



PWSA | USA 2023
NATIONAL CONVENTION

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PARENTING FOR INTERDEPENDENCE

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Goals for today...

- Discuss the feasibility of true independence
- Explore the potential long-term outcomes of our perspectives as we continue to parent and prepare for our children's future
- Provide an opportunity for reflection (with some practical examples thrown in)

What NOT to expect...

- A detailed parenting plan
- A “one size fits all” approach



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Defining Interdependence vs Independence

Independence:

Freedom from the control, influence, support, aid, or the like, of others; having full autonomy over one's own life

Interdependence (as defined by the McDougall family):

Individual with PWS is an active participant in making informed decisions about their future; however, reliant on relational interactions with a guardian for ultimate decision making responsibility



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Why focus on Interdependence as a goal?

- Sustainable
- Acknowledges their experience and inner life
- Allows for the development of advocacy and leadership skills
- Builds stronger relationships
- Emphasis on safety



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Thoughts on Interdependence

Disability justice activist Mia Mingus says: “Interdependence moves us away from the myth of independence, and towards relationships where we are all valued and have things to offer. It moves us away from knowing disability only through 'dependence', which paints disabled bodies as being a burden to others, at the mercy of able-bodied people’s benevolence.”

“This work is about shifting how we understand access, moving away from the individualized and independence-framed notions of access put forth by the disability rights movement and, instead, working to view access as collective and interdependent. I am not fighting for independence [that everyone can and should be able to do everything on their own], as much of the disability rights movement rallies behind. I am fighting for an interdependence that embraces need and tells the truth: no one does it on their own...”

Changing the Framework: Disability Justice | Leaving Evidence



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Developing a mindset focused on interdependence

- Work toward supporting, not managing every interaction and decision.
 - This is a gradual process, and one that should apply for any of our children, PWS or not.
 - Start with the little “day to day” things.
- Build decision making capacity
- Promote communication
 - Instead of **telling** someone what to do, **ask** him or her what they would **like** to do.
 - Acknowledge your own struggles and own your own mistakes.
 - “Talking” may not be the most effective for your child. What works for them?
 - Honesty regarding the syndrome and resulting impact on your child.
- Many adults with disabilities have experienced strongly nurturing and highly protective environments. Decision making power will be a foreign concept as a result, which means that if they are subsequently expected to make decisions too quickly, fear and anxiety can take over.



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Opportunities for Teaching Skills

- Activities of daily living (i.e., self care, safety and functioning in the community)
- Appropriately expressing oneself
- Social skills (play and mediating with others)
- Self-reflection
 - What are my strengths and weaknesses?
 - What am I interested in?
 - What do I want to do with my life and why?
- Advocacy (i.e., What do I need and how can I get it?)



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Parenting Strategies

- Pairing behavioral choices with potential outcomes in advance
- Natural consequences (“did this get you what you wanted?”)
- Modeling
- Allowing ability to take chances... and fail
- Honesty (at their developmental level; may mean minimizing details while staying true to facts)



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Monitoring “Growth”

- Are they able to conceptualize risk as part of making decisions?
- Are they able to accept the rationale for the safeguards that you have put in place?
- What will be the impact on my child if he or she is unable to attain their anticipated goal?



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Closing Thought...

Parent in the hope that a cure/ treatment will become available, yet plan with the anticipation that it will not.



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 Prader-Willi Syndrome Association | USA

THANK YOU



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