

Parental Struggles Toward Life Carrier of Their Disable Children: A Case of District Gujrat-Pakistan

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Abstract: Disable persons of society considered inferior/disadvantageous in wellbeing of society overall and in their life as well. They assumed as Burdon on other family members due to their disability/ body defect. Researchers highlighted struggles made by parents to their disable children's life carrier. By these struggles and efforts to their life may become helpful in their smooth living in whole life. In this view, researchers identified parents of disable children which were enrolled in Deaf and Defective school Gujrat. Parents of all deaf and defective students enrolled in Govt Deaf and Defective school Gujrat were population of this study in which Total 10 respondents were selected randomly by their registration lists of 2 the most up classes of this school which were class 7and8. In-depth interviewing used as technique of data collection while tool of data collection was interview guideline. Enrich data collected by this given process and analysis done in form of themes. The core findings which extracted by study were that parents found much more concerned to their disable children and they were putting full attention and making efforts for their life's wellbeing.

Key words: Parents • Struggles • Efforts • Wellbeing

INTRODUCTION

Progress in social welfare of a society can be appraised by how well physically and mentally disabled persons are being put to productive relations [1]. People with any disabilities, who have any injury, disease or congenital defect is known as handicapped. In short, exceptional people `who either lack any area of the development [2]. The disability discrimination act 1995 declared that a disable child is who have a physical and mental impairment that has a substantial and long term adverse effect on day to day activities. Disabilities can be the result of accident, resulting in paralysis, brain damage etc, while some people may born with certain disabilities by which those persons did not considered as normal person [3].

The birth of a disable child is an event that affects all family members It also requires reassessment of family functioning [4]. Disability can be visible, invisible, temporary or permanent.

According to this record nearly 2% of population suffered from all kinds of disabilities particularly belongs to age group of (0-14) years (Government of Pakistan, 1981). Parents of disabled children faces and feel tough conditions from their disable (handicapped) children. Such child requires special attention by parents and society as a whole. Parents ever aggrieved about the future of that particular children. Society tagged such physically disabled children as burden and useless among them. Parents and even those children face certain harsh comments by rest family members and society. Many of parents did not feel necessary to avail education to those disable children just by thinking that they persons are unable to educate, do something or simply means that they are not carrier oriented. Child physical, mental disabilities sometimes become a serious issue in that family [5]. To get education, enjoy life luxuries and live according to anyone's own choice is the basic human right for any individual irrespectively of sex, creed, and color or on any other bases.

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“A mental or physical disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance, and facilitate child’s active participation in the community” (United Nations Convention on the rights of child, article 23).

Parents in every society play complex roles in training and socialization of their children. These responsibilities become more difficult, perplexing and arduous in the case of mentally retarded children [6]. Within parents particularly mother have more responsibilities about their disabled children and she may face certain conservations by other family members or rest society. Problems may also vary by the sex of disabled children respectively of male and female. People assume that having a female disabled child is some sort of bad luck and may become more problematic (Ergun, et al. 2006). 55% of population of disabled child mostly belongs to poor families or margins of poverty [7].

Parents encompassed by different difficult time periods, they often passed sleepless nights when they worry about disabled children life carrier. Meeting the complex needs of child with a disability can be extraordinary difficult, frustrating, emotionally draining and expensive [8]. Parents did not take such attention to their disabled children just to think that there is no sufficient outcome by those children and think that they will ever be supported by other siblings or family members. Statistics revealed certain results about educational outcomes of disabled children. Approximately 74% of children are unsuccessful readers in third grade are still unsuccessful in the ninth grade (Journal of child neurology, 2005).

Only 52% of students identified with learning disabilities will actually graduate with a high school diploma. Learning disabled students drop out of high schools at more than twice at the rate of their non-disabled peers (Congressional quarterly researcher, 1993). At least 50% of juvenile delinquents have undiagnosed, untreated learning disabilities (National center for state courts and the educational testing service, 1977). 31% of adolescents with learning disabilities will be arrested within five years of leaving high school (National transitional longitudinal study, 1991).

Up to 60% of adolescents who receive treatment for substance abuse disorders having learning disabilities (Hazeldon foundation, 1992). Heiman (2002), conducted a study on “parent of children with disabilities: Resilience, coping and future expectations”.

