Children with disability: Problems and challenges in Pakistan

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Abstract

This article focused the problems and challenges faced by children with disabilities in Pakistan that hampers the integration of such children into the mainstream society. Since the study had primarily been exploratory in nature, an exploratory-sequential method or analysis was employed with a qualitative research design. With the application of this methodical procedure, various themes of the problems had charted out, that were further studied through data from the field. The data was collected from 25 respondents through in-depth interviews. The study finds that disability as a social stigma, attitudinal and physical barriers such as indifference towards disabled and mobility problems, poverty and lack of special education for disable children had existed as well as contributed in worsening the lots of disabled children. The study concludes that children with disabilities cannot be integrated in the main stream of society until and unless their psycho-social problems are addressed. The study recommends that the government should address the needs and problems of these children on priority basis and adopt measures for their rehabilitation. In addition, the non-governmental organizations, civil society and the donors' organizations should also come forward and help the government in the rehabilitation of these vulnerable children.

Keywords: Children; Disability; Social Integration; Inclusive education; Pakistan

Introduction

Definition of disability and related concepts are vague enough and it is difficult to find any acceptable and universal definition. Therefore, disability is defined differently across the globe by academician and practitioners (Boorse, 2010). However; the most comprehensive definition of disability has been given by International Classification of Functioning (ICF) that defines it as "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives" (WHO, 2002:2). While according to Disabled World (2009) an individual with disability is a person who has physical or mental impairment that badly effects the functioning of one's routine activities. It is worth to mention that definition affects the demography of disabled people. In Pakistan, the Census (1998) defines disability as "A person who, on account of injury, disease or deformity is handicapped for undertaking any gainful profession or employment, in order to earn his/her livelihood and includes a person who is blind, deaf, physically handicapped or mentally retarded" (Aziz, 2013:3).

Persons with disabilities can be found everywhere in the world belonging to different socio-economic background, age, race and gender (Farooq, 2012). Among 10 percent of the World population i.e. 650 million in which 80 percent belong to developing countries are faced with physical, mental or sensory disability (United Nations, 2011). In the Western Pacific Region, the occurrence of moderate and severe disability has been reported to be 16 %(WHO, 2010). Moreover, according to Population census of Pakistan, 1998, 3.29 million population is with disability (Aziz, 2013). In practice, such number may vary or change in relation with the framework of definition of disability given in the population census of Pakistan (Ali, 2014).

Owing the endemic prevalence of disability throughout the world including Pakistan, civilized societies have strived to address the problems and needs of these marginalized persons and rehabilitate them accordingly (United Nations, 2008). In this connection, the role of the United Nations cannot be overlooked in the protection of basic rights of the children with disability in the main principle of the United Nations (United Nations, 2005). In 1970s the acceptance of human rights for children with disability, and the adoption of Declaration on the Rights of Mentally Retarded Persons (1971) as well as the Declaration on the Rights of Disabled Persons (1975), led the General Assembly to set principles for the provision of equal rights, access to resources and to integrate these children with disabilities (United Nations,2011). Similarly, celebration of the year of Disabled Person 1981 under the umbrella of the United Nations is a landmark for creating awareness regarding needs, problems and prospects for the children with disabilities (Farooq, 2012). Likewise, in 1992 at the closing of the United Nations Decade of Disabled Persons (1983-1992), the General Assembly declared 3rd

December as the 'International Day of Disabled Persons'. During this period, awareness was raised regarding the issues confronted by Children with disabilities (CWDs) and measures were adopted for addressing those problems (United Nations, 2005).

The Standard Rules on Equalization of Opportunities for Persons with Disabilities (1993) shows the strong political will regarding provision of equal chances of education to weaker segment of society. The world leaders, in 2000 reiterated their commitment to the 'Education for All' 'Salamanca Declaration' and the 'Dakar Framework for Action, Education for All' at the World Education Forum. In addition, Article 24 of the Convention on the Rights of Persons with Disabilities (CRPD) (2006) require the nation states to make sure access to inclusive, quality and free primary and secondary education based on equality with others. Of late, in 2015, the 2030 Agenda for Sustainable Development acknowledged that persons with disabilities should have access to life-long learning opportunities that help them attain the knowledge and skills required to make use of opportunities and to take part in societal development. Moreover, persons with disabilities are also covered in Goal 4 (United Nations, 2019).

