PARENTS’ PERSPECTIVE ON CHILD’S INTELLECTUAL DISABILITY: A CASE STUDY OF KHYBER PAKHTUNKHWA - PAKISTAN.
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Abstract

Intellectual disability is a condition which affects social and intellectual functioning of individual in a society. To explore such effects on the family, the following objectives were devised in this study as:

Objectives: To explore the views and experiences of parents about their child with intellectual disability in joint and nuclear family structure and To know the efficacy of services rendered by different Government-run centers in reducing the miseries of parents.

Methods: This is a qualitative study in which 12 parents for In-depth Interviews (6 from nuclear and 6 from joint family) and 28 parents for 4 Focus Group Discussions (FGD) were selected purposively from the official list of 3 Centers (see table I and II). Furthermore, In charge of each centre (3 In charges) were also interviewed. Before the interview, respondents were debriefed about the purpose of the study. Their responses were recorded and transcribed after their consent.

Results: It was found that parents belonging to nuclear family structure face various problems like social exclusion, strained spousal relation and extra fatigue for working mothers due to their full time involvement with their child (REN) with intellectual disability. However, parents in joint family were relaxed due to family support in child care & house hold activities.

Conclusion: Institutional and family support to parents in child care can reduce extra burden of child care and make them socially included.

Keywords: Intellectual Disability, Social Exclusion, Nuclear family, Joint family, Disability.

Introduction:

The term intellectual disability is defined as “significant limitations both in intellectual functioning and in adaptive behavior, which originate before the age of eighteen, as expressed in conceptual, social, and practical adaptive skills” (10). 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 ability to acquire it (2,15). Intellectual Disability is also known as mental retardation, learning disability or developmental disability. Furthermore, intellectual disability is considered as a proper term which was modified by American Association on Intellectual and Developmental Disability (AAIDD) (10,12). However, in Pakistan and especially in Khyber Pakhtunkhwa, the term mental retardation is still used for intellectual disability in official documents.
In developing societies such as Pakistan, intellectual disability is overshadowed due to fear of stigma (1,16). The reason behind this fear is lack of proper awareness and education about the causes and effects of intellectual disability. As far the exact prevalence of children with intellectual disability in Pakistan is concerned, it is not known due to lack of official census since 2008. The only official available statistics are more than fifteen years old, the total population of persons with disability in Pakistan is 32,93,155 and out of them 8 percent are blind, 7 percent are hearing impaired, 19 percent are physically disabled, 14 percent are intellectually disabled and insane, 8 percent are suffering from more than one disability, and 43 percent are inflicted with other kind of disabilities which are not classified so far. (16) (See Table 1 for details).

The purpose of this research study was to explore the socio-economic and psychological effects of children with intellectual disability on family. This study also sought to explore the perception, experiences and views of parents about their child/children in the selected Districts, namely; Peshawar and Haripur of Khyber Pakhtunkhwa. Such effects, as referred above, have been explained by different studies, however, as regard to Khyber Pakhtunkhwa province (Pakistan) there is no such study available. Hence, this study is the first of its kind to sociologically address the problem of the effects of child with intellectual disability on the families. This is a pioneer study ever taken up in the province for academic discourse. It will benefit teachers, students and social workers to approach and analyze their problem in the light of the findings. It will help them formulate counseling and emotional support strategies for the affected families. In addition, this study will help the policy makers to develop more feasible and effective approach to deal with the issue of intellectual disability.

<table>
<thead>
<tr>
<th>Particular</th>
<th>Frequency</th>
<th>% age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>32,93,155</td>
<td>100</td>
</tr>
<tr>
<td>Blind</td>
<td>2,63,452</td>
<td>8%</td>
</tr>
<tr>
<td>Deaf and Dumb</td>
<td>2,63,452</td>
<td>8%</td>
</tr>
<tr>
<td>Physically disabled</td>
<td>6,25,699</td>
<td>19%</td>
</tr>
<tr>
<td>Intellectually disabled</td>
<td>4,61,043</td>
<td>14%</td>
</tr>
<tr>
<td>Multiple disability</td>
<td>2,63,452</td>
<td>8%</td>
</tr>
<tr>
<td>Others (not categorized)</td>
<td>14,16,057</td>
<td>43%</td>
</tr>
</tbody>
</table>


Methodology:

This research employed Qualitative Research Design and used research tools such as In-depth Interviews (with 12 parents) and Focus Group Discussion (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, with special focus on equal representation from nuclear and joint family structure. In this study, nuclear family was taken as a social. While, joint family system was taken as a social system comprised of parents with their unmarried children and other family members (9). Furthermore, In charge of each center (3 In charges) was also interviewed for
the purpose of exploring the nature and type of services rendered for such children. The interviews were initially recorded in a digital audio recording device, however, before interview; informed consent was also taken from the respondents.

