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What's special about being a mother...

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Mothers of disabled children face stigma and oppression from society, and also from family, friends and loved ones. CE celebrates Mother's Day (May 14) by identifying some of these mothers who are being awarded by Sri Arunodhayam.

CHENNAI: Being a mother is indeed difficult — even more so when you have a child slightly different from the others. When a healthy child is born, everyone congratulates the mother, but if the child has health issues, the very same people blame and shun her. This is the story of thousands of mothers in India, who face immense societal pressure in addition to the inevitable difficulties inherent in taking care of special children.

For Shankaragomathy from Thootukodi, this has been the way of life for the past 17 years. When her two children, Ezhilarasi (17) and Karankumar (15), were born with mental retardation, her husband left her. With a job making candles, soaps and vaicol-craft items, she single-handedly educated her four elder kids while caring for her special children. "I hardly get to sleep. Some days, we only have one meal a day. But I have faith in my job, and I will never ask my family for money," she says proudly.

Despite all odds, they moved to Chennai eight years ago, when she heard of NIEPMED (National Institute for Empowerment of Persons with Multiple Disabilities). But again, finding rental house was tough as house owners considered housing children with disability an ill omen. Now, she takes pride in teaching vaicol crafts and candle making to other mothers. "The only gift I can give my children is education. My eldest son is now studying Siddha medicine, while my elder daughter is working. I pray that these children should always be my children in every birth," she tears up, grateful for her children who help with the care of their special siblings.

Valli and her husband had adopted Lakshmi, their niece, after her parents died when she was 10. Lakshmi has auditory disability, can't speak and also has deformed feet and retardation, which the doctors said was the result of a marriage between close relatives. "Lakshmi is now 40, and still cannot take care of herself. It is very stressful for me when she gets angry often and cries when her items get lost. I hate this..." Valli rues.

This kind of resentment is common among guardians of children with disability. MR children are not capable of expressing themselves and parents/cargivers often end up frustrated, exhausted and even depressed. Additionally, the society places unreasonable and cruel impositions on these mothers. "When I came to Chennai, many relatives and strangers in the bus and trains told me to kill my children, as they will be of no use any way," recalls Shankaragomathy.

There are many cases in India where parents give in to the pressures of society and poverty and abandon their children. But brave souls face the odds and raise their children. To honour these mothers, Sri Arunodhayam, a home for mentally challenged destitute people in Chennai, has launched in their 15th year of service a 'Special Mom's Award' to 15 mothers. "These mothers go through pain, humiliation and stress on a different levels, and still they endure it all. It's truly inspiring. This award honours these women and lets them know that raising special children is a joy," says Iyyappan Subramaniyan, founder of Sri Arunodhayam.

Thilagavathy, who has two sons, Vasanthakumar (23) and Madhan (21) with retardation, concurs and adds, "Everyone gets to lead a normal life of marriage, giving birth to children and then marrying their children off etc. But God has given me a different challenge, and I'm taking it positively. I'm even getting recognised with an award for this!" she beams.

The award comes with monetary incentives and access to a support group. One of the biggest concerns for mothers of children with disability is the fear that nobody will care for their wards after their death, for which Sri Arunodhayam has come up with a solution – a special lifetime pass that entitles them to receive specialised training in caregiving. "It is also a promise that the organisation will assume the role of a legal guardian for these children," says Iyyappan.

causes of disability

1 in 10 children in India are born with disability. Studies show that over 70% of disabilities in children are preventable. Most genetic disabilities are caused by:

Marrying close relatives

Ignorance of hyper and hypothyroidism

Physical trauma & violence to the mother

Onset of diseases like jaundice & yellow fever during pregnancy

Lifestyle habits such as poor diet, alcoholism and smoking

Improper medical attention during childbirth