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Review of National Disability Advocacy Program

June 2016



**Problem of systemic advocacy being intimidated against standing up for the people they support and issues they wish to address – lack of authority real or otherwise – authority needs to be given, granted, acknowledged at all steps of the process – at the beginning, during the process and at the end. (eg dentists – who do you think you are – no expertise in a particular area but still have enormous capacity to recognise the gaps and should have the authority to identify them with credibility.**

This review does not indicate a decreased focus on advocacy. The important role of independent advocacy has been affirmed by the Commonwealth Government in its commitment to maintain a strong and effective programme of independent advocacy for all people with disability, into the future. The Government recognises that outside of the NDIS, people with disability will continue to require access to advocacy.

The most significant reason for a review is the rollout of the NDIS. The new models of service delivery, market development, and change in opportunities for people with disability as a

Developmental Disability WA welcomes the opportunity to comment on the review of the Department of Social Services’ National Disability Advocacy Program.

Developmental Disability WA is not funded currently, nor has it been in the past, by the National Disability Advocacy Program however we strongly support moves to strengthen and sustain a national disability advocacy sector and the individual organisations within it, as well as State based organisations of which DDWA is one.

DDWA is the Western Australian representative of Inclusion Australia, formerly National Council for Intellectual Disability which has been a voice for people with intellectual disability for around 60 years. DDWA is also a member of the national body Disability Advocacy Network Australia, with our Chief Executive Officer having been DANA’s chair since 2014.

DDWA is the peak advocacy organisation in Western Australia for people with intellectual and other developmental disability and their families. Our organisation started in 1986 with the purpose of providing a representative voice for a number of organisations which were providing services to people with developmental disabilities and their families. While we continue to have disability support organisations amongst our membership our primary focus is on the individual and their family as we support them to become stronger advocates, advocate for and with them, and through this experience work with community and decision makers to effect positive system change.

We note the comment in the DSS NDAP Discussion Paper that in 2015-16 approximately 12,000 people are expected to receive individual support in progressing systemic matters on their behalf, under the current funding system of $16.4million which is distributed to 58 advocacy agencies.

We believe the number of people who would be served by a well-resourced advocacy system in Australia would in reality be far more than 12,000 nationally. Conservative estimates by the Productivity Commission, and others, are of 460,000 people who are expected to be supported by the National Disability Support Scheme though we acknowledge that not all those 460,000 people are likely to seek out or require advocacy support. DDWA believes however that access to a funded advocacy service need not be associated with an individual’s participation in the NDIS, but where the need for advocacy exists, the unconditional access to advocacy must exist. Power imbalances exist and advocacy needs to address this power imbalance.

DDWA agrees that it’s important that allocation of funding be distributed evenly, so that people across all areas have as close to even access to advocacy as others.

DDWA acknowledges the changing environment of provision of service from government and non-government sectors and thus the changing environment of advocacy services which have necessarily adapted to reflect and respond to those changes. We consider that advocacy will keep a number of its fundamental tenets and practices but that ongoing reflection of practice, manifested in change in structure, partnerships, service delivery, target and coverage are necessary as needs change with the times.

Power imbalances exist and advocacy needs to address this power imbalance

The corporate memory of advocacy holds the understanding that advocacy is the vital checks and balance mechanism that our society needs in order to be fair and just. Complaints mechanisms are accountability mechanisms but without advocacy there is fear for the consumer who understands that there is a power imbalance and that there can be consequences for speaking up.

**Models of advocacy**

We agree with the comment in the DSS NDAP discussion paper that “the focus should be on the human rights of the person with disability and their individual needs and not on what model of advocacy is available in their local area.”

Individual advocacy can be an end in itself but it can and should where possible also lead to systemic advocacy through the recognition that that which is not working for one person, which has led them to seek advocacy, is also most likely not working for numerous other people.

**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?**

Individuals seeking advocacy should not be turned away because an organisation or agency does not have capacity to support them.

