ADVOCACY
TASMANIA INC.

Submission to the Review of the National Disability Advocacy Program

Introduction
Advocacy Tasmania Inc. (ATI) is an independent, non-government organisation that has been providing advocacy services across Tasmania since 1990. Our client groups consist of people with disability, older persons, people who have lived experience of mental illness and people who use or have used alcohol, tobacco and other drugs. We are also responsible for the operation of Tasmania's Elder Abuse Helpline, providing volunteer representatives for people who appear before Tasmania's Mental Health Tribunal and providing support for people seeking external review of National Disability Insurance Agency decisions.

ATI provides individual advocacy for people with a disability under the National Disability Advocacy Program and Tasmanian disability and home and community care advocacy programs. Over the past three years, we have supported people with disability with over nine hundred individual advocacy issues under these programs. We also work to progress systemic issues based on the recurrent experiences of people with disability we have worked with.

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?

People with disability have a right to access independent disability advocacy. Exercising this right involves making decisions about who to get advocacy support from and how that support is provided. This individual choice and control increases where there are a variety of advocacy services available that work in different ways.

1.2 What are the drawbacks?

Defining advocacy support in terms of prescriptive models, rather than individual rights and needs, creates significant drawbacks in providing effective advocacy services for people with disabilities. The prescriptive nature of the models creates inevitable service gaps and restricts a services ability to be flexible and responsive to need.

We believe effective disability advocacy supports individuals to:

- exercise choice and control over their lives
- understand and realise their fundamental human rights, and
- have their own say in matters that affect them

These rights do not fit neatly into the models of the National Disability Advocacy Program (NDAP). For example, an individual may:

- be able to advocate primarily on their own behalf with support (Self-Advocacy)
- choose to involve their family in the advocacy process (Family Advocacy)
- want an advocate to represent some of their wishes (Individual Advocacy)
- have accessed advocacy because they needed information and support with a specialised legal process, such a guardianship application (Legal Advocacy), and
- be experiencing an issue that is reoccurring due to a systemic factor (Systemic Advocacy)

In this example, the use of discrete models may prevent the individual from accessing tailored and appropriate advocacy, especially if agencies are only funded to provide one or two models of support.

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?

Advocacy should always start with the individual with disability and be built out from there. Our understanding of the currently used models of advocacy is that they are a framework that places the rights and interests of people with disability at the centre of all advocacy processes. Individuals direct individual advocacy and specialised legal advocacy. Individuals have a right to support, including support to self-advocate and support to make decisions. Family advocacy occurs with the consent and direction of individuals, wherever this is possible. Systemic advocacy occurs based on the experiences of individuals.

However by using prescriptive models of advocacy, services inevitably exclude potentially vulnerable people, as mentioned above. We recognise that some forms of legal advocacy involve a specialised skill set that advocates who are not legal practitioners do not possess and that ATI has limited experience of the benefits and drawbacks of the citizen advocacy model.

Under the current modelling system clients are effectively defined by their disability, which is contradictory to the intention of the National Disability Advocacy Program and the National Disability Strategy 2010-2020. ‘The Strategy seeks to promote awareness and understanding of the rights of people with disability, improve responses to people with disability in the justice system, ensure their safety and enable them to participate fully in the economic, civic and social life of our nation.’ (Commonwealth of Australia, 2011)

We believe the future of disability advocacy in Australia aligns with the strategy in that we see the key aim of advocacy in general as promoting and protecting the rights of the individual with disability and empowering them to utilise their autonomy to have maximum choice and control over their own lives. In order to do this more focus should be placed on barriers that people with disability face in realising this goal and less on models that were arguably, primarily service, not client, centred in their establishment. This approach would then allow advocacy providers to develop eligibility criteria and approaches to advocacy that achieve outcomes as defined by the client group and move our society towards being fully inclusive of all members both individually and systemically.

2.1 How do we improve access for:

- people with disability from Aboriginal and Torres Strait Islander (ATSI) communities and their families?

