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**National Disability Advocacy Program**

**Submission, 21 June 2016**

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| “They promptly dealt with issues, kept me informed and I felt good”  “They help you stand up for your rights”  “I can’t speak highly enough of my advocate and Speak Out”  “I can talk to them and they understand where I’m coming from and they work hard and do good things for me”  “When you talk to them, they do something”  “Advocate is approachable, they come out to my house and give me good information on what happens and how to go about things”  “It's my choice, what (advocate) does and helps with”  “My advocate is good at explaining things”  “My advocate helps me make choices”  “(Advocate) helps me keep my voice”  “My advocate helps me talk to people”  “Exemplary! Fantastic”  “My advocate is good value. Always been supportive of me”  “Speak Out is always looking out for my best interests” |

Snapshot of client comments to NDAP Quality Assurance auditors 2013-15

**Speak Out Association of Tasmania**, also known as Speak Out Advocacy is a state-wide, independent, non-government organisation that aims to develop a respectful and inclusive community by promoting and defending the rights of people with disability.

We welcome the opportunity to respond to the Review of the National Disability Advocacy Program (NDAP) Discussion Paper, April 2016.

The NDAP provides us with funding to enable:

* individual advocacy
* self advocacy
* family advocacy and
* systemic advocacy

support to people with disability and families throughout Tasmania. We are also funded for similar advocacy work by the Department of Community Services, Tasmania.

Speak Out individual and family advocacy works in partnership with the person to develop an advocacy plan and empower people through clear communication and problem-solving. Outcomes often include the confidence and skills to self advocate and pursue issues independently/semi-independently.

Self-Advocacy groups and Peer Support groups meet each month across the state. They provide peer support, information and support to understand and exercise rights; and a gateway to access information and participate in the community.

Peer support and information sharing is embedded in a range of activities e.g. the Annual Speak Out Self Advocacy Conference (now in its 29th year); the Road to Success Self Advocacy Program; the peer mentoring program.

Speak Out uses rights-based advocacy as an educative tool to community, government and services. Trends from our advocacy work informs our systemic work and drives systems change in education, community, government and with service providers; at local, regional and national levels.

Speak Out is also a membership organisation for people with intellectual disability and the Tasmanian agency member for Inclusion Australia: National Council on Intellectual Disability. This relationship gives Speak Out, its members, families and clients quality connection with our national counterparts and access to a wealth of information and opportunities.

Speak Out supports our members and the national Our Voice Committee of people with intellectual disability to guide futures planning through participation in reference groups, presentations at national conferences; and in international arenas e.g. United Nations regarding the CRPD, Australian Youth Delegation to the United Nations COSP.

We support people to speak up and be heard, get information, work with the NDIS, know and claim their rights, make decisions, make a complaint; and be represented when needed.

**1. Models of Advocacy**

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| 1.1 How do people with disability, their families & carers benefit when agencies are funded to provide only one or two models of support? |

Where agencies are funded to provide specific models of advocacy, they develop considerable specialised expertise over time that leads to high quality support and outcomes for clients. People with disability, their families and carers who access these agencies and models of support can confidently expect high quality, specialised expertise that is targeted for the issue and their needs. When consumers of advocacy services know about the advocacy agencies in their area and the way they operate, they are able to exercise choice and control in where they go for assistance.

In common with many advocacy organisations, Speak Out provides multiple models of advocacy support. Where the models are specified/limited it also enables agencies to:

* Focus training for their advocacy workforce, again ensuring and building expertise
* Utilise expertise gained over time to mentor/coach other agencies.

All advocacy models are underpinned by equity of access and protection of individual human rights. The most significant issue for models of advocacy is its quality in achieving outcomes.

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| * 1. What are the drawbacks? |

Speak Out Advocacy is funded for individual advocacy, family advocacy, self advocacy and systemic advocacy. We recognise the breadth and depth of expertise we have attained; and routinely use learnings from individual, family and self advocacy to inform systemic advocacy. Without this range of advocacy models the impact of our work would be reduced.

Providing one or two models of advocacy has multiple risks:

* People who ‘need something more’ must access multiple agencies
  + Retelling their story ‘over and over’ is problematic for the individual, privacy is compromised by the multiple people who know your information and the number of agencies in the electronic trail. Experience shows that often these ‘trails’ of cc’d information can outlast an agency’s involvement and breach people’s privacy
  + People become confused about ‘who to go to about what’, may feel overwhelmed, and become frustrated - then disengage
  + Some will become ‘lost in the system’
  + Others lose momentum and interest in pursuing issues and their building capacity
* Skills may be underutilised (people with disability, family and carers, advocates) leading to lesser outcomes for all.
* People may feel helpless in making choices and taking control of their lives – increasing their vulnerability to abuse of their human rights.

