NSW DISABILITY NETWORK FORUM

Review of the *Guardianship Act 1987:*

Response to Question Paper 5

12 May 2017

Contact the **NSW Disability Network Forum** through the NCOSS secretariat
Ya'el Frisch [redacted], ph 8960 7908

About the NSW Disability Network Forum

The NSW Disability Network Forum comprises non-government, non-provider peak representative, advocacy and information groups whose primary purpose is to promote the interests of people with disability. The aim of the DNF is to build capacity so that the interests of people with disability are advanced through policy and systemic advocacy.

NSW Disability Network Forum Member Organisations:

- Being Mental Health and Wellbeing Consumer Advisory Group
- Blind Citizens NSW
- Deaf Australia NSW
- DeafBlind Association NSW
- Deafness Council (NSW)
- First Peoples Disability Network
- Information on Disability and Education Awareness Services (IDEAS) NSW
- Institute for Family Advocacy
- Intellectual Disability Rights Service
- Multicultural Disability Advocacy Association of NSW
- NSW Council for Intellectual Disability
- NSW Council of Social Service (NCOSS)
- NSW Disability Advocacy Network
- People with Disability Australia
- Physical Disability Council of NSW
- Positive Life NSW
- Side by Side Advocacy Incorporated
- Self Advocacy Sydney
- Synapse (Brain Injury Association NSW)

This submission was developed by NCOSS in consultation with the DNF members and approved by NCOSS Deputy CEO.

Introduction

The DNF welcomes the opportunity to respond to the fifth Question Paper of the review of the *Guardianship Act 1987 (NSW)* (*Guardianship Act*), dealing with medical and dental decisions, and the regulation of restrictive practices.

In our response to Question Paper 1, the DNF emphasised that a person's capacity to make a decision should be judged in the context of that particular decision, and that a person must be given appropriate information and support to make a decision. This definition can be applied across a broad spectrum of decision types, rendering it unnecessary to use a specific definition of capacity in the context of medical and dental decisions. The presumption of capacity in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) suggests that it is not a person's capacity that changes according to the decision being made, but rather the level and type of support required to exercise that capacity.

However, we argue that significant safeguards should apply to special medical procedures including sterilisation, as these procedures can have significant effects on a person's personal and social wellbeing. Only a Tribunal should be able to authorise such procedures.

Restrictive practices should be permitted in limited circumstances. In the long-term, the DNF emphasises that NSW should work towards the elimination of restrictive practices, as they may constitute cruel or degrading treatment contrary to Article 15 of the UNCRPD. In the shorter term, we outline strict safeguards that should be applied to restrictive practices.

This submission should be read in conjunction with the DNF's response to Question Paper 1.[1]

Question 2.1: "Incapable of giving consent"

(1) Is the definition of a person "incapable of giving consent to the carrying out of medical or dental treatment" in s 33(2) of the *Guardianship Act 1987* (NSW) appropriate? If not, what should the definition be?

(2) Should the definition used to determine if someone is capable of consenting to medical or dental treatment align with the definitions of capacity and incapacity found elsewhere in the *Guardianship Act 1987* (NSW)? If so, how could we achieve this?

The DNF believes the definition of "capacity" we proposed in a response to Question Paper 1 should be applied in respect of consent to medical and dental treatment. For reference, we argued that the definition of "decision-making capacity" should:

1. Clarify that capacity is decision-specific by using the singular "decision" rather than "decisions about a matter";

2. Mandate that when determining a person's decision-making capacity, the Tribunal ensures that a person has access to:

   - relevant information in a form and format that is accessible to them; (for example Braille, Easy English or a language other than English); and

   - appropriate support to make the decision.

3. Outline that "decision-making capacity" involves a person's ability to:

   (a) understand the nature and effect of a decision (with appropriate support);

   (b) freely and voluntarily make a decision; and

   (c) communicate the decision in some way whether by talking, writing, using sign language, assistive technology, or any other means.

