



Article 12 and the NSW guardianship framework: a case study

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Aim

Highlight key Article 12 compliance issues faced by the NSW guardianship framework

AND

How these create barriers preventing people with intellectual disability from enjoying full capacity and autonomy of decision-making in NSW.

Case study

Tony is a 32 year old man with mild intellectual disability who lives in Wagga and works at a cafe 3 days a week. This is organised through, and supported by, a local disability organisation - Focus. Tony is an NDIS participant and has, in the past, been on the Disability Support Pension.

Sadly, Tony recently lost his parents in a car accident. Both he and his brother, Sam, have always lived with them. Their parents will left the estate (\$300,000 plus the house) equally to both sons. The executor is an Aunt, Frieda.

Frieda has never really had a lot to do with Tony or Sam but feels, as executor, that Tony's intellectual disability means that he should not receive the money or house outright. Frieda consults a solicitor, Ruth, who points to the fact that Tony has been on the DSP and receives NDIS services, stating that Tony, clearly, cannot be capable of dealing with finances. She says his job is just a day program really and makes noises about special disability trusts and the duty of care of an executor. This risk talk scares Frieda.

Further, Frieda is concerned as Tony has said that he wants to use some of the inherited money to go to Europe, where his parents were born, to meet family and see places his parents used to talk about. Frieda thinks Tony won't be safe travelling and might be exploited. She also sees this choice as rash and extravagant.

Frieda considers the trust set up unwieldy and decides to apply to the NSW Civil and Administrative Tribunal for a financial management order for Tony while the estate goes through probate. She is certain that it will be better for Tony to have the NSW Trustee and Guardian as a financial manager.

At the hearing, the Tribunal are presented with a capacity assessment completed by Frieda's local GP who has discussed the situation with Frieda. He saw Tony, administered the mini-mental, asked him some questions about investing funds, assessed him as depressed due to grief and concluded that Tony does not have financial capacity. The GP and Frieda were very convincing in the Tribunal hearing.

Tony also spoke at the hearing. He did not have anyone with him, was particularly upset that day and was confused as to why he was there (no one explained it to him). No evidence was presented by Sam, Tony's employer or colleagues, or Focus.

The up-shot:

- A financial manager was appointed to make decisions about Tony's financial matters. It covered all his finances, including those he already managed plus the inherited estate. There was no end date or date for review.

Article 12 UNCRPD

- A key human rights article recognising that people with disability have:
 - equal legal capacity in all aspects of life;
 - a right to support to exercise their legal capacity; and
 - a right to appropriate and effective safeguards which:
 - respect their rights, will and preferences,
 - are free of conflict of interest and undue influence,
 - are proportional and tailored to their circumstances,
 - apply for the shortest time possible, and
 - are subject to regular review by an impartial authority.

Barrier 1: Ambiguities of Article 12 – UN interpretation of legal capacity

Legal capacity

- An inalienable right - cannot be removed from a person
- Supports a human rights approach to disability

Mental capacity

- Tests of mental capacity cannot be used to limit legal capacity
- Equates to decision-making ability, which can fluctuate
- Must be supported when exercising legal capacity

Barrier 1: Ambiguities of Article - NSW interpretation (via action.... or inaction?):

Legal capacity

- Not an inalienable right - can be removed through substitute decision-making
- Legal and mental capacity conflated

Mental capacity

- Presumption of capacity
- But tests of mental capacity can rebut this presumption
- A person's mental capacity determines their legal capacity
- No emphasis on support

Why does this matter for Tony?

In the case study, Tony has had his legal capacity removed by a NSW financial management order via an interpretation of Article 12 that is contrary to the UN's, but made possible by the text's ambiguity.

If the UN's interpretation were implemented, Tony would keep his legal rights to make decisions about his finances - legal capacity would be inalienable and not linked to decision-making ability.

