Do Socio-Economic Dynamics Matter in Intellectual Disability among Children?

Shakeel Ahmed[*], Noor Sanauddin[†] & Imran Ahmed Sajjid[‡]

Abstract:

This mixed method research explores the socio-economic dynamics contributing to intellectual disability (ID) among children. It is generally believed that ID in children is caused by genetic, biological and psychological factors. Nonetheless, socio-economic dynamics such as financial status, marriage pattern, family structure, locality of residence also contribute to the development of ID among children. A mixed method research designed was carried out to find out the socio-economic dynamics of intellectual disability. A total of 58 parents whose children were admitted in special education centers in Khyber Pakhtunkhwa took part in this study. Out of this total, 10 in-depth-interviews were conducted with parents having children with ID. Similarly, 4 Focused Group Discussions (FGDs) were carried out with parents and caregivers of intellectually disabled children. A questionnaire was also distributed among 20 parents for further exploration. It was found that the number of male children with ID was higher as compared to female children with ID in the special education schools/centers. This higher number of male children was due to the patriarchal structure of society where male are preferred over female in all matters of life. Similarly, endogamous marriages, birth of child at home, low financial background of parents, lack of awareness, cultural hurdles and patriarchal structure of the family were the major causes of ID in the research area.

Keywords: Children, Intellectual Disability, Socio-Economic Status, Special Education

Introduction

The socio-economic status of a person plays significant role in his/her overall social and physical development, including intellectual development (American Psychological Association, 2016). Socio-economic status is measured in terms of income, education and occupation. These factors provide social standing to an individual and family. Researchers such as Link & Phelan (1995) assert that poor socio-economic conditions cause health complication for the children that may lead to intellectual disability. For instance, the exposure of child to poverty may encountered him to various social and material hardships which have vital effects on children's development, life opportunities, and overall life expectancy (Bradshaw *et al.*, 2001). On the other side, individuals and groups who belong to higher socio-economic status who have money, power, education, knowledge and social network have positive health outcome. Resultantly, they are less prone to such vulnerabilities (Peng & Carol, 2009).

[*] Department of Social Work, University of Peshawar
[†] Department of Sociology, University of Peshawar
[‡] Institute of Peace and Conflict Studies, University of Peshawar

Besides socio-economic standing of individual and families, researchers such as Aneshensel *et al.* (1991) propose that the social structure of a community might also contribute to intellectual disability. Furthermore, the adverse socio-cultural conditions, particularly those involving a deprivation of normal stimulation, may play a primary role in the etiology of mental retardation. As Kingsley Devis (1988) wrote in his famous essay "*Extreme Isolation*", the ability to act like others and think like others is dependent upon the exposure the individual has to other people. In the case of Anna, an isolated girl for early six (6) years, it was revealed that deprivation from interaction with other human beings have a strong association with developmental disability. After many studies on isolation, intellectual disability has been divided into two sub-groups: (i) mental retardation resulting from extreme isolation, and (ii) mental retardation resulting from inferior or poor quality of interaction with his/her cultural environment and other people. Children who fall in the second category usually have mild mental retardation. They make up the majority of persons labeled as mentally retarded and show no identifiable brain pathology. They are usually not diagnosed as mentally retarded until they enter school and have serious difficulties in their studies.

A number of studies (see Weiss, 2016 and Liora, 2016) point out that most of these children come from poverty-stricken, unstable, and often disrupted family backgrounds characterized by a lack of intellectual stimulation, an inferior quality of interaction with others, and general environmental deprivation. Islam, Durkin & Zaman (1993) carried out a study on children aged 2 to 9 years in Bangladesh. They found that mild mental retardation was strongly associated with significantly low socio-economic status. However, severe mental retardation has a weak link with socio-economic status. Durkin, Hasan and Hasan (1998) conducted a study on children in Karachi, Pakistan. The results show that both mild retardation and severe retardation were strongly associated with mothers' lack of education, a socio-economic dimension. Slone, Durrheim, Lachman and Kaminer (1998) conducted a 4 year study in Cape Town, South Africa, on 538 children who were diagnosed mentally retarded. They found that a significant majority of mild mentally retarded were from lower socio-economic background. Sharma, *et. al.* (2015) conducted a study on 2420 children aged 1 to 10 years in district Kangrha of Humachalpardesh, India. They used Uday Parekh scale of assessment for socio-economic status. The results showed that of 52 children (2.15%) who were found to be mental retardation positive, 69% of them were from a lower middle class families while 28.3% were from middle class families.

