LA TROBE UNIVERSITY

LIVING WITH DISABILITY RESEARCH CENTRE

“Shake it Off”: Can NSW public guardians overcome an outdated system to meet Disability Convention obligations?

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Overview

- What and Why?
- Background Concepts
- The Human Rights Substitute Decision-Making Outcome Typology
  - Has four Substitute Decision-Making Outcome Types
    - Facilitating full legal capacity
    - Enabling mental capacity
    - Realising Will and Preferences
    - Prioritising Harm Prevention
- Look in detail at two of these, using case studies to highlight important points
- Implications of the Typology
- Questions

What we wanted to know

Can NSW public guardians make decisions that reflect international obligations under an outdated system?

What we did

LOOKED

- at the substitute decision-making process and practice
- of NSW Public Guardians.

TO SEE

- how it stacked up against Australia's international responsibility to
- provide equal decision-making rights for people with disability.

Why did we want to know?

BECAUSE

- Australia has to follow Article 12 of the United Nations Convention on the Rights of Persons with Disabilities

AND

It requires:

- equality of legal capacity for people with disability
- the provision of support to exercise that legal capacity
- appropriate safeguards to prevent abuse when exercising legal capacity

BUT

- The UN Committee's says that Australian legislation does not comply
- Yet they look at 'law on the books' NOT "law in action"

Background Concept - Authorising environment (way of working)

- Ways of working – for NSW Public Guardians

Direct authorising environment – NSW legislation – *Guardianship Act 1987* (NSW)

Indirect authorising environment – International – Article 12 UN Convention

(Alford & Greve, 2017; Australian Public Service Commission, 2021; Moore, 1995, 2013; Salamon, 2002

NSW way of working - NSW Guardianship Act and common law

- Common law presumption of mental capacity
- Functional assessment of decision-making ability
- Guardians appointed when the Tribunal determines a person lacks mental capacity (decision-making ability)
- Binary approach
- Guardians must apply General Principles when making substitute decisions

- General Principles include
  - best interests is paramount consideration
  - person's views must be considered
  - family relationships important
  - protection from neglect, abuse and exploitation - safeguards
  - least restrictive safeguards

NSW way of working - NSW Guardianship Act

- NSW Public Guardians see Guardianship Act as:
  - antiquated
  - paternalistic
  - conservative
  - risk averse

The legislation is old, and quite rightly needs updating (Isaac)

[Guardians] are up against a very protectionist system. It's paternalistic and … quite often view[s] people from a … negative aspect first. Not [from] a positive strengths base (Lisa)

International way of working - Article 12 UN Convention

- Equality of legal capacity - 12(2)
- Legal capacity = legal standing (holding rights) + legal agency (acting on rights)
- Universal capacity model
- Legal capacity is distinct from mental capacity
- Provide support to exercise legal capacity – 12(3)

- Supported decision-making is a safeguard to protect decision-making rights – 12(4)
  - provides for appropriate and effective safeguards
  - to prevent abuse under human rights law
  - respects rights, will and preferences
  - can be scaled up or down depending on individual circumstances

International way of working - Article 12 UN Convention

UN COMMITTEE'S VIEW

- Substitute decision-making frameworks are not within Article 12's scope

BECAUSE

- Legal agency is removed
- Functional tests links legal and mental capacity
- Focus is on safeguarding to protect a person from harm, not decision-making rights
- Decisions based on 'best interest' of the person – to the detriment of their other rights and their will and preferences

Article 12 … is emblematic of the paradigm shift of the convention…. The deceptively simple proposition that persons with disabilities are 'subjects' and not 'objects' — sentient beings like all others deserving equal respect and equal enjoyment of their rights. (Quinn, 2010, pp. 3-4)

Background Concept - Both/And Thinking

- Concept generally applied in psychology and leadership
- Tool used by NSW Public Guardians
- Assists to navigate the two contrasting ways of working – Guardianship Act and Article 12
- Neither are viewed as right or wrong. The way substitute decisions are made is managed to fit both ways of working.
- Managing contrasting ideas means accepting a paradox.

