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CARING FOR CHILDREN WITH SPECIAL NEEDS

Children are the asset of any nation. They positively represent the future. Child development and good health are of paramount importance which in turn impacts our society. Every child deserves a solid education along with nutrition to enhance their growth. The following is a narrative based on a discussion with Professor Gitanjali Sathiadas, Professor of Paediatrics and consultant paediatrician of the Faculty of Medicine, University of Jaffna.

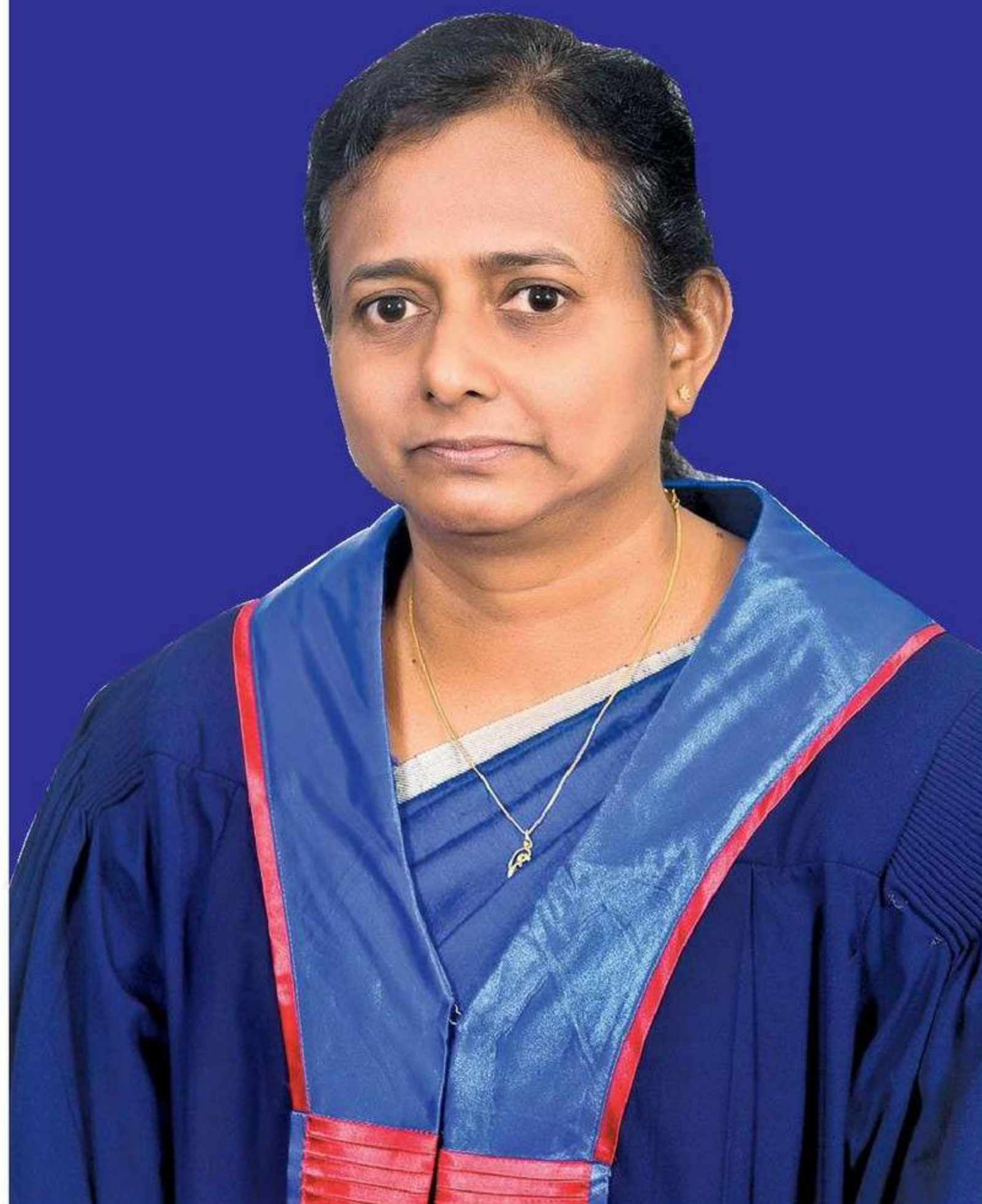
She explained about some of the disabilities that children are born with. Professor Gitanjali said "Cerebral Palsy (CP) is a condition that occurs mainly due to an insult to the developing brain. Insults are due to lack of blood supply and thereby lack of oxygen supply, lack of sugar, infections in the mother which are transmitted through the placenta called TORCH group of infections. In a few instances it can be due to genetic causes as well. Major deficits in patients with CP are loss of selective motor control and dependence on primitive reflex patterns for movement, abnormal muscle tone that is strongly influenced by abnormal body posture and movement, an imbalance between agonist and antagonist muscles that, with time and growth leads to fixed muscle contracture and bony deformity, impaired body balance mechanisms, sensory loss, visual and hearing impairment, superficial and deep sensation associated problems, seizures, mental retardation behaviour problems are associated with this condition".

She added saying "Babies are born with chromosomal or genetic abnormalities like Down Syndrome, Turner Syndrome etc. These genetic disorders are transmitted from parents and they can occur spontaneously as well. These conditions depend on maternal age, exposure to radiation, drugs and environmental pollution as well. In these parts consanguineous marriage is common and if so the chances are high to get a baby with a genetic disorder. We see quite a few babies with a condition called meningomyelocele which occurs due to folic acid deficiency. When pregnancies are not detected or are unplanned the mother fails to consume periconceptional folic acid and there is a high chance for them to develop this condition. Insisting on consuming periconceptional folic acid, high doses of folic acid for future pregnancies if one baby is affected is warranted to prevent this."

It is shown clearly nutrition during pregnancy is key for future development of the unborn child. The vital 1,000 days is between a woman's pregnancy and her child's second birthday - is a unique period of opportunity when the foundations for optimum health and development across the lifespan are established. The internal environment in which the baby grows and develops matter as the embryonic genome undergoes epigenetic modifications, or alterations to the DNA that do not change the genetic code but rather affect how a gene is expressed by turning expression on or off. These modifications are responsive to environmental conditions and nutrient availability, and likely adapt to promote optimal survival under existing conditions.

Autism has affected many Sri Lankan children and often parents don't understand this condition, or some prefer to live in denial saying their child is normal. Professor Gitanjali explained "Neurodevelopmental disorders like autism and ADHD are increasing within our population in the recent past. In Sri Lanka one in 100 children has this condition. Religion and cultural beliefs hinder detection and early intervention of these conditions. These neurodevelopmental disorders cannot be cured but controlled by regular therapy sessions. The misbelief that these conditions are cured interferes with the child being brought in time for certified therapy. Some parents take their children to several doctors, indigenous practitioners, astrologers and temples before realizing that the condition is not curable and by the time they come for therapy it is too late. Awareness is the key to all these problems. It must be initiated at the school level itself regarding the care of children with neurodevelopmental disorders if an attitudinal change is warranted. A cultural and religious change must be initiated at all levels. Some of these religious beliefs are difficult to change in Sri Lanka".

With many decades of experience Professor Gitanjali spoke about helping parents



Prof. Gitanjali Sathiadas

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with love, respect and care to assist any child who may have a condition.

Educating the parents and counselling them that this is not a mental illness, not necessarily associated with mental retardation, not contagious, not inherited except rarely and not curable.

Another key issue is to support and care psychologically the whole family.

Early detection and early interventions are the next key aspect in solving these problems: Signs suggestive of CP in an infant are abnormal behaviour, excessive docility or irritability, poor eye contact, poor sleep, motor problems, frequent vomiting, poor sucking (breast feeding), tongue retraction, persistent bite, grimacing, poor mobility, poor head control, hand preference before two years of age (left or right) and abnormal tone are few signs. These signs must be detected early and further evaluation by a paediatrician must be initiated.

In regards to the management of regular multidisciplinary input at clinics and to have dedicated clinics especially for neurodevelopmental disorders where parents and children feel accepted and comfortable to attend.

Professor Gitanjali further elaborated "Autism Spectrum Disorder (ASD) is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. Although autism can be diagnosed at any age, it is described as a "developmental disorder" because symptoms generally appear in the first two years of life. Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience. People of all genders, races, ethnicities, and economic backgrounds can be diagnosed with ASD. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and daily functioning. It is recommended that all children receive screening for autism. Caregivers should talk to their child's health care provider about ASD screening or evaluation. People with ASD have difficulty with social communication and interaction, restricted interests, and repetitive behaviours. Social communication/ interaction behaviours may include:

- Making little or inconsistent eye contact
- Appearing not to look at or listen to people who are talking
- Infrequently sharing interest, emotion, or enjoyment of objects or activities (including by infrequently pointing at or showing things to others)
- Not responding or being slow to respond to one's name or to other verbal bids for attention
- Having difficulties with the back and forth of conversation
- Displaying facial expressions, movements, and gestures that do not match what is being said
- Difficulties adjusting behaviours to social situations
- Difficulties sharing in imaginative play or in making friends

The prudent doctor also spoke on the importance of Special Needs Education in Sri Lanka and some of her suggestions are -

Liaise with the school positively and to involve relevant educational authorities by helping teachers to understand the genuine needs of these special children, who need more attention and care. The education process must be planned and systematic. There must be a home based and school-based interventions (providing paid leave for care giver in the Government system) where parents are also involved in the learning process of these children. One key mode imparting knowledge to these precious children must be Goal directed teaching - Set 3-5 goals which the child can achieve. Special needs teachers must identify a realistic time frame Eg. 6 weeks or more to achieve a desired target. Teachers must wisely draw up a plan with specific activities designed to achieve each goal. Then they must be able to evaluate the progress of the child. Teachers must also discuss with the family how much time they must spend with the child and this will depend on a case by case basis. It can be a minimum of 30 minutes of 1:1 work. For children with autism, it can be 3-5/days and each session can last 20-30 minutes per day. Children can be lovingly directed to an Individual Educational Plan (IEP). This can be reviewed: 3-6 months to observe the child's progress. When required the child can be referred for necessary investigations and medical opinions.

There are schools solely dealing with special education in case of hearing impaired, vision impaired and children with special diseases. Current trend in education is inclusive education where there should be a special education unit. Government schools have special education units and trained teachers in this aspect. In some instances, these teachers are utilized for other services hence special attention that is needed consistently is not given to these children.

Pets offer friendship and warm bonds to any human. Professor Gitanjali said "Taking care of a pet can help children develop social skills. Emotional needs such as physical activity, comfort contact, love, loyalty, and affection, experience with loss, if a pet is lost or desire met when a pet is around. Studies have shown that children exhibited a more playful mood, were more focused, and were more aware of their social environments when in the presence of therapy dogs. Interaction with dogs may have specific benefits for this population and suggest that Animal-Assisted Therapy (AAT) may be an appropriate form of therapy in certain types of neurodevelopmental disorders.

Parents can always have hope for their children. Professor Gitanjali added "Conducting of the Paralympics itself should give parents hope and perseverance to promote sports in children with disabilities. For children with disabilities who may experience impairments in mobility, functioning, and overall well-being, participation in physical activity may be particularly valuable.

With the conducive atmosphere at home and school and with loads of care and patience these precious children can have a good future.

