

Submission to the Ageing and Disability Commission Act Review

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Physical Disability Council of NSW
3/184 Glebe Point Road, Glebe, NSW 203702 9552 1606

www.pdcnsw.org.au

hayley.stone@pdcnsw.org.au

Family Advocacy
88-90 George Street, Hornsby New South Wales, 2077
02 9869 0866

www.family-advocacy.com

leanne@family-advocacy.com

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Endorsements

This submission has been endorsed by Western Sydney Community Forum.



Who we are

The **Physical Disability Council of NSW** (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure, and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e. self-advocate).
- To educate and inform stakeholders (i.e.: about the needs of people with a physical disability) so that they can achieve and maintain full participation, equality of opportunity and equality of citizenship.

Family Advocacy is a community-based disability advocacy agency formed by families 30 years ago to promote and defend the rights and interests of children and adults who have developmental disability across NSW. Developmental disability is a disability that occurs in the developmental period of a person's life (in the period from conception to adulthood) and includes but is not limited to autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability.

The work that Family Advocacy undertakes falls into three main areas:

- Statewide Advocacy-advice and advocacy information for individuals
- Advocacy development for family members, friends, and allies of people with developmental disability
- Systemic Advocacy

We support families to advocate with and on behalf of people with disability from a wide range of socioeconomic backgrounds, First Nations people, culturally and linguistically diverse people, and people from metropolitan, rural, and remote areas. Some of the areas we provide advocacy support include early childhood education, education, employment, housing, guardianship, and NDIS.

Recommendations

Recommendation 1:

The NSW government should provide long-term funding to the Ageing and Disability Commission based on evidence of existing demand and projected growth across both the ageing and disability populations.

Recommendation 2:

The Commission should be empowered to establish, and maintain, a public register of entities when complaints have been upheld.

Recommendation 3:

Include definitions of abuse, neglect, and exploitation in the Act

Recommendation 4:

Develop an accessible, comprehensive guide to the Act, across a variety of community languages and formats, to support older persons and those with disability to better understand and interpret the Act and the powers it gives across the Commission's operations

Recommendation 5:

Increase penalty rates for corporations and businesses that refuse to comply with investigative processes.

Recommendation 6:

*Add a requirement under s. 14 that if the Commissioner is of the view that a report should be made to an external organisation, complainants and victims should be notified of the Commissioner's view **in advance**, and provided with the opportunity to raise concerns, which the Commissioner must be obligated to consider before making a final decision.*

Recommendation 7:

Expand the scope of the Official Community Visitors Program to include general boarding houses, address service gaps and increase funding to hire Official Community Visitors as paid employees or contracted suppliers.

Recommendation 8:

Ensure that clear guidelines exist in the regulations as to all relevant factors the Commissioner should consider when determining if an individual has the capacity to provide consent and factors to be considered in determining whether to pursue a complaint without consent.

Introduction

Family Advocacy and the Physical Disability Council of NSW, appreciate the opportunity to respond to the review of the Ageing and Disability Commissioner Act (the ADC Act).

The establishment of the Ageing and Disability Commission, (the ADC), in 2019 was a critical milestone towards achieving equitable rights for both older persons and those living with disability across NSW. The Commission has a critical role as the primary body in NSW to promote and safeguard the rights of vulnerable older people and people with disability across NSW, filling a critical gap not previously addressed by other complaint and investigative bodies in NSW.

Across the past few years, there has been far greater community awareness of the vulnerabilities that may exist across both the ageing and disability cohorts, and a significant increase in unanticipated challenges for both communities, including the impacts of natural disasters and the Covid19 pandemic, together with associated cost of living pressures.

It is important to recognise that the Commission is still in its early days of operation, and the unexpected context in which the ADC has had to function, which has resulted in higher than anticipated demand across the Commission's services and made the provision of these services more difficult.

At the same time, in assessing the effectiveness of the Act, it is also important to consider whether the ADC has had access to the necessary baseline resourcing to fulfil its statutory functions. We know that original funding for the ADC was exclusive of population increases or crisis driven demand, and understand that budget requests submitted in 2021-22, based on service demand over the prior two years of operations were declined.¹

The ADC has admirably fulfilled its statutory obligations under constrained financial circumstances, becoming a fully operational body in less than three years. We are acutely aware that the ADC is not on a sustainable financial trajectory and call on the State Government to ensure that the Commission is appropriately resourced as a matter of priority.

