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A SOCIOLOGICAL STUDY ON THE REHABILITATION OF CHILDREN WITH SPECIAL NEEDS IN INDIA

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ABSTRACT

This article discusses the intricate connections between different aspects concerning the rehabilitation of children with special needs and the essential roles parents can assume in the rehabilitation of children with disabilities.

Becoming a parent brings happiness and festivity to the family. However, when a child is born with a disability, it creates a challenging situation for parents to manage. The role of parents in embracing the child and encouraging their growth and development is crucial. Since each child will develop uniquely in sensory-motor, cognitive-perceptual, and psycho-social areas, parents will serve as crucial facilitators and educators for these developments. Multiple challenges exist concerning medical and rehabilitation facilities in India, along with issues linked to parents' educational background, socio-economic conditions, and understanding of disabilities, which further complicates the situation of raising a child with a disability. In this context, parents must play a crucial role in their child's development in every aspect of life and assist them in living with dignity within society.

INTRODUCTION

The arrival of a baby is a transformative experience for the parents. An adorable infant arrives in your home, family, and community. This is a moment for happiness and festivity. Relatives gaze at the newborn and ponder; will he excel in football, will she gain fame as a musician, will she train to be a pilot? But what occurs when this new child is discovered to have a disability? What happens if there are health issues? What if there are inquiries regarding this child's specific needs? Caring for a child with, or vulnerable to, a developmental delay or disability can be daunting. The effort needed to nurture a child with a chronic illness or disability far exceeds that of raising a typical child. "Parenting a child with special needs" refers to the extra attention a child requires, encompassing medical support, enhanced parenting efforts, and navigating various systems. "Reducing repercussions" signifies the effort to juggle family responsibilities, which encompasses raising siblings, nurturing connections, and sustaining your own well-being.

Approximately 10% of the global population, equating to 650 million individuals, have a disability. They represent the biggest minority in the world. Globally, there are between 120 and 150 million disabled youths and children.

The Indian Census 2021 states that 21.9 million individuals in the total population of India (2.13%) are disabled, and that 1.67% of the overall population aged 0-19 years (7 million) are experiencing disability. This information encompasses individuals with visual, auditory, speech, physical, and cognitive disabilities. Among individuals with disabilities, 35.9%

belong to the 0-19 age range. One out of every 10 children is born with or develops a physical, mental, or sensory impairment. Seventy-five percent of disabilities can be avoided. Just 1% of children with disabilities can access education. Fewer than 50% of disabled children make it to adulthood, and only about 20% live to see their forties.

The role of parents is crucial in raising these children, enabling them to integrate into mainstream society and contribute effectively. Parents can act as supporters for their children. From their early infancy through different developmental stages in life, including education and employment, parents have a significant impact.

CONCERNS ASSOCIATED WITH PEDIATRIC REHABILITATION

Numerous infants are born with issues known as congenital birth defects, developmental delays, and developmental disabilities, as well as multiple disabilities. These are irregularities in structure, function, or body chemistry, along with brain lesions that will necessitate medical or surgical treatment and rehabilitation. Nonetheless, the health sector often lacks the strength to respond promptly or proactively to disabilities, particularly in rural regions. There are limited specialized services for children with disabilities.

Government hospital pediatric units are unable to support children with disabilities due to a deficiency in infrastructure and resources. Despite recent scientific progress allowing us to reduce disability and enhance the lives of individuals with disabilities and their families, a cure remains unattainable for numerous rehabilitation patients. In India, services are available from Occupational Therapists, Physiotherapists, Prosthetists, Orthotists, Speech Therapists, and other rehabilitation experts for children with special needs; however, the quantity of professionals in government hospitals across states is quite limited or non-existent. All these challenges for the rehabilitation of a child with a disability only exacerbate the issue.

