

National Disability Advocacy Framework

Response to Discussion Paper

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About DARU

DARU is funded by the Victorian Government, through the Office for Disability, to provide information and resources to disability advocacy organisations which operate in Victoria. DARU is delivered by a consortium of DAV and VCOSS.

About VCOSS

VCOSS is the peak body of the social and community sector in Victoria. VCOSS members reflect the diversity of the sector and include large charities, peak organisations, small community services, advocacy groups, and individuals interested in social policy. In addition to supporting the sector, VCOSS represents the interests of vulnerable and disadvantaged Victorians in policy debates and advocates for the development of a sustainable, fair and equitable society.

About Disability Advocacy Victoria

Disability Advocacy Victoria (DAV) is the state peak agency for independent disability advocacy with a membership of 14 disability advocacy agencies funded through both state and national programs. These funding streams are independent of disability service delivery, providing independent disability advocacy.

Introduction

The Disability Advocacy Resource Unit (DARU), in collaboration with Disability Advocacy Victoria (DAV) and the Victorian Council of Social Service (VCOSS), is pleased to respond to the Review of the National Disability Advocacy Framework (the Framework) discussion paper.

About one million Victorians have a disability, and around 338,200 have a profound or severe disability. There are 33 disability advocacy organisations operating in Victoria, including two resource units. That is, the DARU and the Self Advocacy Resource Unit (SARU).

In early July 2015, DARU convened a roundtable discussion of representatives from 13 disability advocacy organisations and two consumer representatives. The disability advocacy organisations in attendance included a mix of organisations receiving Commonwealth National Disability Advocacy Program funding, Victorian Government disability advocacy program funding, or a combination of the two. With the exception of one organisation, which is funded to deliver systemic advocacy only, all organisations in attendance were funded to provide individual advocacy. This submission draws upon the comments and feedback provided at that roundtable consultation. It also draws heavily upon recommendations and commentary from the Victorian Ombudsman report into the reporting and investigation of allegations of abuse in the disability sector.¹

The participants understood the Framework is the structure that governments currently work within to enable and support people with disability to protect their rights and overcome barriers. However, they strongly believed that the Australian Government needs to take this further by placing the human rights of people with disability in legislation for their rights to be truly protected.

The United Nations Convention on the Rights of Persons with Disabilities, which Australia ratified in 2008, supports this argument.

Subsection 1 of article 16 of the United Nations *Convention on the Rights of Persons with Disabilities* says that:

“States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.”

Further to this, participants believed the role of advocacy outlined in the National Disability Insurance Scheme (NDIS) legislation only goes part way to acknowledging the role of advocacy for people with disability, especially noted that it does not state that advocacy is a right.

¹ Victorian Ombudsman, *Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight*, Victorian Government Printer, Melbourne: June 2015

Clause 4 subclause 13 of the *National Disability Insurance Scheme Act 2013* (C'th) states:

“The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:

- a) Promoting their independence and social and economic participation; and*
- b) Promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and*
- c) Maximising independent lifestyles of people with disability and their full inclusion in the mainstream community.”*

This could be expanded to recognise that people with a disability have the right to the assistance of a disability advocate if they chose.

Vision

Representatives at the roundtable discussion expressed a number of views on the vision for advocacy in the NDIS environment. The central themes of this discussion are captured below.

People with disability have the right to effective disability advocacy

While items 7 and 8 in the introduction section of the Framework state that people with disability are the target group of the Framework, and that they can experience additional disadvantage, there is no mention that people with disability have a right to advocacy. Organisations believed that item 11 in the objectives section should be strengthened to state that people with disability have the right to effective disability advocacy, rather than simply stating that people with a disability have access to it.

The value of advocacy needs to be recognised

Other forms of advocacy such as legal and representational advocacy are much better understood, and as a result have a greater profile in the community. It is important that governments, through the Framework, and by the funding of disability advocacy, recognise its value.

Advocacy empowers and protects people with disability

Individual disability advocacy is about empowerment and information provision, assisting with complaints and informing people about their rights. It can take a simple form such as assisting a person to complete an application for a service or helping them to communicate their need, through to lodging a human rights or disability discrimination complaint.

Advocacy helps to identify systemic issues and inform government policy

Disability advocacy is not only about assisting people with disability to seek justice, it helps identify problems so people can advocate for change at an individual or systemic level. When systemic issues, which create barriers to access and inclusion for people with disability, are identified and addressed, the whole community benefits.

Roundtable participants believed that disability advocacy not only empowers and protects people with disability, but informs and strengthens the development of government policy. Disability advocates are not limited to adversarial confrontation. Disability advocacy can work in partnership, and play a complementary role with all levels of government.