We believe that all advocates need cultural competence in working with ATSI People. Formal cultural awareness training is part of achieving this competence, but advocacy organisations also need to establish links with local ATSI communities and organisations, and actively seek out feedback from ATSI consumers. Advocacy services must use this feedback when developing policies and programs, and to address barriers ATSI people face accessing advocacy services.

Increasing indigenous representation in the sector is also important, in staff, governing boards, and peak bodies. We believe that genuine representation, engagement, and consultation leads to diversity of thought and practice, which in turn improves access.

- people with disability from culturally and linguistically diverse communities (CALD) and their families?

It has been identified that some of the major barriers to CALD communities accessing disability supports of any kind include knowledge of available services, lack of acknowledgement of disability, or family shame leading to a resistance of support outside the family, (Kung, 2004). We believe that education around these barriers is critical alongside establishing links and communication with local CALD groups and organisations.

Advocacy providers need cultural competence in the needs of specific communities. Without cultural competence, services are poorly placed to adapt to the needs of individuals and families within those communities. Efforts to provide ongoing education to CALD communities and their support groups also need to be expanded, and focus on issues such as disability itself, advocacy services, the rights of people with a disability, and the NDIS.

We believe that the development of consultative committees from within various CALD communities would assist peak bodies and advocacy services to develop and improve access, as their views and recommendations will be heard and acted on by advocacy providers.

- people with disability in rural, regional and remote areas?

ATI provides a statewide service in Tasmania, including remote locations on the West Coast and outlying islands such as Flinders and King Island. Providing these services is costly and currently inadequately funded.

There needs to be more effort to develop skills of workers in remote areas, both to negate the likelihood of abuse occurring and increase the likelihood that service providers both understand and provide people with information about advocacy services, as required.

We believe that people with disability would benefit from advocacy providers being funded to increase their local presence. This benefit is doubly important as people with disability in remote areas are unlikely to have access to more than one service provider. Funding should reflect this, especially if remote sites have been or still are a site for institutional settings, as needs are likely to be greater and more intense in these regions.

ATI believes the development of aids and tools that will allow for people with disability to communicate from a distance should be investigated. These tools cannot be relied upon for all people with disability, but can be of great benefit to individuals who can use them. However, there always needs to be sufficient resources to allow face-to-face contact for people who are most vulnerable, isolated, or restricted in capacity and communication.

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

For many people living in current institutional settings or other shared accommodation services, there can be major barriers to accessing advocacy support. As the Parliament of Victoria's recent inquiry (2016) identified, many people in these settings may:

- be dependent on workers to access any external service
- have no family support
- be reliant on a single service for all aspects of their care
- have no knowledge of their rights, choice options, complaints mechanisms, or independent advocacy support, and
- live in fear of repercussion if they do speak up

In Tasmania, only the Senior Practitioner has the power to visit these settings as a right. There is no community visitors scheme operating and advocacy services can be denied access by a residential service without recourse. We have experienced major barriers to reaching people with disability living in these settings.

If an individual in such a situation is referred to an advocacy service, or makes contact themselves, there needs to be safeguards to ensure that advocacy service contact is not impeded. In Tasmania, if a service does block access to a client, there is no complaints avenue, such as a Commissioner with investigative powers as there is in other states. This makes the likelihood of repercussions on a complainant or someone seeking advocacy support more likely, and reduces accountability in institution-like settings.

We believe the development and use of communication aides and devices to assist people with communication disorders it vital. People have a right to these supports to communicate their choices and needs, but for many of those in institutional care, even a basic communication board does not exist, so advocacy services need to provide them when accessing facilities. Development of those tools requires specialist skill, so standardised products made available by the Commonwealth Government or another party for the use of all advocacy services would be beneficial. Access to better technology (such as Go Talk, NovaChat, communication apps) could occur through the loaning of such devices to advocacy services on a needs basis, or provision of funding to allow services to purchase required devices.

