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## **AAG submission to NSW Law Reform Commission (LRC) in response to draft proposals for the review of the Guardianship Act 1987**

Thank you for inviting AAG to respond to the draft proposals for the review of the Guardianship Act 1987 (1). This submission has been prepared by AAG with input from [AAG's NSW Division](#) and [AAG's Elder Abuse Special Interest Group](#).

AAG exists to improve the experience of ageing through **connecting** research, policy and practice. Its principles are to be evidence informed, multi-disciplinary and holistic, independent, collaborative and fair. AAG has a growing membership of over 1,100 professionals working across every State and Territory in Australia representing the full breadth of experts in ageing across sectors including research, policy, education, aged care, health and allied health, and consumer advocates. AAG has 19 Collaborating Research Centres which represent all major research in ageing and aged care, and is connected internationally as the executive office of the International Association of Gerontology and Geriatrics Asia Oceania Region and the International Longevity Centre – Australia.

AAG supports the review of the Guardianship Act 1987 including the following aspects:

- The acknowledgement in term 5 of the [Terms of Reference](#) that “the increase in the ageing population” in NSW must be considered.
- The term “disability” should be removed as a precondition for a Tribunal order and from the legislation altogether.
- Giving greater emphasis on effecting the will and preferences of an older person and the corresponding responsibility on representatives (substitute decision-makers) and supporters (assisting with decision-making) to do this.
- The introduction of a new entity, the separate Public Advocate (draft proposal 9.1), in particular due to the role it can play in educating families, carers and community groups.
  - AAG notes that any such function should be appropriately funded to allow the public education obligations to be met.
  - AAG notes that paragraph 79 of the current [NSW Guardianship Act 1987](#) requires that the Public Guardian shall ensure that information is readily available to members of the public regarding the Act with respect to the appointment of guardians and the exercise by guardians of their functions as guardians as well as the rights of persons and functions, practices and procedures of the Public Guardian. However, to date, AAG feels that there has been little public education and that the public’s knowledge is unacceptably low.

In general, it is AAG’s opinion that the draft proposals do not sufficiently recognise or address the specific and unique needs and rights of older people. Instead, the needs of (younger) people with disability and older persons are to some extent conflated. This is particularly pertinent given that:

- Of the 7,846 applications received by the Guardianship Division of the NSW Civil and Administrative Tribunal (the Tribunal) in the 2016-2017 financial year, 23 % of applications were made in respect of people over the age of 85 years and 61 % were made for people over the aged of 65 years ((2), p.44).
- The Terms of Reference for the Guardianship Review specifically mention the ageing population.
- The Terms of Reference specifically request that the LRC consider “Whether the language of ‘disability’ is the appropriate conceptual language for the guardianship and financial management regime and to what extent ‘decision-making capacity’ is more appropriate.

Any new Act needs to work *both* for younger and middle-aged people *and* for older people. Similarly it must work for people whose decision-making disability is life-long, or acquired in earlier life or in late life.

In additional, if possible, AAG suggests that reference is made to the role facilitated family discussions or elder mediation may play in assisting families before, during and after all the processes outlined in the draft proposals. Understanding the needs and concerns of the family members is important in facilitating the effective care and support of the older person.

AAG submits that, while the use of ordinary terms such as ‘representative’ and ‘supporter’ has advantages, it may also create confusion as these are terms in wide use in very different and non-legal contexts. AAG requests that the LRC consider recommending use of terms such as ‘legally appointed representative’ and ‘legally appointed supporter’ instead.

AAG also submits that the LRC address the following issues:

1. The United Nations work on the rights of older persons (including its Principles for Older Persons) should be considered and acknowledged.
2. The differing needs, circumstances and decision-making abilities of older persons and (younger) people with disabilities should be recognised.
3. The family dynamics and relationship of older persons to their family and support people is often very different to that of a young or middle-aged adult with a disability and their family and support people.
4. The Tribunal must have wider powers to review the suitability of representatives and supporters.
5. Appropriate recognition should be given to the fact that decision-making ability may fluctuate over time.
6. The impacts on older people with degenerative diseases, their families and the Tribunal of a requirement that a support order be tried first before a representation order can be made must be considered.
7. The conflict of interest that some hospitals face when requesting a guardian be appointed should be considered.
8. There is a need to explicitly address the use of restrictive practices in informal care settings.
9. There should be a single registry for all agreements and orders made under the proposed Act.

