Parental Support, Gender, Socio-Economic Status and Habitat of People with Physical Disabilities

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The most important determinant of a country's competitiveness is its human talent - the skills, education and productivity of its workforce and women account for one - half of the potential talent based throughout the world. Over time, therefore, a nation's competitiveness depends significantly on whether and how it educates and utilizes its female talent to foster economic growth and enhance productivity which can be attained by reducing gender inequality. The snap shots of the Gender Gap Index 2009 documenting India to hold one of the lowest positions in the world ranking (114 ranking in the world) is an issue of concern for the stakeholders. Investing in girls' education remains one of the highest return investments that a developing economy can make and, in the current environment (economic recession), may be among the best use of limited funds. The more striking is the fact that 650 million people in the world are disabled of which 300 million live in developing countries, and 160 million are women (Human Rights and Disability Report, 1991). Though the motor disability counts the second highest percentage of disability, it is perhaps the most neglected as it is often felt that this group does not need any special care or attention like the other categories (viz. visual, mental, hearing impaired) and thus characterized as an underrepresented group in the disability movement (DISE, 2009).

There are very few special institutes or organizations which cater to the needs of locomotor disabilities in the country. The normal visibility of the peoples is to focus on the needs of the other categories of disabilities like people with visual disabilities, hearing impaired, and

Volume 5 – Symposium Issue

cerebral palsy as their needs are considered more crucial than the locomotor disabilities where the need is associated with limbs and mobility. Quite often their mobility problem is not taken very seriously by others believing that they don't need any special interventions and that they can have their needs satisfied in a mainstream institute. It's a common practice that people with locomotor disabilities are found in educational and vocational institutes meant for the general population believing they don't need a special one but after some time it is found that they drop out at a greater rate due to accessibility and mobility problem. The absence of a simple ramp in the institutes and community can give an idea of how much this group is neglected. Though this group can smoothly follow the general instruction they face tremendous architectural barriers in the environment which can result in depression, frustration, hopelessness, low level of self concept etc due to absence of a disabled friendly environment to cater their mobility needs (Halder, 2008, Halder, 2009; Tam et al 2003). So one problem leads to another and exaggerates their already existing discrepancies. The role of environment and the important people around where one spent the most crucial days of life is paramount for individual development and wellbeing. Family is the most effective psychological and didactic stimulus for people with disabilities throughout the course of their development. A positive, comfortable and supportive environment provided by the family and its members can bring about amazing and sterling results in the individual in spite of the discrepancies (Sanchez et al 2008; Taylor, 2004).

FAMILY: THE MOST CRUCIAL SOCIAL MINIATURE

Globally family is considered as the most basic unit of socialization, the social miniature which provides its members with protection, companionship and security (Knoll, 1992; Melda, and Agosta, 1992) and because a child's participation in the community typically arises from the

child's participation in the family. Despite modern developments – such as increased mobility, urbanization and industrialization the family still remains the primary support system, the most crucial part of a child's life irrespective of whether the child is with or without disability. Research in Socio-psychological research established the importance of socialization and social support in promoting psychological wellbeing (Raja, et al 1992; Sarason, and Pierce, 1992). Epstein (1992) pointed out that it is the family or home where the child spends much longer than the school so the impact of family and its members is immense (Chen, 1996; He, 1996).

We have come a long way beyond the most controversial debate between segregation and inclusion to finally arrive with the belief that educating and caring for children with disabilities in their families is the best option (Bradley, 1992; Berkson, 1993) for the well being of the child with disability. A secure family attachment throughout childhood contributes to healthy personal development (World Health Organization, 2010; DeVore and Ginsburg, 2005). Research showed that children with disabilities living in residential placements tend to lack close family relationships and normal childhood support required for healthy development (Department of Health, 2001).

All children have a right to a family environment because the family is the "natural environment" for the growth and well-being of children and that children should grow up in family environments to enable the "full and harmonious development of their personalities (Melton, 1996). The parents are the most important teachers who understands and take care of their ward the best and have the most significant impact on them (Lin, 1996). The socio-cultural patterns of society in which the individual lives and stays for the most crucial part of their life have pronouncing effect on a child's life and personality (Chen, 1997; Lin, 1998; Wu, 1997). However, the individual's family is the primary mediating agent acting as a bridge through

Volume 5 – Symposium Issue

which the larger social units exert their influences on the individual. There are interacting and reciprocal effects throughout the family, society and the individual. This means that when we discuss the needs and requirement of an exceptional child it is very necessary to study and know the sub-group where he she is residing and where most part of his/her socialization takes place.