In order to improve the lives of persons with disabilities, the government of Pakistan has framed various policies which include 'Disabled Persons (Employment and Rehabilitation) Ordinance 1981', Literacy ordinance 1985 which was passed by Parliament in 1987 (Khan & Jabeen, 2016). In addition, Directorate General of Special Education was setup in 1986 which introduced national policy for imparting education to persons with special needs (Yousaf, 2011). In 1988, the policy was revised to cater the needs of the people with special needs in a more efficient and effective way. While the 1999 special education policy was introduced to address the problems of this marginalised section of society. Lately in 2002, Pakistan Government launched National Policy on the issue of disability" while in 2006 "National Plan of Action for Persons with Disabilities 2006" was introduced. Later on, "Special Citizens Act, 2008" was passed to give special status to special persons. A year later an act was introduced to facilitate special persons including special students which was named as "Special Citizens (Right to Concessions in Movement) Act, 2009" (Ahmed, Khan, & Nasem, 2011).

In Pakistan National Education Policy 2017 stressed the need to provide maximum facilities to provide equal education opportunities to all. In this regard, the government must provide an inclusive learning environment where all children should have adequate opportunities to intermingle and learn together (Government of Pakistan, 2017).

In developing countries, including Pakistan, children with disabilities are more vulnerable as compared to the developed world (Harland, 2002). In Pakistan, such children face dual problems; on the one hand they are disabled while on the other they belong to developing nations, thus making them more vulnerable in various fields of life (Ali, 2014).

Theoretical framework

The theoretical framework for this study was based on social constructionism which hold the position that the crucial significance of gaining from disabled individual's experience to comprehend implications of disability. For instance, visual impairment contrasts as indicated by the financial cultural and social settings. A classical study reported that in the United States visual impairment was capable as disability requires less management while in Sweden as an issue needing administrative help. However, each neglect to address key underlying variables of disability. Subsequently, disabled individuals will be treated as abstract, some way or another unmistakable from the balance of humanity, and the significant inquiry of the reasons for handicap is falsified instead of explained. For instance, how disability is physically based yet socially developed by the environment disability (Oliver, 1998). This paper is based on the arguments of self or self-identity of children with disability and the issues they confronted.

Statement of the problem

All Human beings, irrespective of any discriminatory grounds i.e. gender, religion, caste, class, ethnicity and disability are entitled to all such basic needs that lead them to a happy and prosperous life. In Pakistan, however, children with disabilities are being deprived of rights that guarantee their safety and prosperity in various spheres of life (Ali, 2014). Such deprivations include lack of access to education, health benefits, recreation and funding opportunities (Boylan, 1991). Groce (2004) for example refers to the UNESCO estimation that reports 98% of male children with disabilities out of schools while 99% girls as completely illiterate in developing countries. In Pakistan, disabled children are not integrated into the society and are faced with multiple problems such as scarcity of health facilities, funds, and non-availability of trained staff to cater to their needs (Despouy, 1991). Research on disability is meagre in Pakistan and a handful of studies has yet been carried out to address it holistically. This study, has therefore, been launched, mainly in response to the felt-need of research

scarcity on the issue at hand, in order to arrive at a best possible understanding of it that may further ensue appropriate measures to overcome its downsides within the country.

Research methods and material

In this study, we aimed primarily at unfolding the various multi-dimensional problems faced by Children with disabilities. Since, the task of unfolding required an in-depth scientific thoughtfulness, an exploratory-sequential method or analysis was thus employed with a qualitative research design. In the first place, a detailed survey of the existing research studies i.e. contents were identified, and major themes were developed for analysis along-with a range of researcher's own observation also helped to chart out various themes of disability with special reference to children of school going age. Secondly, a saturated interviewing tool, based on secondary studies was developed to rectify the existing data and add further information to the issue at hand. Thirdly, based on purposive sampling technique, a total of 25 respondents were identified and thoroughly interviewed within the territory of Chakdara Town District Dir Lower Khyber Pakhtunkhwa Province and its adjacent areas. The data collected from the field has been analysed through discourse analysis method as it is the most suitable method when dealing with a social issue, various accounts has been taken into consideration to draw themes from the data where the secondary information has been linked with the field data to extract findings and results (Abell and Myers, 2008). Based on the data saturation, among all the interviews, relevant sections from the whole samples have been cited, one under each of the main themes while the respondent's anonymity have been kept secret (refer to the results and Discussion)

Results and discussions Disability as social stigma

In Pakistan, Children with disabilities are faced with multiple problems both at the hands of family members as well as the society in general (Driedger, 1991). Due to illiteracy and ignorance such children are considered as social stigma and curse of God especially in rural areas of Pakistan (Rathore, New &Iftikhar, 2011). In addition, mainly due to superstitious beliefs, people consider disability as a consequence of their misdeeds committed in the past(Aryal, 2007). These children are deemed as shame for their family and are often kept hidden from other people so as the social prestige may be safeguarded (Pivik, Mccomas & Laflamme 2002). For a more wholesome picture of the problem, here is an excerpt from one the interviews;

