We are ordinary people
doing ordinary things
of extraordinary importance

Capricorn Citizen Advocacy

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Submission to the Review of the National Disability Advocacy Program

Discussion Paper Questions

Models of advocacy

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?

Many eligible Australians do not have access to any disability model at all as there are no local advocacy agencies available in their area. An analysis of the locations of the current 58 agencies funded by NDAP and the remaining State funded agencies shows many gaps in coverage.

The rollout of NDIS will increase the need for independent advocacy both for participants in the NDIS and those people who are deemed ineligible for supports from the NDIS. The NDAP funding is currently $16.4 million and the total spend by the NDIS is estimated to be $11.7 billion in 2019-20, the first year after the full national rollout, clearly the tiny commitment to disability advocacy at present is unsustainable.

When existing disability advocacy agencies are stable, experienced and have continuity of service and service outcomes, it seems logical to conclude that these single or dual mode programs are meeting a need for their services.

In other words, the agency is fulfilling its mission and the people needing the advocacy, families and carers are all benefiting from the program.

As argued below, advocacy programs function well if they are small and responsive, embedded in their community, report to a local management committee or board and are dedicated to delivering a discrete form of advocacy.

This may seem 'messier' than a corporatised parent program which oversees various models, but it works well in various locations in Australia, albeit with gaps in services.

Therefore we would argue that an expansion of the number of smaller programs will achieve the desired outcome of increasing the overall coverage of agencies. Smaller programs are usually more cost efficient and each person needing advocacy is known well and therefore responses to their needs can be more flexible.

1.2 What are the drawbacks?

In single mode agencies there will always be unmet needs for other forms of advocacy, due to the limits to each of the existing models being able to handle all needs.

Therefore detailed consultation with each agency must establish exactly what alternative forms of advocacy are needed and to formulate options to address this unmet need.

We would be glad to see all models of advocacy funded in every city and regional location, it does not appear that this is the actual intention of reviewing NDAP.

We are concerned that basing the review of NDAP on a Human Rights charter will fail understand that many human needs that citizen advocacy addresses for individuals are not easily defined as human rights but are relational in nature.

In fact pushing a legal barrow to facilitate change is adopting a single means; 'a big stick' for meeting needs of people with disabilities, rather than recognising that achieving lasting change for vulnerable people more often comes from interpersonal identification and one to one advocacy.

Who will be responsible for deciding that a human right is being violated and therefore should be acted upon with some form of advocacy?

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?

Expansion of multi-mode disability advocacy agencies is possible in theory but this particular option requires an increase of funding to allow increased staffing of existing agencies and start-up funding of new programs in areas which currently have insufficient advocacy programs available.

It is impossible to build any evidence based case for multi-mode advocacy programs in Australia attesting of more than two models co-existing satisfactorily under one governing entity. Side by Side Advocacy in Sydney is an example of a dual mode advocacy existing in Australia but the two models in this program are certainly not equal partners.

We are not at all sure that multiple or all models of advocacy can operate productively under the one roof (as a single organisation). Grouping several forms of advocacy under one organisation may sound appealing when it is presupposed that that 'bigger is always better', but closer examination does not support it is the magic bullet. Indeed, we contend that it is more likely that small, autonomous, local agencies will address unmet community needs more effectively than grouping multiple models under one organisation.

This is because inevitably multiple modes will generate an internal competition for resources and the allocation of funds to an advocacy model will depend on what revenue can be raised.

Advocates will experience ongoing pressure to pluck the low hanging fruit to meet expected outcomes rather than dealing with difficult time intensive cases.

Multiple modal programs also will require a significant degree of internal liaison and programmatic oversight which increases overheads rather than improving frontline efficiency.

Mission effectiveness is not merely a product of organisational size but depends to a much greater degree on staff focus on meeting expected outcomes. There is a very important role in keeping advocacy programs true to their mission played by individual Management Committees (particularly for Citizen Advocacy programs). Guiding and encouraging the paid staff is therefore a community driven process.