PARENTAL SUPPORT AND PEOPLE WITH DISABILITIES

The rapid change which has taken place down the years in every corner of society is bound to impact the miniature society- 'family'. In spite of all these the family still continues to be the nucleus of support for the child and its wellbeing. Having a child with disability can be a major and usually unexpected blow to any family (Lin, 1996). In Indian society where parents have so much of expectation from their offspring suffer terrific social pressures and are vulnerable to criticism it becomes the hardest reality to comprehend their child's disability. The socio- cultural stereotype of the ideal child and the parent's expectation regarding their offspring not only create undue pressure on the child with disability but also on their parents themselves. It remains a fact that parent knows their child better than all the professionals and that there is no common path to success in rearing a child with disability (Epstein, 1992; Sanchez, et al 2008). It is a fact that in considering the issues of disability we focus so much on the challenged and their immediate needs that we often overlook the most important sub system - 'family'.

The family is the psycho-social environment in which children grow thus it is a critical element in their development. Abundant research has been done on the family environment which includes factors such as parenting style, parental mental health, marital conflict and family stress having an impact on the current and future mental and emotional health and functioning of their ward (Hilton and Henderson, 1993; Huurre, 2000; Kef, 1999). There is evidence that

Volume 5 – Symposium Issue

supports the presence of a significant, enduring and protective effect of positive parenting on adolescent development (Epstein, 1992; Hornby, 1995). It's a fact that the general intervention strategies have been only focusing on the people with disabilities but it's very rare that the family and the role of the parents who rear up and take care a child with disabilities have been taken into consideration for rehabilitation.

Differences with respect to gender and habitat (rural and urban) were also found on the basis of parenting style. Cultural differences were also found with respect to parenting behavior (Nasir, 2008). A study by Chang and Schaller (2000) demonstrated that adolescents with disabilities experience variation of emotional, informational and tangible support from their parents. Research shows positive effect of parental support on the wellbeing of the adolescents with disability (Helsen et al 2000; Huurre, 2000; Kef, 1999; Kracke, 2002). Various kinds of support like emotional or instrumental support may have diverse effects on the self-esteem of the individual with disability.

SOCIOECONOMIC STATUS AND PEOPLE WITH DISABILITIES

The socio-economic status of an individual is important consideration while focusing and framing on the intervention measures and rehabilitation strategies for the people with disabilities. Globally about 14.08 million people with disability are from rural areas as compared to the urban population estimating only 4.4 million (Human Rights and Disability Report, 2002). There appears to be almost universal recognition among academics, professionals and the public at large that students from various social class, ethnic and racial backgrounds differ markedly in their academic performance and achievement. So economic condition, parent's education, occupation all these factors have significant effect on the life, personality and achievement of the

Volume 5 – Symposium Issue

individual and continue to be a powerful inhibitor or facilitator of academic success for children (Inclusion International, 2006). Poor prospects for education and employment among disabled people, and the intense stigma that they often face, are expected to drive them into poverty (Elwan, 1999). Having a disabled member in a family entails a lot of expense (Elwan, 1999). Around 45 % of families with a person with disability report an adult missing out of work to care for the disabled member. There is a vicious relationship between poverty and disability (Halder, 1999; Thomas, 2005b). Norwich (1997) maintains that the hopes and fears of the parents seemed to be more a reflection of their socio-economic background than their status of being disabled. However research shows inconsistent results regarding the impact of parental education on the ward with disability (Nasir, 2008). Thus further research is necessary for better understanding of this phenomenon.

EMERGENCE OF THE PROBLEM

The marked and profound influence of home environment including role of parents and the socio-economic status have on the development of people with disability is indisputable. Although a lot of researchers have tried to some extent to explore the nature and the effect of parental support on the people with disabilities but much more needs to be done on this very crucial issue (Chian, 1995; Epstein, 1992; Hornby, 1995; Lin, 1996; Wu, 2001). It is very important to study and know the sub-group where the people with disabilities resides and socializes the most. Thus it becomes imperative from the above discussion that family, parental support, socio-economic status of the people with disabilities are significant factor and need thorough investigation in order to provide realistic rehabilitation strategies and intervention

Volume 5 – Symposium Issue

measures. In the light of the above facts the present investigator framed the following objectives for the study:

OBJECTIVES OF THE STUDY

- To investigate the nature of family support of the physically challenged with respect to gender (males and females).
- To investigate the nature of parental support of the physically challenged with respect to habitat (rural and urban).
- To investigate the nature of parental support of the physically challenged with respect to socio-economic status (high, moderate and low).

