**Submission to Review of the National Disability Advocacy Program**

**June 21, 2016**

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The Victorian Rural Advocacy Network (VICRAN) is a network of six regional and rural advocacy agencies that operate across non-metropolitan Victoria.

All VICRAN members receive Federal funding under the NDAP.

VICRAN appreciates the opportunity to respond to the NDAP review and is happy to be contacted for further information or clarification.

**Mission Statement**

*The Victorian Rural Advocacy Network aims to*

* *Ensure that people with disabilities living in rural Victoria have access to resources & services to meet their needs;*
* *Work for the removal of all barriers preventing people with disabilities from participating fully in the life of the community;*
* *Promote community recognition of the rights of people with disabilities.*

Submitted by: Deborah Verdon, VICRAN President

1. **Models of advocacy**

*NDAP agencies receive funding under the Disability Services Act 1986, so they can provide disability advocacy support using a disability advocacy support model.*

*Disability advocacy support models are focused on individual advocacy, systemic advocacy, citizen advocacy, family advocacy, self-advocacy and legal advocacy.*

**Questions**

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

All models apart from systemic advocacy involve working with a person on an individual basis about their specific issue of concern, and can include working with the person’s family or carer/s, provided the person with the disability remains front and centre of any action. An element of working with groups can also be included here.

The designation of advocacy provision into “models of support” is a function of Departmental processes that have developed over time. In reality, cross-disability individual advocacy agencies are characterised by a range of approaches to addressing the needs of their clients. That is the very nature of the work they do. In rural and remote areas the agility of the agency and its readiness to respond, as well as an ability to provide a broad range of skilled advocacy, is vital.

High quality advocacy is tailored to the individual, depending on their capacity. For example, assistance is provided with instances of abuse and neglect, human rights, Child Protection matters, access to services and aids, locating accessible housing, accessing funded supports, assistance with VCAT or AAT matters, legal referrals, and interpretation and personal support during meetings with lawyers and at court hearings.

If individual advocacy agencies are funded to advocate for clients from a human rights perspective their work will draw on the principles of all the models listed above in a holistic approach to their individual work, with the individual and their rights front and centre of every action.

In most cases a person presenting at an NDAP advocacy service for assistance has never heard of the Disability Services Act 1986 and knows nothing of the different models of advocacy. They just want their voice heard and their rights protected. This is the core business of independent disability advocacy.

At the same time, specialised services that work with a specific target group enhance the independent advocacy sector by providing secondary consultation on a particular issue, or when possible providing individual advocacy when there are two parties in need of advocacy in regards to the same issue.

* 1. *What are the drawbacks?*

Specialised support has merit, but includes the risk that a person with a more generalised need will be referred onto another agency, and then possibly another agency, and may ultimately fall through the gaps. It can take a lot of courage to make the initial approach to an agency for help, and the referral merry-go-round can result in the person never receiving the support they seek and need.

***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?*

There are geographical gaps in the provision of advocacy Australia-wide. This can only be remedied by increasing the level of funding provided for the NDAP. It is impossible to provide more coverage for the same amount of funding, or less, without creating other pockets of unmet need and therefore providing no improvement to the overall situation. Currently NDAP funding is at the rate of $4 for each person with a disability in Australia. Chronic underfunding of the NDAP has been a feature of the program to date.

A properly resourced and trained individual advocacy network of NDAP agencies can provide the basics in regards to most of the models listed in the introduction of the discussion paper. For more complex cases a streamlined system of referrals to properly funded specialised agencies could be established, e.g. legal.

Funding for individual advocacy agencies to set up modern telecommunications systems would mean their client could be assisted **on-site** to consult with an agency more experienced in a particular type of advocacy, e.g. legal.

1. **Improving access to advocacy supports**

*We also know that some people with disability find it harder than most to access advocacy supports. The key barriers are geographical distance, social isolation, communication difficulties and a lack of culturally appropriate or accessible supports.*

*We would like to hear about practical strategies to make it easier for people experiencing a combination of barriers, to access the disability advocacy supports they need*.

**Questions**

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

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

People with disability from Aboriginal and Torres Strait Islander communities are amongst the most vulnerable in our society. Barriers to accessing information, particularly electronic and social media has increased the vulnerability of this group. The key to providing effective services to ATSI communities is building relationships with community, families and individuals. It takes time and effort to build trust.

Advocacy agencies respond to self-referrals or referrals from family or other community/professional services. It would be beneficial if all ATSICs had the same access to information and referral. This could be enhanced by advocacy agencies being provided with the resources to develop accessible and culturally appropriate information about local agencies, particularly those in rural and remote areas.