We believe that services that better meet the needs of people with communication difficulty will also require the development of better skills and employment of qualified staff. These skills need to be in relation to understanding the physical communication limitations that are better known and understood, as well as communication disorders that are far more complex and difficult to identify. These include those of the autistic spectrum and acquired brain injuries, in which the communication disorders could be cognitive, linguistic or behavioural (Bellon, Gardner & Riley, 2008). This requires ongoing training to be made available to workers in order that they can identify clear instruction and direction from the client. This leads to the empowerment of the individual with disability and confidence in working with advocacy services.

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

ATI uses a ‘your say’ strategy for provision of advocacy services. In our experience people with disability are often denied autonomy and given little choice and control over their own circumstances. We seek to empower people with disability to have their say on issues that affect them. This strategy puts the client at the centre by ensuring that no action is taken without the express consent and direction of the person with a disability. Our advocates also ensure that the person with disability is given all the available information and options so they can make informed decisions.

This approach is issues based and no case management services are provided. This helps to empower the people we work with and promotes self advocacy as the ultimate outcome. This is not to suggest that clients are not able to utilise the service more than once or that they can not have more than one issue worked on at a time. However, the role of an advocate is clearly defined, explained and reinforced to the client at regular intervals to ensure that the promotion of independence is always at the centre of actions taken.

Our experience has been that any lack of definition around the role of the advocate can lead to blurring of boundaries and can create dependence and deskilling of the person with a disability. There is a particularly high risk of this when an 'ongoing relationship' strategy is put in place without clear expectations and boundaries.

We also feel strongly that an increased community presence of advocacy organisations is imperative for achieving the goals of the NDAP and National Disability Strategy.

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

We believe that systemic advocacy priorities need to be drawn from trends and common issues identified in individual advocacy work, at both a state and national level. The development of a shared online database and communities could assist to centralise this information and streamline the resulting systemic work.

Current NDAP reports have the potential to provide a wealth of useful information on state and national systemic issues and trends. Consistency of data collection and reporting across NDAP providers would ensure accurate and up to date information was always available to facilitate the coordination of systemic approaches.

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**
- **Ombudsmans organisations**
- **aged care advocacy organisations**
- **state disability advocacy organisations**
- **peak bodies**

We are fortunate to provide aged care, state disability and several other advocacy programs in Tasmania. Having these services co-located has assisted us to clearly define the roles and boundaries of our own service, and to share learnings and developments between our programs. This range of experience across multiple sectors provides us with a broad view of advocacy approaches being taken across the entire Community Services sector. The majority do not define themselves in terms of the advocacy 'models' currently favoured by NDAP but rather choose to focus on the rights of their client groups and/or the ability of their client group to access appropriate services. This allows even greater collaboration between service providers on systemic issues as a common purpose and goal for diverse client groups is more easily identifiable.

Our experience has been that organisations mentioned above work effectively with each other when they each have a clearly defined role in the system and well established boundaries. Tasmania is a relatively small state both in physical size and population. The benefits of this have been that there are already a number of well established networks that can be accessed and contributed to by ATI. This also allows us to directly contact other relevant or potentially interested service providers when considering systemic action to collaborate and coordinate responses where appropriate. In return, ATI is contacted by other service providers requesting input into significant systemic issues.

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

We see the independence of all individual advocacy from direct service provision as an essential feature. Advocacy is fiercely partisan, on the side of the person with disability, rather than the side of other individuals or services in the person’s life. If advocacy services and direct service provision are located within a single service, the perception of this independence is lost regardless of the structures used to minimise the risk of conflicts. We strongly believe that advocacy needs to remain independent of the NDIS for this reason.

Were NDAP to proceed on a different basis, at a minimum we believe that organisations would need a separate staffing between individuals providing advocacy and direct service support. Organisations would also need to restructure and erect information barriers between advocacy and service delivery, to minimise the risk of real conflicts occurring. However, these mechanisms do not address issues related to perceived conflicts or mitigate organisational pressures involved where the service is both providing advocacy support and the subject of an advocacy complaint that could lead to a reduced quality of advocacy.

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

We are unable to clearly identify potential gaps due to a lack of clarity around what the NDIS will provide in certain areas. We have identified examples of a number of grey areas in certain sections of service where no one will agree on whose responsibility it is to actually provide or fund particular services. These uncertainties need to be clarified before gaps between the NDIS and NDAP can be appropriately identified and managed.