The ILC framework envisages that community based supports for people with disabilities will provide openings for smaller, responsive and locally driven services to develop. They will respond to unmet needs of NDIS participants, as well as people who are ineligible to receive NDIS supports but still very much need community inclusion.

Nevertheless it is quite possible that in places where sustainable and efficient advocacy programs are embedded, multiple advocacy models could share office space and possibly back-end support.

This approach ensures that independent agencies can each remain focussed on their brief but also collaborate productively with the other programs on an informal basis due to their proximity and shared values.

Improving access to advocacy supports

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?

Legal advocacy is certainly a model of advocacy which lends itself to having a central office (in a capital or regional city) which can also assist people in rural, regional and remote areas with their needs through the use of telephone interviews, teleconferencing and field visits, including court representation. Frequently legal advocacy provided by a Community Legal Centre first relies on non-legal advocates who refer people who need legal assistance to the correct agency.

Systemic advocacy must be directly informed by the experience of people in all locations but can be administered centrally with knowledge of issues collected through regular field trips, seminars and consultations.

A current example is the program to raise awareness of the NDIS through participant readiness and pre-planning workshops. This program is provided by agencies which are based in metropolitan centres but it still enables systemic issues from rural, regional and remote locales to be raised (such as problems for NDIS participants who have intellectual disability and cannot access independent advocacy)

Individual advocacy and Citizen Advocacy by their very nature are face to face and relational and they require local advocates to be recruited in the area where advocacy is needed or at least in a place where contact is reasonably easy to arrange.

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

From the outset it should be acknowledged that vulnerable people are in these situations despite the current array of disability services and service providers. The arrival of new service providers as the NDIS rolls out will therefore not necessarily help these people to participate in the community. This is because the NDIS and providers are set up to treat people with disabilities as savvy customers who can either ably self-advocate or who have family supports.

Institutional care arrangements are only partly responsible for such social isolation as in addition to vulnerable people living in group disability settings with many paid support workers in their life, they can experience a complete lack of natural and informal supports from family, friends and concerned people in the community.

A long proven way of providing advocacy and other supports to people to very socially isolated people is Citizen Advocacy. This model is a very intentional process of assessing unmet needs and vulnerabilities of people with disabilities (including those in these circumstances). It is accompanied by a careful 'matching' of each individual with an everyday citizen who possesses competencies, personal qualities such as a sense of justice and compassion and who has their own network of family and friends in the community.

Often people in close knit rural, regional and even remote communities prove to be willing to help as advocates for people with disabilities if they are asked. In fact the only thing that has stopped such effective informal supports developing and continuing is that these willing people have never been asked.

Everyday citizens in the community are the building blocks for development of strong relational supports, linkages and community networks for isolated people (as envisaged under the NDIS's Information, Linkages and Capacity Building (ILC) Policy Framework).

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

Citizen Advocacy programs in every state of Australia already play a key role in establishing and supporting strong personal connections between everyday citizens and people with disabilities (including those who are socially isolated, with communication difficulties and in institutional care) and these relationships often mean a better life for both the advocate and the person with disabilities.

There are currently 10 Citizen Advocacy programs operating in Australia and there is a capacity for new programs to be established in areas where they are needed. The model of advocacy is time intensive but very cost effective. This is because funding of the program supports only the office which recruits and supports the matches.

The advocates themselves are unpaid; their advocacy is freely given and thus is completely independent of service providers and other statutory bodies such as the Public Guardian or Public Trustee.

> *An example of how Citizen Advocacy works for people who are very vulnerable is a 45 year old man in Queensland who has both life defining physical and intellectual disabilities (Down Syndrome, complex communication problems; nonverbal communications and mobility restrictions requiring hoist assisted physical transfers).*
>
> *This man has no family to advocate for him and has the Public Guardian, Public Trustee and a service provider as the only people in his life. Therefore finding an advocate for a person in this situation is crucial as it helps to ensure continuity of service from his accommodation provider, health care that is responsive and high standard as well as opportunities to be involved in the wider community.*

Citizen advocacy is proven to work for these citizens as the advocate will be carefully and intentionally matched to the protege. The advocate will relate and identify with the person with the disability, whatever their background and life challenges.