(Manderscheid & Freeman, 2012; Smith et al., 2016; Terry, 2001)

Guardians instinctively wonder, 'How can we simultaneously do both X and Y?'

The Typology of Guardians' Human Rights Substitute Decision-Making Outcomes

A way of working that reflects the requirements of the Guardianship Act and Article 12

- Explains how NSW public guardians
  - use both/and thinking to
  - make day-to-day substitute decisions
  - that are human rights focused
  - that come within one of four distinct Decision-Making Outcome Types

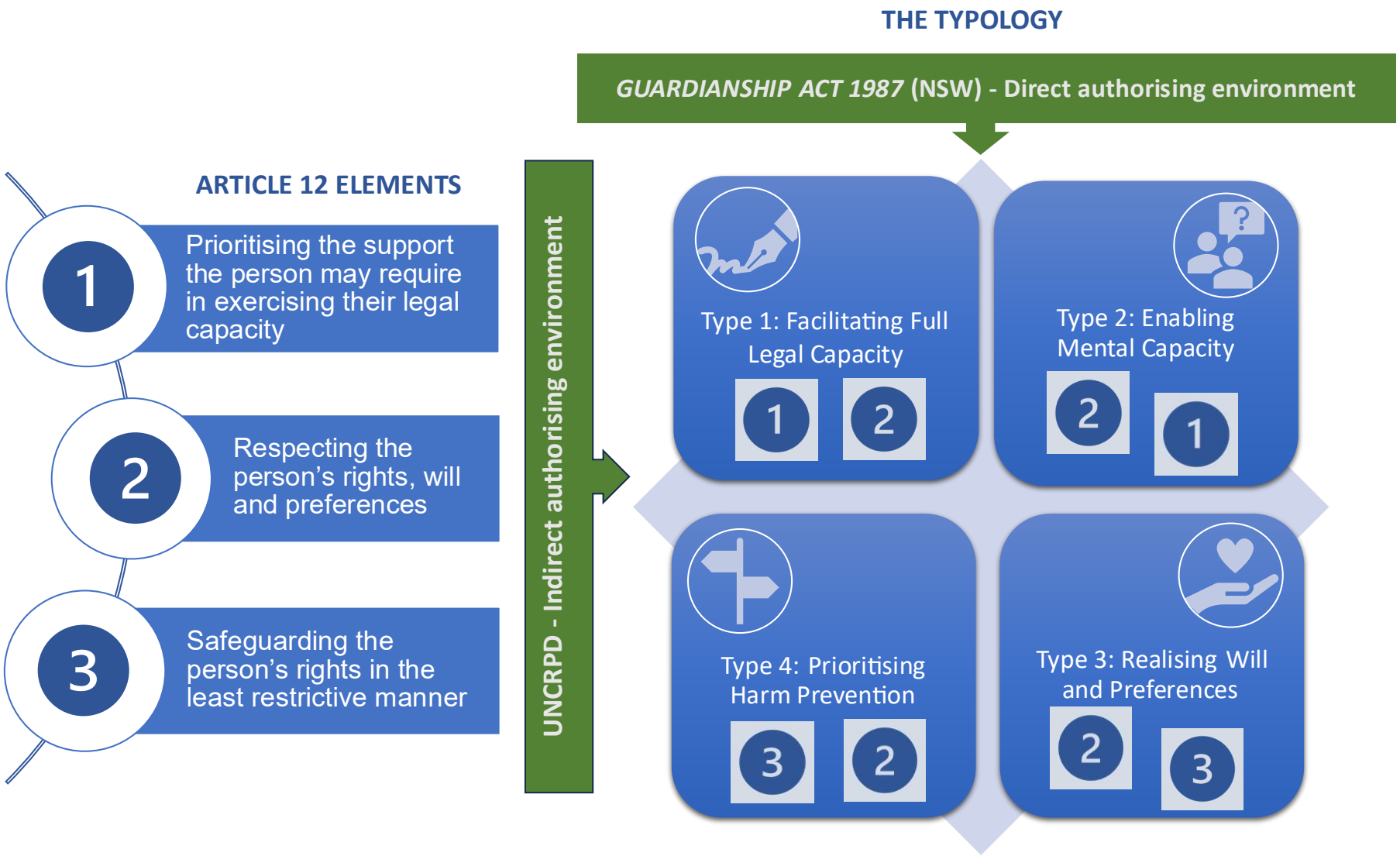
The Typology's four Decision-Making Outcomes Types

