

Therapy

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EARLY INTERVENTION - A DISTINCTIVE ADVANTAGE

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The
Spastics
Society
of India

REFERENCE



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INTRODUCTION

Consider this as a case profile. In their professional life at The Spastics Society, our social workers encounter similar cases with almost predictable frequency.

Shanta - an educated young woman from a middle-class family, twenty five years of age, is expecting her first baby. The due date has approached. She has maintained excellent health throughout thirty-six weeks of pregnancy. Like many first-borns, her baby decides to make an entrance into the world in the wee hours of the day, at 4 a.m. She is rushed to the hospital with frequent labour pains. The expectant father, eager grand-parents and neighbours are waiting to hear the news. Hours tick past. It's already evening and the pains continue. At 9 p.m., seventeen hours after admission and a total twenty-four hours prolonged labour Shanta undergoes a Caesarean Section. A healthy, big, pink, baby boy of eight pounds is born. The doctor reports that the umbilical cord was too short and the boy waited for about half a minute or so before giving his first cry. Everything seems alright though and both mother and baby are doing just fine.

There is so much to rejoice about the birth of Raju. The short gap of thirty seconds between birth and that first cry is forgotten. Friends, relatives and neighbours only talk about Shanta's suffering due to the long hours of labour. They sympathise and hope that she will regain her strength soon.

The hospital stay of a week passes uneventfully. Since Shanta is so weak, nurses have to care for the baby. They often joke about how uneasy, unhappy and cranky the pretty boy is in his new environment and how they hope that he will like his home better. Even the grandparents assure Shanta that she should not worry about these '*minor*' problems.

Shanta brought Raju home. But he really seemed restless. Did he have colic? But he is not nursing very well. Is she holding him correctly? Contrary to what Shanta had read, her son could not suckle at all. She tried bottle feeds. 'The poor baby is probably not getting enough to eat and is crying all the time' she thought.

Shanta was worried. She tried to discuss the baby's problems with the family but everyone laughed it off and attributed her worries to '*postpartum blues*'.

Weeks passed. Raju's spells of crying, irritability and poor sucking continued. To add to this set of problems, Shanta noticed that Raju could not focus. There seemed to be sometimes a '*stiffness*' and sometimes a '*floppiness*' about

him. Shanta observed that he even had disorganised eye movements.

Before any action could be taken, Raju was already three months old. He was still an unhappy, little boy who could not be pacified easily. He was not even holding his head.

All these observations lead to a possible diagnosis of a complex neurological condition called cerebral palsy. Shanta, an alert and observant mother, sought professional help immediately.

Unlike Raju's case, very often the birth history and developmental stages are not correlated. As a result, all the difficulties of the new-born are laughed off or ignored.

The objective of this booklet is to increase awareness about the early signs of cerebral palsy which may help in a proper, prompt diagnosis. An early start to therapy for a baby ensures a better chance of developing as normally as possible and this is what early intervention is all about!

THE NEED FOR EARLY INTERVENTION

Cerebral palsy is a very complex condition. Obtaining and following professional advice, providing appropriate stimulation and creating a nurturing environment for the little bundle of joy who needs extra help is all part of the early intervention programme.

During the early stages of life, while the baby is suffering in his own way, the mother of a child with cerebral palsy encounters unique problems. She feels inadequate and 'disabled' because she is not able to make her baby happy, feed him properly, change or hold him. A distressed mother after hearing the diagnosis asked Dr. A.L. Scherzer, 'Do I feed him ?'

The mother and family need initial support and 'treatment' to learn to cope with cerebral palsy. Parents should be counselled and should come to understand the need for regular visits to professionals, for following exercise routines and about self-help groups as well as other supportive services. Only with the co-ordinated efforts of parents, paediatrician and paramedics can a child with cerebral palsy benefit from early intervention and be helped to attain his maximum potential.

PRELIMINARY EXAMINATION

Evaluative services provided by various disciplines are available in our country. A complete developmental analysis is a prelude to treatment. Emphasis is placed on defining the nature and degree of delay and describing associated deficits. Assessment of neuromotor development is possible in infancy and early childhood. As described in the case study, the traditional approach is to assess the child's developmental competence in relation to a standard '*developmental milestone scale*'. The '*delay*' then becomes obvious to a professional.

A physiotherapist observes a baby's spontaneous postures and movements besides primitive and postural reflexes and reactions. It helps her to make an early motor diagnosis, developmental motor prognosis, in designing a therapy programme and evaluating markers of gestational maturity. In clinical jargon, a therapist is really preparing a check-list of developing an appropriate programme for the child.

PARENT'S ROLE

Fortunately, for management one does not have to study these markings but follow the instructions of therapists and help the child cope with his developmental problems. Considering all the assessment data and after obtaining a clear picture about the baby's present status, a professional suggests the best method for holding, carrying and feeding the baby. Once the mother develops the bond with this physical contact, she feels much happier and rarely considers her baby '*different*' than other so-called '*normal*' ones.

At The Spastics Society of India, we have an early intervention clinic for babies only a few weeks old. After a thorough examination of the infant, we work very closely with the mother and father. Parents are taught correct techniques for carrying, changing and feeding the baby. With this tactile cuddling and nurturing, the baby soon starts giving varying responses which encourages the mother and reduces the feelings of rejection and failure. The baby soon responds by thriving and producing positive

interactions with the parents. Therapists 'talk' to the babies thus indirectly encouraging and teaching her parents to do the same. Feelings of chronic sorrow, depression, grief, anger, loss and guilt experienced by the parents of an infant unable to reach his milestones on time, are reduced with interaction, discussions with and support of the therapists. They know that the child is responding and learning to appreciate and anticipate each maturational state to which he learns to adjust.

