



Submission to NDAP Review 2016

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**Phone 1800 029 904
or visit www.ideas.org.au**



NDAP SUBMISSION

<https://engage.dss.gov.au/national-disability-advocacy-program/>

WHO IS IDEAS?

IDEAS – Information on Disability & Education Awareness Services Inc is a leading specialist independent information service provider to people with disabilities, their families, carers and supporters and the wider mainstream community. IDEAS has been operating since 1984, collecting, collating, interpreting, distributing and maintaining databases to fulfil our vision that **people with disability live full lives of their own choosing**. Operating across NSW and other parts of Australia, IDEAS is committed to enabling the rights of the person with disability and encouraging positive change by identifying gaps in systems and upholding the *UN Convention on the Rights of Persons with Disability*.

IDEAS' core values are intrinsic to the organisation and everything we do. We are **respectful, inclusive, ethical** and **innovative**, and pride ourselves on delivering a series of high-quality, accessible and responsive services that start with a skilled, focused listening to the individual. People come first in all we do to fulfil our mission **to provide access to information and opportunities for people with disability, their supporters and the community to reach their full potential**. We are continually improving and developing in order to meet the changing needs and experiences of people with disability and to promote positive change in the community.

IDEAS' current services include a free national phone line (**1800 029 904**), which people with disabilities or their supporters can call to ask our Information Officers questions about anything that matters to them. All services and supports searched for are made to be customised to the place and the circumstances of the person making the enquiry. This is complemented by promotion of all IDEAS activities and information through hard-copy newsletters, e-newsletters, a website (**www.ideas.org.au**) and social media engagement, attendance at mainstream and disability-specific events, networking and so on.

IDEAS is also well known for our **PossABLE Expos** – large, free expos which expose supports, services, learning opportunities through workshops, seminars and 'speak-up' self-advocacy activities. IDEAS has been convening these expos in non-metropolitan areas for 25 years, and has run two so far as a part of the NDIS rollout in NSW. We are also a provider of **individual advocacy** through a brokerage model that we manage and deliver **supported decision-making** as a subcontractor to another funded organisation.



WHAT DOES IDEAS KNOW ABOUT PROVIDING ADVOCACY?

IDEAS has been formally funded by the NSW Government under the Information and Advocacy Program since 2008, providing individual advocacy under a brokerage model to Southern Highlands, Illawarra, South East and South West Sydney. Through this work, and indeed across the past 33 years, IDEAS has developed a strong understanding of the continuum of advocacy: from independent information to assist self-advocacy, through the provision of individualised advocacy brokerage, and has also facilitated group advocacy and self-advocacy projects, including 'speak-up' groups.

IDEAS appreciates this opportunity to further our **systemic advocacy** work by contributing to the National Disability Advocacy Review (NDAP). Through the experience of our unique lived history, we believe that:

- information and advocacy are inextricably mixed;
- resources must encompass both the current allocation for NDAP and funding for the NSW Information and Advocacy Program, which is part of the state's contribution to NDIS [ie funding must reflect total disability populations, including NDIS-ineligible people]; and
- resources must be grown to meet the new and growing needs created by individualised funding and decision-making under the NDIS [ie funding must reflect Participant projections].

Through our networks, we also know that individual advocates in the NDIS launch sites have consistently reported a growth in need, specifically to:

- assist with pre-planning;
- attend planning meetings with NDIA planners; and
- support people during complaints against service providers and the NDIA (for internal reviews).

We know that the demand for advocacy and information will continue to grow exponentially as the NDIS rolls out. NSW has provided a range of opportunities over the last three years to develop skills in individuals to assist them undertake pre-planning and consider their goals in preparation for the rollout of the NDIS. The NSW Consumer Development Fund – *My Choice Matters*, for instance – has encouraged voice, choice and control. From this, we can see that there is likely to be an increased demand for information to assist with decision-making, and also an increased demand in people looking for planning assistance and complaint resolution. In addition to the increased demand due to the NDIS, we know that people with disability will also continue to require individual advocacy assistance and support to deal with issues from across the systems they are engaging with outside the disability service system, such as education, health and housing.