Decision-Making Outcomes Types alignment with Article 12

Each Decision-Making Outcome Type reflects, to varying degrees, the following key elements of Article 12:

1. Prioritising the support the person may require in exercising their legal capacity (Article 12(3)).
2. Respecting the person's rights, will and preferences (Article 12(4)).
3. Applying appropriate and effective safeguarding to prevent abuse in the least restrictive manner (Article 12(4)).

The Typology's relationship to Article 12 elements



Outcome Type One - Facilitating Full Legal Capacity

CONTEXT

- Article 12 – equality of legal capacity – legal standing and legal agency
- But Guardianship Act removes legal agency by appointment of guardian – it removes a person's ability to action their rights
- The person no longer has full legal capacity because a guardian is the decision-maker.

AIM

- To facilitate restoration of person's full legal capacity
- By working to get the person released from the guardianship order (by NCAT)

Outcome Type One - Facilitating Full Legal Capacity

BOTH/AND THINKING

- Guardians use their role to 'champion lapses' rather than make a substitute decision
- Seeking release from guardianship order
- A guardian is facilitating handing back decision-making to a person – which provides an opportunity to regain legal agency.

Because as soon as I met him, I figured straight away there is no way this man should be under guardianship. So, my goal then is to get him off (Lisa)

Outcome Type One - Facilitating Full Legal Capacity

Guardians champion lapses in two circumstances:

BOTH/AND

THINKING

1. Acknowledge overreach of the Guardianship Act
   - recognise person has mental capacity, and
   - no need for safeguarding
2. Considers person's right to decision-making autonomy and dignity of risk as outweighing their right to protection from harm when
   - person is refusing to comply with the order, and
   - enforcing it will cause more harm to them than if they were released from it

TOM'S CASE

After a functional capacity assessment, Tom was placed under an accommodation order and moved to accommodation with supports for both daily living and to assist him to reduce his alcohol dependence.

However, his wish was to return to living in a park, where he had been sleeping rough, drinking alcohol (methylated spirits) to excess, and subject to physical assaults. The risk of significant harm was high.

Almost daily, Tom tried to abscond from his accommodation and return to the park. Police and ambulance services were called each time to forcibly return him to the supported accommodation. Tom's pattern was to resist and threaten to harm himself, and he often caused himself injury. This resulted in physical restraint and sedation.

Sophia recognised that the guardianship order had become unworkable, and that Tom had regained decision-making capacity for this decision after abstaining from alcohol. Given her judgment that Tom understood the risks stemming from his choice, Sophia acknowledged the legislation's paternalism.

Coupled with the on-going difficulty of managing the workability of the order posed by Tom's non-compliance and the potential for serious harm created by forcibly imposing it, Sophia chose to support Tom to apply to the Tribunal for removal of the order. Sophia linked Tom with services to assist in this and explained the choices, the legal process and the likely consequences.

Sophia worked with other support services, such as NDIS supports, addiction services, independent advocates and legal services to facilitate an opportunity for Tom to be heard and for his will and preferences to be considered within the legal review process.

But, importantly, Sophia herself did not make the decision for Tom to return to the park.

