Submission to the National Disability Advocacy Review from:

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

Organisational background 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 with intellectual disability 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 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 lifelong.

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.

CAPW Submission on the National Disability Advocacy Program (NDAP) review

1 Models of Advocacy

1.1 *How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?*

There is very wide diversity in the circumstances and needs of people with disabilities. This is particularly the case for people with intellectual disabilities.

Availability of advocacy through a range of specialised and Disability Advocacy agencies whose advocacy models and operations are mutually complementary increases the likelihood that the specific advocacy needs of people with disabilities can be appropriately and adequately met.

Smaller agencies funded to provide one particular model of advocacy have some other definite advantages:

1) They allow for a close and personal relationship with the person with disability, enabling the agency to better understand and identify client needs.

2) A capacity for fast decision making and agility of responsiveness, with immediate action when required.

3) Staff of smaller agencies tend to identify with their agency and gain personal satisfaction by providing service above and beyond expectations.

4) Smaller disability advocacy agencies typically have a lean organisational structure, with few staff and administrative overheads, allowing a high degree of concentration on the core business of advocacy.

5) In the case of Citizen Advocacy model, the volunteer advocates make a long-term commitment to an individual with intellectual disability. This allows on-going opportunities for the advocate to work with that person to identify and avoid situations involving foreseeable and preventable risks, whose materialisation could otherwise require more reactive and less optimal advocacy interventions later on.

1.2 *What are the drawbacks?*

Even in areas of high population density, specialised agencies may not achieve complete or comprehensive coverage and catering for advocacy needs. It will be desirable, therefore, to maintain funding to some generalist agencies that have the capacity to fill gaps or deficits in the local and regional availability of advocacy services.

1.3 *How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?*

It may not be possible or even appropriate to seek to provide access to specialist services and models of advocacy everywhere, in all regions. This does not, however, imply that access to model-specific programs and services should not be funded anywhere.

Many people with extensive or multiple disabilities need high levels of ongoing care. This requires ready access to support infrastructures typically situated in more densely populated locations. Many people in this group also need and benefit from access to specialist advocacy services available currently in the areas in which they live.

Meeting of regional needs and coordination of advocacy service provision on a regional basis are important considerations for funding of agencies. Generalist agencies that can provide services with widespread coverage exercise an essential role and function, together with advocacy agencies whose operations have a special focus on advocacy in rural, regional and remote areas should continue to receive an appropriate and adequate share of funding through the NDAP.

2. Improving access to advocacy supports

2.1 ***How do we improve access for:***

- ***people with disability from Aboriginal and Torres Strait Islander communities and their families?***

  Facilitating the development of local capacity for disability support and advocacy services within Aboriginal and Torres Strait Islander communities is an appropriate strategy, particularly for the longer term. Existing advocacy agencies with relevant focus, interest and commitment should continue to be funded through the NDAP.

- ***people with disability from culturally and linguistically diverse communities and their families?***

  Funding should be directed towards agencies that already have the requisite awareness, sensitivity and experience to address cultural and linguistic issues. The promotion of necessary collaboration between disability advocacy agencies and external agencies with relevant expertise in the areas of language and cross-cultural communication is a relevant and desirable funding policy consideration.

- ***people with disability in rural, regional and remote locations?***

  Regionally based advocacy agencies with capability to both identify and respond to individual advocacy needs and provide local on-site access will be best placed to further this NDAP objective. Appropriate use of information and communication technology by advocacy agencies, as far as is practicable, has potential to extend the reach, improve access and contribute to the containment of costs. This will be increasingly important also for provision and dissemination of information to people with disabilities and to their care and support networks generally.

- ***people who are very socially isolated including those with communication difficulties and those in institutional care?***

  Reliable assessment and estimation of the extent of current deficits and shortfall in meeting advocacy needs of people whose disability falls into these categories is important as a starting point for devising and implementation of measures to improve and extend access. Relevant research by academic institutions and specialist agencies such as the Australian Institute of Health and Welfare could usefully inform decisions and policy in this area.

Continued recognition of the skills, experience and commitment developed by the staff of specialist, person-centred models and agencies, such as Citizen Advocacy programs, is an important element for consolidation and for enabling of further progress towards this objective through the NDAP. Personalised and ongoing matching with a Citizen Advocate with sustained, long-term support of these established relationships by committed staff are essential to successful and meaningful outcomes of advocacy through the Citizen Advocacy model.

Lines of communication and formal and informal collaboration between agencies and individuals involved in different forms and models of frontline advocacy will need to be further developed and maintained. Promotion of the extended benefits and advantages of independent advocacy to disability service providers operating in institutional settings will also need to be ongoing.

