**Carers Alliance
Address: 5 Northcote Road, Glebe NSW 2037
Ph: 02 9552 1687**

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**Late submission by Carers Alliance to the Australian Law Reform Commission Inquiry into: Equality, Capacity and Disability in Commonwealth Laws – IP44**

**Questions**

**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. What impact does this have in Australia on:

1. provision for supported or substitute decision-making arrangements;

Provision for supported or substitute decision-making arrangements are intrinsically discriminatory. Please find enclosed a copy of our letter to the Human Rights Commissioner of the Australian Human Rights Commission which sets out our concerns and proposes a remedy which would be applicable across all jurisdictions.

1. the recognition of people with disability before the law and their ability to exercise legal capacity?

**Response:** Upon ratification of the UN Convention on the Rights of Persons with Disabilities Australia made the following Interpretative Declaration:

 *Australia declares its understanding that the CRPD allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safe-guards.*

With such an unambiguous disregard by our government for Australian citizens who are in need of guardianship and in need of decision-making agency, it is little wonder that the parents, families, supporters and allies of these Australian citizens are profoundly aggrieved on their behalf.

It is a fundamental breach of Article 12.1 that our Commonwealth government so disrespects our citizens with decision-making incapacity as to render them non-participants in our society by virtue of denying them agency for decision-making as a matter of course, and does not accord with Australia’s claim that all its citizens are equal before the law.

How can one exercise what one does not have and is not given the legal framework wherein to acquire it?

**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?

**Response:** For the Australian government to withdraw its Interpretive Declaration on Article 12 of the UN Convention on the Rights of Persons with Disabilities would be a good start. It discriminates against a class of people with disabilities in a way that is unfair and unjust. Such a Declaration by the Australian government flagrantly abuses the vulnerability and lack of awareness of a group of people whose most ardent advocates are excluded from the government advisory process.

**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?

**Response:** Accountability is non-existent. The legislation governing accountability is patchy, inadequate, weak and porous. Even when there have been clear breaches of the criminal law against people with disabilities the penalties are non-existent, which means that there is no deterrent factor, no financial penalty and no adverse, reputational consequence. This is because there are no standards of care for people with disabilities and no professional body which oversees the conduct of providers of services to people with disabilities*.* The only recourse is for the person with disabilities and/or their families and/or supporters to engage in expensive, exhausting and often fruitless litigation. Organisations protect the perpetrators out of fear of litigation. The perpetrator of abuse or crime is often released from employment without criminal charge or even a recorded mark against them, leaving the perpetrator able to continue working with people with disabilities with no alerts for future employers.

There is no duty of disclosure and no duty of candour which means there is no incentive to make systemic changes which will give better services, better protections, better outcomes and better living circumstances for people with disabilities and those who work with people with disabilities.

While there legislated standards of care in childcare and aged-care there are no standards of care in disability which again means people with disabilities are not equal before the law.

There is no mandatory reporting for people with disabilities as there is in aged care and child- care with penalties in place for failure to report.

**A uniform approach to legal capacity?**

**Question 4.** Should there be a Commonwealth or nationally consistent approach to defining capacity and assessing a person’s ability to exercise their legal capacity? If so, what is the most appropriate mechanism and what are the key elements?

**Response:** We refer you to our letter hereby enclosed which was forwarded to the Human Rights Commissioner.

**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?

**Response:** Re-asserting the primacy of the family would be a good start. Article 23.1 says

1. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

The natural authority of parents and families of people with disability must be re-asserted and recognized. Over the last 40 years the natural authority of parents and families has been diminished and disregarded by the legalistic approach to human relationships. The legal system has increasingly sidelined the authority of families and this situation must be addressed. Given that the family is the fundamental group unit of society, it is in the interest of our society to allow families to be their natural best. The law has interfered too much with this under the guise of human rights and has had a detrimental effect on the natural authority of the family to the extent that law is now made having regard to the lowest common denominator which is the exception, however it is the exception for which the law gives greater regard without elevating the exception to meet the rule.

We also refer you to our letter hereby enclosed which was forwarded to the Human Rights Commissioner.

**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?

**Response:** Refer to Answer No 5

**General protections provisions**

**Question 7.** In what ways, if any, should the general protections provisions under *the Fair Work Act 2009* (Cth) be amended to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations.