El-Hazmi, Al-Swailem, Al-Mosa, and Al-Jarallah (2003) researched the prevalence of mental retardation in Saudi Arabia. Although their study does not indicate any relationship between socio-economic status and mental retardation, they found that 83.2% of mentally retarded children were not attending school or any special education programme.

Research Question

This research is guided by one question:

- Is there any relationship between intellectual disability in children and socio-economic status of families in Khyber Pakhtunkhwa?

Methodology

This study was carried out in two districts of Khyber Pakhtunkhwa i.e., Peshawar and Haripur. The respondents included parents and other family members, 58 in total. Selection of respondents was made purposively from lists of the following three Special Education Centres.

i. Special Education Complex, Hayatabad, Peshawar
ii. Centre of Physically and Mentally Retarded Children, Bashir Abad, Peshawar
iii. Centre for Physically and Mentally Retarded Children, Haripur.

Table 1 Selection of Respondents from the Special Education Schools in KP

Special Education School/Centre	Interviews	Questionnaire	FGDs
Special Education Complex, Hayatabad, Peshawar	03	05	1 (1 x 7 = 07)
Centre of Physically and Mentally Retarded Children, Bashir Abad	02	05	1 (1 x 7 = 07)
Centre for Physically and Mentally Retarded Children, Haripur	05	10	02 (2 x 7 = 14)
Total	10	20	28

Mixed method of research was adopted for which interview, questionnaire and FGDs were administered for data collection. The purpose of this triangulated method was to find out the various social and economic factors that causes intellectual disability in children. For this purpose, 58 parents were selected purposively. Out of this total, 10 Individual In-depth Interviews were conducted with 10 parents including fathers and mothers. They were from diverse socio-economic background. Moreover, data was collected from 20 parents and family members through questionnaire for exploring socio-economic characteristics responsible for intellectual disability. In addition to that, Focus Group Discussions were conducted with parents whose intellectually disabled children were enrolled in special education centers in Haripur and Peshawar.

Table 2 Area-wise Data Collection/ Number of Interviews

Districts	**Interviews**	**Questionnaires**	**Focus Group Discussions (FGDs)**
Peshawar	05	10	02 (2 x 7 = 14 participants)
Haripur	05	10	02 (2 x 7 = 14 participants)
Total	10	20	28

Study Findings

This section presents data regarding socio-economic causes of intellectual disability among children. Such socio-economic factors reflects the relationship of child with intellectual disability with respondents, gender and age of children, type of disability, place where birth of child occurred, and other socio-economic characteristics of respondents and their children.

Table 3 Relation of Child with the Respondents

Relation of Child with Respondents	No. of Respondents	Percentage
Mothers	20	34
Fathers	26	46
Grand Mothers	05	8
Uncles/Siblings	07	12
Total	58	100

The respondents from whom information was gathered were parents & family members of children with intellectual disability such as father, mothers, grandmother and siblings. They were interviewed at the selected special education schools in Khyber Pakhtunkhwa. In this study, 46% of the total respondents were fathers, 26% were mothers, and 12% were uncles or siblings of the intellectually disabled children.

Table 4 Age of Children with Intellectual Disability

Gender of Child with ID	f	%	Age			
			3-6	7-10	11-14	15-18
Boy	49	84	11 (22%)	14 (28%)	12 (25%)	12 (25%)
Girl	09	16	02 (22%)	04 (44%)	02 (22%)	01 (11%)
Total	58	100	13 (22%)	18 (31%)	14 (24%)	13 (22%)

This study shows that 49/58 (84%) were male children who suffered from intellectual disability and whose parents/family members were interviewed, while, 09/58 (16%) were female children. The selection of the gender of the child was not purposive; they were selected randomly. However, the number of male children in the study area (special education centers) was higher as compared to female children.