Advocacy agencies need to engage in a meaningful way with ATSICs, building relationships first, and then beginning a conversation about the optimal methods for communicating information.

**Example #1: VICRAN member agency Grampians disAbility Advocacy (GdA) received philanthropic funding for a project to develop a meaningful and ongoing relationship with a local Aboriginal Co-op; after two years of working together an advocate from the advocacy agency now is fully engaged with the community and visits the Co-op one half day per week to provide advocacy support to its members; real relationships are achievable, but the work behind the success story has to be properly resourced.**

**Example #2: Disability Advocacy and Information Service (DAIS) is appointing an Aboriginal trainee advocate. The trainee will learn advocacy skills while assisting the other advocates to provide service in a culturally appropriate way. At the end of the program, DAIS hopes to have an indigenous advocate as part of its team and will be able to advocate for the significant number of ATSI people with disability that live in the region. It is hoped that the funding would be made available to enable the trainee to be employed on an ongoing basis.**

The measures detailed above are being taken without the benefit of any extra resources to undertake this time consuming work.

Another way to improve access to advocacy would be to provide information through local community health services, GPs, education services, maternal and child health services and ATSIC Co-ops.

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

Advocacy agencies need the resources to provide specific staff training around the predominant language and cultural groups in their geographical area. It can be difficult for rural advocacy agencies to access the information and appropriate resources to meet this growing need.

One of the difficulties with providing services for people from CALD backgrounds in rural areas is that there are small groups of people from a large number of cultural backgrounds, which makes it difficult to target support in a culturally appropriate way. More recently there has been an increase in refugees settled in regional areas which has created an added challenge for advocacy services. For example, it is not appropriate for some people to meet privately with an advocate of a different gender. These situations can be dealt with sensitively, but additional training and resources are needed to facilitate this within NDAP agencies.

Services for ethnic groups are few and far between in rural areas. Yet there are a growing number of success stories in relation to specific ethnic groups providing a workforce and population boost to small rural towns, e.g. Nhill in northwest Victoria and its Karen community.

Some advocacy agencies have working relationships with their local ethnic community councils, but a lack of resources sees organisations unable to meet all advocacy needs.

Another way to improve access would be for the Department to provide NDAP information to advocacy agencies in a variety of languages and formats to address the needs of CALD communities.

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

It is imperative for people with disability in rural, regional and remote locations to have access to **local** advocacy services. Rural people do not have access to the breadth of services available in larger regional and metropolitan centres. Rural dwellers often rely heavily on GPs or their local neighbourhood house for information and referral, although more often than not they do not have regular access to a GP or their GP is not well versed in the role of an advocate. The ideal is for advocacy to be provided at a local level so that people with disability who have limited resources are not referred to regionalised or city based services at either a large regional centre or capital city which creates issues with access and quite often issues of trust.

There is a demonstrated need for a well-resourced network of advocacy agencies across regional areas to enable access to an advocacy outlet within 2 hours drive of most of the population. In this way advocates would be able to provide outreach to smaller towns and build networks with local providers.

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

People living in institutional care, including young people in nursing homes, experience social isolation and a degree of voicelessness. Systemic advocacy action is well placed to eliminate the barriers created by these models of care, particularly in relation to Supported Residential Services and disability institutions. As systemic action can take a long time, the individuals living in these settings need individual advocacy until they can exit these arrangements. Provision of local individual advocacy enables better access and opportunity for each person to tell their story or have their voice heard. A properly funded active outreach model can be used to identify people who are socially isolated and support them to have a voice.

With the rollout of the NDIS individuals living in institutional care, who commonly don’t have other supports, will need advocacy to ensure they participate fully in the scheme, and therefore the community. This would be in addition to any NDIS provided supports.

For many people social isolation is a fact of life when you live in a rural area, particularly if you have a disability and/or experience low socio-economic status. This disadvantage is augmented by a lack of services, limited information and few, if any, public transport options, all of which are barriers to social inclusion.

* 1. *What are the strategies or models that have worked?*

LOCAL is a key strategy for improved access for people who are disadvantaged by their location, ethnicity, communication or social isolation.

Access to a local advocacy agency provides people with a service that:

* identifies with their community
* provides access to local and regional networks to maximise outcomes
* builds the individual’s capacity to engage in their local community
* engages with local services including GPs and mental health practitioners to enhance referral options for potential consumers
* is identified by local Government and community groups as a resource and reference for local disability access, participation and engagement issues
* ATSIC members have a stated preference for services delivered by local people, including within their own community organisations.