4. Provide that when determining whether a person understands the nature and effect of a decision, the Tribunal should consider factors including whether the person can:

   (a) with appropriate support, understand the relevant information (including the consequences of making or failing to make the decision);

   (b) retain that information for a period that allows the decision to be made within an appropriate timeframe;

   (c) use the information or weigh it as part of the decision-making process.

[1] DNF response to review of the *Guardianship Act 1987*: Question Paper 1.

In summary, the DNF believes that it is important that a uniform definition be applied in respect of all types of decisions as consistent with the presumption of capacity. It is the nature and level of support required that may vary depending on the nature of the decision.

Special treatment

The DNF supports the maintenance of stringent safeguards in the *Guardianship Act* with respect to special treatment due to its invasive nature.

Question 4.6: Person responsible

(1) Is the "person responsible" hierarchy appropriate and clear? If not, what changes should be made?

(2) Does the hierarchy operate effectively? If not, how could its operation be improved?

The DNF supports the following amendments to the "person responsible" hierarchy as modelled on Queensland's legislation:

- Responsibility should automatically pass to the next person in the hierarchy if the previous person is not readily available. [2]
- The public guardian should be empowered to resolve disputes between two eligible decision makers. [3]

Question 4.9: Supported decision-making for medical and dental treatment decisions

(1) Should NSW have a formal supported decision-making scheme for medical and dental treatment decisions?

The DNF believes the features of a formal supported decision-making model that we recommended in Question Paper 2 should apply to decisions regarding medial and dental treatments.[4] As highlighted above in relation to Question 2.1, we believe that while the support required may differ according to the type of decision being made, this should not affect the features of a framework applied.

Question 4.10: Consent for sterilisation

(1) Who, if anyone, should have the power to consent to sterilise a person?

(2) In what ways, if any, could the *Guardianship Act 1987* (NSW) better uphold the right of people without decision-making capacity to participate in a decision about sterilisation?

The DNF emphasises that sterilisation is an irreversible procedure that can have significant effects on a person's personal and social wellbeing. In addition, many people with disability are at significant risk of being sterilised for the convenience of others.

[2] *Powers of Attorney Act 1998* (Qld) s 63.
[3] *Guardianship and Administration Act 2000* (Qld) s 42(1).
[4] See DNF response Question Paper 2.

Accordingly, the DNF believes that if a person cannot consent to their sterilisation, only a Tribunal should be able to authorise the procedure.

Question 4.11: Preconditions for consent to sterilisation

What matters should the NSW Civil and Administrative Tribunal be satisfied of before making a decision about sterilisation?

The DNF supports the current considerations in the *Guardianship Act* with respect to authorising sterilisation. Currently the Tribunal must be satisfied that sterilisation is:

- the most appropriate form of treatment for promoting and maintaining the patient's health and wellbeing, and
- necessary to save the patient's life or prevent serious damage to the patient's health.[5]

We consider that these strict considerations are appropriate given the invasive and irreversible effects of sterilisation, which are likely to have a significant medical and emotional effect on the person.

To strengthen the first precondition, we support adding the additional requirement from Queensland legislation mandating that the Tribunal takes into account any alternative forms of health care, including other sterilisation procedures, which are available, or likely to become available.[6]

Question 4.12: Matters that should not be taken into account in sterilisation decisions

(1) Is there anything the NSW Civil and Administrative Tribunal should *not* take into account when deciding about sterilisation?

(2) Should these be stated expressly in the *Guardianship Act 1987* (NSW)?

As the result of a long history of low expectations of people with disability, the DNF considers it is important that the *Guardianship Act* specifically make reference to factors that should not be considered when authorising sterilisation. We endorse the factors recommended by the Senate Community Affairs Reference Committee report into Involuntary or Coerced Sterilisation of People with Disabilities in Australia*:*

- the risk of pregnancy as a result of sexual abuse, and
- assessments of the person's current or hypothetical capacity to care for children.[7]

[5]*Guardianship Act 1987* (NSW) s 44, s 45(2).
[6].*Guardianship and Administration Act 2000* (Qld) s 70(3)(a).
[7].Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) rec 5, rec 19.

