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**IDEAS Submission to  
Department Social Services  
NDIS Quality and Safeguarding Framework  
Consultation Paper  
April 2015**

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## **IDEAS Submission in response to Consultation Paper.**

### **'Proposal for a National Disability Insurance Scheme Quality and Safeguarding Process'**

IDEAS 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.

IDEAS operate a broad suite of direct product to meet our vision of 'A world where people with disabilities live lives of their own choosing. 'These include collecting, collating, interpreting, distributing and maintaining databases for this purpose.

Our distributive measure for the dissemination of information starts first with a respectful individual listening to whatever enquiry is being made. IDEAS is alive to the working paradox that distribution begins with skilled listening, not a push out of generalised fact sheets or such, even though of course they have their place in the panoply of resources to community. IDEAS dissemination includes: a free national Phone line where people with disabilities or their supporters can ring and ask any question about anything that matters to them. Our information officers listen carefully and then respond with broad and deep information that assists the person to make their own decision. IDEAS information service is not limited to any disability type or age. All services and supports searched for are made to be absolutely customised to the place and the circumstances of the person making the enquiry. In addition to this core service, complementary means of information distribution include hard copy newsletters freely distributed to subscribers, e-newsletters, webpage and social media engagement, attendance at mainstream and disability specific events, networking, and so on and convening of large free expos which expose supports, services, learning opportunities through workshops, seminars and speak up curated activities, as well as engagement in sports, arts and mainstream connections. IDEAS has been convening these expos in non-metro areas for twenty five years, and particularly had two major expo successes in the Hunter trial site in NSW prior to the Newcastle roll out in 2013, and in Maitland in readiness for the extension there in 2014.

IDEAS is well connected with peak bodies in NSW and AFDO and DANA for a national perspective.

The lived history of the independent information provision, individualised advocacy brokerage, and engagement as convenors of speak up groups and self-advocacy projects contributes to a nuanced understanding of the continuum on which information serves at one end towards a support for choice and control and self-advocacy through to brokered advocacy for the individual when necessary. We have deep experience in using the skills of our information officers to conduct phone advocacy with people with disability to get the outcomes they choose. This is a relatively low cost, personal and highly effective contributor to personal desired outcomes and underscores our experience delivering the foundation for self-advocacy by people with disability. Our individualised approach delivers to the rights of the person with disability and assists the protection of the person with disability through what they have done and chosen themselves rather than being done to or for.

## **ACKNOWLEDGING THE NEED FOR A QUALITY AND SAFEGUARDING FRAMEWORK**

- 1. Greater Choice and Control available to people with disabilities demands a similar individualised, personalised and dynamic safeguarding framework underpinned by the UN Convention on the Rights of people with Disabilities to which Australia is a signatory.**
- 2. The framework must be national.**
- 3. The framework must support the entry of new providers into the market, as well as enabling mainstream choices by people with disability in addition or instead of traditional disability specific service providers.**
- 4. The framework must be in place to avoid a vacuum post the dismantling of old block funding and case managed models.**

IDEAS notes the principles suggested in the consultation paper that should guide the development of a Quality and Safeguarding framework for the NDIS. These include: Choice and Control, risk based and person centred approach, the presumption of capacity, national consistency, reducing and minimising regulation, and a push for administrative efficiency. This said, and agreed, IDEAS posit the importance in the creation of life choices to meet the aspirations of people centred plans, that within the individualised risk and safeguarding assessments for that person living that life in that place at that point of time with all of their natural wealth and capacity, always includes a plan “B”. **And** a fluid review opportunity in regard to risk and safeguards so that the ‘predictable’ transitions that any person will make during life

can be very easily accommodated, but that also relatively unlikely, but occasional happenings that a person might experience and their attendant risks have already been thought of with a self-controlled remedy available.

We offer an example from the Jon Glasby scoping paper for the Joseph Rowntree Foundation. "Whose risk is it anyway? Risk and Regulation in an era of personalisation." September 2011.