Parents were selected from the official lists of the three centers working for children with intellectual disability in district Peshawar and district Haripur (see Table 2 & 3) with special focus on equal representation from nuclear and joint family structure.

Results:

Table 2: Detail of In-depth Individual Interview (IDI) with parents at the following Institutes:

<table>
<thead>
<tr>
<th>Name of Districts</th>
<th>Total IDI with parents</th>
<th>Parents would be selected from the following age group of CID</th>
</tr>
</thead>
<tbody>
<tr>
<td>District Peshawar:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Institute of Physically &amp; Mentally Retarded Children- Bashirabad.</td>
<td>06 (3 Nuclear &amp; 3 Joint Family)</td>
<td>2 2 2</td>
</tr>
<tr>
<td>ii. Special Education Center-Hayatabad Peshawar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>District Haripur:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Institute for Physically &amp; Mentally Retarded Children- Kala Bad Haripur</td>
<td>06 (3 Nuclear &amp; 3 Joint)</td>
<td>2 2 2</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>4 4 4</td>
</tr>
</tbody>
</table>

Table 3: Detail of Focus Group Discuss (FGD) with parents in both districts

<table>
<thead>
<tr>
<th>Name of Districts</th>
<th>Total Number of FGDs</th>
<th>Fathers</th>
<th>Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>District Peshawar:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Institute of Physically &amp; Mentally Retarded Children- Bashirabad and</td>
<td>02</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>ii. Special Education Center-Hayatabad Peshawar</td>
<td>7 x 2= (14 parents)</td>
<td>(7 fathers)</td>
<td>(7 mothers)</td>
</tr>
<tr>
<td>District Haripur:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Institute for Physically &amp; Mentally Retarded Children- Kala Bat- Haripur</td>
<td>02</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>7 x 2= (14 parents)</td>
<td>(7 fathers)</td>
<td>(7 mothers)</td>
</tr>
</tbody>
</table>

After In-depth Interviews and Focus Group Discussion (FGD) with parents and family members having children with intellectual disability as per study design, the following effects were found.

- Social exclusion was found among parents in nuclear family structure as compared to joint family.
- Strain relation and family break-down was found among parents from nuclear family due to lack of family support as compared to joint family.
- Extra fatique was found among working mothers due to extra care of child, multiple roles in the home and works.
- Institutional support was found significant among parents in releasing extra pressure of child care.

Discussion:

- Social exclusion was found among parents in nuclear family structure as compare to joint family.
Social exclusion, which refers to lack of participation of people in activities such as employment, voting and family relations and customary activities (3), was found caused by the presence of child with intellectual disability. The parents of such children could not participate in social activities due to their full time involvement in taking care of such children. Even they were unable to participate in the vital ceremonies of their community like deaths and marriage ceremonies which are celebrated and performed collectively in Khyber Pakhtunkhwa.

On the other hand, parents of joint family structure could easily participate in social activities of their community due to the family support they sought from mother-in-law, sister-in-law or other members. A mother in this regard stated her story of social exclusion in Individual Interview as:

“I was living a very happy life: participated in family events actively; was a happy person and used to attend happy occasions like marriage ceremony. But after the birth of my two disabled children my life totally changed. Now, I do not participate in ceremonial activities of my due to full time involvement with my children. Similarly, my husband used to go to gym and met frequently with friends. Now, he is thinking all the time about the treatment and rehabilitation of his children. After office time, he spends most of the time at home to manage his children” (Individual Interview in Peshawar).

The same was endorsed by mothers in a Focus Group Discussion (FGD) that:

“We cannot participate in most of the ceremonies due to the care of our child. In case of unavoidable situations, we attended but for a very short time, however, extremely worried about our child at home” (FGD in Peshawar).”

A mother in this regard reported in an Individual Interview that:

“My sister in law and other relative look after my child during my job timing and, hence, I am somewhat able to participate in community events” (Individual Interview in Haripur).”

The same was almost explained by a father in Individual Interview in Haripur that:

“My mother and sisters strongly supported my wife in child care of both normal and disabled child. Furthermore, she participates in community events by leaving her child with sister in laws in the family”.

It shows that parents residing in nuclear structure are more prone to social exclusion which have also been endorsed by Jamison (1965) in his study that extreme burden of care of the defective child in home cannot be endured long without some form of help. However, parents belonging to joint family structure have no problem of social exclusion to family support. Furthermore, Institutional support in child care can also reduce social exclusion of parents. (8)

- Strain relation and family break-down was found among parents from nuclear family due to lack of family support as compared to joint family

A child with intellectual disability may have impact on the rapport of husband and wife. The child may carry parents nearer together with a pledge to distribute the burden and liability of children and household behaviors. On the other hand, the child’s existence may result in discord and conflict. Strained spousal relationships were found as an adverse affect of extra care due to lack of family & institutional support. In such situation, children with intellectual disability have been abandoned either by
both or one parent. However, the family members were reluctant to share that the separation occurred due to the birth of child.

