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New Zealand Law Commission | Te Aka Matua o te Ture

Submission on Second Issues Paper – Adult Decision-Making Capacity Law

By email: huarahi.whakatau@lawcom.govt.nz

I am making this submission to the Law Commission on behalf of our organisation in an advocacy role, and in a personal capacity as a family member with lived experience.

I would like to receive future updates on this review by email and for it to be recorded that PWSA(NZ) wishes to be involved in any future consultation / feedback opportunities around law changes that have potential to affect the health, safety and wellbeing of adults living with PWS. We also wish it to be noted that if this review extends into the development of formal national guidelines on restrictive practices, we would like the opportunity to contribute feedback on the environmental restrictive practices necessary when supporting people living with PWS.

PWSA(NZ) submitted an initial submission to the preliminary issues paper which contained some supporting research / studies. Unfortunately, we have not had the time to write a detailed response to all the issues and questions in the Second Issues Paper before today's deadline, but our submission outlines our main concerns, mainly focusing on Chapter 7: Decision Making Capacity. We would be happy to answer any questions or to provide any supplementary information required at a later date.

Background 1 - The need for environmental restrictive practice in Prader-Willi syndrome.

Prader-Willi syndrome is a complex neurodevelopmental disorder which is genetic in origin and affects multiple body systems. It can have substantial impacts on physical development, cognition, behaviour, emotional regulation, metabolism and appetite. Communication skills and the level of intellectual disability are variable amongst individuals, but significant learning disabilities are typical, particularly in executive functioning. Whilst PWS is a spectrum disorder and the severity of each symptom can vary from person to person, it is also a complex medical condition with common health and safety concerns relevant to all people diagnosed with the syndrome.

Cognitive impairments, brain chemistry and hormone imbalances all influence the decision-making ability of people living with PWS. They are unable to reliably monitor and assess the quality of their supports independently and to safeguard themselves from harm. People living with PWS are reliant on supports, both informal and formal. Formal support mechanisms might be the use of regulatory official support practices, and additional court ordered legislation may sometimes be necessary.

Decision-making capacity in PWS is complex. There are some areas specific to PWS where a person lacks that capacity (food and food environments), but other areas where capacity varies from person to person. The specific concerns relating to food and food environments also extends to unregulated access to money that can be used to purchase food.

Hyperphagia is a key symptom of PWS for which there are no treatments. A person living with PWS needs a carbohydrate and calorie restricted diet to maintain a healthy weight because weight gain occurs rapidly due to having an altered body composition and metabolism. In addition to the need for a restricted diet, the altered appetite and satiety signalling can drive people with PWS to feel intense hunger and to use extreme measures to seek food. This can be extremely dangerous and have life-threatening health implications.

It is essential that restrictive practices can be easily applied around food by those working in support roles for people living with PWS, whether in residential settings, the workplace, or in the community. When restrictive practices around food environments cannot or will not be implemented, this actually has a more limiting and restrictive impact on the person living with PWS, because if an environment is unsafe for them, they simply cannot attend or participate. At PWSA(NZ), we often hear parents remark that their child misses out on something their peers can participate in because a lack of restriction around food prevents them from enjoying the same activity.

“In planning the support environment for persons living with PWS, some contradictions are evident. While persons with PWS need extensive food support, they often show fewer needs for support in other aspects of their lives. Indeed, many persons with PWS show good competencies and decision-making abilities outside the food arena. Nonetheless, until there are medical or pharmacological interventions for this physiologically driven eating behaviour, structured environments with restricted access to, and intake of, food must be standard care for persons with PWS. It might be argued that these recommendations conflict with concerns for choice, personal rights, and least restrictive environments. We do not take issue with these goals. Instead, we assert that the appropriate frame of reference is the ‘least restrictive environment’, given that the individual has PWS. The concept of ‘least restrictive environment’ implies as normal a life as possible within the framework of a given disability.” *Adapted from article by PWSA(USA) ¹*

As you are aware, Ireland has very recently reviewed and updated their decision-making capacity law, but this has also coincided with the publication of new national restrictive practice guidelines. Australia and Ireland both have clear national guidelines on restrictive practice.

The National Development Manager at PWSA Ireland (PWSAI) tells me that their health service policy on consent is very orientated toward clinical settings and they have asked their health service if they could include guidelines that are disability (PWS) specific.

I would also like to recommend that the development of specific guidelines for PWS on capacity, consent and restrictive practice are considered in New Zealand due to the unique support needs of the syndrome.