Instead, Sophia facilitated Tom's wishes by championing a lapse, supporting return of his legal agency (thereby full legal capacity) so that he could make the decision himself if discharged from guardianship. This reflects Decision-Making Outcome Type One - a decision-making outcome facilitating restoration of Tom's full legal capacity.

TOM'S CASE

Outcome Type One - Facilitating Full Legal Capacity

ARTICLE 12 ALIGNMENT

- Most closely links with the intent of

1. Article 12(3) – to provide the support the person may require in exercising their legal capacity

2. Article 12(4) – to respect the rights, will and preferences of the person

- Guardians do not *uphold* full legal capacity, but they *facilitate* the regaining of it

even though

PARADOX

- Guardians do not have authority under the Guardianship Act to discharge a guardianship order

Outcome Type Three – Realising Will and Preferences

- Decisions have person's best interest as paramount – Guardianship Act
- Best interest test based on reasonable person's objective view – focused on protection from harm
- Person's views need only be considered after best interest's.
- Not compliant with Article 12 – decisions based on rights, will and preferences

CONTEXT

But it's in the human rights context. What's their right to have [this] outcome? Because they've said this is important to them (Julie)

Outcome Type Three – Realising Will and Preferences

AIM

- Make a decision that realises the will and preferences of a person to the greatest extent possible
- Decisions closely reflect, but not identical to, the decision person would have otherwise made

BOTH/AND THINKING

- Guardians enhance and reinforce the person's views by recognising them as integral to best interests tests
  - expands the ambit of best interests
  - shifts focus from objective reasonable person best interests standard to a more subjective one

Outcome Type Three – Realising Will and Preferences

- will and preferences are central to reimagined standard
- broader focus than just protection from harm
- harm assessed through will and preference lens but does not always equate to accepting risk
- use stepped approach to manage risk
- least restrictive safeguards implemented – trials - stepped up and down

BOTH/AND THINKING

TOM'S CASE

As seen above, Tom was under guardianship and moved to accommodation with supports. However, he continually absconded to live at the park where he could drink alcohol freely but was at risk of physical assaults and serious health problems.

Sophia spent time with Tom talking about her role, the decisions, options and consequences. They also discussed Tom's life in the park, what he liked and disliked about it, doing the same for his current accommodation. They spoke about his views and wishes. From these interactions, Sophia confirmed that Tom lacked decision-making capacity for the decisions covered by the guardianship order.

She also felt that she understood his will and preferences, which were to:

- be able to drink alcohol
- not have routines, such as eating, sleeping and showering regularly or at specific times
- feel part of a community, and
- sleep outside so he could see the stars.

To understand more about Tom's will and preferences, and his safety and health if he returned to the park, Sophia gathered opinions from people Tom had connections with while living there.

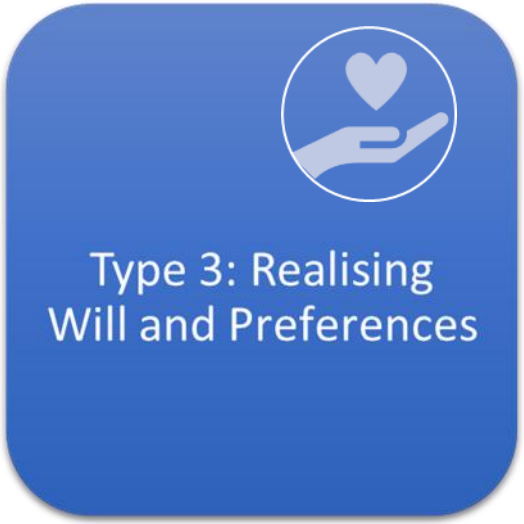
These included staff from homelessness services, emergency personnel, and volunteers providing regular showering and laundry services to people sleeping rough. She consulted Tom's current support staff and GP. Sophia spoke about what Tom wanted, explained dignity of risk, and collaborated on options while mitigating conflict.

