



Unplanned Journey of Parenting a Child with Special Needs

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ABSTRACT

To a parent every child is special in its own way, but becoming parent of a special child is an entirely different situation. The label of disability signals the child out and being different from others not only affects the child but it also affects the parent and siblings. Given the fact that their child falls in the category of special needs; often a range of emotions such as rejection, guilt, blame, frustration, anger, despair & sweep through the parents. Major child-related parental stresses include: initial diagnosis, identities and roles, care giving, level of disability, availability and access to necessary services, education, financial stresses, and decisions about guardianship. Parents also find themselves worrying about their child's future welfare after they themselves (the parents) die, especially those whose children are unable to live independently. The analysis of relationship between special child and its environment from ecological system perspective also highlights the facts that the child with special needs leaves major impact on the family at each level of ecological system.

KEYWORDS

Experiences, Parenthood, Children, Disability.

Birth of a child; the most awaited moment for parents



Child is a golden filament that knits a man and women into a single piece; parent. Becoming a parent is generally imagined to be a happy and natural life event. The addition of a newborn in a family changes the entire prospects of a family and now family is considered complete. Fundamentally the process of

parenting starts when a couple decides to have a child. It encompasses all the physical, monetary, social and psychological changes in one's life that are somehow linked to planning or rearing of child. "It is true that parents also re-enters into every stage of human life cycle with their children and plays a major role in their children's successful transition from one stage to another" (Chand & Singh 2016). Children are important for their parents, and parenthood is influenced by their competence and ability to create a harmonious environment. But birth of special child in a family always put parents into misery of what went wrong.

According to Lungile et al. (2015) "the birth of a child with disabilities or the discovery that a child has disability is intense and traumatic event for parents". After finding out that the child is in some way abnormal, the whole world of parents turns upside down. No matter how severe the special needs of the child is the parents are inevitably affected in one way or the other and most of the parents are affected emotionally (Beresford et al. 2007). Though parenting is a very demanding job but raising a child with special needs leaves the parents with great stress and a number of care giving challenges, such as more health problems, greater feelings of restriction, higher level of depression grief and financial problems (Lungile et al. 2015).

Journey of parents; raising a child with special needs



Around the globe, disability is still viewed in terms of a tragedy, a common perception of society behind this scenario is that it is not viable for special child to be happy or enjoy a good quality of life. Parents find themselves different because their child is not normal. Many negative emotions that flood into

parents' mind when they observe their child getting social attention because of abnormality. Raising a child with special needs often has negative effects on both relationships within the family and interactions with extra-familial people. Within the family, strained husband wife and parent-child relationships are very common. According to Dobson et al. (2001) parents of children with disability undergo the period of grieving which is similar to that of bereavement. Parents grieve for the 'death' of the

perfect child who existed in their minds. Universal parental perceptions includes seeing their children as developing usually, identifying their children's condition as a temporary or passing circumstance, and perceiving a disability as God's punishment. Parents' perceptions on the nature of a disability may differ from each others' to some point, based on their cultural ethics; educational level and past experiences. Some common experiences of parent's raising a special child are as follows:-

- Parental reaction towards disability of Child:** Family integrity and individual well-being are profoundly affected by the birth and raising of a child with special needs. Shock, denial, and disbelief are common reactions to the sudden or unexpected discovery that a child has a disability. Whatever the degree of severity of disability the child has; parents are scared of upcoming uncertainties. The initial reaction of most parents on being informed of their child's disability is shock. The shock reaction usually lasts from a few hours to a few days to months. Shock is typically followed by a phase that is characterized by rejection or disbelief of the reality of the situation. As a temporary coping strategy, rejection can be quite useful in giving parents time to adjust to the situation. But on a long run when parents begin to accept the reality of the situation; they experience anger about the loss of a normal healthy child and ultimately it lead to a deep grief and profound sadness. This sadness can be due to loss of the opportunities and ambitions which this special needs child will not be able to fulfil. By this prolonged sadness parents typically experience a sort of detachment, sometimes they feel empty and nothing seems to matter and generally and parents life goes on from day to day surrounded by uncertainties and fear feeling of self-blame is also common among parents as most of the parents, directly or indirectly, believes that other people hold them responsible for their child's illness which harms their self esteem.
- Parental Identities and roles:** Parental roles are often altered or adjusted to provide the necessary care. Ambivalence about their new identity as parents of a child with disability and anxieties about the uncertainty of their child's future only add to the parents' stresses. Many children affected by impairments are dependent on others for self care tasks that are typically taken for granted by normal ones (e.g., bath, dress, eat, move, follow directions, and communicate) consequently, requirement of caregiver are often challenging, persistent, and prolonged. Along with this parenting a child

with developmental disabilities not only affects the intensity of care giving, but may also result in extending the period of parental care giving, as the development of autonomy for children with disabilities is often compromised and/or delayed.