Background 2: A personal story of obtaining welfare guardianship

Last year I lost my son who had lived with PWS. He died in May, aged 20, after being placed by the court to live with a provider who had a contract for providing RIDSAS secure care under the IDCCR Act. He had unmet mental health needs and had committed an offence (which is another story), but we were very concerned about him being sent to live with a service provider who had no experience of supporting people with PWS, and their staff had no training or understanding of the syndrome.

Not long after being sent to live with this provider, he began to rapidly gain weight. He quickly became prediabetic, which developed into diabetes, and then diabetic ketoacidosis after suffering an intestinal perforation. He had been physically healthy before being placed there, but only survived six months living in their care. Due to our concerns about the deterioration in our son's health, the poor standards of care received, and the provider not prioritising training or listening to our advice, we sought a Welfare Guardianship order in the hope that we could have more say in the care provided. Our application was supported by our son's consultant psychiatrist at the mental health unit where he had previously stayed temporarily.

Unfortunately, the court appointed lawyer for our son opposed the order. Our son was quite happy for us to become his Welfare Guardians because he knew I understood the health implications of the syndrome and he was also worried about his health, but after meeting with our son, the court appointed lawyer thought he had good capacity to make decisions. Appearing to be more cognitively capable than he was had caused problems throughout his life. He had a mild intellectual disability (cognitive score of 64), various learning disabilities, was diagnosed with autism and impulse control disorder as an adult, had a history of behavioural disturbance and putting himself in dangerous situations after reaching emotional meltdowns, yet he had never qualified for any learning support funding through the education system. The difficulties he experienced were often masked by being very sociable, quite articulate, and sometimes displaying remarkable islands of competence.

It took several months for the court appointed lawyer to eventually allow a tailored Welfare Guardianship agreement, as shown below. Of course, the costs of obtaining this agreement also grew whilst our lawyer argued with the court appointed lawyer. It was only agreed after the court appointed lawyer had a long phone conversation with myself in which I was able to explain all about PWS and the need for food security / restrictions around food. In this conversation, the lawyer argued that you would not have a WG order in place for someone who suffered alcohol or drug addiction, or someone with bulimia, and it took a lot of discussion before they understood that the behaviours associated with hyperphagia in PWS are completely different – and that they cannot be treated through psychotherapies, counselling, anxiety and depression medications etc.

- a. This Order applies to decisions in relation to –
 - i. Diet, nutrition and food environment (including access to food environment); and
 - ii. When *** is no longer subject to a Compulsory Care Order, residence only insofar as any proposed living environment is not, in the view of the welfare guardian, conducive to ***'s health and safety needs.
- b. The welfare guardians are permitted to access and request the release to them of medical and therapeutic information held about ***
- c. The welfare guardians are permitted to attend ***'s medical and therapeutic appointments.

The court appointed lawyer appeared to question our motives for applying for a welfare guardianship order with an implication that we were parents who felt a need to maintain control without valid reason. I had to convince the court appointed lawyer that our intentions in seeking a WG order had only stemmed from our serious concerns about our son's health and care and that we had no intention of trying to make all decisions for him.

KEY TOPIC 4: Whilst I was experiencing these difficulties, I was unaware if we had any avenues of complaint that we could pursue. Our lawyer didn't advise that it was possible to do so, or that we could request a change in the court appointed lawyer. I would have assumed that there would be supports and simplified complaint procedures in place to help those with affected decision-making to raise any concerns, but there is no mention in key topic 4 information about the potential support needs of the applicants.

We finally obtained the tailored agreement two months before our son's death and sent copies to those involved with his care management. I don't think the service provider made all their staff aware of the WG order because when our son initially became unwell, we were not contacted. He had been seriously unwell for at least a whole day before they took any action and sought medical advice. We were finally notified two hours after an ambulance had been called.

If we had been notified of changes in our son's behaviour and wellbeing during the week prior, we would have suspected something was wrong, and if we had been informed when he first became unwell, I would have immediately visited and would have recognised how seriously unwell he was. I would have been able to get help much earlier, but this sadly did not happen and by the time our son was admitted to hospital, he was already organ compromised and his condition proved unrecoverable. Due to the staff at his home being untrained and unaware of the complexities of his rare medical condition (altered temperature regulation, high pain threshold, etc) and we, his parents, being the only people involved in his care who seemingly understood about PWS, it would have been essential that we were notified as soon as he became unwell to save our son's life.