**1.2 What are the drawbacks?**

Systemic advocacy always starts with the understanding of the experience of an individual or group of individuals and so must therefore be characterised by the experience of the individual or group of individuals.

DDWA’s model of systemic advocacy has been developed to allow the maximum engagement with individual members and people in the community, despite our only being funded for systemic and not individual advocacy. Through the positive system changes to which we have been able to contribute individuals have also had access to individual advocacy and to opportunities to develop and build on their own advocacy skills.

Ideally an advocacy organisation would be given scope to adjust its capacity as it experienced changes in need within its constituency. Mechanisms which would allow for internal changes, for example provision for application for additional shorter term or longer term contractual funding, would assist organisations to be more responsive to their constituencies. The current frameworks, tender processes and grant and funding applications are rigid and do not necessarily allow for the recognition of emerging issues or the changing needs for individual and systemic advocacy.

DDWA believes very strongly that individuals seeking advocacy should not be turned away because an organisation or agency does not have capacity to support them.

**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?**

The corporate memory of advocacy organisations often outlasts the corporate memory of governments, their departments and the longest serving of their public servants. This should not be a reason for governments to be concerned about the role of advocacy, but should be a reason government would embrace the sector and organisations as helpful and willing partners. The long associations, networks and working relationships between organisations provides further strength to the experience and understanding of many advocacy organisations.

The corporate memory of advocacy organisations and their members and constituencies often outlasts the corporate memory of governments, their departments and the longest serving of their public servants.

DDWA considers that in this period of significant change in particular, with the trials, roll out and eventual national implementation of the NDIS, the continuity and value of the

corporate memory of advocacy organisations and their relationships with individuals, their families and other agencies will be more critical than ever before.

Government and academia in particular would be disadvantaged if they were to lose the direct links to individuals which advocates and advocacy agencies provide them in order to progress their policy and research work.

Advocacy organisations can effectively exercise dual roles of informing and assisting government on behalf of their constituencies, and also as the trusted and independent conduit working with and on behalf of their constituencies to disseminate and communicate relevant government information.

Advocates and advocacy organisations are critical brokers also in supporting Government when Government needs to hear direct from their constituency. Advocates and advocacy organisations play a vital role in facilitating the consultations and enquiries of Government, by ensuring individuals, families, carers, supporters and others, have a voice in communicating their experiences and expertise – through their making submissions, attending hearings, roundtables, participating in forums and other ways. Government approaches advocates and advocacy organisations to connect with people and to facilitate because advocates have the personal, trusted and direct connections which Government often do not.

Likewise, academics seeking the experience and expertise of people with disability often do not have the direct connections required to progress their own research, including research which is undertaken on behalf of Government. Advocates often work closely with academics to ensure research undertaken is as personal as it can be and that it reflects the human experience as much as possible.

DDWA considers that an inherent problem of individual and system advocacy is that of perception of having little to no authority to act in a given situation - by some but not all sectors in some but not all settings.

Greater promotion to raise awareness of the rights of individuals to seek and access advocacy as a human right, and to exercise this right in their negotiations with services and systems of all sizes and cultures is critical to the future of advocacy, not for the sake of the legitimacy of advocacy but for the sake of the legitimacy of those human rights.

The rights of the individual seeking advocacy must be acknowledged in the form of the legitimate authority they have to seek and exercise advocacy. This authority needs to be recognised at all steps of the process they are seeking to address or change. A change in the language, perception and in turn the given authority of advocacy must be part of this review if it is to honour genuinely the rights of people who seek and access advocacy as is their human right.

It must be remembered that so much of advocacy is undertaken by people who are not paid to do so, but who do so as members of support groups, community groups, and as concerned and interested citizens.

The rights of the individual seeking advocacy must be acknowledged in the form of the legitimate authority they have to seek and exercise advocacy.