**If a weighting is applied for the funding of rural and remote advocacy, it would be advantageous to also apply a weighting for other barriers that augment the experience of disadvantage: socio-economic background, lack of family support, experience of institutionalisation in certain geographic locations.**

*What are the strategies that do not work?*

**Centralised 1800 call centres do not work for people with a disability, especially a cognitive impairment, intellectual disability or mental ill-health.** This model has been tried in the mental health arena and failed dismally.

**Example:** A funded and community based psycho-social rehabilitation service in the Grampians region was defunded, in preference for a centralised system. As a result, none of the 20-30 participants who used to attend the local service is receiving any supports at all, other than a limited amount of clinical services. They were deemed by the centralised system not to be in need of a service.

Services based only in larger regional centres or metropolitan based services do not work for people in rural communities, evidenced by the difficulty exhibited by statewide agencies in reaching out to rural consumers, despite their level of resourcing. Rural people identify with organisations that have a presence in their community.

An emphasis on electronic information (internet, social media) risks the further marginalisation of people who do not have the resources, literacy, education or understanding to navigate the World Wide Web. Information might be available round the clock, but that doesn’t mean the target group for advocacy agencies has ready access to that information. Many disadvantaged people still do not own a computer, or have more than occasional access to one. The target group is more likely to rely on local networks and their community organisations for the information they need.

People living with disability in rural and remote areas needing support from services in metropolitan or larger regional centres find it difficult to gain access due to a range of barriers, such as transport, economic limitations and a lack of informal supports, e.g. family and friends, to assist them.

1. **Improving the advocacy evidence base and coordination on systemic issues**

*What is the best way to make sure the information gathered by NDAP agencies and the information collected by other organisations interested in the rights of people with disability is used to improve the lives of people with disability at a local and national level?*

***Questions***

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

NDAP advocacy agencies undertake some systemic work even if they are not funded to do so. Agencies that are grounded in their local communities understand that long term change is best achieved through united systemic action, and will become involved whenever they are able, and whenever resources allow.

NDAP advocacy agencies need to be provided with reporting software for systemic issues so that all issues, however large or small, can be logged in a centralised system, and priorities that emerge can be forwarded to the appropriate systemic agency, e.g. Women with Disabilities Australia. An annual symposium could be held to identify commonly occurring systemic issues and agree on an action plan to deal with one issue per year.

Regional and rural advocacy agencies have a long history of dealing with local systemic issues, e.g. public transport, access to the built environment, breaking down the economic barriers to participation. Many issues that impact on rural residents are best dealt with at the local level.

Case Study

The Executive Officer/Systemic Advocate from a rural advocacy agency recently attended a housing forum organised by a local council who was developing an affordable housing strategy. With reading the pre forum papers and during the presentations, there was no mention of adaptable or accessible housing being considered as part of the affordable housing strategy.

The systemic advocate was able to argue that 27.4 per cent of people with disability live below the poverty line. Any of these people may require housing that is accessible and also affordable. Without a systemic advocate attending the forum this issue would not have been considered.

A state wide systemic advocacy agency probably would not have been in a position to be able to attend a local forum in a rural area.

Systemic issues experienced at a national level are best collated by a national peak body like DANA, which unfortunately is no longer receiving recurrent funding. The last DANA conference was in 2013. This lack of resourcing of professional development and the opportunity to meet face-to-face with other advocates impacts on the outcomes that can be achieved by the sector as a whole.

**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?

NDAP advocacy agencies are experienced and skilled at networking and engaging with other like-minded advocacy organisations. What they lack is the time and resources to do so on a regular or systematic basis. A component of any new funding for NDAP advocacy agencies needs to include specific resources for collaboration and systemic action.

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

*The NDAP will be funded and run independently of the NDIS. However, the NDIS may provide education, capacity building and decision-making supports as part of Individually-Funded Plans or Information, Linkages and Capacity-Building. This does not mean these services cannot continue to be provided by NDAP-funded advocates.*

*A number of organisations already deliver both advocacy supports and some services funded by the NDIS.*

**Questions**

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

Advocacy organisations generally have existing robust conflict of interest policies. Advocacy organisations that provide NDIS services need to ensure their conflict of interest policies are comprehensive and transparent. It is also advisable that organisations engaging in both advocacy and NDIS service provision set up a separate division or entity, so that there is no perceived conflict of interest by clients and other parties. This ensures also a separation of funding and avoids duplication. Advocacy organisations are rights-based and can use this approach to provide NDIS services similarly. Clients are then supported to exercise choice and control in participating in the NDIS and using advocacy organisations (through both individually funded plans and information, linkages and capacity building), as choice and decision making are vital to the future landscape of disability supports. Advocacy organisations have the vision, background, experience and the unwavering interests of people with disabilities at their core to ensure choice and control actually happens.