- **Providing extra necessary services:** Common services needed by parents include: reprieve care, work-related therapy, substantial therapy and educational and recreational services. Even after appropriate services are in place, high work place demands in terms of quality, time or quantity often leave parents in circumstances where parents especially mother have to choose between job and child. Besides finding well trained caretaker and activities centers is also a very tough job for parents in Indian Scenario.
- **Institutional vs. Home care:** Which form of education and training is most beneficial for the child is the biggest and most complicated decision for parents. In spite of challenges, most parents desire to raise their children with special healthcare needs at home even though for some individual conditions and some community factors strain the family's ability to provide for their child's special needs.
- **Parental involvement in education of Special Child:** The placement of the child in school/special schools or residential facility on the basis of child's abilities and early intervention to check further environmental damages are the pre request of special education. Parents of children with developmental disabilities need to be more involved with their child's education than parents of children without developmental disabilities. In fact, parents of children with disabilities have key responsibilities for enhancing their child's development by providing an integral part of their child's educational experience at home which demands lots of their time and energy.
- **Financial overload:** Exorbitant health care costs, necessary services expenses, and reduced family income are common challenges faced by parents of children with special needs. Special diets, facilitative equipment, medical care, and special transportation are common expenses among children with developmental disabilities.
- **Decisions about Guardianship:** Parents of special children constantly worries about the future of their children and when they see other children of same age growing into responsible independent individuals they wish same experiences for their children. Parents find themselves frequently worrying about their child's future like job and marriage. Though parents' guarantees taking care of their child but what will happen to the child after parent's death is a major cause of worry. Asking someone else to take over the guardianship is an extremely difficult and emotional decision for parents who know firsthand how stressful some of the responsibilities may be. Parents expect other siblings to take responsibilities of their special one after their death. However parents of more independent or successful the special person worries comparatively less than the parents of fully dependent special child.

An ecological system perspective of special children and its parents



The ecological system theory by Uri Bronfenbrenner perfectly describes how a child and its environment affect each other. Similarly, if we look at the ecological system of special children it is usually overwhelmed with demands of time, energy and money on parents' part. No doubt that nothing is more valuable than a child for parents and most of the parents enjoy the process of parenting and consider all extra responsibilities as natural. But everyone cannot handle the excessive demands caused by disability of the child. At microsystem level parents own interpersonal relationships get affected by excessive demands caused by child's disability, luckily,

some parents strengthen their relation in this phase (like spouses respecting each others for their sacrifices etc.). It usually happens in such cases where parents accept the child and keep positive outlook towards it. On the other hand situations like lack of quality time for spouse and other family members, compromising needs of other family members to provide needful to special child, sour the interpersonal relation of special child's family. The mesosystem is basically the interaction between the components of microsystem. Again an excessive demand is placed on all components of mesosystem to provide a healthy environment to the child and the components have to co-operate equality in this process. Parents has to be extra visitant about child's learning at schools and child safely at neighbourhood and even in family itself as bullying and labelling is very common phenomenon for special children.

The system basically comprise the social network and workplace of parents and both plays key role in determining parental attitude towards the special child. The social network includes extended family (Kins) and friends of parents. Being social animal individuals adopts behavioural patterns and belief system which are considered appropriate by its society. When it's come to rearing or having a child with special needs, the mindset of parents, which they have adopted from their social system, determines how parents react to the disability of child. Beyond their own attitude how relatives; friends of parents look into child's situation also affects parent's attitude about the child. The workplace environment, in term of facilities provided by organisations like provision for maternity/ paternity leave, child care leave, bearing education expenditure of children by govt. organisations free of cost health care facilities provided by organisational etc. affects parents and ultimately the child with special need in a family.



The cultural beliefs and national policies are the part of macrosystem of an individual. The dominant values, customs, economic and social system passed down from generation and become a part of individual's daily live has major impact on a family of child with special needs, even the child's self concept is also shared by these believes. The economic and social system of family allows utilization of resources in rearing a special child. Favourable government policies for both parents and special children smoothen the process of education and training for making the child competent enough and independent. A cursory look at the chronological level history of people with special needs shows the impact of advanced medical, health care, education and training facilities on children as well as on their families. Luckily the advanced health care and education facilities are very favourable for families with special need. Parents who are aware can avail facilities for their children and give them near normal life in the best possible manner.

Changing the perspective from disability to different ability



Dealing with child's disability creates lots of stress in a family unit but a careful and systematic planning can reduce stress to its minimum. Along with the disability a special child can acquire its potential to the maximum level and live the near normal life, if the child is provided with psychologically and educationally enriched environment for learning. Though going back and forth through a range of emotions is justified and natural on parents part but the soon parents come into terms with the situation and exhibits a mature emotional acceptance of their own child, the process of empowering the child begins. Besides these awareness about various components of ecological system of child and family can be very helpful for parents. Availing maximum benefits from the environment like referral services, policies, programmes of government and rehabilitative services can be very helpful in bridging the gulf between disability and different ability of child.

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