

IDEAS – Information on Disability & Education Awareness Service Inc.

Submission in response to the
**Productivity Commission Draft Report
into Disability Care & Support**

Contact:
SMS: 0458 296 602
Toll Free: 1800 029 904
Website: www.ideas.org.au

All Correspondence to:
PO Box 786, TUMUT NSW 2720
ABN: 73 877 964 532

Forward

This submission is made in response to the release by the Productivity Commission, in February 2011, of a Draft Report – Disability Care and Support.

Our Purpose

IDEAS is time honoured in NSW as the central resource that assists people with disabilities, their families and carers in the ‘whole of life’ decision making process by providing them with timely and accurate information so they can gain more control over their lives.

We have worked since 1981 to support all people with disability, their families, carers and other supporters to self advocate, enabling them to make informed decisions about matters of importance to them. As disability knowledge brokers, we do this by providing a range of free information services and products. Using our specialist expertise, we source information and then filter, interpret and disseminate it on request, through a variety of methods for the benefit of our service users. We also provide “soft” information that is not specifically about a service but can assist people with disability to make informed choices about their daily living.

Response to Draft Report

Statement on the role of information in the NDIS

- Information should support people with disability, their families and carers to make informed decisions about their lives, it should be a continuous wheel of high quality outflows that meets the person with disability where they are; on diagnosis, at life transition points, or in-crisis; for planning; - accommodation, employment, education, sport, leisure, travel, health, spirituality, and intimate relationships, etc. The person at centre and whole of life!
- Disability information should be universally available, independent from service provision and the NDIA, at no cost to the individual and link the person to their needs and aspirations.
- The independent information provider should be block funded.

Chapter: 3

3.2 A Tiered approach

- As per Recommendation 3.1 the provision of information is an integral part of ensuring that people with disability have the same rights in society as the rest of the community. Provision of information at the appropriate time is a very cost effective intervention in allowing people with disability to control their own lives. As in other provision of services there are inherent costs. Ensuring that information provision meets certain quality standards including accuracy, relevance and timeliness, DOES come at a cost and any quality provider will ensure it is cost effective by using quality assurance processes as any other disability provider does.
- The assumption that the cost of information provision can be cut to provide for direct service has been an issue for disability information providers for many years. This is an opportunity for information provision to acquire the appropriate role in supporting individual's choice of daily living.

3.4 Tier 2 – ensuring appropriate support from any system

- The draft report refers to one aspect of the information services, *“being a centralised electronic database of service providers that would indicate the ranges of products and services, availability and links to measure of performance and quality”*.

A centralised database is one aspect in the provision of information and a centralised database of service providers nationally will be a necessity for any quality information provider. However, in addition there are many other forms of information and resources that experienced Information providers will utilise.

People with disability don't only need information about disability specialist service provision but may need information about the mainstream provision i.e. access to education; access to health services such as public dentistry program; individual and systemic advocacy; as well as providers of accessible recreation, leisure and tourism to name a few.

- IDEAS understands participants comments about not having adequate information to base decisions on and the considerable time spent undertaking their own research. With over 30 years experience in providing information to people with disability, feedback from our service users informs us that they find the system frustrating and confusing. The benefit of our specially trained Information Officers is that they bring understanding

and knowledge of the numerous systems, supports, products and services that cater for the specific needs of people with disability (whether they be disability specific services, mainstream services or private goods and services). They know how to navigate the system, preventing the frustration that people with disability experience by being put on hold, being transferred to the wrong person, wasting time in a Queue, etc. A specialist Disability Information Officer can provide accurate information in a timely manner, in a format that meets the individual's needs which allows the person to get on with making their decision.

A maze with extra barriers

- IDEAS supports the notion that the provision of information and referral services should also take into account cultural and linguistic diversity particularly in non English and Aboriginal and Torres Strait Islander communities.
- Additional barriers to information are faced by people with disability when information services are only available through online provision. The complexities surrounding many types of disabilities make accessing the internet difficult and the information provided not appropriate to the individual with the disability.
- Maintaining online databases for people to access is one way of delivering information: However, it is un-interpreted information and quite often doesn't provide the whole story. Access to information services need to be in multiple forms i.e. toll free telephone access, online, by email, SMS, in person.
- In the same regard dissemination of information needs to be in the most appropriate and relevant format of the individuals choosing, whether that be verbal, written, Braille, audio, audio visual, easy English. All forms of dissemination should be available for people with disability on demand.

