

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Organisation: Information on Disability & Education Awareness Services
Date Received: 15 August 2018

IDEAS Submission to

NSW Parliament Portfolio Committee No 2 Health and Community Services.

Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.

Submission date: 15th August 2018

Submitted by: Diana Palmer
Executive Officer

IDEAS – Information on Disability & Education Awareness Services Limited purpose is to provide access to information and opportunities for people with disability, their supporters and the community to reach their full potential to enable people with disability to live full lives of their own choosing.

We believe the following are intrinsic to the organisation and everything we do:

- Respectful
- Inclusive
- Ethical
- Innovative

We work to support all people with disability, their families, carers and other supporters to self-advocate and to make informed decisions. As disability knowledge brokers, we do this by providing a range of information services and products. Using our specialist expertise, we source information and filter, interpret and disseminate it on request, through a variety of methods for the benefits of our customers.

As a membership-based organisation with over 400 members and is widely recognised in Australia as a leading information provider in our field. We are a not-for-profit organisation, endorsed as a deductible gift recipient under subdivision 30-BA of the Income Tax Assessment Act 1997, and registered with the Australian Securities and Investment Commission (ASIC) as an Australian Company Limited by Guarantee.

IDEAS works collaboratively with our partners and all stakeholders to maximise the effectiveness of disability information and resources. These stakeholders include people with disability of all ages and their families, carers and supporters; non-government and government professionals; service providers; and members of the public.

After having been funded by the NSW Government since 1993 to provide information and advocacy (through a brokerage model) IDEAS is now in receipt of a one year ILC grant to provide generic information services for people with disability in NSW.

We fought for and retained a one year extension of advocacy funding from the NSW government in 2018 to provide individual advocacy in the South west and south east Sydney regions as well as Southern Highlands and Illawarra regions. This funding is dependent on an additional application through the Community Grants Hub for an ILC grant when they are next released.

IDEAS is proud of our heritage, having commenced operations as the first national one stop shop for information in 1984. We currently have 170 years of health sector knowledge and experience 80 % of staff living with or have lived experience of disability

Not all PWD can access digital means to access information so IDEAS connects with people via other means. IDEAS delivers services through a multi-modal information project through multiple channels including:

- By phone (info-line)
- SMS
- Live Chat
- In writing
- Face to face
- Group conversations
- Peer to peer
- In the community
- Online data and information
- Electronic, digital and hardcopy publications

Information Knowledge Management is our asset with activities including collection, maintenance, and curation of data and information resources that are independent, accurate, verified, relevant, accessible and up-to-date. Activities include various means and modes of dissemination of information that meet the needs of all PWD where they're at. Our activities will utilise our extensive networks to increase the effectiveness of referrals resulting in stronger links for people with disability in their community.

Our NSW target group is:

- 1.383 million PWD
- 152,000 NDIS participants (at full rollout)
- 904,400 carers

In addition to these primary markets for information are peers, colleagues, professional workers, local government, mainstream and community services and businesses.

In particular:

a) *The implementation of the NDIS and its success or otherwise in providing choice and control for people with disability:*

Choice and control as concepts and practice has at best been a mirage for pwd entering the NDIS. The intellectual and practical policy and practice frameworks around choice and control is a good idea gone begging. At best its current status can be described as token.

The language of choice and control in the implementation of the NDIS in NSW lost traction in the rush for plans to be assessed and implemented and became usurped by the language around prosaic goals.

Goal setting and stepping out has been uneven.

Features to note are that the experience of the NDIS is by its nature individual, however it can be reported that people with physical disabilities have been able to exercise choice and control at a higher incidence and therefore satisfaction than people with dual disabilities, people with intellectual disabilities, people with acquire brain injury and people with psych-social disability. People with complex neurological conditions have also been poorly served in choice and control unless able to be represented with advocacy and information, e.g. people with MND, Multiple sclerosis, Parkinson's and stroke survivors.

The traction of choice and control for citizens in NSW living with disability has been lost also due to churn in LAC staff, and uneven service quality in individuals engaged as planners and linkers in the state and their held sector knowledge, engagement and awareness of disability.

Recommendation.

Choice and control is a key element of the architecture of personalisation of supports whether they be disability specific or mainstream supports that are more inclusive for people with disability throughout the state.

