

The Executive Director
Australian Law Reform Commission
GPO Box 3708
Sydney NSW 2001

Equal Recognition Before The Law And Legal Capacity For People With Disability

This submission responds to the call by the Australian Law Reform Commission for comment on the Commission's November 2013 issues paper regarding Equal Recognition Before The Law And Legal Capacity For People With Disability.

The following paragraphs identify the basis of the submission, provide overarching comments and then address specific matters raised in the paper.

Basis

This submission is made by Bruce Baer Arnold and Dr Wendy Bonython.

Mr Arnold is an Assistant Professor in the School of Law & Justice Studies at the University of Canberra. His research centres on questions of privacy, health law, human rights and capacity. His writing has appeared in a range of Australian and overseas journals and books, including *Melbourne University Law Review*.

Dr Bonython is an Assistant Professor in the School of Law & Justice Studies at the University of Canberra. She teaches torts and mental health law, and researches health and biotechnology law, including questions of autonomy, dignity and ethics. She has made invited submissions and testimony to parliamentary inquiries (for example regarding the Senate inquiry into involuntary or coerced sterilisation of people with disabilities) and law reform bodies. Her writing has appeared in international and Australian law journals such as *Juridical Review* and *Journal of Medical Ethics*.

The submission is independent of the University of Canberra and does not necessarily represent the views of the University or affiliated bodies.

The authors have no commercial or other relationships that would be reasonably construed as a substantive conflict of interest.

We would be happy to meet with the Commission to discuss particular points.

Context

The paper is a laudable engagement with issues facing Australians with disabilities and the people around them, including family, medical practitioners, legal practitioners, the courts and tribunals. However, we suggest that in construing responses the Commission should be conscious of three pitfalls, which we itemise immediately below and then unpack.

Much of the paper is predicated on law reform to promote equality, whether on a formal or substantive basis. In seeking the best outcomes for all stakeholders it is

desirable to look beyond inequality and resolve inherent policy tensions by emphasising flourishing.¹

That emphasis is consistent with the Commission's reference to dignity and autonomy. It is also consistent with the lived experience of

- individuals with disabilities and
- people who seek to facilitate the flourishing of those individuals on an ongoing or instance by instance basis.²

Capacity, not disability

The paper conflates 'disability' as a single status or degree of incapacity. That is consistent with the binary nature of identity in much Australian law, which is predicated on a norm and a difference that is addressed as an incapacity.³ As with the preceding paragraph, it is desirable for the Commission and Australian governments to acknowledge that disabilities are contextual, may not be static and affect flourishing in different ways.

Similarly, capacity may not be best represented by a binary model. It may be context-dependent, and fluctuate, rather than static and permanent. In many instances, the primary focus of the law is not whether the individual has a disability; rather, it considers whether that disability impairs the individual's ability to act as a legally recognized entity, with the powers and obligations such recognition attracts. A person who is physically disabled, therefore, is entitled to exactly the same presumption of capacity at law as someone without a physical disability. The issue of capacity only arises when there is evidence to suggest that a person's ability to make decisions has been compromised by their disability, as a consequence of substantial cognitive impairment or serious mental illness. Even then, the person is NOT presumptively disentitled to claim capacity; instead, it becomes an issue requiring further consideration by a tribunal or court, who make a determination about whether the person does have adequate capacity to make legally-recognised decisions. For many disabled people, the question of capacity is no more relevant to them than it is the remainder of society.

Furthermore, disability is not, in many instances, the only grounds under which this ability can be examined. It is overly simplistic to assume that all disability is the same, all incapacity is the same, and a simple alteration to the law will overcome any inequality. In the interests of achieving justice and promoting dignity for people with disability, there must be sufficient flexibility within the law to permit subjective context as it pertains to individuals to be taken into account.

Thirdly, it is important to recognise that people with disabilities are individuals within a social context. There is a risk that in construing responses to the paper the Commission will under-recognise the impact of disability-based discrimination on

¹ The notion of flourishing and its usefulness in dealing with intractable policy dilemmas are discussed below.

² We have specifically referred to 'individuals' as a reminder that people with 'disability' are first and foremost individuals, worthy of respect on that basis and not to be objectified as one or more attributes (in particular as deficits that negate their personhood.)

³ At its most reductive, the bureaucratic convenience evident in a range of welfare programs and agencies results in characterisations such as 'disabled people', a taxonomy of deficits that objectifies and thereby militates against individual flourishing.

carers, in particular the families of young people and adults with severe disabilities.⁴ Equality before the law involves respect and support for those carers, irrespective of any national disability insurance regime. It is also important to note that those carers are entitled to lives of dignity and flourishing, and the protections offered under human rights instruments, as individuals in their own right.

Flourishing

In considering changes that would give effect to the Commission's recommendations we encourage an emphasis on flourishing and dignity rather than formal equality.

Ultimately equality is a pernicious abstraction unless it fosters flourishing. Equality is significant because inequality is associated with discrimination, in particular the non-recognition of capabilities on the basis of stereotypes and the retention of barriers to the fulfilment of both people with disabilities and people around them. Much human rights law has conceptualised law reform as achieving social goods through –

- the reduction or removal of statutory civil disabilities⁵
- a requirement that public/private sector entities change infrastructure or practices in order to remove barriers that prevent the enjoyment by some people of the facilities, services and pleasures that are enjoyed by peers who do not have disabilities⁶
- restrictions on vilification and other expression that inhibits participation in civil society and that fosters exclusion in areas of life such as employment.⁷

Analysts such as Martha Nussbaum, Alan Gewirth and John Rawls have acknowledged the importance of equality. They have however emphasised flourishing (well-being) as a value that subsumes equality initiatives. In a contemporary liberal democratic state equality is a means to an end, rather than the end as such.⁸

Respect for flourishing recognises diversity, avoiding the bureaucratic convenience that –

- results in a reductive labelling of cohorts as 'disabled',
- denies individual aspirations and circumstances, and

⁴ We counsel in particular against an uncritical acceptance of claims by some advocacy groups that certain medical practices, eg sterilization or medication, can never be permissible when performed on people with a disability, notwithstanding the individual's ability to provide valid consent to the procedure. Often predicated on an overly simplistic understanding of international human rights law, such claims themselves discriminate against people with disabilities by denying them access to services available to people without a disability, and the benefits those services provide.

⁵ A salient example is suffrage, with law reform respecting the personhood of women, the poor and Indigenous people by including them on electoral rolls.

⁶ Such barriers for example encompass buildings that are not readily accessible by people in wheelchairs and online services that are not readily accessible by people with poor vision.

⁷ In that respect we recognise that the Commission will be exploring the extent to which human rights law impinges on what has been characterised as "traditional rights and freedoms", noting that law reform has performed an invaluable role in addressing traditional discrimination such as denial of suffrage to most people on the basis of gender, ethno-religious affiliation or poverty.

⁸ Treating equality as an end rather than as a means or metric fosters formal rather than substantive equality and potentially impedes the achievement of well-being on an individual and/or contextual basis.

- fosters the conceptualisation of people with disabilities as embodying fundamental deficits relative to the norm.

In emphasising fulfilment we accordingly encourage the Commission to be wary of an emphasis on equality that is reductive and that for example means that the fertility of people with severe psychological/physiological conditions can never be restricted or that some therapeutic action regarding people who are at high risk of harm to themselves and others is always impermissible.⁹

In making that statement, which we discuss in more detail below, we emphasise that we are **not** advocating systematic or unconsidered sterilisation, psychosurgery or other medical interventions.

We are instead suggesting that the Commission recognise that circumstances vary and that the paramount interest should be the wellbeing of all Australians, with disabilities or otherwise, rather than the labels assigned to particular cohorts.

We also note that in practice Australian governments have resolved tensions regarding equality through reference to a cost-based 'accommodation'. Despite rhetoric about the inalienability and indivisibility of rights within international human rights laws, those rights, as noted by the Commission (and by other bodies such as the Australian Human Rights Commission), are often 'stacked' in a hierarchy by policymakers and administrators on the basis of cost or on the basis of advocacy by special interest groups.

Diversity

Much of the rights, legal and administrative literature refers reductively to 'disability'.¹⁰

We encourage a consistent recognition that disability, in particular disability regarding discrimination and the exercise of rights under the justice system, is not a matter of 'one size fits all' and 'one size for all time'.

Disability may be transient or ongoing. It may be fundamental, affecting all aspects of an individual's life (and the lives of carers). It may instead only be apparent and/or significant in particular contexts.

In some contexts there is for example a qualitative difference between someone who is blind and intellectually acute (for example Disability Discrimination Commissioner Graeme Innes), someone whose reasoning is periodically affected by episodic mental illness and engages in reasonably foreseeable harm to self and others, someone with congenital cognitive impairment, someone who is in a permanent vegetative state with no prognosis for recovery, and someone – such as one author of this submission – who is identified in Australian government statistical collections as 'disabled' because he needs to wear spectacles for reading footnotes.¹¹

⁹ Observations by the Committee on the Rights of Persons with Disability should accordingly be treated with caution rather than as definitive in terms of Australian law and policy.

¹⁰ That reduction is evident in the title of the Committee on the Rights of Persons with Disability.

¹¹ Upwards of 20% of legal academics at Australian universities are members of a 'disabled' cohort in some Commonwealth data collections on the basis that they need an optical prosthesis on a day by day basis. Membership of that cohort does not tangibly inhibit their participation in civil society

Social Context

Finally, the paper can be read as eliding the social context in which individuals with disabilities live, potentially experience discrimination that is substantive or otherwise, and that facilitates or inhibits their wellbeing.

Few people live outside a social context. Their relationships with family, with guardians and others can be fundamentally important to their happiness and self-fulfilment. That might involve a sense of security and love that is consistent with dignity (ie respect as an individual). It might involve the willingness (and capability) of carers to ensure that a person with disability is fed, takes medications and is kept from harm attributable to learning or psychiatric difficulties.

The personal fulfilment that is implicit in the Commission's questions, for example exercise by some people with disabilities of rights to participate in elections and juries, will often involve carers rather than individuals in isolation.

Data Collection, Analysis and Communication

In addressing particular questions in the following paragraphs we note two issues in relation to policy dilemmas such as respect for intimacy.

The first is that although data is often collected by service providers, regulatory bodies and third parties that data is often held within institutional silos and is not readily accessible. That inaccessibility militates against informed policy-making and means that in considering responses to the paper the Commission will on occasion be reliant on assertions about harms or other outcomes that are unsubstantiated and strongly contestable.

We suggest that in its report the Commission should highlight the need for both consistent reporting and for ready access to data. Particular data collection and analysis could be tasked to bodies such as the Australian Institute of Family Studies and the Australian Institute of Health & Welfare. The failure of governments over the past 15 years to appropriately fund research entities is short-sighted and likely to result in regulatory capture that is contrary to national budgetary objectives in the mid to long term.

As a corollary, the second issue is that much public debate is uninformed about the realities of disability. Governments over the past decade have articulated policy-making as a matter of cost, with few indications that people with disabilities should be respected as people rather than objectified as financial burdens or one or more deficits. Leadership brings with it a responsibility to foster a dialogue and for example to articulate a recognition within the community at large that location within a particular jurisdiction means that some Australians with disabilities enjoy fewer rights and less equality than peers in an adjacent state or territory. That leadership requires engagement with areas of life, such as intimacy, that may be confronting and that may be politically challenging but are inextricable with the flourishing of people with disabilities and people around them.

Specific Comments

The Convention

Q1: 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: (a) provision for supported or substitute decision-making arrangements; and (b) the recognition of people with disability before the law and their ability to exercise legal capacity?

A1: The Declaration is distinct from a formal Reservation in international law. It identifies what the Australian government considers to be the meaning of Article 12. As such the Declaration is not binding on other nations. It would guide Australian courts in interpreting Article 12, for example if a litigant argues that an Australian statute is invalid because that Act conflicts with the Convention.

The paper (at pages 20 and 31) refers to uncertainty and suggestions that the Article precludes supported or substituted decision-making. Given our emphasis on diversity and flourishing – the wellbeing of people with disabilities – we suggest that the Article must be read in Australia on a common sense basis in accord with the Declaration. There is a strong recognition in Australian law that in some contexts it is appropriate (and in exceptional circumstances imperative) to make decisions on behalf of people with disabilities and to assist them through supported decisionmaking. That recognition is consistent with the body of human rights law over the past fifty years, with accepted bioethical standards and with the practicalities of both health care and social activity.

It is both doctrinaire and contrary to flourishing to hold that substitution/support is never necessary and never permissible for human flourishing.¹²

It is axiomatic that all Australians, with or without disabilities, may experience life-threatening circumstances in which a decision should be made by a medical practitioner or other recognised decision-maker within a coherent and transparent legal framework to preserve the life of the individual. From a human rights perspective it is also axiomatic that interventions that are contrary to the will of some individuals will be necessary in order to both preserve the life of those individuals and the lives of the intimates or other associates of those individuals.

A doctrinaire disregard of those axioms means that the rights of a person with disability, for example someone with schizophrenia, necessarily override the rights of family or third parties who are in danger of serious harm attributable to the individual's refusal to adopt an appropriate medication regime.

Similarly, in the absence of life-threatening emergency, circumstances may arise when a decision must be made, and the natural decision-maker is unable to make it, even with provision of support. These decisions include financial, care and welfare decisions relating to people with advanced cognitive decline, such as dementia, or who are unconscious for extended periods.

For people in these circumstances, no amount of support will be sufficient to enable them to make the required decision.

Substitute decision-making exists to fill what would otherwise be a void, in which no one could authorise certain actions, actions without which the person involved may experience harm, discomfort, or other effects contrary to their human rights and fundamental dignity.

¹² In that respect we note that in reality all members of the UN Committee on occasion disregard the wishes of some people with disabilities and for example engage in practices such as confinement of people who are highly likely to harm themselves and/or others.

Suggestions that Australian governments are wholly precluded from maintaining supported and substituted decision-making mechanisms are, in our view,

- legally incorrect
- impractical and
- contrary to the objectives of the *Convention*.

We look forward to any substantiation of the suggestions and envisage addressing them as the Commission's consultation progresses.

National Disability Strategy 2010–2020

Q2. 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?

A2: Our submission contends that consistency in the definitions and tests used to determine capacity, and appointment and recognition of substitute decision-makers and supported decision-making, is essential to effect meaningful reform in this area (discussed further in A4). The *National Disability Strategy 2010-2020*, should be amended to ensure consistency with other laws in this regard.

Framing principles

Q3: 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?

A3: As per the discussion in *Context* above, we suggest that dignity and individual flourishing – reflecting autonomy where appropriate, and enabling inclusion and participation – is more desirable objective than formal equality. Capacity has meaning – it is the test that distinguishes those who are legally recognised as being capable of making their own decisions, including bad decisions, and being held accountable for the consequences of those decisions, from those who experience disadvantage of a type that justice demands they be absolved from the consequences of their choices, or protected from the consequences of decision-making contrary to their best interests.

If formal equality is the overriding objective, then it may seem desirable to 'tweak' the legislation in such a way that the presumption of capacity is unassailable, or that the effects of a severe cognitive or mental disability on decision-making must be disregarded in considering capacity. However the consequences of such a move for the lived experience of those people who are denied alternative decision-making pathways could be disastrous, creating a decision-making void in which no one is capable of making a legally-recognised decision in the person's interests.

A uniform approach to legal capacity?

Q4: 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?

A4: The authors of this submission argue that there needs to be nationally consistent approach to issues of capacity, substitute and supported decision-making including cross-recognition of appointments, and mental health laws.

At present, there is no single recognised test for capacity. In part this is because capacity is very much a context-dependent concept, and possession of capacity will vary based on the nature of the decision the person is being asked to make. There is a well-recognised difference between the tests for capacity applied by medical practitioners, and those used by legal practitioners; however it is also clear that within the legal context, different tests are applied for different functions within law, for example fitness to stand trial (capacity to make decisions and instruct about the process of a trial), executing a will, and appointing a welfare guardian.

The situation becomes more complicated when the individual legislative instruments dealing with appointment and recognition of guardians and Powers of Attorney are considered. Terminology varies considerably between state/territory jurisdictions, including terms such as guardian, manager, administrator, which are inconsistently defined. Powers held under these appointments may also vary – noting that they are often specified by orders of a tribunal, within the scope of powers outlined in legislation; and cross-recognition is, at best, arbitrary. Furthermore, this falls outside the scope of Commonwealth powers, notwithstanding that some clients of Commonwealth Departments also require substitute decision-makers vested with authority similar to that held by Powers of Attorney, or tribunal appointed substitute decision-makers. This has contributed to the rise of yet another class of substitute decision-makers or power-holders- albeit with more specialised scope of powers – who are authorised to deal with specific Commonwealth Departments, e.g. ‘nominees’ under the *Social Security (Administration) Act*.

This is unsatisfactory for a number of reasons, not least of which is that it creates uncertainty about the validity of pre-emptive appointments made by people in anticipation of future loss of capacity, particularly if they lose capacity outside the jurisdiction the appointment was made in, or if they hold assets in multiple jurisdictions. In the event that this occurs, and an instrument is not recognised, the default is appointment of a guardian by the tribunal under the relevant jurisdictions guardianship frameworks- a process which contributes a significant burden to all involved, including family members, healthcare and social workers, and the tribunal itself.

Similar issues arise in the context of mental health laws; each state and territory has its own legislation and frameworks for dealing with issues including involuntary treatment and detention; this lack of consistency creates significant issues for people affected, for example those living in areas on the border between jurisdictions where they may have residence in one state, but receive healthcare in another; or those who move between states and territories.

The Commonwealth may be able to argue that it has power to legislate in this area on the basis of its external affairs power, and its role as signatory to numerous human rights instruments. However it would be difficult to sustain such a position in light of the Commonwealth’s demonstrated reluctance to engage meaningfully with development of a Bill of Rights, and such an approach is likely to antagonise the States and Territories, who will – quite rightly – perceive it as a power grab.

A more constructive approach would be for all jurisdictions to collaborate on the drafting of a suite of uniform legislation incorporating standardised tests for capacity, and involuntary treatment, procedures for appointment and recognition of substitute or supported decision-making, incorporating minimum safeguard provisions, and then enact it- without amendment- in their own jurisdictions. The success of this as a strategy in the past has been somewhat mixed – frequently the Acts bear little

resemblance to one another by the time they come into effect, or may only be adopted by some jurisdictions. It would, however, encourage jurisdictions to at least start thinking about how these laws could meaningfully be amended in a way to create a nationally consistent approach to supporting some of the most vulnerable people in the community, including minimising the bureaucratic inconsistencies that bedevil people who are trying to support them in their engagement with the wider world.

The role of family, carers and supporters

Q5: 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?

A5: Autonomy is the idea that individuals should be able to make their own choices and decisions about their own destiny, free from unnecessary interference- ‘unnecessary’, because nearly all decisions are influenced, to some extent, by external factors – very rarely are they purely the product of the individual’s will.¹³

For many people, their decisions are influenced by the impact those decisions will have on the people around them. For people in circumstances where they are dependent on others to support them by providing care, these considerations may play a significant role in the choices they make.

This is not in itself a bad thing- people do not live in isolation, and enabling people to live within the network of support provided by friends, family members and even professional care providers is a critical component of human dignity and flourishing for many. However in some instances these considerations can be inappropriately influential, either deliberately or inadvertently. Factors such as undue, or inappropriate, influence are not specific to decision-making by disabled people; nonetheless steps should be taken to ensure that their decision-making – particularly decision-making with serious consequences, such as extensive or potentially high-risk medical treatment, or decisions about care – are not a consequence of inappropriate consideration of factors of this type.¹⁴ The law should recognise that family members, carers, and others have a role in helping people make decisions, particularly in the context of supported decision-making; however it should also ensure that adequate safeguards are in place to protect people from having *all* their decision-making power eroded. Not to do this creates the potential for others to usurp the decision-making powers held by the person, and arbitrarily act as a substitute decision-maker, rather than a supporter.

Anti-discrimination law

Q6: 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?

A6: This question initially raises issues around the use of the term ‘legal capacity’ in this context. Elsewhere in the paper it appears to be used in the narrower sense, which relates to the ability of a person to make legally recognised decisions. The

¹³ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (Oxford University Press, 6th ed, 2009) 101.

¹⁴ Article 12 of the *Convention on the Rights of Persons with Disabilities* specifically imposes an obligation on states to implement safeguards to ensure that persons with disability exercising capacity are doing so free from undue influence or conflicts of interest.

Disability Discrimination Act deals with discrimination against people exercising more than their ability to make legally recognised decisions- instead it currently- and rightly in our view- protects the right of a disabled person to exercise all aspects of their legal personhood, which encompasses rights, powers, benefits and obligations, in addition to the comparatively narrow power to make decisions. Its emphasis is on capacity on this broader sense, rather than on disability *per se*: it makes it an offence to discriminate against a person on the basis of their disability, but permits exceptions where that disability is such that it would limit or eliminate the person's capacity to meet their responsibilities, or access their benefits- even if reasonable adjustments are made.

No amount of 'reasonable adjustment' has to date enabled a blind person to pilot a commercial aircraft in a manner that will assure passengers and regulators of its safety, for example; or allowed a double amputee to deploy effectively as a commando. However if reasonable adjustments can be made to overcome any impairment to a person's capacity caused by their disability, it is right that implementation of those adjustments should be required. The current legislation achieves this objective; we submit that any less than satisfactory outcomes arising under the legislation may have more to do with interpretation of what is 'reasonable' by way of adjustment than the legislation as a whole.

