67. Caxton Legal Centre

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**RESPONSE TO AUSTRALIAN LAW REFORM COMMISSION INQUIRY INTO EQUALITY, CAPAPCITY AND DISABILITY IN COMMONWEALTH LAWS**

**January 2014**

**Response to ALRC Equality, Capacity and Disability in Commonwealth Laws**

**Q.1. The impact of the Interpretative Declaration on:**

**a. provisions for supported or substituted decision making arrangements, and**

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

**Response in summary:**

The Interpretative Declaration on Article 12 may conflict with the Concluding Observations and the General Comment of the Committee in October and November of 2013 respectively. However, it may be argued that:

1. given the projected exponential increase in the ageing population and the consequent increase in the incidence of terminal cognitive diseases such as dementia and Alzheimer’s, coupled with the factor of social isolation and sparse or non-existent support networks for many older people, the retention of a process of formal substituted decision making may be essential.
2. It is possible that the constituency of the CRPD did not address this issue in light of the necessity to assure coverage of the human rights and freedoms of the disability community whose treatment has been so egregious in the past. Some evidence of this arises from the wording of the Committee’s Concluding Observations CRPD itself. In the comment on Article 5, Equality and non-discrimination, the Committee ”*recommends the State party to strengthen anti-discrimination laws to address intersectional discrimination and to guarantee the protection from discrimination on the grounds of disability to explicitly cover all persons with disabilities including children, Indigenous people, women and girls, hearing impaired, deaf, and people with psychosocial disabilities.”* This is not an exclusive list but it indicates the area of focus.
3. Regardless of the above issue, the provisions of the CRPD, the Concluding Observations and the General Comment have created strong pressure to invest in supported decision making regimes. Key factors in considering models should include monitoring of arrangements, provisions for accountability and regular and unscheduled review as safeguards against exploitation and abuse.
4. The social and legislative investment in supported decision making models which would confine guardianship to a genuine measure of last resort where there were no least restrictive alternatives would arguably be consistent with the provisions of Article 12 in recognizing people with disability before the law and their ability to exercise legal judgment.

**Provisions for substituted decision making arrangements**

It is arguable that the wording of Article 12(4) preserves a possibility of regimes of substituted decision making: “*measures that relate to the exercise of legal capacity…are proportional and tailored to the person’s circumstances.”*

However, in the Committee on the Rights of Persons with Disabilities: Concluding observations on the initial report of Australia, distributed on 4 October 2013, Australia was requested to review its Interpretative Declaration on Articles 12,17 and 18 in order to withdraw them.[[1]](#footnote-1) The Committee specifically notes its concern about the “*possibility of maintaining the regime of substituted decision making and that there is still no detailed and viable framework for supported decision making in the exercise of legal capacity’* and recommends that the State party *“uses effectively the current inquiry process to take immediate steps to replace substitute decision making with supported decision making and provides a wide range of measures which respect the person’s autonomy, will and preferences and is in full conformity with article 12 of the Convention, including with respect to the individual’s right, in his/her own capacity, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry and to work.”[[2]](#footnote-2)* 34:429

Further, in the General Comment on Article 12 released on 25 November 2013, the Committee on the Rights of Persons with Disabilities noted in the introduction that, “*a person’s status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in Article 12.”[[3]](#footnote-3)*

The Committee declares: “*Support in the exercise of legal capacity must respect the rights, will and preferences of the persons with disabilities and should never amount to substitute decision making.* *Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity*.”[[4]](#footnote-4)

A detailed analysis of the discussions and debates that influenced the Committee’s construction of capacity in the CRPD is provided by Amita Dhanda[[5]](#footnote-5) who comments that the wording of Article 12 was finalised only after an exhaustive debate over the distinction between the legal capacity to act and the legal capacity for rights.[[6]](#footnote-6) Dhanda argues strongly against the “dilution of the universal reach of the capacity formulation” in order to reach the conclusion that Article 12 supports the possibility of guardianship, and this argument is understandable in light of the egregious treatment of the disability community in the past. She notes that even if it is conceded that the rule of substituted decision making is incorporated in the Convention for a relatively small proportion of the disability community, the impact would be...”*for questionable advantages to a small group of persons...all persons of disability would be disadvantaged.”[[7]](#footnote-7)*

However, the Concluding Observations and the General Comment of the Committee in October and November 2013 respectively, appear to entertain no equivocation over the possibility of the retention of guardianship.

The fact that the Concluding observation and the Draft General Comment appear to rule out the possibility of guardianship raises other issues however.

 In the Victorian Law Reform Commission’s Report into Guardianship[[8]](#footnote-8) the Guardianship and Administration Act (Vic) is identified as a response to the recommendations of the Minister’s Committee on Rights and Protective Legislation for Intellectually Handicapped Persons (Cocks Committee) to provide for the legal needs of persons with intellectual disability moving into community life following deinstitutionalisation.[[9]](#footnote-9) The Commission noted that the scope of the original Guardianship and Administration Act was widely viewed as directed towards people with an intellectual disability.[[10]](#footnote-10) It further commented that over time, people with age related disabilities have become significant users of the legislation and that with projected exponential increases in the ageing population, the incidence of dementia is predicted to rise accordingly –dementia is now the leading cause of disability in Australians aged 65 and over, and the prevalence of dementia doubles every 5 years from the age of 65.[[11]](#footnote-11) Given that dementia is a condition implying irreversible cognitive decline, those persons who have not made a prior enduring power of attorney or do not have informal networks to assist may need access to a guardianship regime to facilitate important decisions especially in the later stages of illness.

It should be noted that many older people – those most likely to suffer from dementia –simply do not have supportive extended family support networks to call on for supported decision making purposes. They may in fact be vulnerable to abuse and exploitation because of cognitive decline, other health issues, and the absence of other supporters. They may also be vulnerable to predatory behaviour from the attorneys holding enduring powers who have been appointed, and/or their existing family network. While there has been some research into the recognition of the interdependency of “normal” human decision making processes (ie a consultative process with others in the family or community) and the ways in which these can be accommodated within supported decision making, [[12]](#footnote-12)the weak point can be the changing nature of family structures.[[13]](#footnote-13) The reality is that for some persons with disability and especially for older people whose family arrangements may have been disrupted by bereavement, divorce, second and subsequent marriages (of the older person as well as of their children) there is consequent potential for shifting of personal loyalties and emotional dynamics as new individuals are accommodated within the family structure and others are lost to it.

While for many more fortunate people, both those who are older with disability and younger, a support network may function well, there will always be the necessity of a guardianship regime for that increasingly large group (rather than “small” as identified by Dhanda[[14]](#footnote-14)) of sufferers from illnesses such as dementia and Alzheimer’s which are terminal, for whom natural supports are not available or have been compromised, even prior to a profound loss of capacity.