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

It is our understanding that a number of policies and strategies already exist to protect the rights of people with a disability. The gap has been in the implementation of these policies and strategies at both state and national levels. As such, a focus on ensuring consistent, national implementation of key strategies and educating providers and community members on existing policies and strategies is most prudent at this stage.

An example of this is that, in our anecdotal experience, many disability support services and their workers are still unaware of the rights of a person with a disability. Many staff we have worked with:

- have not heard of the UN Convention on the Rights of Persons with Disabilities (UN Convention), or
- are not fully aware of the rights the UN convention identifies

Service providers, who are often the main ongoing presence in the life of a person with a disability, cannot protect and identify breaches of these rights if they cannot identify what those rights are and the education role of disability advocacy has inherent limits. In order to mitigate this significant risk, training on the full rights of people with disability needs to be mandatory for all staff of disability service providers. Legislative change to allow the adequate enforcement of these rights is also required.

In addition to this there is a major national inconsistency in that Tasmania does not have a Community Visitors scheme or a Disability Services Commissioner. Both of these things have been adopted in other states to protect the rights of people with disability. A Community Visitors scheme could be achieved simply by an expansion of the Official Visitor Program already in place for prison and mental health facilities, which would ensure that all accommodation services are monitored and accountable for abuse of rights. These Schemes have had a major impact on the identification of abuse in other states, with Victoria’s Community Visitor voluntary scheme alone identifying 1145 cases of abuse in disability and mental health services between 2009 and 2015 (Office of the Public Advocate, 2015).

The introduction of a Commissioner would then serve to ensure that a complaints mechanism, with full investigative powers, is available when allegations of abuse occur. The need for such a body of oversight is highlighted by the fact that in 2015, 50% of complaints that were raised with the Victorian Commissioner were found to require intervention from the Commissioner to make services more rigorous and accountable in their complaints processes, (Disability Services Commissioner, 2016).

Historically, there has been very slow progress in state and national reform in regards to legislation and policy that impact on the rights of people with disability. The review of guardianship laws is a key example. There is currently inadequate support provided prior to the implementation of guardianship in Tasmania to allow the person with a disability to engage in a supported decision making process. ATI is currently researching and developing potential options for providing supported decision making to people with a disability in Tasmania. It is hoped this will provide a less restrictive option for people with a disability who may need some assistance but should be afforded more autonomy than guardianship currently allows.

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

We provide representation services before Tasmania's Guardianship and Administration Board, Mental Health Tribunal and Equal Opportunity Tasmania (formally the Anti-Discrimination Commission). These specialised bodies interact with people with disability on a daily basis, who regularly request support to ensure that their own views and opinions heard.

From our individual advocacy work we know that people with disability regularly experience discrimination, are victims, or are accused of, abuse and domestic violence, and are involved in incidents that may entitle them to compensation. They may not know or understand their legal rights, how to access legal information, or be able to access appropriate skilled lawyers to support them to exercise their rights.

Numerous studies and reports have identified that justice is not easily accessed for people with a disability who are victims of crime, (South Australia Attorney General's Department 2015; VEOHRC, 2014) or accused of criminal activity (Hayes, 2007; Herrington, 2009). Legal support and representation in this area is critical for people with a disability, and more so when statistics show that people with disability are over-represented in prisons, (Jackson, Hardy, Persson & Holland, 2011; Holland, Persson, McClelland, & Berends, 2007). When people with a disability are victims of crime, they are less likely to report it, and less likely to be adequately supported when they do (VEOHRC, 2014).

5.2 What barriers prevent people with disability from accessing justice?

It is difficult to fully quantify the experience of accessing justice for Tasmanian's with disability. Tasmania still has a number of institutions that house and/or provide whole of life services to people with a disability. The absence of a Community Visitors scheme, or any legislative mandate to allow access to advocates in Tasmania means that there are a number of clients who, at this stage, may require access to justice, but do not have any avenue through which to do so.