What model has yet been demonstrated to work? A one stop shop.

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?

Advocacy programs each need to have an evidence base, but there is always a danger that advocacy becomes a numbers game where the quantity of people helped is the entire measure of evidence, rather than the quality and longevity of an ongoing personal Citizen Advocacy relationship which not only addresses issues but acts as a powerful preventative to further issues developing.

The aim of providing gathered information to "human rights" based organisations assumes that legal and rights based advocacy takes precedence over relational advocacy. In fact a model like Citizen Advocacy which is actually far more effective and cheaper for people with disabilities in many cases than pursuing legal redress.

A properly resourced independent national peak body is also essential if systemic reforms are to be achieved on behalf of disability advocacy programs. DANA is the peak organisation which brings a national voice to the many forms of disability advocacy in Australia and it plays a vital role in ensuring all organisations are kept fully informed.

An organisation like DANA must be funded in future to address sectoral and systemic issues that are common to all advocacy models and programs.

The strength of smaller advocacy programs is their responsiveness to their local community. DANA however, can fill a valuable role to assist where programs are not as skilled; by regularly and effectively engaging with the big picture on their behalf.

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?

The interface with the NDIS and addressing conflict of interest

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

The draft "NDAP Vision" proposed in the discussion paper is that NDAP "integrates with and complements the services provided within NDIS" doesn't seem to take into account that the "advocacy" may sometimes be against NDIS. An integrated approach to the NDIS raises the question of how can the NDAP in this situation be truly "independent" as stated in the first point of the vision?

An "equitable" funding model for advocacy is also proposed in the draft vision. This is a concept that can be contested and tricky. It is similar to saying people should have equity of access to health care - those with greater need for advocacy will use advocacy programs more. Funding for disability advocacy services must therefore always favour the most vulnerable in our community.

The NDIS must facilitate advocacy mechanisms (independent disability advocacy programs which provide individual advocacy) to ensure only people who are not affiliated with service providers (employees or contractors) can act as independent advocates on behalf of NDIS participants or people undertaking the intake process.

Independent advocates for people being assessed for NDIS packages must always act in the interests of the NDIS customer. It is intolerable for a heavily skewed power play to become commonplace whereby the interests of other stakeholders are given precedence. A fundamental conflict of interest occurs where the advocate actually owes their ongoing and primary loyalty not to the NDIS participant, but to the interests of their employer (being the NDIS or an existing service provider).

This scenario means the deck is stacked in favour of the status quo; being maintenance of the existing service profiles and perpetuation of arrangements with current service providers. The aim of such 'advocates' is simply to focus on minimum service standards and cost profiles of NDIS participants. In effect it provides a monetary based incentive for service providers to keep their clients and minimise any changes.

Lost in this process is the raison d'etre underpinning the NDIS; participants exercising choice and control, innovative design of supports and the ability for participants to change providers in order to find their preferred supports.

There must never be an inbuilt dependence or de facto acceptance of service providers playing a substantive role in the interview process. Sadly, this situation is currently happening and may continue. There are insufficient independent disability advocacy programs available, particularly for vulnerable people with intellectual disability who lack the informal community supports of family and friends which can protect them from being exploited.

As there is no truly independent advocacy available for those who need it, a two tier process for NDIS participants is likely to become enshrined.

1. *A model scenario being NDIS participants who have the support of vigorous advocacy from independent people who have primary loyalty to them and who will help them over the long term to deal with the NDIS bureaucracy and its policies, practices and technology.*
2. *A fall back scenario; for the most vulnerable people who have nobody else who will speak up for them. They will customarily be represented by an 'in-house advocate'; from an existing key service provider. An 'advocate' is present but who clearly has a vested interest to ensure the service provider keeps their client and their attached funding. In these situations there are currently no checks, balances or probity audits in place to protect their client's interests.*

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

A proven way of providing advocacy and other supports to people who slip through the gaps for NDIS supports is Citizen Advocacy. This model of disability advocacy is a very intentional process of assessing unmet needs and vulnerabilities of people in these circumstances accompanied by a careful 'matching' of each individual with an everyday citizen who possesses competencies, personal qualities such as a sense of justice and compassion and who has their own network of family and friends in the community.