"Well to be very honest as a child, I was unaware that my family members felt shame on my presence whenever some special guests would visit our house. It was later that I knew of it, when guests were coming to our house for seeing my sister for marriage purpose etc. I still remember that on an excuse, I was sent to my Aunt's house for a day. I didn't however, faced the same attitude mainly from my parents as they would and are still apparently kind on me. This kind of indifference has been more in display from my siblings and other relatives" (R-05-M).

Analysis of the above extract reveals heart-breaking personal conditions of disabled people. Not only their social life is thwarted by their disability but also their very personal, emotional and psychological life is at stake. In addition, especially in Pakistan, such children are considered weak and no more than an unnecessary burden on the family lot. Such children are faced with triple discriminations that make them live in pathetic life condition in which they have no easy access to education, rehabilitation services and vocational trainings opportunities (Harper & Momm, 1989). This makes for them leading a normal life as others nothing else but an illusion. Later in their lives, age and poor economic conditions drag them further towards disadvantageous position that includes only rejection by the normal majority. Such children are also often attributed to be the main cause of lowering down the social ranks of their parents especially mothers. In Nepal, for instance, a woman who gives birth to a disabled child is given low status and considered as 'Alachhini' i.e. somebody who carries bad luck to the family (UNDP, 2004). Moreover; research study by International Labour Organization in six Asian Pacific nations also confirms that there is gender disparity in the provision of education, health facilities, and employment opportunities for the disabled children (Economic and Social Commission for Asia and the Pacific, 1995). Unfortunately Pakistan does have any institutionalized mechanism to provide special services and care to these children which in turn remains in the hands of their family and society whom not only consider them as a burden but also a social stigma for them.

Attitudinal and physical barriers

Children with disabilities start living a miserable life right from their families. In the first instance, attitude of parents becomes discriminatory towards disabled children and they are assumed to be inferior as compared to their non-disabled children (World Health Organization and the World Bank, 2011) afterwards, they are socially excluded from mainstream communal activities (Aryal, 2007). In Pakistan parents consider their disabled offspring as an economic burden and curse of God (Malik, 1988). Added to it are the numerous attitudinal and social constraints some of which include inapt remarks, impolite behaviour, cursing and teasing both by adults and children (Pivik, Mccomas, Laflamme, 2002). For further details, here is an extract for further analysis:

"My family hasn't felt the need of my education even yet. My other siblings were being preferred on me even my sisters to be educated. It could either be due to my parental perception of mine as being an inefficient and unproductive person or if not this, then it could have been the lack of educational institution specific to children with disabilities. There is a special school in Timergara Dir (Lower), but it takes a lot to travel all the way from Chakdara to Timergara regularly" (R-03-Z).

The above extract reveals many other things than it apparently does. It parallels the life of a disable to a lifeless object. They are also labelled with inappropriate names that distort their personality and affects their performance (Ali, 2014). As a result, a disabled child loses self-respect, and confidence that further exacerbates their vulnerability (Lavin, 2001). Besides; attitudinal constraints, physical hurdles also create problems for disabled children. In developing countries, for example, the public buses lack stairs for special children causing them transportation and mobility problems (Rajah, 1989). No such measure in Pakistan has yet been adapted to ensure such vehicles design that may suite or fulfil their needs of mobility to remote areas (Ali, 2014). In addition; the study findings of Law (1993) concludes that steep ramps, uncut curb, heavy doors and one-inch thresholds are also the physical constraints for disabled children (Pivik, Mccomas & Laflamme, 2002).

Educational opportunities

Education is an effective tool that can shape the future of disabled children in positive direction. In Pakistan, however it remained a major concern for the policymakers and educationist to educate children with disabilities (Farooq, 2012). Teachers employed in ordinary, special and inclusive educational setups have different opinion about the ways of imparting education or training to the children with special needs (Mason, 2005; Sarwar & Asgher, 2005). The shift from separate to mainstream and then to inclusive education is part of the

mission to provide educational services to this weaker section of the society and to make them self-supportive and independent(Ali, Mustapha & Jelas, 2006). Relevant to it, one of the respondents cites as below;

