



Council for
Intellectual Disability

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Preliminary submission on review of the Guardianship Act 1987

Contact

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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 is providing advice to the NDIA on supported and substitute decision making arrangements in the NDIS.

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

Focus of this submission

This preliminary submission focuses primarily on the central questions of models of supported and substitute decision-making including critiquing the recommendations of the Australian Law Reform Commission and the first legislative response of the Commonwealth to those submissions in the My Health Records Act 2012.

Models of supported and substitute decision making

The need for reform

NSWCID strongly supports the movement in recent decades towards maximum control by people with intellectual and other disabilities over their own lives. Far too often, decisions have been made for people with intellectual disability rather than people being offered any support that they need to make their own decisions. Where decisions have been made for people, too often they have been overprotective and not taken enough account of the person's views.

NSWCID has sought to be a role model on these issues in its own operations. In particular, our constitution requires that the majority of our board are people with intellectual disability and they are offered skilled support to assist them to carry out their responsibilities. For many years, our chairpeople have been people with intellectual disability.

Guardianship legislation such as the NSW Guardianship Act already acknowledges the importance of the individual's views and freedom but does need a major review to better reflect the importance of supported decision making and the rights in the UN Convention on the Rights of Persons with Disabilities.

Critique of ALRC proposals

The Australian Law Reform Commission (ALRC) has emphasised the importance of supported decision-making in its report, *Equality, Capacity and Disability in Commonwealth Laws*. The ALRC has also recommended moving away from the 'best interests' model for substitute decision making which has a paternalistic connotation and history.

NSWCID strongly supports the main thrust of the ALRC report. However, we also do have some concerns about the way the report deals with decision-making by people who, related to their disabilities, have the greatest difficulty in making their own decisions.

The ALRC recommended that

1. A representative decision maker could be appointed if a person lacks ability to make particular decisions. (Recommendations 3-2 and 3-4)
2. Even if someone has a representative, the representative would have to give effect to the person's 'will and preferences' unless it is necessary to override the person's views to prevent harm to the person or others. (Recommendation 3-3)
3. If it is impossible to work out what the person would want, or if acting on the person's views would cause harm, the representative would act to promote

the person's human rights and in the way least restrictive of those rights.
(Recommendation 3-3)

NSWCID strongly agrees that a person who has the ability to make a decision should never be prevented from making it.

However, if a person lacks that ability, we question whether the person's 'will and preferences' should always bind their representative. We are concerned about how this would work for a person who:

- has very narrow horizons and experiences to base their views on,
- is used to saying exactly what his mother says,
- says different things from hour to hour or week to week, perhaps depending on who she is talking to, and/or
- lacks insight into options and the consequences of decisions.

For example, a 30 year old woman with intellectual disability may have lived all her life with her caring but highly protective parents who have discouraged her from participating in social or vocational options away from the family home. She (and her parents) may be very clear that they do not wish to take up on opportunities of a broader life through the NDIS.

Some people with intellectual disability have extremely limited communication and ability to see options and consequences. You may be able to infer the person's wishes from their body language or from yes/no responses. However, for those wishes to be binding may deny the person access to opportunities for skills development, community participation and other options that would enhance the person's lifestyle and skills.

Particular challenges may arise for many people with autism whose limited information processing skills and wish for order, routine and predictability make them very reluctant to accept any changes in their lives.

A lot of thinking is occurring around the world in relation to what is meant by 'will and preferences' and whether these are just what the person is saying or should this expression be interpreted much more broadly. This thinking might address some of our concerns but it also might open up an area of great complexity where the values of the interpreter of will and preferences take centre stage, as is the case with 'best interests' now.

The ALRC did say a person's will and preferences would 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.

The ALRC said that, if it is impossible to decide what the person would want, or if acting on the person's views would cause harm, the representative would act to promote the person's human rights and in the way least restrictive of those rights.

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.

In our submission to the ALRC inquiry, NSWCID suggested that representative decisions should be made on a basis like that recommended by the Victorian Law Reform Commission in its 2012 report *Guardianship – Final Report*. The VLRC recommended that:

- A substitute decision maker could be appointed where a person has decision making incapacity in relation to particular decisions.
- Substitute decision makers be required to exercise their powers 'in a manner that promotes the personal and social wellbeing of the person'. This broad concept would be guided by a list of factors 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.

