



IPWSO
International
Prader-Willi Syndrome
Organisation

PWS, Capacity and Decision-Making – A view from Ireland

FamCare –
November 23rd 2024



What is capacity?

Capacity is defined as 'the person's ability to understand, at the time a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time'.

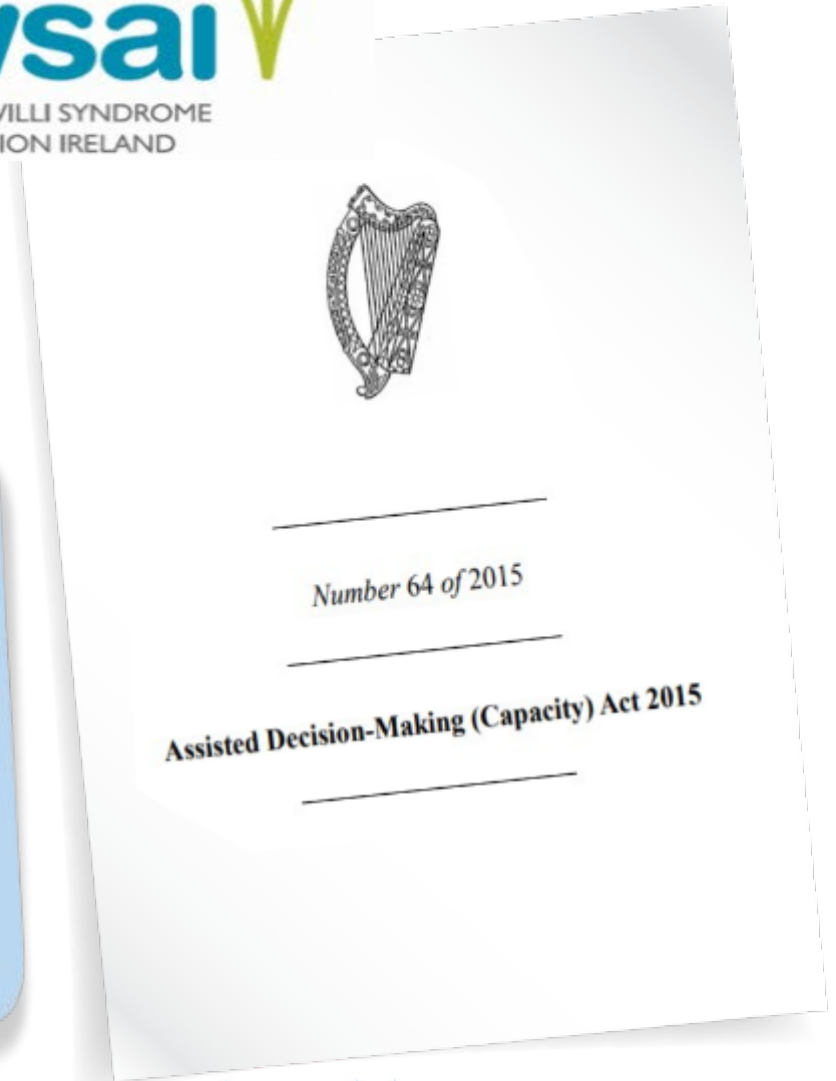


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Hyperphagia and Decision-Making Capacity

Although people with PWS can make decisions about many areas of their life, dysfunction in areas of the brain that control eating behaviour and energy balance means that they will rarely have the capacity independently to make decisions about eating.



National Office for Human Rights and Equality Policy

What Maria says....

'People don't understand, I'm not like other people. With me I have very little or no control, I know for me it takes over. When I have a compulsion, especially when it's one of the stronger ones, it takes over my mind, literally all I can think of is food and how to get food. It completely takes over my mind and turns me into someone that I'm not.'



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Considering PWS and Decision Making



Impaired Executive
Functioning.



Altered Reward Sensitivity.



Obsessive-Compulsive Traits.



Emotional and Social Factors.



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Supporting Decision-Making in PWS

To establish a supported decision-making methodology in service delivery, the following elements should be considered:

Food Security	Environmental Controls.
Therapies	Behavioural Therapies.
Medication	Medications and Hormonal Treatments.
Education	Education and Skill Building
Training	Ensuring the continuous upskilling and reskilling of the carers