"Well I belong to an educated and sensible family. My father admitted me into a Government School which I think now couldn't fulfil my needs. I encountered many problems including physical, social and psychological problems. Though the school wasn't too far, but it would take me a long time and labour to reach the school in time. In addition, due to my specific physical disabilities, I would be unable to pick up what teachers said. Social issues like abusing, and remarks from my class fellows were yet other factors that made me leave my education incomplete" (R-01-K)

Usually, educational institutions for disabled (both separate and inclusive) are too far and inaccessible mainly due to the lack of transportation facilities (UNICEF, 2013). According to recent statistics, in Pakistan there are 1.4 million children with disabilities of school going age who have no access to either inclusive or special schools due to limited capacity in existing facilities (Daily Times Pakistan May 8, 2014). Moreover, the available transport lack special stairs/lifts which could help the disabled to board on to the bus (McPherson, 1989). Such a situation lead students to a no or low education, thus, causing them problems searching a suitable occupation in future 1989). Furthermore, there is also a lack of trained teachers in educating the children with disabilities (Hodkinson, 2006). In Pakistan, majority of educational institutions have no sign language practice for the deaf and no Braille instruction for students with visual impairment (Ali, 2014). This situation is not only miserable for the disabled children but also an alarming situation for the country literacy rates.

The cycle disability, poverty and isolation

There is a close relationship between poverty and disability, and both produce each other (Eide 2004). Research studies show that the ratio of disabled persons is less in developed countries as compared to the developing countries including Pakistan (Eide, Van Rooy, &Loeb, 2003). The available information concludes that the children with disabilities are more exposed to poverty which further

gives rise to disability (Gauchan, 2009). This fact is reinforced by the following excerpt by one of the respondents at a mature age;

"Since, I have been doing nothing right from my birth and remained a burden on my family; little attention is being paid to my needs and even pocket money. Now that I have some sense of life, I assume that my future life would be no more than a hell. Since my parents are getting old, and my brothers are settling in separate houses after marriage, I foresee a very bad future of the household. Now I wish I could have some education or skills, so that I may be able to support myself and parents" (R-06-Q).

These and many other such conditions may lead them to low education level or illiteracy, unemployment, segregation from social and political processes, lack of access to resources such as food and clothing (Yeo and Moore 2003). Due to poverty the disabled children are at risk of illness and a lack of access to medical treatment (Turmausani, 1999). Approximately, 1 in 10 Poverty Assessment of the population in most 3rd world countries are handicapped or disabled in some way due to poverty (WHO, 2011).

Conclusion

Children with disability can be found everywhere in the world belonging to different races, religion, sex and socio-economic condition. Being a marginalized section of Pakistan, it faces different socio-cultural and economic and psychological problems i.e. poor health facilities, lower education attainment, less involvement in economic activities, attitudinal and physical barriers, transportation problems, depression and higher rates of poverty than people having no disability. Due to illiteracy and ignorance children with disabilities are considered a shame for the family and are kept hidden from the people especially on ceremonies. These children are also considered as the punishment for parent's deeds in religious perspective. On the other side of the coin, such children are absent from the government agenda and are deprived of their basic rights. Due to the discriminatory policies, they are segregated from the society. The attitude of parents towards disabled child is also discriminatory and they consider it a liability as compared to a normal child. In addition, parents of children with disability also have complaints from adults in the vicinity for uttering inapt remarks and impolite language at the disabled child.

As a result, they lose self-respect, worth, dignity and confidence on their capabilities.

Suggestions

Children with disabilities can be rehabilitated through concerted efforts by the government as well as the society in general. The government should take up problems of such children on main agenda of the welfare and provide them with facilities for fulfilling their needs as well as their rehabilitation. The educational institutions for the children with disabilities should be established in areas easily accessible for this marginalized section of society. Schools should be established in the rural areas so that the rural people can educate their disabled children. In educational institutions, stairs/pathway should be constructed so that they can easily reach the class. The teachers of regular schools should be trained in the art of imparting education to children with disabilities. The instructional material should be provided to students and teachers should be trained in the 'sign language'. Media can also play an effective role in highlighting the needs and problems of such children and can influence the policymakers for removing gaps in the implementation of existing laws or making new laws. The religious leaders can also guide people regarding the rights of disabled children, the role of the family members and state in the fulfilment of their needs. Provision of lifts and stairs in the multi storied buildings should be made compulsory by the government. The non-governmental organizations can also play an important role in mobilizing resources for the fulfilment of needs of the CWDs and can also create awareness regarding the issues faced by this weaker section of society. The government of Pakistan should establish a special fund for the financial assistance of disabled children so these children may become part of the main stream society of Pakistan which will not only make them a contributing member of their families but also a productive citizen for the country.

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