Sophia felt that Tom did not have full insight into the consequences of his choice to return to the park, including the related risk of serious harm. However, placing Tom at the centre of decision-making, she made decisions that realised his will and preferences as far as possible.

Knowing that implementation would be challenging, Sophia still made the significant safeguarding step of refusing Tom's requests to return to living in the park. But realising that Tom's welfare and interests included freedom of choice and action, she implemented his will and preferences to the greatest extent possible in other ways. Sophia made the decision for Tom to live in supported accommodation that allowed him to drink alcohol.

However, this necessitated Tom attending tailored, one-on-one education about the effects of alcohol, being of good behaviour, and working with professionals to reduce his intake.

TOM'S CASE



TOM'S CASE

This was part of a stepped approach to safeguarding, with more restrictive safeguards to be considered if Tom was not able to reduce his alcohol, engaged in disruptive behaviour, or if his health problems escalated. Sophia made these decisions as substitute decision-maker in accordance with her services, healthcare and medical functions.

Sophia also chose accommodation with a large, tree filled backyard. She collaborated with the service provider to allow Tom to sleep outside occasionally when weather permitted. Tom was also to be assisted to choose his routine each day and not be confined to a schedule.

These plans were to be monitored and reviewed by the service and Sophia with a view to imposing more restrictive safeguards where necessary (which would lead to Outcome Four: Prioritising Harm Prevention). Or, to step safeguarding down by handing some decisions back to Tom (which would lead to Outcome Two: Enabling Mental Capacity)

Incorporating Tom's will and preferences into her consideration of what was in Tom's best interests, Sophia made a decision that implemented safeguards to mitigate, rather than negate, risk. The decision-outcome reflected Tom's will and preferences to the maximum degree possible, reflecting Outcome Three.

Outcome Type Three – Realising Will and Preferences

ARTICLE 12 ALIGNMENT

- Most closely aligns with the intent of

2 Article 12(4) – to respect the rights, will and preferences of the person

- Reflects the intent of

3 Article 12(4) – applying appropriate and effective safeguarding to prevent abuse in the least restrictive manner

- Guardians reflect will and preferences by redefining best interests test to centre around what the person wants

even though

PARADOX

- Guardianship Act best interests test is about what a reasonable person thinks is best AND the guardian still makes the decision for the person.

Implications

- The Typology reveals that
  - NSW Public Guardians' substitute decision-making practice
  - is better aligned with Article 12 obligations
  - than the text of the NSW Guardianship Act suggests

OPPORTUNITIES

- Legislative change
- Policy, Procedural and Practice Change
- Inclusive change

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Thank you

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Living with Disability RESEARCH CENTRE

Supporting inclusion of people with cognitive disability

Design and method

WHO?

- 7 NSW public guardians
- All 3 NSW Public Guardian Offices
- Covering 9 of 10 NSW regions
- Included regional, rural, remote

HOW?

- Purposive sampling
- Experience
- Rich, relevant data from diverse range of demographics
- Recruitment via NSW Office of Public Guardian
- Voluntary

WHAT?

- 1:1 semi-structured, intensive interviews
- Between 50 to 120 minutes
- At NSW Guardian's offices
- Written interview transcripts constituted the data

Methodology – Grounded Theory

Formation of Theories

- Routine
- Deliberate
- Self - reflection
- Specific questions

Memoing (reflexive strategy)

Focused codes

Initial codes

Substantive codes - categories

Comparative analysis

Situating the researcher

Government

Lived Experience

Advocacy

Theoretical codes

Derived from Charmaz, 2014; Corbin & Strauss, 1990b; Glaser, 1978, 1998; Glaser & Strauss, 1967; Strauss, 1987