IDEAS' RESPONSES TO QUESTIONS IN THE PAPER

These beliefs and principles underline our response to questions posed in the paper:

- Advocacy requires specific skills; self-advocates must be trained and supported; professional advocates must be paid appropriately and need resources and supervision; all thrive with the knowledge, support and experience of their peers.
- Society, through government, should bear the cost of protecting and defending the rights of people with disability; advocacy and the things that enable it [transport, communication, information etc] should be free to the individual.
- Good advocacy features face-to-face awareness-raising, seminars and self-advocacy groups in the communities where people live; it is resource-intensive, but effective.
- Information is a powerful advocacy tool; both information and advocacy must at all times be independent.
- NDIS is about growth in the confidence and capacity of individuals, the community and the Scheme itself; investment in accessible advocacy is essential to achieving this.
- Advocacy must be available quickly and easily as the need occurs, and cannot be planned for; the only way to ensure this capacity is for providers to receive ongoing block-funding, and not be reliant on individual clients' packages.
- Quality and Safeguarding systems rely on information about the rights of people with disability and where to get help exercising those rights.
- Systemic advocacy is a key ingredient in co-design processes; the exploration of individual complaints using advocates together with group views and trends identified through peaks are the best agents for improvement and change.
- The provision of advocacy must be separated from profit and potential conflict of interest, as much for the client as the advocate.

IDEAS believes that people with a disability and their families and carers must have access to a range of different types of advocacy, with the support tailored in response to their individual circumstances, including the issue to be addressed, timeliness of response and communication needs of the person [see Question 1]. It is imperative that all six broad models of advocacy remain in place – they each have proven benefits and have been developed over time by, and for, the disability community. Access should be available across a broad spectrum of platforms: ad hoc face-to-face or by telephone; through workshops; through mentoring/counselling; through peer-to-peer contact etc.



In the previous consultation round of the NDAP Review, which reviewed the *NDA Framework*, IDEAS contributed to a submission by NSW Community Care Forum, which emphasised the need for funding distribution to reflect the real costs of providing each advocacy type, together with the real elements of accessible advocacy. This included a call to

“acknowledge that the nature of delivery of advocacy supports, and therefore the potential outcomes for an individual, differ greatly depending on whether it is formal/funded or informal/unfunded.” [pg 4]

The matrix on page 5 clarified when paid workers are required as advocates: Legal Advocacy [see Question 5 of this consultation paper], Individual Advocacy, Systemic Advocacy and also in education, which CCF grouped with the other informal/unfunded forms in a new stream we named Community Advocacy Supports.

We also described accessible, individualised, fit-for-purpose advocacy, regardless of location:

“Individual advocacy needs to be available when needed, where needed and at no cost to the person/s with disability or carer/s who require help with an issues or a complaint. This means the provision of an appropriate number of advocates, as well as funding to make their services accessible and to meet Work Health and Safety requirements for both the clients with disability and the advocacy staff, including:

- *location in safe and accessible offices for people with disability who can visit them;*
- *availability of technology to assist individuals with communication disabilities;*
- *assistance with travel costs, if needed, by people with disability to visit the office or other sites*
- *during the process of advocacy;*
- *operation outside business hours for people with disability who are working and/or where necessary to address specific complaints; and*
- *availability of in-home advocacy services for housebound clients.” [pg 6]*

IDEAS is concerned that this current paper suggests that NDAP providers may be required to have knowledge and expertise across all models of advocacy. This is not realistic, and unfairly favours a small number of large providers. Furthermore, it threatens to create a system based on mediocrity, not expertise, and might require individual agencies to maintain unsustainable staffing levels. In addition, in our experience, people seeking advice or advocacy services are quite often unaware of exactly what they do need.



Instead, we recommend a 'hub-and-spokes' model which builds on the brokerage model currently delivered by IDEAS, combined with the funding of agencies to provide the models of advocacy in which they are specialised and more expert at providing. Under this model, a series of knowledge brokers in each State/Territory act as the one-stop-shop for advocacy services, helping to link the individual to the most appropriate service. Such a system has 'no wrong door' and people with disability can access help from any advocacy provider directly, but the knowledge broker [ie the 'hub'] can also assist them to navigate to the most appropriate advocate and, in the event of a waiting list, purchase on their behalf with discretionary funds.

