

## **The Challenges Face By Parents of Differently Abled Children**

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### **Introduction**

Special needs is an umbrella term for a wide array of diagnoses, from those that resolve quickly to those that will be a challenge for life and those that are relatively mild to those that are profound. It covers developmental delays, medical conditions, psychiatric conditions, and congenital conditions that require accommodations so children can reach their potentials.

No matter the reason, the designation is useful. It can help you obtain needed services, set appropriate goals, and gain an understanding of your child and the stresses your family may face. Family is the basic unit of social security for every individual, old or young, male or female, healthy or sick, able-bodied or disabled. In families having persons with a disability (physical or mental), the needs and responsibilities of the family definitely increase manifold. In the past, parents were usually advised to institutionalize their mentally retarded child but it is not a practice anymore. The goal envisaged for the child with mental retardation is to stay in the family and take part in the community (Farheen, 2008). The family environment is also very important to the child's welfare and development (Altiere, 2006). Differently abled children means a child "with mental retardation, hearing impairments (including deafness) speech or language impairment, visual impairment (including blindness) serious emotional disturbance, orthopaedic impairment, autism, traumatic brain injury, other health impairments or specific learning disabilities and who by reason thereof, need special education and related services". Parenting is a challenging process. The parents and family's role in caring for a child is very essential especially in development, socializing and protecting the child which is well established across the country. The challenges face by the parents of disabled children find it difficult to assist their children with daily task such as feeding dressing, toileting and mobility parents of the mentally disabled are on theselecting and appropriate child care setting, arranging play activities and involving the child community activities, consistent with his/her interest or even special needs. The third family patterns of interaction consist of those parental activities relevant to ensuring the health and safety of the child. Providing proper nutrition, minimizing exposure to toxin, ensuring to immunizing schedules are followed and protecting the child from injury and violence (Hidangmayun, 2010) Parenting a child with disability depends very much on the gender of the parents as parenting is a very challenging task. The family experiences mental health problem themselves which in return will have an effect on their parenting and caring abilities. On the other hand there is also an impact on sibling which is likely to affect their relationship in many ways which can create a problem where they cannot share their opinions which will affected their contact, affection and fulfilment. Caring for a child with special need may have a considerable impact on the family. The parents of the child are likely to experience increased burden and parenting stress as compared to parents with healthy and normal children. The economic stability and family structure are important determinants in family burden. The single parents will be facing more problems as compared with two parents as the socio-economic disadvantage will add up to the burden of the child's mental disorder. There is also a care-giver burden which will be affecting the family members in daily life of family as well as their relationships. The interaction between the parents and the siblings also increase and sometime even leads to marital conflicts (Norman 2005). As parents

without a disability have a possible relief of distributing the household task to their children, but one of the stressor of the parents having children with special needs is that they may continue to care the child for an extended period of time, which can be emotional challenging.

## Review Of literature

This term was coined by the US Democratic National Committee in the early 1980s as a more acceptable term than handicapped (or, in the UK, disabled). The motivation seems to have been both a genuine attempt to view the people previously called handicapped in a more positive light and also as need to be seen as politically correct. The Los Angeles Times reported it this way in September 1980: Festival workers constructed dozens of adjustable ramps to make Camp Mather accessible to the disabled - referred to at the festival as 'differently abled' or 'physically challenged'. Differently abled is complex, dynamic multidimensional and contested over recent decade, the disabled people's movement together with numerous researchers from the social and health sciences have identified the role of social and physical barriers in disability. The transition from an individual medical perspective to a structural. Social perspective has been described as the shift from a "medical model" to a "social model" in which people are viewed as being disabled by society rather than by their bodies. WHO (2011). Meaning and definition The word "disabled" is defined as having a physical or mental disability: unable to perform one or more natural activities (such as walking or seeing) because of illness, injury, etc. The word disabled came to be used as the standard term in referring to people with physical or mental disabilities in the second half of the 20th century - and it remains the most generally accepted term in both British and US English. Lately, "Disability" and "Disabled" are terms that are undergoing change due to the disability rights movement in the U.S. and U.K. Handicapped or disabled. The world organization (WHO) in 1976 provided a three-fold definition of impairment, disability and handicap explaining that "an impairment is any loss or abnormality of psychological or anatomical structure or function: a disability is any restrictions or lack 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 fulfillment of a role that is considered normal (depending on age, sex, social and cultural factors) for that individual. Today more people live with a disability than ever before due to our aging societies as well as improved medical treatments helping manage long-term health problems. Some people are born with a disability, others become disabled as a result of an illness or injury, and some people develop them as they age. At some point in our lives almost all of us will have some type of disability. One of the key challenges for a person with a disability is to be seen by the public, to be portrayed in media outlets, and treated by health care professionals, as an individual with their own abilities, not just stereotyped as a "disabled person".

