

Equality, Capacity and Disability in Commonwealth Laws Issues Paper

Submission

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Introduction

Children with Disability Australia welcomes the opportunity to respond to the Australian Law Reform Commissions (ALRC) Issues Paper, Equity, Capacity and Disability in Commonwealth Laws.

Background

Children with Disability Australia (CDA) is the national peak body that represents children and young people with disability, aged 0-25 years. The organisation is primarily funded through the Department of Social Services (DSS) and is a not for profit organisation. Additional project funding is also currently received by the Department of Education. CDA has a national membership of 5000 with the majority being families.

CDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CDA's purpose is to advocate systemically at the national level for the rights and interests of children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

- **Education** of national public policy-makers and the broader community about the needs of children and young people with disability.
- **Advocacy** on behalf of children and young people with disability to ensure the best possible support and services are available from government and the community.
- **Inform** children and young people with disability, families and care givers about their rights and entitlements to services and support.
- **Celebrate** the successes and achievements of children and young people with disability.

There are numerous issues that CDA would like the ALRC to consider following the release of the issue paper, which are outlined below.

One overarching comment is for the United Nations Convention on the Rights of the Child should provide the foundation for the inquiry when examining how all the facets raised in the issues paper have relevance to children.

United Nations Convention on the Rights of Persons with Disabilities

Question 1. Australia has an Interpretative Declaration in relation to Article 12 of the United Nations Convention on the Rights of Persons with Disabilities.

The Interpretative Declaration supports the existence of the Migration Health Test, which essentially allows discrimination on the basis of disability in this context. This is contrary to a recommendation of the United Nations Committee on the Rights of Persons with Disabilities in October 2013 that Australia “review its interpretative declarations ... with a view to withdrawing them.” Families have contacted CDA where residency and citizenship have been denied because their child has a disability. It is the opinion of CDA this is incongruous with all aspects of legislation and policy reform which are based on a rights based model of disability which divorces itself from a ‘deficit’ model of disability.

National Disability Strategy 2010–2020

Question 2. What changes, if any, should be made to the National Disability Strategy 2010–2020 to ensure equal recognition of people with disability before the law and their ability to exercise legal capacity?

CDA is pleased with the current areas for future action contained with the National Disability Strategy’s Chapter 2, Rights protection, justice and legislation. However, in order for the Strategy to be useful it must be measured. Currently the only indicator for this chapter is the number of complaints received by the Australian Human Rights Commission, which does little to measure the majority of the future actions. CDA recommends that other existing or new data sets are established to measure the reach and effect that the National Disability Strategy is having.

Framing principles

Question 3. The ALRC has identified as framing principles: dignity; equality; autonomy; inclusion and participation; and accountability. Are there other key principles that should inform the ALRC’s work in this area?

CDA believes that it may be advantageous to include ‘citizenship’ as a principle. This principle involves consideration of responsibilities and active participation within community life whereas the other principles reflect more the rights and legal protections of people with disability.

The role of family, carers and supporters

Question 5. How should the role of family members, carers and others in supporting people with disability to exercise legal capacity be recognised by Commonwealth laws and legal frameworks?

CDA believes the role of families, carers and other supporting people should hold

consistent and enduring regard in the eyes of all legal structures.

Anti-discrimination law

Question 6. What issues arise in relation to Commonwealth anti-discrimination law that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to the Disability Discrimination Act 1992 (Cth) to address these issues?

As it currently stands only individuals or their endorsed legal representatives can take action under the Disability Discrimination Act 1992 (Cth). Whilst this is an effective process for rectifying individual complaints and situations it has the ability to exclude broader complaints being brought forward in the interest of systemic advocacy. CDA believes there would be merit in allowing representative organisations to bring forward complaints to the AHRC, this also has the ability to save the AHRC resources if there are many similar individual cases.

Privacy

Question 11. What issues arise in relation to privacy that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to privacy to address these issues?

There are a number of concerns that CDA has with the privacy and protection of personal information of children and youth with disability. The main overarching issues relate to the provision, accessibility and sharing of confidential information.

It is of concern to CDA that access to services and supports is often conditional on participants signing very “loose” formal consent agreements which don’t articulate what specific information will be shared and the purpose or context for doing this. Examples include the NDIS (see below for more details), education settings, funding programs and disability services.

It is CDA’s opinion that the NDIS greatly compromises the rights and protections to privacy, which are afforded to children and young people with disability. In order to gain access to the NDIS and subsequently receive services through the NDIS a large amount of extremely personal information is required throughout the application and assessment phase. It is still unclear to CDA where this information is stored, shared or used for broader analysis. This is vastly different to the protections that Medicare has about handling personal information, where it is de-identified before being analysed.

The Nationally Consistent Collection of Data on School Students with Disability is also believed to offer insufficient information and transparency to parents or guardians. There is no visibility on what information about their child is actually being passed on by the education facility.