**Guardianship regimes post CRPD**

In Queensland, the guardianship regime is predicated upon the general principles in the Guardianship and Administration Act (Qld) 2000 and the Powers of Attorney Act (Qld)1998 which are broadly consistent with the CRPD[[15]](#footnote-15)

The question for consideration is twofold:

Can a guardianship system remain as indicated by Australia’s Interpretative Declaration and still provide full recognition of people with disability before the law and their ability to exercise legal capacity? The key issue centres around the adequacy of support mechanisms to assist persons with disability in decision making, so that substitute decision making truly is the last resort.

**Substituted decision making and the assumption of global incapacity**

One of the current dangers with the current system of guardianship and substituted decision making is that once orders have been made by a tribunal appointing the Adult Guardian and Public Trustee, or an enduring power of attorney is active, there is an assumption commonly held by staff in residential care facilities and hospitals, and often by attorneys with enduring powers and families themselves, that loss of capacity of the adult is global. There is a widespread disregard of the general principles at a systemic level. Our service has been refused access to clients by staff in private psychiatric hospitals and nursing homes on the instructions of attorney’s intent on avoiding scrutiny for alleged exploitation and abuse, even though the client has called requesting help. We have experienced attorneys announcing “*I can do what I like.”*  Too often, the fact that an adult has a diagnosis of dementia is taken to mean that there is no capacity for any decision at all, whereas anyone who has worked with older people suffering even advanced dementia will know that there can be periods of lucidity.

It could be argued that failure to comply with the general principles is simply a matter of resourcing and to some extent this might be true. But experience with clients in the guardianship process indicates that failure to consider the principles is widespread. It may also be argued that tribunal processes are cheap and quick but the fact that guardianship exists within QCAT’s human rights jurisdiction emphasizes the centrality of the general principles. As Tait and Carney point out , the very accessibility of the guardianship system has always exposed it to the risk of “least restrictive alternatives” falling by the wayside. Perhaps some examination of the NZ system within the Family Court is worthwhile -which Tait and Carney report has the broadest range of non-guardianship options available to the guardianship body. [[16]](#footnote-16)

A matter of concern to the Senior’s Legal and Support Service at Caxton Legal Centre is the perception that guardianship orders are readily made, often without reference to the general principles, and without considering the least restrictive alternatives. People from CALD backgrounds and those with hearing impairments are particularly at risk of having their views overlooked or discounted, or being found to have impaired capacity when their responses to questions have not been understood.

Case study 1

Mr M-T was a 78 year old client who had made an excellent recovery from a stroke. During the period of acute illness, his son, from whom he was estranged, brought an interim application for guardianship and administration. Mr M-T had been a canny investor prior to his stroke, and when he called our service for assistance at the hearing, could still recite the banks and interests rates he had been receiving prior to his illness. While his son was acting as guardian following the interim order he never contacted Mr M-T who was left to fend for himself in regards to money, (his accounts had been frozen by his son) shopping, cooking, and looking after himself, his home and his garden.

The son had removed all Mr M-T’s financial and personal documents, his car and some other belongings from his house while he was in hospital. At the final hearing Mr M-T was not able to answer questions about his current investments even though he pointed out that he had not seen any bank statements for 3 months and could only say where his funds had been placed in the period prior to his stroke. Mr M-T had a hearing impairment and had difficulty hearing some of the questions put to him by the tribunal. There was medical evidence to indicate some loss of executive functioning, but on our visits to Mr M-T’s home, it was apparent that the house was clean and tidy, there was food in the fridge, and the garden was well-kept. He was receiving regular assistance from a beloved niece, who had been assisting him long before his stroke. The niece was greatly resented by Mr M-T’s son. Orders for guardianship and administration were made appointing the niece (with strong opposition from the son), despite our view that Mr M-T had acquitted himself well in terms of his recollection, and his understanding of current affairs, and allowing for the occasional difficulty with his hearing impairment.

It was our view that this was a case in which the least restrictive alternatives were not considered, although informal arrangements were working well, and could have been continued to be accessed without the formality of an appointment. It was also a concern for us, that had we not represented Mr M-T at the hearing, his son, who was vocal, well-educated and well presented, might well have persuaded the Tribunal that he had learnt from his past mistakes and was an appropriate person for appointment regardless of his father’s views on the matter.

Case study 2

Mrs L, aged 83, was a physically frail woman of European origin, who had a heavy accent. She was in a nursing home, but wished to be returned to the care of her husband. There was no medical evidence of dementia, but the nursing home had assumed she had dementia because she was difficult to understand following a surgical complication that affected her speech. Mrs L was also extremely depressed at the separation from her husband. At the guardianship hearing, questions were asked about her ability to cook and care for herself. Mrs L was a proud woman and acknowledged later that she felt too embarrassed to admit in front of strangers in an intimidating setting that she was too frail to cook. However, this was taken by the tribunal to mean she “lacked insight” and therefore must have impaired capacity. There were also misunderstandings by a tribunal member about the type of food Mrs L was describing, as a result of her heavy accent. An interpreter had been requested for Mrs L but was not provided. The Adult Guardian and Public Trustee were appointed.

This was a very long running case for our service, and we were finally successful in reuniting Mrs L with her husband, six months before she died.

A serious concern the Seniors’ Legal and Support Services across Queensland have identified is the role played in guardianship proceedings by family members intent on gaining financial control of the older person’s assets, or occasionally also, as in the case of Mrs L, taking every opportunity to disrupt a long standing marriage and partnership because of unresolved family resentments. Our experience has been that there can be a lack of recognition of the adult’s preferred supports in proceedings, and lack of awareness of the impact of cultural differences and impairments. In the case of Mrs L, it took perseverance with her speech difficulties and her accent to realise that her cognition and understanding appeared to be good. She was able to articulate her despair and depression about being separated from her husband, and it has been recognised that the symptoms of acute depression can mimic those of dementia (lack of recall, ability to concentrate).[[17]](#footnote-17)

The focus now enjoined on Australia and other member states to provide supports that protect the autonomy of persons with disability, acknowledges equality and non-discrimination (Art 5),that provide “*appropriate and effective safeguards against abuse and require that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict and undue influence proportional and tailored to the person’s circumstances, apply for the shortest time possible, and are subject to regular review by a competent, independent and impartial authority or judicial body..”* (Art 12(4) creates acute pressure on a guardianship process that is already over-subscribed, but gives a clear indication of the paths to change.

By way of comparison, two further case studies are provided below.

