

6th International Prader-Willi Syndrome Caregivers' Conference

21-23 May 2024, Berlin, Germany

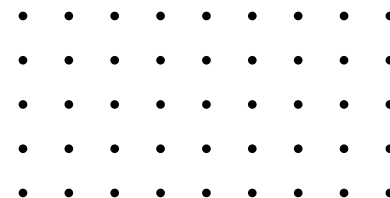
BALANCING RIGHTS AND RESTRICTIONS FOR INDIVIDUALS WITH PWS

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#PWSCARE24



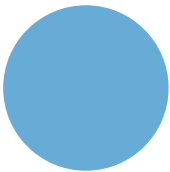
Balancing Rights and Restrictions for Individuals with PWS

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.



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 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

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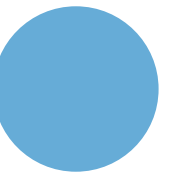


“The support of children and adults with PWS requires that tensions between individual rights are recognized, and that people with PWS are helped to understand the nature of the syndrome, and that informed support is available and accepted with the agreement of all concerned.”

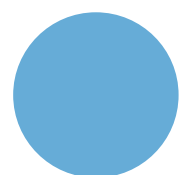
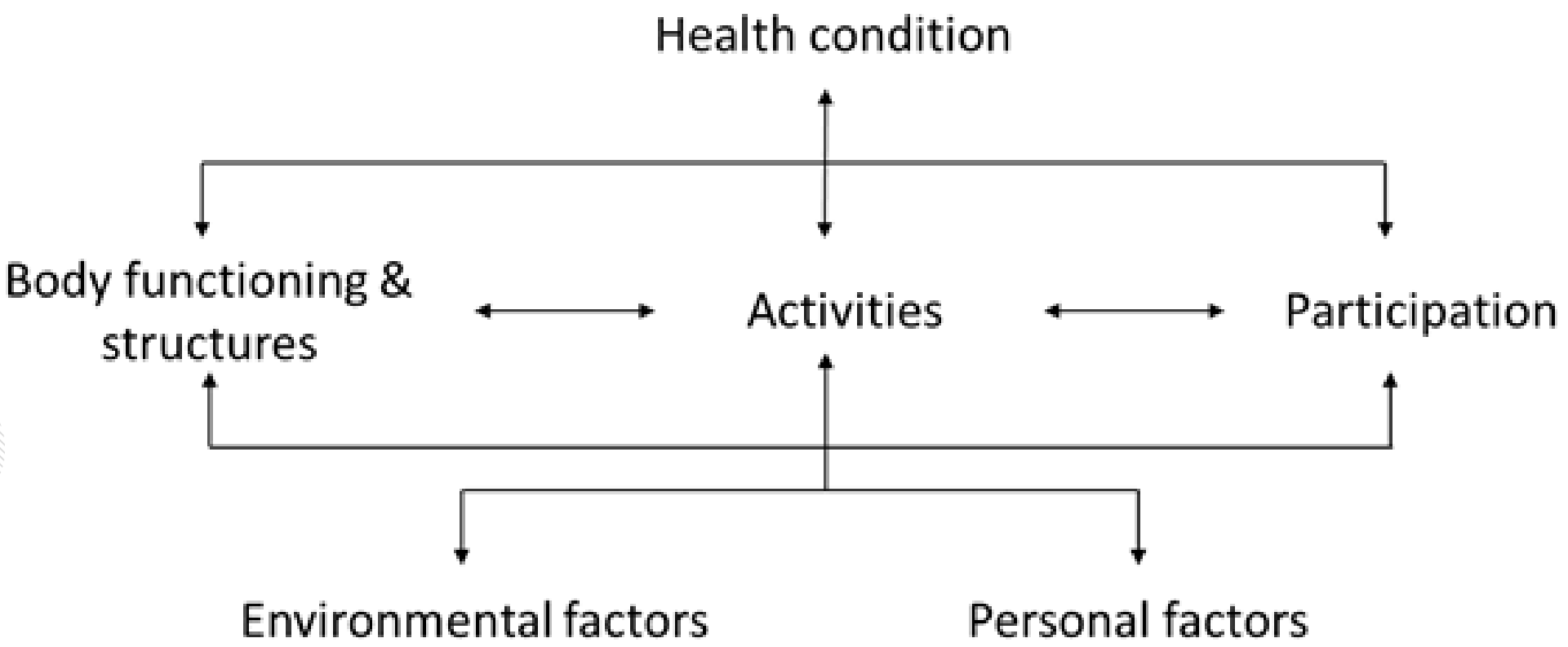
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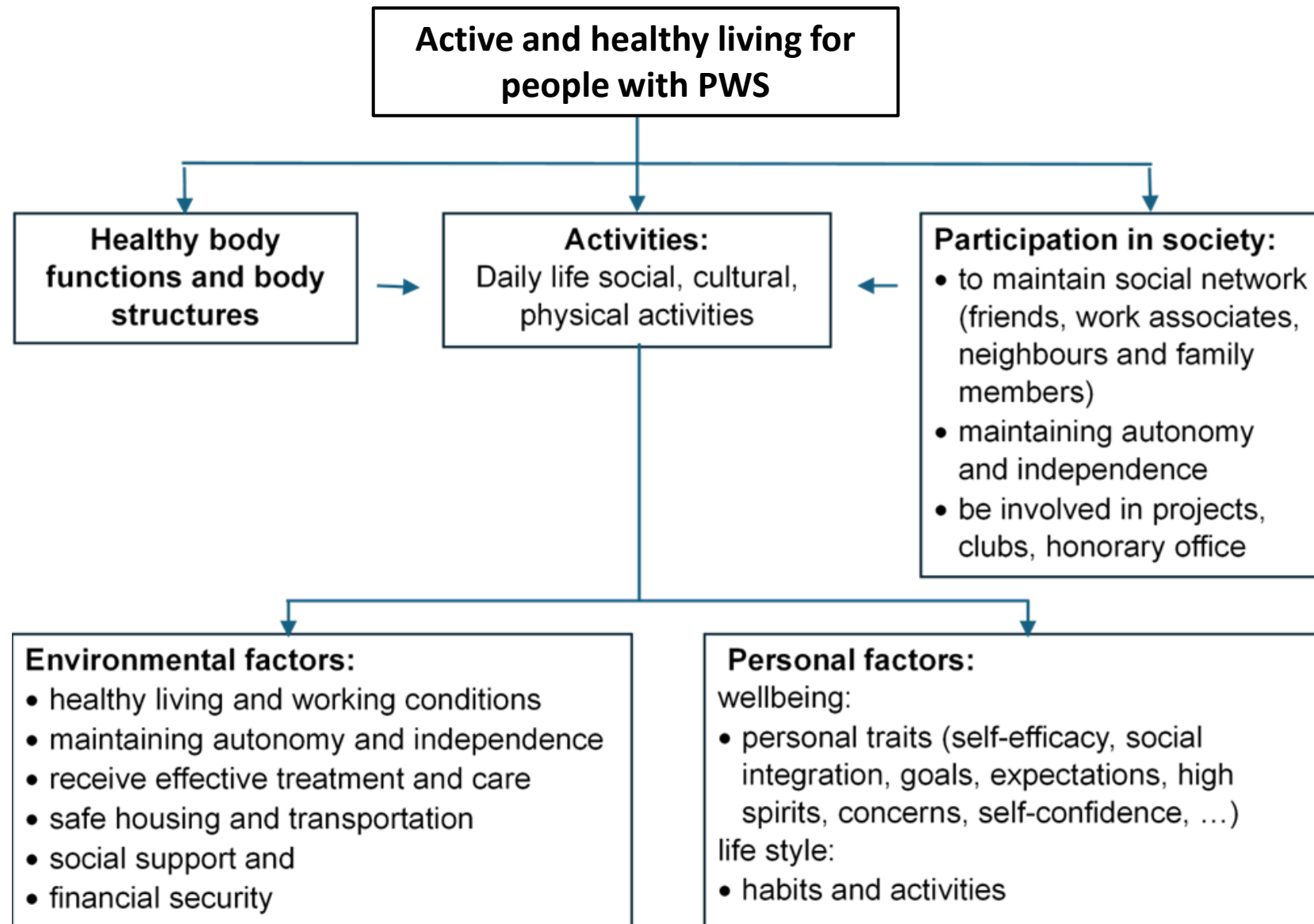
Ethical Implications of Restrictions



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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



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Birds born in
a cage
think flying is
an illness

Alejandro Jordorowski