- About 1 in 5 people in America currently has a disability.
  - 33% of 20-year-old workers will become disabled before reaching retirement age.
  - Over a billion people, around 15% of the world's population, have some form of disability.
  - Between 110 million and 190 million adults worldwide have significant difficulties in functioning.
- ### 2.2.1 Differently abled are various types

- Psychiatric disability.
- Intellectual disability.
- Drugs and alcohol dependence.
- Physical disability.
- Acquired brain injury.
- Reading and writing difficulties.

The General Principles Outlines in Article 3 of CRPD

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choice and independence of persons.
  - Non- discrimination.
  - Full and effective participations and inclusion in society.
- Equality between men and women.

- Equality of opportunity.
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (WHO 2011).
- Respect for difference and acceptance person with disabilities as part of human diversity and humanity.

Physical disability

A person with a physical disability may require some kind of equipment for assistance with mobility, include people who have lost limbs or others because of the shape of their body, due to which they required adaptations to be made to enable them to participation fully in the society.

Physical disability can be classified into

- Wheelchair User such as cerebral palsy (cp), multiple sclerosis (MS). Muscular dystrophy (MD), spinal bifida.
- Mobility impairment which include amputees, arthritis, lupus, diabetes, medical illness, cystic fibrosis (CF), multiple sclerosis (physical disability ScrantonEdu).

Types of physical disabilities (According to National Educational Association of Disabled Students 2013)

- Paraplegia (loss of control of feelings in the legs and lower body)
- Quadriplegia (a person permanently unable to use arms or legs)
- Dystrophy
- Polio (An infectious disease that central nervous system and can cause temporary or permanent paralysis).
- Absent limb/ reduced limb function
- Cerebral palsy (medical condition cause by brain damage before or after birth that cause loss of control in the arms and legs).

Problems face by disabled parents

"Parenting is a process and supporting the physical, emotional, and social intellectual development of a child from infancy to adulthood parenting may be defined as purposeful activities aimed at ensuring the survival and development of children" (Hidangmayun, 2010). Birth of the child is the happiest moment of the parents, whereas many parents have a mixed feeling of stress and depression. Parenting becomes even more stressful job and becoming the parent of a child with disability becomes even more stressful and experience

life more differently than other parents of normal children. Mothers are the primary caregiver as they remain with the child during the treatment and appear to carry more burdens and have the feeling that they need to be with the child so that they experience stress related to coping with heavy load of care giving to the child (Moawad, 2012). Parents of children with disabilities cope with the same responsibilities and pressure that other parents face, however, one reoccurring theme reported among these parents is the higher amounts of stress they experience and greater demands made by caring for a child with special needs. The everyday task of feeding, toileting, traveling, and communicating are much more physically and emotionally demanding for parents who have children with disabilities. Parents of children without a disability have the potential relief of sharing household responsibilities with their children. One stressor for parents who have children with special needs is that they may continue to care for their child for extended periods of time, which can be physically and emotionally draining. The number of parents in the home and family size also seems to be related to the amount of stress experienced by the parents. The presence of older sibling can help take care of the child with special needs and sharing household responsibility appears to reduce stress. Parents and child interactions also influence the degree to which a family who has a child with special needs experience stress. Depending on the child's ability to interact and communication with their parents, Parents may have to adjust their interaction style to meet the needs of their child. When parents correctly identify the meaning of a child's cues, parent-child interactions often bring about desired effects and enhance parental feelings of efficacy and competence (Pritzlaff, 2011) communication with their parents, Parents may have to adjust their interaction style to meet the needs of their child. When parents correctly identify the meaning of a child's cues, parent-child interactions often bring about desired effects and enhance parental feelings of efficacy and competence (Pritzlaff, 2011).