Case study 3

Mrs G was a 78 year old woman of European origin, who was the victim of physical and psychological abuse perpetrated by a close family member. She had few family members in Australia and those that existed were intent on accessing her assets. At the tribunal, she was provided with an interpreter and our service was present to assist her. There was no direct evidence of impaired capacity and it was the view of our service that the impact of the trauma she had experienced may have affected her ability to make her own decisions. She received sympathetic and careful questioning from the tribunal around a range of issues – decisions to be made about her assets, feelings about her family and her current accommodation. Mrs G asked for “government appointments” to be made, as she admitted she could not understand the decisions that had to be made and that she did not trust her family. The tribunal decided after a painstaking process that she lacked the capacity for complex decisions and did require an appointment of the Adult Guardian and Public Trustee.

Several factors stood out in this case: there was no informal network which could provide support “free of undue influence,” there had already been significant abuse, there was uncertainty whether the client’s inability to make decisions was affected by her traumatic experiences of assault and exploitation, or whether there was an underlying cognitive impairment. The appointments in this case were genuinely “last resort” and made after a careful consideration of the issues, including the likelihood that the abuse would continue if the previous family arrangements were adhered to. Importantly, Mrs G requested the appointments that were made, acknowledging that she was unable to make important decisions without assistance, and no assistance was otherwise available.

Case study 4

Mrs H, in her mid-70’s, of European background, called our service from a locked dementia ward, stating that she had been diagnosed with Alzheimer’s disease, that she “did not have any form of dementia” and that she had googled us on her laptop. When our service visited her, we found her actively using her laptop, printer and mobile phone. She was highly articulate, and expressed her anger very pointedly about the diagnosis (made some years earlier and noted on her medical chart) and the role her attorney had played in her admission to a secure dementia unit. Our service arranged extensive testing for Mrs H, and when all results confirmed that she did not have dementia or Alzheimer’s, assisted her to revoke her EPA.

At the hearing, during which Mrs H was treated sensitively and allowances were made for her European accent, the President commented that Mrs H must be “the most tested adult ever to appear before the tribunal.” Mrs H was granted a declaration of capacity, a copy of which was then filed with her treating hospital. However, Mrs H spent 10 months in “prison” as she termed it, at a substantial cost to herself.

In Mrs H’s case, she was extremely fortunate that she still had a home to return to – her attorney had attempted to sell it but had not been successful. Again, in this case, Mrs H had a very small support network – bereavement, and fragmentation of a very small family network had made her particularly vulnerable to “friends’ offering assistance.

The common theme running through the cases our service has represented or assisted at guardianship hearings is the vulnerability of older people in regards to existing support networks, which are often compromised by bereavement, divorce, estrangement from children, and the impact of mental health issues (of the adult or family members) as noted above. Where the support networks are fragile, there is a correspondingly high risk of abuse and exploitation, and this has characterised almost all the cases our service has taken to the tribunal.

The issue of lack of consistency with regards to guardianship decisions is troubling, At worst, it has been the experience of our service that capacity assessments can be cursory, the adult may be given little opportunity to speak for themselves, and allowances are not made for time to digest a question and prepare a response. As noted above, CALD clients and those with hearing difficulties are the most vulnerable in this regard.

At best, the tribunal looks to the existence of functioning support networks, and declines to make an order where these are clearly working well and endorsed by the adult. In the cases where orders are made, the adult is given time to speak, and all due consideration is provided for the adult’s difficulties, acknowledging that the process can be highly intimidating.

The latter point is an important one. The tribunal process is intimidating, and in the experience of our service, even a confident older person feels great anxiety during the proceedings. This is exacerbated when family relationships are conflicted, and the adult will be facing estranged children or other family members. In the case of Mrs H, (Case study 4) the hearing was attended by her attorney and staff members from her treating hospital. Normally, Mrs H was a confident and articulate woman but acknowledged after the hearing that “*my knees were knocking …could you hear them? I was so nervous*.” This scenario is also applicable to other clients with disabilities facing tribunal proceedings, especially where they have no legal representation, advocacy or support person available – and even when they do, as confirmed by Mrs H’s experience and those of our other clients. The stakes are very high – personal autonomy is in question, and notwithstanding the presumption of capacity, if the principles are not applied carefully and consciously there is a risk that pressure of time and casework will facilitate the “lack of insight equals impaired capacity” equation so prejudicial to many clients.

The QLRC report canvasses many of the issues relating to recognition of informal networks of supported decision making and outlines the significant concerns identified in relation to the uncertainty of third parties dealing with informal decision makers - such as banks, service providers and health agencies under more informal decision making structures.[[18]](#footnote-18)

**Supported decision making options**

The existence of a number of models of supported decision making operating in other jurisdictions is evidence that supported decision making is not only possible but effective, and may, as in the case of Sweden, operate to completely replace the system of guardianship.[[19]](#footnote-19) A number of writers have critically examined the current models of supported decision making operating, for example, in Canada, the US, New Zealand, Sweden, Holland, Germany and Ireland.

As Kohn *et al* [[20]](#footnote-20) point out, there is a moral critique of substitute (surrogate) decision making as *“an affront to the humanity of those subject to it.”* The writers provide a clear analysis of a number of supported decision making schemes concluding that there are a number of different schemes currently used in Canada and North America, in some of which the underlying features of the statutory framework are inconsistent with generally understood notions of supported decision making. For example, under the British Columbia Representation Agreement, a “reasonability” test is imported for the representative in terms of their obligation to consult with the principal.[[21]](#footnote-21) By comparison, the Saskatchewan model which has a co-decision maker, also has a reasonability test but it functions somewhat differently – the co-decision maker must agree to any decision made by the adult “so long as a reasonable person could have made that decision and the decision is not likely to result in a loss to the adult’s estate.” Even the “god man” mentor system in Sweden is characterized as requiring the adult’s consent to act but a “god man” can still be appointed without the consent of the adult. The tension between protection and providing a full suite of rights for persons particularly with IDMC is evident. Kohn et al cite Carney’s statement *“Adoption of supported decision making has been described as an “opportunity to re-imagine the disabled subject”*– and thus may have political and symbolic value in and of itself.” [[22]](#footnote-22)However Kohn et al then note the dearth of evidence based research on both uptake and outcomes which creates difficulty in determining what systems work best, amongst which demographics, and the reasons for their effectiveness. A problem identified by Kohn et al is that of undue influence whether intentional or not, and this is a very serious issue for guardianships and attorneys generally. The writers cite health care research to advance the proposition that older adults tend to prefer a trusted surrogate decision maker rather than expressing a treatment preference themselves (at 1138). Anecdotally our service would agree that this can be a common practice in the elderly - the proviso being that the supporting person/surrogate decision maker was in fact trusted. The spectre of abuse and exploitation is always present, however, particularly where the adult has assets – even if these are a pension.