HYPOTHESIS

- There would be no significant difference in parental support of the physically challenged with respect to gender (male and female)
- There would be no significant difference in parental support of the physically challenged with respect to habitat (rural and urban).
- There would be no significant difference in parental support of the physically challenged with respect to socio-economic status (high, moderate and low).

METHODOLOGY

Sample

The sample was restricted to locomotor disabilities. Data was collected by situational sampling technique from different sources namely educational institutes, vocational institutes, vocational rehabilitation centers, government and non government NGO's, employment

Volume 5 – Symposium Issue

exchanges, hospitals etc. The Eastern part of India (West Bengal) was used for the study due to its significance as the most crowded state and because it has been reported as having a high number of people with locomotor disabilities (DISE, 2009). The study is the result of a project involving 200 (100 male and 100 female) with locomotor disabilities. The age range of the subjects was 18 years to 20 years. The nature of disability includes amputee, burn, polio, or bone anomalies, and disabilities due to various diseases etc. The sample consists of 45% to 90% disability as certified by the government hospitals in India. The disability assessment certificates by the board of doctors indicating the percentage/severity of disability has been taken as a measure. Figure 1 shows the nature of disability of the samples in the study.

The final break of the samples is as follows:

Persons with Locomotor disability	Sample Size		
Male	100		
Female	100		
Total	200		

Tools

• General information schedule (GIS): The *first* section comprised of demographic characteristics of the subjects such as age, gender, habitat etc. The *second* section comprised of information about their nature of disability.

Volume 5 – Symposium Issue

- Socio-economic background schedule: This consisted of information regarding parent's education, income and occupation.
- Parental support semi structured interview schedule: This comprised of selected dimensions for the study (viz medical support, physical support, Moral support, educational support, and vocational support).

Data Collection and Statistical Treatment

At initial stage tracking these locomotor disabilities was really a cumbersome affair, which was done by taking help from various special institutes and special employment exchanges spread over different parts of West Bengal. After collecting the addresses the survey packets were made containing an informal cover letter and self-addressed, stamped envelope and mailed to 1000 randomly selected potential respondents. Instructions were provided for those needing help and they were directed to consult the author for assistance. Only 250-300 locomotor disabilities responded via phone or letters. Final data was collected from 200 persons with locomotor disabilities and their families, teachers and parents by personally visiting each individual and their family at their home or institutes on the basis of personal interviews, discussions with parents, teachers and the disabilities person concerned. Some of the institutes also arranged for some interviews to be taken at the spot. Very few with minor disability also managed to come at the researcher's home. Quantitative and qualitative analyses were done for the study and findings were supported by case studies of few locomotor disabled. The greatest challenge for the researcher was to get persons with locomotor disabilities who have at least

Volume 5 – Symposium Issue

qualified class X as most of them dropped out before or after class V due to various architectural barriers.

Quantitative analyses was done for the study including 't' test, one way ANOVA and correlation.

Results have also been graphically plotted for vividness.

FINDINGS AND DISCUSSION

Nature of Disability

Data revealed that 46% (Figure 1) of the people with locomotor disabilities to be polio victim, 13% did not knew much about their own specific nature of disability although they had locomotor problem, 25% cases were congenital, 6% were victim of various other diseases, 4% have acquired disability due to burn, another 4% were amputee cases, and finally 2% were victim of accidents and acquired disability in later years of their life. Parents were unaware and ignorant of the medical treatments available. Some parents were even unaware of the immunizations available and some also didn't have the knowledge of polio or its consequences or other related disease. Some parents from rural areas instead of going to doctors went to local quacks or applied some home remedies easily accessible as advised by neighbors which in some cases adversely affected in impairing the child exaggerating the situation.