In preparation for this submission, PDCN undertook two online focus groups each lasting 2 hours in duration. Each group was made up of four people with a disability. In addition, one individual undertook the questions via a one-on-one phone call to meet their accessibility requirements.

Participant demographics were as follows:

1. Disability Type:

Arthritis (1), Blind (2), Cerebral Palsy (1), Hearing Impairment (2), Lymphoedema (1), Multiple Sclerosis (1), Paraplegia (2), Psychosocial (1), Tetraplegia (1)
(note – some participants identified with more than one disability)

2. Gender:

Male (4), Female (5)

3. Age:

35-44 (1), 45-54 (3), 55-64 (3), 65-74 (2)

¹ Ageing and Disability Commission Annual Report, 2021 – 2022 <[2021-22 Annual Report \(nsw.gov.au\)](#)> accessed 14 December 2022.

4. **Locality:**

Metropolitan (6), Outer Metro (1), Regional (2)

5. **Employment Status**

Full Time (1), Part Time (2) Unemployed (2), Retired (2), Volunteer (1), Unknown (1)

Prior to the sessions the participants were provided with links to the Ageing and Disability Commissioner's Act 2019 and the Ageing and Disability Commission's website.

We also received advice from Western Sydney Community Forum (WSCF), the regional peak body representing the collective interests of the Western Sydney community. In this context, WSCF represents the collective interests of approximately 50% of the population of Greater Sydney. WSCF provided important insight specific to the interests of older people and people with disability across Western Sydney, including Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse backgrounds.

Four key themes emerged across our research – firstly, that people with physical disability value the ADC as a mechanism to ensure that people with disability can live in safety, irrespective of whether they personally have reason to use the ADC's services. The ADC is seen as an important safeguard for vulnerable members of the community and seen as vital for monitoring the actions of disability and aged care providers.

The second observation is that full scope of services provided by the ADC are not necessarily understood by the disability community, and more could be done to both increase the community profile of the Commission and to ensure that older persons and people with disability are able to better understand their rights and the statutory duties of the ADC. This is particularly important for members of culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people, and those with low health literacy. It is essential that the ADC is provided sufficient resourcing to achieve broad public awareness of the important function it provides in protecting the health and wellbeing of those at greatest risk across the ageing and disability communities.

A third theme was whether the Act provided sufficient powers to the Commissioner to act in instances where there was proven harm to individuals, particularly in the context of service providers, and whether more could be done to impose penalties and sanctions on entities that have been found to operate in ways that are abusive, neglectful, or exploitative to those within their care. There was a call for perpetrators of abuse, neglect, and exploitation of individuals subject to a complaint to the Commission, to be recorded on some form of public register, to better safeguard those in the community against harm.

A final issue was whether the Act strikes the right balance in terms of the power of the Commissioner to disclose sensitive personal information about an individual, versus the right of the individual to retain control over such information. Participants were concerned that such powers, unless exercised carefully, could result in reprisals against those at risk and/or complainants, and unwarranted release of individuals' personal information, including sensitive health information.

We will address each of these themes in turn below and will also talk specifically to the operation of the Official Community Visitors Program (the OCVP).

Perceived value of the Commission and the Act

Our members unanimously supported the Commission and agreed that it was critical to have such an act to both respond to instances where abuse may be occurring, and safeguard the rights of people with disability, and older people, to live safety within their communities.

Our research indicates that the rights within the ADC Act are fit for purpose and should remain as they are, however, while the rights in the Act were deemed to be sufficiently broad to cover all anticipated circumstances where acts of abuse might arise, it was noted that these rights need to be coupled with enforcement powers, or they become simply aspirational. On this point, several participants across our consultations noted a disconnect between the rights and their own lived experience, suggesting that mechanisms for enforceability must be strengthened.

'No, they are not good enough – I am still being constantly discriminated against and can't access assistance to allow me to remain independent.'

-Quote from ADC Act review consultation participant.

There was concern that the rights guiding the Act were not developed in codesign with the disability community in the first instance:

'Too much about us without us'.

-Quote from ADC Act review consultation participant.

These concerns extended to the statutory processes around the appointment of the Commissioner. Participants were in favour of a broad selection process, via a panel with lay representatives from both the ageing and disability communities. A Commissioner with lived experience was also seen as highly desirable, while other important considerations participants considered relevant included candidates having experience across relevant sectors, a track-record of proactivity as well as avoiding any real or perceived conflicts of interest.

Participants expressed the view that the Commission currently appears constrained in its capacity to address broad, systemic issues affecting the NSW ageing and disability communities. These constraints were understood to be a resourcing issue, with participants stressing the need for the Commission to have both the funding and staffing capacity it needs to act quickly on any complaint received.