Interestingly the writers suggest that in considering substantive outcomes the most important and difficult questions are:

1. how to ensure that a decision made under a supported decision making arrangement truly expresses and effects the wishes of the person with disability and
2. whether such decisions are more beneficial to the person with disability than those made using other approaches such as forms of substituted decision making.

Kohn et al conclude by finding that further research is necessary before institutionalizing supported decision making regimes by State actors, and suggesting five primary areas for research. However in Australia the consensus seems to be that the states’ guardianship legislation does allow for least restrictive alternatives (at the very least). But authors such as Carney & Beaupert [[23]](#footnote-23)and Shih Neng Then[[24]](#footnote-24) echo the call for further empirical research to evaluate how best supported decision models would work to achieve the aims of the legislation.

It should finally be noted that the Victorian Law Reform Commission Guardianship Final Report[[25]](#footnote-25) proposes a supported decision making and a co-decision-making structure. The supporter should ideally be a trusted person who will provide support and assistance to an adult who needs help in making a decision for which external oversight would be provided by VCAT.[[26]](#footnote-26) The co-decision maker is to act jointly with the adult, and decisions taken must be with the consent and authority of the represented person, and will be treated as if they were the acts of the represented person with capacity.[[27]](#footnote-27) Appointments are to be made at VCAT and the range of decisions specified for which the person needs support, which in principle can range across the areas previously covered by guardians and administrators. Safeguards against exploitation are detailed and include registration of co-decision making agreements, regular review on a range of grounds (on an unscheduled basis where need arises) and the options at VCAT to renew, amend or revoke the agreement.[[28]](#footnote-28)

Carney and Beaupert [[29]](#footnote-29) however point out the risk of a binary combination of substitute decision making and supported decision making – for people with cognitive and psychosocial disabilities, informal pressure may be brought to bear to establish a supported decision making (or co-decision agreement) whether they want one or not – thus the prospect of “net widening.”

While it is true that no system of decision making, whether substituted or supported, can offer complete protection against abuse and exploitation of an adult, the CRPD raises the bar in terms of the expectations of the level and provision of supports, the quality of education for all stakeholders[[30]](#footnote-30), whether families, workers, managers or institutions themselves, and highlights the importance of regular review of processes whatever the form of decision making support.

But as Carney and Beaupert acknowledge,[[31]](#footnote-31) “*Australia’s efforts to reform or replace its current system of guardianship under state and territory laws: a system which has valiantly sought to shake off its paternalist philosophy from Roman law and 13th century prerogatives of Chancery, but which is disfavoured under the CRPD,*” raises many issues – not the least of which are supply side reforms crucial to any serious change. Public sector, NGO and civil society responsiveness to consumer agency and choice as well as “demand side” measures – “*informal supports, supported decision making, advocacy and other measures – the form and social contribution of supported decision making and its very design and connection to other social supports, remains very much a work in progress”.[[32]](#footnote-32)*

The task is a tremendous one. The greatest challenges to ensuring equality before the law and the exercise of legal capacity for persons with disability involve the political will to endorse change to reflect consistency with a social model of disability, to provide sufficient education to the entire community, to stakeholders including all levels of employment and management, and to institutions and to implement the supply side and demand side reforms to ensure that supported decision making can effectively operate. *There must be reforms to our service systems to reflect personalisation and choice… and a commitment to overcome inequity and discrimination*.” [[33]](#footnote-33)A number of writers comment that insufficient research has been done on both supported decision making models and guardianship itself, and warn against inviting a “bricolage” of experimental models resembling a “young child’s pocketful of melted lollies on a hot summer’s day” [[34]](#footnote-34) The task is complex and highly nuanced and as Terry Carney suggests, perhaps the best recommendation is to marshall the evidence and debate which is the least imperfect of the policy options at the disposal of the law.[[35]](#footnote-35)

**Q. 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?**

**Summary of Response:**

A nationally consistent approach to defining capacity would be advantageous. The presumption of capacity should be retained, as should the element of “voluntariness” in the second limb of the capacity test as defined in the Guardianship and Administration Act (Qld) 2000, and the Powers of Attorney Act (Qld) 1998. This requirement provides for the possibility of undue influence, which is particularly important given the heightened vulnerability of persons with cognitive disability. Some issues with this test have been addressed in the main body of the response.

**Capacity**

The widespread transition from status concepts of capacity to outcome and/or functional tests has been well documented.

The QLRC Review of Queensland’s Guardianship Laws at Volume 1 provides a good analysis of the debate over functional vs status and outcome based capacity frameworks in light of the impact of the CRPD. Interestingly, some debate has occurred on whether a combination of functional and status tests is appropriate to allow for eccentricity and an adult making decisions with which others do not agree. The Commission itself supported the retention of the functional approach to defining capacity and commented that the intrusion of a status element would “violate the adult’s right to freedom from discrimination on the grounds of disability.” [[36]](#footnote-36) The Commission added that this approach “*maximizes the adult’s decision making autonomy by enabling the adult to continue making decisions in the areas of life for which they have capacity, is consistent with the presumption of capacity, and reflects a number of aspects of Article 12 of the CRPD including the recognition of legal capacity and the principle of least restriction*.”[[37]](#footnote-37)

**The current capacity test in Queensland:**

1. **The presumption of capacity**

While this is the cornerstone of the capacity assessment there is at least one way in which it operates to the disadvantage of the client at a guardianship hearing – this is that because the presumption is in effect, the person is not entitled to legal representation as of right. There is a very strong argument that because the person is present to essentially defend their capacity against other stakeholders, representation should be as of right. The stakes are extremely high – personal autonomy is in debate, and as the general principles – let alone the provisions of the CRPD - are not generally flagged by the adult, there is at least a reasonable chance that they will not be mentioned at all. A related practical difficulty ensues for those conducting legal representation for a client at a hearing following on from the making of an interim order - such that legal representation must be conducted on the basis that the presumption of capacity has been rebutted. It could be argued that this conflicts with Articles 5 (1) and (2) but on the ground, there may be implications for the legal practice’s insurers.

Perlin[[38]](#footnote-38) identifies the need for legal representation as both the key to meaningful enforcement of the CRPD and as the most critical determining factor of whether the CRPD will be actually as emancipatory as its potential suggests. He goes on to state that “without the presence of vigorous, advocacy – focused counsel, the CRPD may turn into little more than a paper victory for persons with disabilities and their advocates….the legislative and judicial creation of rights – both positive and negative – is illusory unless there is a parallel mandate of counsel that is (1) free and (2) regularised and organised.””[[39]](#footnote-39)

The American Bar Association Centre for Professional Responsibility (2002) provides the Model Rules of Professional Conduct for state bars in the US. MRPC Rule 1.14 confers discretion to take protective action for the client if three criteria are met: (1) the client has diminished capacity; (2) the client is at risk of substantial harm unless action is taken; and (3) the client cannot act in the client’s own interest. The third criterion provides limited discretion to reveal confidential information to the extent necessary to protect the client’s interests when protective action is merited.[[40]](#footnote-40)

The situation in Australia is less straightforward. There are currently no provisions in Australia’s states and territories’ Solicitors Rules of Conduct for breaching a client’s confidentiality for protective purposes although there are possibly discretions to do so.[[41]](#footnote-41) There has been some suggestion that the ABA rules offer a workable model.[[42]](#footnote-42) Such a model would go some way to providing legal protections for a client with cognitive impairment where the only current completely safe option is to refuse to see the client at all.

Free legal services in Australia are provided by community legal centres which are notoriously under -resourced and over-subscribed. It has been well recognised that persons with disability are highly disadvantaged in legal proceedings; that the barriers to access to justice are many and varied, and that persons with cognitive or psychosocial disability may suffer a compounding disadvantage of poor health and poverty in relation to their legal matters. Resources on the demand side are needed to boost the capacity of community legal services in order to effectively meet the goals of access to justice for persons with disability.

Currently the Guardianship and Administration Act (Qld) 2000 requires capacity (which is to be presumed) to be established by a 3 part test:

1. understanding the nature and consequences of decisions
2. being able to make decisions freely and voluntarily
3. the ability to communicate the decision in some way

The Commission notes the importance of adequate information being provided to the adult in order to understand the nature and consequences of a decision –failure to provide such information and allow time for deliberation “may result in the appearance of impaired capacity.” [[43]](#footnote-43)

 In considering the issue of guidelines in this area the Commission highlighted the necessity of emphasizing the ability to understand and retain information, consideration of reasonably foreseeable consequences, the use of appropriate language to explain the above to the adult, and importantly, acknowledging that the adult’s ability to retain the information for only a short period should not be treated as an inability to make that decision. This is consistent with CRPD Articles 5 and 12.

Possible but significant problem areas however may occur with lack of consistency in the way the first limb is assessed for a client. This is particularly the case when hearings are held by phone (see case studies below) but can and do occur at hearings where the adult is in attendance. Pressure of time and casework at tribunal hearings may result in cursory assessments which do not allow for the least restrictive options to be considered.

Case study 5

Miss P was an 88 year old woman calling from a nursing home. She had never been married, there were no children, and none of her siblings were alive. She stated that she had had a tribunal hearing but “*it was on the phone, and the line was very bad – static and noise – I could hardly hear what was being said*.” Miss P said that she thought the Public Trustee was controlling her money, but that “*no one will tell me anything – even the nurses won’t talk to me about it. I am never asked about anything or told anything*.”

Miss P’s social isolation was extreme. Additionally, she had been completely excluded from a process which effectively disenfranchised her from all aspects of decision making about her life. As a previously independent woman she was able to express her anger and sadness at her total loss of autonomy and dignity. Although she had early stage dementia and her recall on some matters was hazy, she had a sharp appreciation of the position she was in.

Mrs B, an 82 year old woman with mobility problems, was seen by our service in a secure dementia ward in a nursing home. She was a widow with no children. Mrs B stated that she had had a Tribunal hearing by phone and reported that “*it all seemed to be going well, when suddenly there was a lot of whispering from the social worker from the hospital I was in before and the next thing I knew, I was under the Adult Guardian and Public Trustee. Now I’m in this locked ward.”*

Case study 6

Mrs B eventually returned home upon a later review of her case at the tribunal, but both these cases illustrate the great dangers of undermining the legislative process in denying the adult the ability to hear, respond, or both, to issues raised in the capacity assessment. The general principles were completely overlooked it may be argued, in the interests of speed and efficiency, but the impact on the clients concerned was devastating.

**Making a decision “freely and voluntarily”**

This is a particularly interesting aspect of the capacity test and one which the Commission noted does not feature in the statutory capacity test in any other Australian jurisdiction. [[44]](#footnote-44) It is clear that the aim of this requirement is to provide for the operation of undue influence impacting on the adult’s decision making, thus importing an equitable consideration into the test.

This requirement does provide a valuable safeguard for adults vulnerable to undue pressure in their decision making as this is most likely to occur in regard to financial matters.

However there may be some unintended consequences – our service has been aware of cases concerning older persons who apparently have sufficient cognitive ability to understand the nature and consequences of decisions, but who are unable to make decisions “freely and voluntarily” – not necessarily because of undue influence but because they have never been habituated to the role of decision maker in the family and find themselves unable to take it on when the primary decision maker becomes incapacitated or dies. The lack of freedom or voluntariness is cultural rather than cognitive. The risk is that the inability to make decisions for whatever reason can merge into the first limb of the capacity test to rebut the presumption of capacity. While our experience relates to the experience of older clients it may well be extrapolated across the disability field.

Case study 7

Mrs T was a 79 year old socially isolated woman with a chronic and debilitating illness recently admitted to a nursing home following physical abuse by her adult child and his partner. She had been recently bereaved by the loss of her husband and was clearly traumatised by the events that had occasioned her admission to the nursing home. After several visits, our service was unable to get instructions from Mrs T and was uncertain of how to proceed as a number of decisions needed to be made by her. Eventually Mrs T was able to tell us that in her culture, her husband had made all the decisions, and she simply didn’t know what to do. She had been capable of paying recurrent bills such as electricity and phone, and had kept a bank account of her own, but had always been discouraged from accessing any information or participating in decision making. With supportive assistance from our service Mrs T was able to make some of the decisions necessary to give instructions and make some plans for her future.

Mrs T was a client for whom supported decision making would have been a great benefit – but there was simply no informal network available to assist her. The risk would have been that if this matter had gone to the tribunal, it is possible that her lack of knowledge and difficulty in making decisions might have been interpreted as impaired capacity under the first limb of the capacity test.

It is noted that the pilots of supported decision making run in other states address this issue of cultural expectations around decision making where the person has IDMC by intensive support so that the person practices and develops decision making skills but it is possible that in the older population there may be factors mitigating against this – cultural reluctance to change lifelong habits, anxiety, and the impact of health issues. However there is every possibility that such reluctance could be overcome in many cases by a systematic and functional process of supported decision making.

Without such assistance, the result may well be the appointment of a guardian. If the guardian is one chosen by the adult (failing a previous EPA appointment) all may be well. But for many older clients, their available network may be small or non-existent, and an order for formal guardianship is highly likely.