Noting that the term 'reasonable' is used in order to make the legislation applicable to the widest possible range of situations, nonetheless some guidance as to what should be considered in determining 'reasonableness' – cost, size of business, impact on other employees/customers/tenants etc – may be useful.

We also note that the *Disability Discrimination Act* requires that someone initiate enquiries in response to making a complaint. For many people, making that formal complaint represents a significant obstacle. Pursuing that complaint is also subject to perceptions of futility, as in many instances that penalties applied for breaches are minor.

Without wishing to pre-empt the issues regarding access to justice and people with disabilities, we believe that it would be beneficial if the Disability Discrimination Commissioner was adequately resourced to undertake own-motion enquiries, and the penalty provisions within the *Disability Discrimination Act* enhanced to ensure that breaches of the Act are meaningfully addressed.

General protections provisions

Q7: 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?

A7: As noted above, we think there is much to be said in favour of consistency between and within jurisdictions. We would recommend that the *Fair Work Act 2009* (Cth) be amended to reflect standardised criteria for capacity, and recognition of substitute and supported decision-making frameworks.

Q8: 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?

A8: As per above

Administrative law

Q9: 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?

A9: As noted above, the key legal issue is capacity, rather than disability. If a person with disability has capacity, they are entitled to equal recognition before the law- noting that there may be significant logistical barriers in place impeding their ability to exercise that recognition, but which are more appropriately addressed through Access to Justice reforms.

It is axiomatic that in some instances differences in capability will be recognised in law. Lack of capacity is one those instances, and is not inherently discriminatory on the basis of disability.

Competition and consumer law

Q10: 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?

A10: Please see A9.

Privacy

Q11: 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?

A11: Please see A9.

The National Disability Insurance Scheme

Q12: 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?

A12: Please see A9.

Q13: 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?

A13: It is important to note that recognition of a child's decision-making capacity about medical treatment at law is not determined by age. Rather, the Australian position is based on the Gillick test for competence,¹⁵ which requires that a child has a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law."¹⁶

Children are also actively involved in decision-making about their welfare prior to attaining a legal majority under the *Family Law Act*. This recognition of decision-making capacity is based on capacity and understanding, not disability; the disability of the child has no impact on recognition of their capacity, apart from any impact that disability may have on their capacity. Provisions relating to appointment of a child's representative should be based on this consideration. Furthermore, there may be sound reasons for requiring that communication involving a child should reflect any rulings made by the Family Court with respect to parental responsibility, to ensure the welfare of the child.

Q14: 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?

A14: As discussed above, these provisions should be consistent- see A 4.

Employment

Q15: 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?

A15: As per above.

Citizenship rights, public service and board participation

Q16 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?

A16: As per above

Q17: 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?

A17: As per above.

¹⁵ *Department of Health & Community Services v JWB & SMB* ("Marion's Case") [1992] HCA 15; (1992) 175 CLR 218.

¹⁶ Lord Scarman, *Gillick v West Norfolk & Wisbech Area Health Authority* [1985] UKHL 7.

Q18: 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?

A18: As per above.

Q19: 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?

A: As per above.

Q20: 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?

A20: Similar to the discussion on the *Disability Discrimination Act* above, the determining criteria here should be capacity – ability to perform the role of a juror successfully – rather than disability *per se*. In considering this issue, it would be useful to see information about the extent to which people with disabilities are affected by this issue, noting that the roles of a juror – against which capacity should be measured- have been well defined by the court.

Q21: 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?

A21: As per 9 above.

Q22: 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?

A22: On a day by day basis Australia has three default identity documents: the passport (Commonwealth), the drivers licence (state/territory governments) and financial transaction cards (debit and credit cards issued by private sector entities). Individuals will sometimes complement those default cards with one or more other cards of varying authority (eg ‘proof of age’ or ‘seniors’ cards) and with hardcopy documents such as local government rates and electricity invoices.

Although we have not encountered authoritative data, there are indications that some people – with or without disabilities – are concerned with idiosyncratic interpretations by business and nongovernment entities of ‘100 points’ requirements and with the assumption by some gatekeepers that a ‘proof of age’ card must be held and displayed by anyone who does not have a drivers licence (ie people who are legally blind) or passport. As at least one submission to the Commission has noted, people should not have to identify themselves with a proof of age card except where age is an issue (eg to gain access to age-restricted premises). We suggest that the Australian governments should signal respect for people with disabilities by restyling their proof of age cards as government identity cards.¹⁷ More broadly, they should review the charges and procedures relating to those cards.

