Council for Intellectual Disability

Response to NSWLRC Question Papers

2 – Decision-making models

3 – The role of guardians and financial managers

January 2017

Contact
Jim Simpson
Senior Advocate
[redacted]

www.nswcid.org.au
www.facebook.com/NSWCID
1800 424 065

Who we are

For 60 years, NSWCID has been the peak advocacy group in NSW for people with intellectual disability. We have a diverse membership of people with intellectual disability, family members, advocates, professionals and advocacy and service provider organisations. Our Board must have a majority of people with intellectual disability and we actively involve people with an intellectual disability in all aspects of our work.

NSWCID has a long history of focusing on supported and substitute decision-making for people with intellectual disability. We were represented on the working parties that developed and implemented the Guardianship Act 1987 and have taken a very active ongoing interest in the legislation, for example taking a leading role in the development of the then Guardianship Tribunal's role in regulation of restrictive practices.

Especially in the last 10 years, we have had a heavy focus on the development of the capacity of people with intellectual disability to not only make their own decisions but also lead our organisation. The NSW government has funded our *My Choice Matters* project which is focused on developing the ability of people with intellectual disability to control their own lives in accordance with the principles of choice and control that are inherent in the National Disability Insurance Scheme.

We have two representatives on the Intellectual Disability Reference Group of the National Disability Insurance Agency which has provided advice to the NDIA on supported and substitute decision making arrangements in the NDIS.

www.nswcid.org.au
www.mychoicematters.org.au/

NSW CID generally support the submissions of the NSW Disability Network Forum

We had input to the submissions prepared by the DNF and now elaborate on a key issue that we have given detailed consideration to in recent years – what decision-making principles should substitute decision makers be required to observe? In particular, should the law move to a will and preferences model and if so with what qualifications?

In summary, we favour either:

- substitute decision-makers being required to act in accordance with a person's personal and social well-being, with will and preferences being an important part of determining personal and social well-being; or
- a structured will and preference model along the lines of that in the My Health Records Act 2012.

We also briefly address one other issue:

Question 5.2 (3) Should NSW have formal co-decision-makers?

We are doubtful about enacting a power for a tribunal to appoint a co-decision-maker so that a person with a disability and the co-decision-maker needs to agree on a decision for it to be effective. It seems odd to have someone with effective power of veto over a decision of a person with disability in the absence of a guardianship order. We also fear that protective instincts may lead tribunal members too readily to resort to co-decision-making rather than leaving a person free to make their own decisions with or without support.

What decision-making principles should guardians and financial managers observe?

Question 4.2: Should guardians and financial managers be required to give effect to a person's "will and preferences"?

(1) What are the advantages and disadvantages of the current emphasis on "welfare and interests" in the *Guardianship Act's* general principles?

The advantage is that "welfare and interests" allows a full and flexible consideration of the full gamut of factors relevant to a person's interests, just as anyone might consider in determining their own interests. A more constrained list of factors risks missing some significant factors.

The disadvantage is the potential for paternalistic approaches and ones unduly influenced by the values of the decision maker. "Welfare and interest" carries a paternalistic flavour in view of the history of its use in many spheres.

(2) Should "welfare and interests" continue to be the "paramount consideration" for guardians and financial managers?

"Welfare and interests" should be discarded in view of its paternalistic flavour. However, there is much too be said for using instead the form of words recommended by the Victorian Law Reform Commission (VLRC) - that a substitute decision maker should be required to exercise their powers "in a manner that promotes the personal and social well-being" of the person. For financial managers, the word "financial" could be added after "personal".

This approach would allow the flexibility of the "welfare and interests" approach while discarding its historical baggage.

If such a paramount consideration is retained, its interpretation should be guided by a list of relevant factors as proposed by the VLRC, including:

- The decision the person would have made if able to do so.
- Any wishes of the person.
- Encouraging the person to be independent and participate in the community.
- Respecting the person's supportive relationships.
- Taking account of the person's cultural and linguistic circumstances.

- Protecting the person's rights and dignity.

The language in the first two dot points could be updated to "will and preferences" of the person.

(3) What could be the benefits and disadvantages of requiring guardians and financial managers to give effect to a person's will and preferences?

The benefit is maximum consistency with Article 12 of the UN CRPD and maximum focus on the autonomy of the individual, which historically has received inadequate focus under the welfare and interests approach.

The disadvantages are the challenges of interpreting will and preferences:

- For people who have impaired cognition or communication. For some people with intellectual disability, it can be extremely difficult to interpret their views beyond observing whether they appear to gain some satisfaction or dissatisfaction from current experiences.
- For people whose views may be unduly influenced by those around them. It is common for people with intellectual disability to be highly influenced by those they depend on – close family or support workers. Quite often, these influences favour the status quo or a risk averse approach to life which can constrain a person's community inclusion and development of skills and independence.
- For people whose views are highly changeable related to their disabilities. For example, some people with intellectual disability and mental health conditions related to childhood trauma tend to have very changeable life plans and goals on a month to month and even hour to hours basis.
- For people with lifelong cognitive disabilities. This limits the opportunity for a decision maker to be guided by will and preferences that a person had before they acquired their cognitive impairment.

