

Effects of disability and the path ways to prevent disability on the families

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Abstract

This article focus on children with disabilities, causes for disability, types of disability, and also discusses the effects of disability on families and explores the present condition of disabled children in India. Recent research's highlights that a child's disability will affect parent's health and economic conditions of the family, also it will have impact on the parents' relationship. In longer term disability will have impact on a child's school education and its capacity to get a good employment. There is greater negative impact on the future wellbeing of the children with mental health problems when comparing with the children with physical disabilities. The recent statistics reveals that out of total population of disabled in India, 72 percent lives in the rural India and families in the rural India see the disabled as a burden and stigma to the family. The interesting part of this article is the discussion on how to prevent disability from the family point of view and the role of parents, siblings and relatives in reducing the effects of disability on the families. Suggestions were made on the need and implementation of research, more effective programmes and role of voluntary organisations and social workers to prevent and reduce disability in India. Role of academic institutions focussing on starting of field research units in the area of prevention of disability were discussed.

Keywords: disability, impact, effects, stigma, prevention

Introduction

Physical disability is a major problem in India. A disability may be physical, cognitive, mental, sensory, emotional, and developmental or some combination of these. A disability may be present from birth, or occur during a person's lifetime due to sudden sickness or accident. Disability is a term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (Johnson, 2017) [9]. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives (WHO).

What is Disability?

The term "disabled young person" tends to convey a message that the only thing worth mentioning about a person is their disability. It is better to say "young person with a disability" as this emphasises the person first without denying the reality of the disability. One recent conceptualization suggests that disability is a process by which a person's health, environment, and personal factors influence his or her body structures, activities, and participation (World Health Organization 2002). The most commonly cited definition is that of the World Health Organisation in 1976(1), which draws a three-fold distinction between impairment, disability and handicap, defined as follows. 'An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function; a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that

prevents the fulfilment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual'. A Disability is generally a condition either caused by accident, trauma, genetics or disease, which may restrict a person's mental processes, senses or mobility (Johnson and Hariharan, 2017) [10]. A Handicap is a physical or attitudinal constraint imposed on a person regardless of whether or not that person has a disability sometimes they are isolated just like Dalits who are struggling to gain their status in India (Johnson, 2014 b) [16].

Types of Disability

The Disability Discrimination Act (DDA) identifies and defines the following categories of disability:

- Physical - affects a person's mobility or dexterity
- Intellectual - affects a person's abilities to learn
- Psychiatric - affects a person's thinking processes
- Sensory - affects a person's ability to hear or see
- Neurological - results in the loss of some bodily or mental functions

Prevalence of Disability

Different prevalence rates for disability are available in India. According to the Census 2011, there are 2.61 thousand people with disabilities in India who constitute 2.27 % of the total population (Census 2011).

Effects of Disability on families

The effects of children's disability or chronic illness on aspects of family life such as family functioning, structure, and the effect on siblings of the disabled child. Substantial realignment of family responsibilities, dyadic relationships, and the care and attention spent on other members of the family occur when a child is born with disabilities or develops them during childhood (Darling, 1987; Seligman, 1991) [2, 29].

In the face of shifting emotional and financial burdens, and changes in family structure, the siblings of disabled children often develop emotional and behavioural problems of their own (Felicia *et al*, 1994)^[6].

Childhood disabilities entail a range of immediate and long-term economic costs that have important implications for the well-being of the child (Stacy-Ann & Johnson, 2017)^[30], the family and society but that are difficult to measure (Mark and Sara, 2012)^[26]. The reason may be that disability in late life is affected by a complex set of biological, medical, behavioural, economic, social, and environmental determinants throughout the life course (Robert *et al* 2008)^[28]. Recent theories of stress and coping in parents of children with intellectual disabilities (ID) emphasize the importance of cognitive appraisals in influencing parents' levels of stress and their adaptations to difficulties presented by the children. This study investigated the relationships between parental cognitions, child characteristics, family support and parenting stress. The aspects of cognitions studied were: parenting self-esteem (including efficacy and satisfaction) and parental locus of control. (Hassall *et al*. 2005)^[8]. Deirdre in his study highlights that family environment and parental distress jointly predicted children's ability to function with pain. Family environment moderated the relationship between pain and functional disability; in this group, greater pain associated with more functional disability in children from disruptive family environments, but not in children from more adaptive family environments (Deirdre, 2004)^[3]. Education is important for all children, but even more so for children with disabilities whose social and economic opportunities may be limited (Johnson, 2014.c)^[17]. Socially fulfilling and intellectually stimulating, economically productive life and a future with few of these qualities (Johnson, 2012)^[23]. Education also has the potential to affect children's health by influencing their ability to advocate for themselves, manage chronic health conditions, and navigate complex medical, insurance, and social service systems during childhood and later in life. (Laudan and Pamela, 2012)^[25].