Compartmentalising advocacy models is problematic:

* Situations that call for advocacy are intertwined and the notion of clear cut-off points between models is not realistic
* Capacity building and opportunity for choice and control is potentially impacted
* Systemic advocacy would be less proactive/preventative as evidence and emerging trends from individual, family and self advocacy may not be actioned.

People with disability have the right to access independent advocacy and make decisions about how their advocacy support is provided. Restricting the models of advocacy available could be argued as contrary to a human rights framework as it restricts a person’s access to support that will meet their needs.

However, knowing the model of advocacy and consciously operating within them can enhance opportunities and outcomes and decrease the likelihood of conflicts of interest:

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| Clarrie lived with his Mum. Everything was going well until his mother was diagnosed with breast cancer and commenced treatment. Both want the living arrangement to continue, but more help for Clarrie was needed. Through family advocacy the advocate assisted access to additional support. This was a positive outcome for all.  Six months later Clarrie’s community access service referred him to Speak Out and reported he was unhappy at home – the complexities of Mum’s illness and changed dynamic meant there were less opportunities for him. Clarrie told the advocate that he wanted to move from the family home into semi-independent accommodation but Mum opposed this. There was a conflict of interest. Individual advocacy provided to Clarrie enabled him to move out into semi-independent accommodation.  Data from his situation strengthened statistics that evidenced the need for a systemic response - increased accommodation options in the local area. |

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| 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? |

Fit-for-purpose Advocacy has a Human Rights perspective, is professional, independent, client directed and empowering. It is reviewed, timely, time limited, accessible, equitable, outcome focussed, responsive and personalised. None of these qualities are exclusive to particular models.

It should be acknowledged that disability type can impact how advocacy support is delivered. Many individuals with disability have complex communication needs so face-to-face interaction is the most effective strategy. Many people experience barriers to accessing advocacy such as no transport, no phone, active discouragement/retribution by service providers, restrictive and institutional living arrangements.

Equitable access must consider ways to redress barriers; and recognise that fit-for-purpose advocacy must be flexible and humanistic.

Frequently the most vulnerable people cannot access advocacy independently. Speak Out accepts referrals from individuals, families, carers, government departments, service providers, professionals and other community organisations. For highly vulnerable people, we gauge and work in their best interests and utilise multiple strategies for ensuring and documenting consent.

To value and support the various models of advocacy, key strategies should be:

* Honour the knowledge and insight of those who understand the context
* Ensure advocacy is independent from service provision
* Invest in advocacy and provide additional resources at all levels
* Enact proactive advocacy approaches for the most vulnerable
* Mandate advocacy access to institutional settings
* Ensure community awareness of advocacy and referral processes
* Recognise the importance of a peak National body such as the Disability Advocacy Network of Australia (DANA) and allocate appropriate funding to enable leadership and coordination of Professional development for advocates and organisations, complement the goal of equitable access regardless of location; and share planning and development between jurisdictions.

Undoubtedly it is challenging developing a consistent and equitable funding model. While funding can be weighted for various complexities, history also impacts need e.g. the institution may have closed but people are still living in the local area so there are higher concentrations of people with disability in that community, with higher levels of need. The most appropriate strategy is for DSS to work in partnership with the advocacy sector and draw on their experience to gain shared understanding of considerations.

1. **Improving Access to Advocacy Supports**

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| * 1. How do we improve access for: * People with disability from ATSI communities and 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? |

Speak Out proactively employs advocates from ATSI and CALD communities to ensure cultural diversity within the workforce and recommends this strategy to improve access for ATSI and CALD communities. While all advocates require cultural competence, we believe our employment approach demonstrates our values and embeds cultural awareness in all aspects of organisational life. Other ways to improve access include:

**People with disability from ATSI communities and their families**

* Establish links and develop trusting relationships – attend events
* Raise awareness of aboriginal world views by linking with the local ATSI community for training/mentoring of Advocates
* Visit communities / events within communities – over time
* Partnership approaches and encouraging collaboration
* Include Elders or community leaders in Governance structure and/or organisation reviews
* Link advocacy agencies with specialist ATSI advocacy agencies for mentoring/advice/ guidance particularly regarding communications and information
* Build the capacity of families that may not wish to engage with disability advocacy.