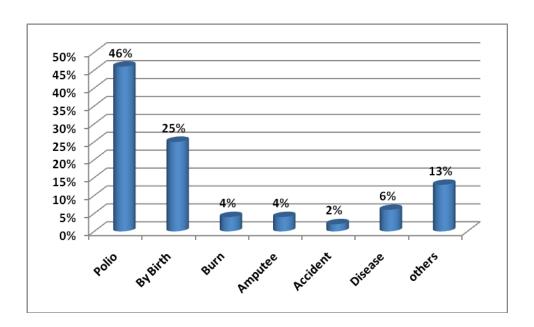


Figure 1: Nature of Disability

Verification of Hypothesis (H1); Parental Support of the People with Physical Disabilities with Respect to Gender (Male and Female)

Table 1 shows one-way ANOVA results of parental support of the people with physical disabilities with respect to gender. The F values indicated significant differences in parental support along with the variables 'peri-natal care', 'physical support' and 'vocational support' with respect to gender (F = 3.22, F = 13.36, F = 3.07, F = 3.67) respectively. In the dimensions of the parental support as mentioned ('peri-natal care', 'physical support' and 'vocational support') it was found that the males had received more support from the parents as compared with the females. Similar findings has been established by many earlier and ongoing studies in the developing country like India that a female being born with a disability faces triple jeopardy; due to their gender, disability and their birth in the developing nation (Ghai, 2001, 2003, Halder,

Volume 5 – Symposium Issue

2009, 2008). The present study also highlighted the biasness of family environment and parental behavior and responses towards their ward with disability with respect to gender. The study showed very strong difference in the peri-natal care with respect to gender as during interview we found that most of the delivery took place in an unhygienic condition by a local person (commonly called Dhai in India). There are evidences of parental rejection (Mittal, 2003) and low level of involvement (Paulson and Sputa, 1996) towards their ward due to their disability.

Thus Hypothesis 1, there is no significant difference in parental support of the people with physical disabilities with respect to gender (male and female) is rejected.

Table 1: One-Way ANOVA results of parental support scores of the people with physical disabilities with respect to gender

Variables	Gender	N	Mean	S.D	F
Pre-natal care	Female	100	17.14	7.59	2.97 NS
	Male	100	19.42	5.47	
Peri-natal care	Female	100	2.34	1.89	13.36**
	Male	100	3.72	1.88	
Post-natal care	Female	100	13.74	4.91	1.85 NS
	Male	100	15.04	4.64	
Medical support	Female	100	52.86	12.78	2.58 NS
	Male	100	56.62	10.51	
Physical support	Female	100	24.62	4.20	3.07*
	Male	100	26.02	3.78	
Mental support	Female	100	16.58	7.85	0.01 NS
	Male	100	16.48	3.54	
Educational	Female	100	60.54	10.74	2.41 NS
support	Male	100	63.46	7.86	
Vocational	Female	100	6.82	3.39	3.67*
support	37.1	100	10.70	4.00	
	Male	100	10.70	4.09	
Parental	Female	100	203.16	32.1	3.22*
Support Total	Male	100	213.6	23.70	

^{*=} significant at 0.05 level, **= significant at 0.01 level

Volume 5 – Symposium Issue

No significant differences were noted in the other dimensions of parental support namely 'post-natal care', 'medical support', 'mental support', 'and educational support'. It was found in the study that the male child got very positive 'physical support' (M = 26.02) meaning providing physically accompanying the child for daily activities in and outside the house when compared with the female child with disability (M = 24.62). Parents in the study tried their best to provide physical support as and when needed from time to time right from very early period. They were moreover overprotective so much so that they did not let their ward alone anywhere which resulted in over dependence of the locomotor disabled on their parents in some cases. Due to their disability it was difficult for them to move from one place to another so constantly accompanying them physically was mandatory for the parents.

In 'vocational support' as well the parents were found to be more supportive towards the male child with disability (M = 10.72) as compared with the female child with disability (M = 6.82). In some cases it was also found that parents were more focused on vocational courses so that they may be financially independent, this may be taken as a reason that very few went for further education. Parents were unaware of the facilities, provisions, courses available, and the institutes offering such courses with no fees or with nominal charges. Most of the institutes offering such courses were far away beyond their reach or with no residential facilities. The Vocational Rehabilitation Center (VRC) offering courses to the challenged were on full time basis thus it was not possible for the parents to send their female child with disability to pursue vocational courses. Due to financial constraints if the parents have to acquire the course from a private organization with more fees they normally chose it for their male child. In such cases the female child seems to suffer. Moreover there was also a huge gap in the type of courses offered

in the VRC's and the demand of the job market. As most of the courses in the government institutes meant for the disabled were for the males and were not conducive for the females so usually the females did not get interested or later on dropped out.