1. **Summary of Issues under the second limb of the test for capacity**

Problems with the statutory capacity test have also been outlined in the case studies. These include inconsistent approaches to assessment under the first limb, and it is suggested that adults from CALD backgrounds or with hearing difficulties are particularly affected. It is understood that pressure of time and caseloads may play a role but it is crucial that the human rights of those for whom their autonomy is in question receive all the benefits enshrined in the general principles and under the Convention.

Some issues under the second limb regarding voluntariness of the adult’s decision making need to be considered in the light of cultural vs cognitive capacity, and the burden required to establish undue influence needs reconsideration.

An interesting question relates to the frequency with which consideration is given to the second limb of the capacity test in guardianship decisions in Queensland. Anecdotal evidence suggests that focus is almost always on the first limb.

 The problem with the voluntariness requirement as it does relate to undue influence, may be the degree to which evidence satisfies the tribunal that it exists, and is sufficient to overcome the will of the adult. The standard for undue influence in equity is high and it is arguable that a) it may be too high taking into account the vulnerability of an older client (who may be bereaved, ill, and have sparse support networks – or none at all) and b) some clarification is needed about the more appropriate ways of assessing undue influence across the disability sector and including the older adult, consistent with the requirements of CRPD Art 5 and Art 12(4).

A related issue is that of the “eccentric’ adult – a tendency in tribunal decisions to interpret opinions that are not mainstream (eg the decision not to take out property insurance) as impaired judgement even when the adult is able to provide a rationale (for example, based on a perception that insurers are reluctant to pay out on claims). In that particular case the imperative to protect property may be understood, but nonetheless there remains an inclination on the part of the tribunal to impute impaired capacity when it is determined that the adult “lacks insight” – which can be for example, when an adult refuses services. However, a discussion may not then be held with the adult about the basis on which they would accept them - which would of course provide key information as to whether insight was present. Some inquiry into why the adult is refusing services may reveal a sense of pride and difficulty acknowledging in a public arena in front of strangers that they need assistance or may do so in the future. “Lack of insight” may have its foundations in pride and embarrassment which is a different prospect altogether.

The quote below is particularly apposite:

“*The criteria of elements needed to establish legal incapacity are the products of society’s prevailing beliefs concerning individual autonomy and social order, tempered by the restraint of legal precedent. Just as societal values and needs have evolved over time, so will the legal criteria for capacity and incapacity.”* [[45]](#footnote-45)

**Q.35 Issues arising in aged care that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity. What changes should be made, if any, to Commonwealth laws and legal frameworks to aged care to address these issues?[[46]](#footnote-46)**

**Summary of Response:**

Key issues in aged care include concerns about proposed recent reforms to aged care residential and community care services outlined in the Living Longer, Living Better suite of Aged Care bills of 2013. The National Association of Community Legal Centres (NACLC) provided a submission to the Senate Committee on Community Affairs in 2013 addressing these issues. The submission addressed the Quality Agency Bill, and in particular the amendments to the Quality of Care Principles, which effectively diminish the human rights of persons in residential care (in comparison to the previous legislation).The loss of the Resident Lifestyle Principle from the Quality of Care Principles is also noted in this regard. A strong focus on education of staff providing aged care services – from aides and nurses to administrative staff and managers in human rights is essential to meet the requirements of the human rights of persons in residential care generally and the requirements of Article 12 in particular.

The Bills identified special needs groups to include Aboriginal and Torres Straits Islander, CALD and LGBTI persons and every care must be taken to ensure effective consultation with these groups about appropriate and culturally safe care provision.

 It is noted that while there is reference to the rights under the ICESCR and ICCPR in the Bill, there is no mention of the CRPD despite the fact that persons in residential care almost always have some form of disability - and in fact have to meet the criteria for entry to residential care as set by the Aged Care Assessment Teams (ACAT).

**“Ageism is insidious and menacing, a conspiracy to sap confidence and deny competence.”[[47]](#footnote-47)**

The National Association of Community Legal Centres’ submission to the Senate Committee on Community Affairs Inquiry into the Living Longer, Living Better suite of Bills 2013, which addresses the human rights concerns in the Aged Care Quality Agency Bill and the Quality of Care Principles for aged care services (including the “Townsville Seniors Speak Out” Report) is attached**.**

**The main points are summarised below.**

Ageism is endemic at individual, community, institutional and corporate levels of society.

“Despite the sole function of providing “care” to the “aged” the aged care system is festooned with examples of ageism where the rights and interests of older persons are overlooked, or even sacrificed for the sake of efficiencies, policies or exigencies.” [[48]](#footnote-48)There is a view widely held amongst older people that residential aged care is a dumping ground in which human rights once held as a younger person, have evaporated or have simply become irrelevant.

In the explanatory memorandum to the Bills, the then Minister for Mental Health and Ageing, the Hon Mark Butler MP states in acknowledging ICCPR and the ICESCR, that:

 *“This Bill is compatible with human rights because it promotes the human right to the highest attainable standard of physical and mental health, and to the extent that it limits the human right to protection against arbitrary interference with privacy, those limitations are reasonable, necessary and proportionate*.”

There is no mention of the CRPD. One area of great concern for NACLC was the diminution in human rights in the area of provision of aged care standards in community (home) care.

**The Quality of Care Principles:**

On 1 March 2011, there was a significant shift for Community Care standards. Schedule 5 replaced Schedule 4.

Schedule 4 Standards included:

1. information and consultation
2. identifying care needs
3. coordinated, planned and reliable service delivery
4. social independence
5. privacy, dignity, confidentiality and access to personal information
6. complaints and disputes
7. advocacy

Schedule 5 standards include:

1. effective management
2. appropriate access and service delivery
3. service user rights and responsibilities

Although independence is still encouraged in Schedule 5 Part 3.5, it is not defined as in Schedule 4.

**The Resident Lifestyle Principle**

This has been omitted from the new Quality of Care Principles. The superseded Resident Lifestyle principles reflected a number of human rights – the right to dignity and privacy, the right to a cultural and spiritual life, and the right to participate in decision-making.

The submission provides in Case Study 1 of the NACLC submission [[49]](#footnote-49)an example of a visually impaired older client who received medical advice to exercise. He wished to take up his old pursuits of fishing and walking, but his service provider refused to reduce the hours provided for shopping and cleaning to allow for this. Instead he was offered group social activities which were not acceptable to the client. He remained lonely and isolated with no opportunity for exercise or pleasure in life.

Apart from the fact that the client’s human, economic, social and cultural rights were contravened, there is an argument that under the CRPD, Article 5(2) and (3), and Article 19 the client experienced discrimination in denial of his request for fishing and walking activities in preference to house cleaning. It might be thought that the operative factor was the client’s age rather than his disability – as an older adult, it may have been assumed that his wishes were unimportant and the provisions of the CRPD were irrelevant.