**People with disability from CALD communities and their families**

* Being there regularly in communities - attend festivals, meetings and connect
* Establish links and develop trusting relationships
* Interpreter services that are free and readily available
* Cultural competence in the needs of specific communities
* Diversity of Advocacy staff – agencies should have to evidence staff diversity and real relationships with a range of communities

**People with disability in rural, regional and remote locations**

Speak Out provides a state-wide service in Tasmania, including remote locations on the West Coast, East Coast and far North-West.

Access could be improved by:

* Identifying community champions to help communicate the advocacy message
* Building the knowledge and skills of workers and service providers about rights and consumer empowerment to increase likelihood they will provide advocacy information and refer clients
* Hub and spoke models that enable an advocacy organisation to have a local presence.

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

* A robust Quality and Safeguarding Framework
* Adequate time and resources for Outreach programs
* Funding formula that has significant weighting for addressing the complex issues of people facing multiple disadvantage and challenges
* Mandated Community Visitors Scheme
* Resident meetings and advocacy visits to ensure/maximise access to advocates
* Legislative change so people with complex disabilities have the right to unimpeded access to advocates
* Strengthen standards / protocols for service providers - must involve advocate
* Why institutional care? Close them.

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| * 1. What are the strategies or models that have worked? What are the strategies that do not work? |

In providing individual advocacy, self advocacy, family advocacy, systemic advocacy; and an annual Self Advocacy Conference, the Speak Out model is highly successful in addressing the needs of diverse groups of people with disability and their supporters; and influencing systemic change at local, regional and national levels.

Successful strategies include:

* Dual governance structure – Speak Out Board and Speak Out Members Executive

The regional representative leadership structure for Speak Out members who have intellectual disability is a conscious focus for people with intellectual disability to learn and apply their skills. The governance process as per the Speak Out Constitution with limited terms of office enables a flow of people coming through the group and gaining skills, mentorship and renewal. Structure adapted over years to continue to provide support and also run an advocacy service.

* Person-centred, issues-based individual advocacy
* Face-to-face interaction with advocates that enables quality communication, supports understanding of options, desired outcomes and informed decision making
* Connectedness to the community/communities
  + Local networks, credibility in the area
  + Co-locating with complementary agencies, e.g. Peak bodies, community groups
  + Workplace meetings in ADES
  + Resident Meetings and visits
* Quality and diversity of team
* Diverse staff / backgrounds – Speak Out currently employs diverse team from ATSI community, CALD background, people with disability, family members of people with disability
* Self advocacy groups and conferences
* Multiple entry points for contact with the Advocacy agency – Self Advocacy Groups, Conference, referral from others, Self-referral
* User-friendly referral process - Speak Out Advocacy’s intake process includes assisting the person to identify/articulate their issue; explore options and referral/linking with community services and supports
* Capacity building programs – e.g Road to Success, Peer Mentors
* Use high quality technology for training and networking for consumers and members via links with schools / health hubs to reach community etc.
* Access to information for people with intellectual disability/low literacy levels through support to understand materials, production of easy English information/Fact Sheets, information via the Speak Out facebook page and website
* Development resources and video clips/DVDs e.g. Decisions Decisions <https://www.youtube.com/watch?v=WmWO3E1kJT4>
* Developing a culturally aware and sensitive workforce
* Using interpreters
* Somewhere to come to i.e. office – Referral / Self-Referral
* Ensure info widely distributed
* Choice / alternatives of advocacy services
* The multi-faceted role DANA plays as a peak body to the Advocacy Sector
* The DANA Conference and its high quality professional learning and networking for advocates.

**What are the strategies that do not work?**

* Fly in / fly out approaches
* “One size fits all”
* Automated telephone systems – press 1; say your name etc.
* Call Centre approaches
* Locked doors or lack of physical access to an advocacy agency
* Dependence on technology and web-based information for consumers - technology can be unpredictable, access to technology is variable for people with disability because of cost; and internet in regional and remote areas unpredictable. Access via Community Centres also raises privacy issues.

1. **Improving the Advocacy Evidence Base with Co-ordination on Systemic Issues**

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| * 1. What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations? |

Don’t take away the small amount of systemic funding that is currently allocated to Advocacy agencies – it has impact way above expectations. Certification auditors consistently describe Speak Out’s systemic work with expressions like “punching above its weight”.

