



# Balancing Rights and Restrictions

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# Human Rights and our Responsibility

Human rights belong to everyone and should be the center of everything we do.

Human rights represent all the things that are important to us as human beings, such as being able to choose how to live our life and being treated with dignity and respect.

They are the basic rights we all have simply because we are human, regardless of who we are, where we live or what we do

Need to focus on quality of life and individual outcomes rather than needs and processes



# Legal framework disability laws and acts

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- There are 121 countries that have laws/acts to protect the rights of disabled individuals
- Disability laws and acts are instruments through which countries abolish discrimination against persons with disabilities and eliminate barriers towards the full enjoyment of their rights and their inclusion in society. These laws and acts contribute to progress towards the implementation of the [Convention on the Rights of Persons with disabilities \(CRPD\)](#) in national legislation





# UN CRPD

United Nations Convention on the Rights of Persons with Disabilities

1. Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons with disabilities
2. Non-discrimination
3. Fully and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacity of children with disabilities and respect for the right of children with disabilities to preserve their identities



# Understanding PWS

Prader-Willi Syndrome is a genetic disorder characterized by hyperphagia and developmental delays. Individuals often face challenges in managing their appetite and behavior.

# Ethical Principles

Beneficence

Nonmaleficence

Autonomy

Justice

# Reasons For and Against Restrictions

- Maintain safety
- Maintain health
- Create dependence
- Can cause behaviors



# Bias When Applying Restrictions

Self-awareness is the key to identifying biases

- Generalizations
- Past experience's
- Assumptions
- Safety



# Restrictions



- Who decides what to restrict?
- How much risk is acceptable?
- How often do you assess the need for ongoing restrictions?

# Common Restrictions in PWS

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- Restricted access to food
  - Restrictions surrounding spending money
  - Others...
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- Apply ethical principles to these restrictions and the principles of the UNCRPD
  - Do they match up?

# Other restrictions

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- Limits on activities (no more than 2 movies a week)
- Limits on belongings
- Need to fit their activities based on caregivers schedules
- Other examples
- How can we offer more choice?

# Draft Model of Restrictive Practices

discussed at prior caregiver's conference

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- Individuals with PWS can gain independence throughout the lifespan
- Providing the right support can hasten new skill development.
- Aim at minimizing restrictions to those that are needed to ensure the safety of the person with PWS.
- Provide opportunities to learn by giving the individual with PWS the chance to make mistakes and learn. These opportunities would still ensure that there is no significant safety risk to the person with PWS or others.
- Restrictive practices are NOT a one size fits all. Any restrictive practice will meet their individual and changing needs.
- Require additional funding for flexibility of continued support and monitoring restrictions throughout and once they are lifted.
- Provide rights to all people with PWS, including those who require higher or more complex levels of support.

# Discussion