I have asked our lawyer since our son's death whether the service provider would have been legally obligated to contact us with the tailored WG agreement that we had in place, and she thought that they should have done. However, I wonder if it perhaps wasn't clear enough or didn't carry enough weight with the service provider when they viewed it. I have also wondered what difference it could have made if we had been able to get a WG order in place much earlier.

Review of Decision-Making Capacity Law – Focus on Chapter 7: Decision-Making Capacity

Our main concern is this (taken from the Overview of the SIP):

32. The legal test for decision-making capacity and the legal consequences of not having decision-making capacity are questions of policy. Currently, the law uses a 'functional' approach to assessing decision-making capacity. Broadly, this asks whether the person understands the general nature and likely consequences of what they are doing and whether they can communicate the decision they have made. How the law responds when a person is assessed not to have decision-making capacity depends on the context.

Many adults living with PWS do have a good understanding of their need for a reduced carbohydrate / low calorie diet and some are aware of the life-threatening risks of rapid overeating. Therefore, they may be aware of the likely consequences of what they are doing if they obtain access to food and start to consume dangerous amounts, but it is extremely unlikely that they are able to make a decision to stop eating 'in the moment'. Hyperphagia in PWS is so complex that it is still not fully understood by scientists and researchers due to there being multiple drivers of the food obsessions and food-seeking behaviours at work. A person who does not have PWS may have some food addiction issues or a tendency toward binge-eating episodes, but they will stop eating at some point because they feel uncomfortably full, they feel sick and vomit, or their gut/brain satiety signalling makes them stop eating. In PWS, these physical and biological cues do not work as they should which can make it impossible for a person with PWS to exert self-control around food, despite having prior understanding of the consequences.

We are pleased to see the problems faced in determining capacity are discussed in depth in the standard format paper. I have highlighted statements which are particularly relevant to PWS:

7.29 Third, decision-making capacity is criticised for not adequately reflecting how people actually make decisions in various ways:

- (a) The functional approach is focused on a person's cognition. However, it is clear that people often make decisions on an emotional or intuitive basis, rather than a (purely) rational or cognitive basis.*
- (b) Decision-making capacity is also usually assessed in a decision-specific manner. However, decisions are often "ongoing, interwoven with other decisions, and the decisions of others".*
- (c) The concept is binary — a person either has or does not have decision-making capacity. In reality, the ability to make a particular decision varies from person to person and from decision to decision and is often dependent on environmental and social factors.*

The statement below (7.43) is also very true in PWS, particularly the highlighted text.

7.43 The ways that a person's decision-making is affected and the extent to which it is affected may vary. A person's decision-making may be more affected at some times than others or more affected for some decisions than others. People's decision-making may be less affected at a later date. A person's decision-making might be affected temporarily or on an enduring basis. It might be relatively stable, fluctuate or be deteriorating. In turn, this means that when and for what decisions a person has decision-making capacity may vary.

Hyperphagic symptoms can fluctuate considerably (there is a described progression in published literature - Nutritional Phases, J Miller), but not much is known about what can cause irregular lulls and extremities. Sometimes it may simply be that a person is bored / not stimulated enough and their thinking has become stuck on food. At other times, severity could be due to a person feeling tired, unwell, or more stressed than usual. However, behaviours attributable to hyperphagia are not always predictable and it could be dangerous to suddenly reduce monitoring and levels of support because of a recent improvement in these behaviours.

It is certainly true in PWS that decision-making is likely to be more affected for some decisions than others – those relating to food. However, it is important to recognise that whilst all people living with PWS will need some degree of support in food environments, the amount of support needed in

other areas of decision-making will vary greatly from person to person, situation to situation, day to day, and this needs to be carefully and separately assessed.

Question 6 – A single test for decision-making capacity and the four factors identified for assessing capacity

In principle, I agree with a single test that can simplify processes and ensure consistency, but the four factors suggested are not appropriate for assessing the ability to make decisions in PWS, especially those regarding food and food environments. When assessed, there are many individuals with PWS who would be able to do (a), (b) and (d). The concern is whether it may appear that they are also able to use or weigh information as part of making a decision (c), but in reality, they are unable to do this. The assessment of ability to do (c) is complicated.

7.55 In our view, there should be a single functional test for decision-making capacity. A single test should reduce confusion and cost and facilitate greater consistency in practice.

7.56 We suggest that, under a new Act, a person should be considered to have decision-making capacity if they are able to do four things:

(a) Understand the information relevant to the decision and the effect of the decision.

