NSW Council for
Intellectual Disability

Submission on Discussion Paper-Equality, Capacity and Disability in Commonwealth Laws

NSW CID is the peak body representing the rights and interests of people with intellectual disability in New South Wales. The Council is a membership based organisation and engages widely with its members and key stakeholders.

The Council is founded on the centrality of the voice of people with intellectual disability in decisions that affect them. This is reflected in our governance structure. Our constitution requires that the majority of our board be people with intellectual disability and for many years, successive chairpersons have been people with intellectual disability. We have structures for independent support of people with intellectual disability to assist them to exercise their duties as board members.

The Council has considerable expertise in policy development including on issues related to decision making. NSW CID has prepared two submissions for this inquiry.

The first has been prepared by NSW CID Senior Advocate and this explores in detail some of the technical aspects of paper and takes a broad view of the experience of intellectual disability. This includes a wide variety of life circumstances and experiences that will impact on people's capacity to be involved in decision making.

The second has been prepared by the Speak Out Reach Out Committee (SORO) which is convened by NSW CID and whose membership is all people with intellectual disability have prepared a response. This has a particular emphasis on decision making and reflects the experiences of the Committee's Members.

Please feel free to contact NSW CID should you like any further information.

Aine Healy
Executive Director Advocacy

P: 02 9211 1611
E: aine@nswcid.org.au
W: www.nswcid.org.au

Jim Simpson
Senior Advocate

P: 02 93455504
E: jcsimpson@optusnet.com.au

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Submission 1

Introductory comments

This submission is particularly focused on people with intellectual disability. However, a high proportion of it has broader relevance.

NSW CID is very concerned that the inquiry does not appear to have submissions from groups with a specific focus on people with dementia, in particular Alzheimer's Australia. These groups do not necessarily identify with 'disability' issues and, so far as we know, were not active participants in the development of the UNCRPD.

There are approximately 400,000 people with intellectual disability in Australia and approximately 250,000 people with dementia. These groups stand to be particularly affected by the Commission's proposed decision making system

NSW CID is very supportive of much of the thinking in the discussion paper. We are highly supportive of an approach that maximises the circumstances in which a person with disability can control his or her own life, with such decision making support as the person needs.

However, we provide the following comments which, in some important respects, disagree with the approach in the discussion paper.

Supported decision making hour by hour, day by day

The submissions of the Speak Out Reach Out Committee of NSW CID on the ALRC Issues Paper and Discussion Paper contain considerable guidance on how people with intellectual disability can learn how to make decisions and be supported to make decisions. Speak Out Reach Out is a group of people with intellectual disability.

NSW CID is very cautious about over regulation of supported decision-making. We see provision of support for decision-making as primarily an issue of good practice that should be developed and promoted. People with intellectual disability will often need support with decisions hour by hour and day by day, not just in relation to major or formal decisions. A person may need support in relation to what time to get up, when to shower, what clothes to wear, what to eat for breakfast and so on through the day. Families, disability workers, staff in mainstream government agencies and others in the community should be given guidance, education and encouragement to provide support to people with intellectual disability on this hour by hour basis.

In some situations, however, there does need to be scope for a supporter or representative to be appointed who then has authority to assist the person in dealing with particular agencies or kinds of decisions.

Need for an accessible and simple system for decision making

Any decision making system needs to be accessible to people with disability and their informal supports. This requires that the system generally:

- Is easy to understand and use.
- Avoids undue formality and 'red tape'.

Otherwise, people with intellectual disability and, to a lesser but significant degree, their families and other informal supports, will find the system confusing and too difficult to use.

Also, if the system is not easy to understand and use, service agencies and health professionals will tend to either ignore the system or deny access to services to people with disability. For example, doctors are much less likely to embrace the system of eHealth records with their patients who have intellectual disability if the system for supported or representative decision making is complex. Similarly, complex decision making systems can unduly delay important exchange of information in relation to a person so that the person suffers detriment.

The proposed will, preferences and rights regime

(Proposal 3-5, 3-6, 3-9, 4-8)

We question whether the discussion paper elevates will, preferences and rights too high.

The proposals say that decisions should be determined by a person's will and preferences (actual or likely) unless this will cause harm to the person. This includes people who lack legal capacity (as defined in Proposal 3-7) for the relevant decision.