Difficulties understanding and interpreting the Act

It was noted by several participants that they were unaware of the statutory responsibilities of the ADC prior to participating in the consultation and the Commission should be given additional resourcing to build broad public awareness of its work.

'Seems like it does not have enough visibility in the community, many people do not know it exists or what issues they can take to the Commission'

-Quote from ADC Act review consultation participant.

Being able to understand the Act in the first instance is critical not only for people with disability and older people to be able to understand, and enforce their rights, but also in facilitating their full and effective participation across any statutory review processes.

It was suggested that a formal public launch of the Commission (an opportunity which may have been lost across the pandemic), and a targeted campaign on elder abuse and the abuse of people with disability, coupled with promotion of the Commission's role across a variety of channels, including TV,

Radio, internet, and other forms of media, would increase community awareness of the Commission and enhance its overall effectiveness.

In preparation for the consultations, several participants read, or attempted to read, the Act itself. While the leading questions in the discussion paper provided some insight, participants still struggled to understand the legislation, hampering the collective ability of the group to make informed comment about the Act's functioning.

'Act needs more clarity, plain English definitions, and no jargon to ensure all people can understand it.'

-Quote from ADC Act review consultation participant.

A primary issue raised was that participants were unsure what types of actions could constitute abuse, neglect, and exploitation, with suggestions that these terms should be explained in the definitions.

'If I can't use a website because I'm blind, and it's inaccessible to me, is this neglect? And is it different (or more substantial) if a government body does this, as opposed to a small individual business?'

-Quote from ADC Act review consultation participant.

We note that the ADC itself provides comprehensive, plain English definitions of abuse and neglect in its *'For the Community'* tab on the ADC website as well as information about general the role of the Commission. The ADC website also provides the option to switch across several languages.

We would recommend promotion of these resources, as well as the development of an accessible, comprehensive guide to the Act, across a variety of community languages and formats, to support older persons and those with disability to better understand and interpret the Act and the powers it gives across the Commission's operations.

Concerns regarding the public consultation process

It is important to ensure that the diverse views across the ageing and disability communities are heard in relation to the functioning of the Act.

It is particularly vital to understand whether the Act provides scope for the Commission to address the safety needs of marginalised sub-groups of persons, including Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds, women, young people, and the LGBTIQ community. The input of carers of older people and people with disability is also significant.

We received complaints that the standard guiding document was too simplistic and did not go into enough detail to allow participants to have an informed opinion without having to go directly to the legislation. We would also suggest that greater community buy-in might have been realised if the review had been more inclusively framed as a review into the effectiveness of the Commission, as opposed to inviting the community to invite comment on how the Act is operating.

While we appreciate that the discussion paper was available in both easy read, and a variety of community languages, interpreting assistance was advertised on the Have Your Say website, and that a variety of options were available to participate in the review, we are concerned that the limited consultation time in which to respond, and the timing of the consultation (across the latter part of the calendar year) may have reduced the capacity for both individuals and representative organisations to participate.

Powers of the Commissioner to act in instances of abuse

Participants across our consultations noted that the Act was not mature enough to make any real assessment on the overall effectiveness of the Commissioner's powers in driving systemic reform to address abuse neglect and exploitation of older people and people with disability.

Irrespective, participants were satisfied that the protections and safeguards provided under the Act. appeared appropriate, so long as they were able to be practically executed. The capacity of the Commissioner to self-initiate complaints, compel any person to attend a meeting or provide information, and apply search warrants were all considered highly important given the seriousness grounds being investigated, as was the ability for the Commissioner to refer reports to the Commissioner of Police or the Director of Public Prosecutions for pursuit via the Local Court.

Penalties were viewed as a vital tool to facilitate investigations, providing they had sufficient weight. Current penalty rates were seen as too low, particularly in the context of non-compliance with requests by corporations and businesses. Participants were keen to see perpetrators of serious cases of abuse, neglect, and exploitation against older people and people with disability incur severe penalties, including the options for imprisonment.

Although this is not made explicit in the Act itself, we anticipate that more serious penalties are already available via the Local Court system.

We note that, although the Commissioner has the capacity to conduct public inquiries in cases in the public interest, there is no statutory requirement for the Commissioner to report publicly on complaints that have been upheld.

Consultation participants noted that this meant that there was no way for the public to know whether a care provider had committed previous acts of abuse, and that this information would be extremely important when making decisions about which care provider to use.