The results are as that 50% population of current study suspected that their child had a disability due to certain birth complexities, pre mature birth. 68% parents claimed that we observed our child disability after one year of his/her birth. 88% parents responded feeling of depression, grief, emotional breakdown. 62% parents claimed that we badly effected by their child’s disability. 26% population of study claimed that they had found no effect on their lives due to their disabled children. Parents concerns and expectations were mixed. 55% parents were keenly concerned about their child inclusion in society including his/her financial and physical independence while 30% of population was aggrieved about their disabled offspring and claimed that they will survive after them. Who will be responsive of them? 15% were concerned that how they will merge with their other siblings and peers. Finally, parents responded emotionally mostly with uncertain situation about their disabled offspring.

Background of Disabled Persons in Pakistan: In traditional societies like Pakistan where education level is low and economy of individuals is also not enough to meet their needs in such situations child disability present as very pathetic issue for all family members. An explanation behind the birth of disabled children in Pakistan is “exchange phenomenon in marriages”. There was no reliable data available before 1961 in Pakistan.

A comparison of 1961 and 1981 census show an alarming growth of disabled population in Pakistan (Ahmad, 1993). The Government of Pakistan recognizes its responsibility to educate disabled portion of population first time in 1959 but that was implemented until education policy of 1972-1980. The Government of Pakistan launched special education centers in 1980 by influencing some international events. As a result, considerable number of special education institutes established and full-fledged policies formulated as well. But the need is to expand number of schools so the maximum number of population takes advantage by this initiative [9].

More females than males suffered from any type of disability in Pakistan and it lies in rural area than urban respectively. The highest lighting type of disabilities recorded which blindness, dumb and deaf is the most dominant disabilities (Ahmad, 1993).

“States are required to ensure the provision of effective medical care for persons with any disability (physical, mental, emotional). They must also ensure that

person with disabilities particularly infants and children are provided with the same level of medical care within the system as other members of society” (UN standard rules on equalization of opportunities for persons with disabilities).

Objectives: To know about parents intentions and struggles toward their special (disable) children

MATERIALS and METHODS

The handed study was designed to investigate parental expectations to their disable children. It is basically subjective approach so varies person to person and has uniqueness in each experience so qualitative dimension used to study the respondents of this research. To fulfill this purpose disable children and their parents extracted in scientific way from Deaf and Defective child school, district Gujrat. List of class 7-8 students was available by where researcher selected respondents both of male and female and located parents of those selected children for data collection. In-depth interviewing was technique and interview guideline was tool in this research journey. Thematic analysis was done to compile this report.

RESULTS AND DISCUSSIONS

The refined data collected by parents of disabled children was managed by themes to finalize their views about this study.

Demographic Profile: Respondents of the study was parents any one of both (mother, father) of those disable children who enrolled in Govt. Deaf and Defective school NarowaliGujrat and belonged to higher classes of this school. 10 children selected in which 4 were females and 6 were male disable students to meet their parents. 5 mothers alone and 5 both (mother and father) independently were interviewed. 1 mother of them was school teacher and remaining all mothers were housewives, 4 fathers were settled in any other country while 2 fathers were businessman and rest was agrarian. Children ages were from 14-18 years.

Plan of Parents about Their Disable Children: Parents of disable children found much anxious about their disable children and they were much more concerned for their future and further life. Parents were more interested in

disable child life as compare to normal one. Mothers looked more worried and involved in this journey of disable child life. They (parents) never thought to discriminate in their children on any of basis. But many of them said and expose their worries about disable child specifically female disable child parents were tensed about future of child even their child was getting education but they said that in any case they can't put their steps with other normal children in any life ground. Their life is much difficult than normal without influence of education. Given below certain responses of parents by which it can be more understood phenomenon.

