

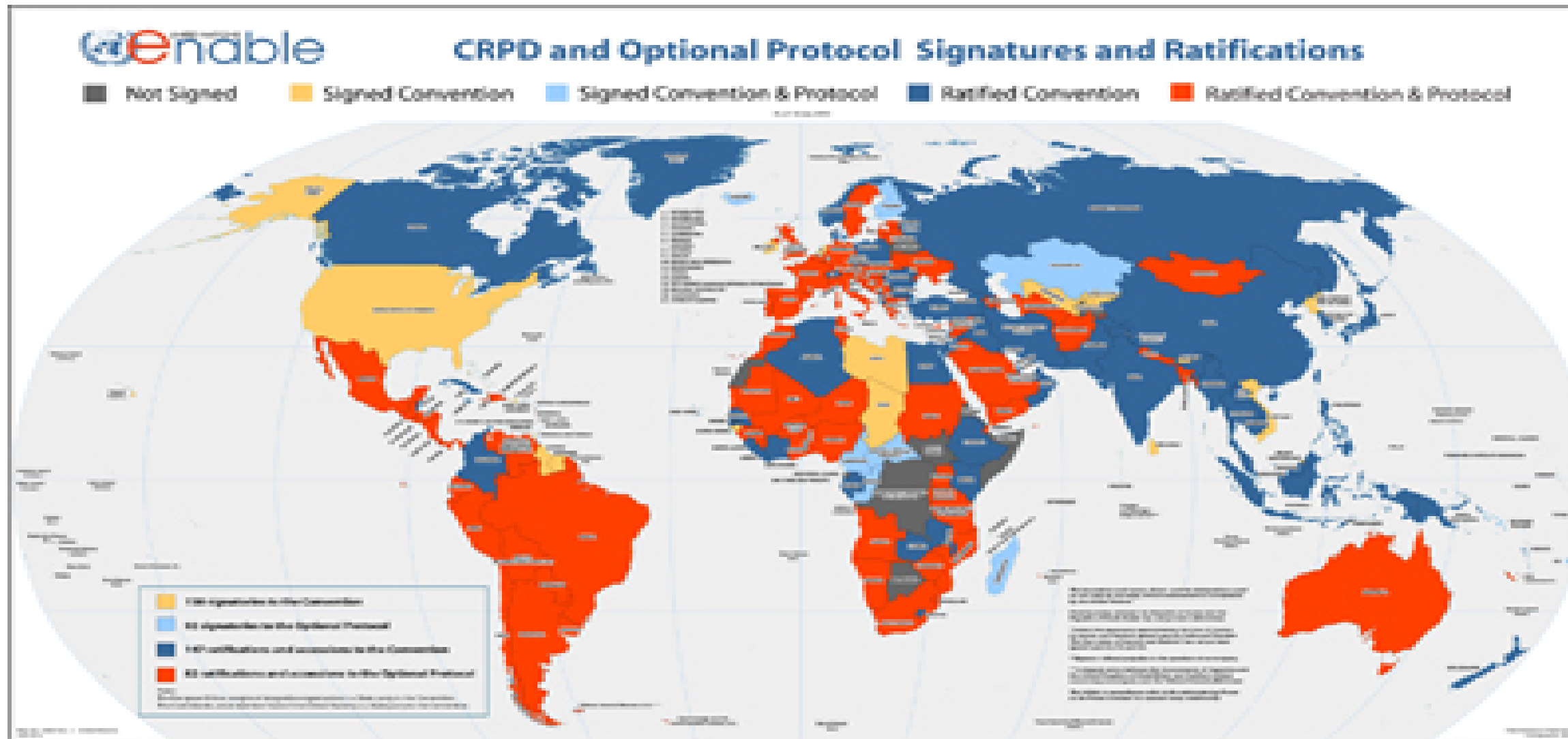
# Prader-Willi Syndrome (PWS) and Restrictive Practice

Damien Jones

# Overview

1. Convention on the Rights of Persons with Disabilities (CRPD).
2. What is Restrictive Practice?
3. Formal Restrictive Practices and PWS.
4. Informal Restrictive Practices and PWS.
5. Draft Model for Restrictive Practice and PWS.
6. Discussion.

# Convention on the Rights of Persons with Disabilities (CRPD)



# Convention on the Rights of Persons with Disabilities (CRDP)

- Under the CRDP, people with Disability have rights to fully participate in society and to self-determination.
- As a principle (article 3), a general obligation (article 4) and as a right (articles 29 & 30).
- There are also human rights embedded in the Convention, such as the right to control spending, the right to privacy, the right to make decisions, the right to employment and to education.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

# Human Rights

- Some rights involve freedom from others interfering in your affairs e.g. rights to privacy, property, self-determination, decision making etc. They can be referred to as negative rights and involve non-interference.
- Others rights have been referred to as positive rights and involve some action from others. They involve the right to participate in life and society, to be included in society and to be protected by society. These rights **also** include issues of accessibility- accessibility to work, accessibility to an education, having internet access as well as protection under the law in the form a police force etc.
- There can be a tension between positive and negative rights.
- Disability often involves reliance on others to achieve rights and this can make people vulnerable to: abuse, other people making decisions on their behalf, or not being in control of their own life.