We agree that, if a person has legal capacity for a decision, their actual wishes should be binding. However, where a person lacks that capacity, their wishes may be unduly influenced by their circumstances, for example a narrow and protective life experience, and they may lack the ability to recognise and weigh up life 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 National Disability Insurance Scheme. In existing legal structures, an application for guardianship would be an avenue to address this situation. Under the regime in the discussion paper, the woman’s wishes would appear to be final.

The discussion paper does suggest that a person’s wishes might not be determinative if they are likely to cause harm to the person. However, ‘harm’ would need to be very broadly defined to encompass the above scenario.

Further, in relation to harm such as risks of abuse, it may be very difficult to prove that a decision is likely to cause harm. If there is to be a test based on harm it may be better to express it in terms of an ‘unacceptable risk of harm’. This would allow the situation to be weighed up on the basis of evidence of risk rather than whether there is clear evidence of actual harm. For example, a resident of a boarding house may insist to Centrelink that he wants his pension paid to the manager despite there being grounds for concern that the manager may misuse the pension.

We need to stress that 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 determinative may deny the person access to opportunities for skills development, community participation and other options that would enhance the person’s lifestyle and skills.

We also question whether human rights is an adequate basis for decisions where a person’s will and preferences cannot be ascertained. Proposal 3-6 is to this effect though Proposal 4-8 is expressed less definitely.

We all make decisions about our lives based on much more than consideration of our human rights. For example, our decisions quite reasonably may be influenced by our important relationships, by the views of those we trust 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. Further, 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 view of all of the above factors, we favour representative decisions being made on a basis such as that recommended by the Victorian Law Reform Commission (Guardianship – Final Report Chapters 12 and 17). The VLRC recommended that:

- A substitute decision maker be able to 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 relevant 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.

In taking this position, we note that Article 12 of the CRPD says that measures relating to the exercise of legal capacity must 'respect the rights, will and preferences of the person'. The word respect is softer than the word 'direct' used in Proposal 3-5.

Safeguards and supporters

(Question 4-4)

We agree with the caution expressed at 4.59 that substantial regulation of supporters would unduly interfere with the relationship between person and supporter. However, there needs to be some process for informing supporters of their responsibilities and to seek intervention by a tribunal if a supporter is not fulfilling their responsibilities to a person who lacks decision making capacity – this may entail an application to have a representative appointed as occurs now with applications for guardianship.

Mechanisms to appoint a representative

(Proposals 4-6, Question 4-5)

These mechanisms should be proportionate to the situation. For example, there should be a straightforward process for a close family member to become representative of a person for processes like Centrelink and eHeath records. Also, there are arguments for consolidating these processes so that there was one process for seeking to be representative for all relevant Commonwealth processes, eg Centrelink, Medicare, eHealth and financial assistance with insanitary pads.

NSW CID has recently had input to the development of a system of "authorised representatives" under the Personally Controlled Electronic Health Records Act 2012. Our approach was that, so far as possible, people with intellectual disability should be supported to make their own decisions in relation to the creation of and access to their e-Health record. Where maximum support proved inadequate, there needed to be a system of authorised representatives. This system needed to strike a balance between safeguards on the privacy and related rights of the person and allowing an authorised representative to be appointed without undue administrative complexity. If it was unduly time-consuming or complex to create an authorised representative for an individual, the strong likelihood would be that families and doctors would be deterred from taking this course and the person with disability would be denied the considerable advantages to their health of having an e-Health record. We see the authorised representative system that was established by the Department of Health as a useful attempt to achieve this balance. See the PCEHR Act sections 6 and 7 and policies made to give effect to those sections.

On the other hand, there will be situations where the enormity or contentiousness of the situation or the alleged inappropriateness of a proposed representative means that the issue of whether there should be a representative and who that should be needs to be determined by a tribunal analogously to guardianship proceedings in the current state and territory tribunals.

National consistency and symbiosis

(Question 4-6)

There will be great confusion and major detriment to people with disabilities if the Commonwealth creates a new system that is very different to the long established substitute decision making systems that exist in states and territories.

Those systems need updating and the ALRC report can hopefully be a pathfinder for this. A national approach is highly desirable that involves a high degree of consistency and symbiosis between State/Territory and Commonwealth approaches.

Submission 2

About us

This letter is from the Speak Out Reach Out Committee (SORO).

We do a lot of work on the big issues.

We talk about our own lives.

We ask other people about their lives too.

SORO decided to meet again to talk about the ALRC paper.

It's important to take part in this process.

We did not have time to think about all the issues. So we have stuck to areas we covered in our last submission.