The following sections elaborate more on these issues and provide suggestions as to how they may be addressed.

**1. The United Nations work (including its Principles) on the rights of older persons should be considered and acknowledged.**

The United Nations Principles for Older Persons adopted in 1991, included that

- “• Older persons should have access to social and legal services to enhance their autonomy, protection and care. [...]
- Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.” (3)

The United Nations Open-ended Working Group on Ageing (OEWGA) was mandated to present, at the earliest possible date, a proposal for an international legal instrument to “promote and protect the rights and dignity of older persons” to the United Nations General Assembly (4). A joint submission to the OEWGA’s 8<sup>th</sup> Working Session on 5-7 July 2017 on neglect, violence and abuse was made by AGE Platform Europe, HelpAge International, The Law in the Service of the Elderly and the National Association of Community Legal Centres Australia (5). This submission explored the types of elder abuse, settings and perpetrators, including stating that:

*“The diversity of the potential perpetrators and particular contexts distinguishes violence, abuse and neglect in older age from other forms of violence, for example male violence against women. Perpetrators may include spouses and partners and other family members, community members (non-family) known or unknown to them, community leaders, local militia or law enforcement groups, service providers, legal representatives, guardians and attorneys. Whilst interdependence between the perpetrator and the older person is critical in some contexts, perpetrators are not limited to those who might be considered to fall within an expectation of trust.” ((5), p.1)*

In this joint submission, they state that the consequences of a normative international framework will include:

*“The right to freedom from violence, abuse and neglect in older age relate [sic] to other rights in older age, including:*

- *Freedom from torture, or other cruel, inhuman or degrading treatment or punishment*
- *Right to physical and psychological integrity*
- *Autonomy and independence*
- *Freedom from ageism and age discrimination” ((5), p.2)*

AAG urges the LRC to make specific accommodations for this in the proposed *Assisted Decision Making Act* to address the rights of older persons identified in the joint submission ((5), p.2), including:

*“[...] an obligation on States to take comprehensive steps to prevent violence, abuse and neglect of older persons in public and private settings [...]”*

*“[...] an obligation on States to assist survivors with making a complaint and investigating and laying criminal charges.” [...]*

*“[...] an obligation to build the capacity of the judiciary and law enforcement to protect people from violence, abuse and neglect in older age.”*

Guardianship (or assisted decision-making) legislation plays an important role in offering protection from elder abuse to older people with decision-making difficulties. However, the same provisions may contribute to abuse and exploitation if not used wisely or without sufficient checks, as has been noted by the Australian Law Reform Commission’s report on elder abuse (6).

AAG supports the development of a United Nations Convention on the Rights of Older Persons, in the absence of other international, universally accepted standards to protect the rights of older people to guide member national and regional legislation (7,8). As noted by a large number of delegations at the eighth working session of the United Nations Open-ended Working Group on Ageing (OEWGA):

*“[...] in order to fully empower older persons so as to allow them to contribute actively and effectively to development, it is fundamental to consider older persons as specific rights holders and agents of change; and to provide guarantees with respect to the full and effective enjoyment of their human rights and fundamental freedoms, in order to allow for their participation in social, economic, cultural, civil and political life, and to seize their experience and potential for contributing to all areas of development.” ((7), p.7)*

**2. The differing needs, circumstances and decision-making abilities of older persons and (younger) people with disabilities should be recognised.**

As noted in the United Nations Secretary-General Follow-up to the Second World Assembly on Ageing:

*“[...] some measures that address issues such as mobility, supported decision-making, legal capacity or home-based care can respond to various human rights issues affecting both older persons and persons with disabilities. However, failure to establish and address issues specific to each group or to enact policies for older persons and to devote adequate financial and human resources to their needs creates the risk of neglect.” ((9), p.12)*

The risk of inadvertently reinforcing discrimination against older people by failing to distinguish between the needs and circumstances of older persons and (younger) people with disabilities (10) is something that the NSW LRC must be mindful of.