ROLE OF THERAPISTS

Research studies in cerebral palsy have shown that because of the difficulties in childhood, a baby's learning opportunities are extremely restricted. For example, due to gross motor problems, movements like creeping, crawling and rolling are restricted, so exploring the environment is difficult. Lack of fine motor co-ordination such as restricted grasping and poor holding capacity, limit the learning experiences through touch. Due to a 'rigidity' of muscles the baby can not really 'feel' his own body. Thus an infant with cerebral palsy receives only very limited sensory stimuli. If there are associated problems of hearing and sight, the situation is, naturally, even more complicated.

Families, especially the parents, have to compensate for this lack by providing necessary inputs through an alternative, modified environment. Working closely with

the therapy team, parents learn to create a sustainable nurturing environment at home.

Early in infancy, a baby with cerebral palsy is helped to feel her body, play with her feet and legs, put her hands in the mouth, move the hands and observe them and move the feet and legs. Even though he may not immediately be able to clasp, hold and feel toys, he is provided with toys of various textures, colours and shapes. This helps in increasing the eye-hand co-ordination, correlating speech and communication and intellectual development. Thus, by bringing in a high-risk infant to an early intervention clinic or infant stimulation clinic, the physio, occupational and speech therapists can help in sensory-motor and early speech development.

DESIGN OF THE THERAPY PROGRAMME

Design and identification of a suitable therapy programme is a very specialised and crucial area. Beneficiaries, parents and families really do not play any role in this process. However, to sustain the proposed activities at home and to understand the logic behind a particular selection, it is helpful to know the process. Parents can then appreciate a suggested position and do not make compromises of either positioning the baby because they think he does not *'like'* doing what therapy experts have told or doing the exercise less frequently because there is not enough time due to domestic work pressures. In short, by understanding the therapy programme, they also understand the consequences.

Therapists try t/o inhibit abnormal reflex activities through careful positioning. An expert is watchful about the postural responses as a result of this inhibition. As these responses appear, the professional encourages development of related motor skills. Although based on general guidelines, these responses are a direct consequence of the therapists' clinical experience and knowledge of the individual patient. Parents should carefully follow instructions and avoid doing any unscientific, baseless modifications in treatment. For example, the expert will observe that trunk stability, and extension of the arms to support the weight are pre-requisites for independent turning, sitting and movement in and out of the sitting position. By careful observation, the therapists will suggest appropriate supported positions.

It must be remembered that an expert is seeing the overall picture and not every muscle, movement and reflex in isolation. She considers other factors like righting, equilibrium and protection reactions. A relationship between all these factors together provides a rationale for treatment of the child with cerebral palsy. When a child reaches a certain stage of postural readiness, it is realistic to expect that intensive therapy would result in attainment of a specific motor skill. If the pre-requisites are absent an expert realises that, at that point of time, attempts to develop that particular motor skill are unrealistic. She may emphasize other skills instead. Untrained, lay persons like parents and families should

resist the temptation of *'forcing'* the child into a motor activity that he is not ready for! There is a clear warning against this, as it may prove to be completely unproductive and may even make the baby's condition worse rather than better. In other words, it is totally inadvisable to go against nature !

OTHER NECESSARY INPUTS

As the baby grows older, he starts responding to visual and auditory stimuli. Some children with cerebral palsy have visual or auditory perception problems. Assessments of visual perception including depth perception, figure-ground discrimination, spatial relations, position in space, visuo-motor and auditory perception tests like localisation, memory and sequential memory are recommended. Perceptual status is important when adaptive devices and equipment are to be considered. For example, without adequate perceptual abilities, a motorised wheelchair or a even communication board cannot be used.

Teachers, occupational therapists and speech therapists design programmes and activities to facilitate development of perception. The parents of a child with cerebral palsy sometimes set their own priorities and objectives for their baby. Naturally, these goals could be faulty. For example, some parents discontinue therapy because they often find that *'even after two years the child cannot sit independently'*. When the physiotherapist requests them to go for speech intervention they observe *'What is the use? He cannot even*

stand still'. Now, we, as lay people, must realise that we are in good hands and must rely on the guidance in the best interest of the baby's overall development. As already mentioned before, if any early signs of a problem are detected or even suspected it is best to be brought to the notice of a paediatrician. An interaction with therapists and understanding of the problem would give a child the best opportunity to rise to his full potential.

SUMMARY

When a warning bell sounds in the minds of parents or if there is a high-risk baby with a history of premature birth, low-birth weight, a fall in infancy or lack of oxygen at birth, for however short a duration and for whatever reason, immediate consultation with an expert is advised. With an early, thorough assessment followed by early intervention through accurate therapeutic treatment a baby with cerebral palsy has a good chance of rising to her full potential.

Physiotherapists, occupational therapists and speech pathologists form a professional team of paramedics. A social worker is available as an intermediary to provide a common platform where professionals and parents can meet. Proper referrals and follow-up are the basic needs in the total care and management of this complex condition.

Regular check-ups with a paediatric neurologist or paediatrician and on-going intervention provided by physio, occupational and speech therapists, teachers and an educational psychologist, with the social worker as the intermediary for the team, give the baby the holistic care and management needed for this complex condition.

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