Often people prove to be willing to help as advocates for people with disabilities if they are asked. In fact the only thing that has stopped such effective informal supports developing and continuing is that these willing people have never been asked.

Everyday citizens in the community are the building blocks for development of strong relational supports, linkages and community networks for isolated people (as envisaged under the NDIS's Information, Linkages and Capacity Building (ILC) Policy Framework).

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

The best strategies to provide protection for people with disabilities come through the natural freely given advocacy of fellow citizens; family members, neighbours, church members, workmates, businesses, service clubs, sporting associations and friends.

The natural and ordinary networks and everyday relationships and bonds between community members can be widened through intentionally including citizens with disabilities. This can give people with disabilities the access to vigorous advocacy, legal advice and redress of wrongs that other competent and high status citizens possess.

In practical terms, everyday people are the best form of protection. They are not part of the world of paid disability service providers, they are unpaid and thus willingly enter into freely given advocacy relationships with people whose rights are threatened or breached. They can act as whistle blowers, advisors, helpers and can represent the interests of the person with the disability as if they were their own interests.

Strategies should reach out to community groups and encourage them to include others with disabilities and to celebrate those who already do this. There is no doubt it is a long term process and would need sufficient time to work, but an example can be seen in the latest strategies to get people in the community (such as sporting clubs) talking about combatting domestic violence and ensuring the community takes some ownership of the problem.

Understanding and improving access to justice

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

An ongoing systemic legal problem for people with intellectual disability is that they are automatically deemed to lack legal capacity to make ordinary decisions which everyday citizens can make. If a person with an intellectual disability has the Public Trustee making financial decisions and the Office of the Public Guardian making decisions about health and other matters, that person is unable to sign documents which may well be within their ability to understand (with some support as necessary). Legal capacity however, is not seen by practitioners as being evident within a spectrum and an issue that can be managed in many cases, rather it is viewed as either existing for a person, or not existing.

A current example of how this situation can heavily impact on a person with an intellectual disability is a lady aged in her early 30's with intellectual disability in Rockhampton. This lady can speak for herself and express her goals and preferences and would love to regularly ride horses. Despite possessing many everyday competencies she legally cannot join a Riding for the Disabled Association (RDA). She is not allowed to sign a liability waiver herself and her Public Guardian has refused to sign it on her behalf.

The RDA Membership Application Form requires the applicant (or guardian) to agree to the following clauses;

> *“**7 Exclusion of Liability:** Except where provided or required by law and such cannot be excluded, I agree that it is a term of my membership (if accepted) that RDAA is absolved from all liability however arising from injury or damage however caused (whether fatal or otherwise) arising out of my membership and/or participation in any RDAA Activity. I acknowledge that the services and benefits I receive under my membership are “recreational services” as defined under the Trade Practices Act 1974. Where I am a consumer, as defined by any relevant law, certain terms and rights may be implied into a contract for the supply of goods or services for my benefit. I acknowledge that these terms and rights, and any liability of RDAA flowing from them, are expressly excluded, restricted or modified by these membership terms and conditions.*
>
> ***8. Release and Indemnity:** In consideration of RDAA accepting my application for membership;*
>
> *(a) release and forever discharge RDAA from all Claims that I may have or may have had but for this release arising from or in connection with my membership and/or participation in any RDAA Activity;*
>
> *(b) indemnify and hold harmless RDAA to the extent permitted by law in respect of any Claim by any person including but not only another Member of RDAA arising as a result of or in connection with my membership and/or participation in any RDAA Activity. In this clause 8 “Claims” means and includes any action, suit, proceeding, claim, demand, damage, penalty, cost or expense however arising but does not include a claim in respect of any action, suit, made by any person entitled to make a claim under a relevant RDAA insurance policy or any personal insurance held by the member.”*