Question 7.1: Problems with the regulation of restrictive practices

What are the problems with the regulation of restrictive practices in NSW and what problems are likely to arise in future regulation?

The DNF acknowledges the problems identified in the Question Paper in relation to the regulation of restrictive practices, namely that there is:

- no consistent approach to regulation;
- inadequate consent and authorisation requirements; and
- no independent body for monitoring and reporting.

Question 7.2: Restrictive practices regulation in NSW

(1) Should NSW pass legislation that explicitly deals with the use of restrictive practices?

To overcome the problems listed in Question 7.1, the DNF supports restrictive practices being explicitly regulated in the *Guardianship Act*. Regulation through legislation has the advantage of setting clear and consistent standards, and clarifying the circumstances in which a breech occurs.

Question 7.3: Who should be regulated?

Who should any NSW regulation of the use of restrictive practices apply to?

The DNF believes that while all services should be regulated, it would be inappropriate for a law governing restrictive practices to apply to informal carers who lack training and support to implement positive behaviour supports.

Question 7.4: Defining restrictive practices

How should restrictive practices be defined?

The DNF believes that a NSW law should adopt a definition of restrictive practices consistent with The National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector.

> **Seclusion**: the sole confinement of a person with disability in a room or physical space at any hour of the day or night where voluntary exit is prevented, impeded or not facilitated.
>
> **Chemical restraint:** the use of medication or chemical substance for the primary purpose of influencing a person's behaviour or movement. It does not include the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or physical condition.
>
> **Mechanical restraint:** the use of a device to prevent, restrict or subdue a person's movement for the primary purpose of influencing their behaviour. It does not include the use of devices for therapeutic or non-behavioural purposes. For example, it may include the use of a device to assist a person with functional activities as part of occupational therapy or to allow for safe transportation.
>
> **Physical restraint:** the sustained or prolonged use or action of physical force to prevent, restrict or subdue movement of a person's body, or a part of their body, for the primary purpose of influencing the person's behaviour. Physical restraint is distinct from the use

of a hands technique in a reflexive way to guide or redirect a person away from potential harm/injury, consistent with what could reasonably be considered the exercise of care towards a person.

Psycho-social restraints: usually involves the use of 'power-control' strategies.

Environmental restraints: restricts a person's free access to all parts of their environment.

Consequence driven practices: usually involve withdrawing activities or items.[8]

Question 7.5: When restrictive practices should be permitted

In what circumstances, if any, should restrictive practices be permitted?

Restrictive practices should be permitted in limited circumstances. In the long-term, the DNF emphasises that NSW should work towards the elimination of restrictive practices, as they may constitute cruel or degrading treatment contrary to Article 15 of the UNCRPD.

The DNF supports the criteria for restrictive practices identified in the NDIS Quality and Safeguarding Framework, namely that the intervention is the least restrictive response available, is used only as a last resort, and that the risk posed by the proposed intervention is in proportion to the risk of harm posed by the behaviour of concern.[9] In addition, the DNF supports the position of the NSW Council on Intellectual Disability that a restrictive practice:

- should only be permitted in the context of a positive behaviour support plan;
- should only be authorised by an independent official such as a senior practitioner or guardian who has been appointed for that purpose; and
- should be mandatorily reported.

Finally, the DNF supports the NSW Trustee and Guardian's submission that restrictive practices should only be used in exceptional circumstances, on a short-term basis, and when necessary to protect the person's safety and interests.[10]

Question 7.6: Consent and authorisation mechanisms

(1) Who should be able to consent to the use of restrictive practices?

As discussed above, the DNF believes that restrictive practices should only be authorised by an independent official such as the senior practitioner or a guardian appointed specifically for this purpose.