Where the ALRC speaks about the obligations that a representative should have, it does bring in the concept of acting to promote the person's 'personal, social, financial and cultural wellbeing' (Recommendation 4-8). If implemented, this may address some of our concerns.

First Commonwealth response to the ALRC proposals

The new section 7A of the My Health Records Act 2012 addresses various of the concerns we raise above. This is the first Commonwealth legislative response to the ALRC report.

The section is focused on the duties of an authorised representative for a person who lacks capacity to understand decisions about their electronic health record. The section basically says:

- Any authorised representative must make reasonable efforts to ascertain the person's will and preferences or likely will and preferences.
- The 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.
- Similarly, if likely will and preferences cannot be ascertained, the representative must again follow personal and social well-being.

This approach has much to be said for it. We see it 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.

Basis for decisions made under a supported decision making model and the relationship between this and substituted decision making

What we have said above is relevant to these questions. We also note that we have no fixed view on whether supported decision making should be regulated by legislation as opposed to development of good practice. We are inclined towards the latter.

We do suggest that any legislative test for when a Tribunal might appoint a substitute decision maker should include an element that maximum available supported decision making is not adequate to address the situation.

Relationship between guardianship law in NSW and developments at the federal level, especially the NDIS Act 2013

In our submission on the 2015 review of the National Disability Insurance Act, we recommended as follows

1. If a person cannot be supported to make NDIS decisions and substitute decision making is in fact needed, the NDIA should be required to appoint a nominee. This would bring in safeguards through the statutory obligations of the NDIA in choosing nominees and the statutory responsibilities of nominees.
2. If a guardian has been appointed by a state/territory tribunal with authority to make decisions about services, then that person should automatically be recognised as nominee. Similarly, if there is a nominee and a different person is appointed as guardian, the guardian should automatically take over as

nominee. We say this because guardianship tribunal hearings are a much more rigorous way than NDIA administrative processes to consider issues of capacity, need for a substitute decision maker and who is the most appropriate decision maker.

3. The Act should require the nominee and the NDIA to form and implement a plan to develop the participant's capacity to make their own decisions.
4. All appointments of nominees should be periodically reviewed.

Whether the 'disability' is the appropriate conceptual language

We favour an approach where a substitute decision maker could be appointed where a person has a relevant "decision-making incapacity" rather than the current focus on disability, need for supervision and social habilitation and incapability to managing person. The latter approach brings in irrelevant issues and the underpinning of disability is unnecessarily discriminatory.

Restrictive practices

There is a range of complexities in this issue including the interplay between any role for guardianship and Commonwealth and State legislation regulating funded disability services, licensed boarding houses, aged care facilities and mental health facilities. Our expertise is focused on intellectual disability services. The appendix is an extract from our submission to the National Consultation on Quality and Safeguards under the NDIS. That submission drew on our experience and discussion at the National Roundtable on Quality and Safeguards that we convened in 2015.

Key arguments from our submission in relation to the role of guardianship law are:

- Restrictive practices should only be permissible with approval from an independent person who could be a guardian or senior practitioner.
- There should be mandatory reporting of restrictive practices similarly to the Restrictive Interventions Data System in Victoria. A senior practitioner should monitor the data and conduct reviews and spot audits aimed at enhancement of providers' behaviour support and intervening where restrictive practices are being used inappropriately. This intervention could include applying for a guardianship order.
- To date, regulatory regimes have focused on restraint and seclusion. There are other restrictive practices such as monitoring devices and confining a person to their residence.
- There is no clear distinction between chemical restraint and treatment of a mental disorder as current regulatory regimes tend to assume.

Regular review of financial management orders

As a matter of principle and good practice, financial management orders should definitely be regularly reviewed just as guardianship orders are. This would need to be accompanied by a substantial boost in resources to ensure that the reviews were carried out properly.

Other matters

Tribunal reviews of appointments of enduring guardians

There should be greater consistency between the broad powers the Tribunal has when reviewing a power of attorney and the very narrow powers it currently has when reviewing an appointment of enduring guardian.

Decisions to make a guardianship order

Instead of the current regime, the Tribunal might appropriately need to be satisfied that:

- the person lacks capacity to make or implement relevant decisions,
- maximum available support with decision-making is not adequate to address the situation, and
- there is a need for a guardianship order.

A similar approach should apply to financial management orders.