Anecdotally, however, the key issues in accessing justice we see for those clients who do access our service fall under one of two main categories:

- many of the forms of criminal abuse people with a disability are subjected to have been normalised, and
- services tend to deal with matters in house, rather than referring to police

For example we have worked with a number of people with a disability who have been assaulted by another resident in a group home or other residential facility and appropriate safeguards, processes and management strategies to ensure their safety are often minimal or inadequate.

Communication difficulties also provide a significant barrier to justice, at every stage of the process. Reporting an incident to a third party, then the police, then giving evidence to a court – each step is a huge barrier and increases the risk the victim will withdraw from the process making any repercussions for the perpetrator almost non-existent. Having an independent support person ensures that a person with disability is provided appropriate opportunity to express their account of events at each of these stages. This is an important avenue to acquiring justice, and a role advocacy services should be funded to fulfil.

Accessing justice for people with a disability accused of a crime is also more difficult. Without appropriate supports, such as an Independent Third Person, a person with a cognitive disability may be more suggestible in the interview process, and easily led to a confession; have less understanding of their right to silence; and may advise they understand questions when they do not (Baroff, Gunn & Hayes, 2004). Having a police force with better knowledge of disability is also important, but so too is ensuring there is independent observation to ensure a person is given a fair opportunity to understand what is going in, and advised of their rights in a form they understand.

Tasmania is currently in the early stages of developing a Disability Justice Strategy that will review these and other issues. It is hoped this will go a long way to improving access to justice for Tasmanian's with disability; however, this work needs to be complemented with appropriate support from advocacy organisations and the sector more generally.

5.3 What models of legal advocacy are most effective?

We are not able to comment on the different models of legal advocacy.

References:

- ABC TV, (2014). *Lateline: Jailed Without Conviction*. Broadcast on ABC TV on March 13th, 2014.
- Bellon, M., Gardner, J., & Riley, R., (2008). *Strengthening Communities: A Mentoring Program for Adults with Acquired Brain Injury - CRP Research Report*. Flinders University, Adelaide.
- Commonwealth of Australia (2011). *National Disability Strategy (2010 - 2020).*
- Hayes, S., (2007). Missing out: offenders with learning disabilities and the criminal justice system. *British Journal of Learning Disabilities*, 35(3), p. 146-153.
- Herrington, V., (2009). Assessing the prevalence of intellectual disability among young male prisoners. *Journal of Intellectual Disability Research*, 53(5), p. 397-410.
- Holland, S., Persson, P., McClelland, M., & Berends, R., (2007). *Intellectual Disability in the Victorian Prison System: Characteristics of prisoners with an intellectual disability released from prison 2003-2006*. Department of Justice (Vic), Melbourne.
- Jackson, M., Hardy, G., Persson, P., & Holland, S., (2011). *Acquired Brain Injury in the Victorian Prison System*. Department of Justice (Vic), Melbourne.
- Kung, W., (2004). *Consultations on Disability Services for Culturally and Linguistically Diverse (CALD) Communities*. Migrant Information Centre, Mitcham.
- Office of the Public Advocate, (2015). *Community Visitors Annual Report 2014-15*. OPA, Melbourne.
- Office of the Disability Services Commissioner, (2016). *Disability Services Commissioner 2015 Annual Report*. ODSC, Melbourne.
- Parliament of Victoria (2016). *Inquiry into Abuse in Disability Services - Final Report.* Victorian Government Printer, Melbourne.
- Pearson, J. (2009). *Research of the Models of Advocacy Funded under the National Disability Advocacy Program: Final Report*. Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.
- South Australia Attorney General's Department (2015). *Disability Justice Plan Annual Report 2014-15*. Government of South Australia, Adelaide.
- United Nations (2006). *Convention on the Rights of Persons with Disabilities*. Office of the High Commissioner for Human Rights, New York.
- VEOHRC, (2014). *Beyond Doubt: The Experiences of People with Disabilities Reporting Crime – Summary report*. Victorian Equal Opportunity and Human Rights Commission, Melbourne.