Organisations such as DDWA work to support the advocacy activity of many unpaid community members, through supporting them as individuals to develop and build on their own advocacy skills, and by working with support and community groups to build their capacity with their members.

**2. Improving access to advocacy supports**

A core activity at DDWA is widening our reach within WA – because we have a membership which has grown over 300% in the past 4 years and we welcome around 40 new members each month, we have come to know that individuals and families are in main part unware that advocacy is available to them. We know that there are yet thousands of people in our State who have not connected with us and who may find value in their association with us. Service providers and government bodies do not promote advocacy and so it is incumbent on our organisation and others like ours to make the connection and engagement with people in our constituency a priority area of our work.

A proactive approach to seeking greater engagement within a constituency should be considered as an integral and legitimate part of the work of any advocacy organisation.

This said, DDWA and other advocates are acutely aware of the risks associated with creating demand which cannot be responded to due to the sheer numbers of people who would potentially connect with us and whom we could not reasonably support without adequate funding and capacity.

**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 culturally and linguistically diverse communities and their families?**
* **people with disability in rural, regional and remote locations?**
* **people who are very socially isolated including those with communication difficulties and those in institutional care?**

Acknowledging and respecting the diversity of experience is as critical in disability as it is for any other sector in order to properly present and progress the issues unique to an individual or a group of people.

Naturally the experience of a person with disability is similar in some ways but dissimilar in many other ways depending on the nature of the disability the person lives with - a person who is vision impaired or quadriplegic who does not live with intellectual disability has a different experience than the experience of the person who lives with intellectual disability, or who lives with a combination of intellectual disability and a mental health condition.

Acknowledging and respecting the diversity of experience is as critical in disability as it is for any other sector in order to properly present and progress the issues unique to an individual or a group of people.

Just as the experience is different for different disability so too is the experience of the person from one cultural community in comparison with the experience of a person from a different cultural community. The experience and expertise in working with people with specific cultural needs must be acknowledged through supporting those organisations to continue that work.

Improving access for people from ATSI communities and their families requires engagement directly within those communities or by engaging with representatives who are trusted within those communities from larger nearby communities. Increasing mainstream agencies’ capacity to develop those relationships must be seen as integral part of a commitment to improving engagement with ATSI communities. Mechanisms for communicating essential information, for example about how to connect with the NDIS, must take into account the specific cultural and communication practices of people in ATSI communities. To discuss this in this submission would be to generalise what we have learned however we would be pleased to provide further detail at another opportunity.

Agencies dedicated to advocating for and with people from culturally and linguistically diverse communities and their families serve their constituencies well in ways which others less familiar with the cultural mores would, and with growing numbers of people from CALD communities requiring advocacy as our data indicates, the capacity of those dedicated organisations would necessarily need to be increased.

Where ready access to advocacy in a particular area or to meet a particular need does not exist within an organisation capacity should be available to make that advocacy available by the promotion and development of partnerships either within community or more widely. Mentoring or support from advocates and advocacy agencies which have experience other than the specific cultural and linguistic understanding could be of value to potential advocates who have the understanding and experience to connect with the people seeking advocacy. Gaining experience in situ is another way to share and broaden the experience between advocates who have different areas of experience, expertise and understanding.

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

Some of the barriers presented by geographic location can be addressed by visiting services, improvements in communications with existing community agencies and maximising utilisation of technology where appropriate and where feasible.

In a State as vast as Western Australia, there are many remote and regional areas where people do not have ready access to disability or mainstream services nor to advocacy. As an organisation we consider engagement with people in remote and regional communities in WA to be a critical element of our work in disability advocacy.

6 years ago DDWA employed a deliberate strategy to increase our organisation’s profile with the specific aim of connecting with more people in WA. This strategy was designed to improve our systemic advocacy by identifying and taking action on issues emerging through the broader experience of people with intellectual and other developmental disability.