Organisations regularly link and discuss issues relating to regional, rural and remote communities – via DANA

Clear and accurate data:

* A consistent funded data collection process that reports to an independent body and coordinates/guides/feeds back the systemic issues – this could be a role for DANA
* Performance Data Reporting and similar requirements that go to DSS is also sent to DANA to inform strategy, research and project development
* Collect data that tells us where people are e.g. group homes/institutions so know where trends/vulnerability is

Mapping and monitoring of systemic issues – getting traction

* Transparent processes and access to unedited data – e.g. data and reports from the Hotline should be publicly available
* DANA – peak body to analyse and distribute information back to advocacy services
* Should DANA get data and help set priorities / co-ordinate strategy?
* Strategy for systemic advocacy also needed at a state/territory level so local focus

National collaborations

* + Knowing what others are working on
  + Not just one picture of systemic advocacy as the needs vary at different levels – local, regional, national.

Involve peak organisations e.g DANA and Inclusion Australia

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| * 1. How can we help disability advocacy organisation 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. |

On the whole advocacy organisations work with these organisations, however targeted funding needs to be provided to allow networking and collaboration.

A Bi-annual Conference hosted by DANA – a regular, large multi-strand conference that is fully supported by DSS so all organisations can attend will give a solid platform for colleagues, DPOs, peaks and other statutory bodies to learn from each other and collaborate. For small organisations in small states, opportunities to meet and network like this is rare.

DANA could also lead shared projects - funding specifically for collaborating and networking would have immeasurable return on investment.

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

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

Advocacy organisations have a deep understanding of conflict of interest and many years of experience in effectively managing conflict of interest. Consequently articulating the steps or organisational structures that should be put in place is best done through workshops with advocacy representatives and stakeholders.

There is considerable tension/anxiety surrounding the notion of advocacy agencies as registered NDIS providers.

The positions include:

* Advocacy should be ‘pure’ and untouched by any sense of service provision
* If advocacy agencies provide support services under the NDIS, then service providers may seek to provide advocacy
* There are some areas that are ok and don’t constitute conflict of interest, and other ‘no go’ zones that do.

If you consider current advocacy practise includes decision making support, you are likely to think registering for decision making support is ok. This is Speak Out’s position.

Suggestions to ensure COI does not arise or are minimised include:

* Structures to ensure individuals do not receive advocacy and traditional support services from the same organisation
* Advocacy and plan management - clear distinction / separation of advocacy from plan management with clear policy / procedure separation across all levels

🡺 separate reporting structures

🡺 separate line management

* Plan management reporting to include junctures where referral and involvement of independent, timely advocacy is required
* During intake for plan management there should be a requirement that agencies clearly state that they cannot provide advocacy
* Training / understanding of independent advocacy
* External Feedback and Complaints Service / investigative process.

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

NDIS could block fund information, education and capacity building (and decision making supports) for individuals through the ILC to advocacy organisations. This should not replace advocacy but enhance it.

* LACS will need to have clear understanding of the availability of advocacy services and refer to them. (A key risk with the LAC description is that they may consider ‘they do advocacy’)
* Advocacy actively promoted by NDIS as independent and client directed
* Supported decision making is essential to avoid “substitute decision making by default” – which is more likely without an advocate
* What isn’t covered by NDIS
  + Currently we:
    - NDIS – support planning and preplanning at meetings
      * Ensure consumer voice in process
      * Appropriate pace / engage / information
      * Support people with issues within NDIS / Service Provider
* NDIS should ensure access to advocacy / referral / information

The ILC and Quality and Safeguarding will have impacts but we don’t yet know what those impacts will be since the information is not available

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

* Awareness and education programs to increase knowledge and understanding of the Convention on the Rights of Persons with Disability; and Australia’s responsibilities as a signatory to the convention
* Robust Quality and Safeguarding System with advocacy adequately funded to perform their crucial role in safeguarding people
* The NDAP needs structure and policies to stop service providers coming in and getting advocacy tenders i.e. service providers should be precluded from any tendering process
* The development of policy about decision supports that recognises that independent advocates have a long history of providing this support as an integral part of advocacy and this experience should inform policy development and practise
* Advocates need to be part of the picture – people need to be entitled to an advocate
* The NDAP should ensure that independent advocacy includes choice of advocacy provider – this is particularly crucial where multiple issues often arise at the one site (e.g. group home, ADEs) and more than one individual requires individual advocacy
* National Standards for Disability Services – Standards are there but implementation is the issue. There needs to be a concentrated effort on effective monitoring, evaluation and reporting and shared publicly so kind of issues advocates need to engage with are known e.g. Mandatory reporting of incidents in Group Homes
* Community Visitors scheme or similar in Tasmania
* Commonwealth government needs to properly fund work on the National Disability Strategy.