IDEAS recommends that:

- Renewed training with accredited practice in choice and control be instated. Compulsory for LACS and linkers and for personnel in Service providers.
- That the state invest in a sustained independent one stop shop for independent information that supports choice and control through multi-channel dissemination.
- That the state invest in a mobile five year model of outreach across the state to give unbiased information live that supports individual choice and control wherever people live. The accountability for such a service be by outputs of connections and outcomes for individuals being connected and having the power to exercise their choice and control in contracting the services they need as well as engaging with inclusive practices in other mainstream life domains which are the responsibility of the state. E.G Health, Education, Transport, Housing, Justice,
- That the state invest in peer leadership programs to educate and engage people with disabilities on their opportunities for choice and control so that self-advocacy is enhanced
- That the state fund independent organisations which provide individual advocacy to stand alongside people to exercise their choice and control, to support them when things go wrong.
- To actively resource appropriate partnerships between independent organisations and existing departments such as fair trading and the civil arm of legal aid to ensure bolstered consumer protections as people with disability engage in the new world of the quasi market for disability supports and services.

b) The experience of people with complex care and support needs in developing enacting and reviewing NDIS plans

Staff member: I am standing behind our exhibitor table at a Disability Expo in Sydney when a mum approaches me. Her teenage son is sitting in his wheelchair and looking off in to the distance – he is disengaged and disinterested. As his mother talks to me about her son’s goals for the future, I notice he is looking at the floor. I try to engage with him about what interests him, what motivates him. He doesn’t really care about anything I have to offer.

I pick up a brochure for our classified service, eBility, and explain to them both that it is a space for buying and selling equipment and modified cars. I get an idea. I ask him, are you interested in driving? He shrugs and pointing to his chair says, “I can’t drive”. I explain that actually he very well may be able to.

For the first time in the conversation he is engaged, he is listening and he is excited. He moves as close as he can to the stall. I explain how cars can be modified for wheelchair drivers and point out that there is a modified car just a couple of stalls to my left. I explain that there are driving instructors that specialise in teaching people with modified cars and that this is something he might be able to do with his funding. As they leave, I can see a smile on his face as he directs his mum to the modified car a few spaces up. It was really nice to see that glint in his eye at the possibility of being able to drive just like his friends.

A man with serious agoraphobia called the info line in desperation as he needed to apply for a disability pension and had to go to Centrelink in person to submit his paperwork. He had actually worked himself up to going in once (which was a huge effort), but was told that they needed more evidence and he needed to make a second visit. He couldn’t bring himself to go a second time, so IDEAS connected him with an advocate locally who supported him to attend on the second visit.

Separate from the examples above IDEAS submits that the government examine the pathways and gatekeepers for good practice where the individual’s human right are protected. Service providers have had too much unmitigated power in this space.

Recommendation:

- Mapping of proper primary data about the numbers of people living with high support needs without family connection and advocacy supports, and mapping processes for them to be served with independent information, communication facilitation and choice of their needs.
- That the State fund independent organisations which provide individual advocacy to stand alongside people to exercise their choice and control, to support them and ensure their NDIS plans are enacted as chosen.
- That the State enhance community visitors' schemes to ensure people with complex needs are having their plans implemented and their needs met if living in group and institutional residential settings.

d) The effectiveness and impact of privatising government run disability services

IDEAS comments that here is poor understanding that the NDIS is enacting a quasi-market

The issues around market failure have not been dealt with by the agency, or by state actors.

In rural and remote areas, this is even more crucial where the risk of market failure is all the more expected. Ken Baker CEO of NDS (National Peak Service provider body) recently noted at an NDS Essential briefing session that “while the causes are hard to identify- the pricing structure is inadequate, there are workforce shortages, policy uncertainty, it is hard to make decision due to that, as well as the additional cost of doing business in this climate and it is hard for organisation to find money to invest in growth. Indicators to watch include business confidence and NDS recent survey noted confidence to invest in growth is dampening; a small survey showed 50% of community access services are planning to reduce or cease, or not grow.”

IDEAS highlights that where there is asymmetry there is risk.

IDEAS recommends the investment in sustained continuing independent information services to enhance choice. Without information there can be no choice.

The majority of people with disability who are residents of NSW will not have a funded individual plan from the NDIS. People with disability will need access to high quality, relevant and accurate information to assist them navigate mainstream options available.



CONDITIONS FOR A SUCCESSFUL QUASI MARKET

Conditions which need to be satisfied for a quasi-market to work
(adapted from Bartlett and Le Grand 1993)

competitiveness	the quasi-market should be competitive on both sides (many purchasers, many providers)
information	both providers and purchasers need access to accurate, independent information in order to monitor quality and minimise opportunistic behaviour on the part of the provider
transaction costs	(whether set-up or continuing) should be no higher than any cost savings generated by competition
Motivation	economic theory suggests that providers should be motivated by financial considerations, and purchases by user interest
cream-skimming	there should be no motivation for providers to pick and choose some patients over others on the base of cost of complexity of treatment

Porter et al. BMC Health Services Research 2013 13(suppl 1):S2 doi:10.1186/1472-6963-13-S1-S2

e) *The provision of support services (including accommodation services) for people with disability regardless of whether they are eligible or ineligible to participate in the NDIS*

IDEAS submits that this is the outstanding and urgent issue for the NSW government to deal with to be certain that they comply with their own legislation and instruments which they are signatories to in concert with the Australian government and other states. (e.g. NSW Disability Inclusion Act, NSW Disability Service Standards, National Disability Strategy and UNCRPD)

IDEAS submits that there is a poor understanding of the numbers of citizens who live with disability but who will be ineligible for funded supports through the NDIS.