Barrier 2: Ambiguities of Article 12 - Substitute decision-making – UN interpretation

- Supported decision-making and guardianship cannot co-exist.
- Providing appropriate and effective safeguards for the right to legal capacity does not include substitute decision-making.
- State Parties must abolish substitute decision-making regimes.

Barrier 2: Ambiguities of Article 12 - Substitute decision-making - NSW interpretation

- Supported decision-making and guardianship can co-exist.
- Substitute decision-making is an appropriate and effective safeguard for the right to legal capacity.
- Substitute decision-making will not be abolished.

Australia's understanding

Interpretative Declaration regarding Article 12:

*“Australia declares its understanding that the Convention **allows for fully supported or substituted decision-making** arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards.”*

Why does this matter for Tony?

Substitute decision-making has been used as a safeguard to protect Tony from perceived financial risk. His legal capacity has been removed through substitute decision-making. Tony now lacks the authority to make his own finance decisions, and so his self-determination and autonomy are diminished.

Adhering to the UN interpretation of Article 12 would prohibit the use of substitute decision-making. Other safeguards would need to be put in place – such as supported decision-making or capacity building.

Barrier 3: Current guardianship framework – based on mental capacity

- Presumption of capacity is often disregarded for people with intellectual disability.
- Legal capacity is removed on the basis of mental capacity assessments. This creates a binary system.
- Assessment of decision-making is often not well understood or well done, compounding an already unfair system.

Why does this matter for Tony?

Tony was not afforded the presumption of legal capacity.

A mental capacity assessment formed the basis of removal of Tony's legal right to make financial decisions. The assessment was not decision-specific and didn't address the legal elements of the test for financial decision-making. The GP didn't know Tony or his life, used a global capacity tool (mini-mental) and took into account extraneous factors (risk, grief, Frieda's beliefs).

The Tribunal relied on the medical evidence and did not hear evidence from Tony's relevant networks, nor did he have appropriate support to assist him to understand and participate in the hearing.

This contravened Article 12 and also NSW law, leaving Tony without decision-making rights.

Barrier 4: Current guardianship framework

– no supported decision-making

- Contrary to Article 12, NSW law does not formally recognise or foster supported decision-making.
- The recent NSW Law Reform Commission's report recommends a legislative framework. Implementation is challenging.
- Supported decision-making could prevent unnecessary appointments of substitute decision-makers and ensure more people retain autonomy. It would provide a stepped approach to the current binary system.

Why does this matter for Tony?

There were numerous points at which Tony's ability could have been enhanced by supports. Instead of undertaking a capacity assessment, Freida might have gained an understanding of Tony's decision-making skills with a view to finding what supports Tony may need/want (if any) to enhance his ability. This focuses on the presumption of capacity and moves away from the binary approach.

Talking with Tony, Sam, Focus, Tony's work colleagues, NDIS service providers and other networks may have assisted in developing supported decision-making approaches.

Supported decision-making may have prevented Frieda's application to the Tribunal. Also, if used during the hearing it may have prevented the appointment of a financial manager.

Barrier 5: Current guardianship framework – best interest decision-making

- NSW substitute decision-makers are required to make decisions for a person based on their best interests.
- They must take into account the person's wishes.
- This differs from Article 12, which uses a rights, will and preference model.
- With will and preference the person's wishes are paramount. There is a risk enablement focus on decision-making.
- Best interests allows a risk aversion approach and a person's wishes may be discounted.

Why does this matter for Tony?

Under Article 12 a person's rights, will and preference guides decision-making and is essential to legal capacity. It applies also to supported decision-making, and where utilised, substitute decisions.

So, Frieda would have been guided in her actions by Tony's will and preference – to inherit his parents estate unencumbered and have the right to autonomous decision-making, including to decide to go on a trip to Europe.

Determining that he needed a financial manager was not consistent with Tony's rights, will and preference.

The Tribunal determination, appointing a financial manager, was also inconsistent with this.

