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EQUALITY, CAPACITY AND DISABILITY IN COMMONWEALTH LAWS

About NCOSS

The Council of Social Service of NSW (NCOSS) is the peak body for the non-government human services sector in NSW. Through its organisational membership, NCOSS represents a vast network of service delivery and consumer groups. NCOSS has a vision of a society where there is social and economic equity, based on cooperation, participation, sustainability and respect. We work with our members, the NSW Government and other relevant agencies, towards achieving this vision in New South Wales.

Introduction

Thank you for the opportunity to provide feedback on the Issues Paper 'Equality, Capacity and Disability in Commonwealth Laws' by the Australian Law Reform Commission (ALRC) as part of its Inquiry into legal barriers for people with disability. NCOSS has drawn on its networks and previous submissions for feedback to this consultation. This submission provides a list of relevant issues with short explanations for further investigation by the ALRC.

At the very welcome presentation to the October meeting of the NSW Disability Network Forum, Professor Rosalind Croucher of the ALRC invited feedback and comment on law and regulation at all levels of government. Accordingly, NCOSS has not confined feedback to Commonwealth legislation and has included NSW law and regulations with possible implications at the federal level.

Our feedback references the Shadow Report to the United Nations Review of Australia's Performance against the Convention on the Rights of Persons with Disabilities (UNCRPD). The Shadow Report can be obtained at <http://www.disabilityrightsnow.org.au/node/65>. This Report to the UN details Australia's performance against the articles in the UNCRPD from the viewpoint of non-government representative organisations, many providing the voice of people with disability.

At this point in time, NCOSS feedback on the Issues Paper is high level, highlighting and summarizing key issues that would benefit from further consideration and investigation by ALRC. We also suggest some key subject matter experts whose views it would be worthwhile seeking on specific issues. NCOSS looks forward to providing more detailed feedback to the next consultation process in mid-2014.

OVERALL Comments

Not attitude but behaviour change

NCOSS is aware that legislation may, by itself, not change attitudes but can contribute to behavioural change. For many years, people with disability have been working towards acceptance and inclusion. While some gains have been made, overall progress has been unacceptably slow. It is extremely important to raise the bar for access, inclusion and participation with and for people with disability in all aspects of a person's life.

While the NDIS can support a person to operate more capably in their community and environment, that community and environment must be ready, willing and obligated to accept and treat that person with disability like any other person. The laws of the land must support this obligation.

NCOSS therefore recommends that the ALRC uses the NDIS principles of choice and control, participation and inclusion of people with disability as a guide to the amendment and upgrading of Commonwealth laws.

The issue of Safeguards

The provision of safeguards against exploitation and danger is necessary in any legislation, including where it focuses on vulnerable people. However, NCOSS is aware of the potential for the provision of safeguards to be used, under the guise of 'protecting' people with disability, as a means of supporting and maintaining discriminatory and non-inclusive practices.

Rather than the application of safeguards in extreme or unusual circumstances only, in some services and programs there has been a tendency to use safeguards in everyday circumstances and as regular practice. This has sometimes served to limit the opportunities of people with disability, to deny them the freedoms and risks that others enjoy and to exclude their participation in decisions affecting them.

Again, we recommend that the ALRC consider the provision of necessary safeguards so as to uphold the principles of principles of choice and control, participation and inclusion of people with disability.

SPECIFIC Comments

Legal capacity of the person with disability

NCOSS contends that the person with disability should always be deemed to have capacity in the first instance. In a submission to the NDIS draft Rules, NCOSS gave this feedback in relation to personal decision-making capacity of the person with disability:

NCOSS recommends that the CEO assumes that the person (and their family and/or chosen supporters) has capacity for self-management in the first instance. The Rules should stipulate the assumption of capacity unless there is a reason not to assume capacity for self-

management. Reasons could include personal choice and recent history. Reasons must be determined on an individual basis, never by a class of people or by groups or stereotypes.

NCOSS Submission to the NDIS Rules March 2013

Regarding the capacity to make decisions on preferences in life, support priorities, etc. a person with disability must always in the first instance be assumed to have capacity. Determinations about capacity must be made not only on a person-by-person basis, but also about every separate decision for each person, because people may have different capacity to make different decisions at different times.

Further, in its submission on the NDIS Bill, the NSW Disability Network Forum [the Forum] said:

Regarding the participation of people in decisions and their plans, the Forum has received some intense wisdom regarding a tendency by some over-zealous or prejudiced decision-makers to make assumptions about groups or classes of people with disability automatically considered unable to make or even be involved in their own decisions and plans. In keeping with the Objects and Principles of the NDIS (sections 3 and 4), the Forum strongly recommends that every person using the NDIS should be individually approached and no automatic assumptions should apply, based on stereotypes of level or type of disability, geographical or living circumstances, cultural identity or any other general characteristic or grouping.