Thus the overall results showed that gender differences prevailed in providing support to their disabled ward and that parents were more supportive in the case of a male child (M=213) than the female child (M=203) with disability. This brings back the general notion that still the societal responses are biased towards females with or without a disability.

Verification of Hypothesis (H2); Parental Support of the People with Physical Disabilities With Respect to Habitat (Rural and Urban)

Table 2: One-Way ANOVA results of parental support scores of the people with physical disabilities with respect to habitat (rural and urban)

Variables	Gender	N	Mean	SD	F
Pre-natal care	Rural	50	17.16	7.04	2.35 NS
	Urban	50	19.20	6.28	
Peri-natal care	Rural	50	2.60	1.98	2.88 NS
	Urban	50	3.38	1.97	
Post-natal care	Rural	50	14.24	4.73	0.08 NS
	Urban	50	14.51	4.89	
Medical support	Rural	50	52.82	11.70	2.19 NS
	Urban	50	56.31	11.75	
Physical support	Rural	50	24.98	3.93	0.59 NS
	Urban	50	25.60	4.13	
Mental support	Rural	50	16.47	3.38	0.01 NS
	Urban	50	16.58	7.61	
Educational support	Rural	50	60.29	10.02	2.71 NS
	Urban	50	63.40	8.86	
Vocational support	Rural	50	5.89	3.41	0.81 NS
	Urban	50	6.47	3.08	
Parental Support Total	Rural	50	205.42	26.86	1.18 NS
	Urban	50	211.36	30.6	

NS = Not significant

Volume 5 – Symposium Issue

The insignificant 'F' values indicated (Table 2) no significant difference in parental support with respect to geographical location (Rural and urban). Thus people with disabilities in both rural and urban locality projected their uniformity in parental support.

Thus Hypothesis 2, there is no significant difference in parental support of the physically challenged with respect to geographical location (rural and urban) is accepted.

Parental Support and Socio-Economic Status (High, Moderate and Low)

The F values (table 3) clearly indicated that there were significant differences in parental support with respect to socio-economic status (high, moderate and low) of the people with physical disabilities. People with disabilities belonging to high socio-economic status were able to be supportive for the upbringing of their ward with disability as compared to moderate SES, on the other hand the lowest SES people seem to be providing the least supportive environment (F = 225.79, F = 215.50, F = 200.76) respectively.

Significant differences were noted among high, moderate and low SES with respect to 'pre-natal care', 'post-natal care', 'medical support' and 'educational support'. The people with disabilities with high SES established to have the highest support from their parents with respect to 'pre-natal care', 'post-natal care', 'medical support' and 'educational support' (F = 21.86, F = 17.07, F = 62.29, F = 66.14) respectively. Whereas the people with disabilities with lowest SES established to have the lowest support from their parents with respect to 'pre-natal care', 'post-natal care', 'medical support' and 'educational support' (F = 16.07, F = 13.21, F = 51.03, F = 59.84) respectively. People with disabilities who belonged to moderate SES depicted moderate

Volume 5 – Symposium Issue

level support from their parents with respect to 'pre-natal care', 'post-natal care', 'medical support' and 'educational support' (F = 21.07, F = 15.50, F = 58.64, F = 64.39) respectively. In the rest other dimensions no significant differences were noted among the people with disabilities belonging to different SES.

About 53% of the challenged people belong to the lower income group. Large percentage of this population lives in rural areas. It appears that poverty and low education is the root cause of disability in most cases (Elwan, 1999). There is a vicious relationship between poverty and disability (Mehta, and Shah, 2001). Studies reports poverty leads to more disability by making people more vulnerable to malnutrition, disease, and unsafe living and working conditions (Groce, 1997). There are other factors like nutrition deficiency during pregnancy, lack of money to treat the disability at an early stage and even lack of awareness of the treatment available. Although the College money; including tuition fees, books, and living costs, have been increasing rapidly over the past two decades in relation to student and family income levels but the increase in the financial assistance on the part of the government has been negligible. The amount of student financial aid available to students from low-income families has not kept pace with the increase in price of various commodities (Elwan, 1999). The financial barriers to educational opportunities are faced more intensely by challenged students from low-income families. In some cases it was found that those who belonged to the low socioeconomic group were somehow able to carry on their studies with financial, physical and material help from others but it was noted that as soon as the help stopped there was no other option left but to drop out. Thus in the present study it was found that the parental support was the least from the mow SES and the highest from the high SES.