Present condition of Disabled children in India

Parents had lower levels of parental stress, they had more positive perceptions and attitudes concerning their child's disability and their parental situation, (Johnson, and Christine, 2016): they were more confident in their own resources and

the help they could receive from others, they had lower levels of emotional distress, anxiety and depression and they perceived more emotional support from their spouse (Johnson, 2013, Diane *et al*.1999)^[18, 4].

Disability Act in India

The following are the major four Acts in India which covers the legislative framework for the protection of the rights of disabled people (Thomas 2005)^[31]:

- Mental Health Act 1987
- Rehabilitation Council of India Act 1992
- Persons with Disabilities Act 1995
- The National Trust Act 1999

Prevention of Disability

There is an increase in the use of mainstream technologies towards the physically challenged children in the families. The members of the families have major role in identifying the causes of physical impairment at the early stage in order to provide treatment facility immediately to avoid further damage (Johnson & Rajarathnam, 2012b)^[22]. Greater educational attainment, declines in poverty, and declines in widowhood also appear to have contributed. Changes in smoking behaviour, the population's racial / ethnic composition, the proportion of foreign born, and several specific conditions were eliminated as probable causes.

Three societal trends in areas other than health or functioning that might contribute to declines in disability levels: a reduced supply of informal care (Johnson and Rodrigues, 2016, Johnson and Worme- Charles, 2016)^[12, 13], changes in the technology of self-care, and changes in the definition and perception of both "ability" and "disability" (Douglas *et al*, 2005)^[5]

The health care need of the people with disabilities represent an increasingly recognized target population which can be addressed and has to be improved through research on health services (Johnson & Patil, 2010)^[24]. The aims of the health services research is to improve health and health care systems on the structure, processes, and effects of health services (Hadley 2000). More social work students can be placed for the field work practicum in the field of disability to gain in-depth knowledge and exposure (Johnson, Bailey & Padmore, 2012)^[23].



Fig 1: Path Ways of Prevention of Disability in Families

Need for research to prevent disability

There is an urgent need to encourage the young research scholars to actively involve in more research in the area of disability to find a good solution to prevent the rate of disability at an earlier stage in India. Social workers have to play a major role in providing more interventions and support (Jacqueline and Johnson, 2016) ^[14]. Though India is one of the leading countries at the global in the field of education and research many research institutes and National Research Universities are concentrating in doing research in other fields and not in particular in disability. This is the right time for the universities to encourage more students to do research in the field of disability in order to reduce the rate of disability and to prevent. The challenges of disabled students are higher than the challenges of persons who are not attending schools (Johnson & Rajarathnam, 2012a) ^[21]. There is a need to increase research in this area.

Conclusion

Counselling works to repress the needs and wishes of the disabled and to impose its own ideas and understandings upon their experience (Johnson, 2012) ^[23]. There is a need to empower the physically challenged to sensitise the family members of the disabled to prevent further distress in the life of physically challenged persons (Johnson & Suvitha, 2012) ^[19]. Special schools and educational institutions for the physically challenged should step forward with innovative ideas and excellent intervention programmes to prevent disability in the families (Messiah & Johnson, 2017) ^[27]. It is high time for the professional social workers to extend the support to the Physically Challenged to get out of their challenges and to channelize the government machineries to actively involve in more research in the field of disability.

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