2.2 *What are the strategies or models that have worked? What are the strategies that do not work?*

STRATEGIES THAT WORK:

Facilitating informed decision making and choices by people with disabilities and, where necessary, by others in their personal support network is an essential element of effective strategies. Implementation requires sharing of information and inter-agency communication to ensure reliability of advice to those seeking/needing advocacy services.

Specific advocacy models have been developed, tested and implemented in particular operational contexts that reflect the wide variety of circumstances in which individuals with disabilities may need access to advocacy. The six advocacy models that are recognised currently within the NDAP are all effective in serving and addressing common advocacy needs, in differing contexts.

Citizen Advocacy Perth West has been operating successfully for over 35 years. It is a small community based organisation which involves long-term volunteer advocates in the lives of people with intellectual disability. The Citizen Advocate assists in addressing immediate needs, providing a voice, monitoring ongoing needs and issues and working to prevent those issues from developing into major difficulties.

Citizen Advocacy programs harness the commitment, personal interest and goodwill of volunteers who look out for the welfare of some of our community's most vulnerable and isolated members – those with intellectual disability. (Often literally or metaphorically without a voice, it is hard to imagine how many in that specific cohort could meaningfully engage in decision making and choice without a parent or Citizen Advocate patiently by their side.)

The matching with a dedicated, orientated and supported volunteer who becomes friend, mentor and advocate can transform a life and convey a message of hope and value. As members of our community, we surely owe no less. The long-term commitment of the volunteer Citizen Advocates to individual persons with intellectual disability also ensures that Citizen Advocacy model is cost-effective in its implementation.

The internal ratings and evaluation criteria of the Citizen Advocacy model (Citizen Advocacy Program Evaluation or CAPE) have a high degree of commonality and consistency with the National Disability Service (NDS) Standards that apply to agencies funded under the NDAP.

The needs of people affected by intellectual disability extend beyond the physical. Governments, Commonwealth and State, should be commended on filling this need so adequately.

Like the Family Advocacy and Self Advocacy models, the Citizen Advocacy model is strongly person-oriented. It is specifically designed to counter the social isolation experienced by some people with intellectual disabilities, thereby reducing risks of further, preventable disadvantage or adverse outcomes.

The model allows opportunity for ready access and timely initiation of advocacy whenever a need arises. It also extends opportunities for people with intellectual disabilities to express and articulate personal goals and through some of the same kinds of psycho-social connection that the majority of people in the community enjoy in their own personal support networks.

CAPW has access to the services of a number of skilled volunteer Crisis Advocates who are, together with CAPW program staff, able to support people with intellectual disability and their Advocate whenever instances of acute need for advocacy arise. Information, advice and assistance in decision making and the choices available are some of the forms of support available from Crisis Advocates.

STRATEGIES THAT DO NOT WORK:

On the operational level, models of advocacy and strategies that rely entirely on formal procedures and have purely instrumental focus may be adequate in meeting some advocacy needs of people with intellectual disabilities. This approach, however, has its limitations.

For people with intellectual disabilities and for some with multiple disabilities, however, formal approaches are likely to be less effective than the Citizen Advocacy model in meeting advocacy needs, as generally these people have on-going needs, particularly in the areas of *Participation and Inclusion* (NDS Standard 2) and *Individual Outcomes* (NDS Standard 3). People with intellectual disabilities are more likely to encounter social isolation, and to experience difficulty in communicating their needs and interests. In these circumstances especially, advocacy in relation to the objectives of these two Standards involves a significant personal dimension, which the Citizen Advocacy model is designed to address.

The merging of small agencies into one large organisation/agency might appear to hold out the prospect of cost savings, but is considered by CAPW to run a high risk of ultimately producing quite the opposite result, while at the same time reducing the efficiency and quality of the service provided.

Synergies and improvements in operational effectiveness are achievable through alternative means that also help to preserve independence of advocacy. Alternatives will involve well-directed inter-agency referral practices, based on sound understanding and familiarity with the advocacy service options that are available through external agencies and, when necessary, more formal inter–agency collaboration arrangements also.

It is our view that the different models of advocacy currently in use complement each other and ensure the best outcome for the person with disability. For example, formal processes are likely to work effectively for people with disabilities if a specific issue requiring an advocacy response has been identified and communicated to the advocacy agency. This would generally apply in the areas of *Rights* (addressed in NDS Standard 1), *Feedback and Complaints* (NDS Standard 4), *Service Access* (NDS Standard 5) and *Service Management* (NDS Standard 6)

On the administrative level, CAPW takes the view that seeking to provide advocacy services to people with differing disabilities from a “one stop shop” is a strategy that is unlikely to result in improvement or to succeed in producing beneficial outcomes. Rather, it will exclude the very people who need advocacy the most – those with no close family or friend to speak up for them and no ability to seek out advocacy for themselves.

