Furthermore, a small segment of women population participates in economic activities due to cultural reasons.

³Mental Backwardness here refers to Intellectual Disability.

parents give more time to mentally retarded children compared to the normal ones (Cook, 2006 cited by Atiya 2012: 3).

This study is intended to find out how different family structures (nuclear and extended) respond to incidence of child with intellectual disability and what is the role of institutional services in this regard.

Objectives of the study

To fulfill the purpose of the study, following objectives were formulated:

- To explore the parents view and experiences about their child with an intellectual disability in extended and nuclear family structure.
- To know the efficacy of services rendered by different centers in reducing the misery of parents in KP.

Methodology

This research adopted a Qualitative Research Design. Research tools were in-depth interviews (with 12 parents) and focus group discussion (FGD) (with 28 parents, 7 in each FGD). Along with this, participant observation was also carried out during the study. Parents were selected from the official lists of the three centers working for children with intellectual disability in district Peshawar and district Haripur (Tables 2 and 3). Furthermore, in-charge of each center (three in-charges) was also interviewed for the purpose of exploring the nature and type of services rendered for such children. The interviews were recorded in a digital audio recording device. Informed consent was taken from the respondents. Transcription was made into native language and later on translated into English by the researcher(s).

Results and Discussion

Parents of children with intellectual disability face social exclusion in nuclear family structure

Participants spoke about the social exclusion face due to care

Table 1: Incidence of disability in Pakistan – 1998 census

Particular	Frequency	% age
Total	32,93,155	100
Blind	2,63,452	8
Deaf and dumb	2,63,452	8
Physically disabled	6,25,699	19
Intellectually disabled	4,61,043	14
Multiple disability	2,63,452	8
Others (not categorized)	14,16,057	43

Source: Government of Pakistan (1998). Population Census Organization: Islamabad

Table 2: Detail of IDI with parents in both districts

Name of districts	Total IDI with parents	Parents would be selected from the following age group of CID		
		5-8 years	9-13 years	14-18 years
Peshawar	06 (3 from nuclear and 3 from extended family)	2	2	2
Haripur	06 (3 from nuclear and 3 from extended family)	2	2	2
Total	12	4	4	4

IDI: In-depth interview, CID: Children with intellectual disability

of their children with intellectual disability and other household activities. Participants belonging to nuclear family setup were unable to participate in the vital ceremonies their community such as deaths and marriage ceremonies which is attended collectively for 3 days in there. They spent most of the time in managing care of both normal and their disabled child and household activities.

On the other hand, parents living in extended family setup participate in social activities of the community due support of mother-in-law, sister-in-law or other family members.

A mother from nuclear family narrates her story of social exclusion as:

I was living a very happy life; participated in family events actively, was a delighted person and used to dance on happy occasions like marriage ceremony. But after the birth of two children with problem, it has totally changed my life. Currently, I do not participate. Similarly, his father used to go to gym and frequently met with friends. But now, he is thinking all the time for the treatment and rehabilitation of his children. After office time, he spends most of the time at home to manage their children [Field Notes, July 2014].

Another mother from nuclear family structure shared that:

I cannot participate in most of the ceremonies because my children need my full attention and care. In case of unavoidable social activity then I go for a short while, however, I am extremely worried about my child at home [Field Notes, July 2014].

The finding shows that parents residing in nuclear setup are prone to social exclusion. Incidence of such a child prohibits parents from attending communal gatherings, attending weddings, participating death ceremonies or performing other community, and neighborhood activities. Such families need some form of external support in order to reduce social exclusion. Jamison (1996) reported that extreme burden in the care of the defective child in the home cannot be endured long without some form of help. Institutional support from state institutions can reduce this social exclusion.

Besides social exclusion, working parents, particularly mothers in nuclear families, find it extremely difficult to manage the child care and their jobs. Such mothers feel fatigue and extra burden. On the other hand, working parents living in extended families leave their child with a family member, usually the

Table 3: Detail of FGD with parents in both districts

Name of districts	Total number of FGDs	Fathers	Mothers
Haripur	02 7×2=(14 parents)	1 (7 fathers)	1 (7 mothers)
Peshawar	02 7×2=(14 parents)	1 (7 fathers)	1 (7 mothers)

FGD: Focus group discussion

grandmother, during duty hours. It is, they think, the blessing of extended family. Jamison (1965) reported that parents who have support of other family member feel relax. This research also confirms the assertion by Jamison.

