**Action for More Independence & Dignity in Accommodation**

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*Advocacy, Self Advocacy, Rights, Accessibility, & Community Living for People with a Disability*

**16.6.16**

**Response to the Review of the National Disability Advocacy Program Discussion Paper April 2016**

“They help me talk about issues people with disability face”

“My Mum and I trust my advocates judgement”

“I’d recommend them to any disabled person”

“I wish there were more organisations available like them”

“I think this service is excellent. One of the good ones”

“I’m so impressed with this service”

“Professional in every way”

“They are proper advocates”

“They are exceptional”

“They have passion, knowledge and belief and support people to work together”

“They support the benefits of how self-advocacy and systemic change link together”

“They are a small group but they do a significant amount”

“They make good use of their time-with strategic moves that are in line with their goals”

Suggestions for improvement- “The government should give them more resources so they can do more.”

A snapshot of consistent Client feedback on AMIDA from Quality Audit processes every year from 2012-16

We would like to begin by acknowledging that the value of small, specialist independent and experienced advocacy groups must be acknowledged and that this review while it attempts to address increasing advocacy demand and gaps, must not result in the loss of trusted and competent advocacy services at a time when they are needed by so many to navigate the changes of the NDIS. AMIDA has had 35 years of investment by governments, volunteers, workers and people with a disability to become a valuable asset. While equitable access to advocacy is a vision we support this cannot be addressed by removing funding from existing services to redirect it to other areas. There are 3,000,000 people with a disability in Australia and the NDAP program meets the advocacy needs of 12,000 people per year. Redistribution of funds will not result in equitable provision, just more waiting lists and the loss of experienced advocates. Furthermore there have been agreements that people with a disability will not be worse off under the NDIS. The discussion paper around this review of NDAP states, “The most significant reason for a review is the rollout of the NDIS”. If an outcome of this review is that current funding is redistributed away from areas it has been available then many people will be worse off in terms of their access to advocacy.

AMIDA provides individual, self-advocacy, family advocacy and systemic advocacy via the National Disability Advocacy Program (NDAP). We fear that this review will not result in **significant investment to National Disability Advocacy Program funded advocates, to deliver equitable access and representation of issues and to match the increased demand for advocacy anticipated under the NDIS;**  as recommended by the **Senate Inquiry into Violence, Abuse and Neglect of people with a disability in residential and Institutional settings.**

We fear it will instead result in tendering out the provision of advocacy resulting in a loss of continuity, expertise, independence, all at a time when the NDIS changes are creating an increased demand for competent, experienced advocacy. We are also concerned that any increase in funding will go to advocacy peak bodies at the expense of smaller providers of individual advocacy. This would fly in the face of the **Senate Inquiry into Violence, Abuse and Neglect of people with a disability in residential and Institutional settings which recommended the NDAP,**-**Ensure that current model of funding peak bodies does not inadvertently result in the closure of smaller specialist or local advocacy organisations.**

### With the review of NDAP, we fully expect it will find there is not enough Advocacy provision to meet demand and that coverage across Australia is not complete. However without additional funding the NDAP program cannot hope to meet the demand. The problem is not one of inefficient advocacy service provision. Many groups provide extraordinary outcomes on limited budgets by collaborating and with the assistance of voluntary committees of management. AMIDA’s committee is made up of dedicated people of whom 50% are people with a disability who have supported and led the organisation over its 35 year history to become a leading contributor on matters of housing for people with a disability and self-advocacy via our management of the Victorian Self Advocacy Resource Unit.

### Our focus on housing has meant we can create self-advocacy resources on rights and systemically advocate for these rights when no other group took these issues up. Our leadership has seen other advocacy organisations and government departments support this policy. As a result under the NDIS, housing and tenancy will be separated from support provision nationally allowing tenancy rights and choices about support provision. We have also taken a leadership role along with others in calling for the closure of institutions and have seen the announcement to close these one by one in Victoria. The NDIS housing framework position paper recently released has stated institutions will be closing and subsidies in future will not go to any dwelling larger than a 5 bedroom house.

Our passion for and focus on self-advocacy led to us successfully winning the bid to manage the Self Advocacy Resource Unit. Specialisation and focus has supported the resurgence of the self-advocacy movement across Victoria and we hope in future across Australia. AMIDA supports the Raising Our Voices self-advocacy group via our NDAP funding. This group has over 29 years given public air space and a voice to people with an intellectual disability and other disabilities.

### We are a highly experienced, quality service as shown by the investment over recent years in external certification. It would be wasteful in the extreme to discard this investment and pay for an expensive tendering process. What is required is targeted pilot funding to reach areas and cohorts of people with a disability not currently able to access advocacy. For example AMIDA ran a successful pilot outreaching to people in group homes who cannot otherwise access advocacy. This pilot was not refunded by the State government however and although we reached 86 different group homes there are 1000 in Victoria alone. This is the type of program expansion that is required.