Draft Recommendation 3.1:

- IDEAS is pleased to see the high level acknowledgement (described as one of the three main functions of the NDIS) of the role of information in determining the quality of life for people. Possibly add to the description: - *"to provide information and referral services, which would be targeted at people with, or affected by a disability" **that assists their decision making about matters of importance to them.***

Chapter: 5

- IDEAS supports the notion that people's needs should be reassessed when their circumstances change, however we believe people should be able to have free access to independent information at any point in their lives to assist with their decision making at any given time or instance.

5.10 How the assessment might work in practice

- Included in the early planning and information package sent to potential NDIS candidates should be information about access to the independent information services so that an individual can choose to contact an information service prior to accessing either the DSO or planning for the assessment process.

Figure 5.2 Suggested Assessment Process

- The inclusion of information services as a key component of need in assisting a person with a disability early in the assessment process is positive.
- How and what Information Services look like is not detailed in the document. We have seen over many reforms that the provision of information is implicit in policy development, the explicit provision of information has quite often not been thought about until after the architecture of the system is built (more as an afterthought than intrinsic).

This is an opportunity to ensure that information provision is developed as part of the architecture of the system and as such the detail of - What will it look like? How and who would operate it? This has begun to be discussed in this paper. A lot more detail is required to ensure that it is an information system that will support the decision making for individuals with disability across their whole of life needs.

- IDEAS believes the information services referred to in the draft report should be independent of the NDIA and service system. This allows for independent and impartial information to be provided about not only the products and services offered by the NDIS, mainstream government service provision, but also about the mainstream private sector goods and services that people with disability need to access on a daily basis.
- A national centralised service database is not enough on its own to respond to the information needs of people with disability. This has been recognised in the draft report where the Commission refers to Web based information and information services. A national centralised database can be an excellent starting point but it must stand beside a service that has information inflows and outflows. A service which has outflows which

are product oriented like health information i.e. Disability Information Line, Newsletters, fact sheets and other resources, and inflows services which are process oriented such as collecting information on new products and services and gaining knowledge from local contacts who understand idiosyncrasy's in that local community; to maintaining close relationships with the individual and systemic advocacy sector, Human Rights Commission and the NDIA to ensure that issues identified during the provision of information are fed back into the system to build capacity. All this process information should be housed in the information services knowledge management systems. See *figure 1*.

- Independent and impartial information services are able to meet individuals where they are, both geographically and in time – on diagnosis, at a time of crisis, on assessment, at pre-assessment and in various times of transition.
- Information services independent of the NDIA or Service system will ensure that people with disability will obtain information across the broad range of options that may be available to them as there is no inherent conflict of interest. Information services are purely serving the interest of the individual with a disability, their family member, carer etc.
- Independent information services are able to assist the individual make an informed decision about any matter of importance to them by utilising the resources available to them. This would include experience and knowledge of the information service staff, knowledge of the NDIA, DSO's, service providers, mainstream government agencies and private sector goods and services.
- Independent information services need to be able to interpret peoples' needs by deciphering what information the individual really wants and ensuring they respond to the individuals needs at the time. The individual is quite often more open if they are discussing their needs anonymously to an independent provider who can then interpret and respond to their needs with no conflict.
- Intermediaries (i.e. DSO's) should be separate to service provision and service providers should not be able to act as a DSO's.

Chapter: 7

Table 7.1 Functions of the NDIA (page 6)

- 9. Provide people with (web publications, call centres, and ratings of suppliers) and provide a single point of contact.

The single point of contact needs to be widely known - “a household number”. This will require appropriate advertising and promotion to ensure that it is known nationally and easy to find. Our experience as an information provider with national toll free telephone line access has shown that quite often people do not understand that they may require information until they need it. Therefore the advertising and promotion needs to be regular and consistent and provided in places that people go to generally to find other information in their lives.

- 10. Address the social contributors to disability (Stereotyping, prejudice and stigma, inappropriate public infrastructure).

This is best done through independent provision to ensure minimization of conflict of interest and the upholding of human rights for people with disability.