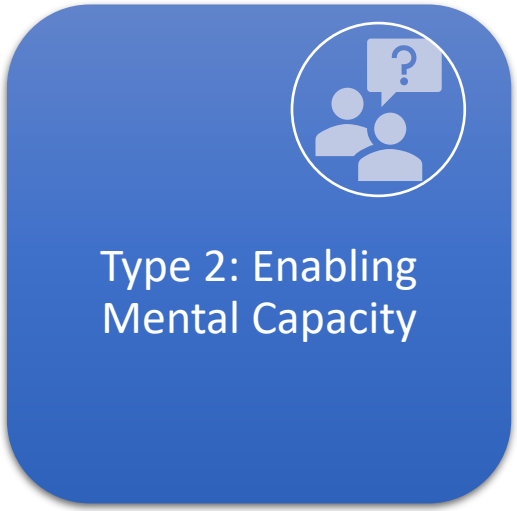
Outcome Type Two – Enabling Mental Capacity

- Article 12 – legal capacity is distinct from mental capacity (decision-making ability) – cannot be linked
- Guardianship Act conflates these – legal capacity can be removed after assessment of mental capacity

CONTEXT

- Hand back decision-making to the person despite them being under substitute decision-making

AIM

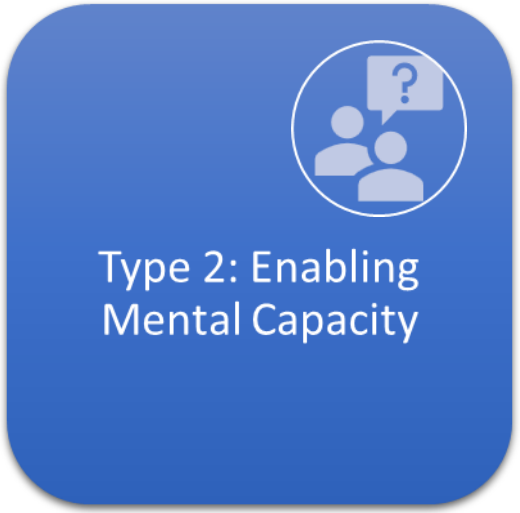


- Distinct from Outcome One because person remains under guardianship

There are examples where you can just go 'everybody else, like it doesn't matter what you think, this person, there's still some capacity there. Why aren't we trying our best (to enable it)?' (Rose)

Outcome Type Two - Enabling Mental Capacity

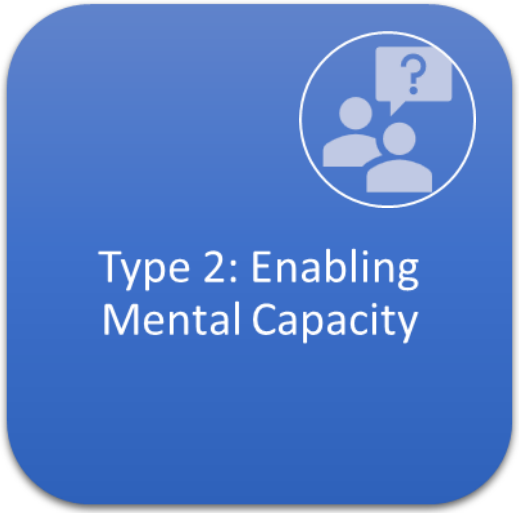
BOTH/AND THINKING



- Guardians create a space in which decision-making autonomy can exist – Article 12
- Even within substitute decision-making legislation that denies it – Guardianship Act
  - ie: guardian appointed after functional assessment deems mental capacity (decision-making ability) lacking
- Guardians are decoupling legal and mental capacity on a practical level
- Guardians do this in two ways