Table 5 Types of Disability

Types of Disability						
Gender	Moderate disability	Sever disability	Hyper disability	Cerebral Palsy	Multiple Disability (physical, visual, hearing & ID)	Total
Boys	12 (25%)	13 (26%)	06 (12%)	12 (25%)	06 (12%)	49 (84%)
Girls	02 (22%)	03 (33%)	02 (22%)	01 (11%)	01 (11%)	9 (16%)

It is evident that a total of 49 (84%) male children who were enrolled in the special education centers were suffering from different types of disabilities such as moderate, severe, hyper-activity, cerebral palsy while 9 (16 %) female children were suffering from different types of intellectual disability. In this study, it was found that most of the children were inflicted with severe type of disability i.e. 26% among boys and 33% among girls. While 24% boys and 22% girls were suffering from moderate ID. Hyper-active intellectual disability is a type of disability in which a child is showing aggressiveness and hyper activity. Such problem was present in 24% of boys 22% of the girls admitted in the special education centres. Similarly, 12% boys were suffering from multiple disabilities at one time i.e. physical, hearing, speech as well as intellectual disability while 12% girls were suffering from the same type of multiple disability. The high prevalence of intellectual disability among male children was not due to any genetic reason rather the number of male children were higher than female in the selected institutes. This shows that parents are more likely to admit their male children in the special education centers as parents are more concerned about their male children as compared to female in Khyber Pakhtunkhwa.

Table 6 Place Where the Birth of the Children Took Place

Gender	**Place of Birth**			
	Home		**Hospital**	
	f	**%**	**f**	**%**
Boys	33	67	16	32
Girls	06	66	03	33
Total	39	67	19	33

When the parents and other close family members were inquired about the birth of child, it was a surprising fact that most of the children were born at home under the custody of traditional nurse called *Daee.* This study shows 67% children who suffered from ID were born at home while 33% children were born in local dispensary or hospital. It is generally believed that due to the expansion of health facilities at grass root level in Pakistan in general and Khyber Pakhtunkhwa province in particular, more children might be born at

hospital under the custody of professional medical practitioners. However, the situation is totally inverse. When it was probed during In-depth Interviews, most of the parents said that they are either unable to afford the cost of hospital, or that they believed that the help of a traditional birth attendant (*daee*) was enough. It was noted most of such parents were poor and had lack of resources as well as awareness. In addition, it is culturally considered prohibited that pregnant women shall be expose to other persons in hospitals during birth which is considered a matter of honour (*ghairat*) for the family.

These socio-cultural and economic hindrances cause intellectual disability among children. As the family members and traditional nurse (*daee*) were unable to handle children during complication in delivery stage, resultantly, the children either died or suffered from permanent intellectual disability. Cerebral Palsy and other severe intellectual disability is the cause of damage to the backbone or lack of proper supply of oxygen to the children during pregnancy stage.

Table 7 Marriage Type of Parents

Relationship of Parents						
Gender	**f**	**%**	**Cousin**		**Outside family**	
			f	**%**	**f**	**%**
Boys	49	84	29	59	20	41
Girls	09	16	06	67	03	33
Total	58	100	35	60	23	40

Beside socio-cultural constrains and economic deprivation, endogamous marriages is considered as the major cause of intellectual disability in children. Endogamous marriages is cultural practice which is prevalent in Pakistan in general and in Khyber Pakhtunkhwa province in particular. In this study, it was found that 60% parents had endogamous or cousin marriages while 40% were from exogamous marriages. It is generally believed that the defected genes multiply during endogamous marriage wherein the chances of disability is higher as compared to exogamous marriage.

Table 8 Family and Residence Pattern

Gender of Child with ID	**f**	**%**	**Family Structure**		**Residence**	
			Nuclear	**Extended**	**Rural**	**Urban**
Boy	49	84	21 (43%)	28 (57%)	20 (41%)	29 (59%)
Girl	09	16	03 (33%)	06 (67%)	02 (22%)	07 (78%)
Total	58	100	24 (42%)	34 (58%)	22 (38%)	36 (62%)

In this study, participants were selected from both type of family structures and locality pattern i.e. rural and urban. These two social factors have close association with prevalence of intellectual disability as rural areas are normally deprived from health

facility such as hospitals, doctors and other medical professionals. Moreover, people follow strict code of conduct, such as observing purdah which restricts their access to health facilities. It was noticed that slightly more parents of intellectually disabled children were from extended families (58%) as compared to nuclear families (42%). Further, 62% parents were residents of urban areas while 38% came from rural areas. However, it was found in this study that in spite of residence in urban area, children were born at home instead of hospital in most cases. This shows that people either avoid hospital due to cultural reasons or poor financial conditions. Further, the people's confidence in maternity hospitals was very low as some participants were highly critical of treatment facilities at government hospitals.

