IPWSO SUMMIT MEETING – 12 NOVEMBER 2025

CULTURAL PERCEPTIONS AND STIGMA SURROUNDING INDIVIDUALS WITH PWS AND OTHER INTELLECTUAL DISABILITIES

DECLARATION

The information shared today is based on my professional experience working in academic hospitals in South Africa that primarily serve low- to middle-income populations. My insights are also informed by the findings of my PhD research study, which focused on individuals from similar socioeconomic backgrounds. These communities are often characterized by high unemployment rates and a heavy reliance on various Social Grants from the South African Government. Therefore, these reflections represent the perspectives of a limited group and should not be generalized.

INTRODUCTION

Prader-Willi Syndrome (PWS) is a complex genetic disorder characterized by intellectual disabilities, behavioural challenges, and physical symptoms.

Intellectual disabilities are defined as neurodevelopmental disorders that begin in childhood and are characterized by significant limitations in both intellectual functioning (such as reasoning, learning, and problem-solving) and adaptive behavior (the everyday social and practical skills needed to live independently).

Today, I will discuss how cultural beliefs, stigma, and limited awareness shape the way individuals with Prader-Willi Syndrome (PWS) and other intellectual disabilities are perceived — and how these factors can hinder access to appropriate treatment and support. I will also discuss ways to promote greater understanding, acceptance, and inclusion within our communities.

UNDERSTANDING CULTURAL PERCEPTIONS, STIGMA, AND THEIR IMPACT

The cultural perceptions and stigma surrounding individuals with Prader-Willi Syndrome (PWS) and other intellectual disabilities can vary widely across societies. In Gauteng, South Africa, individuals with intellectual disabilities face significant stigma rooted in misinformation, fear, or lack of awareness.

Like many other intellectual and neurodevelopmental disabilities, PWS carries significant social stigma. Some community members attribute conditions like PWS and other intellectual disabilities to supernatural or spiritual causes, such as curses, divine punishment, or witchcraft.

The child's condition may be perceived as: A punishment from ancestors or God, it can be attributed to an extended family member that has bewitched the child to ensure the child does not have a bright future or it can be perceived as the result of parents being related by blood or sharing a clan name - thus framing the condition as a curse. Therefore, the family will be advised to consult with a traditional healer. These misconceptions contribute to a lack of acceptance of individuals with PWS and other intellectual disabilities, often hindering early diagnosis and access to appropriate treatment.

- **The Role of Stigma in Family Acceptance**

For parents of children with Prader-Willi Syndrome (PWS), acceptance of the diagnosis may be achieved, however, extended family members, mostly members of the paternal side of the family often find it difficult to acknowledge the condition and may remain in denial due to the stigma surrounding anything perceived as different from the "norm." As a result, parents may experience a lack of familial support, with some relatives believing that the child will be "fine" and should be treated like any other child, which can delay appropriate care and intervention**.**

- **Parental Quest for Understanding**

Some parents struggle to come to terms with their child's PWS diagnosis, leading them to explore the genetic origins of the syndrome, as they find it difficult to accept that their own genes might have contributed to the condition. Once again, it is often the fathers who conducts extensive research, going so far as to map out family trees and have siblings tested in an effort to understand why their child was affected. Their search for answers reflect a desire to make sense of the diagnosis within the context of their own family history. In the course of conducting this research, the child's treatment and care may be delayed.

- **Protecting the Child Through Non-Disclosure**

Primary caregivers often seek to shield their child from both self-stigma and felt stigma by choosing not to disclose the diagnosis to others. Their intention is to prevent the child from being pitied or treated differently. However, this decision to withhold information sometimes limited access to valuable familial support, resources, and specialized care that could have benefited both the individual with PWS and the primary caregiver.

- **Paternal Rejection and Stigma**

Several mothers of children diagnosed with neurodevelopmental disorders often reported that following the diagnosis, the fathers of their children had rejected them and refused to take parental responsibility. This rejection is often linked to the stigma surrounding disability, with some fathers insisting that the child could not be theirs, they argued that there is no history of disability within their family and urged the mothers to “find the real father,” thereby distancing themselves from the child and the diagnosis.

- **Misconceptions About Weight and Health**

Hyperphagia in individuals with Prader–Willi Syndrome (PWS) is often misunderstood by extended family members, live-in helpers, and the wider community. Many interpret a child’s excessive appetite as a sign of good health, describing them as “well-fed” and strong. This misconception can undermine efforts to manage obesity and, in turn, heighten the risk of developing other chronic health conditions. The situation is further complicated by cultural practices in which children are frequently rewarded with food and sweets.