**Appropriate access and service delivery**

The submission notes that appropriate access and service delivery must be flexible enough to meet the broad range of needs, rights, and interests of users.[[50]](#footnote-50)

**Social activities in residential care:**

Schedule 1 of the Quality of Care Principle requires that programs encourage residents to take part in social activities that promote and protect their dignity, and to take part in community life outside the residential care facility.

In case study 6 in the submission, an example is provided of a client with tertiary qualifications who had entered residential care following a stroke. She had physical disabilities and was unable to communicate verbally. She was forced to go to bingo, which she hated and felt was demeaning. She would have preferred audio books and poetry to have been arranged for her.

Our experience of clients in nursing homes is that many are intensely lonely, that social activities are not always suitable or desired by them, but few options are made available. Clients who are wheelchair bound may find themselves excluded from outings and there may be insufficient staff to take them outside or for a walk. One client we visited recently who has mobility difficulties and is very frail has joined a knitting club. However, this meets only once a week, and the client over a period of months, was seen to be knitting only one colour of wool. When asked about it she said: “That is all they give me to knit.”

**Education in human rights**

Thisis considered to be essential to community care and aged care workers and the CRPD provides for this extensively in Articles 4 (1), 8, and 13. This extends to administration and managerial staff at all levels. For example, in the case of Mrs H, case study 4 above, the nursing staff had commented frequently that “Mrs H doesn’t belong in a dementia ward.” However, after a number of discouraging attempts to discuss this with the business manager at the facility they were reluctant to raise the matter again or speak to our service further about their views.

**Other areas of concern for older people in residential aged care**

1. The need for a clear dispute resolution process for breaches of the Quality of Care principles, for which the outcome must be enforceable and have a bearing on quality or accreditation reviews. Complaints about the previous complaints process are legion, with no clients known to any Network members having received a response to a complaint which was regarded as “in scope” or with which they were satisfied.
2. The power to investigate resident deaths. Network members are aware of clients whose family member is alleged to have died following rough or punitive treatment in nursing homes.[[51]](#footnote-51) Attempts to have the deaths queried has met with denials, delays and frustrations.
3. The requirement to adequately maintain buildings and grounds. Case study 2 in the submission describes the plight of a resident in a nursing home who was obliged to share a one bedroom room with a patient with behavioural difficulties for 3 weeks while building works were going on. The 3 weeks extended to 18 months, and the client felt discriminated against in being refused a reduction of aged care fees as compensation in the way that she would have been if she were a tenant in a rental property.[[52]](#footnote-52)
4. The diversity of the ageing experience must be acknowledged. As part of the reforms, national strategies have been developed for CALD and LGBTI and these groups together with Aboriginal and Torres Straits Islanders have been identified as “people with special needs” which is commendable. The Aged Care (Living Longer, Living Better) Bill 2013 at clause 4 states that an independent review must be taken of the operation of the amendments made under the Bills and that this review must make provision for public consultation with these groups. Consultation is considered to be essential to ensure that the amendments are appropriate and that the care provided is culturally safe, respectful and informed.[[53]](#footnote-53)

**Some quotes about ageism from seniors themselves[[54]](#footnote-54)**

**“You feel like people are pushing you. They think because you are old they have to make the decisions for you, as they think they know what is right for you.”**

**“People think you are hard of hearing.”**

**“The media forget about older people. If you are not young and beautiful you are not on TV or in magazines.”**

**“Advertisements with older people in them are all about continence aids and funeral insurance.”**

**Conclusion**

It is arguable that the impact of ageism and ageist attitudes has been to effectively marginalise older people with disabilities as a subset of the disability community generally. The omission of the CRPD in the Living Longer Living Better suite of Aged Care bills is some evidence of a lack of will and vision to regard older persons with disability as worthy rights holders (as it is axiomatic that most nursing home residents are suffering some form of disability )and there is further evidence as to the weakening of human rights principles for older people in residential care in the amendments to the Quality of Care Principles and the loss of the Residents’ Lifestyle Principle.

Article 1 of the CRPD expresses the shift from a medical model of disability to a social model: “The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their dignity.” It has been noted that the Convention embraces human rights, civil, political,social and economic rights in the same document – a departure from previous Treaty models which have aligned civil with political rights, and social with economic and cultural rights.

For older people, this marriage of political and economic and social rights is especially significant. Kanter mounts a strong argument that the CRPD marks an important step towards equality, dignity and access to society for older persons – with and without disabilities.[[55]](#footnote-55) She notes that the language of Article 1 (at note 22) “will help ensure the right to equal rights of older people and who have a mental or physical disability, *particularly in those societies in which being elderly has become synonymous with no longer being in need of rights protections.”* (italics mine)*.*

Guardianship will be necessary in some cases particularly for those in advanced stages of degenerating cognitive diseases (who are predicted to greatly increase in coming years) – who have no informal supports, but models of supported decision making need to be thoroughly researched and evaluated particularly given the implications of profound change – the paradigm shift – across institutions, agencies, services and the community generally. The suggestion has been made that there is little evaluative research into the efficacy and acceptability of guardianship systems, and this too should be remedied. At the very least, guardianship should not continue on the basis of ‘business as usual.” And as a number of writers have observed, legislative change without equal attention to supply side and demand side reforms, including adequate resourcing of free legal services for persons with disability, will only be as useful as the paper it is printed on.

The question of whether there is a political will for such change is another matter. The example of Sweden, where profound changes to disability laws doing away with guardianship altogether, pre-dated the CRPD and which had both bilateral party support and the good will of Swedish citizens, is an inspirational model and it should be noted that community supports, packages and advocacy arrangements costed 15 years in advance, were at the forefront of these reforms.