Changing ideas

We are very happy that ideas about capacity are changing.

'Capacity' to 'Ability'

SORO agrees that there is more to it than the idea of capacity or incapacity. Everyone needs some kind of support in decision making. Just like all people, we are somewhere on a spectrum of need for support.

How supporters or representatives think and act.

SORO liked the words 'supporters' and 'representatives'. But the words were not nearly as important to them as how supporters and representatives might think and behave.

Choosing your supporters/representatives

Choosing and being able to change supporters when you want to is good. But we think there is more to it. We looked at why we felt uneasy about how this could work:

“How do you find the right person, so they listen to you and take action? They might mean well but take action in the wrong way, Can you tell them? Negotiate with them?”

A supporter, in this case a family member “might make a decision without talking to the person. How do you make sure the person is part of the process, and knows about it?”

Services as supporters might have “vested interests. Conflicts of interest”.

‘What happens if you pick the wrong person? What if another one is not available?”

“It will be hard to find supporters in the new system. People change positions and don’t tell you about it”

> “The (right) choice of interpreters is very important here”, meaning that for people with communication support needs, and particularly people who also primarily communicate in a language other than English, will be very vulnerable to having their will and preferences misinterpreted.

What you want (your will) over what someone thinks is best for you (best interests)

We like this idea a lot. But we still want to make sure that supporters and representatives really do their homework!

Expectations of good support or good representation included:

> “be there to *help* you, not make the decision for you”

> “make sure you get the right information”

> “should know (understand) what you *can* do with the right planning and support” (in this case, become parents)

> “look around at other people with intellectual disability who have children and support, so they can see it can work”

When it is hard to know what someone wants

How will representatives “know if they are making the right decision for the person?”

“look into it properly

“use the right communication”

ask “the right people” for their views on it,
who are going to be “truthful”.

People who have complex problems

SORO knows there are people who can be in a lot of trouble.

They might be

- excluded
- isolated,
- abused,
- neglected
- exploited.

They thought about a case-study of people in an unsafe boarding house. It was a very bad place to live. There was no hope of it getting better. Advocates could see that their human rights were being squashed. But some people did not want to leave

These people were given a substitute decision maker. That way a guardian could say they must move to a safer place.

They also thought about people being kept away from others, by a family or other group. They might be doing things like stealing from them or abusing them, or not caring for them properly. They might not want to leave.
Should their right to decide be taken away so they could be safe?

SORO talked about why people were saying they wanted to stay in their situation:

- “They had been there a long time”
- “They had ‘got used to it’”
- “They were frightened of change”
- “They were frightened of backlash”
- “They had not been allowed to do their own thing” (so going to another situation in which they did not feel they could understand or cope with may have been too daunting)
- “They might have been lied to (in the past), and told there was nowhere else to go. Or nowhere better”
- “They might have hoped someone nice would take over” or
- “They hoped the (abusive) person would be dealt with” (so they could stay in what they considered home)
- “They might not want to be separated from friends”

The right to be safe

SORO thought there should be a way for people to help you to safety. Even if you said no.

Representative to ‘Super-representative’?

Should a representative sometimes have extra strong responsibilities?
SORO said there should be someone who can make sure that you get help when you can’t see your rights, or take action.

Staying part of the decisions

If someone has to take action to get you to safety, they must keep you in the decision making steps. You should be involved in discussions and decisions about what is happening, both through the change and after.

They should - "keep me involved in all the decisions, even if I don't agree with the decision made".

Conflict of interest is a big issue

We saw that families, carers and services can feel challenged by what we want and decide. They might stop us for their own reasons.
We have had experience of this.

Good training about supporting and representing

We said people need good training in

- understanding conflict of interest
- in problem-solving so that you can still have your right to decide about your own life respected.

Some good skills are

- Stepping back, being objective
- Getting a good knowledge of a person's issues
- Learning how to understand you
- Working with a complex situation
- Seeing when there is a conflict of interest
- Knowing what to do
- Understanding the difference between your informed decision and their idea of your best interests.

Training for people with intellectual disability

We should get training and to get better at making our own decisions, so we

- Might not need as much support in the future.
- Make more of our own decisions in the future.

Training for community and services

The rest of the community must learn that we have the have the right to make our own decisions. Some places that could learn more are:

- Centrelink
- Doctors and hospital staff
- TAFE and Community colleges
- Supported employment agencies

Thank you for the chance to say some more about this important work.

The Speak Out Reach Our Committee