**Question 8.** There is substantial overlap between the general protections provisions under the *Fair Work Act 2009* (Cth) and Commonwealth anti-discrimination legislation. In what ways, if any, should this legislation be amended to improve or clarify their interaction in circumstances of disability discrimination?

**Response:** All laws must be harmonized.

**Administrative law**

**Question 9.** What issues arise in relation to review of government decisions 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 administrative law to address these issues?

**Response:** All tribunals that make decisions regarding the life circumstances of people with disabilities including where they live, with whom they live, how and from whom they will receive services and access to family and friends must only be made through the application of rules of evidence. All tribunal decisions must be subject to judicial review. All persons appearing before Tribunals must be given the right to advocacy.

**Competition and consumer law**

**Question 10.** What issues arise in relation to competition and consumer 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 Commonwealth laws and legal frameworks relating to competition and consumer law to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**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?

**Response:** All private information in relation to a person with disabilities must always remain personal to the person. Consent must be obtained from the person with disability themselves or through the agency of their parents or family or guardian or attorney.

Where a person with disability resides with other unrelated co-residents, privacy must not exclude parents, family members and friends known to the person with disabilities.

 Privacy considerations have been invoked to prevent parents from making social visits to the homes of their children or have been required to make appointments a considerable time ahead when a phonecall and reasonable timeframe would suffice. As it does with other family members without disability.

**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?

**Response:** National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules must incorporate Article 23 of the UN Convention on the Rights of the Child which it does not do. It is not sufficient to simply incorporate the UN Convention on the Rights of Persons with Disabilities because that Convention was to a large extent written by adults for adults with disabilities. In Australia, during the ad hoc phase of the Convention consultation, there was no consultation whatsoever with the representatives of children or young people with disabilities and this must be addressed by incorporating into the NDIS legislation the Rights of the Child expressed in Article 23 which unfortunately either by oversight or intent was not migrated into the UN Convention on the Rights of Persons with Disabilities.

People with disabilities are not a homogenous group, there are vast differences in physical ability, intellectual or cognitive capacity and the ability to self advocate. Our concern is for people unable to self-advocate because of reduce cognitive function. Disability is for most a limitation that can be overcome with the correct supports. For a much smaller cohort , disability is harder to overcome because it relates to additional roadblocks in communication and conceptualisation. These people must be afforded the protections having regard to the inherent vulnerabilities.

We also refer you to our letter hereby enclosed which was forwarded to the Human Rights Commissioner

**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?

**Response:** The NDIS legislation and rules are extremely formulaic and rigid. They effectively sideline parents, families and carers to by-stander status. This is a shortcoming that inherently disrespects the person with disability and objectifies them. The impersonal language of the Act and its rules imply that the person with a disability is to be simply a passive recipient of services rather than a human being connected to parents, families, friends and communities.

This is particularly so for children and young people. Furthermore the Act should recognize community as being intrinsic in the life of the person with disability. The definition of community must be the community in which and with which the person with disability is familiar. If this were recognized there would be lesser need for behavior intervention strategies.

We also refer you to our letter hereby enclosed which was forwarded to the Human Rights Commissioner

**Question 14.** What changes, if any, should be made to the nominee provisions or appointment processes under the following laws or legal frameworks to ensure they interact effectively:

(a) the National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules;

(b) social security legislation; and

(c) state and territory systems for guardians and administrators?

**Response:** (a) & (b) there should be seamless sharing of information (by prior consent) to avoid the continuous and interminable requirement to complete forms.

(a, b, c) The primacy and authority of the family should be given due regard and not relegated to by-standers when it is the family which is the vehicle on the journey of disability.

(c) We refer you to our letter hereby enclosed which was forwarded to the Human Rights Commissioner

**Employment(a) & (b)**

**Question 15.** In what ways, if any, do Commonwealth laws or legal frameworks relating to employment diminish or facilitate the equal recognition of people with disability before the law and their ability to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Citizenship rights, public service and board participation**

**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?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 17.** What issues arise in relation to electoral matters that may affect the equal recognition before the law of people with disability or their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 18.** How does the language used in Commonwealth laws and legal frameworks affect the equal recognition of people with disability before the law or their ability to exercise legal capacity?

