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A D V O C A C Y

**Submission to the NSW Legislative Council  
Standing Committee on Social Issues Inquiry into  
the provisions of the Ageing and Disability  
Commissioner Bill 2019**

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## Introduction

Family Advocacy is a state and federally funded disability advocacy organisation that works across New South Wales (NSW) and was founded just under 30 years ago by families of people with developmental disability who were concerned with the rights and interests of people with developmental disability in NSW (hereinafter “disability”).

Our goal is to advance and protect the rights and interests of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. This includes the right to live safely and with dignity, free from abuse, neglect or exploitation. Part of our work encompasses representing the rights and interests of a person with disability to government regarding legislation, policy, funding, monitoring, and practice in areas that impact on their needs.

We appreciate the opportunity provided by the NSW Legislative Council’s Standing Committee on Social Issues to respond to the inquiry into the provisions of the “Ageing and Disability Commissioner Bill 2019 (hereinafter, “the Bill”). Our comments are premised on nearly 30

years of accumulated experience working with families that have a family member with disability and their interactions with the many services in NSW.

On the whole, Family Advocacy supports the main objectives in the establishment of the Ageing and Disability Commission and the enactment of the Ageing and Disability Commissioner Bill 2019. However, there are recommendations we submit for the Committee's consideration to ensure that the Bill is strengthened in a way that protects people with disability further. The concerns raised below will highlight weaknesses within the current Bill.

We would be very interested in providing oral evidence should the Standing Committee deem it relevant to do so in the upcoming hearings. We do express our concern regarding the very short turnaround time (24 hours) to provide this written submission and hence, strongly welcome the opportunity to be able to elaborate on our comments and recommendations.

## The Issue of Consent

We are concerned with the phrase in Section 13 (10) (a) that states that consent is sought unless "the adult is incapable of giving consent". Firstly, there are no parameters within the Bill that determine how a person is deemed incapable of giving consent. Secondly, there is no mention of how a person, if deemed incapable, will be represented by a substitute decision maker in the investigation process, or if this is even the case.

All efforts should be taken to maximise the involvement of the vulnerable adult to disclose and give evidence and to the response that is provided to the alleged abuse and neglect – including through the provision of appropriate substitute decision making supports.

This is also supported by the recent NSW Ombudsman's report into the '*Abuse and neglect of vulnerable adults in NSW - the need for action*', 2 November 2018. This report strongly highlights the critical need for all efforts to be exhausted in relation to the involvement, including the voice of the person with disability, regardless of the deemed decision making capacity of the person.

The report upholds that:

*“It is vital that the presumption is always that the person has the ability to make their own decisions, and that substitute decision-making is a last resort. Where there is evidence to suggest that the person is currently unable to make an informed decision in relation to the matter at hand, the first response should be the provision of decision-making supports (in whatever form works best for the person)”.*

Family Advocacy recommend that it is essential to strengthen this section of the Bill to safeguard the rights and autonomy of the person with disability and to ensure that ad hoc decisions regarding a person's capacity are not being made by the Commissioner and their delegated staff. We would further recommend in the event that a person is considered unable to make an informed decision, that a substitute decision making model should be adopted without exception.

## Commissioner Independence

The independent functions of the Ageing and Disability Commissioner form one of the most critical foundational pieces to the success of the role in reducing the abuse, neglect and exploitation of people with disability across NSW. This also extends to the role and authority of the Minister over the work conducted with the Ageing and Disability Commission.

To this end we recommend that all functions of the Commissioner, as expressed on page 6, Clause 12 (1) (a) to (g) be independent and not subject to the control or direction of the Minister, not just those expressed in Clause 12 (3) (a) to (c).

## Minister's Power to Remove a Board Member

We refer to Part 6, Section 27 (9) which gives the Minister absolute power to remove a Board member “at any time”. We see this as a significant concern as there is currently nothing in the Bill that highlights when and under what conditions this can occur. To ensure that the independence and the integrity of the Advisory Board is maintained, we believe that it should be clearly stated in the Bill under what conditions the removal of an Advisory Board member can occur by the Minister.

## Independent advocacy

We welcome the role of the Commissioner in the Ageing and Disability Commissioner Bill and see this as another important layer of protection to safeguarding people with disability in NSW particularly in relation to the abuse, neglect and exploitation. However, we hold significant concerns regarding the view from Government that this mechanism can act in isolation to achieve its objectives. This concern was also expressed in the aforementioned NSW Ombudsman's report.

*“It is important to recognise that the role of a Public Advocate should complement, not duplicate or replace, the role of community advocacy. In our view, community advocates would be an important stakeholder for the Public Advocate, including playing a key role in raising concerns about suspected abuse and neglect of people for the Commissioner’s investigation and action; and providing critical decision-making support”.*

For many years, there has been a strong and respectful working relationship that has existed between the NSW disability advocacy sector and the work of the NSW Ombudsman. This relationship has no doubt contributed to the mutual objective of working towards promoting and defending the rights and interests of people with disability. With the NSW Ombudsman losing many of its functions as of the 1st of July, Family Advocacy see that it is critical to continue this close collaboration with the Ageing and Disability Commissioner and the Advisory Board.

Further, it is our experience that in many cases in NSW, a vulnerable person with disability would tend to be hesitant or fearful to take a significant issue directly to an authority or independent body such as the Ageing and Disability Commission. For many people experiencing abuse, neglect and exploitation their first port of call would be their community based connections through the advocacy sector. Vulnerable adults generally will only disclose abuse and neglect to people they are familiar with and/or trust. In the first instance, we would provide advice and support concerning serious issues and, where deemed appropriate, support and direct them to the relevant authorities.

We echo the view expressed in the aforementioned Ombudsman’s report that:

*“There is a vital continuing role for community advocates who work with and support people with disability and other individuals who require decision-making and advocacy assistance, and who advocate for broader, systemic issues across a range of life domains.”*

With this in mind, we strongly recommend that the Bill incorporates as one of the functions of the Commissioner and the Advisory Board “to consult regularly with the NSW disability advocacy sector”. This will provide a safeguard to continue the essential work of collaboration so as to ensure the essential multi-layered supports exist across NSW for people with disability.

## Conclusion

Family Advocacy is in principle, supportive of the Bill, the establishment of the Ageing and Disability Commissioner, and its overarching object to protect and promote the rights of people with disability and older people from abuse, neglect and exploitation.

We do, however, make recommendations with regard to strengthening the Bill in relation to the issue of consent, the independence of the Commissioner, the Minister’s power to remove a Board member, and acknowledging the vital role of independent advocacy. We strongly request that due consideration be given by Standing Committee and our recommendations be adopted.