Disability advocacy must be funded outside of the NDIS

Disability advocacy is a necessary service which can ideally be funded outside of the NDIS. Otherwise, there will always be a gap between people who can afford to pay for advocacy and

those who cannot. There is also very little community understanding of what is involved in disability advocacy, and as a result, people are less likely to know what it is and to ask for it.

The NDIS will impact on the range of disability advocacy issues

Roundtable participants believed that the principles and nature of disability advocacy will not change in an NDIS environment. However, the NDIS will impact on the range of issues for which people will seek and require disability advocacy. People with disability will not only require advocacy support to navigate the NDIS, but once they are in receipt of a package of support, they will need advocacy to assist in preparing for the NDIS planning process, knowing that they are entitled to apply for it, and understanding what their entitlements, and rights are under the NDIS, not to mention needing support through an internal or external complaints mechanism process.

Once their NDIS supports are in place, people with disability will meet the next set of barriers in life. They will encounter barriers such as access to mainstream systems and support, access to the built environment, public transport, education and employment, and most significantly, access to information and communications systems.

Outreach services are required to ensure that all people with disability are able to access advocacy

One disability advocacy organisation reported that less than 35 per cent of their clients have access to the internet or telecommunications. This combined with the need to use augmentative and assistive communication technology often means that people with complex communication needs will benefit from, and indeed require, outreach services in order to gain information about their rights and entitlements.

There is a continued need for advocacy support outside of the NDIS

There will also be many people who will not be eligible for NDIS. They will require disability advocacy to achieve their access and support needs from other systems.

This argument is supported in section 559 of the Victorian Ombudsman report, which states:

“The evidence of this investigation strongly suggests that the role of advocacy will need to be strengthened further with the introduction of the NDIS. While I support the guiding principles of the National Disability Insurance Scheme Act 2013 (C’th) promoting equality, social inclusion and choice, the practical application of these principles in relation to people with cognitive impairment, limited communication or no informal supports must be highly questionable. Throughout my investigation, my officers and I have attended disability forums and taken extensive evidence from which it is clear that many people with disability have no family or friends in their lives, and often rely on the goodwill of paid staff or scheduled visits by Community Visitors for support.”

In addition, systemic advocacy outside the NDIS will still be required to ensure that children and young people with disability and their families maximise their role in the community. People with disability from culturally and linguistically diverse backgrounds will still require advocacy support to know about their rights to access services, to learn that there are services available to them, how and where to seek support, and how to ask for what they want, need and are entitled to receive.

Principles of the framework

Representatives at the roundtable discussed the principles of in the current framework, developing a number of themes that could improve the framework.

The advocacy framework should protect the rights of people with disability

Overall, the principles of the Framework are quite broad and it is recommended that they are amended to be more specific and direct in their aim. The principles should state that disability advocacy must be free and independent, and be guided by a human rights approach.

In section 562 of her report, the Victorian Ombudsman states:

“It is not viable for advocacy to take a secondary position in the safeguards framework. I consider advocacy to be key in a framework for Victorian people with disability who have no prospect of becoming empowered consumers and have no family or friends to voice their best interests.”

Again, roundtable participants asserted that advocacy should be a right. A right only exists if it is provided for under legislation.

Outreach services should be incorporated into the framework

Roundtable participants believed the Framework should include scope for outreach. People with complex communication needs, in particular, require direct contact and engagement in order to be empowered. It is one thing to receive information about rights and entitlements; however, it is entirely another process to then assert them or even to express one's needs.

Advocacy needs to be independent

Funding to deliver independent disability advocacy needs to be independent of agencies or departments which also deliver services for people with disability. In Victoria, disability advocacy is currently funded through the Department of Health and Human Services. At best, this can lead to perceptions of conflict of interest, and in some circumstances it can lead to unnecessary tensions and protracted negotiations.

Systemic issues should be monitored and addressed

Participants believed the principles of the Framework should also include monitoring systemic issues.

This past year, there have been many welcome reviews, consultations and inquiries into matters such as abuse in institutions, family violence, social inclusion, young people in nursing homes,

NDIS quality and safeguards, and reviews of the Disability Standards for Education, public transport and access to premises.

Many of these inquiries and reviews occur in isolation from each other. There is no single body or authority which logs or records and reports on systemic issues faced by people with disability, meaning they are left to be dealt with in a siloed way, by different agencies and levels of government. This fragmented approach works against cohesive and sustained policy-making.

Outcomes and Outputs of the Framework

Organisations and individuals commented on the current outputs and outcomes of the framework. The overarching message is that while their content was agreeable, it lacked sufficient clarity to be meaningful.

The current set of outcomes is relevant and appropriate as a set of ideals. However, the framework would be strengthened if the outcomes were more clearly defined so that they could be easily measured and reported against.