We know that the strategies we employed to connect with more people are having an impact and one of our primary measures is the significant increase in our membership of over 300% in the past 4 year period, not taking into account the increased connection we have with others who are not members of our organisation.

Our strategy seeks to continue to connect and engage with more people in WA, which we have done in a number of ways:

* Presenting opportunities for members and others to connect with us and with others in our network on issues of interest and importance to them, hosting events such as workshops, information sessions etc.
* Increasing direct communications with members and others
* Wider and increased social media
* Collaborating with our extensive networks within the disability sector, community sector, government and others
* Utilising mainstream media on issues on which we are seeking to effect change, and which in turn provide opportunities for the community to find out more about our organisation and our work
* Developing practical resources (eg written and video) which engage members and provide them ongoing touchpoints for returning to our organisation for support and advocacy where needed

Above all else we consider the most effective strategy for improving access to advocacy to be establishing a level of relevance, consistency and longevity as an organisation which people come to trust as being of value to them.

Exhibitions, fairs and open days are in our experience losing currency as forums for effective information and engagement and are being replaced by communication and contact methods like those listed above. One-stop-shop type of online arrangements are also generally seen as having little benefit to the majority of our members and constituency.

**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?**

It is appropriate that organisations which receive funding from Government be required to report to Government about their activities, objectives and outcomes. It is also appropriate that the information collected and reported to the funder be relevant to the activity undertaken by the advocacy organisation and relevant to the organisation’s objectives and outcomes.

As suggested earlier, in order for advocacy organisations to work with and on behalf of their members and others, a greater legitimacy afforded to the practice of advocacy would assist in the work of progressing the rights of people with disability. Resistance to advocacy is experienced more often when negotiating with mainstream services than with disability support organisations or related service providers. We believe government has a major role to play in the acknowledgement and promotion of the legitimacy of advocacy, particularly in endorsing advocacy to its mainstream services within government, with which advocacy agencies often work on issues involving their members.

…a greater legitimacy afforded to the practice of advocacy would assist in the work of progressing the rights of people with disability.

Collaboration must exist between individuals, advocates and advocacy agencies, community, government and others to determine and define the gaps in community, culture, practice and service which when addressed would improve the opportunities for people with disability.

The question of how best to collect the information can be resolved in part by discussion direct with those organisations so that information collected is effective and accurate. Difficulties in reporting and accountability occur where the guidelines are unclear and do not reflect the activities, objectives or outcomes of the organisation concerned.

The question of what to do with data collected by agencies once collected and how to ensure it is used to improve the lives of people with disability at a local and national level lies with the understanding of what gaps in community, culture, practice and service remain, and what can be done to address those gaps. Understanding “the number and type of people with disability” an organisation supports goes only a fraction of the way to understanding the work to be done, in the absence of understanding what the actual gaps are and what the actual experience is of those individuals.

Collaboration must exist between individuals, advocates and advocacy agencies, community, government and others to determine and define together the gaps in community, culture, practice and service which when addressed would improve the opportunities for people with disability. Ongoing consultation with all parties in direct and personalised and in collaborative formats must be part of the practice of review and working to address the systemic issues which have arisen.

If advocacy organisations are to be required to report on their activity and outcomes, as they should, so too must government and their agencies be required to report regularly on their activity and outcomes against agreed benchmarks and objectives set by the collaboration of individuals and agencies listed above.

Advocates and advocacy organisations often make information on their work and their findings available to others in the sector and to the public generally through a range of mechanisms – by providing discussion papers, submissions, reports and other publications to government, peak bodies, associated consumer bodies, on their websites, and other avenues. How this work then translates to systemic change necessarily requires collaboration with other bodies – government, community and others. For that work to be progressed to have an opportunity to effect change also requires capacity at an organisational level. Advocacy agencies are notoriously underfunded and therefore understaffed and so lacking in the capacity to meet the need that already exists amongst their constituency, let alone the idea that they would seek to broaden their reach to others who may also benefit from involvement with that organisation on a particular area of advocacy or work. As such organisations are often limited in their scope, activity and outputs even where they know they can have significant impact on an individual level or systemic level.