Economic and cost of disability are important and difficult to quantify, which include direct and indirect cost, some born by people with disabilities, their family, friend, employer and some by the society. Many of these costs arise because of inaccessible environments and could be reduced in a more inclusive setting. Knowing the cost of disability is important not only for making a case for investment, but also for design of public programmes. People with disabilities and their families often incur additional cost to achieve a standard of living equivalent to that of non-disabled people. This additional spending may go towards health care services, assistive devices, costlier transportation option, heating, laundry services, special diet, or personal assistance ("World Report on Disability", 2011).

MCDD Study provides that parents of children with ASDs were more likely to have attended a parent-teacher conference and to have met with the school guidance counsellor than parents of children in the general education population. These parents were also actively involved in helping their children with homework and were generally dissatisfied with the level of communication provided from the school. Children with ASDs who presented with co morbid disabilities had less involved parents, as well as parents who were less satisfied with the school. There was a significant positive correlation found between the level of parent involvement and the level of satisfaction with the school. The study provides insight into the challenges faced by parents raising children with ASDs and the inherent difficulties in ensuring their children receive the school services necessary to reach their full potential. The need for schools to actively engage parents of children with disabilities is paramount, particularly when developing an Individual

Education Program. An engaged parent is more likely to be satisfied with the school, which can reduce the parent's stress levels.

#### National Standards for Disability Services

There are six National Standards that apply to disability service providers.

1. Rights            2. Participation and Inclusion            3. Individual Outcomes
4. Feedback and Complaints            5. Service Access
6. Service Management

#### Objective

- To understand the relationship of the parents toward with the persons with disability.
- To examine the challenge faces by the parents.

#### Significance of the study

The challenge skill used by parents and family members in bringing up their children, as there are many parents who are finding difficulties to cope up with the situation due to which there is a high level of stress among the parents. Thus it is necessary to analyse the challenge techniques used by the parents in bringing up their child and high light in various aspects of perception of the child where they need special attention love and care that a child need in the growth and development process.

#### Methodology

Research methodology refers to the process of solving research problems and the way to systematically solve research problem. In methodology it considers the various steps adopted by a researcher in studying the research problem along with the logic behind it. It is said that research methodology has dimension and the research methods are part of research methodology (Khato, 2006)

#### Research method

##### Quantitative Research

When we used numbers and standard units of measurement to express the observation of a material or characteristics and the data are analysed quantitatively called as quantitative research. It is based on the measurement of the quantity or amount (Khato, 2006)

##### Sampling unit

30 respondent will be choose using convenient sampling technique which will be best suitable for the setting in order to collect data from the parents of children with special needs.

#### Tools for data collection:

##### Questionnaire

It is a list of plan written questions relate to a particular topic with space provided for indicating the reason to each question, and easy means to collect data. Especially in education research questionnaire is widely used.

##### Sources of data

Primary data are the data which are collected from some primary sources.

Methods for collecting primary data are



- Direct personal investigation.
- Indirect oral investigation

Secondary data are those data which are collected from the secondary sources, the sources of reservation or storage.

Secondary data can be also collect by following methods. The secondary data from the books, journals, dissertations and articles which were helpful information for the research.

