6th International Prader-Willi Syndrome Caregivers’ Conference

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BALANCING RIGHTS AND RESTRICTIONS FOR INDIVIDUALS WITH PWS

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#PWSCARE24
Restrictive Practices
Restrictive practices in health and social care refer to the implementation of any practice or practices that restrict an individual’s movement, liberty and/or freedom to act independently without coercion or consequence.

Appendix 4: HSE National Disability Operations Community Services & Prader-Willi Syndrome Association of Ireland
Balancing Rights and Restrictions for Individuals with PWS
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Back to the 90th
In the pursuit of efficient habilitation, many service providers exercise a great deal of control over the lives of clients with developmental disabilities. For example, service providers often choose the client’s habilitative goals, determine the daily schedule, and regulate access to preferred activities.

Habilitation involves teaching the skills needed to live as independently as possible (Favell, Favell, Riddle, & Risley, 1984)

Balancing the right to habilitation with the right to personal liberties: the rights of people with developmental disabilities to eat too many doughnuts and take a nap
Balancing Rights and Restrictions for Individuals with PWS

Fourteen years ago, 2010

Basic support needed for individuals with PWS to succeed:
- Safety and personal growth must be ensured before care

Essential environmental supports:
- Food security, daily schedules
- Personal growth and development plans
- Continuum of care throughout the day
- Trained caregivers
- Importance of collaboration among care providers
- Ongoing education, training, awareness

Appendix 3: HSE National Disability Operations Community Services & Prader-Willi Syndrome Association of Ireland
“The support of children and adults with PWS requires that tensions between individual rights are recognized, and that people with PWS are helped to understand the nature of the syndrome, and that informed support is available and accepted with the agreement of all concerned.”

Improving the mental health and wellbeing of people with PWS: An IPWSO special initiative Report of the IPWSO Mental Health NetworkApril.2024  unpublished.
Balancing Rights and Restrictions for Individuals with PWS

Ethical Implications of Restrictions
Balancing Rights and Restrictions for Individuals with PWS

- Health condition
- Body functioning & structures
- Environmental factors
- Personal factors
- Activities
- Participation
Balancing Rights and Restrictions for Individuals with PWS

Active and healthy living for people with PWS

Healthy body functions and body structures

Activities:
- Daily life
- Social, cultural, physical activities

Participation in society:
- to maintain social network (friends, work associates, neighbours and family members)
- maintaining autonomy and independence
- be involved in projects, clubs, honorary office

Environmental factors:
- healthy living and working conditions
- maintaining autonomy and independence
- receive effective treatment and care
- safe housing and transportation
- social support and
- financial security

Personal factors:
- wellbeing:
  - personal traits (self-efficacy, social integration, goals, expectations, high spirits, concerns, self-confidence, ...)

- life style:
  - habits and activities
Balancing Rights and Restrictions for Individuals with PWS

- Autonomy vs. Protection
- Access to Food and Nutrition Control
- Integration vs. Protection from Overstimulation
- Right to Education and Employment
- Inclusion in Decision-Making Processes
Balancing Rights and Restrictions for Individuals with PWS

- Accessibility and Support Services
- Empowerment and Support Groups
- Family Support and Resources
- Inclusive Education and Promotion
- Protection from Stigmatization and Bullying
Balancing Rights and Restrictions for Individuals with PWS
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Birds born in a cage think flying is an illness

Alejandro Jordorowski