**Response:** The lack of recognition of Article 23.1 which says

 The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

**Question 19.** In what ways do Commonwealth laws and legal frameworks relating to holding public office diminish or facilitate the equal recognition of people with disability before the law and their ability to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 20.** What changes, if any, should be made to Commonwealth laws and legal frameworks to ensure that people with disability are not automatically or inappropriately excluded from serving on a jury or being eligible for jury service?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 21.** In what ways do Commonwealth laws and legal frameworks relating to membership of, or participation on, boards diminish or facilitate the equal recognition of people with disability before the law and their ability to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 22.** What issues arise in relation to identity documents for people with disability? In what ways, if any, should Commonwealth laws and legal frameworks relating to identity documents be amended to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

**Response:** The inconsistency of social security law which will not accept a birth certificate as final identification, when for many people with disabilities it is the only means of identification they have. And whereby each of the other items which make up the 100 points of identification, can be applied for separately simply by means of a birth certificate. This makes it extremely difficult for families and for people with disabilities in need of guardianship. This could be alleviated by using the 100 points of identification of either the mother or the father.

See our letter to the Human Rights Commissioner provided herein.

**Access to justice, evidence and federal offences**

**Question 23.** What issues arise in relation to access to justice 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 access to justice to address these issues?

**Response:** There is an unjust prejudice in our civil and criminal law against people with intellectual disability where giving and accepting evidence is concerned. For example:

A person with cognitive and language incapacity is gravely assaulted but despite the doctor’s report and family evidence the police can do nothing This is a grievous injustice but it is what happens across our nation, and what will continue to happen unless the law changes to give proper regard to the evidence.

Another scenario is that an accommodation provider is aware of the grievous nature of the assaults and yet do nothing. This indicating a systemic willingness to condone a lesser standard, simply because the very nature of their disability prevents them from reporting the commission of crime against them.

This is a situation that is played out across many settings, in many states and jurisdictions and goes back to the fact that there is no mandatory reporting for disability service providers, there is no accountability of service providers to protect vulnerable people and fulfill the obligation of duty of care.

Most people can provide evidence, the issue is in having the skills to be able to have the evidence delivered in a way the person can deliver it – this may be difficult, it may be expensive, it may be a reactive response rather than verbal but in the name justice it must be provided – off camera- so that the person is not intimidated.

See the Report of the Australian Human Rights Commission [Equal Before the Law](https://www.humanrights.gov.au/publications/equal-law) released in February, 2014

Also see Case Study Report by JacksonRyan Partners released Feburary, 2014 entitled [Deception-The Illusion of Care, Protection and Rights in Victoria’s Disability Accommodation Sector](http://u.b5z.net/i/u/10196230/f/Case_Studies_Folio_-_Deception_-__Victoria_s_Disability_Services__February_2014.pdf).

**Question 24.** What issues arise in relation to evidence 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 Commonwealth laws and legal frameworks relating to evidence to address these issues?

**Response:** See above and our letter to the Human Rights Commissioner

**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?

Response: See above and our letter to the Human Rights Commissioner

**Social security, financial services and superannuation**

**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?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 27.** What changes, if any, should be made to the nominee provisions under the Social Security (Administration) Act 1999 (Cth) to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 28.** What issues arise in relation to banking for people with disability? What changes, if any, should be made to Commonwealth laws and legal frameworks to ensure people with disability control their own financial affairs and have equal access to bank loans, mortgages and other forms of financial credit?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 29.** In what ways, if any, do Commonwealth laws or legal frameworks relating to insurance deny or diminish the equal recognition of people with disability before the law and their ability to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 30.** What changes, if any, should be made to the insurance exemption under the Disability Discrimination Act 1992 (Cth) to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 31.** What additional guidance or supporting material relating to the application and operation of the insurance exemption under the Disability Discrimination Act 1992 (Cth) would assist people with disability?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 32.** What changes, if any, should be made to the superannuation exemption under the Disability Discrimination Act 1992 (Cth) to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 33.** What issues arise in relation to superannuation for people with disability that may affect their equal recognition before the law or their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Health care and aged care**

**Question 34.** What issues arise in relation to health care 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 health care to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 35.** What issues arise in relation to aged care 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 aged care to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**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?

**Response:** It must be made illegal for individual service providers, government or non-government to have their own restrictive practices panel for the person they support. All restrictive practices must be overseen by an independent rotating panel auspiced under the Attorney General’s Department in all jurisdictions. Panels should comprise of a community member, behavioural intervention specialist, psychologist and medical doctor.