(b) Retain that information as necessary to make the decision.

(c) Use or weigh that information as part of the process of making the decision.

(d) Communicate the decision (whether by talking, using sign language or any other means).

In the case of decisions regarding food and food environments, it would generally not be possible for a person with PWS to reliably do (c). However, there is a high likelihood that a person may be very convincing that they will be able to use what they know about their diagnosis to make the decision. Some people living with PWS have been known to go to extensive and cleverly planned lengths to obtain food. They may also go to great lengths to hide their plans and thoughts from anyone who may put a stop to them.

A specific safeguard may need to be in place when assessing capacity in medical conditions that create genetic, biochemical or anatomical barriers to aspects of decision-making being possible. This is particularly relevant when there will be people assessing capacity who do not have sufficient knowledge or awareness of the medical condition, especially in the case of a rare disorder.

I am pleased to see that this issue might be partially addressed in 7.59, but it is disappointing that it has been placed out of scope of the review.

7.59 We acknowledge that there are other forms of vulnerability that can have adverse consequences for people's decision-making without necessarily meaning the person does not have decision-making capacity in terms of the test we suggest. For example, for a range of reasons some people may have a compulsion to act in ways that they understand will cause them harm that they wish to avoid. However, this review only concerns decision-making capacity. While there may be benefits to general safeguarding legislation, its consideration is outside the scope of this review.

I do not agree that legislation for both safeguarding and decision-making capacity should be viewed and assessed in isolation, as this only adds to the current disconnect in our health, social and

legal systems. Furthermore, gaps in understanding based on the interpretation of just one area of legislation have the potential to create considerable risk.

I agree with the sentiments of 7.60 below regarding dignity of risk, but in relation to PWS, the key problematic word in this statement is “wants”.

*7.60 As we note above, under the PPPR Act, the fact that a person **wants** to make a risky or imprudent decision cannot, by itself, lead the court to determine a person does not have decision-making capacity. We consider this should be retained. It assists in reducing the potential for assessments influenced by bias, assumptions or stereotypes. It also helps give effect to the dignity of risk, which (as we explain in Chapter 3) is the concept that dignity requires people to have the ability to exercise choice, including risky choices. Proper respect for the dignity of risk is a necessary part of ensuring people can make decisions consistently with their rights, will and preferences.*

People living with PWS do not “want” to put themselves in life-threatening situations from binge-eating episodes, or to become morbidly obese triggering the associated shortened life expectancy that is typical in PWS. They have not developed an addiction habit by choice – they were born with a genetic syndrome that predetermined the metabolic pathway of their life, altering the gut and brain biochemistry which controls their appetite, hunger and eating behaviours.

Many adults with PWS will tell people that they prefer their food environment to be controlled, which includes locked food stores and limiting access to money. They tell us that they prefer this because it makes them feel safe and able to focus on other aspects of their life, as long as this is done in a way which also provides security about food being available (what and when), and with no chance for food related anxiety to develop. However, when unexpected situations arise and this food security is lost, a person with PWS will be unable to rationalise their thinking and will “want” to desperately consume food, possibly large amounts, as anyone would who is feeling a very intense hunger and anxiety about the availability of food in future. Those who support people with PWS need to be able to stay firm and consistent in their support to ensure food security is maintained.

We need to ensure that the food seeking behaviours associated with PWS do not lead to an assessment that decision-making support is not needed on the basis that it appears to be a “want”. (As mentioned in the background information, I have personal experience of an assessor who took this approach.)

In addition to decisions about food and access to food, there are other cognitive and behavioural characteristics associated with PWS that can affect decision-making which would also not be assessed appropriately using the four suggested factors. Making a decision using information previously understood may not be possible for a person with extreme stress sensitivity or someone with obsessive compulsive thoughts, rigid behaviours, significant executive functioning impairment, sensory impairment, and tenuous emotional control. In this instance, decision-making ability is likely to fluctuate. Information could be ‘used and weighed’ appropriately at one time, but not another. We would like to suggest that assessment and support planning for this is given further consideration, as per 7.29 and 7.43.

Question 7 asks what considerations should be insufficient, by themselves, to lead to a finding that a person does not have decision-making capacity? I think such specifications could be useful in serving to reduce unconscious bias, but I would like to suggest that the Law Commission also consider **what considerations should be sufficient**, by themselves, to lead to a finding that a person does not have decision-making capacity, **in that specific area**.