- **Public Stigma and Community Misconceptions**

Primary caregivers often report that when they are in public and their attention was diverted, individuals with Prader–Willi Syndrome (PWS) would sometimes take advantage of the situation by asking people around them for money or food. When caregivers intervened and requested that people refrain from giving the child food or money, their instructions were occasionally met with resistance. Some people expressed fear of being punished by God for denying a request from a person with a disability, making it even more difficult for caregivers to manage the child's behaviour and dietary restrictions.

INTELLECTUAL DISABILITY IN PWS

Intellectual disability in individuals with Prader–Willi Syndrome (PWS) continues to pose significant challenges during their school years. The majority of children with PWS are enrolled in special schools due to cognitive limitations. Despite attending special schools, many children still demonstrate poor academic performance. For some primary caregivers, this inability to perform academically was a source of distress, while others came to accept that their children could not be educated in the conventional manner.

- **Caregiver Guilt and Concerns About the Future**

Primary caregivers often blame themselves for their children's struggles, despite their best efforts to support them. They frequently worry about their children's academic progress and the likelihood that they may not achieve the independence enjoyed by their peers. The prospect of a child with Prader–Willi Syndrome (PWS) remaining dependent on them throughout life can feel overwhelming. Some caregivers expressed deep pessimism about the future. Learning about the potential for intellectual disability led to disappointment, as their hopes and expectations for the child's future were dashed. For a few caregivers, these feelings extended beyond disappointment, manifesting as profound despair and thoughts that life might not hold meaning for a child who may not achieve a fulfilling future.

- **School Environment and Acceptance of PWS**

It is important to note that private schools in more affluent areas, typically attended by middle-class families, are often less tolerant and accommodating of children with Prader–Willi Syndrome (PWS). These schools are quick to consider expulsion, perceiving the child's behaviour as disruptive to the wider student body. In contrast, public schools serving low-income communities tend to be more flexible, making adjustments to the school environment to manage behavioural challenges and learning difficulties. However, some teachers still express that they will not be controlled by the child, reflecting ongoing difficulties in fully integrating learners with PWS.

- **Socioeconomic Differences in Perceptions of Education and Support**

Parents from low-income communities, many of whom had limited formal education themselves, were generally less concerned about their child’s academic performance. Instead, they welcomed the disability grant, which significantly contributed to their family income. In contrast, middle-class parents tended to be more focused on their child’s academic progress and future prospects, and some are even unaware of the availability of the disability grant.

SUGGESTED STRATEGIES TO PROMOTE UNDERSTANDING, ACCEPTANCE, AND INCLUSION

Awareness campaigns:

- The South African government needs to invest more in awareness campaigns particularly for healthcare professionals by conducting workshops on PWS, designing posters and pamphlets with the clinical symptoms and distribute them to clinics and hospitals in order to enable the healthcare professionals to identify PWS early and to manage it effectively.
- Awareness campaigns are necessary for different communities, both in urban and rural communities.

Community education:

- Culturally sensitive outreach programs to explain conditions like PWS in simple, relatable terms.
- Community engagements will assist to foster empathy, inclusion, and respect for the dignity and rights of people with PWS and other intellectual disabilities.

Partnerships:

- Strengthen collaborations between healthcare workers, traditional healers, department of education, Non-Governmental Organizations; PWS support groups and community leaders to bridge understanding.

Genetic Counselling

- Psycho-education on PWS, in a language the primary caregivers understand, should be an integral part of the genetic counselling.
- During genetic counselling, parents should be informed about support systems that are available to them including special schools and the option of a disability grant from government.

Supportive Educational Environments for Learners with PWS

- Schools and teachers need to be adequately equipped to support learners with Prader-Willi Syndrome (PWS). These learners thrive best in educational settings that offer a consistent, predictable structure and maintain a high teacher-to-student ratio, ensuring individualized attention and appropriate support for their unique needs.

CONCLUSION

Individuals with PWS, Intellectual disability and other rare diseases, are often marginalized or excluded from community life, education, and employment, often viewed as dependent or incapable. Most of them rely on disability grants from the South African government. This has lead to isolation, low self-esteem, and limited opportunities for personal development.

A collective effort from the government, healthcare sector, educational institutions, and communities is vital in improving the lives of individuals with PWS. By raising awareness, building strong partnerships, and creating inclusive environments, society can foster understanding and provide meaningful opportunities for those affected. Through collaboration and compassion, we can ensure that individuals with PWS are treated with dignity and respect, empowering them to reach their full potential and live fulfilling lives.