A mother in this regard narrated her experiences during Individual Interview as:

“My husband is a daily wager; he is also addicted to drugs. The child needs extra care in term of medication and nutrition but he cannot afford it. He blames me for disability of his child and beats me” (Interview in Peshawar).

Similarly, a teacher and family friend of child with intellectual disability explored facts about the family break-up as:

“I know the family of child whose parents got separated since long. They were living in nuclear structure and both were doing job. Owing to extra care of child, mother was unable to extend care to him; it affected the relation of the spouses which ended in divorce. Currently, he lives with his grandparents where he lives a happy life; however, they cannot extend care like his own mother”

Furthermore, a paternal uncle of the child with intellectual disability shared almost the same issue that:

“He lives with me and he considers me as his father. His parents were living in separate home; however, 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 him; however, she is marrying in near future and hereafter his grandmother will look after him” (Interview in Haripur).

It was found that family face disturbed relationship between spouses due to the birth or presence of such children. In such situation, children with intellectual disability were abandoned either by both or one parent. However, the family members were reluctant to share that separation occurred due to the birth of child.

- Extra fatigue was found among working mothers due to extra care of child, multiple roles in the home and works

It was observed that such children also disturbed parents in making balance between work and household activities. The husband or wife, typically the latter, might have to give-up a job that contributes a substantial amount of family income to stay at home with the child. Working mothers in nuclear family faced psycho-social burden. They faced extra problems in making balance in household and work activities. They are supported by institutional care like day care centers and special education centers in advanced societies; unlike, family support provide relief to such parents in under-develop societies like Pakistan.

Working parents faced extra burden and fatigue due the care of children with intellectual disability in managing household and work activities. Working Parents belonging to joint families left their children with their grandmothers or other close family members during duty hours which they considered as the blessing of such family. Similarly, a working mother sharing her feeling as:

“I remained continuously in stress due to the multiple roles performed both within as well as outside the four- wall; I need 2 hours for feeding my child with intellectual disability. I am a working woman as well and have to give time to my other normal children. Beside this, I give time to household activities; this extra effort has made me sick with high blood pressure.”
Almost the same was expressed by another working woman who stated that:

“Initially, I was doing a private job, but after the birth of Sibghaa (child with Intellectual disability in Haripur), it was extremely difficult to make balance in work and household activities, hence, I had give up that job for the sake of my daughter. But, I have restarted my job after admission of Sibgha in the Centre for Children with Intellectual Disability; however, extremely worried now owing to the suspension of school transport facilities due to installation of barrier on the road for security reason in my area”

It was found that parents especially mothers dwelling in nuclear families, having no support of other family members or any institution, face psycho-social problems. The same is also asserted by Jamison (1965) that the health of the mothers who usually bear the brunt of care for these children are often drastically affected. Chronic fatigue and nervous exhaustion is common in those families where there is limited help in the management of a retarded child. Occasionally the mother may verge on a mental breakdown. (8,12,13) On the other hand, parents who have support of other family member feel relaxed.

- **Institutional support was found significant among parents in releasing extra pressure of child care.**

It was found that the instrument in the centers for physiotherapies were out-dated and dysfunctional. Speech therapy is unavoidable need of the children suffering from speech problem; however, there was no trained professional at any institute. Moreover, no such instrument or technology was found for speech therapy. However, parents were happy due the child’s participation in the school for getting breathing space for managing other household activities.

A mother in this regard shared her feeling during an Individual Interview in Peshawar as:

“They have not observed any development in the social and academic skill of my child, however, I feel relaxed due his enrollment in the center which provided me a breathing space for managing household activities”

An older brother of three children with intellectual disability stated almost the same in an Individual Interview in Haripur:

“They are not satisfied from the progress of our children at school. My two younger brothers have learnt abusive language there. Even, they acted 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 teachers in their school is trained. However, my mother manages household activities during absence”

It was found that children with intellectual disability were unable to develop their social skills or treat physical defect through different therapies (14). The burden of such care almost exclusively lies on the family and family members. Hence, it was noted that institutional support carry significant positive effects on the sharing go burden of care taking of such children.

**Conclusion:**

Intellectual disability among children is a condition which affects their learning and social functioning in day to day life. Furthermore, its prevalence also affects the family members in carrying out multiple social roles in their respective communities. Such affects are more adverse in nuclear families as compared to joint families. However, the adverse
affects on the families in general and nuclear families in particular can be minimized by the social (family) and institutional supports. Such support can make them socially included and protect them from psychosocial breakdown.

Beside family support, there is a need of expanded institutional support by establishing day care centers and institutes in rural as well as urban localities of the province. The already existing centers in the province need proper equipments, trained teachers, therapists and modern technologies.

References:


