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People with Disabilty Australia (PWDA) The Australian Centre for Disability Law (ACDL) The Australian Human Rights Centre (AHRCentre)

Australian Law Reform Commission (ALRC): Equality, Capacity and Disability in Commonwealth Laws Discussion Paper May 2014

Submission July 2014

About Us

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

The Australian Centre for Disabilty Law (ACDL) is a community legal centre which specialises in disability discrimination and human rights law and policy. We provide legal advice and representation to persons with disability and their associates. ACDL campaigns to change and improve the law for a society where people with disability will be able to participate in all aspects of life. We undertake law reform, continuing legal education, and community legal education activities.

The Australian Human Rights Centre (AHRCentre) aims to promote public awareness and academic scholarship about domestic and international human rights standards, laws and procedures through research projects, education programs and publications. The Centre brings together practitioners, research fellows and student interns from Australia and internationally to research, teach, and debate contemporary human rights issues.

- 1. PWDA, ACDL and the AHRCentre warmly welcome the ALRC Discussion Paper Equality, Capacity and Disability in Commonwealth Laws, and its thorough consideration of the views submitted by the myriad stakeholders who have an interest in this Inquiry. Our organisations have substantial expertise in this area of the law, and a long history of advocating for the recognition of legal capacity for people with disability in Australia and internationally. PWDA and ACDL were at the forefront of civil society's involvement in the negotiation of the UN Convention on the Rights of Persons with Disabilities (CRPD), and see this review as a once in a generation opportunity to significantly progress the implementation of Article 12 into Australian law and practice. For more information on our international engagement on the CRPD, including Article 12, please see the website of the Australian Civil Society Parallel Report Group to the CRPD http://www.disabilityrightsnow.org.au/ and the UN Ad Hoc Committee pages of the PWDA website http://www.pwd.org.au/issues/un-ad-hoc-committee-meetings.html
- 2. This submission should be read with reference to our previous <u>submission to the ALRC Issues Paper</u> <u>regarding Equality before the Law in January 2014</u>, and our <u>submission to the UN CRPD Committee</u> regarding the Draft General Comment on Article 12 of the CRPD.

Introduction

- 3. The Discussion Paper puts forward proposals for National Decision Making (NDM) Principles and a Commonwealth Supported Decision Making (CSDM) model, then goes on to consider how the application of these principles and model may affect Commonwealth law.
- 4. The authors of this submission agree that a national framework must be created, but disagree with the development of an "ability test", Discussion Paper Proposal 3-7, which a person has to pass in order to be considered capable of decision making and thus to have their capacity to act (legal agency) recognised. Commonwealth laws should not be amended to include such a test. This formulation would not realise equality before the law for people with disability, and would not go far enough in establishing and implementing the regimes of support necessary to adequately support people with disability to exercise their legal agency.
- 5. The "ability test" runs counter to the principles and human rights premises that the Paper puts forward as arguments for the tests development. The inclusion of any kind of functional test of capacity would be a continuity of a binary model whereby some people have ability and some do not. Application of the "ability test" would merely provide an overarching exception to the right to equal capacity before the law, and embed discrimination against people with disability further into Commonwealth laws.
- 6. What is required is a regime that recognises that all people have legal agency, but that some people may require support in order to exercise it. When this premise is genuinely accepted, the question shifts to how to create a mechanism through which a person can express their will and preferences, and have those expressions of legal agency recognised as decisions before the law. The authors suggest that the answer is to create a mechanism of support provision which fulfils the requirements of any person who needs it in order to exercise their legal agency.
- 7. In doing this, the test as to whether the will, preference or decision of a person should be recognised by the law, turns on the integrity of the support process that was used to express and communicate that decision. It follows that it is supports that must be tested on their functional ability to meet the requirements of a person to make and/or communicate a decision to a third party.
- 8. The remainder of this submission outlines the mechanisms that need to be created to develop a regime of supports that would: be responsive to the needs of any person who required them to exercise their legal agency; test the integrity of supports used to exercise legal agency; create certainty in the application of the law; and apply uniformly to all people, in all situations, and across all areas of the law.

A National Framework for Equality before the Law

9. This submission outlines an alternative version of Principles, the National Framework for Equality before the Law. These Principles are in harmony with Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD), and can also coherently be applied to Commonwealth laws in order to fulfil the realisation of other civil and political rights that are dependent on Article 12. For example,

access to justice, the right to political participation, the right to bodily integrity, and the right to live in the community.¹

- 10. The interpretation of CRPD Article 12 underlying the formulation of the proposed National Framework outlined below is that:
 - Every person has the right to equal recognition before the law. This includes the capacity to have rights and the capacity to act on those rights (to exercise legal agency) as well as to have those acts recognised by the law.
 - This is a non-derogable civil and political right requiring immediate implementation.²
 - Legal agency is exercised when will and preference is expressed.
 - Every person has the right to support to express their will and preference if required. For some people this may include decision making support.
 - The State is obliged to provide the support necessary for a person to express their will and preference. As equality before the law is a civil and political right there is no limit to the level of support that must be provided to achieve this.
 - Failure to provide adequate support, including the inadequate resourcing of support options, may constitute discrimination.
 - Where there is no formulation of support that can determine will and preferences then legal agency is not being exercised. In this circumstance a representative may be appointed to make decisions based on the previously expressed will and preference of the person and/or their human rights as applicable to the situation.
- 11. To summarise, the onus is on the support to facilitate the expression of a person's will and preference and hence their legal agency. Any test of a person's ability to exercise their legal agency is actually a test of whether the supports provided to the person are adequate and appropriate to the task in hand. If not they should be altered until will and preference can be expressed, or it becomes apparent that this is not possible. The CRPD does not provide for a circumstance whereby a person is tested on their ability or impairment type.

Underlying premises of the proposed National Framework for Equality before the Law

In formulating the National Framework for Equality Before the Law (the National Framework), the following premises have been applied:

- i. The National Framework should be applied nationally and in all areas of Commonwealth and State and Territory law.
- **ii.** The National Framework should be the basis from which State and Territory guardianship law and practices are reformed.
- **iii.** Commonwealth laws should be amended only to the extent that is required to permit the application of the National Framework, to remove references to tests of mental capacity, legal capacity, unsound mind, ability, competence or any other discretionary exclusions based on actual

¹ Articles, 13, 29, 17, 19 CRPD respectively.

² By virtue of Article 5 and 12 of the CRPD.

or perceived disability, and to remove the role of third parties such as medical practitioners and courts from making decisions about a person's legal capacity.

- **iv.** The language of the National Framework should be disability neutral, albeit disability responsive. This would acknowledge that all people have equal recognition before the law, all people utilise supported decision making to some degree, and that any person may experience impairment that means they require support to exercise their legal agency at some point in their life.
- **v.** The National Framework should be a mainstream instrument outlining the principles and processes relevant to the entire spectrum of ways to exercise legal agency. These are:
 - Independent exercise of legal agency
 - Exercise of legal agency with support, including decision making support
 - Exercise of legal agency through an agent, such as power of attorney or advance directive
 - Representation

A person may exercise their legal agency using a combination of these methods at any one time.

- **vi.** The National Framework should be inclusive of all support types required to exercise legal agency. Supported decision making is only one of those options; other examples include interpretation services, assistive and communication technology, or physical modifications of the environment.
- vii. The National Framework should recognise the role of formal and informal supports.
- **viii.** An independent body, the National Legal Capacity Support Agency, should be established to regulate and administer the support arrangements made under National Framework.
 - ix. The National Legal Capacity Support Agency should utilise transparent, flexible and person centred approaches; provide clarity and instil the confidence of stakeholders; and raise awareness and understanding of the role of support for the exercise of legal capacity.
- 12. These premises provide further guidance as to what the aim of this Inquiry really should be: to create a universally applicable mechanism through which people can express their will and preferences, and to have that will and those preferences recognised as decisions under the law. Thus the Inquiry and proposed framework are not directly concerned with people with disability per se, but on how our laws and policies should operate to enable the realisation of fundamental rights in a fair, accessible, and non-discriminatory way.
- 13. Goals such as maximising the autonomy and independence of people with disability, promoting ability, valuing contribution, and enabling social and economic participation are all necessary to ensure that people with disability are included in our communities. However, what people with disability need as a result of this Inquiry is a mechanism through which to exercise legal capacity as is their right.
- 14. It is true that history has marginalised people with disability, but focusing on the above goals still places the person with disability as the focus of 'improvement', when it is the environments in which they live which are the disabling factors. These goals can be considered in parallel, but should not be emphasised at the expense of a clear focus on how the provision of supports to exercise legal capacity must be improved.

- 15. Changing laws and implementing new policies regarding legal capacity is only the first step in realising the right to equal recognition before the law for people with disability. Prejudicial community attitudes need to be addressed; awareness of support for exercising legal capacity has to be raised; the capacity of communities to provide support for legal capacity has to be developed; and the countless other barriers to inclusion for people with disability need to be dismantled. There is no escaping the reality that realising the right to equal recognition before the law for all people in our community requires resourcing from the grassroots up, as well as the top down.
- 16. As a prerequisite this resourcing must include the allocation of resources to support services to increase the quality and availability of all types of support. For example, Auslan interpreters, supported decision making organisations, accessible buildings, and information in accessible formats. The greater the investment in these services, the simpler the application of the National Framework and consequently the application of Commonwealth laws for people who require support to exercise their legal capacity.

A new National Legal Capacity Support Agency

- 17. Moreover, a new Commonwealth Structure is required, the proposed new National Legal Capacity Support Agency (the National Agency), to:
 - provide expertise on the adequacy and appropriateness of supports;
 - regulate support providers and representatives; and
 - act as a complaints body and mediator between people, their supports and third parties.
- 18. A central regulating body is required to create consistency in the provision of support arrangements and uniformly assess the adequacy of supports. This would remove the role of doctors, courts, tribunals or other agencies to make decisions about whether a person is or is not able to exercise legal agency. The consideration of whether a person's supports are or are not adequate is between the person, their support or supporter, and the National Agency. Third parties may wish to raise concerns as to the adequacy of support, or provide information as to the legal context in which support may be required, but they do not have the expertise to be making decisions about support arrangements.
- 19. For example, the National Disability Insurance Scheme Agency may believe that a person requires decision making support to manage their disability support package. In this case they should contact the National Agency who will investigate further. It would not be in their remit to appoint a nominee to make decisions on the persons behalf based on their own assessment of the persons support needs or their 'best interests'. This option merely removes legal agency from the person and does nothing to address their support needs.
- 20. The National Framework should provide the basis for reform of State and Territory guardianship laws, with the proposed National Agency fulfilling a central role in this revised system. A new structure is required to implement a national and universal approach and to adequately address the magnitude of the shift from 'best interest' substitute decision making by guardians to representative decisions based on a balancing of human rights. This latter task requires an expertise and understanding of human rights that people who are currently eligible to be guardians do not necessarily have.

21. The proposed National Agency should also be responsible for the guidance and training of potential informal and formal support people, providing information about support options for the general public, public services and mainstream services, awareness raising about the regime, capacity building of disability support organisations, and training of government agencies in the facilitation of supported decision making. This would also assist in consolidating the move away from the medical approach to legal capacity and towards the social model of supporting the exercise of legal capacity.

Proposed National Framework for Equality before the Law

22. This framework is an amended and combined version of the proposed National Decision Making Model and the Commonwealth Supported Decision Making Model as outlined in the Discussion Paper.

Principle 1 – The Right to Make Decisions

- 1. Every adult has the right to exercise their legal capacity. This includes the right to make decisions that affect their life and to have those decisions respected.
- 23. This principle is of universal application to all people, and reflects the right to legal capacity in both the International Covenant on Civil and Political Rights (ICCPR) as well as the CRPD. It also introduces the notion that decision making is a fundamental element of exercising legal capacity.

Principle 2 – The Right to Support³

- 2. Every person who may require support to exercise their legal capacity must be provided with the support required to express their will and preferences. This includes support necessary for them to make, communicate, and participate in decisions that affect their lives.
- 24. This principle is also of universal application. It creates a right for a person to receive support and introduces the notion that the expression of will and preference is the pivot on which the integrity of support is judged. It then sets out the elements of the decision making process that can be supported.
- 25. This approach would be inclusive of any person with an impairment. For example, people who require information in alternative formats; people who require augmentative communication devices to communicate, people who need accessible environments in order to participate in decisions about their life; and people with cognitive impairment who may require supported decision making.
 - 2 (a) A person who requires support should be able to appoint a supporter or supporters at any time:
 - where a supporter is appointed, ultimate decision making authority remains with the supported person;
 - any decision made with the assistance of a supporter should be recognised as the decision of the supported person; and
 - a person should be able to revoke the appointment of a supporter at any time, for any reason.
 - 2 (b) Support may include:

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³ National Decision Making Principle 2 (Proposal 3-3) is reflected in 2(a). There is no need for support guidelines (proposal 3-4) as these are merely a reiteration of principle 2 (a). Appointment and Recognition of Supporters (Proposal 4-3) is now integrated into Principle 2(b). Aspects of Potential Roles of a Supporter (Proposal 4-4) are integrated into Principle 2(c). Aspects of Supporter Duties (Proposal 4-5) are implicit through Principle 2.

- support to obtain, receive or understand information relevant to a decision and the effect of a decision:
- support to retain information necessary to the extent necessary to make a decision;
- support to use or weigh information as part of the process of making a decision;
- support to communicate a decision to third parties;
- 2 (c) Support persons may also:
- provide advice;
- handle the relevant personal information of the person;
- endeavour to ensure the decisions of the person are given effect; and
- assist the person to develop their use of decision making supports.
- 2 (d) In addition to formal support providers, the role of families, carers, and other significant persons in supporting persons to exercise their legal capacity should be acknowledged and respected.
- 26. These principles outline the appointment of a supporter, what roles support may fulfil, what other roles support persons may fill, and acknowledges the role of families and carers. 2(c) provides additional tasks that a support person or support organisation may undertake and 2(d) recognises that informal and formal support arrangements can exist.
- 27. All of these principles have universal application. For example, a person with a hearing impairment may appoint a support person in the form of an Auslan interpreter to communicate information about a decision to a third party. A person with episodic psychosocial disability may appoint a support person to assist them in using information to make a decision about where to live, and then to use their personal information in order to make this happen.
- 28. 2(b) reverses the "ability test" put forward in the Representative Decision Making Guidelines (Proposal 3-7) and creates a functional assessment of support as opposed to a functional assessment of a person. If a person needs support to express will and preference and adequate support is provided then they are exercising legal agency and their decisions must be recognised before the law. If supports are not available or if they are inadequate to facilitate this expression then the decisions do not have to be recognised before the law as the integrity of the support process is lacking. This reflects a failure of support provision, as opposed to an inability of the person.

Principle 3 – Implementing Will and Preference⁴

- 3 The will, preferences and rights of persons who may require support to exercise their legal capacity must direct decisions that affect their lives. This includes people who use decision making supports.
- 3 (a) Safeguards to ensure respect for will, preferences and rights include:
- that support persons are free from conflict of interest and undue influence;
- that the National Legal Capacity Support Agency acts as regulator, arbitrator, investigator and complaints body regarding the integrity of decision making support arrangements.
- 3 (b) A person may appoint an independent Agent to implement their will and preferences on their behalf. This may include:
- the implementation of advance directives; and

⁴ National Decision Making Principle 3 (Proposal 3-5) is reflected in 3(a).

- the power of attorney to carry out specific acts according to pre agreed instructions.
- 29. These Principles reiterate the centrality of will and preference as the essential elements around which support to exercise legal capacity is utilised. It also reaffirms the supported person as the decision maker as established in 2(a), and in doing so implies that safeguards are required in order to secure this.
- 30. 3(a) introduces safeguards to protect the integrity of the support process, including reference to a central body, the National Legal Capacity Support Agency, to resolve conflict between support persons, people who are being supported, and third parties.
- 31. This would primarily apply to decision making support arrangements. For example, resolving a conflict in which a support person has acted improperly or outside of their role, or otherwise misrepresented the will and preference of the person they are supporting. This is significant because the supported person is legally responsible for the consequences of the decisions they are making. Therefore, an authoritative body is required through which disputes can be resolved, especially if they have had adverse consequences for the supported person and their relationship with a third party.
- 32. 3(b) introduces the concept of an Agent into the spectrum of support types for the exercise of legal agency. It is important that this is included so that advance directive and power of attorney regimes fall under the same rubric and safeguards as other decision making regimes.

Principle 4 – Representation of Rights, Will and Preferences⁵

- 4 Where the will and preferences of a person cannot be determined through the provision of support, an independent representative may be appointed:
- the representative must give effect to what the person would likely want, based on all the information available, including consulting with supporters.
- if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.
- 33. Representative decision making is not supported decision making, or 'fully supported' decision making as it is described in the Discussion Paper. This is because the person is not directly involved in the decision making process, albeit that their previous will and preferences are being taken into account. Representative decision making is decision making by an independent person which applies only when support cannot facilitate an expression of will and preference.
- 34. Principle 4 contains the "test for representation" and it is a high threshold. It can only be reached in circumstances where current will and preference cannot be determined despite all efforts being made to provide adequate supports where there is no functional support that can meet the requirements of the person. Any circumstance that does not meet this threshold should not result in the appointment of a representative decision maker.

⁵ Will, Preferences and Right Guidelines (Proposal 3-6) are reflected in 4(a) and (b) as far as they remain relevant without duplication or amendment. National Decision Making Principle 4 (Proposal 3-8) is no longer necessary as it is implicit in 4(b). Safeguards Guidelines (Proposal 3-9) is reflected in 4(d). Potential Roles of a Representative (Proposal 4-7) and Representative Duties (Proposal 4-8) are irrelevant.

- 35. There is no justifiable or logical reason why a person who receives adequate support to exercise legal agency should require the voluntary appointment of a representative. The only situation whereby a person is able to voluntarily hand over decision making about their lives to another person is when they act through an Agent as per Principle 3(b). Advance Directives and Powers of Attorney are mechanisms that already exist for people who want others to make decisions on their behalf. Under the proposed National Framework people would be entitled to support in making those arrangements if required.
- 36. Moreover, there is no justifiable or logical reason why an agency should be permitted to appoint a representative for another person. If any agency or other third party believes that a person may benefit from support, including supported decision making, they should refer them to the proposed new National Agency for information on how this can be obtained and/or provide advice to the Agency on the kinds of decisions that the person is required to make.
 - 4 (a) The opportunity to determine the will and preferences of a person may evolve or fluctuate over time.
 - 4 (b) The appointment of a representative decision maker must be limited in scope, be proportional and tailored to the person's circumstances, and apply for the minimum time possible.
 - 4 (c) Decisions and interventions made by representatives must be:
 - the least restrictive of the person's human rights;
 - subject to appeal; and
 - subject to automatic regular, independent and impartial monitoring and review.
 - 4 (d) Representatives are accountable to the National Legal Capacity Support Agency for their conduct.
- 37. 4(a) is an inverse application of the principle that a person's capacity may fluctuate over time. The 4(a) formulation puts the onus on the performance of supports in the determination of whether will and preferences are being expressed. Coupled with 4(b) it also strengthens the obligation to continually reassess the opportunity for support to assist a person to exercise their legal agency. 4(b)(c) and (d) are all safeguards to regulate the performance of representatives.

Examples of application to Commonwealth law

The NDIS

- 38. The National Disability Insurance Scheme (NDIS) Act 2014 should be amended to remove the nominee provisions. If a person requires support, including decision making support to engage with the NDIS, to manage the financial aspects of their support package, or to receive supports then this should be arranged with reference to the National Framework Principles. If a person cannot be supported to exercise legal agency then a representative should be appointed by the National Agency.
- 39. The Commonwealth should fund and build the capacity of Disabled Persons Organisations (DPOs) and independent advocacy organisations to provide decision making support to participants and potential participants of the NDIS. This would raise awareness of supported decision making as an option, increase the supply of support, and reduce situations whereby representatives may be appointed due to a lack of adequate support. The NDIS should also fund supports that enable people to exercise their legal capacity as core elements of their support packages where appropriate, such as providing communication aids and equipment for a person to understand information and communicate decisions.

Election Matters

- 40. The Commonwealth Electoral Act (CEA) 1918 should be amended to remove the 'unsound mind' provisions in Section 93(8)(a). All Australian citizens of voting age are required to vote and must be permitted to exercise that right with support where required. Supports in this context may require the provision of information and ballot papers in alternative formats, accessible voting procedures, or support to mark, fold and deposit a ballot paper for example.
- 41. A person who does not vote is liable for a fine by virtue of section 245 of the CEA. A lack of support to vote should be considered a "valid and sufficient reason for failing to vote" as provided by section 245(4). This would cover instances where a person was too ill to vote, their intended support service failed them, or where supports were not able to facilitate an expression of will and preference. None of these options necessitate a person's removal from the electoral role, and all retain the recognition of the person's legal capacity to make a decision about electoral matters.

We thank the ALRC for the opportunity to contribute to this Inquiry, and we would be happy to participate in further consultation on any of the matters raised in this submission.

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