All too often service providers make decisions based on expediency and ease of management of the person with disability, irrespective of the physical and/or psychological effects of the physical and/or chemical restraint. There are people who have been a chemical cocktails who have never had a review, nor a blood test to indicate the blood-levels of the drugs administered.

There must be a legal requirement for an annual review of medications administered and behavior intervention strategies sought as an alternative to restrictive practices.

**Question 37.** What is the most appropriate approach to the regulation, reduction and elimination of restrictive practices used on people with disability at a national or nationally consistent level? What are the key elements any such approach should include?

**Response:** See response to Question 36.

**Marriage, intimate relationships, parenthood and family law**

**Question 38.** What issues arise in relation to marriage that may affect the equal recognition before the law of people with a disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to marriage or marriage celebrants to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 39.** What issues arise in relation to people with disability and intimate relationships that may affect their equal recognition before the law or ability to exercise legal capacity? What changes, if any, should be made to Commonwealth law and legal frameworks to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**Question 40.** What issues arise in relation to family law that may affect the equal recognition of people with disability before the law and their ability to exercise legal capacity? What changes, if any,should be made to Commonwealth laws and legal frameworks relating to family law to address these issues?

**Response:** We are confident that this question will be comprehensively addressed by other organizations

**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; - The primacy of Article 23.1 which says :

**Response:** The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 23 of the UN Convention on the Rights of the Child is to be included in the National Disability Insurance Scheme , 2013 Cth.

Parents and families to be integral to the Act and not relegated to by-stander status and a Carer Assessment to be included as part of the assessment process which identifies the range of services required by the person with disabilities.

(b) women; - We are confident that this question will be comprehensively addressed by other organizations

(c) Aboriginal and Torres Strait Islander; - We are confident that this question will be comprehensively addressed by other organizations

(d) from culturally and linguistically diverse backgrounds;- We are confident that this question will be comprehensively addressed by other organizations

(e) older;- We are confident that this question will be comprehensively addressed by other organizations

(f) lesbian, gay, bisexual, transgender or intersex;- We are confident that this question will be comprehensively addressed by other organizations; or

(g) living in rural, remote and regional areas?- We are confident that this question will be comprehensively addressed by other organizations

**Matters which have not been addressed in the Questions:**

1. In tenor of question 41 is of concern to Carers Alliance which is an inclusive community-based organization. Concern and responsibility for the needs of Australian men with a disability who are not from a culturally and linguistically diverse background and who are not indigenous appears to have been overlooked. We are concerned that the individual human rights of Australian men with a disability who are not from a culturally and linguistically diverse background and who are not indigenous will be ignored in favour of what appears to be specific concerns for identified groups and those who self-identify as belonging to those groups. This is wrong. We are fearful that Australian men with a disability who are not from a culturally and linguistically diverse background and who are not indigenous will be systemically discriminated against simply because they do not belong to one of those identified groups. We want re-assurance that they will not be discriminated against and an explanation as to why they have been excluded as a group in Question 41.
2. There are commonwealth laws which discriminate with respect to the financial arrangements for children, young people and adults with disabilities. Specifically we would like to see the Australian Taxation system make provision for the tax deductibility of disability-specific expenses such as wheelchairs, home modifications, therapies, vehicle modifications, care arrangements which allow families to gain remunerative employment or undertake educational qualifications. These taxation arrangements should not be only made available to people with disabilities themselves but to families of children who have disabilities whether those children come within the ambit of the National Disability Insurance Scheme or not.
3. Health care – There is little or no recognition of or provision for the discrete health care needs of people with severe and profound intellectual disabilities. There is no specialist nursing or medical training given in our places of higher learning. Our healthcare system should be providing this care and it is not doing so. There needs to be systemic change and legislative provisions for a responsive individualized approach to healthcare for all our Australian citizens.

 Moreover the lack of specialist psychiatric care de-legitimises mental illness as an illness. We have specialist paediatric hospitals, we have specialist maternity hospitals (and let’s remember how many deaths were recorded in the rudimentary maternity hospital which were not sufficiently off-putting to close maternity hospitals, they just became better providers of maternity care). We need to have centre of excellence for mental health care provisions then and only then will the stigma of mental illness be eradicated.

Maree Buckwalter and Mary Lou Carter
President Secretary