**Submission from:**

**The Board of Management of Citizen Advocacy Perth West (CAPW)**

**Organisational background and Advocacy program of CAPW**

CAPW is a volunteer - based Disability Advocacy Agency that connects people with intellectual disabilities with volunteer Citizen Advocates. The program operates in the north - western suburbs of Perth. Volunteer advocates are matched with a person with an intellectual disability, on a long - term, one to one basis. Orientation of prospective citizen advocates to the particular needs of an individual person with intellectual disabilities is a key component of this matching.

Core functions and objectives of the program operated by CAPW include:

* Enabling and facilitation of timely access to independent advocacy
* Stronger social integration of people with intellectual disabilities through increased participation and interaction within the wider community.
* Demonstration and fulfilment of long - term commitment and loyalty of citizen advocates to the individual with whom they are matched

Matching of an individual with an intellectual disability with a volunteer citizen advocate is implemented by experienced staff members. The aim is to ensure that matches are compatible, and therefore likely to be effective and enduring. This aids stability and continuity of planning and development of personalised advocacy over the longer term. Some matches are life - long.

CAPW is one of a relatively small number of not for profit organisations in Australia supporting Disability Advocacy programs that are volunteer - based and delivered free of financial charge or cost to people with intellectual disability. The CAPW program seeks to prioritise access on the basis of need. Indicators of need include personal isolation, risk and vulnerability.

All individuals assisted by CAPW have a degree of intellectual disability and usually have no family or friends in a position to help them. The spectrum includes those with mild intellectual disabilities living alone in the community, heightening their vulnerability, through to those with profound or multiple disabilities reliant on 24/7 support.

Many of the participants in the CAPW program will access disability support services through Tiers 2 and 3 of the National Disability Insurance Scheme (NDIS). The nature of intellectual disability is also such that it often poses barriers to formulation, articulation and realisation of personal choices and decisions.

An excerpt from our newsletter is attached at the end of this submission. The attachment exemplifies the profound and positive difference that citizen advocates can make to an individual’s life, in this instance over a 15 year period.

**CAPW’s comments on the National Disability Advocacy Framework (NDAF)**

**Definitions**

In essence, CAPW agrees with the descriptive definitions appearing in Article 9 of the NDAF. In accordance with NDAF Attachment A (Glossary definitions), we interpret the term ‘Individual Advocacy’ as being broadly generic in application to a number of distinct and complementary models of Disability Advocacy. The personalised, independent, one to one Citizen Advocacy model complements the models of Individual Advocacy whose program operation is largely short term instance or event - oriented.

**Principles**

CAPW endorses the statement of principles in the NDAF as encompassing almost all of the essential aspects and features of effective Disability Advocacy. Independence of advocates is a defining feature of the Citizen Advocacy model and programs. CAPW therefore supports the proposal by Committee of Management of the North East Citizen Advocacy (NECA) Program (Melbourne, Victoria)for inclusion of an additional statement of principle:

‘*Disability advocacy recognises the right of people with a disability who need support to be able to access independent advocates*’ (1)

CAPW considers a reference to advocate independence in the statement of guiding principles to be desirable for promotion of independence of advocacy as a quality consideration in Article 12 (e) and Article 15 (b) of the NDAF.

**Objectives**

CAPW endorses the statement of objectives in the NDAF.

**Outcomes**

Safeguarding of the interests of people who are vulnerable and at increased risk of harm as a consequence of their disability is a core objective of Citizen Advocacy programs. Endorsing the outcomes specified in the NDAF, we therefore also concur with the observations by NECA that:

‘*The NDAF also needs to ensure that people with disability are properly supported to report abuse and make complaints*’ (2)

The Productivity Commission 2011 Inquiry *Report on Disability Care and Support*foresaw an important role for Disability Advocacy Agencies in assisting and facilitating system navigation processes by people with disabilities seeking to access support services under the NDIS.(3) CAPW supports the related observation of NECA that:

*‘The current framework does not address the capacity requirements (ie 60% intellectually disabled). People with disability who engage with the NDIS will in all likelihood require an advocate in order to make choices under the NDIS’* (4)

The Citizen Advocacy model has the capacity to contribute to the meeting of additional advocacy needs engendered by the transition to the NDIS. When necessary, Citizen Advocates are supported in their role by specialist Advocate Associates, with relevant skills and qualifications. Recruitment of Advocate Associates who can provide expert advice and assistance to citizen advocates and staff is an essential part of the CAPW program.

**Outputs**

CAPW endorses the specifications of Outputs in the NDAF.