NSW Disability Network Forum Submission to the National Disability Insurance Scheme Bill 2012

In its submission to the Review of Lifetime Care and Support Scheme, NCOSS said:

The National Disability Insurance Scheme legislation clearly identifies that the first assumption regarding decision-making by a person with disability is that the person has capacity to make decisions. For people requiring assistance with decisions, supported decision-making processes should be used. NCOSS has received feedback that substitute decision-making may not always produce the best outcomes for the person with disability and in some instances may not even involve them or may become an unnecessary default position. The use of this process should be regularly reviewed. Further, NCOSS recommends that LTCSA [Lifetime Care and Support Authority] undertake research into the role and appropriate use of substitute decision-making to ensure best practice.

NCOSS Submission to the Review of the Exercise of the Functions of the Lifetime Care and Support Authority October 2013

Privacy and Information of people with disability under the NDIS

The NDIS (Protection and Disclosure of information) Rules Part 1 states:

- 1.2 The Rules deal with the circumstances in which a State or Territory law may prevent the disclosure of information or a document by a person to the Agency, and the ability of the CEO of the Agency to disclose information in the public interest or to a Commonwealth, State or Territory Department or authority.
- 1.3 The Act sets out a number of principles for the NDIS. The following are particularly relevant to these Rules:
 - (a) people with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation;

- (b) people with disability should have their privacy and dignity respected.

However, NCOSS has advocated on the protection of information and personal details to be held by the Agency and distributed by the CEO. The NDIS Rules deal primarily with administration issues and the protection of the CEO and Government authorities in the handling and distribution of information. The Rules do not specifically deal with the consent of the people about whom the information is collected. There are two forms of information to be held by the NDIS Agency:

- a. Eligibility assessment information
- b. Individual plans, in the form of two parts:
 - i. Dreams, aspirations, strengths, family circumstances and supports, interests and lifestyle etc. (belonging to the person with disability but held on record by the Agency)
 - ii. Goals and funded supports (held and approved by the Agency)

NCOSS, in a submission to the consultation when the Rules were in draft form, stated:

Further to this, there should be no release of individual information without the express consent of the person or their nominee in every instance.

Participants own their own plans

Participant's plans will contain substantial amounts of very private information about the person with disability and the significant people in their lives. The Agency will hold and be responsible for, the security of important personal information of many thousands of people. It is very likely that service providers will require information from participants in order to deliver appropriate supports, despite information held by the Agency. The best way to overcome repetition is for participants to own, hold and be in control of their information. In this way, participants (or their nominees or chosen supporters) can use, amend, show and filter information for specific purposes to specific targets as they require it.

NCOSS Submission to the NDIS Rules March 2013

Further,

Section 60 (1) and subsequent sections [i.e. sections on privacy and disclosure of information] refer to a "person" not defined in this Bill. The NSW Disability Network Forum is concerned that, while this may appear to be superficially reasonable, the person could have access to participants' plans and other private details. Participants' plans will contain personal details about the individual person with disability, their hopes and dreams, details about their family and significant relationships and their local community. As well, the Plan could describe when the participant will be present or absent at their home, their regular movements and those of others in their immediate vicinity. With access to this kind of information, it would conceivably be possible for a person to build an identity profile of a participant or other significant person for improper purposes. It is therefore unacceptable to allow access in this Bill to persons not specifically defined.

NSW Disability Network Forum Submission to the National Disability Insurance Scheme Bill 2012

Note: the term *participant* here refers to a person who has been approved for a funding allocation under the NDIS.

Independent Advocacy and Information

NCOSS promotes the importance of independent advocacy and information alongside choice and control for people with disability. The provision of timely, non-aligned, free-of-charge independent

information and advocacy to support people with disability and their families at critical times could mean the difference between effective supports with quality life outcomes, compared to lack of support, having to 'make do', unnecessary dependence on others and undue stress.