**3. The family dynamics and relationship of older persons to their family and support people is often very different to that of a young or middle-aged adult with a disability and their family and support people.**

The nature of the relationships and inter-dependencies between family and other support people that surround an older person often differ in nature to that of a young or middle-aged person. An older person has often experienced a lifetime of autonomy and indeed had a caring and/or decision-making role for their own children. This is a very different scenario to a person born with or who has acquired a disability at a younger age who perhaps has always been cared for and been supported in decisions by family members and who may well wish to exercise greater autonomy in decision-making. Of course, these are generalisations, but they point to the very different family dynamics that may exist between, say, a 30-year old person with a cognitive disability and their parents and an 85-year-old person with dementia and their adult children.

The nuances of the tensions between family and other support people, and the potential distress this can cause to the older person, must also be explicitly acknowledged and accounted for in the Tribunal’s processes.

For example, in the case of an application regarding an older person appearing before the Tribunal, it is often the case that multiple family members are in dispute amongst themselves regarding a decision that affects that person or about who should have a decision-making role. This may place the older person in the very difficult position of having to publicly ‘favour’ one adult child over another and may cause much distress to the point that older people may opt out of participating in a hearing or expressing a view at all. Moreover, if abuse is occurring, for example psychological abuse or exploitation by an adult child on whom they depend for care and may love, it may be wholly impossible for an older person to disclose this in a public forum in the presence of the adult child.

Some simple protections may ensure that an older person is heard and has their rights respected in such a situation and especially in situations of suspected undue influence or abuse, including:

- The ability for the older person to provide evidence to the Tribunal in a setting where they feel safe and comfortable (including with any necessary supports such as assistive listening devices).
- The ability for the Tribunal to speak to the older person in private.
- The ability for the Tribunal to provide edited summaries of the evidence and proceedings of the Tribunal in a format that is appropriate for them.

***4. The Tribunal must have wider powers to review the suitability of representatives and supporters.***

There are no legislated functions currently in place or proposed that allow the Guardianship Division of NCAT to assess the suitability of representatives or the proposed ‘supporters’ (draft proposals 2.1-2.16) through, for example, criminal record checks. For example, there are no protections in place to ensure that guardians and supporters have not previously been convicted of violence (although bankruptcy ‘offences involving dishonesty’ in the context of financial functions is considered in draft proposals 2.3, 4.3). The effect of these prior convictions upon the care of the older person by that particular support person should be considered by the Tribunal. Rigorous protections of people from inappropriate supporters should be considered, including extensive criminal record checks, because:

- If someone is making the decision that they cannot make a decision without support, then their ability to make a decision as to an appropriate supporter must therefore also be compromised.
- Even a supporter with the best intentions to not influence the person they are supporting, may inadvertently do so through unintentional gestures and other behaviours.

***5. Appropriate recognition should be given to the fact that decision-making ability may fluctuate over time.***

AAG welcomes the proposed adjustments to acknowledge the fact that “a person’s decision-making ability can vary depending on the circumstances” (draft proposals (1), p.5) as decision-making ability can fluctuate over time due to, for example, Lewy body dementia (11). This includes the definition of decision-making ability being for a particular decision (draft proposal 1.12) and draft proposals 4.5 and 5.6(2). In addition, AAG supports the draft proposals which allow the Tribunal to review support agreements, support orders, enduring representation agreements, representation orders on its own motion or if requested to do so (draft proposals 2.12, 3.14, 4.13, 5.20 and 12.2, respectively).

***6. The impacts on older people with degenerative diseases, their families and the Tribunal of a requirement that a support order be tried first before a representation order can be made must be considered.***

A high proportion, 42% in 2016/2017 ((2), pp.44-45), of persons who are the subject of hearings have dementia, a degenerative condition. While older people with dementia in its earlier stages may definitely have the ability to make certain decisions some of the time – and this must be recognised and supported – unfortunately the likelihood is that their decision-making abilities will decline over time. Sometimes this can occur very quickly, over a matter of weeks or months.