APPENDIX

Extract from NSWCID submission

NDIS Quality & Safeguarding Framework

April 2015

Reducing and eliminating restrictive practices

Key Points

Workforce skills - The NDIA needs to develop a strong workforce of behaviour support practitioners who meet rigorous criteria for professional qualifications and competencies.

The NDIA needs to maintain the structures or at least roles of State/Territory regimes that underpin quality behaviour support.

Authorisation - Restrictive practices should only be allowable in the context of high quality behaviour assessment and support.

Any prescription of psychotropic medication to a person with intellectual disability should be made by a doctor with established competencies in intellectual disability mental health.

Restrictive practices should only be permissible with the authorisation of an independent official such as a senior practitioner or a guardian who has been appointed for that purpose.

If there are to be any situations where providers have the power to authorise restrictive practices, there need to rigorous safeguards in relation to the skills of the authoriser, independent monitoring and/or involvement in decisions, and review rights.

Monitoring and reporting - There should be mandatory reporting of restrictive practices similarly to the Restrictive Interventions Data System in Victoria. A senior practitioner should monitor the data and conduct reviews and spot audits aimed at enhancement of providers' behaviour support and intervening where restrictive practices are being used inappropriately.

Which restrictive practices? - The proposed framework is focused predominantly on restraint and seclusion. There are other restrictive practices such as monitoring devices, confining a person to their residence and apprehended violence orders. Further consideration is needed of which practices are covered by the NDIS framework and how.

Chemical restraint versus mental health treatment - This is not a clear distinction. The framework needs to include a focus on improving doctor skills in intellectual disability mental health and collaboration between doctors and behaviour support practitioners.

Authorisation

Questions

- Who should decide when restrictive practices can be used?
- What processes or systems might be needed to ensure decisions to use restrictive practices in a behaviour support plan are right for the person concerned?
- Are there safeguards that we should consider that have not been proposed in these options?
- For providers, what kinds of support are you receiving now from state and territory departments that you think would be helpful if it was available under the NDIS?

Existing authorisation and monitoring regimes for restrictive practices have been established in a context of often poorly funded and lowly skilled disability support. The NDIS should mean that these assumptions no longer apply so that restrictive practices will much less often be perceived as needed.

However, this evolution requires considerable development of the disability workforce both in quantity and quality (and ensuring that NDIS funding packages are adequate to pay for expertise in behaviour support).

One key need is a strong workforce of behaviour support practitioners. The NDIS should establish clear criteria for what professional qualifications and competencies are required to be a behaviour support practitioner and a workforce development plan to ensure that there is an adequate supply of practitioners. One of the required competencies should be in person centred active support.

The list of dot points under the heading *Our aim* in the proposed framework is a good starting point for the necessary requirements of quality and safeguarding in relation to restrictive practices.

However, the following additional points should be added:

- A restrictive practice should not be permissible in the absence of person centred active support and a comprehensive positive behaviour support plan.
- A behaviour support plan should always be informed by:
 - A review of the reasons for and function of the behaviour and

- A medical review by a doctor skilled in working with people with intellectual disability – is there is any physical or mental health contributor to the behaviour?
- Any prescription of psychotropic medication should be made by a doctor with specific competencies in the mental health of people with intellectual disability and as part of a collaborative decision-making approach with a behaviour support practitioner
- Where a person has complex challenging behaviour, multidisciplinary collaboration will often be vital including for example a speech pathologist, an occupational therapist and a psychiatrist. (NSWCID 2013)
- Any behaviour support plan including a restrictive practice should include a process for reducing and eliminating the use of the practice.
- Input of families and other advocates are important to development of behaviour support plans. However, it also needs to be taken into account that many families are not well informed or empowered in relation to behaviour support issues.

In principle, it is highly inappropriate for decisions about restrictive practices to be made by staff of a support provider, including if they have had the input of an independent professional chosen by the provider. There is a conflict of interest here. The only argument we can see against authorisation being required from an independent body or guardian is the extremely large number of people currently subject to restrictive practices in Australia.

In NSW, the combination of government policy and a role developed by the guardianship system means that physical and mechanical restraint and seclusion should only occur with the consent of a guardian specifically appointed for this purpose. The consent of the Tribunal is also specifically required for libido reducing dedications. The caseload is easily manageable.