A centralised hub could monitor waiting lists and spare capacity and use technology, such as teleconferencing, to maximise access to advocacy and to match client demand with local advocacy services/spokes, where appropriate. They could also use their discretionary funds to negotiate partnership arrangements, such as an advocate accompanying the Royal Flying Doctor Service to reach people with disability in rural, regional and remote locations [see Question 2]. The hub can also co-ordinate each State advocacy network [see Question 3].

IDEAS also recommends, now that the Australian Government is delivering services through the NDIS, that advocacy should be the responsibility of the States. The above model is ideal for ensuring the independence of advocacy and removing any conflict of interest [see Question 4]. Through a COAG agreement mandating the structure and allocating funding to each State/Territory jurisdiction, NDAP would place advocacy responsibility where it should sit, allowing that each State Government to ensure proper services and support for its residents.

In order to ensure equitable access [see Question 2], advocacy services must always be culturally appropriate services which derive from meaningful consultation and, ideally, from employment and training of members of these communities. People will tend to trust and take advice from someone from their own community, to whom they relate and who relates to them. This is particularly evident in times of confusion and stress, when advocates are called upon. We have some excellent providers under the NSW Information and Advocacy Program who would add value to NDAP, not to mention the fact that they are known and valued in (and knowledgeable about) their communities. On occasions when a funded advocacy provider is not available to support special-needs groups, the central hub recommended by IDEAS could also use their discretionary funds to broker to mobile or short-contract advocates from a list of approved subcontractors.

Advocacy is not a well-understood service and people with disability will not seek it until faced with a crisis. Promotion of NDAP must therefore be constant across a range of communities and communication formats, yet consistent, in order to inform those who need advocacy, when they need to access it. IDEAS would particularly like to see NDAP information crafted to meet the needs of people with disability who are living in group homes. Recent inquiries have shown that the discrimination and



abuse suffered by many people in institutions goes unchecked, partly because the victims are simply unaware of their rights and/or see no avenues for redress [see Question 5].

Other organisations that have similar aims [see Question 3] are a good starting point, but are only a small part of the communication strategy. IDEAS believes this is a key role for a central hub in each State/Territory, drawing on the expertise of advocacy services/spokes with expertise in working with special-needs groups to coordinate the creation and maintenance of a suite of promotional materials for general distribution. Individual agencies' contracts should mandate their specific involvement in such centralised planning and projects, including the use of the NDAP-badged materials. The hub then maintains links with these other organisations at State and National levels and assists the advocacy services/spokes to identify who they need to work with locally.

This coordinated structure is particularly important in achieving consistent data collection, and evidence which is measurable and comparable across areas, providers, communities and so on. Evidence-based planning is best made possible by all stakeholders – policymakers, advocacy providers and related systems – through an agreed, transparent two-way flow of information. In our recommended model, the hub is the neutral body for filtering and processing State/Territory data sets. IDEAS believes that NDAP has a role to play in identifying gaps and trends in the experiences of people with disability and informing the NDIA about areas for improvement in the NDIS in the future, such as the processes for individual plan development, quality and safeguarding and the ILC services, including Local Area Coordinators. This way, all advocacy providers will contribute to systemic advocacy.

The removal of conflict of interest is central to the success of NDAP. IDEAS strongly believes that providers of disability services that directly assist with daily living should not be funded to provide advocacy; however, we exclude provision of support co-ordination and information from this definition. In our experience, advocacy, information and support coordination can be provided by the same organisation without causing conflict. Indeed, we believe that many of the advocacy organisations will likely look at working across both frameworks – information [ILC] and advocacy. The separation of information from provision of advocacy allows for a strong alliance and connection between the two parts of the sector by giving information a place in its own right, rather than as a sub form of advocacy. Information can stand alone, but advocacy needs information to work (in the same way that people need information to assist decision-making).





Contact

Toll Free: **1800 029 904**
Website: www.ideas.org.au
SMS: **0458 296 602**
Email: info@ideas.org.au

Administration

Po Box 786
Tumut NSW 2720
ABN: 73 877 964 532

Regional Office

53 Merivale Street
Tumut NSW 2720
Telephone: (02) 6947 3377
Facsimile: (02) 6947 3723

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