

CULTURAL STIGMAS IN INDIA

- ◇ Prader Willi syndrome is a multisystem neurodevelopmental disorder which is one of the many disabilities.
- ◇ India is a nation with great heterogenicity and age old beliefs. Individuals with disabilities face social isolation mainly due to myths, misinformation.
- ◇ Lack of awareness and proper education has led people to think :

Disability as Karma: ie disease as a result of some past act or their fate

Disability as superstition: sometimes disabled persons are considered as inauspicious and they can be socially shunned.

- ◊ Burden on the family: people usually consider disabled person are of no use at large and considers them as burden both financially and emotionally.
- ◊ Resignation by family: families develop a sense of resignation and instead of seeking treatment they believe that nothing can be done to change the situation.
- ◊ Marriage prospects: in traditional Indian families marriage prospects and family reputation are highly valued so a disabled member is considered burden.
- ◊ Children with disabilities are usually kept at home with no access to school due to lack of resources.
- ◊ Social judgement. Families hide about disability and do not seek help due to social stigma.

SHIFT IN MINDSET: BREAKING THE STIGMA

India has progressed economically and socially and advances in medical technology have played a crucial role in changing mindsets. Legal Reforms

India has implemented the Rights of Persons with Disabilities (RPwD) Act, in 2016 which increased the number of recognized disabilities to 21 from 7

This act ensures equal rights in education, employment, healthcare marking a major step toward inclusion.

Education and Employment Opportunities have increased

Many schools and universities now offer inclusive classrooms, assistive technology, and special education programs to support students with diverse needs.

Scholarships and financial aid programs to encourage children with disabilities to pursue higher education.

- ◇ Employment opportunities for individuals with disabilities have also expanded, though challenges remain.

Despite these advancements, implementation remains a challenge especially in smaller towns and rural areas.

Over time, India has modernized and traditional beliefs about disability have started to evolve. There is a growing awareness that disability is not a curse or stigma.

Awareness and advocacy continue to be essential in ensuring that these rights translate into real change.

Diagnosing Prader-Willi syndrome (PWS) in India can be challenging due to several problems:

OTHER CHALLENGES IN DIAGNOSIS

- **Initial symptoms mimic other conditions:**

PWS symptoms like hypotonia and feeding difficulties can be mistaken for birth asphyxia, sepsis, or other congenital disorders, leading to delayed or missed diagnosis.

- **Complex and expensive genetic testing:**

DNA methylation testing is a costly process that requires specialized labs usually not present in rural and smaller cities.

Trained geneticist are limited to bigger hospitals in large cities.

- **Difficulty in diagnosing females**

In females with PWS, hypogonadism is less apparent at birth.

- **Symptom variability:**

Features like obesity and behavioral issues develop later, causing further delays if initial neonatal symptoms are not followed up.

OBESITY

This in particular is very misleading. Clinicians often underdiagnose it as simple case of over eating and patients are told simply to restrict food.

Moreover, in India children are not restricted to eat. Its our culture to offer more to a child.

Parents often fail to recognize obesity as major health issue. They think that obesity will go away as the child ages. This thing is told to mothers who are concerned about child becoming fat.

Traditionally we Indians live in joint families so ROLE OF GRANDPARENTS is very important in managing diet of child.

- ◇ Indulgence and "Treat" Foods: Grandparents often provide "treat foods" high in sugar or fat (e.g., sugary drinks, candy, fast food) as an act of love and a core part of the grandparental role. They may use food as a reward or to calm negative emotions.
- ◇ Overfeeding: Some grandparents tend to encourage children to eat more than necessary, a practice sometimes rooted in their own experiences where "fat" was associated with health and wealth.
- ◇ Misperceptions of Healthy Diets: Many grandparents may lack updated nutritional knowledge, believing that a high-energy diet is more nutritious or that childhood obesity has no health consequences until adulthood.
- ◇ Conflict with Parents: Parents may find it difficult to enforce rules when grandparents are present.

Although we cannot generalize this and grandparents can also be instrumental in preventing obesity by promoting healthy eating and daily activity.

Grandparents can help create a home environment that supports a healthy diet and lifestyle.

they should be included in educational programs. This can improve their understanding of healthy eating and activity, which can lead to better outcomes for children.

❖ LACK OF AWARENESS AND GUIDELINES:

There is a need for better awareness of PWS among healthcare providers and for standardized guidelines to prompt early genetic testing. Without a high index of suspicion, the appropriate diagnostic tests may not be ordered in a timely manner.

Paediatricians are usually the first doctor to examine after a child is born. So there is need for building their skills as they can help in

- ❖ Early recognition of symptoms: Pediatricians must be familiar with the signs of PWS, especially in newborns.
- ❖ The pediatrician should maintain a high index of suspicion if a child presents with a combination of PWS-related symptoms.

Arrange for genetic tests like DNA methylation analysis.

- ❖ Initiating early intervention: Even before a formal diagnosis, a pediatrician should start multidisciplinary and developmental supportive care for high-risk infants
- ❖ Family education and counseling

- ◊ Referral to specialists: Pediatricians are essential in coordinating care with a multidisciplinary team, including endocrinologists, geneticists, orthopedists, and developmental specialists.
- ◊ Connecting patient with the parent support group for emotional and psychological support.

ALL THESE FACTORS LEAD TO DELAYED OR MISSED DIAGNOSIS CAUSING POOR RESULTS OF TREATMENT.