However, the NSW system does not require consent of a guardian for chemical restraint which comprises the overwhelming majority of restrictive practices in Australia. Chemical restraint is the predominant reported restrictive practice in Victoria. 95% of those restricted are receiving chemical restraint. (Office of the Senior Practitioner 2011)

In NSW, whether psychotropic medication is characterised as being for chemical restraint or treatment of a mental disorder (itself not a clear distinction), consent is required from a “person responsible”. This is usually a closely involved family member unless a guardian has been appointed for medical consent purposes. The rigour of these consents as a safeguard varies greatly with how informed and confident family members are in dealing with these decisions.

In principle, our view is that restrictive practices should only occur with authorisation from either an independent official such as a senior practitioner or consent of a guardian appointed for this purpose. However, we do recognise the challenge of the numbers involved here and are concerned that a requirement for such approvals would create a workload that could not be met with any sort of quality in decision-making.

If there are to be some situations where people within service providers are authorised to approve restrictive practices, there are at least need to be very rigorous independent processes for deciding whether a person has the high levels of competencies in positive behaviour support to be so authorised.

An alternative approach would be to broaden the approval process to a panel which also includes an independent duly qualified professional and an independent advocate experienced in behaviour support.

In any case, there should be safeguards including a capacity for independent review and overturning of authorisations of restrictive practices and/or a backstop that, if a guardian has been appointed with a relevant decision-making function, then that guardian's consent is also required for the use of the restrictive practice. At present, at least in NSW, the quality of behaviour support around the state is highly dependent on a range of structures, multidisciplinary skills and expertise within ADHC, the State government disability services agency. Also, ADHC has funded two chairs at UNSW that are playing extremely valuable roles in enhancing behaviour support and the related issue of intellectual disability mental health. With the NSW government being committed to cease being a disability service provider, the NDIS needs to ensure that there is very robust similar system created outside the state government structures. We see maintenance of the UNSW chairs as a vital part of this.

Monitoring and reporting

Questions

- Would you support mandatory reporting on the use of restrictive practices? Why/Why not?
- If you support mandatory reporting on the use of restrictive practices, what level of reporting do you believe should occur?

We support 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.

This system should extend to a capacity to require independent approval of restrictive practices for some individuals either by the Senior Practitioner or via a guardianship application.

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.

Part of the role of a community visitor scheme should also be to identify situations where restrictive practices are being used inappropriately or without authorisation and to report this to the Senior Practitioner.

Other key issues

What about other restrictive practices?

The National Framework on restrictive practices and the Proposed Quality and Safeguarding Framework focus predominantly on restraint (physical, mechanical or chemical) and seclusion. There is a range of other restrictive practices used to address challenging behaviour including:

- confining a person to their home, in some cases by having the doors locked whenever the person is at home
- restricted access to spaces within the person's home or to items belonging to the household or the person
- monitoring devices.

Confining a person to their home without legal authority via guardianship or other specific legislation may amount to false imprisonment. Restricting a person's access to their own chattels may be unlawful as "detinue".

Further consideration is needed of which restrictive practices are covered in an NDIS regime and how, and issues of interplay with existing State/Territory legislation such as the Disability Act Vic Part 8.

The distinction between chemical restraint and mental health treatment

There is not a clear distinction between 'chemical restraint' and use of psychotropic medication to address a mental disorder (NSWCID 2013):

- Mental disorders are very hard to diagnose in a person with intellectual disability and limited verbal communication.
- There are very limited skills in intellectual disability mental health in GPs and psychiatrists.
- The distinction can be in the eye of the beholder. What one doctor may call chemical restraint, another may call treatment for anxiety.
- Because the distinction is unclear, it is open to abuse.
- There can be pressure on doctors to specify a mental disorder diagnosis so that medication is available under the PBS.

Therefore, the quality and safeguards framework should include a focus on all prescription of psychotropic medication to people with intellectual disability rather than just on what a doctor characterises as chemical restraint. This should include a focus on:

- Doctor skills
- Cross disciplinary collaboration between behaviour practitioners, doctors and other relevant professionals.
- The general need for a positive behaviour program whenever psychotropic medication is used, not just when it is characterised as chemical restraint.

The role of the Senior Practitioner or equivalent should include proactive systemic action to improve decision-making by doctors in relation to psychotropic medications for people with disability and the capacity to seek appointment of a guardian for medical decisions where appropriate.