PARENTAL ISSUES

The family is crucial in the child's development. When a child is born with a disability, it causes significant emotional strain on the parents, particularly the child's mother, in India. In developing nations such as India, it is still thought that women are accountable for giving birth to a child with a disability. A parent’s ongoing sorrow or remorse due to a child's congenital defect, trauma, or if the child has developed a chronic illness potentially linked to genetics, can adversely affect the child's growth. Parents need to maintain a balanced emotional reaction and a strong positive outlook regarding their children and while managing the situation. They are able to give their child more constructive feedback, feedback that enables the child to grow and mature correctly. Parents of children with disabilities go through shock, denial, sorrow, and sometimes rage. Recognizing the emotional reactions after having a child with a disability is crucial for parents. This will assist them in managing the disability and exploring various options available for the child while providing support to the child.

CONCERNS REGARDING CHILDREN

The child with certain disabilities might not be able to engage with the environment and various learning resources for physical-motor, cognitive, social, and psychological growth. Because of the disability, there is a shortage of chances to engage and connect with peers of the same age. The child serves as a medium for the parents, particularly the mother, to convey her anger and sorrow. In reaction to the mother, the child exhibits specific behavioral issues that subsequently complicate the rehabilitation of disabled children. As a child enters their teenage years, body image gains significance more than at any other stage. A disease or disability that causes an adolescent to look different can significantly harm their long-term self-perception and the identity they carry into adulthood. Interactions with peers hold significant importance for children with disabilities. When these children face teasing or mocking from peers without physical issues or those who lack understanding, it can significantly affect the developing child’s self-image. A child's ability to adjust physically, emotionally, and intellectually plays a crucial role in addressing their deficiencies or differences and transitioning into independent adult life.

DEVELOPMENTAL CHALLENGES

In the initial years of life, significant developmental changes happen; starting as a completely dependent being with reflex-driven movements, the newborn evolves over five years into a relatively independent child prepared for school.

Recognizing that biological, social, cognitive, and behavioral factors are all significant is crucial in comprehending child development. The child's advancement in one area influences the others too. When interacting with children, it is crucial to consider the whole picture rather than concentrating solely on a single element. According to Piaget, childhood is categorized into five distinct stages as shown in the chart on Developmental Issues. The first and second years of life include significant changes physically and psychosocially, making it essential to differentiate them. When the child attains the ages of three to five, there is greater consistency in developmental matters. Between the ages of six and twelve, development is both qualitative and quantitative. The final phase of child development that requires distinct focus is adolescence. During puberty and into early adulthood, significant physical, intellectual, and psychosocial transformations take place that are both qualitatively and quantitatively distinct from those in earlier childhood.

Physically, the initial year of life is characterized by the child’s enhanced strength and development of gross motor skills. The child grows from the center outwards. This means that the child needs to initially build strength and coordination in the trunk and head, and afterwards, acquire additional strength and gross motor skills in the limbs. The phases of cognitive development, as outlined by Piaget (1952) from birth to two years, concentrate on sensorimotor progress. Sensorimotor development indicates that a child, for intellectual growth, is engaged in gathering information via the five senses and reacting physically to their surroundings.

Erik Erikson (1968, 1977), in defining the psychosocial stages of development, states that the child is in a crisis of learning trust versus mistrust. At this point it is very important that the child have consistent parenting, particularly in a significant social relationship with the mother or mother substitute. It is only through consistent parenting and meeting of the child’s needs that the child can develop a sense of trust and, as a favorable outcome, be able to trust and have optimism as he/she faces future years.

The second year of physical development is primarily geared to fine motor development. It is during this time that the child is able to walk and begin to focus on using fingers for finer activities. The ability to explore the environment and stabilize gross motor development occurs till the age of 5 years. If the parents notice any abnormality/delay in these developments, they should seek the advice of the physician and rehabilitation professionals.

ROLE OF PARENTS IN PEDIATRIC REHABILITATION:

Prevention of problems related to disability of the child

Research into the environmental and genetic causes of birth defects and disabilities is ongoing. Technology contributes to understanding and preventing defects in various ways; for example, prenatal testing is growing increasingly sophisticated. Safer and more accurate tests include:

- Results of ultrasound tests and magnetic resonance imaging (MRI), which are sometimes combined with information from blood tests to determine the risk of having a child with certain birth defects
- Maternal blood screening to determine risk of chromosomal abnormalities
- Amniocentesis
- Pre-conception counselling

The knowledge regarding these technological advancements can give a clearer, safer, and more accurate diagnosis at an earlier stage of pregnancy, giving parents more time to seek advice and consider their options.