Putting the fox in charge of the henhouse – conflicts of interest? (Page 7)

- To ensure the minimization of conflict of interest IDEAS does not believe that service providers should be able to act as DSO's. There is an automatic conflict of interest when an individual requires assistance from a DSO to negotiate the service system and is presented with a service provider acting in that role.
- Similarly we believe advocacy and information provision should sit outside the NDIS to ensure independence.

What would the National Disability Insurance Agency do? (Page 10)

- As highlighted the NDIA would have the authority to decide whether to take on the function internally or choose to contract it out. While we see it the responsibility of the NDIA to ensure information is provided to people with disability to allow them to make informed choices, we believe people with disability would be best served if this function was contracted out to independent community based information provision.
- Some of the information required to be collected, collated and maintained to support the provision of information services will be best collected by the NDIA themselves (the national database of service providers including ratings and pricing) however it may be difficult for the NDIA to be fully aware of and develop and maintain databases on products and services that support people with disability which sit outside the NDIS.

What would others do in the NDIS? (Page 13)

- IDEAS finds the role of the DSO as described to be confusing and contradictory throughout the document, at one level the DSO is independent of service provision, while elsewhere a service provider can act as a DSO.
- In Box 7.2 a DSO is described as “providing people with disability with information of the quality and choice of support services available from specialist and main stream service providers”, where as on page 13 they are described as “an agent for a person with a disability on matters concerning the NDIS”?
- The role of the DSO needs to be clarified and better defined. The DSO role as an advocate on behalf of people with disability will only be applicable if there is integrity in the system. This will only be seen by showing separation between service provision and the DSO role. Ideally advocacy provision should be fully supported by the NDIA but be independent of the NDIS.
- The proposed role of the DSO is described as an agent for a person with a disability on matters concerning the NDIS. People with disability should be able to access information about matters other than that of the NDIS. This supports the argument that Information services should be independent of the NDIS and not that independent information services should become a DSO.

Chapter: 8

- That Recommendation 8.1 which is about the provision of information services (i.e. supporting consumer decision-making) in the scheme sits within the chapter titled delivering disability services shows a lack of understanding of information provision in supporting people’s decision making power. This topic would have been more relevant in Chapter 6 or even Chapters 5 or 7.
- And while the provision of information is given high acknowledgement in Draft Recommendation 3.1 the reality is that THERE IS a lack of understanding of the product and processes that form high quality information provision to support informed decision making. This is demonstrated by only this small section in Chapter 8 being focused on this highly important topic. Further we understand the importance of making collection of information relevant to quality service provision. Whether it is personal individual information relevant to service delivery, or that of service provision data that is relevant for quality performance, capacity building and improvements - it is important and relevant to the NDIS and developing disability services. We see this as a totally different scope of information service; it is information collection rather than information provision. As discussed earlier information provision is often mentioned as intrinsic or implicit, however the explicit information on how or what this will look like is given little detail.

- The provision of high quality information services to allow people with disability make informed decisions about matters of importance to them require a different skill set and a different focus to that of developing a national database of service providers which includes service provision and quality data. Information provision for people with disability could certainly access this centralised services database for information on services as part of the suite of information products they access to meet the information needs of the individual with disability, their family member or carer.
- To ensure high quality provision of information service to support people with disability make informed decisions requires collection of information, filtering and interpretation of the collected information, collation of the collected information and then dissemination of the collected information through a variety of means to ensure that people with disability are able to access the information needed when, where and how it suits them.

Equitable opportunity to participate in community life

Making informed choices through the provision of disability information and resources

People with disability (families and carers)



(Outflows)

INFORMATION PROVISION – PRODUCTS

Specialist generic information experts

Free access for people with disability to independent information providers (a real person)

Whole-of-life information and resources maintained for accuracy and currency

Information dissemination products provided in a range of alternative formats

Information provision that meets people where they are and has them at the centre.

Community education activities that provide opportunities to disseminate disability information through face to face contact.



(Inflows)

INFORMATION PROVISION – PROCESSES

Collection of information to develop resources databases

Maintenance of resource database – internal knowledge management systems

Global/Local – Connections with local communities through NDIS Case Managers and key local champions

Relationships with and access to the expert knowledge of disability specific and disability specialist support organisations

Relationship with the NDIA

Connection with people with disability in their location and through their input via feedback mechanisms