Organisations funded through the National Disability Advocacy Program (NDAP) are required to submit an annual report to the Department of Social Services. Similarly, Victorian Government funded disability advocacy organisations are required to submit quarterly reports. However, neither qualitative nor quantitative data arising from such reports is broadly published, publicised or reported on. As a result these data are not able to be used to build a profile of disability in the community.

Similar issues exist with the framework's current outputs. While the list of outputs is a good summary of what disability should achieve, the statements are relatively wide ranging and difficult to measure. For example, dot point 2 states that disability should be delivered in a transparent and accountable manner. It is not clear to whom it must be transparent and accountable, and how.

This section of the Framework may be better served by outlining mechanisms such as accreditation of organisations, quality assurance audits, and having strong legislation recognizing the role of advocacy underpinning the Framework.

Future environment

Participants reported their feedback on the future environment for disability advocacy, and the directions that could underpin its development.

Increase the profile of advocacy

The availability and types of advocacy need to be heavily promoted throughout the community. People with disability and their families/carers need to know that advocacy exists before they can ask for a disability advocate.

Advocacy should be funded across Australia

Participants agreed that disability advocacy must be funded and available in all states and territories. This would ensure that all Australians with a disability have access to the same levels and variety of disability advocacy as their interstate counterparts.

Currently, there is a disparity between states and territories with regard to the amount and types of advocacy available to people with disability. Victoria, relative to other states, has a large, well organised and funded disability advocacy sector. Participants would like to see this to continue to be the case, and participants were keen to see that other states are similarly resourced.

As previously stated, participants believed that rights-based legislation should underpin the framework, otherwise other mechanisms put in place risk being weakened.

The unique needs of different diagnostic groups require recognition

Participants believed that it is important to recognise the advocacy needs of specific population groups, including women, children and young people.

For example, the period of adolescence and young adulthood often includes important life transitions and growing independence. It is important that the unique needs young people face during this period that are distinct from those of children with disabilities and parents of children with disabilities are recognised and supported through funding of specialist services.

Participants also argued that it is of equal importance to recognise diagnostic specific groups such as people who are blind, deaf or have complex communication needs.

Advocacy should remain the joint responsibility of State and Commonwealth Governments

State and Commonwealth Governments should continue to have joint responsibility to fund disability advocacy programs. The dual focus of both levels of Government allows for a greater

level of oversight and gives disability advocacy the recognition it needs in order to be best utilised by people with disability.

Both levels of Government have responsibilities that affect the lives of people with disability. They each have different capacities to identify the needs of people with disability and, combined, can provide more stable and complete coverage of services. Dual funding arrangements would also enable disability advocacy to maintain a greater level of independence.

The NDIS

Participants were especially engaged in the response of advocacy to the development of the NDIS, providing a number of relevant comments to inform the future role of advocacy.

Getting ready for choice and control

The NDIS has been presented as incorporating the principles of choice and control over what people with disability want, and their need to lead full lives. The implementation of the NDIS must include these principles in the distribution of information about the planning process. People with disability should be able to have choice and control of how they receive information about their entitlements under the NDIS, and this should not be restricted to the planning process with National Disability Insurance Agency planners. A similar comment could be made about the pre-planning and readiness processes.

Advocacy should be available to all people with disability

Disability advocacy does, and will, play a vital role in empowering people with disability to think about their rights and entitlements in a new way. At a systemic level, disability advocacy will provide a significant role in advocating for the needs of people who will not be eligible for the NDIS. There will be a large number of people who are not able to access the NDIS or may not be happy with decisions about their NDIS package of support.

The NDIS is likely to increase the demand for disability advocacy

The NDIS has already had, and will continue to have, a significant impact on the workloads of disability advocates in the Barwon region launch site. Disability advocates located in the Barwon launch site report that 90 per cent of their current caseload is taken up with NDIS matters. While the organisation receives some Commonwealth funding through the External Merits Review Program, this does not allow them sufficient time to conduct other advocacy work.

Advocacy is essential to helping people understand their rights under the NDIS

Participants believed the Framework should recognise that disability advocacy plays an integral role in ensuring that people with disability are aware of their rights and entitlements under the NDIS.

Strong relationships

Disability advocacy plays a role in assisting people to gain a sense of agency in their lives. The six models of advocacy outlined in the Framework provide a good framework for the function and role of advocacy. However, it is the connections with organisations they trust and have experience with which brings people to advocacy. The importance of these relationships cannot be underestimated.

Locally and community based organisations of and for people with disability are common points of engagement for people with disability. Disability advocacy organisations are very mindful of this community based approach, and as a result are very successful at building such connections.

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