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

There will be many people with a significant disability who do not qualify for an NDIS package of support, and yet their disability will not go away. An obvious example of this is a person with a disability who is over 65 years of age at rollout. This is why the continuation of the NDAP is of vital importance, so that advocacy support remains available for all. The provision of independent advocacy remains important, even though organisations may diversify their activities due to the rollout of the NDIS. While the NDIS may provide for “advocacy-like” services, only independently funded advocacy agencies can truly safeguard the human rights of people with a disability in their local communities. A shrinking advocacy program in real terms will significantly impact the participation and contribution of those who are ineligible for the NDIS (approx. 3.9 million people with a disability Australia-wide).

It is important that advocacy agencies have a profile in the NDIS landscape. Advocacy organisations should have close contact with NDIS local/regional offices and LACs to ensure that gaps for clients do not occur. An ongoing relationship should be encouraged at the local level. The NDIS regional offices can then take issues of gaps in service provision back to the NDIS central and national offices.

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

Advocacy organisations should continue to include people with disabilities at Board level and as employees. People with disabilities should also be involved in organisations’ business and strategic planning and policy development to ensure the protection of rights.

The provision of advocacy needs to remain independent of other service provision. It is important that advocacy remains grounded in the not for profit sector and does not fall victim to the ever expanding market place resulting from the NDIS rollout.

Where an advocacy agency pursues a diversification strategy within the NDIS this should be done through the establishment of separate entities, firewalls and clear conflict of interest policies.

**5** **Understanding and improving access to justice**

*People with disability can be highly vulnerable to a wide range of legal problems. They are also significantly over-represented in the criminal justice system, both as offenders and victims. People with disability often experience barriers to justice, which prevent them from fully participating in legal and justice system processes.*

*Legal advocacy supports people going through legal processes and can lead to better and faster outcomes. With the changes associated with the rollout of the NDIS, DSS is seeking feedback on what types of legal advocacy are needed and if there are gaps in the supports available to help people with disability to get access to justice.*

**Questions**

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

***Legal advocacy is a term that has a specific context within the legal profession. It is used to define the type of work undertaken by a qualified lawyer who has been admitted to practice. In terms of the NDAP, it is used by the Department to describe the work advocates do in supporting their clients when they are confronted with complex and challenging legal issues.***

The Australian Human rights Commission’s 2013 report Equal Before the Law and Victorian Equal Opportunity and Human Rights Commission report Beyond Doubt (2014) both demonstrate that people with disability are over-represented in all aspects of the justice system. With Legal Aid increasingly difficult to obtain, people are seeking alternatives, including advocacy, to assist them with their legal and paralegal issues.

Advocates are called upon to support people at Administrative Appeals Tribunals including appeals to rejections of disability support pensions. Without the assistance of an advocate, people with disability can be overwhelmed by the process and therefore are significantly disadvantaged to the point where they cannot pursue their rights. **See case study on following page.**

**Case Study**

X has a terminal heart complaint and is expected to only have a further 12 months of life remaining. The treating Doctor and Specialist attempted surgery but had to abandon the procedure due to threatened heart failure. The medical professionals involved determined the condition to be untreatable and X was unable to undertake employment, stressful situations, physical activity etc.

Unable to work, X applied for a Disability Support Pension (DSP) in June 2015. The original application was refused and then appealed through the internal process which was also rejected.

X then asked for assistance from a professional advocate to make an application to the Administrative Appeals Tribunal (AAT). It is only when an application to the AAT is made and accepted that the applicant is able to view their own file, which she received a few days before the hearing. It was not until the advocate looked through the file with X that it was discovered there was information on X’s file that did not relate to X, and that statements made by Centrelink staff were untruthful. As well as having documents on the file that clearly related to another person, some comments from the Centrelink staff (for example the Appeals Officer) were derogatory, and included that X “was catastrophizing” her health circumstances.

At the AAT hearing the advocate had the opportunity to raise concerns with the Chair regarding the incorrect information on X’s file and the incorrect statements made by the Centrelink staff. Fortunately the Chair was receptive to hearing the issues from the advocate and was able to see the errors that had occurred. The AAT order stated that X is eligible for the DSP. Fortunately no appeal was lodged by Centrelink, and X was informed that she is now a recipient of the DSP, backdated to June 2015. Unfortunately the stress and financial hardship placed on X cannot be reversed.

Advocates are also often called upon to support people at Guardianship and Financial Administration hearings at state-based Civil and Administrative Tribunals, particularly when family members and service providers are not acting on the wishes of the person with disability, or in their interests.