*"At the time I was very struck by a story I read in an independent living magazine about a personal assistant who turned up late at night to hoist a disabled person into bed-but turned up drunk. Fellow social work students often saw this as evidence of direct payments exposing people to inappropriate levels of risk. However I always felt that a local authority home carer could just have easily turned up drunk-and there would probably have been nowhere for the disabled person to turn in an emergency. Because this was a direct payments package, the person had planned what to do in an emergency and could seek alternative support, even out-of-hours. They had also received helpful advice from the direct payments support service and were using an employment contract that enabled them to terminate the person's employment immediately. Many direct payment recipients would also have some sort of contingency fund that they could draw on in a crisis and /or to meet any extra costs while they were seeking more staff and rethinking their support-and this seems crucial if the experience of direct payments is to be a positive one(especially for people with fluctuating conditions).Receiving a direct payment and being an employer may have also have increased the person's confidence so that they felt better able to deal with a difficult situation than if the home carer had been employed by the local authority or a private service. Ironically, therefore this person felt safer to me with a direct payment system than with a direct service."*

IDEAS agree overwhelmingly with the statement in the consultation paper that the NDIS quality and safeguarding framework is designed to give participants choice and control over their supports and allow people to take reasonable risks to achieve their goals. We confirm the objectives as set out in thirds of advancing the rights of people with disabilities, minimising the risk of harm **WHILE maximising the sovereign choice and control they have over their lives.**

## **INFORMATION MUST BE DETAILED AND PERSONAL**

The place for information provision in the development and securing of these objectives is hard to overstate. Ubiquitous, free, accurate, relevant and personalised information provision contributes powerfully to build a person's natural safeguards at home, work, education, leisure and community.

A focussed twinning of information with capacity building of the development of self-advocacy by all people with disabilities is not too high an ambition for the NDIS in Australia. This is a major place for government investment in facilitating the information and exchange systems within communities which allow people with disabilities to share their knowledge. Absolute individualisation is possible in these activities as individuals bring all that they are and all of their talents and their life experience to support each other. If the ways and wares of the design of these offerings include diffuse offerings in face to face opportunities as well as on-line opportunities as well as social, cultural and fun opportunities it secures the local and national aspiration for fully invested citizens at their fullest capacity taking their place in society. This leads to a desired outcome for people with disabilities as it should be for any citizen, in a properly supported shared risk that is congruent with the true and potent delivery of complete choice and control. This of course assumes support in developing capacity as it grows.

Information itself, that is accurate, relevant, freely available in Omni distribution channels is an under sung contributor to being a safeguard itself. What is poorly understood and IDEAS has a responsibility to point out is that all information is not the same. Information that supports good choice and control is way beyond a mere service listing. It must be broad and deep, and include the exquisite detail that makes the difference. So for instance it cannot be like an old phone book listing, it must have all the details that will enable a person to successfully choose whether that support or service is right for them. It must have a detailed outline of the replete details of the service or support, the eligibility that sits around that, the names of the key people to contact for particular service, the details for contact, (all of them), the address of the service, the hours of opening, whether the premises is accessible, are their bathroom facilities there and so on and what are the transport links to that service. These details then have to be available in accessible formats for the person. The challenge in maintaining the informatics principles that provide a

high quality information service are financially onerous and have limited opportunities to be monetised.

This is especially so if the principle of access and equity for people with disabilities includes the values of endless provision, to meet the person where they are, and should not be purchased as a cost to them. However the value of an investment in broad, deep and accurate information services which complete opportunities for choices including the mainstream is very high for people with disabilities themselves as they craft their own life choices.

IDEAS practice is that we up-date our detailed records at least once every twelve months. In addition to that on taking an enquiry, our information officer will, depending on the age of the record, phone the service on our time to double check the facts before getting back to the enquirer. This might happen with-in an hour, or within the same day or be the next day depending on the complexity of the inquiry being made. We promise our enquirers that we will get back to them and not give up. If we don't have data sets that support the enquiry being made our officers search for a service that might suit the customer's enquiry. Our information officers are like terriers in that endeavour.

IDEAS argue that while there will be many and diffuse information opportunities in a market offering like the NDIS; there must be a hierarchy of a trusted, independent source that is disinterested in the commercial or contractual outcome, and has no conflict of interest at all. IDEAS is of the strong view that while service providers will ramp up their own information supports, these must be marked as inferior as they are unacceptably conflicted and sets the person with disability into the space of 'buyer beware', an unnecessary burden in the development of the NDIS. It is IDEAS view that these conflicts must be explicitly marked.