1. CRPD/C/Aus/Co/1 IIIA para 9 [↑](#footnote-ref-1)
2. CRPD/C/AUS/CO/1 III B at para 24 [↑](#footnote-ref-2)
3. CRPD/C/11/4 at p.3 [↑](#footnote-ref-3)
4. Ibid, para 12 at p.4 [↑](#footnote-ref-4)
5. Amita Dhanda*,* Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future? (2007) *Syracuse Journal of Law and Commerce* 34:429 [↑](#footnote-ref-5)
6. Ibid at 443 [↑](#footnote-ref-6)
7. *Ibid* at 445 [↑](#footnote-ref-7)
8. VLRC Guardianship Final Report 24 2011 [↑](#footnote-ref-8)
9. Minister’s Committee on Rights and Protective Legislation for Intellectually Handicapped Persons, Parliament of Victoria (1982) cited in VLRC 2011 at 32 [↑](#footnote-ref-9)
10. *ibid* [↑](#footnote-ref-10)
11. Alzheimer’s Disease International, World Alzheimer Report 2009 6 cited in VLRC Report 2011 at 33. [↑](#footnote-ref-11)
12. Eg R. Gordon, The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making: *International Journal of Law and Psychiatry* Vol 23,61 at 65 [↑](#footnote-ref-12)
13. See Terry Carney, “Participation Rights, Family Decisionmaking and Service Access: A Role for Law? A paper delivered at the *6th Roundtable on Intellectual Disability*, La Trobe University 29 November 2011. [↑](#footnote-ref-13)
14. See note 5 above [↑](#footnote-ref-14)
15. Queensland Law Reform Commission: A Review of Queensland’s Guardianship Laws, Vol 1 at 52. [↑](#footnote-ref-15)
16. David Tait and Terry Carney, “*Too Much Access? The case for Intermediate Options for Guardianship*,” Australian Journal of Social Issues 1995 Vol 30 445-461 at 448. [↑](#footnote-ref-16)
17. Lilian Thorpe ,”*Depression vs Dementia: How Do We Assess?* The Canadian Review of Alzheimer’s Disease and other Dementias*,* September 2009 17-21; Krishna Prasad Muliyala and Mathew Varghese, “The complex relationship between depression and dementia.” Annals of Indian Academy of Neurology 2010; 13 (Suppl2) 69-73 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3039168 [↑](#footnote-ref-17)
18. See also Shih Neng Then, “*Evolution and Innovation in Guardianship Laws: Assisted Decision-Making,”* Sydney Law Review 2013 Vol 35 , 133-166 [↑](#footnote-ref-18)
19. This is covered in detail by Stanley S. Herr, “Self-determination, Autonomy and Alternatives for Guardianship,” - it is notable that the Swedish mentor system pre-dated the CRPD. [↑](#footnote-ref-19)
20. Nina A Kohn, Jeremy Blumenthal,and Amy J. Campbell, “*Supported Decision –Making: A Viable Alternative to Guardianship?”* Penn State Law Review 2013 Vol 117:4 1111-1157 at 1120 [↑](#footnote-ref-20)
21. *ibid* at 1122 [↑](#footnote-ref-21)
22. i*bid* at 1127 [↑](#footnote-ref-22)
23. Terry Carney and Fleur Beaupert, “Public and Private Bricolage – Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making UNSW Law Journal 2013 Vol 36(1) 175-200 [↑](#footnote-ref-23)
24. See note 17 above, at 166 [↑](#footnote-ref-24)
25. 2012 Chapters 8 & 9 [↑](#footnote-ref-25)
26. Chapter 8 at 137 [↑](#footnote-ref-26)
27. Chapter 9 at 164 [↑](#footnote-ref-27)
28. *ibid* at 167 [↑](#footnote-ref-28)
29. Carney and Beaupert 2013 [↑](#footnote-ref-29)
30. CRPD Articles 8, 12(4), 13(2), 16(2), 16(3) [↑](#footnote-ref-30)
31. Carney& Beaupert 2013 at 177 [↑](#footnote-ref-31)
32. *ibid* at 179 [↑](#footnote-ref-32)
33. John Brayley, “The Future of Supported and Substituted Decision-making,” cited in Carney and Beaupert at 177 [↑](#footnote-ref-33)
34. Carney and Beaupert at 177. See also Kohn et al, note 19 above; Shih Neng Then, note17 above; Carney, *“Participation Rights, Family Decision-making & Service Access: A Role for Law?*’ andTerry Carney*,”* *Guardianship, Social Citizenship and Theorising*,” in “Beyond Elder Law,” (Israel Doron and Ann M. Soden (eds) 2012, 1-17 [↑](#footnote-ref-34)
35. *ibid* at 15 [↑](#footnote-ref-35)
36. Queensland Law Reform Commission: *A Review of Queensland’s Guardianship Laws 2010* Vol1 at 270 [↑](#footnote-ref-36)
37. *ibid* [↑](#footnote-ref-37)
38. Michael L.Perlin, “Striking for the Guardians and Protectors of the Mind,” Penn State Law Review 2013 Vol 117:4, 1159-1190 [↑](#footnote-ref-38)
39. *ibid* at 1180 [↑](#footnote-ref-39)
40. Sabatino & Wood, “*The Conceptualization of Legal Capacity of Older Persons in Western Law*,” in “Beyond Elder Law,” Doron & Soden (eds) 2012. [↑](#footnote-ref-40)
41. Justice Paul le Gay Brereton, “Acting for the Incapable,” Law Society Journal, December 2011 57-61 [↑](#footnote-ref-41)
42. See Andrew Lynch article – citation? [↑](#footnote-ref-42)
43. J.Deveraux and M Parker “*Competency for young persons and older persons”* in I. Freckleton and K. Petersen (eds) “Disputes and Dilemmas in Health Law (2006) 54,72 cited at 274). [↑](#footnote-ref-43)
44. QLRC : *A Report into Queensland’s Guardianship Laws 2010* Vol 1 at 280 [↑](#footnote-ref-44)
45. Kristin Booth Glen, “*Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond*, Columbia Human Rights Law Review 2012 44-93 at 95, citing Charles P. Sabatino & Erica Wood, “The *Conceptualisation of Legal Capacity of Older Persons in Western Law* in “Beyond Elder Law” (Israel .Doron and Ann M. Soden eds 2012 Ch 3) [↑](#footnote-ref-45)
46. Much of the information provided for this question is attributable to the National Association of Community Legal Centre’s Submission to the Senate Community Affairs Legislation Committee Inquiry into the Living Longer, Living Better Bills 2013 [↑](#footnote-ref-46)
47. Margaret Morganroth Gullete,”Fighting the New Ageism in America,” 2011, in National Association of Community Legal Centre submission to the Senate Community Affairs Legislation Committee Inquiry into the Living Longer, Living Better Bills 2013. [↑](#footnote-ref-47)
48. NACLC submission at p.7 [↑](#footnote-ref-48)
49. At p.17 [↑](#footnote-ref-49)
50. *Ibid* [↑](#footnote-ref-50)
51. NACLC submission case study 8 at p.24 for example. [↑](#footnote-ref-51)
52. *Ibid* at 18 [↑](#footnote-ref-52)
53. *Ibid* at 27 [↑](#footnote-ref-53)
54. The Townsville Seniors Speak out Report, Townsville Community Legal Centre 2011 [↑](#footnote-ref-54)
55. Arlene S. Kanter, *“The United Nations Convention on the Rights of Persons with Disabilities and the Implications for the Rights of Elderly People Under International Law,*” Georgia State University Law Review, 25:3, 527-573 at 528 [↑](#footnote-ref-55)