People with disability are at a higher risk of being victims of violence and abuse from family members and neighbours. They often seek advocacy support to complete applications for Violence Intervention Orders, including completing and lodging the application form, attending court and collecting evidence of breaches of the Order.

People with disability have reported that they have been physically and sexually abused while in care. Many have been assisted by their local advocacy agency to write their victim statement and attend hearings of the Royal Commission into Institutional Response to Child Sexual Abuse.

There are very few NDAP funded organisations that employ lawyers who have the resources to provide representation for advocacy clients. Apart from providing secondary consultation and training, these organisations often do not have the resources required to provide services to individuals in rural areas.

**5.2** *What barriers prevent people with disability from accessing justice?*

As indicated in 5.1, people with cognitive and communication disabilities have significant barriers accessing the justice system. Without their advocate’s support a person with a disability would not have equal access to justice as they would not have an understanding of the justice system. Our experience is that people do not always need a lawyer, but support and advice to help them navigate the legal system and to ensure that their voice is heard.

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

This is an example of how an advocacy agency can provide hands on, practical support for a person engaging with the legal system.

Since 2009, VICRAN member Disability Advocacy and information Service (DAIS) has run the Justice Support Program in Southern NSW and North East Victoria, which utilises volunteers to provide support to people with cognitive or communication disability who are involved in the Justice system. The Program was introduced after it was recognised that a lot of advocates’ time was spent at court, often waiting hours for a matter to get underway. Once in court there was very little an advocate could do as it was the lawyer’s role to speak on behalf of the person in the court room. It was felt that volunteers could undertake this task, leaving the professional advocates to focus on more complex issues.

The role of the justice support volunteer is to meet with the person with a disability at the court house at the beginning of the day and sit with the person until it is time to go into court. The volunteer will ensure the person is linked with the duty solicitor and that the solicitor is aware that the person has a disability and may be eligible for an alternate corrections order. After the hearing, the volunteers will make sure the person is aware of any orders to ensure they do not reoffend or breach conditions. The volunteer will advise the project coordinator if the person being supported is required to reappear or requires additional advocacy support.

In the four months to the end of April, 2016 a total of 82 supports were provided to 49 people across five courts.

The development of the Justice Support Program has been made possible through a series of small one-off grants which enabled the employment of a project coordinator whose role it is to recruit, support and train volunteers. The project officer is responsible for processing the requests for support, and linking the appropriate volunteer with the client.

The project is currently funded with a one-off grant of $50,000 received from the Victorian Department of Justice and Legislation which enables the project worker to be employed for 21 hours per week. The impact of not having a Justice Support Program was experienced during the second half of 2015 as there was no funding to employ a coordinator. Volunteers tried running the program, with limited support from staff, which resulted in only half the number of supports provided compared to the previous six months.

**Case Study: Mrs M. – County Court trial**

A last-minute, week long, court support in County Court involved “Mrs M” who has early onset dementia and also a hearing impairment.

Justice Support Program Coordinator received a phone call from one of the local legal aid providers who recalled at the last minute about the DAIS Justice Support Program and was concerned it might be too late to organise volunteer support. “Mrs M” had been charged with 16 counts of assault of a significant nature.

“Mrs M” was having an emotional breakdown while in the dock due to the stress of the trial and her disabilities. A solicitor had to be called off duty and placed in the dock with the client to keep her calm during this particularly difficult trial. This led to another Lawyer being taken away from other court cases causing a three week adjournment. The Lawyer remembered they had used our services in the past and hoped we were able to support the client.

On short notice the Coordinator was able to arrange eight of the 10 court supports needed for the duration of the trial. It was a highly emotional case, not just because of difficulties associated with “Mrs M’s” disability, but also the graphic nature of the charges laid. The Coordinator offered extensive debriefing and counselling to the volunteers if they needed it, however the 3 volunteers said that counselling was not required but it was an ‘eye opening case’ due to nature of the charges. The Coordinator personally had to fill in on one trial day and confirmed that the nature of the charges were particularly serious.

The senior barrister and solicitors conducting the trial noted that, without the volunteers’ support at this trial listing, conveying notes, and explaining to “Mrs M” what was going, they may have experienced unexpected delays which would have increased “Mrs M’s” time in court, further adding to the stress she was under. The volunteer’s main role of *individualised support without judgement* was seen as the key to success at court. The legal team have also stated they would be happy to provide a letter of support for the continuation of the program, and would highly recommend this service to other law firms in the region with similar cases or trial at County Court.

End of VICRAN submission