This formal collection of data process will be rolled out over three years. In the initial phases of trial and commencement of data collection 'consent' has been identified as an issue as many families did not provide a formal consent. It is now being considered as to whether participation in this data collection should be made an 'opt out' process rather than an 'opt in'. CDA is very concerned that these instances do not represent 'informed' consent.

The National Disability Insurance Scheme

Question 12. What changes, if any, should be made to the National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules, or disability services, to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

There are elements within the NDIS that cause specific concern to CDA. It is clear that they not applicable or appropriate to the life and circumstances of a child or young person with disability. For example CDA believes that the objects and principles contained within the Act are more relevant to adults than children. As a model, CDA believes the principles contained in the Victorian Child, Youth and Families Act 2005 are comprehensive and relate to the activities of courts, the bureaucracy and service providers. CDA recommends that similarly styled principles be included in this Bill to ensure relevance for children and families.

There is minimal reference to the purpose of the scheme in facilitating child or adolescent development, which is a crucial consideration where the provision of services and supports to children with disability is concerned.

CDA is worried that the currently the NDIS is positioned to take an overly prescriptive approach in dealing with families and children with disability. For example, the CEO of Medicare does not have the authority to make decisions for children if it was believed it was in the best interests of the child but rather situations where child welfare are believed to be compromised are subjected to existing legal processes.

CDA wishes to specifically emphasise its concerns regarded the required planning process within the NDIS. Having a child with a disability is not straight forward. There is no clear pathway in our community for families when they learn their child has a disability. Most families are very vulnerable when their child is born or diagnosed with a disability. For some children there is no definitive diagnosis for many years. Some families go through a period of denial and or grief and find it difficult to engage. For others there is cultural stigma related to disability which needs to be considered, others make it their business to be well informed, but it is a difficult road. Some families struggle with the many pieces of advice and varied information they receive in the process. All families have an emerging understanding about what this means and capacity to take in information, and it is certainly not a linear or predictable process for any family.

The absolute requirement for all participants to prepare a participant's statement

of goals and aspirations is thus very problematic where children with disability are concerned.

Many families would be insulted by the need to complete such a statement on behalf of their child in order to access essential supports, and we believe they should not have to do this in order to access essential supports.

For some families with school age children, goals and aspirations will be related to their child's ongoing health issues or their educational attainment, which are not even the primary role of the NDIS. For other families (as with many people across the community), the formal setting of goals is a highly contrived activity.

The responsibility for developing a coherent goal based service plan that is absolutely relevant to the child and family sits with NDIS. It is unreasonable to expect participants and families to present their life and needs in a bureaucratic format. CDA accepts that there needs to be a service plan in order to activate funding, however the relevance and purpose of this additional layer in the current scheme design is highly questionable.

The requirement of a participants plan is thus quite problematic for children and youth with disability

Also the dynamic and variable nature of services and support provisions to children with disability through the NDIS will be difficult balance with the prescriptive nature of participant's plans.

Disability should not define children or the families of which they are a part. The NDIS should not increase the stigma of disability, or put its needs before those of families and children who are participants.

We should not prescribe different childhoods for children with disability in the design of our community programs– rather, we should be promoting community participation and citizenship opportunities on the same basis as everyone else. The NDIS will be an important part of this, but only one part.

An additional area of significant concern to CDA is the power vested in the CEO of the NDIS. CDA is concerned about the power provided to the CEO to decide whether parents are appropriate decision makers for their children. It is unusual for a bureaucracy to take decision making away from parents without reference to existing systems. It is unclear as to why, that in the event there are questions regarding the capacity of parents, that the matter is not referred and assessed under existing child protection systems and relevant legislation.

CDA is of the view that the CEO's power to decide whether parents are appropriate is removed. Referrals should be made to existing processes children's agencies and programs in the event a review of circumstances is required in this instance.

It is also noted that the Act provides the CEO the power to decide whether a child is capable of making decision for him or herself. CDA also notes that in such circumstances, for example where conflict may exist between children and

parents or guardians regarding the decision of children regarding medical treatment for cancer or decisions around terminations, there are established processes which look at the competency and capacity of the child to make an independent decision within the relevant legal context and parameters. It is believed that these processes should be examined and applicability to similar scenarios within the NDIS scheme ascertained and referred to if the need arises. CDA believes that such a power needs to be well justified with clear rules and protocols for coming to a view about a child's capacity to make decisions in the context of their family and other parts of their lives.

For older children, developing decision making capacity is an important part of their development, but the extent of this in regard to the NDIS will have to be carefully managed with families. Our community values and instils within families considerable responsibility for making decisions in the best interests of their children. This community structure is supported and promoted extensively. It is only when there are significant concerns regarding a child's wellbeing or safety that intervention regarding parental decision making occurs. In the first instance, extensive services and supports are available to children and families, except in extremely exceptional circumstances, which are less restrictive interventions or methods of conflict resolution. This model of service provision and community value of children and families should be consistent, and reflected, in the NDIS.