3. Improving the advocacy evidence base and coordination on systemic issues

3.1 *What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?*

As the peak representative body for advocacy agencies at a national level, the Disability Advocacy Network Australia (DANA) will continue to have important and valuable facilitating and coordinating roles, especially with regard to systemic issues. Further enabling and support of regular communication and collaboration between DANA and representative bodies for advocacy agencies at the State and Territory levels would aid the timely and accurately targeted dissemination of relevant information.

Audit and reporting processes for NDAP–funded agencies already capture relevant information and data. If necessary, they might be adjusted to expand on their current collections; likewise with the activities and reporting of a variety of agencies, organisations and institutions at the local community, state and national levels which already provide significant information and data sources. These include the National Centre for Longitudinal Data (1) and the DSS Data Exchange website (2) which are recent internal DSS initiatives, and a number of external bodies, such as research institutions. The capability statement of the Australian Institute of Health and Welfare (3) indicates the suitability of that organisation to a major role in analysis integration and evaluation for relevance of data from this wide range of sources.

3.2 *How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:*

- ***disabled people's organisations (DPOs)***
- ***the Australian Human Rights Commission***
- ***Ombudsman organisations***
- ***aged care advocacy organisations***
- ***state disability advocacy organisations***
- ***peak bodies***

Promoting and facilitating the free flow of information, subject to appropriate privacy and confidentiality safeguards would help to increase and improve awareness and understanding of opportunities and options for collaboration.

The ongoing development of an integrated national database of key information about organisations that are actively involved in advocacy, or which actively share interests and objectives with advocacy agencies, would be useful. Peak bodies have the appropriate experience and background to continue to act as managers and custodians of such a shared resource.

4. The interface with the NDIS and addressing conflict of interest

4.1 *What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised*?

Maintenance of diversity of funded advocacy models, including continuation of the role of volunteer–based programs, will help to provide access to independent advocacy where needed. Advocate and advocacy program independence is an important and critical rating and evaluation criterion within the Citizen Advocacy model in particular.

4.2 *How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?*

Promotion and facilitation of communication and collaboration between agencies funded by either of these schemes will be important to ensure effective complementation of coverage of services funded under each scheme thus avoiding inefficiencies that could result from service duplication. Maintenance of access to independent advocacy is also important in this context.

4.3 *What policies and strategies do we need to protect the rights of people with disabilities?*

Risks to people with disabilities that could result from conflict of service provider interest can be mitigated by:

- Positive encouragement and incentives to work with other agencies to provide joint support.
- Recognition of the possibility of conflict of interest should be addressed in agency policies, and in management of operating procedures.
- In situations where direct support service and support coordination are provided by a single agency, facilitating access to independent advocacy is an appropriate safeguarding measure.
- Unnecessary impediments to accessibility and transparency of information should be avoided. For example, inappropriate citation and interpretation of privacy and confidentiality requirements as grounds for withholding information in situations

where it is not genuinely necessary or essential to safeguard individual privacy and confidentiality.

5. Understanding and improving access to justice

5.1 *What forms of legal review and representation do people with disability need most?*

Litigation is generally a last resort for people with disabilities, as it is for most others in the community. It is expensive, time-consuming and often stressful in itself. It will be important to ensure that people with disability have access to professional and specialist legal representation where required. This may not always be available through the more conventional legal aid and service channels that cater for the general community.

Adequate representation for people with disabilities is also likely to be needed in a range of quasi-legal proceedings, such as administrative review and appeal processes and formally mediated disputes. The services of specialist legal advocates for people may also need to be called on in either representative or advisory capacities when people with disabilities are engaged in these kinds of processes. In those circumstances, access to other appropriately skilled and qualified advocates and to personal support is also important.

Like other Citizen Advocacy programs, CAPW retains the generously provided, pro bono services of a number of qualified and skilled volunteer Advocate Associates with a range of relevant professional expertise, including legal, providing advice to participants in the program.

5.2 What barriers prevent people with disability from accessing justice?

For people with intellectual disability without a trusted confidant, the articulation of difficulties and problems can be a real impediment. Further examples of barriers include financial limitations, lack of access to relevant information, and limited availability of personal and logistical support to assist in making appointments or arranging transport.

5.3 *What models of legal advocacy are most effective?*

Models that can ensure access to legal advice and to representation by suitably qualified legal practitioners, experienced in working on behalf of people with disabilities, are likely to be the most effective in a variety of instances. Enabling access to other advisers, spokespersons and personal support providers with relevant skills and personal qualities will be essential in many cases.

References:

1. **https://www.dss.gov.au/about-the-department/national-centre-for-longitudinal-data**
2. **https://dex.dss.gov.au/**
3. **http://www.aihw.gov.au/capability-statement/**