Acknowledging the emotional responses

The emotional responses after the birth of a child with disability is quite natural, but the parents have to acknowledge their emotional responses in order to participate in the rehabilitation of their child.

Seeking appropriate support

One of the best things the parent can do for themselves and for their child is to seek support. Getting in touch with someone who’s been through the same thing can be helpful; ask doctor or a social worker at your hospital if they know any other parents in the area who have children with the same condition.

Celebrating the child

Enjoying with the child the same way any parent would: by cuddling or playing, watching for developmental milestones (even if they’re different from what they would be if your child didn’t have a disability), and sharing joy with family members and friends is very important. This will impart belongingness in the child and the child will cooperate in the rehabilitation process.

Gathering Information

The parent should have adequate information regarding the needs of their children and how to seek for solution to those. They can read books written on pediatric rehabilitation, get information through internet and other sources. Availability of information can reduce tension and anxieties of the parent.

Facilitate early diagnosis

Parents can facilitate early detection and diagnosis of any disability or growth and develop mental delay for early treatment and management in order to avoid any complication affecting the child health in the future. Seeking early intervention is usually the best strategy. Early Intervention is designed to bring a team of experts together to assess the child’s needs and establish a program of treatment, early intervention services include feeding support, identification of assistive technology that may help your child, occupational therapy, physical therapy, speech therapy, nutrition services, and social work services. In addition to identifying, evaluating, and treating the child's needs, early intervention programs will provide information about where one can get information about the child's disability; help to learn how to care for the child at home.

Collaborate with professionals

Parents should collaborate with professionals at all levels of health care like, Care of the individual child, Program development, Implementation, and evaluation. Parents should be sportive to know complete information about their child's progress in a continuing basis. Can seek support from family to family basis. Most research shows that when parents are involved they themselves experience less anxiety as they feel more in control over what is happening to their own child. In turn they transmit less anxiety to the child. A parent can become an extra pair of hands for the therapist who can teach the intervention to the parents to practice at home. Most importantly if the mother is accompanying the child for therapy, that will reduce lots of anxiety of the child and their by reducing development of behavioral problems of the child. Positive attitude of the parents are very important in the rehabilitation of their child.

Active participation in therapeutic program

A child learns by touching, looking, listening and communicating. A parent can contribute a lot in the early learning of the child. The parent can become an educator for the child through out the rehabilitation process.

Evaluating the progress of the child

By keeping constant note of the questions coming to the mind and getting the answers from the treating rehabilitation professional can be an important tool for parents in order to evaluate the progress of their child.

Addressing all aspects of a child's life

The child will not grow in terms of physical motor developments only, other aspects of a child's life, like interaction with peers, social and cultural involvements, education in the school, sports, competitions etc are very important. Parents most importantly mother can play an important role in mediating these aspects of a child's life.

Creating awareness in the society

The most important aspect of being the parent of a child with disability is that they can contribute for the development of society by creating awareness regarding the problems a child faces and their solutions**.** They can make easy the life of lots of parents going through the same situation.

Parent to parent support program.

Through parent to parent support programs, parents can play an important role in helping other families those who are going through the same experience of bringing up a child with special needs. Various researches have shown the effectiveness of this strategy as part of a parental role playing.

In a study by Kurani D et al using a Parental Involvement/Engagement Scale it was seen that children with lower parental involvement had less improvement in the above areas whilst children with higher parental involvement showed greater improvement.

CONCLUSION:

A large number of disabilities in India are preventable, including those arising from malnutrition, accidents and injuries as well as medical issues during pregnancy or birth. Measures must be taken to ensure that children with disabilities are registered immediately after birth as well as to provide rehabilitation services .The role of a parent becomes important here for the future of their children and for the society.

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