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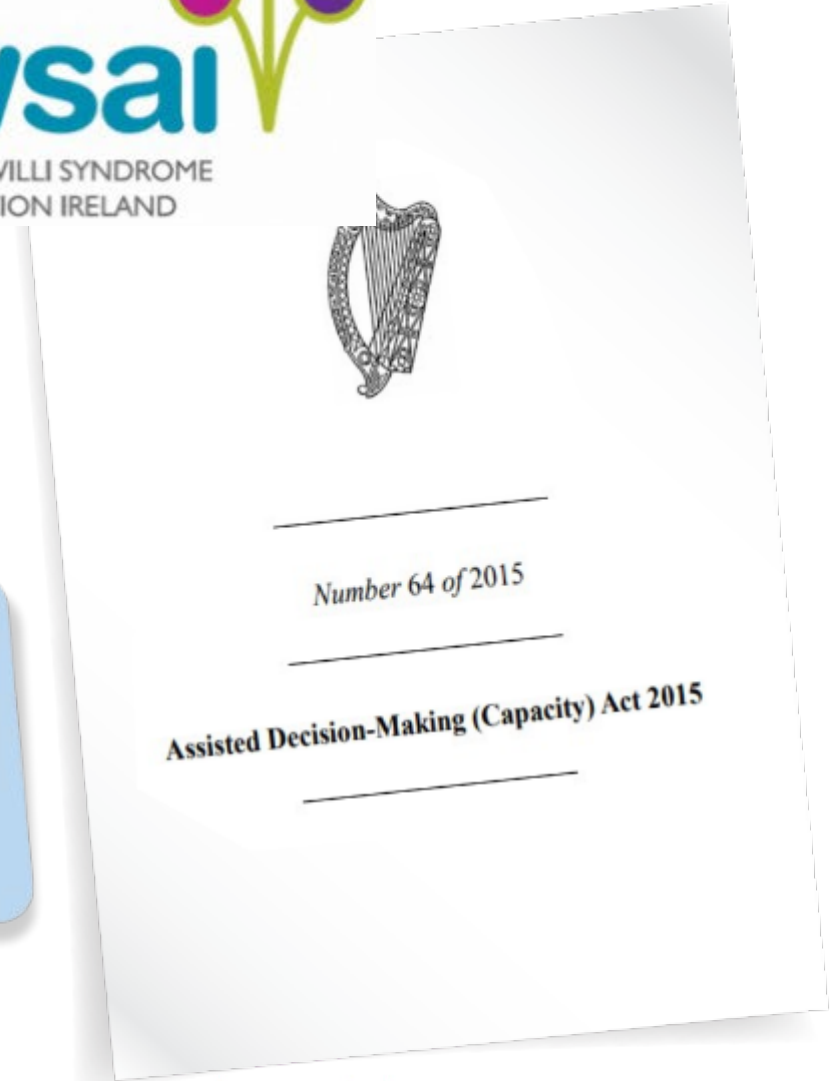
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Assisted Decision-Making (Capacity) Act 2015

An Act to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity, whether immediately or in the future.

- Signed into law 30 December 2015
- Commencement 26 April 2023



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Who is the legislation for?

It applies to a person whose decision-making capacity is being called into question, may shortly be called into question, or lacks capacity, in respect of one or more than one matters.

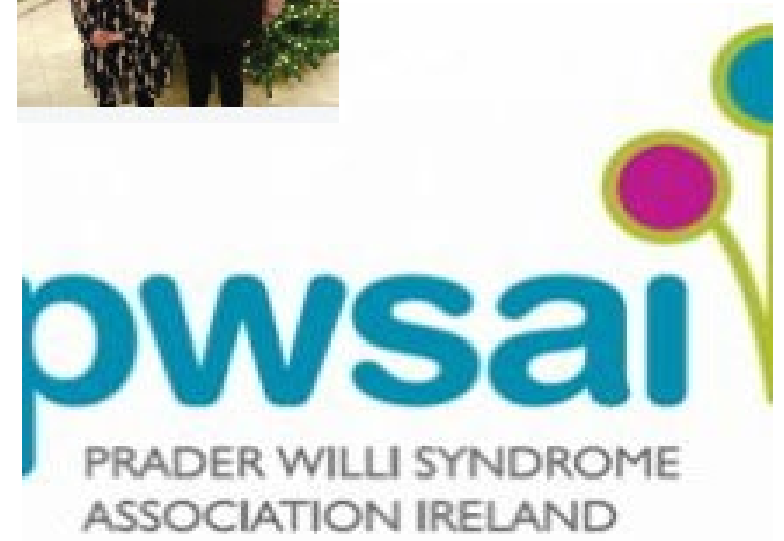
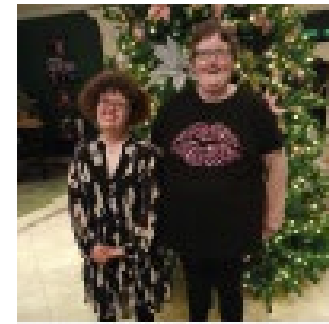


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1. Presumption of capacity.
2. Support to make a decision..
3. Unwise decisions.
4. Accessible information.
5. Legally recognised persons.
6. Retention for short periods.
7. Least Restrictive Intervention.
8. Functional Approach to Capacity.





3

Decision-Making Representative (DMR)

2

Co-Decision-Maker (CDM)

1

Decision-Making Assistant (DMA)



Our message to parents and carers



Plan for the possibility of greater independence



Consider that in some cases this may mean managing access to food and monitoring the spending of money.



Choice is returned by reducing anxiety, which can undermine executive function and limit freedom



Ideally these strategies have the agreement of the person with PWS



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