DEPARTMENT OF HEALTH

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Cultural Perceptions and Stigma Surrounding Individuals with PWS and Other intellectual disabilities

GAUTENG
PROVINCIAL GOVERNMENT
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GROWING GAUTENG TOGETHER

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

☐ Stigma Surrounding Intellectual Disabilities

- In Gauteng, South Africa, individuals with intellectual disabilities often face strong social stigma.
- This stigma is largely driven by misinformation, fear, and a general lack of awareness.
- Prader-Willi Syndrome (PWS), like many other intellectual and neurodevelopmental disabilities, carries a particularly heavy social stigma.
- Some community members attribute such conditions to supernatural or spiritual causes, including:
  - Curses
  - Divine punishment
  - Witchcraft

UNDERSTANDING CULTURAL PERCEPTIONS, STIGMA, AND THEIR IMPACT

❑ **Cultural Perceptions of the Child’s Condition**

- The child’s condition may be perceived as:
    - A punishment from ancestors or God.
    - The result of witchcraft by an extended family member seeking to harm the child’s future.
    - A consequence of the parents being related by blood or sharing the same clan name — framing the condition as a curse.
- Families may be advised to consult a traditional healer rather than seek medical help.
- Such misconceptions often lead to:
    - Limited acceptance of individuals with PWS and other intellectual disabilities.
    - Delays in early diagnosis.
    - Barriers to accessing appropriate treatment and support.

UNDERSTANDING CULTURAL PERCEPTIONS, STIGMA, AND THEIR IMPACT

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

- Parents of children with Prader-Willi Syndrome (PWS) may come to accept the diagnosis, but extended family members—especially on the paternal side—often struggle to do so.
- Stigma surrounding differences from the “norm” can lead to denial or rejection of the diagnosis.
- This lack of acceptance may result in limited family support for parents.
- Some relatives believe the child will be “fine” if treated like any other child, which can delay appropriate care and intervention.

❑ **Parental Quest for Understanding**

- Some parents struggle to accept the PWS diagnosis.
- Fathers often take the lead in researching genetic causes.
- Family trees mapped; siblings tested for answers.
- Search for meaning may delay treatment and care.

UNDERSTANDING CULTURAL PERCEPTIONS, STIGMA, AND THEIR IMPACT

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

- Caregivers avoid sharing the diagnosis to protect the child from stigma.
- The intention is to prevent the child from being pitied or treated differently
- Non-disclosure limits access to support, resources, and care.

❑ **Paternal Rejection and Stigma**

- Some fathers reject children after diagnosis.
- Disability seen as a source of shame.
- Fathers may deny paternity — “no disability in my family.”

UNDERSTANDING CULTURAL PERCEPTIONS, STIGMA, AND THEIR IMPACT

☐ **Misconceptions About Weight and Health**

- Hyperphagia often seen as a sign of good health.
- Cultural norms: food = care and love.
- Misunderstanding increases obesity and chronic disease risk.

☐ **Public Stigma and Community Misconceptions**

- Individuals with PWS may ask for food or money from others.
- Caregivers’ boundaries often ignored.
- Fear of divine punishment prevents cooperation.

INTELLECTUAL DISABILITY IN PWS

❑ **Intellectual disability in PWS poses significant challenges during school years.**

- Most children attend special schools due to cognitive limitations.
- Despite specialized education, many still experience poor academic performance.
- Caregivers' responses vary — from distress to acceptance of their child's learning limitations.

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

- Caregivers often blame themselves for their child's struggles.
- Deep concern about limited independence and future dependence.
- Feelings of disappointment and despair when realizing the extent of the disability.
- Some caregivers experience emotional exhaustion and hopelessness.

INTELLECTUAL DISABILITY IN PWS

❑ **School Environment and Acceptance of PWS**

- Private schools (affluent areas): less tolerant; often consider expulsion.
- Public schools (low-income areas): more flexible and accommodating.
- Persistent challenges with behaviour management and inclusion.
- Teachers report difficulty controlling or engaging learners with PWS.

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

▪ Low-income parents:

  Less emphasis on academic performance.

  Disability grant valued as financial relief.

▪ Middle-class parents:

  Focused on academic achievement and long-term prospects.

  Often unaware of available social grants.

SUGGESTED STRATEGIES FOR TO PROMOTE UNDERSTANDING, ACCEPTANCE AND INCLUSION

☐ **Awareness campaigns**

- ▪ Goal: Improve early detection and management of PWS.
- South African Government needs to investment in awareness campaigns.
- Conduct workshops for healthcare professionals on PWS identification and management.
- Develop posters and pamphlets outlining clinical symptoms for distribution to clinics and hospitals.
- Promote awareness in both urban and rural communities.

☐ **Community education**

- ▪ Goal: Foster understanding and empathy within communities.
- Implement culturally sensitive outreach programs explaining PWS in simple, relatable terms.
- Encourage community engagement to promote inclusion, empathy, and respect for people with PWS and other intellectual disabilities.

SUGGESTED STRATEGIES FOR TO PROMOTE UNDERSTANDING, ACCEPTANCE AND INCLUSION

- **Partnerships**
- Goal: Bridge understanding and ensure coordinated care and support.
- Key Partners: Healthcare workers; Traditional healers; Department of Education; community leaders, NGOs and PWS support groups.
- **Genetic Counselling**
- Purpose: Empower families with knowledge and resources.
- Provide psycho-education on PWS in a language caregivers understand.
- Inform parents about available support systems, such as: Special schools; Government disability grants; PWS support networks

SUGGESTED STRATEGIES FOR TO PROMOTE UNDERSTANDING, ACCEPTANCE AND INCLUSION

❑ **Supportive Educational Environments for Learners with PWS**

- Objective: Enable learners with PWS to thrive academically and socially.
- Schools to be equipped with resources and training to support learners with PWS.
- Provide consistent, predictable classroom structures.
- Maintain a high teacher-to-student ratio for individualized support

CONCLUSION

- Individuals with Prader-Willi Syndrome (PWS), Intellectual disabilities, and other rare conditions are often marginalized or excluded from community life, education, and employment.
- They are frequently viewed as dependent or incapable, limiting opportunities for inclusion.
- Many rely on disability grants from the South African government as their primary source of income.
- These lead to isolation and social exclusion; low self-esteem and reduced confidence; limited personal growth and development opportunities
- Collective effort from government, healthcare, education, and communities is vital.
- Raising awareness, building partnerships, and creating inclusive environments can transform lives of individuals with PWS.
- Together, we can ensure dignity, respect, and opportunity for all individuals with PWS

THANK YOU