**Funding considerations**

The community volunteer base of the Citizen Advocacy and its focus on the needs of socially isolated and vulnerable people with intellectual disability currently appear to preclude any transition of CAPW program operation to a user pays, fee for service scheme. For this reason and for reasons cited in the Productivity Commission 2011 Inquiry Report on *Disability Care and Support*, CAPW also supports the following finding and recommendations of the Productivity Commission’s 2011 report:

* The finding that neither individually based nor systemic forms of advocacy are well - suited to a user - pays system(5)
* The recommendation that Disability Advocacy funding by the Commonwealth and State Governments should be administered separately from the National Disability Insurance Scheme(6)
* The recommendation that block funding be retained for Individual Advocacy models and for Systemic Advocacy(7)

It is expected that the majority of people with intellectual disability and heightened vulnerability will be supported financially through the NDIS in their accessing of services. Non - financial transaction costs (8) will nevertheless continue to act as barriers to access to needed supports for people with intellectual disabilities. Continuity of ready access to Disability Advocacy will need to maintained, especially during the NDIS transition process and the initial stages of NDIS development and evolution.

In this context, CAPW shares the concern expressed in the Productivity Commission’s 2011 report that:

‘*Relying on an individual’s capacity to privately pay for advocacy is likely to render it unobtainable to those who need it most’*

**References:**

1. North Eastern Citizen Advocacy submission to the 2015 National Disability Advocacy Framework consultation round, under heading of ‘*NDAF Principles*’, Melbourne.
2. North Eastern Citizen Advocacy submission to the 2015 National Disability Advocacy Framework consultation round, under heading of ‘*NDAF Outcomes*’, Melbourne.
3. Productivity Commission 2011, Disability Care and Support, Report No 54, Canberra, vol. 1, p 507 - 508.
4. North Eastern Citizen Advocacy submission to the 2015 National Disability Advocacy Framework consultation round, under heading of ‘*NDAF Outcomes*’, Melbourne.
5. Productivity Commission 2011, Disability Care and Support, report No 54, Canberra, vol. 1, p 26.
6. Productivity Commission 2011, Disability Care and Support, report No 54, Canberra, vol. 1, p 524 - 525.
7. Productivity Commission 2011, Disability Care and Support, report No 54, Canberra, vol. 1, p 524
8. Productivity Commission 2011, Disability Care and Support, report No 54, Canberra, vol. 1, p 479

**Attachment**

***“How Winnie found joy – and her voice”*** *(excerpt from CAPW Newsletter)*

*Thanks to the dedication of two citizen advocates, Winnie’s final years contained much happiness.  Her funeral was a joyful celebration of the last years of Winnie's life.*

*Here’s just a little of her story:*

*Despite not having a mental illness, Winnie spent half a century in the mental health system.  She shared a cramped room with 3 others.  She learned to “put up and shut up” and for decades never spoke a word.*

*As a result of the commitment, perseverance and passion of Patrick, her brother’s citizen advocate, Winnie left the grim psychiatric hostel and moved into a friendly home for ladies with intellectual disability.  Patrick also became Winnie’s advocate and ensured she had regular contact with her two brothers, also with intellectual disability.*

*When Patrick went to Rome to study to become a priest, we introduced Winnie to her new citizen advocate, Michelle.*

*In her latter years Winnie was given the opportunity to experience many pleasures previously denied to her, including a room of her own and the ability to make choices.  She enjoyed countless outings with Michelle who recounted time and again how Winnie continued to surprise her.*

*Understanding that Winnie was non-verbal, Michelle said “you could have knocked me down with a feather when one day Winnie read aloud the sign on the car ahead: ‘Western Suburbs Driving School’!!!”   After decades of silence Winnie finally found her voice!  She used to love singing along to songs and recently even read books aloud.  Michelle liaised with the Public Trustee in order that Winnie could access her inheritance.  With Michelle’s support she was finally able to make choices: going out to shop for her own clothes (rather than wearing the clothes of deceased residents), where and what to eat, and so much more.*

*Winnie’s sudden passing came as a surprise.  Many of her friends at Citizen Advocacy attended Winnie's funeral, conducted by Patrick with a eulogy by Michelle.  Including some favourite songs, it was a joyful celebration of the last years of Winnie's life.  Patrick spoke of learning much from Winnie, admiring her remarkable resilience and acceptance.*

*In closing, Patrick took the opportunity to acknowledge Professor Wolf Wolfensberger, who developed the model of Citizen Advocacy and contributed so significantly to the wellbeing of countless devalued individuals.  Thanks to Wolf’s insights, two wonderful advocates were in a position to make Winnie’s life so much richer.*