

Rehabilitation of Children with Special Needs in India: Role of Guardian

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Introduction

The birth of a child is a life changing event for the parents. A beautiful baby comes to your house, family and neighborhood. It is a time for joy and celebration. Family members look at the new child and wonder; will he be a football star, will she be a famous musician, will she become a pilot. But what happens when this new child is found to have disability? What if there are health problems? What if there are questions about the special needs this child may have. Parenting a child with, or at risk for, a developmental delay or disability can be stressful. The work required to raise a child with a chronic illness or disability is above and beyond that of raising a typical child. "Special needs parenting" describes the additional care that a child needs and includes medical care, parenting plus, and working the systems. "Minimizing consequences" reflects the struggle to balance the rest of family life and includes parenting siblings, maintaining relationships, and keeping yourself going. [2]

Around 10% of the world's population, or 650 million people, live with a disability. They are the world's largest minority. Between 120 and 150

million disabled children and young people live in the world. [3].

The Indian Census 2001 reports that 21.9 million persons in the Indian total population (2.13%) are disabled, and that 1.67% of the total population within the age-group 0-19 years (7 million) are living with disability. This data includes persons with visual, hearing, speech, physical and mental impairments. Of all persons with disability, 35.9% are in the 0-19 age-group. One in every 10 children is born with, or acquires, a physical, mental or sensory disability. 75% of the disabilities are preventable. Only 1% of children with disability have access to education. Hardly 50% of disabled children reach adulthood, and no more than 20% survive to cross the fourth decade of life. [4]

Role of parents become immensely important in bringing up these group of children and making them able to come to the main stream and contribute to the society. Parents can play the role as advocates for their own children. [5] Starting from their early infancy, developmental stages in various aspects of life till their education and employment, parents play an important role.

Issues related to Pediatric rehabilitation

Many babies are born with problems called congenital birth defects, developmental delays and developmental disabilities, multiple disabilities. (7) These are abnormalities of structure, function, or body chemistry and lesions in the brain that will require medical or surgical care and rehabilitation. However, the health sector most of the time is too weak to react on time or proactively to disability, especially in the rural areas. There are few special services for disabled children.

Paediatric units at government hospitals are incapable of dealing with children with disabilities as they lack infrastructure and resources. Although recent scientific advances have enabled us to minimize disability and improve the quality of life for people with disabilities and their families, cure is still not possible for many rehabilitation patients. (8) There are services provided by Occupational Therapists, Physiotherapists, Prosthetist and Orthotists, Speech Therapist and other Rehabilitation professionals for children with special needs in India, but the number of professionals in government hospitals in states are very few or nil. All these obstacles for the Rehabilitation of a child with disability further adds to the problem.

Parental Issues

The family plays an important role in the development of the child. When a child is born with some disability, it creates a lot of emotion- al stress in the parents and specifically in the mother of the child in India. In developing countries like India, women are still believed to be responsible for the birth of a child with disability. A parent's constant grief or guilt because the child was born with a congenital defect, experienced a trauma, or if the child has contracted a chronic disease which may be genetically related, can have a negative impact on the child's development. (6) It is important that parents should have a balanced emotional response and strong positive attitude towards their children and in handling the situation. They can provide

more positive feedback to their child, feedback that allows the child to grow and develop appropriately. Parents of children with disability experience shock, denial, grief, and even anger. Acknowledging the emotional responses after having a child with disability is very important for parents. This will help them to cope with the disability and try out different facilities available for the child and be supportive to the child. (6)

Issues related to Child

The child, who has got some disabilities, may not become able to explore the environment and other sources of learning for the physical-motor, cognitive, social and psychological development. (6) Due to the disability the lacks the opportunities to play and interact with the children of same age group. The child also becomes a media for the parents and specially mother to express her anger and grief. As a response to the mother the child develops certain behavioral problems which further create problems for the rehabilitation of those children with disability. As a child reaches adolescence, body image becomes more important than at any age. When there is a disease or disability that makes the adolescent appear different, it can be very damaging to the long-term sense of self and the identity that an adolescent carries into adulthood. Peer interactions are particularly important for children who have disabilities. When these children are teased or taunted by other children who do not have physical problems or who do not understand, it can have a dramatic impact on the growing child's self-concept. How a child is able to adapt physically, emotion- ally and intellectually is very important in overcoming their deficit or their difference and moving into independent living as an adult. (6)

Developmental Issues

In the first few years of life rapid changes occur in development, from being totally dependent, with reflex controlled movements, the new born baby is transformed over 5 years into a comparatively independent child who is ready for school.

In understanding child development it is important to realize that biological, social, cognitive and behavioral components all are important. How the child progresses in one area affects the others as well. In dealing with children, it is important to think comprehensively, not focusing exclusively on only one aspect. (6) Referring to the chart on Developmental Issues, childhood, according to Piaget, is divided into five different stages. The first year of life and the second year of life encompass such major changes both physically and psychosocial-ly that it is important to list them separately. By the time the child reaches ages three to five there is more cohesiveness in issues of development. From ages six to twelve, progress is more qualitative and quantitative. The last stage of child development which warrants separate attention is that of adolescence. When children reach puberty until the age of early adulthood, major physical, intellectual and psychosocial changes occur that are, again, qualitatively and quantitatively different from earlier childhood.

Physically, the first year of life is marked by the child's increased strength and gross motor functioning. The child develops proximodistally. This simply means that the child must develop strength and coordination of the trunk and head first and, later, gain more strength and gross motor functioning of the limbs. The stages of intellectual growth, as defined by Piaget (1952) from birth to age two, focus on sensorimotor development. Sensorimotor development simply means that the child, in order to grow intellectually, is attuned to taking information through the five senses and responding motorically to the environment.(9)

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.(6,7)

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 counseling

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 co-operate 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 developmental 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 throughout 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. [10]

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.[11]

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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