Barrier 6: Current guardianship framework

– FM orders are not least restrictive

- Financial management orders are interpreted by NSW as being a safeguard under Article 12.
- Unlike guardianship orders, they are usually made in general terms, are on-going and are not subject to regular review.
- This is in contravention of Article 12 which requires that they are:
 - proportional and tailored to their circumstances,
 - apply for the shortest time possible, and
 - are subject to regular review by an impartial authority.

Why does this matter for Tony?

Tony's financial management order covered all his finances, including those he already managed plus the inherited estate. The order presumably removed the right for him to make decisions that he was previously making about his work salary and NDIS funds.

This all encompassing order breached Article 12 as it was not proportional, there was no time limit, and no review date.

Effectively, Tony's financial decision-making autonomy was removed indefinitely by the order, unless he (or another interested party) initiated proceedings to prove his legal capacity.

Barrier 7: Lack of an evidence base for supported decision-making

Uncertainties/difficulties with developing legislation and policy to implement supported decision-making because:

- Trials have not had the benefit of being backed by legislation – not formalised and constrained by existing legal boundaries.
- Trials have not produced a consistent definition or model.
- Complex decisions/situations were not generally included in trials.
- Trial evaluations have been mainly non-existent or inadequate in assisting to build a robust evidence base.
- Supported decision-making is resource intensive.

Why does this matter for Tony?

Consistent information about supported decision-making – what it is and how to do it – was unlikely to be readily available to Tony's network and the professionals involved in the situation.

This decreased the chance of support being offered and escalated the situation to a capacity assessment.

Notably, professionals did not have the resources to know either that support could be included in the capacity assessment process or how to include support in the process.

Barrier 8: Lack of knowledge impedes true societal inclusion

- Reviews of the Mental Capacity Act (UK) demonstrate that even with clear legislative change to reinforce decision-making rights, a conscious, well-resourced education campaign to change attitudes and question entrenched bias is needed.
- This must be across all relevant sectors, including the community, and legal, medical, financial, disability and aged care sectors.
- The NSW Law Reform Commission acknowledged this.
- Additionally, the reviews showed that there needs to be one body responsible for monitoring and reviewing accountability across sectors otherwise there is only piecemeal efforts.

Why does this matter for Tony?

Maybe with education, Frieda, the solicitor, the GP, and the Tribunal, might have placed Tony's legal capacity to make his financial decisions in accordance with his rights, and will and preference at the centre rather than take a risk averse perspective.

Even within a substitute decision-making framework a different outcome may have been possible for Tony if:

- The presumption of capacity was well understood and actioned.
- There was an emphasis on providing support to enhance decision-making ability before and during capacity assessment.
- The relevant capacity tests, including mental capacity assessments, were used before legal capacity was determined as lacking.

Why does this matter for Tony?

Tony being subject to a restrictive financial management order may have been avoided if traditional interpretations of best interests were redefined/widened to incorporate the intention of Article 12, including placing paramountcy on equality of autonomy for decision-making, risk enablement, and respect for will and preference.

The order may have been framed differently to reflect a more proportional safeguarding approach, including being restricted to specific decisions, having time limits and incorporating regular reviews.

Recapping barriers

Under the current NSW guardianship system

- Legal capacity is NOT an inalienable right as it can be removed by substitute decision-making.
- Legal capacity is removed on the basis of mental capacity assessments often determined based on misunderstood or misapplied tests.
- Supported decision-making is not formally included.
- Rights, will and preference are NOT placed at the centre – best interests is paramount.

Recapping barriers

- Financial management orders do not comply with Article 12.

AND

- A robust evidence base on what constitutes supported decision-making, what benefits it provides and whether it works is lacking
- Without widespread education and training change will not occur.

The ***“... magnitude of changes now asked of countries is enormous”***

(Freeman et al., 2015, p. 845)

which may

“... reduce the provision to mere rhetoric”

(Pearl, 2013, p. 2)

Thank you

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