< Datacube Project - Profile ☆ Favor

General Disability NSW

[Summary Table](#)
[USA Map](#)
[State Comparison](#)
[Federal Comparison](#)

Commonwealth Electorate: **All** :State Electorate **All**

Age	Disability		Avg. Rate (Disability)		Persons		Disability Total	Avg. Rate (Disability) Total	Persons Total
	Female	Male	Female	Male	Female	Male			
00 to 05	9,144	12,087	3.58%	4.45%	267,223	281,956	21,231	4.02%	549,179
06 to 12	19,108	35,450	6.27%	10.93%	310,899	328,858	54,558	8.60%	639,757
13 to 17	15,697	20,949	7.61%	9.60%	210,670	221,884	36,646	8.61%	432,554
18 to 64	331,610	306,444	15.20%	14.87%	2,291,938	2,228,944	638,054	15.03%	4,520,882
65+	315,351	265,499	48.38%	46.99%	645,822	555,344	580,850	47.69%	1,201,166
Grand Total	690,910	640,429	16.21%	17.37%	3,726,552	3,616,986	1,331,339	16.79%	7,343,538

Extract from NEDA (National Ethnic Disability Alliance) and based on the 2016 census with the latest SDAC disability local area estimates.

There will be a projected 152,000 number of people in NSW with disability who will be funded participants in the NDIS scheme.

This leaves approx. 600,000 people living with disability aged between 0-64 (and 580,850 over 65 yrs.) who live with disability and will have to navigate existing complex systems to get their supports and services in an inclusive way which enables them to live a good ordinary life wherever that they be, and to enjoy their inalienable human rights.

IDEAS Recommendations:

- A clear easily accessed portal of navigated assistance in person, face to face, online and by phone free supports for people to get what they need. This should be away from government and away from service provision. It should be free to all.
- A safety system of easy advocacy for people to navigate mainstream services to get services that are suitable to their needs in health, education, housing, employment, transport and justice.
- This needs to be the subject of a government advertising campaign as the one stop shop for all citizens to be included in their daily needs and choices to be 'just like everyone else' in their activities. Dreams and goals as contributing citizens in the state.

Investment in the above supports choice and control through multi-channel dissemination.

This should be financially supported through ongoing block funding, ensuring sustainability for independence, accuracy, relevance and currency of the information collected, curated and disseminated.

The NSW State Government could consider encouraging these funds be quarantined from ILC monies to support a national information service for people with disability as there are efficiencies gained in developing one; or the state could continue its early and activist part in its adoption of the NDIS by held funding with the federal government to gain gold standard capacity for independent information absolutely tailored to the NSW market.

There are numerous examples to draw from of existing national helplines that are funded by government and operate independently to allow Australian citizens get the information they need to live a normal life and get help when the need it. Life line, Mens line, Kidsline, 1800 RESPECT and so on. Through our experience dealing with people with disability we understand the deficiencies of some Help line services such as Health Services Australia – Info Direct; My Aged Care and Carers Gateway in that they are scripted, timed, and calls tipped out.

IDEAS assert that people with disability, especially those who will not be funded under the NDIS scheme should have a discrete, excellent and expert service to navigate complex specialist and general systems, and be soft advocates for inclusion in everything available in the community, from swimming to child care to sports. This service would listen

attentively to the individual's story, understand their needs and provide them with the relevant information in the appropriate format allowing the individual make an informed decision about matters of importance to them. For NSW, this could be achieved for the cost of \$3.5 million annually at a cost per person with disability of any age of \$2.50.

Just as in the aged care sector any solution that limits themselves to the web and digital platforms disrespect at least 50% of the available population. Nationally, Telstra's Digital Inclusion Index average is 56.5 points. Last year in NSW People with disability scored 45.9, 10.6 points below national average.

Additionally, IDEAS Recommends

- that NSW fund advocacy and representation on an ongoing basis

Disability advocacy is an essential support - for people with disabilities and their families and loved ones, and as a resource and asset for good government.

The National Disability Strategy, agreed to by all States and Territories and the Federal Government, clearly recognises the importance of advocacy and representation. The Federal Government contributes to disability advocacy by funding nationally focused work, however the NSW Government is responsible for local advocacy funding of \$13 million per annum, which will come to an end in 2020.

Without disability advocacy organisations, NSW Government departments would lose access to the input and expertise of disability advocates who participate in departmental and Parliamentary committees and help government get things right. Disability advocacy helps government understand the needs of people with disabilities and help stem problems before they blow up into preventable tragedies.

Without disability advocacy support, the 10% of people with disability provided with an NDIS funded plan, won't have access to an independent champion to help them navigate the fledgling NDIS system.

Submitted by:

Diana Palmer

Executive Officer



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



Head Office

53 Merivale Street

Tumut NSW 2720

Telephone: (02) 6947 3377

Facsimile: (02) 6947 3723



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