Thus Hypothesis 3, there is no significant difference in parental support of the physically challenged with respect to Socio-economic status (SES) is rejected.

Table 3: One-Way ANOVA results of parental support scores of the people with physical disabilities with respect to socio-economic status (high, moderate and low)

Variables	SES	N	Mean	S.D	F
Pre-natal care	High	14	21.86	3.44	8.84**
	Moderate	28	21.07	5.44	
	Low	58	16.07	6.99	
Peri-natal care	High	14	4.64	1.08	2.52 NS
	Moderate	28	3.29	2.02	
	Low	58	2.52	1.96	
Post-natal care	High	14	17.07	3.22	5.09**
	Moderate	28	15.50	4.36	
	Low	58	13.21	4.98	
Medical support	High	14	62.29	6.11	8.33**
	Moderate	28	58.64	11.01	
	Low	58	51.03	11.84	
Physical support	High	14	26.79	3.09	2.03 NS
	Moderate	28	25.93	4.59	
	Low	58	24.67	3.88	
Mental support	High	14	16.14	5.10	0.11 NS
	Moderate	28	16.21	4.08	
	Low	58	16.77	7.05	
Educational support	High	14	66.14	6.48	3.95*
	Moderate	28	64.39	9.83	
	Low	58	59.84	9.43	
Vocational support	High	14	7.50	3.11	2.28 NS
	Moderate	28	6.68	3.23	
	Low	58	5.67	3.18	
Parental Support	High	14	225.79	19.79	5.74 **
Total	Moderate	28	215.50	32.93	
	Low	58	200.76	27.12	

^{*=} significant at 0.05 level, **= significant at 0.01 level, NS = Not significant

Volume 5 – Symposium Issue

The study strengthened earlier findings establishing the role of socioeconomic status (parental education, income and occupation) in the level of parental support of the individual with disability. Financial barriers have been found to be the greatest barriers in providing rehabilitation services to the people with disability (Elwan, 1999; Halder, 2008, 2009). Having a ward with disability entails a lot of expenses (Carolyn et al 1994; Elwan, 1999; Halder, 2008, 2009; Thomas, 2005b). Around 45% of families with a person with a disability report an adult missing out of work to care for the disabled member. It appears that poverty and low SES is one of the root causes of disability in most cases (Emerson E. (2004). There is a vicious relationship between poverty and disability. Poverty can lead to more disability by making people more vulnerable to malnutrition, disease, unsafe living and working conditions and disability in turn contributes to poverty because of the additional expenses that it entails (Elwan, 1999; Thomas, 2005b; Yuster, 2009).

LIMITATIONS OF THE STUDY

Data was limited only to 200 people with locomotor disabilities as it was very difficult to contact these people due to lack of information resources and institutes. It is a fact that people who have not attained any schooling or not at least completed class X were excluded from the study due to difficulty of locating or identifying them. So in a sense may be all of these 200 people with locomotor disabilities were in a much better position from the rest whom we have not considered in this study in terms of parental supports which may be taken as the reason that these locomotor disabled were able to at least complete their class X. The data excluded may be severely in a negative state and may need immediate exploration and intervention by various advocates and research workers in the field.

Volume 5 – Symposium Issue

CONCLUSION

Disability is a major problem in the developing world which affects large sections of the society. Specially challenged persons are a large diverse group whose education need has gone unnoticed. Challenged suffer on multiple accounts not only because of the physical handicap but also from stigma and social ostracism. Earlier, care and support for the challenged was not a priority for the governments and whatever little was done was on service or charity mode. As observed by Bornsteen (1995), the events of a child's' first years are of paramount important for his or her whole subsequent life. Parents of challenged have been one of the most influential stakeholders and advocates in the delivery of services to their wards with disabilities since time immoral. The findings of the present study will help in planning and formulating intervention strategies for the people with physical disabilities including the families. Understanding the role that the family plays in a person's life provides one with valuable insights in understanding and managing a child with disabilities. This research emphasizes the role of parents in the development of the child with disability.

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Volume 5 – Symposium Issue

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