#### Data collection process

Data will be collecting by interacting with the parents in the school. Before collecting data the Researcher will take permission from the parents and explains to them about the purpose of the research and then will proceed with filling up the details.

#### EXPECTATION OUTCOME

Following point are the expectation outcomes from the researcher while studying the challenges face by the parents of differently abled children

FAMILY	COPING	DISABILITY STRESS	INTELLECTUAL
DISABILITY	PHYSICAL	DISABILITY	

Data analysis

#### AGE OF THE RESPONDENT

Majority of the parents are between the ages of 30-45. Which means majority of the parents under this age is facing more of stress and burden living with a child who is physically and intellectually disabled.

#### Types of family

Respondents are mainly from the nuclear family. It shows that 86 percent of the respondents are from nuclear family and 14 percent from joint family. Whereas joint families have a better opportunity compared to nuclear family as the family members can share responsibilities and provide support to reduce burden of the parents.

#### TOTAL NUMBER OF CHILDREN

50.4 percent have only one child, and only 9.1 percent have more than two children. Parents having first child with disability are emotionally at lost and trauma due to which they are scared to have another child particularly when the child is intellectually disabled.

#### TIME SPENT WITH THE CHILD

55.5 percent of the parents are always with the child whereas only one of the respondents does not spent much time with the child. It shows the strong bonding between the parents and the child, and that the parents are always in demand because the child always wants the parents to be beside them and spent maximum time with them.

#### EXPENSES TOWARDS EDUCATION OF THE CHILD

Amount of money spent on education for the children with differently abled is very high as compared to normal children as they require special attention and better facilities. It also shows that the expenses incurred on education is very high, 70 percent of the respondent express that they spent more on education.

## HANDLING THINGS ALONE

60.7 percent of the respondents are not being able to handle things alone whereas only 37.3 percent expressed that they are being able to handle and prefer to do things alone.

## Findings and Conclusion

1. From the study the researcher came across more of intellectually differently able children as compared to physically disabled children with 67 percent intellectually differently able and 35 percent physically differently able children during data collection.
2. Most of the time parents spent more time with the child as the study shows that majority of the parents 62 percent are always with the child, 38 percent of the parents said they spent time with the child once in a while and only one parent never spent time with the child sometime as they were busy, percent of the parents spent time with the child once in a while and only 5.1 parents never spent time with the child.
3. It was observed that the children like to share their feeling with their near and dear one, but sometimes they find it difficult to express as the parents are not being able to understand them even if they do so. 30 percent of the children share their feeling sometime, 25 percent likes to share with the parents always 10 percent of the child share only when they are happy or sad and 17 percent of the child never shares their feeling to their parents.
4. The children who attended the school were regular for their classes with 70 percent but there are also 24 percent of the children who do not attend school as their parents feel that it is not necessary for them to attend school. Some are not able to send them to school due to financial problem and time constraints.
5. Parents of children's with differently able face more financial burden as compared to parents with normal child because they have to pay higher fees in the school and it also involves many other expenses apart from school fees.
6. The parents of the differently able children often get upset at household work and office work thinking about the child and the future of the child especially when they become older and no longer available for the child. From the study it was seen that 45 percent of the parents are always upset at any point of time, thinking about the child.

The study focuses more on the parent's relationship with the child, the development pattern, socializing and protecting the right of the child. Coping patterns of parents living with differently able child depends very much on the ability of the child, due to which many parents have difficulty in coping with the child whereas on the other side parents are able to adapt with the situation. Parents also face lot of stress related problem which may indirectly have on their daily work performance and may even lead to misunderstanding in the family as well as among the partners. Due to which the parents have increased stress burden and health related problems. Hence it is very essential that there is a mutual understanding among the family members by distributing their roles and responsibilities among themselves so that they may not have much problem in the family. Financial burden is one of the major problems faced by the parents as the expenses incurred on the education of the child is much higher compared to children studying in normal school due to high fees structure.

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