[8] Australian Government Department of Social Services, NDIS Quality and Safeguarding Framework (2016) 67 citing Australian Government Department of Social Services, National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service (2014) 4–5.

[9] NDIS Quality and Safeguarding Framework, p 76.

[10] *NSW Trustee and Guardian*, *Preliminary Submission PGA50*, 10.

However, if these procedures are not practicable given the large number of people subject to restrictive practices, it is important that rigorous processes are put in place to ensure persons authorising restrictive practices have a high level of competency in positive behaviour support.

(2) What factors should a decision-maker have to consider before authorising a restrictive practice?

The DNF endorses the following factors, taken from other jurisdictions, for a decision-maker to consider before authorising a restrictive practice:

- whether it is the least restrictive option or the last resort;[11]
- whether there is a behaviour support plan and whether the proposed restrictive practice is included in it;[12]
- the nature and degree of any significant risk associated with the restrictive practice;[13]
- whether the person will be safeguarded from abuse, exploitation and neglect; and
- in the case of seclusion, whether the person will be supplied with the necessary comforts such as adequate bedding, food, and toilet access.[14]

(3) What should be the mechanism for authorisation of restrictive practices in urgent situations?

The DNF endorses the adoption of the requirements with respect to restrictive practices in urgent situations in the Northern Territory and Victoria because the requirements impose tighter controls and hence greater safeguards.

Under the Northern Territory regime:

- the disability service provider must believe the restrictive practices are necessary because there is an imminent risk of the person causing serious physical harm to themselves or others;
- the restraint must be the least restrictive possible; and
- notice must immediately be given to the CEO of the residential facility in an approved form.[15]

Question 7.7: Safeguards for the use of restrictive practices

What safeguards should be in place to ensure the appropriate use of restrictive practices in NSW?

In accordance with Article 12 of the UNCRPD, it is important that restrictive practices are a proportional response to the behaviour of concern and applied for as short a time as possible. To ensure this occurs, the DNF recommends the following safeguards:

- any application to apply a restrictive practice must include an outline of what has been done to respond to the underlying cause of challenging behaviour and evidence that a plan to work with

[11].See, eg, *Disability Services Act 2006* (Qld) s 143(2)(c)(ii).
[12].See, eg, *Disability Services Act 2006* (Qld) s 43.
[13].See, eg, *Disability Services Act 2011* (Tas) s 43(2)(e), s 38(5)(e).
[14].See, eg, *Disability Services Act 2006* (Vic) s 140(d).
[15].*Disability Services Act* (NT) s 42(2).

the person to resolve unaddressed issues is in place for the period after any restrictive practice has been instituted; and
- restrictive practices must be authorised by an independent practitioner.

The DNF supports the proposal that a state register of restrictive practices be kept, outlining the restrictive practice, the reasons for the practice, the age of the person subject to the practice, and the facility that is administering the practice.[16]

As recommended in relation to the NDIS Quality and Safeguarding Framework,[17] the DNF supports the establishment of a system for mandatory reporting of restrictive practices based on the Restrictive Interventions Data System in Victoria. This system would need to be supported by a Senior Practitioner or equivalent with a skilled team of professionals who can collate and analyse the data; and carry out audits and reviews of concerning trends in relation to particular providers or particular individuals. The Senior Practitioner should also have a well-resourced power to conduct random audits and then work with providers to enhance their positive behaviour support and decisions in relation to restrictive practices.

Question 7.8: Requirements about the use of behaviour support plans

(1) Should the law include specific requirements about the use of behaviour support plans?

(2) If so, what should those requirements be?

The DNF strongly supports the *Guardianship Act* containing requirements about the use of behaviour support plans. The support plan should consider whether a less restrictive option is available and has been considered, as well as whether the person has been consulted about the use of the practice.

[16] See Question Paper [7.49].
[17] Disability Network Forum Submission to discussion paper on quality and safeguards in the National Disability Insurance Scheme.