This view has been endorsed by the Senate Inquiry into Violence, Abuse and Neglect of people with a disability in residential and Institutional settings which recommended,

* **Increased training for people with disability to recognise violence, abuse and neglect so they can self-report;**
* **Government service contracts to include provisions to enforce access to facilities for advocates,**

### Finally this issue of abuse and neglect has been placed in the spotlight with a number of state and federal inquiries. Advocacy featured highly in the recommendations as it can prevent and respond to abuse. The Victorian Inquiry into abuse in disability Services highlighted the importance of advocacy as a safeguard preventing and improving response to abuse. The Victorian Ombudsman Inquiry into Reporting and Investigating Abuse found, “There was strong support for the broad principle of the recommendation, which concerned the need to comprehensively assess the need for advocacy and fund this need accordingly.”

Small, low funded advocacy groups like AMIDA have been value adding for years in the advocacy and self-advocacy space with philanthropic funds, state government funds and local government funds. We are a scaffold that supports not just the NDAP but a range of other initiatives in advocacy which complement each other. To address gaps and spread coverage the NDAP must identify areas and models currently lacking and offer the tender to existing advocacy services first as many will welcome this however services may not have the capacity or mission to diversify into all models of advocacy. AMIDA offers 4 models currently and further diversification into legal and citizen advocacy may be at the expense of our strong focus on the other 4 models. We would however welcome more funding to outreach to people in institutions and residential services who cannot readily access advocacy as this builds on our expertise and focus. We believe the NDAP should value the services it has invested in first and begin the process of change by asking them what their mission is and how they would wish to expand the availability of advocacy if given the resources to do this. If these proposals were then funded as pilots, evaluated and funded long term if successful, a significant and meaningful expansion of the program would occur without loss of service, expertise and value. Any gaps still existing after this process could be filled by a tendering process to advocacy services first and then to other community providers who are independent of service provision.

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?

**Agencies develop expertise in these models, People with a disability, their families and carers know which services are expert, and that they can have confidence and trust in them to receive expert and specialist advice. Agencies can also provide secondary consultation to other advocacy providers**

* 1. What are the drawbacks?

**PWD are disadvantaged if a model they require is not available in the region they live in. If it is not provided at that agency this can be addressed where other advocacy agencies within a region provide this model**

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

**Recognise the expertise and agencies have developed and respect their decision to focus on particular models and particular issues. Support those agencies that have more than one advocacy model by reducing the certification burden where currently a minimum number of service users from each model must be interviewed. Fund each region to provide all models of advocacy without requiring all agencies to provide all models. This will necessitate an increase in funding but is required.**

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

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

**Disability Advocacy funding needs to be first offered to these communities so they can provide support to their own people and network with the wider disability advocacy sector. Funding also needs to be provided to existing advocacy agencies to undergo cultural training, to network and if necessary where Aboriginal and Torres Strait Islander communities choose not to deliver advocacy services, to establish culturally appropriate services**

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

**Advocacy agencies expert in issues for the CALD community need to be funded but other advocacy agencies also need to be funded to train staff in providing culturally appropriate services, eg. in Victoria Action for Disability in Ethnic Communities is a state funded service and provides advocacy and secondary consultation however it lost its systemic advocacy which has meant issues are not identified and acted on.**

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

**The discussion paper says the most significant reason for a review is the rollout of the NDIS. A commitment has been made that with the introduction of the NDIA people with a disability will not be worse off. If advocacy funding is withdrawn from some areas of Australia to redistribute it to others this will mean that there will be less access in large population areas than there currently is. Funding must be increased to provide access to advocacy in rural, regional and remote areas rather than spread current funding more thinly across Australia.**

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

**Outreaching to people who are socially isolated is an important strategy to providing advocacy access. It is time consuming and expensive and current funding will have to be increased to enable more outreach. Given recommendations from various government inquiries into the importance of this outreach to people in residential settings, funding should be made available to all regions of Australia for those advocacy agencies wanting to focus on outreach in self-advocacy, and individual advocacy. In addition service specialist in communication rights are very important to fund. Eg in Victoria Communication Rights Australia is funded to provide advocacy and secondary consultation.**

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

**In our experience what is effective is Plain English resources and video, face to face discussions, peer education that is culturally appropriate, about rights and how to recognise and prevent abuse and about advocacy and how to access it. Self advocacy groups and movements also are excellent vehicles for individual empowerment and systemic advocacy. This needs to be provided in tandem with individual advocacy to follow up on issues disclosed to advocates when discussion of abuse of rights occurs.**

**Strategies that do not work include over reliance on web based information.**

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

**The model in Victoria of Disability Advocacy Resource Unit and the Self Advocacy Resource Unit have assisted advocacy and self-advocacy groups to network, collaborate and partner on systemic issues. This model could be rolled out across Australia to allow better co-ordination of effort. Disability Advocacy Network Australia also has an important role to play also in resourcing advocacy to come together which allows co-ordination of systemic effort nationally.**