This contrasts with the situation of, for example, a younger person with an intellectual disability, whose cognitive abilities may be stable over many years who, with support, can and should be enabled to assume greater autonomy in decision-making.

The LRC’s draft proposals recognise and respond to this latter scenario well, but less so for people in later age with neurodegenerative diseases such as dementia. While the introduction of a new regime of supporters and supported decision-making definitely has merit, it also has the potential to introduce considerable bureaucracy, distress and cost on older people with degenerative diseases and their families (and the Tribunal), if it becomes a requirement that a support order be tried first before a representation order can be made.

It could also be helpful for the LRC to give some guidance on how much weight should be given to current versus previous will and preferences. For example, how much weight should the Tribunal, supporters and representatives give to a newly expressed will and preference of an older person with dementia as compared to their will and preferences expressed over many years, even decades, prior to the onset of dementia.

AAG supports the greater emphasis on decision-makers’ responsibility to give effect to the will and preferences of an older person. This should be the case, even where it exposes the person to some risk.

**7. The conflict of interest that some hospitals face when requesting a guardian be appointed should be considered.**

It is a common scenario that the Tribunal receives applications from hospitals asking for a guardian to be appointed to make accommodation and perhaps care decisions for a person, because of a view that the person would not be able to live at home safely. This is in the context of hospitals being under pressure to discharge people who no longer need acute beds. Older people's will and preferences to return home, even when health professionals consider it may not be safe, should be given greater weight and not overridden simply because of a lack of forms of post-acute care such as transition care, restorative care and ComPacks.

**8. There is a need to explicitly address the use of restrictive practices in informal care settings.**

AAG welcomes the role the proposed Public Advocate can play in "educating families, carers and community groups about restrictive practices and the need for their reduction and eventual elimination" (draft proposals 8.1(2) and 9.1(3)(b)(iii)). AAG notes that chemical restraints must be included in any definition of restrictive practices, and supports this definition used by the National Disability Insurance Agency (NDIA):

*"Restrictive practices include using restraint (physical, chemical, mechanical and environmental) and seclusion, as well as other ways to prevent an individual from exercising their rights." (12)*

AAG also supports "the standing recommendation from the Australian Law Reform Commission that the Commonwealth should regulate restrictive practices in residential aged care, and that the regulations should be consistent to those operating under the NDIS" (draft proposals, (1), p.60).

We recognise that the Commonwealth regulates restrictive practices in aged care (and will shortly do so for the NDIS) but we have some concerns that this means that there will be no mechanism requiring an aged care provider or prescribing health professional to seek prior approval for restrictive practices other than, in the case, of medical treatment, seeking the consent of the person responsible.

We would also like to see a further exploration of how the new Guardianship Act may consider and mitigate harm to older persons through the use of restrictive practices in informal settings beyond education by the Public Advocate.

**9. There should be a single registry for all agreements and orders made under the proposed Act**

AAG does not support that "The new Act should not require registration of support agreements, support orders, enduring representation agreements or representation orders." (draft proposal 10.2). This can lead to the avoidable and difficult situation where multiple people present for example, in a health care setting, with signed formal decision-making agreements or it is difficult to establish whether an agreement or order has been made. Similarly, financial institutions have no easy way of checking whether a particular power of attorney document is the most current one.

AAG would also like to submit the following regarding some specific proposals under the proposed Act that we would like the LRC to further consider:

- Whether the requirement to consult with other important people in the represented person's life, where appropriate, should be included in draft proposals 4.9 and 5.12 regarding the responsibilities of enduring representatives and representatives, respectively.
- Whether it should not sometimes be the case that an appointment *does* lapse if an enduring representative (or their spouse, child, brother or sister) is subsequently engaged to provide for fee or reward healthcare, accommodation or other support services to the represented person (draft proposal 4.3(2)). Such situations may present financial conflicts of interest that should be addressed. For example, it would allow an enduring representative to decide that a person needs

care or accommodation and then to decide to provide that care or accommodation themselves, or by their spouse, child, brother or sister, for a fee.

Yours sincerely,

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