Question 8 asks about how the circumstances of a capacity assessment can be improved, and after personally experiencing a lack of understanding by the court appointed lawyer in my son's case, I would say that training and guidance for assessors could be improved. It also seems that there needs to be a more cohesive and coordinated approach to assessments, but the lack of collaboration between health, education and social systems is already causing issues with all the care and supports provided to people with disabilities in New Zealand. In the Second Issues Paper there seems to be a focus on any training or guidance being related to preventing unconscious bias, but as mentioned above, an assessor also needs to understand when to take note of medical advice in terms of assessing decision-making capacity. Perhaps there needs to be clearer ways for health practitioners to express, define and classify the impact of a medical condition on decision-making capacity. Codes of Practice could also be a good tool for assessing capacity.

Submitted by:

Jo Davies

CEO, Operations and Projects Manager
Prader-Willi Syndrome Association NZ Inc.

jo.davies@pws.org.nz

ph 021791391

References

1. **ADULTS WITH PWS - Decisions Regarding Least Restrictive Environment and The Right To Eat**
Article by PWSA(USA) from The Gathered View (ISSN 1077-9965). Approved by PWSA (USA) Board of Directors.
<https://www.pwsausa.org/wp-content/uploads/2015/09/DecisionLeastRestrictive-CR-02.pdf>

Supporting document attached to this submission

"The Mental Capacity Act: Supporting People with PWS", revised 2022.

Article by Professor Tony Holland, written for PWSA UK. Prof Tony Holland is a Professor of Psychiatry at the University of Cambridge and Head of the Cambridge Intellectual & Developmental Disabilities Research Group. He is also the President of the International Prader-Willi Syndrome Organisation

also available here:

<https://irp.cdn-website.com/1b38aac2/files/uploaded/PWSA%20MCA%20guidance%20October%202022.pdf>

Links to further supporting information

Prader-Willi Syndrome: Client's Rights and the Medical Necessity for Food Security

Article by PWSA(USA) from The Gathered View (ISSN 1077-9965). Adopted 2016, reviewed 2022.

(A revision of the 1998 article referenced above.)

<https://www.pwsausa.org/wp-content/uploads/2022/03/Medical-Necessity-for-Food-Security-Statement-2022.pdf>

Best Practice Guidelines for Standard of Care in PWS

The proceedings of the 2008 and 2009 International PWS Caregivers Conferences, published by IPWSO

https://www.pws.org.nz/wp-content/uploads/2022/02/PWS-Best_Practice_Guidelines-for-Standard-of-Care-in-PWS-IPWSO.pdf

A scoping review of case law relating to support and treatment for people with Prader-Willi Syndrome

Anna Murray , Isla Kuhn , Gautam Gulati , Elizabeth Fistein, pub 2021.

International Journal of Law and Psychiatry, Volume 78, September–October 2021, 101733

<https://www.sciencedirect.com/science/article/abs/pii/S0160252721000625>

Aims: 1) To review case-law from English-speaking common law jurisdictions concerning support arrangements for people with PWS with a view to identifying issues that have required the intervention of the courts. 2) To identify principles on which to base clinical guidelines relating to the issues identified, ensuring that such guidelines are consistent with ethical and human rights imperatives.

Restrictive practice links

Restrictive Practices in Australia - Australian Law Reform Commission, 2014

<https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/8-restrictive-practices/restrictive-practices-in-australia/>

Regulated Restrictive Practices Guide - NDIS Quality and Safeguard Commission, Oct 2020

<https://www.ndiscommission.gov.au/sites/default/files/2022-02/regulated-restrictive-practice-guide-rrp-20200.pdf>

Guidance on Restrictive Practice – Health Information & Quality Authority, Ireland, updated 2023

“...guidance to promote a care environment that is free from restrictive practice, and to assess the use of restrictive practices in their centres with a view to reducing or eliminating their use.”

<https://www.higa.ie/reports-and-publications/guide/guidance-restrictive-practice-dcd>

Fact Sheet: Locking of Fridges and Pantries – Office of the Senior Practitioner, Tasmanian Govt, July 2020

https://www.dpac.tas.gov.au/_data/assets/pdf_file/0033/227985/20200716-OSP-Admin-Factsheet-locking-of-Fridges-and-pantries.pdf

Reducing the Use of Restrictive Practices (learning modules) – National Institute of Intellectual Disability Studies, Ireland

<https://niids.ie/Services/RESTRICTIVE-PRACTICES->

Example of codes of practice

Decision Support Service, Ireland

<https://decisionsupportservice.ie/resources/codes-practice>