# Formal Restrictive Practices/ Legal Definitions

- The formal rules on what is considered restrictive practice vary around the world.
- Systems are evolving and the trend is often to increase oversight and formalisation of restrictive practices or to stop them being used altogether.
- Obvious examples of restrictive practices that are used to manage common behaviours in PWS include:
  - Locked kitchens/ fridges.
  - Restraints: environmental or physical.
  - Medications that manage behaviours either as a PRN (as needed) or through daily medication.
  - Restricted access to money, knives or dangerous items or the community.
  - Car restraints/ child locks.
- There is ongoing debate on what should be formally classified as restrictive practice. We have to apply complex evolving frameworks and definitions to individual circumstances.
- The rules that are applied to formal restrictions vary in each jurisdiction.

# Formal Restrictive Practices

- In Australia, formal rules and legal frameworks around restrictive practices are evolving. There is increased oversight and monitoring of the use of restrictive practices and there is an emphasis on using the least restrictive strategy to manage behaviour.
- When formalising restrictive practices in the Australian context, some complexities and issues that are often raised when determining if a practice should be formally classified as a 'restrictive practice' include:
  - Was a medication prescribed for a diagnosed mental health condition or for behaviour management?
  - Could it be considered duty of care, WHS or normal community practice to take an action?
  - Is this restriction done to manage a behaviour or for some other reason?
  - Is the provider taking the action or someone else e.g. a parent or medical professional?
  - Who is authorised to consent to the practice?
  - Consent to the restrictive practice under Australian rules can be withdrawn at any time.
  - Services and workers who do not comply with rules around restrictive practice are at risk of severe consequences.

# Informal Restrictive Practices

- Service Providers may restrict people in a way that is not formally monitored and may not even be acknowledged. Often this is due to lack of funding, but this can also occur due to power dynamics. Support staff may also manipulate people with PWS in a way that could result in restrictions. Some restrictions that may not be seen formally as restrictive practice include:
  - Rules that are set may be stricter than are seen in the general community.
  - Limits on the types of activities or risks a person can take.
  - Limits on money or belongings that is accessible to the person.
  - Consequences or expectations that don't apply in the general community.
  - Lack of choice in food, routine, workplace etc.
  - Needing to fit in with the schedules of workers or other people that you live with.
  - Lack of choice as to where you live, or a general lack of freedom, parental influence.



# PWS and Restrictions

- PWS results in a diverse range of cognitive competence; social competence; behavioural issues; and health issues.
- Some people with PWS have cognitive issues that make it hard for them to keep safe in everyday life e.g. they may not have the cognitive ability to safely cross the road.
- Some people with PWS can lack social awareness. This can make things awkward or even unsafe for themselves and others e.g. eating items from bins, stealing, public nakedness, trespassing, inappropriate behaviour, **inappropriate** touching or language.
- Issues of the hypothalamus such as hyperphagia or lack of control when angry or when around food.
- Mental health issues such as psychosis.
- Health issues such as insulin dependant diabetes, stomach rupture and chronic obesity.
- Restrictions can also cause behaviours, which in turn can result in further restrictions.
- Restrictions can also result in dependency and lack of responsibility for one's own actions (it becomes a game).
- We need to understand what is causing the behaviour when we think about restrictive practice and restrictions.

# Draft model for Restrictive Practices

- In the Berlin Caregivers Caregivers Conference, a model of understanding restrictive practice was discussed.

## This draft model of restrictive practice would:

- Acknowledge that a person with PWS would gain further independence and skills, as they move from childhood to adulthood.
- Recognise that people naturally develop and become more independent with the right support.
- Aim at minimising restrictions to those needed to ensure that a person with PWS is safe. But also take into account that these restrictions will progressively allow them to become more independent.
- Provide learning opportunities, by giving the person with PWS a chance to make mistakes and learn. This opportunity would still ensure that there is no for significant threats to the safety of the person with PWS or to the safety of others.
- **Not** be a one-size fits all approach. It will be a model that understands that each person with PWS is an individual, and any restrictive practice will 'meet' their individual and changing needs.
- Require funding to provide flexibility for continued support and monitoring after restrictions have been lifted.
- Provide rights to all people with people with PWS, including those who are difficult to support. It would acknowledge that with PWS have a right to support even when they are particularly difficult for service providers to deal with.

# Discussion

- What types of restrictions are needed for some people with PWS?
- What indicators are there that restrictions are needed for an individual?
- What is the trend in Restrictive Practices for people with PWS around the world?