Question 13. What changes, if any, should be made to the nominee or child's representative provisions under the National Disability Insurance Scheme Act 2013 (Cth) or NDIS Rules to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

Further to the above, CDA understands the need to include provisions for Nominees in the Act however believes that the choice to appoint a nominee should rest with a participant (and family in the case of children) unless there is a guardianship order, a specification in a community treatment order or forensic order.

The Act provides the CEO the power to appoint a nominee at their own initiative. CDA does not believe that this power should be available to the CEO. If the circumstances exist where the CEO believes a nominee should be appointed other than at the participants initiative it should be dealt with by the relevant systems for obtaining administration or guardianship orders.

There are many people with disability that require support with decisions, but are not managed by state appointed guardians. The NDIS needs to make every effort to support the decision making of participants in the planning, implementation and review components of their plan as part of its modus operandi.

The fact that money is being transferred to the control of participants in the NDIS model requires a degree of safeguarding to ensure that this funding is used for purpose under this legislation. CDA appreciates that these safeguards need to be

in place, however there is a dilemma about how to balance the need to protect the NDIS funding with the autonomy of participants to retain control of key decisions. There is concern that the nominee provisions are potentially oppressive in that it is possible for the agency to decide to take away a person's decision making entitlement in preference to supporting their decision making.

Question 16. What changes, if any, should be made to the Commonwealth Electoral Act 1918 (Cth) or the Referendum (Machinery Provision) Act 1984 (Cth) to enable people with disability to be placed or retained on the Roll of Electors or to vote?

CDA takes issue with the current arrangements allowing people with disability access to the Roll. It is concerning that the presumption of capacity is placed against the person with disability and must be proved that they are not of 'unsound mind' as per the legislation.

CDA believes that this presumption of needs to be reversed in accordance with the United Nations Committee on the Rights of Persons with Disabilities, Draft General Comment on Article 12 of the CRPD: Equal Recognition Before the Law.

Access to justice, evidence and federal offences

CDA is highly conscious of the issues faced by children young people with disability as victims of abuse and neglect and also of failures by other service systems that can lead to the justice system becoming involved in the lives of these young people.

CDA has done significant work on the issue of abuse and neglect of children and young people with disability in recent years. CDA commissioned Dr Sally Robinson of Southern Cross University to complete the organisational annual issues paper on this issue. The aim of the paper being to progress greater recognition, better responses and safeguarding for children and young people with disability. The report titled "Enabling and Protecting: Proactive approaches to the abuse and neglect of children and young people with disability" – a copy is attached to this submission.

An overwhelming concern of CDA is that there is a significant disconnection between what is known to be a high prevalence of abuse of children and young people with disability and the response and involvement of the criminal justice system.

There is a great paucity in the local data on the prevalence of abuse of children and young people with disability. Research available however has found that:

- Children and young people with disability experience abuse and neglect at rates considerably higher than their peers who do not have disability (the prevalence of abuse).

- Children with communication impairments, behaviour difficulties, intellectual disability and sensory disability experience higher rates of abuse.
- Abuse and neglect of children and young people with disability is likely to be under-reported.
- Children with disability are often abused on multiple occasions (the incidence of abuse)
- This maltreatment is significant (the impact of abuse).

There are many circumstances where actions and behaviours are not classified as abuse, or identified properly as crimes. It is common for abuse to be characterized as ‘poor practice’ or a procedural or policy issue simply because it takes place in a service environment such as a school or disability service. There are other circumstances where abuse can even be regarded as appropriate, good or necessary practice, such as in instances of restraint or seclusion.

There has been media reports recently that highlight this systemic and broader community placement of what in other circumstances would be perceived as criminal acts. Abuse has been described as something that is par for the course because disability is a difficult area in which to work, or expected because people with severe levels of disability are ‘challenging’.

Question 25. What issues arise in relation to the law on federal offences that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to federal offences to address these issues?

The issue of forced sterilization of people with disability (predominately young women and girls) is an issue that needs to be addressed.

The involuntary or coerced sterilisation of women and girls with disability violates a number of their rights as set out in the CRPD, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the Convention on the Rights of the Child (CRC), among other international human rights instruments. The Office of the UN High Commissioner for Human Rights, international organisations representing medical professionals, and this commission have all recognised involuntary or coerced sterilisation (referred to as ‘non-therapeutic’ and/or ‘forced’ sterilisation) as a form of violence. The practice therefore breaches the rights of people with disability under the CRPD to be free from violence and to retain their physical integrity¹.