Table 9 Financial Status of the Children's Parents

Gender			**Upper**		**Middle**		**Lower**	
	f	**%**	**f**	**%**	**f**	**%**	**f**	**%**
Boys	49	84	08	16	13	27	28	57
Girls	09	16	01	11	02	22	06	67
Total	58	100	09	16	15	26	34	58

It was discussed in earlier part that many people prefer child birth at home. It was found that in total 59% of the parents who took part in this study belonged to lower financial background. This shows that the prevalence of ID is higher among families which have low financial status. Hence, poverty is responsible for the cause of ID among children as poor mothers suffer from malnutrition, unable to get vaccination during pregnancy and could not afford the expenses of hospital for child's delivery. Similarly, such families prefer endogamous marriages over exogamous marriages as the former type is less expensive financially. In other words, poverty of parents has a multiplying effect as it increases all the risks and causative factors associated with ID in children.

Discussion

There is high prevalence of endogamous marriages in many communities throughout the world, especially in countries of the Middle East, Northern Africa and South Asia. Among the major populations studied, the highest rates of endogamous marriages have been associated with low socioeconomic levels, illiteracy and rural residence (Mokhtar & Abdel-Fattah, 2001). Although marriages between close relatives are discouraged (or even illegal) in North America, in many cultures (particularly in the Middle East, Asia, and Africa) preferred marriages are between first cousins, or less commonly, between an uncle and niece or between double first cousins (Bittles, 1998; Harper, 1998). The offspring of endogamous unions may be at increased risk for genetic disorders because of the expression of autosomal recessive gene mutations inherited from a common ancestor. The closer the biological relationship between parents, the greater is the probability that their offspring will inherit identical copies of one or more detrimental recessive genes (Robin *et al.,* 2002).

Socio-economic dynamics play an important role in causation of intellectual disability. In the study, it was found that 60% of the parents had endogamous or cousin marriages as result of which wherein the chances of intellectual disability are higher as compared to exogamous marriage. According to the findings of recent study conducted by Shaheed Zulfiqar Ali Bhatto Medical University, Karachi, this is a landmark discovery for Pakistan as mental retardation is comparatively high in the country owing to cousin marriages (Akram, 2016). The elevated level of endogamy in Pakistan has led to increased prevalence of genetic disorders, including autosomal recessive intellectual disability (ARID) with an average of 1.1 cases of severe ID and 6.2 cases per 100 live births of mild ID (Akram, 2016).

It was found in this study that in spite of residence in urban area, most children were born at home instead of hospital. This shows that people either avoid hospital due to cultural reasons or poor financial conditions. 48% parents were belonging to lower-middle background and a further 8% respondents were from low financial background. This mean that a total of (48+8) 56% parents having children with ID were from low financial background. Hence the prevalence of ID is higher among families have low economic status.

Similarly, it was found that the participation and enrollment of female children with ID in the centres were low as compared to male children. The study shows that the first reason for low enrollment of female children in special education school was that they were generally considered as non –productive segment of society. Consequently, most of the parents and family members are least interested in their education and rehabilitation. It was also found that parents tend to drop-out female children early from the special education school due to fear of sexual exploitation when they reached puberty. Such sexual exploitation may be from other children or staff of the institutes/centers. To add to the problem, it was discovered that that there is no separate centres or schools exclusively for female children. As a result, female children suffering from ID remain neglected as compared to male children.

Conclusion

While the role of genetic factors in causing intellectual disability among children cannot be ignored, intellectual disability has a strong association with socio-economic dynamics. This has been so far a neglected area of investigation and debate in Pakistan. The culture of cousin and endogamous marriages is a significant cause of ID among families in Khyber Pakhtunkhwa. Significant association reflects that most of the marriages in Pakhtun society are consanguineous in nature which are preferred for maintaining their cultural and family stability.

Furthermore, low economic condition of families was also found responsible for ID among children. Families with low socioeconomic condition do not prioritize pre-natal screening and normally prefer delivery of children at home under the custody of traditional nurses. As a result, children receive damages due to mishandling during complication which is considered as the other major cause of ID. Such situation can be

prevented if free of cost health facilities are extended to poor area of the districts which may minimize such disabilities. Moreover, a mass awareness campaign is needed about the adverse effects of cousin marriages which causes many health complications among children.

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