- “I (mother) am much more tensed for my child (boy) life and its disability. Treatment is not affordable for us. But I tried my best to make him little functional human being for his survival of next life”.
- “I (mother) am fully conscious of my disable children which are 3 out of 7 total. I spend most of my time to think about wellbeing of these children and pray to Allah for their secure future”.
- “I (father) have total 5 sons in which 3 of them are disabled. I am died even in my life just to think of my disabled children. I am unable for their treatment which is much more expensive. I enrolled them in school for their betterment in life”.
- “We put our all attention to our disable daughter. We wish to provide them higher education but current school of Yasira is comprised on 8 years of education and we are worried to send her in hostel or away by us”.

Children are much more worried and concerned for child future. They supposed education as ladder and support for their life survival so they are all interested in child education.

Parents of disabled children put their maximum attention and concern to them and they have wished to show them equal in success as with others of their normal children. Their expectations varied per circumstances and provided environment. Following responses reveals parental expectation by disabled children.

- “I (mother) wished that my disable son have bright future but this available education is unable to meet my expectation. We (parents) trying to settled him anywhere abroad because disable person just to look him functional”.

- “I (father) only want that by this available opportunity of education he becomes able to read and write of bills or any other thing in his life otherwise he almost knows about agriculture and after his completing education he definitely will indulge in it”.
- I (father) wish to provide him education but in Pakistan special education is not in easy access as for others. My expectations are not with my son rather these are with education, because expecting by disable is useless without personal effort”.
- “I (mother) sent my daughter for getting education I also focused to learn her Quran Pak and Namaz but I can’t remove her disability”.
- “To teach and manage such children is very much tough but I (mother) always ready to give this duty. In return I only wants her polite behavior with siblings but she never behaves such for this I am much more worried”.
- “Such children remains in inferiority complex after any effort made only for them. They feel themselves incomplete”.

Parents of occupying disable children ever remains in tension and depression. Their all efforts, priorities are those children but they sometimes becomes un-understandable for them. Parents found much more struggling toward their life but they personally have their own mind sets and they only works and behaves according to those mind sets and sometimes they even take any harmful step also for family and friend’s parents also got tensed by this behavior. Following responses by parents reveals children behavior.

- *“My daughter is much more aggressive and sometimes she takes such steps by which we suffered by severe tension. She burns the household things most of the times”.*
- My daughter is of 18 years old now she also has her menstrual cycle but she has no idea about it and also do not listen me for this. I remained worried all the time for her behavior”.
- “He (child) demands all the times different luxuries like laptop, internet, games, motorcycle and I am unaffordable to provide him all this. His reaction ever remains harmful for this”.
- My 3 sons are disable have hearing problem and they together goes somewhere and do harms for other society members”.

Disable children have their own sense of understanding and predicting about things and issues they never thought as normal being [10-13]. To understand them is also tough for normal human beings so parents of such children also face hurdles, tough times to manage them. Mostly disabled children found aggressive in their behavior and they had least concern to their siblings. Their behaviors sometimes become very painful for their parents and especially their mothers mostly suffer by this tension. Quarreling, beating, snatching things of other age fellows such habits found in male disable children.

DISCUSSION

The current study was comprised on disable children’s parents to know about their parents efforts for their children life. Many of respondents had strong socio-economic background and some of them found disadvantageous and hand to mouth and have many kids also along with that disable children. Parent’s expectations, struggles which they made for their disable children found with their socio-economic background, as much strong socio-economic background they had as much they found active in making efforts for their disable children. But they all were trying to their level to secure their disable children and make them able to live their life independently and without even any of sibling help. Parent’s intentions were different according to their disable child sex. Parents having male disable child were worried for his earning source while female disable child parents had tension about her marriage and marriage related other issues were prominent in their intentions.

CONCLUSION

To sum up this study of disable children’s life and their parental efforts made by him for their betterment in life it is concluded that parents of such children remains constant in tension and tough time for their disable children and to think about their life carrier that how they will compete with other normal being. Disable children found annoy and self-centered. They did not bother or think for others even they put their least attention toward parent’s request. Parents feel themselves helpless to socialize them but they relied on special education centers where their children dealt by specialized teachers by which they may become well socialized. Special education center is developed for such children but it has only

education till grade 8. Parents found much tensed for this phenomenon as well because after grade 8 they do not have any opportunity to send their disable children for education or getting socialization. Parents put their total effort toward disable children just to make him functional and smooth runner with others family member and belt of society.

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