1. **Understanding and Improving Access to Justice**

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| * 1. What forms of legal review and representation do people with disability need most? |

People with disability have little support in the legal system yet face multiple barriers to engaging with legal processes.

* Legal advice
* Representation
  + General crime
  + Domestic violence
  + Abuse
  + Consumer issues
  + Employment
  + Child protection issues
  + Neighbourhood and community disputes
* At interviews (whether witness or alleged perpetrator) with Police
* Representation at Tribunals
  + Administrative Appeals
  + Mental Health Tribunal
* Guardianship and Administration Board
* Tenancy
* Discrimination

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

Barriers to access:

* People don’t know what to do
* Knowing and asserting their rights
* Lack of support through the process
* Perceptions/influence of support staff and/or families to “Just let it go” “It’s not worth it, it will be too stressful”. They do not always come from a rights platform.
* Fear of retribution
* Low self esteem – “I probably did something to deserve this”
* Contact with perpetrator in court, in waiting room, in the street
* Long delays
* Legal representation availability
* Fear of police
* Alleged perpetrators don’t understand the police caution and are ‘encouraged’ to ‘come in for a friendly chat’ which often results in a video interview and prejudicing their case.
* Alleged perpetrators can’t have access to lawyer till they are charged – hence need independent advocate

Problems/barriers people with disability face when reporting incidents or other experiences that may amount to criminal behaviour against them include:

* Lack of empathy from police
* Perception of being a poor witness
* Lack of timeliness in police responding increases anxiety and ability to recall incidents
* Long delays provide opportunities for the victim to be intimidated by alleged perpetrator
* Not believed
* Poor understanding of the communication needs of people with intellectual disability
* Specific difficulties faced by people with intellectual disability e.g. describing spatial events such as time, distance
* Reluctance by some people with ID to identify as having a disability – this generally relates to people with mild ID and results in support not being sought throughout the process, poor witness statements as adjustments aren’t made.
* People with intellectual disability will acquiesce unless experienced people support them. This acquiescence results in people questioning their ability to be a good witness.

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| * 1. What models of legal advocacy are most effective? |

* Legal representation with support of advocate to explain / communicate processes
* Training to upskill (key) people to navigate the system
* State specific / jurisdiction specific information. Each state have legal advocacy funded and websites “personalised” by Jurisdiction
* Court familiarisation process/access for people with disability
* Knowledge / understanding of needs of people with disability re time and pace etc.
* Advocate support to the person to understand the process

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| **ANY OTHER SIGNIFICANT ISSUES AND IDEAS THAT WOULD HELP IMPROVE FUTURE DELIVER OF DISABILITY ADVOCACY?** |

* Longevity of funding – agencies need a 5 year funding agreement with an option, to enable quality organisation strategic planning, workforce planning, goal setting and to maximise outcomes
* Training opportunities and recognition of skills of advocacy - over the next 5 years a significant number of older, highly experienced disability advocates will leave the sector. It makes sense to capitalise on their skills in order to sustain a robust advocacy sector. Extending the leadership impacts of senior-level advocates and maximising the transference of their skills should be a high priority - through national projects coordinated by DANA with foci such as mentoring, supervision skills
* Recognition of the specialised knowledge stream that advocates have and need – development of accredited Human Rights training units – this could build on the work of the Human Rights Commission and be undertaken by DANA in collaboration with NDS. Multiple projects could emerge from this e.g. training open to advocacy agencies/advocates and service providers, service providers could be matched with advocacy agencies for training, communities of practise
* Clarity of roles – only advocates and advocacy agencies seem to know the depth and breadth of what advocates actually do and the outcomes they achieve – a campaign to inform the community and disability sector would be beneficial and support Quality and Safeguarding
* Frequency of quality audits – certification every 5 years and surveillance every 18mths is a more realistic schedule that would better fit operational/service demands
* Self Advocacy opportunities and connections at a national level
* Fundamental to helping improve delivery is an appropriately funded national peak advocacy body i.e. DANA.

Speak Out Association of Tasmania

June 2016