Also, a cognitive or psychosocial disability will often limit a person's capacity to see the advantages and disadvantages of options that face the person. This is the more so in the common situation where a person has led a restricted and protected life with very limited exposure to the range of life's options and very limited opportunity to choose between options.

Further, many people with autism have limited information processing skills and a wish for order, routine and predictability. These factors can make a person very reluctant to accept any changes in their lives.

(4) Should guardians and financial managers be required to give effect to a person's will and preferences?

We support will and preferences being at least an important part of the formulation of the obligations of substitute decision-makers, either in the Victorian personal and social well-being approach (4.2(2) above) or a structured will and preferences approach (4.4 below).

Question 4.3: Should NSW adopt a "substituted judgment" model?

(1) What could be the benefits and disadvantages of a "substituted judgment" approach to decision-making?

(2) Should the *Guardianship Act* require guardians and financial managers to give effect to the decision the person would have made if they had decision-making capacity (that is, a "substituted judgment" approach)?

(3) If so, how would guardians and financial managers work out what the person would have wanted? Should the legislation set out the steps they should take?

We shall not specifically answer these questions. However, we do support much increased weight being given to a person's current and historical will and preferences than is currently the case – see above and below.

Question 4.4: Should NSW adopt a "structured will and preferences" model?

(1) What could be the benefits and disadvantages of a "structured will and preferences" approach to decision-making?

(2) Should guardians and financial managers be required to make decisions based upon a person's will and preferences?

The benefit of a structured will and preferences approach would be to give maximum weight to the autonomy of the individual and provide a framework for this. The disadvantage may be to give insufficient weight to factors that a person may have considered in making his or her own decisions if he or she did not lack capacity.

(3) If so, how would guardians and financial managers work out a person's will and preferences? Should the legislation set out the steps they should take?

We support the legislation providing guidance to guardians and financial managers in how to interprets a person's will and preferences. This would assist guardians and managers, reduce the potential for the guardian's own values to unduly impinge and provide a benchmark for accountability of guardians and managers.

In determining will and preferences, guardians could be required to consider the following variations on the list of factors recommended by the VLRC:

(a) the wishes and preferences the person expresses at the time a decision needs to be made, in whatever form the person expresses them

(b) any wishes <u>and preferences</u> the person has previously expressed, in whatever form the person has expressed them

(c) any considerations the person was unaware of when expressing their wishes which are likely to have significantly affected those wishes

(d) any circumstances that have changed since the person expressed their wishes which would be likely to significantly affect those wishes

(e) the history of the person, including their views, beliefs, values, culture, relationships, sexuality and goals in life.

(5) What should a guardian or financial manager be required to do if they cannot determine a person's will and preferences?

We support the My Health Records Act formulation of a guardian then acting in a manner that promotes the person's personal and social well being. The word "financial' could be added after "personal" for decisions by financial managers.

We do not support the guardian's obligation instead being to "uphold the person's human rights" as recommended by the ALRC. As we said in our preliminary submission:

> NSWCID sees human rights as very important. However, we question whether human rights is a sufficient basis for decisions. We all make decisions about our lives based on more than consideration of our human rights. For example, our decisions quite reasonably may be influenced by our important relationships and by our cultural and linguistic backgrounds. Should people with disability be denied the influence of these inputs? So far as we can see, these kinds of issues are only partially reflected in human rights instruments.
>
> The other problem with decisions being based predominantly on consideration of a person's human rights is that there is very limited understanding of the detail of human rights in the community and there is a range of lengthy and somewhat complex human rights instruments. Different rights may point towards different outcomes so that quite complex balancing exercises are required to make a decision. The result of all this might be that only highly educated people were qualified to make many representative decisions. We are concerned about the prospect of removing from eligibility as representatives, down to earth practical family members who have a lifetime's knowledge of a person with disability.

(6) Should a guardian or financial manager ever be able to override a person's will and preferences? If so, when should they be allowed to do this?

As explained in 4.2(3) above, will and preferences is too narrow a focus in some circumstances, especially for people with cognitive disability.

The ALRC did say a person's will and preferences should not be binding if acting on them would cause harm to the person or others. This rider may cover situations where a person is clearly placing themselves or others at great risk. However, where there are concerns that a person is being abused or neglected, proving this is often difficult due to the person's impaired communication, disempowered situation and isolation from the community. Also, unless "harm" is very broadly defined, it may not cover many situations where a person is not being abused or neglected but is missing out on access to opportunities to live a rich and varied lifestyle and develop skills.

Section 7A of the My Health Records Act 2012 provides a better formulation than did the ALRC of when and how a representative should be able to override will and preferences. This was the first Commonwealth legislative response to the ALRC report.

The section basically says that a representative must give effect to will and preferences unless this will "pose a serious risk" to the person's "personal and social well-being". Then the representative must instead "act in a manner that promotes the personal and social well-being" of the person.

We see section 7A as improving on the ALRC approach in particular by:

- A representative being able to go against will and preferences if they would lead to a serious risk to personal and social wellbeing. This would presumably encompass both risks of injury, abuse and exploitation and risks of the person having a narrow and unfulfilled lifestyle.
- A focus on personal and social well-being as the backstop basis for decisions rather than human rights.