¹⁷ Critics of this suggestion will presumably assert that renaming the proof of identity card will foster identity crime. The reality is however that identity crime is occurring with proof of age cards –

Access to justice, evidence and federal offences

Q23: 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?

A23: As per above.

Q24: 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?

A24: As per above.

Q25: 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?

A25: As per above.

Social security, financial services and superannuation

Q26: 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?

A26: As per above.

Q27: 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?

A27: As per above.

Q28: 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?

A28: As per above.

Q29: 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?

A: As per above.

typically involving young people altering photo-id to improperly gain entry to entertainment venues – and drivers licences. A national card is not necessarily abhorrent in relation to privacy; from a privacy perspective the key concern is whether any card or other identify is situated within a legal and administrative framework founded on the privacy principles that are integral to human rights.

Q30: 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?

Q31: 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?

A31: As per above.

Q32: 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?

A32: As per above.

Q33: 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?

A33: As per above.

Health care and aged care

Q34: 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?

A34: A key issue facing the aged and people with disabilities in the health care sector and aged care sector is that few have the resources (including expertise, professional contacts, physical resilience and access to communications) that would enable them to vigorously exercise their rights through litigation or complaint to a conciliation or oversight body. It is easier to articulate statements of aspiration or best practice (and even to mandate particulate statements) than it is to ensure that people who are disadvantaged – but regrettably often not acknowledged as such – are able to give effect to their rights.

We suggest that the issue can be addressed by a national Health & Aged Care Advocate, a statutory position that is appropriately funded, has the requisite expertise and commitment, reports directly to Parliament and is seen by the community at large to engage in own motion investigations on a timely basis.¹⁸

Overall there is need to look beyond legislation and consider how that legislation (or policy statements and cross-jurisdictional protocols) are given effect.

Q35: 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?

¹⁸ The autonomy of an Advocate is important, given concerns that ongoing funding stringencies – for example those lamented by the Commonwealth Ombudsman and Office of the Australian Information Commissioner – are tangibly eroding the functionality of key rights agencies. Own motion investigation is important as a way of building the Advocate's legitimacy and ensuring that its operational model is not belated and reactive.

What changes, if any, should be made to Commonwealth laws and legal frameworks relating to aged care to address these issues?

A35: As per above.

Restrictive practices

Q36: In what ways, if any, should the proposed National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector be improved?

A36: As per above.

Q37: 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?

A37: Please see discussion above at A4.

Marriage, intimate relationships, parenthood and family law

Q38: 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?

A38: The presumption in Australian law is that people are free to enter into marriage.¹⁹ That presumption is bounded by requirements regarding age, gender, the absence of coercion, the lack of an impediment in the form of a concurrent marriage and understanding on the part of the individuals entering into marriage as a legal relationship.²⁰ Disability *per se* does not mean that marriage is void at that time or thereafter. There is for example no requirement in law for consummation (nor should there be) and the legal relationship does not automatically cease if one party experiences dementia on a transient or ongoing basis.

Understanding on the part of the parties is and should remain a prerequisite for a valid marriage and civil partnership. Although there are isolated indications that celebrants should have been more zealous in seeking to discern whether individuals have capacity, data on this point is limited.

It should be noted that marriage has a specific legal meaning distinct from any intimacy. As a binding legal agreement, inherent with responsibilities as well as rights, it is of fundamental importance that parties *entering* a marriage understand what it is they are binding themselves to.

For people who lack the capacity to understand this, marriage should not be available.

Q39: What issues arise in relation to people with disability and intimate relationships that may affect their equal recognition before the law or ability to

¹⁹ The same presumption and requirements are evident in the Australian civil partnership regimes.

²⁰ We note and condemn as contrary to flourishing a range of eugenicist, class or other discriminatory restrictions that are evident in marriage as a legal institution over the past 400 years. Mechanisms such as certification of physical and psychological 'fitness' for all people wishing to enter into marriage/partnership are inappropriate

exercise legal capacity? What changes, if any, should be made to Commonwealth law and legal frameworks to address these issues?