Since the High Court’s ruling in 1992 in *Marion’s Case* it has been required that court authorisation is required before any child can be sterilized. Currently, in all Australian states and territories, the authorisation of either the Family Court of Australia or a state or territory guardianship tribunal is required before a child or adult with disability can be involuntarily sterilised (except in emergency situations

in which there is a serious threat to life or health). Despite this legal framework being in place it is the view of many disability organisations and the AHRC that it has failed to protect girls and women.¹

It is CDA's opinion that national legislation needs to be enacted to criminalise, except where there is a serious threat to life the sterilisation of children (regardless of if they have a disability).

Question 26. In what ways do Commonwealth laws and legal frameworks relating to social security diminish or facilitate the equal recognition of people with disability before the law and their ability to exercise legal capacity?

There have been issues raised with CDA in relation to the Child Support system and children with disability. CDA would like to ensure that specific regard is given to the differing needs and requirements of parents of children with disability when Child Support payments are decided. This also includes how the Child Support system interacts with the broader Social Security system in particular with payments like Carers Allowance/Payment to ensure consistency following decisions by the Family Court.

Restrictive practices

Question 36. In what ways, if any, should the proposed National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector be improved?

CDA has previously provided feedback on the National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector and will draw once again on this. CDA would like to see further explanation as to the limits on the Framework – especially if this will apply to all 'institutions' used by people with disability. It would also be useful to provide a comparison of the current safeguards and use of restrictive practices that are used in different jurisdictions – this would allow for visible benchmark to begin the process of implementing the Framework.

CDA would like to see the inclusion of why the Framework is a priority for Australia and perhaps reference or comparison to other countries such as the USA or UK where the use of restrictive practices is markedly higher.

CDA would like to see reference within the Framework of the difference between abuse and restrictive practices. CDA is concerned that 'restrictive practices' and 'seclusion' are often seen as a way of justifying maltreatment and the abuse of people with disability.

CDA also would like to see acknowledgment that behavior is a powerful form of

¹ Senate Community Affairs Reference Committee Report into the Involuntary or coerced sterilisation of people with disabilities in Australia Report 2013

communication for children with disability – and shouldn't be immediately labeled as 'challenging behavior'. Institutions and organizations need to work to develop an understanding of the person with disability concerned and the context and reasons for this behavior. This may involve working with families, friends, carers and health professionals to develop this knowledge and understanding, and taking a person-centered focus in developing tools such as positive behavior support plans.

CDA would also like to see greater transparency involved in the reporting of the use of restrictive practices – involving public annual reporting.

The issue of changing the culture around the use of restrictive practices after such a framework is implemented also need to be addressed and CDA recommends that an education campaign be executed to advise of best practice.

It is noted that this framework are not applicable to educational institutions such as schools. There is a real need for a legislative framework around the use of restrictive practices and seclusion within the education system.

Particular disability communities

Question 41. How do Commonwealth laws and legal frameworks relating to equal recognition before the law and capacity affect people with disability who are:

(a) children

One area, which has not been specifically mentioned within the Issues paper, is the role of the education system. CDA is currently concerned about the role that segregated education settings currently have throughout Australia given this being in contradiction to the UNCRPD's Article 24.

CDA is further concerned about the Australian Education Act 2013 Regulations which currently provide provision of an increased funding loading to 'Special Schools' or segregated education environments to a much higher level compared to the loading for children with disability in mainstream education settings (223% for a special school compared to 186% in all other schools). CDA does note that the Government is currently undergoing work to develop a disability loading formula that will provide for a consistent approach across all schools. But whilst this is in development the additional funds being provided to special schools provides for a perverse incentive for children to attend special schools - out of line with the UNCRPD. As outlined in CDA Issue Paper Inclusion in Education, "inclusion requires the abandonment of special educational stances which focus on compensatory approaches to individual 'needs', to embrace a pedagogy of inclusion and a commitment to the rights of all to belong".²

2 D'Alessio, 2011, p.141

Additional issues

CDA would also like to see further legal accountability of organisations that provide services to people with disability. Too often we have heard of shocking circumstances that people with disability have endured under the supervision and duty of care of organisations. The cases are abhorrent because they have involved sexual assault, appalling treatment and in some instances death of vulnerable and dependent people with severe disability but also because they highlight potential systemic failures and gaps in present organisational processes.

These incidents raise significant concerns about the adequacy of accountability mechanisms which exist for disability service organisations at an operational and Board level regarding a) obligations to provide adequate safeguards to minimize the risk of harm, including abuse, to their clients and b) requirements regarding response to reported incidents of abuse and arguably most importantly c) what are the organisational consequences for failing to provide the duty of care stipulated in relevant accountability mechanisms.

Such legal mechanisms already exist for Boards of companies in regard to Occupational Health and Safety requirements and it seems to be deficient that there is not a similar compliance regime for the safety of vulnerable people in human services.

Thank you for the opportunity to contribute to this inquiry.