**Information on systemic issues isn’t always getting to the right people and organisations because not all advocacy services are funded to allow time to communicate this information. All services should be offered funding to at least compile and communicate systemic issues. Advocacy groups funded to a greater proportion to do systemic advocacy can co-ordinate this information and plan systemic advocacy and take action.**

**However it cannot be assumed that there are not professional and quality systemic advocacy actions already taking place simply based on failure of governments to accept the recommendations of advocacy. For example The Senate Inquiry on Abuse and Neglect (sic) recommendation that the government make**

**significant investment to National Disability Advocacy Program funded advocates, to deliver equitable access and representation of issues and to match the increased demand for advocacy anticipated under the NDIS**

**If funding for the NDAP does not increase to match demand we do not therefore conclude that the Senate Inquiry was inadequate in its advocacy and we do not shoot the messenger and blame the Senate Inquiry for lack of government action; we blame the government of the day if they fail to respond. Systemic advocacy can take years to effect change in fact, as attitudes are often at the base of inequality. However without systemic advocacy on institutions, housing, and human rights this change may not occur at all. We do not necessarily therefore support investing needed funds for advocacy into a new “mechanism” on the assumption that somehow the message isn’t getting through. Unless there is a mechanism that encourages governments to listen and act on the message it will be a waste of resources.**

**So the most effective program to fund is that which takes our leaders on the journey they need to take to shift their thinking. In terms of what persuades governments it is the authentic, lived experience of people with a disability. Well-funded self-advocacy and advocacy services managed by a majority of people with a disability are the best social change mechanisms we have.**

**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?
* **Funding for advocacy must be adequate to allow networking and collaboration with the various DPO, peaks and statutory bodies. DARU, SARU and DANA have provided recent forums doing just this and are an excellent model**
* **4.1** What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimized?
* **We are not sure these conflicts can actually be effectively dealt with. If this practice is allowed however there will have to be diversity of advocacy service where advocacy agencies choose to provide services as a registered NDIS provider; otherwise if clients receiving this service need advocacy they will have nowhere independent to access advocacy. Therefore in rural, remote and regional centres or where there is currently only one advocacy provider, funds to establish an additional advocacy provider would be necessary to prevent conflict of interest. This will provide diversity but if population numbers are not large this may not be cost effective. Independent advocacy must be accessible even if this means discouraging sole advocacy providers from registering as NDIS providers**
* **Also there is a concern that if advocacy agencies can provide support services under the NDIA, then support providers may seek to provide advocacy. This is a major concern as people with a disability will be unlikely to trust service providers to protect their rights. Service providers will be in competition under the NDIS to provide support and may act in ways that are in their interests as a competitor when advocating against other services which they compete with.**
* **4.2** How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?
* **If there is a need for support which neither the NDIA nor advocacy currently meets, this will be an issue for government to monitor, review and respond to. The NDIA will no doubt throw up many unintended consequences and as long as the commitment that people with a disability will not be worse off is honored, these issues can be addressed. Advocacy will be at the cutting edge of identifying these issues and data collection could seek to capture this.**

**At the moment the NDIS is operating differently in different states and even in different launch sites within states. It is not being equitably rolled out at all. The NDAP can aim for equitable access but like the NDIS it should look to local conditions and requirements.**

* **4.3** What policies and strategies do we need to protect the rights of people with disability?
* **Independent, experience, specialist, advocacy must be widely available as a policy and funded to meet the demand as a strategy to protect the rights of people with a disability.**
* **5.1** What forms of legal review and representation do people with disability need most?
* **People need legal representation and support related to legal issues affecting them because of disability such as the NDIA access, guardianship, tenancy in disability specific accommodation, discrimination in accessing education, employment and other services and their treatment by those services but also they require legal support and representation around issues that affect any person, but with adequate support to assist them navigate the legal services they might otherwise find it difficult to access.**
* **5.2** What barriers prevent people with disability from accessing justice?
* **People with disability may have difficulty understanding the legal system including how to access legal support services and without advocacy support to navigate it they are effectively barred from legal justice. They may also need additional advocacy support to consider options and make decisions, without which mainstream legal services may be reluctant to accept referrals. Mainstream legal services sometimes don’t support people with a disability adequately, or outreach to socially isolated people with a disability in institutions and disability specific housing. Mainstream legal services are often unable to provide direct representation on legal matters and instead provide advice to disability advocates so they can represent them at tribunals. Without well-funded disability advocacy people with disability would not be able to use these advice services, eg Consumer Law Advocacy service and Tenants Union of Victoria.**
* **5.3** What models of legal advocacy are most effective?
* **The tendency of some mainstream legal services to move to a more secondary consultation model is concerning. There is still a need for disability advocacy legal services that can employ lawyers to directly represent people when the issue requires legal representation. It is most effective when there is a combination of disability specific legal services, mainstream legal services, legal services providing advice and secondary consultation to advocates and a well-funded disability advocacy sector.**