NCOSS contends this to be an essential part of the supports to people with disability in all aspects of their lives, not specifically just for the NDIS. Accordingly, the NSW Disability Network Forum has developed a Position Paper which sets out the importance of independent advocacy and information to people with disability in every day life as well as in their personal supports. The Position Paper also includes a series of useful advocacy and information stories. NCOSS strongly commends this Position Paper to the ALRC:

<http://www.ncoss.org.au/resources/DNF/forum/120903-NSW-DNF-Submission-to-the-Ability-Links-NSW-Taskforce.pdf>

Complaints and appeals mechanisms

NCOSS is aware that many people with disability who will access the NDIS will also rely on the disability support pension as their major source of income. Therefore they may not be in a position to pursue a complaint using legal means should this be warranted. The COSS Network is the joint Network of the Councils of Social Services from across Australia. In its submission to the NDIS Bill the COSS Network said:

The COSS Network notes the review mechanism and appeals processes outlined in the [NDIS] Bill. It is also noted that the Bill provides that the NDIS Launch Transition Agency will not provide funding for the purposes of seeking a review under the Act. The COSS Network would stress the importance of facilitating adequate legal advice and support for people who may wish to question a decision especially during the first stage of the NDIS. Government needs to consider how to support access to timely and appropriate independent advice on such matters. This will ensure transparency and equity in the early stages of the Scheme and provide important lessons for its ongoing development.

COSS Network Submission to the NDIS Bill 2013

Health

NCOSS has anecdotal evidence of instances where people with disability have been treated differently from those without disability by the health system. In many cases these have involved value/moral/prejudicial judgments by the treating health professional, which are often 'dressed up' as medical decisions. While viability of life decisions are the realm of the health professional, quality of life decisions belong to the person. NCOSS commends the Health section in the UNCRPD Shadow Report and case studies to the ALRC as an example.

Another concern is the access to certain health treatments; for example, medically necessary organ transplants if a person has a disability. Anecdotal reports to NCOSS suggest there is widely varying practice in this regard despite no clear policy or regulation known to NCOSS excluding people with disability.

Voting and electoral issues for people with disability

As part of the NSW Electoral Commission Reference Group, NCOSS has advised on inequities of voting access and practice for people with disability in NSW. This has contributed to the NSW Electoral Commission initiating amendments to NSW legislation to enable:

- persons with disability to apply for a postal vote (previously ineligible)
- persons with disability to register as a general postal voter
- persons with disability to apply for a pre-poll vote
- taking a poll at a declared institution
- procedure for voting at a declared institution
- technology-assisted voting. [*iVote* was available in the 2011 State Election to eligible persons with disability. This is not yet available for Commonwealth or local government elections.]

NCOSS recommends that the Commonwealth standardize access and practice in all elections at every level of government to the most inclusive available extent.

This means, on a continuous improvement basis:

- addressing the long-term discrimination in voting for people with disability in elections,
- determining and implementing optimal access for voters with disability, and
- encouraging people with disability to register and to exercise their right and responsibility to vote.

NSW Anti-Discrimination Board

NCOSS is familiar with the ADB's complaints data in relation to disability. In recent ADB annual statistics, complaints and matters relating to disability rated very highly in discrimination issues.

In the 2011-12 ADB Annual Report, NCOSS notes that the highest number of discrimination enquiries, around 19.9%, were on disability matters, particularly employment and goods and services, then education and accommodation. NCOSS also understands that many people with disability may not have the means to make complaints and that some people with high support needs, physical disability, as well as some people with intellectual or cognitive disability and/or brain injuries, may not be able to exercise their rights to make complaints to the ADB without support.

NCOSS strongly recommends that the ALRC follows up with the following key subject matter experts in relation to equal recognition of people with disability under the law:

1. NSW Anti-Discrimination Board
2. NSW Fair Trading
3. NSW Office of Public Guardian and Trustee as well as the Guardianship Tribunal

Justice system

NCOSS recommends that the ALRC contacts the following subject matter experts for more detailed feedback on recommendations regarding people with disability in contact with the Justice system:

- Professor Eileen Baldry, Deputy Dean, School of Social Sciences, University of NSW,
email: e.baldry@unsw.edu.au ph. 02 9385 1878

- Aboriginal Disability Network email: enquiries@adnsw.org.au ph. 02 8399 0881
- People with Disabilities Australia email: pwd@pwd.org.au ph.02 9370 3100
- NSW Council of Intellectual Disability, Aine Healy & Jim Simpson email: info@nswcid.org.au ph. 02 9211 1611

Conclusion

NCOSS appreciates the opportunity to provide input to the review of the Equality, Capacity and Disability in Commonwealth Laws by the Australian Law Reform Commission.

If you require any further information or clarification, please contact NCOSS, Christine Regan at chris@ncoss.org.au ph. 02 92112599 ext. 117.

Yours sincerely



Alison Peters
Chief Executive Officer