We have extended family system and our income is combined. All family members send their share which is spent collectively, bearing his (a child) expenses are not a burden on the family [Field Notes, July 2014].

According to a mother who lives in extended family setup:

My sister-in-law and other relatives look after her (the child) during my job timing. [Field Notes, July 2014].

On the other hand, a mother from nuclear family shared in an FGD that:

I remained continuously in stress due to the multiple roles I performed both within as well as outside the four-walls. I need two hours for feeding child with intellectual disability..., I am a working woman as well and have to give time to my other children because there is no other family member. Besides, I give time to household activities; which has made me sick with high blood pressure [FGD, August 2014].

Likewise, another mother from nuclear family setup shared in an FGD that:

Initially, I was doing a private job, but after the birth of Sibghaa (the child), it was extremely difficult for me to make balance in working and household activities. However, I gave up that job for the sake of my daughter. But later on, I restarted my job after admission of Sibgha at the Center for mentally retarded children. Moreover, after the suspension of school transport facilities due to installation of barriers on the road for security purpose; I am again in trouble [FGD, August 2014].

It was found that parents especially mothers dwelling in nuclear families that have no support from other family members or any institution face psycho-social problems. Jamison (1965) confirms that the health of the mothers who usually bear the brunt of care for these children is often drastically affected. Chronic fatigue and nervous exhaustion are common in homes where there is limited help in management of a retarded child. Occasionally the mother may verge on a mental breakdown. On the other hand, parents who have support of other family member feel relax.

Birth of a child with intellectual disability may result in divorce in nuclear and extended families alike

It was discovered during the course of this research that incidence of a child with intellectual disability severely affects marital relationship between husband and wife. This disturbance can result in many forms. In such situation, children with intellectual disability have been abandoned by either both or one parent(s). However, it was also discovered that the family members are reluctant to admit that the separation was a result of the birth of the child.

An uncle of the child with intellectually disability, who was from extended family structure, shares that:

He (the child) lives with me and he considers me as his father. His parents were living together; however, they (the parents) got separated after the birth of the child with intellectual disability. Currently, the child lives with us. His mother dwells in Karachi while his father is at Saudi Arabia. My sister is extending care to the child, however, she is marrying in near future and hereafter his grandmother will look after him [Field Notes, July 2014].

Teacher of child with intellectual disability told that:

I know the family of child whose parents got separate since long. They were living in nuclear structure and both were doing job. Owing to the extra care of child, mother was unable to extend care to him; it has affected the relation of the spouse which ended in divorce. Currently, he lives with his grandparents where he lives a happy life; however, cannot extend care like his own mother [Field Notes, July 2014].

In both of the cases cited above, separation occurred as a result of the birth of the child with intellectual disability. Likewise, the care of the child was shifted from parents to uncle and grandparents.

Institutional support release the extra pressure of parents having children with Intellectual disability

Institutional support may not enhance the child's capacity to function; however, it helps the families in myriad ways.

I have not observed any development in the social and academic skill of our child, however, I feel relaxed that his enrollment in the center provided me a breathing space for managing household activities [Mother of the Child, July 2014].

Similarly, another respondent reported that:

We are not satisfied from the progress of our children at school. My three younger brothers have learnt abusive language there. Even, the repeated very bad action and have developed bad habits. So far learning is concerned, they are learning automatically in the family but in the school their learning are not very effective. None of the teacher at their school is trained. However, my mother

managed household activities during their absence [Elder brother of the Child, July 2014].

It was found that institutional support is necessary for social training through different therapies for children with intellectual disability. Furthermore, it provides support to parents live nuclear family structure and does jobs.

Themes

From the analysis of the field data, this research identifies the following three themes:

1. Parents of children with intellectual disability face social exclusion in nuclear family structure
2. Birth of a child with intellectual disability may result in divorce in nuclear and extended families alike
3. Institutional support releases the extra pressure of parents having children with intellectual disability.

Conclusion

This research concludes that extended families are better equipped in caring for an intellectually disable child as compared to nuclear families. In such families, the child's care, like other responsibilities, is shared by the entire family. Providing the parents of the child with a breathing space falls onto the shoulders of all the family members. In nuclear families, however, the parents are between the devil and the deep sea.

Besides shouldering the burden, extended families also provides enough support to working mothers. In nuclear families, the working mothers usually leave their job with the incidence of the child with intellectual disability. Incidence of child with intellectual disability also might result in separation/divorce amongst spouse.

Wide-ranging institutional support is recommended for providing a breathing space to families with child with intellectual disability.

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