Expanded powers of public reporting should be provided to the Commission in cases where complaints have been upheld to allow the aged and disability communities to make informed consumer choices.

We note that Fair Trading already provides a public register to help consumers make informed purchasing decisions that could be instructive in developing such a resource.²

Powers of the Commissioner verses confidentiality and safety of the complainant and the person who may be experiencing harm

Participants were uncomfortable with the powers invested in the Commissioner under s. 8 to conduct investigations without consent of an older person or person with disability where the if the Commissioner either believes that the individual is incapable of giving consent, or that the seriousness of the allegation or the risk to the personal safety of the adult overrides this requirement.

There were also concerns about the Commissioner's capacity to exchange information with a relevant agency under the grounds specified in s. 14.

'What is the cut-off point? Where do we stop? There needs to be clear guidance on when it is acceptable to do this'.

² Department of Fair Trading, Complaints Register <[Complaints register | NSW Fair Trading](#)> accessed 14 December 2022.

-Quote from ADC Act review consultation participant.

Participants stressed the need for clear guidelines for determining whether an individual has the capacity to give consent, and the types of circumstances in which it would be appropriate to waive the requirement of consent.

While the value in having the Commissioner report to other relevant organisations when abuse occurs was recognised, participants were concerned about the potential for that this power could have an adverse impact on complainants/and or the person believed to be at risk. It was noted that significant power imbalances can exist in the relationships between care recipients and their providers, and that reprisals might occur if details of a complaint are given to the provider purported to be at fault.

If the Commissioner is of the view that a report should be made to an external organisation, complainants and victims should be notified of the Commissioner's view, and provided with the opportunity to raise any concerns, which the Commissioner should be obligated to consider before making their decision.

[The right to provide consent] should not be taken lightly!

-Quote from ADC Act review consultation participant.

If consent is NOT given, there must be consideration of the person's understanding and their ability to make a decision

-Quote from ADC Act review consultation participant.

Referral of complaints must align with 'no wrong door' principles

We stress the importance of resourcing the Commission to ensure staff can apply a supportive, holistic lens when engaging with complainants, irrespective of whether an issue of abuse falls within the Commission's remit.

The process of being transferred between different service providers is often traumatic for individuals, particularly if this involves reiterating traumatic information. In line with trauma-informed practice principles, a 'no wrong door' transfer process incorporating 'warm' transfers of clients between the Commission and other relevant organisations should be utilised.

The operation of the Official Community Visitors Program

PDCN supports the Official Community Visitors (OCV) Program as an important mechanism to gain 'on the ground' insight into the lived experience of older people and people with disability residing in supported accommodation. We have reports that the OCV program is overworked, and under-resourced, compromising the capacity for OCVs to perform duties, for example, consulting with everyone at a particular accommodation provider.

Given the serious nature, and the skills and expertise necessary to carry out the duties of an OCV, it would be more appropriate for OCVs to either be paid employees of, or contracted by, the Commission.

Supply and demand must be tracked on an ongoing basis

The Commission should be funded to collate data on supply and demand of the OCV across NSW on an ongoing basis to identify and respond to gaps in service delivery (we are mindful that gaps currently exist in Western NSW). This data should then form the basis for determining future funding.

Expand the OCV Program into general boarding houses

We note that the scheme currently only operates across assisted boarding houses and accommodation services where an adult with disability or older adult using the service is in the full-time care of the service provider. The OCV program should be extended into general boarding houses to account for reports that some proprietors provide accommodation for people with disabilities without registering as an assisted boarding house.

Lastly, it is important to highlight that while Official Community Visitors (OCVs) play a vital role in safeguarding the rights of older people and people with disabilities, they perform a vastly different function to specialist individual advocates and should not be considered as a subset of the latter

Final comments

The Ageing and Disability Commissioner Act provides authority for the Commissioner to conduct vital work in ensuring that older people and people with disability across NSW live free from abuse, neglect, and exploitation in fulfilment of the NSW Government's human rights commitments under international and domestic law.

It is vital that the Act is in alignment with the internationally recognised rights of older persons and those with disability, and that it provides sufficient power to the Commission to champion these rights in line with community expectations.

Our research has indicated that the Act, as it currently stands, is fit for purpose with no significant deficiencies or shortfalls. The greater concern for the disability community is that the Commission has been constrained from realising its full potential to date on account of consistent underfunding, despite clear demand and community investment in its services.

This is a concerning trend, which accords with recent Government disengagement from the disability community, and its chronic underinvestment and divestment across all state disability support services.