Outcome Type Two - Enabling Mental Capacity

BOTH/AND THINKING

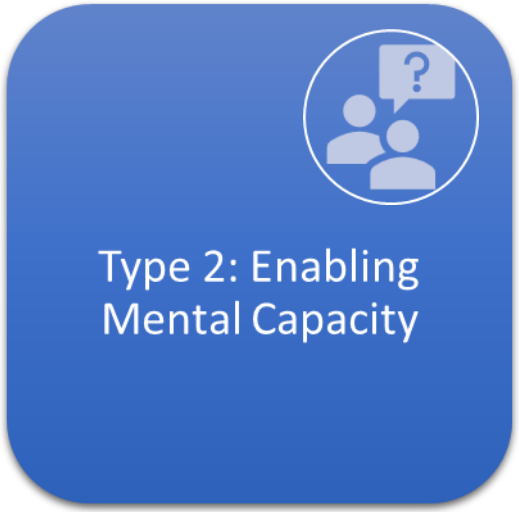


1. Respecting the presumption of mental capacity – NSW common law
   - even though Guardianship Act displaces presumption
   - in practice guardians informally reinstate presumption – reflecting Article 12's ethos

- Paradox - employ the presumption within the substitute decision-making structure under which it was refuted
- Often for small decisions, but also discrete components of more significant decisions

Outcome Type Two - Enabling Mental Capacity

BOTH/AND THINKING



2. Endorsing the person's decision
   - Guardianship Act appoints substitute decision-maker – no legal recognition of person's decision-making ability or decision
   - in practice guardians empower person to make a decision

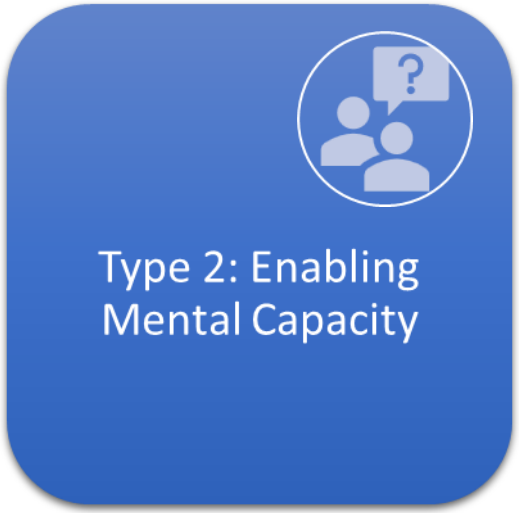
- Paradox
  - guardians 'rubber stamp' decision – providing legal authority
  - once valid, decision can be acted on - rights, will and preferences implemented

Decision-Making Outcome Type Two - Enabling Mental Capacity

- Most closely aligns with the intent of

2 Article 12(4) – to respect the rights, will and preferences of the person

ARTICLE 12 ALIGNMENT



- Potentially some alignment with

1 Article 12(3) – to provide the support the person may require in exercising their legal capacity

(vicarious legal agency)

Outcome Type Four – Prioritising Harm Prevention

CONTEXT

- Safeguards must be relative the extent that they affect rights, will and preferences – Article 12(4)
- UN Committee says all rights must be protected
- Guardianship Act focused on protection from harm – not will and preferences - protecting *all* rights is difficult

AIM

- To safeguard person from harm

I try to say to him, 'You do get into trouble, and you'd be in gaol otherwise' … And he believes, he thinks he'll manage really. So, so yeah, it's very, it is hard. Decisions that go against people's wishes are the most difficult decisions really (Isaac)

Outcome Type Four – Prioritising Harm Prevention

BOTH/AND THINKING

- Reinterpreted best interests standard is used – will and preferences integral
- All rights are considered and balanced, but prevention from harm is more likely when
  - risk is immediate and significant
  - decision complexity increases
  - there is a beneficial impact on other rights that have been negatively affected
- Continual monitoring and review of safeguards to stepping down of safeguards so person's will and preference can be given maximum effect

Outcome Type Four – Prioritising Harm Prevention

ARTICLE 12 ALIGNMENT

- Most closely aligns with the intent of

3 Article 12(4) – applying appropriate and effective safeguarding to prevent abuse in the least restrictive manner

- Potentially aligns with the intent of

2 Article 12(4) – to respect the rights, will and preferences of the person