While annual or biannual reporting methods are effective for an organisation’s internal reflection on practice, opportunities to provide feedback and information in other more flexible or ad hoc ways are also important mechanisms for ensuring organisations are on track in meeting their objectives.

Inviting responses to reviews and inquiries are useful mechanisms for framing questions and focussing topics, and it is critical that individuals and the community are invited as well as representatives from organisations and that their personal contributions through attendance at forums are welcomed as well as their written submissions.

Timeframes set by Government committees and departments are at times unrealistically short for genuine consultation with stakeholders to take place and should be avoided to ensure they do not appear to be cynical demonstrations of ‘ticking the consultation box’.

Where recommendations are made by governments or departments following consultations it is incumbent on them to attribute those recommendations to the source where it has come from a stakeholder, to foster greater participation, cooperation and trust between all parties involved in system change.

Reporting by stakeholders external to the administering departments or agencies, on practices, programs and policies would provide a more rigorous analysis and assessment. Mechanisms which require external as well as internal assessments should be part of systems and services to ensure the rights of people with disability have been upheld. This should apply to disability and mainstream services and systems.

There will always be people who will not be eligible for the NDIS but who will keep and access advocacy and this must be available for them.

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

**Questions**

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

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

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

In an ideal world advocacy would continue to be funded in such a way that it would be funded and organisations would not consider engaging in discrete forms of service delivery. We understand the sector is grappling with the changing environment and that some organisations are looking to provide advocacy along with other functions or services which would have been deemed advocacy but which are now functions complimentary to or described previously as advocacy.

DDWA agrees that the NDIS brings with it a heightened demand for advocacy for individuals - to support with planning, reviewing, technical advice, support to negotiate grievances, and so on. However as also suggested earlier, it is our view that the funding for advocacy organisations need not and should not be tied to the arrival of the NDIS.

There will always be people who will not be eligible for the NDIS but who will seek and access advocacy and this must be available for them.

Fiscally it is not necessary that funding come from an area of the economy ‘designated’ for ‘disability’ – in truth such funding can come from anywhere if the need has been identified by Government, as indeed it should, and to portray those workings of the economy as otherwise is an untruth.

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

**Questions**

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

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

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

DDWA’s experience of advocating on legal issues includes individual and systemic advocacy in relation to disability justice particularly in relation to indefinite detention under the Criminal Law Mental Impaired Accused (CLMIA) Act. Under the Act individuals can be detained indefinitely under a Custody Order if they are unfit to plead or are not guilty because of their disability or mental illness. They can be detained indefinitely without ever being convicted of a crime and have no right to appeal the decision to make an indefinite custody order.

Family members and carers of accused persons have described the experience of navigating the CLMIA system as very confusing and challenging, and argued for a form of advocacy to also be made available to families and carers. In our joint submission with the WA Association for Mental Health to the WA Attorney General we stated that advocacy must be available to all people under the Act, not just those on a custody order or in hospital but also those in prisons, detention centres, declared places and the community.

People with impairments in communication and decision making are highly vulnerable both as victims of crime and as people accused of crime.

Lack of access to advocates, to legal services, to interpreters, to specialist practitioners, present further barriers for many people with intellectual disability who come into contact with the justice system – both victims and people accused of crime.

DDWA is aware of some of the systems with experience in the rights of people with disability, in other Australian states. Some of these we would like to emulate in our State but we are concerned for the future of those systems also, as they are negotiating their funding with their own States and funders.

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DDWA thanks the Department of Social Services for the opportunity to present our case for supporting moves to strengthen and sustain a national disability advocacy sector and the individual organisations within it, and would welcome a further opportunity to discuss this to expand in more detail on points outlined above.