When it was asked to explain its refusal to let this particular lady attend horse riding on Sunday mornings, the Office of the Public Guardian stated;

> *“OPG Policy does not permit the delegate Guardian to indemnify the association as this would limit the legal rights of our client, whom the Public Guardian is exercising a statutory function for”.*

However when it was asked to clarify its waiver, the RDA also noted in its explanation;

> *“RDA AUSTRALIA INSURANCE INFORMATION*
>
> *I can also tell you that the clause does not remove a client’s right to pursue legal action against RDA for negligence. We have very good public liability insurance policies to protect the organisation against the liability risk of accidents and we also have personal accident insurance for injury to riders for any accident that happens during RDA activities. The Personal Accident insurance covers riders for comprehensive medical expenses including ambulance and carer’s expenses.”*

It defies logic to state that; “… the clause does not remove a client’s right to pursue legal action against RDA for negligence”, and yet on the other hand, the RDAA also requires its clients to “… <u>release and forever discharge RDAA from all Claims that I may have or may have had but for this release</u>…”

It is a contradictory and unethical impasse and it is very disrespectful to people with disabilities. This service provider requires its clients to agree to waive their legal rights, but also simultaneously acknowledges (not on the waiver form) that clients in fact are not stopped from pursuing legal actions!

A combination of systemic, legal and community advocacy is needed to address this unfair situation which is an everyday occurrence. In this case a person who is eligible to join the RDA is being denied the dignity of risk. She would still love to join the local RDA in Rockhampton as she regularly rode horses quite safely earlier in her life.

The fundamental purpose of the NIDS being rolled out is to enable people with disabilities to participate fully in the community and live richer lives. Inexplicable legal advice to the RDA however prevents this citizen with a disability from doing something which is very safe (due to the guidelines and safety practices in place), within her capacity and which would add to her enjoyment of life.

5.2 What barriers prevent people with disability from accessing justice?

There is currently a dearth of options for legal advocacy for people with disabilities in many parts of Australia as community legal centres are not resourced adequately and cannot cope with the existing demand for legal advice and legal representation.

Assistance for people with disabilities in even everyday legal situations including court representation must be provided by qualified legal practitioners working in conjunction with individual advocacy. Unlike the tradition in the USA where many legal professionals provide help for disadvantaged people, private legal firms in Australia do not generally provide bro bono legal assistance to people with disabilities even when such assistance is critical to achieving a just outcome.

The biggest barrier to accessing justice is the unconscious attitudes of the court, police and correctional system which devalue the rights of people with disabilities to equal treatment. There is decades of history to prove when people with disability are seeking justice their needs are not taken seriously. When punishment is meted to perpetrators of crime against people with disability, the perpetuators are not sentenced as heavily.

5.3 What models of legal advocacy are most effective?

Legal advocacy is a model which lends itself to working from a central office (in a capital or regional city) which can also assist people in rural, regional and remote areas with their needs through the use of telephone interviews, teleconferencing and field visits to other locations as required, including court representation.

Resources expended in this type of program will always be much more cost effective than trying to fund many multi-modal 'one stop shop' disability advocacy programs which include in-house legal advocacy. For cost reasons these programs will be restricted to employing early career lawyers working alone, versus a central program with a team of professionals who can mentor inexperienced practitioners.

Legal advocacy cannot and should not work in isolation from other forms of disability advocacy. For example; Citizen Advocacy can ensure that any legal recourse is obtained by referring protégés to legal assistance and the outcome which is achieved fair and 'ordinary' rather than being sensationalised or swept under the carpet.

As noted above the overall emphasis of the discussion paper is skewed towards rights and legal issues. Clearly all the legal advocacy in the world will never solve the common situation of people with disabilities who are socially isolated, lonely and without anybody in their lives who is not paid to be there.

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