A39: Consistent with the preceding comments regarding the importance of avoiding a ‘one size fits all’ conceptualisation of ‘disability’ and respecting diversity we suggest that questions regarding intimacy in practice often fall outside the law. It should be uncontentious that people with disabilities may have a same sex affinity and more broadly may wish to engage in sexual expression, a facet of human identity that is consistent with dignity and implicitly with the foundational human rights agreements.²¹ In practice there are indications that carers are on occasion inappropriately restricting that expression on the basis of idiosyncratic moral codes or purely personal distaste rather than on legitimate grounds such as a reasonable perception that the individual will be financially or otherwise exploited. Individuals who experience that restriction will typically not be in a position to effectively assert and enforce their rights through litigation or through formal recourse to an advocate.

The articulation of a national standard for capacity should address some of the concerns highlighted at pages 84 through 85, particularly if complemented by non-statutory best practice guidelines for carers. People with disabilities should not be objectified and we accordingly advise against permitting sexual intercourse with people who in law are unable to consent because of cognitive incapacity. We note the importance of context and instance by instance decision-making. In that respect we draw the Commission’s attention to jurisprudence in the United Kingdom that is explicitly respectful of diversity and informed by European Human Rights law.²²

The Commission recognises inconsistencies in service provider facilitation of access to sexual services. Given our preceding comments about a coherent national approach – people in essence should not be regarded as less human simply because they are on the wrong side of a state/territory border – we suggest that this inconsistency should be addressed through positive national protocols. Those protocols should be tied to Commonwealth funding, ie jurisdictions that do not abide by the protocols should forgo Commonwealth support.

We suggest that a body such as the Australian Institute of Health & Welfare be tasked with identifying the implementation of those protocols and reporting on any abuses. We recognise that facilitation is contrary to deeply held beliefs of some people in the community and personnel within some service providers. Both the Commission in its final report and the Commonwealth Government in responding to that report have an opportunity to foster a dialogue about the humanity of people with disabilities.²³

²¹ We note that the agreements typically refer to the impermissibility of restrictions on ‘family’ or ‘fertility’. Our contention is that the agreements should be read positively as encompassing the flourishing of people whose affinity is heteronormative and whose sexual expression is not necessarily directed to reproduction.

²² *D Borough Council v AB (Rev 1)* [2011] EWHC 101 (COP); *Re E (an Alleged Patient)*; *Sheffield City Council v E and S* [2004] EWHC 2808 (Fam), [2005] Fam 326, [2005] 1 FLR 965; *X City Council v MB, NB and MAB (by his Litigation Friend the Official Solicitor)* [2006] EWHC 168 (Fam), [2006] 2 FLR 968; *Local Authority X v MM and KM* [2007] EWHC 2003 (Fam), [2009] 1 FLR 443; and *A Local Authority v SY* [2013] EWHC 3485 (COP).

²³ In that respect we note that Australian governments have on occasion provided a clear and effective leadership in addressing matters, such as the prevention of HIV in the gay community, that some people have regarded as distasteful or contrary to religious values. The Commission’s inquiry is an opportunity for stakeholders to show leadership through a respectful and nuanced affirmation of the needs and rights of people with disabilities.

Q40: 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?

A40: Please see comments above at A13.

Particular disability communities

Q41: How do Commonwealth laws and legal frameworks relating to equal recognition before the law and capacity affect people with disability who are: (a) children; (b) women; (c) Aboriginal and Torres Strait Islander; (d) from culturally and linguistically diverse backgrounds; (e) older; (f) lesbian, gay, bisexual, transgender or intersex; or (g) living in rural, remote and regional areas?

A41: Para 314 of the paper notes concerns regarding the operation of religious exemptions in relation to the LGBTIQ communities. Those exemptions are of increasing significance because the ongoing restructuring of the human services sector (in particular health care and aged accommodation but extending to other matters such as employment services) means that organisations with a religious affiliation, including some that operate on a quasi-commercial basis, are often the dominant or only service providers in a particular location.²⁴ If those entities are receiving public funding it is reasonable that they adhere in principle and practice to policies that are consistently non-discriminatory. The paper has referred in places to paternalism. It is important that religious organisations respect diversity and for example not give effect to doctrinal heteronormative values under the guise of 'good' or 'standard' medical practice and service delivery.

²⁴ A consequence is that consumers in reality may not enjoy the freedom to choose service providers, for example aged care accommodation, that is assumed by commentators who are unaware of questions regarding market concentration, consumer mobility and so forth.