## **INFORMATION DISTRIBUTION**

In summary, information supports must be many and varied. They should however include a single national independent clearing house and data rich cache available and searchable on line, by free phone, through SMS, have live Chat facility and the full suite of social media platforms. This would be the gold standard of independent high quality information provision, the trusted source. (An example being the 1800 Respect line, which doesn't replace kids help line or the rape crisis centre or other but is nationally recognised as the first best option for the communities it serves) There should also be publishing options in hard copy periodicals/magazines, and e-distribution of the same. Information supports should also be

available in many mainstream settings such as Centrelink, Centrelink 'roadshows' jobs and skills expos, and community festivals and market days. Information should also be available in person through shopfronts and on-road through the LACS and also the Ability linkers. But they should use the gold standard information sets available nationally. Information should be available through doctors surgeries and in other preventive and primary care settings. Moreover there must be a concerted time limited effort to publicise and advertise information provision that is decided upon for the NDIS. IDEAS has a keen understanding of this as we have for instance been engaged with FREE SMS service for many years and have a poor take up of this service due in large part to a lack of marketing funds to advertise its availability. Text services we would see have a good alignment for young people with disability, to enhance privacy or indeed report abuse. We find the same with our phone line services and website to a degree, as it remains in the dreaded space of unknown unknowns. In our case our operational budget is a constraint for the funding of paid community engagement and amplification of the availability of service message.

## **E MARKETS**

The Purple Orange report referred to in the consultation paper takes as its e-model a version of the Shop for Support site from the United Kingdom. IDEAS are agnostic about this especially for purchasing propositions, however point out the very high capital costs invested to ensure the success of the shop for support scheme over time.

## **EXPOS**

Purple Orange also discussed the existence of expos in the trial sites. Our convened expo (possABLE) in Newcastle in May 2013, brought 5000 people over two days to come out for themselves to get the information they needed in a large scale expo, with many opportunities for workshops and seminars about the NDIS itself, as well as many other curated topics, including leisure, the arts, 24 accessible sports, safeguarding, human rights, humour, disabilities caused by rare genetic disorders, and sex and relationships. What you see at these expos is a large number of people who currently receive services and who are looking for "What else? Or "What other?". Even more powerfully though, you witness people with disabilities coming out under their own steam to get what they want on that day. There is no staring or discomfort as people with disabilities take their place to access information to make their choices. Even more potently are people who come from many different demographics who might be at the beginning of new diagnoses for themselves or a family member. They seek and get bold and vivid evidence of the

supports available to them, in a context of optimism and good futures. IDEAS has showcased many people with disability as leaders, experts, and paid professionals in the production of these expos including extreme sports and high risk activities. Smiles are wide as you see the evidence of you can't be what you can't see. Our events, as with the events that Valid have run in Victoria, are sometimes life changing experiences for people with disability who attend. IDEAS put that expos have a real and exciting place as conversation starters about information services from many sources. Scale equals expense, but they are a great opportunity to slot disability as just a diversity in a whole life, and they can properly show access to the many 'normals' available to people with disability from holidays, to accessible cinema, to learning about friendships and relationships that are not paid, to making art, to trying sports that might never have been available in that community. More profoundly, the cross subsidies available through such expos, make it possible for key protective bodies to get some space and some 'air in a non –threatening setting. These include in NSW the Council for Intellectual Disability, The Ombudsman services, Law Access, Companion Card, Multi-cultural disability advocacy networks, Aboriginal Disability Networks, and Family Planning. Moreover, while challenging to do, an expo can bring utterly mainstream services into serving people with disabilities better by engaging them in an expo. Examples include local libraries, RSPCA services, Fire services, financial planners, doctors, educational toy suppliers that serve mainstream education, and mental health services such as Headspace. Each of these exhibitors after being involved with our expo went away with profound learnings themselves as to how they can fulfil their mission better in service to all Australians. A tiny beginning to better inclusion.

## **EFFECTIVE CAPACITY BUILDING FOR NATURAL SAFEGUARDS**

IDEAS recommend that community awareness raising in face to face contexts, seminars on rights, and self-advocacy groups are the best way to build capacity for people with disability to know their rights and speak up for themselves. The long time practices of Valid in Victoria are a good example, as are the My Choice Matters program in NSW and also NSW CID. IDEAS have experience in running training for people with disability about their rights and about being a self-advocate. This work is resource intensive but can have very good outcomes. Shared features of these programs are that they are small, personal and on-going.



IDEAS have a strong view that detailed information is required prior to planning and any notions of access checking. This is because people still have a relatively poor understanding (even for all of the fine work done by the agency) about what the NDIS is and indeed what a personal plan might mean for them or their loved one. We promote that for there to be a chance to properly dream in the setting of their life goals and aspirations it has to be slow cooked. Our experience demonstrates that it takes a while for participants to reach their 'ah ah' moment of understanding their own possible stewardship in their life futures. Information prior to planning of course should not be all about supports and services, life is bigger than that, and we purport that it is also the place to discuss risks and safeguarding for the person themselves as they move to exploit their own path. We also assert that independent information provision must be available at planning, and also in review processes.

We counsel that at whatever points where a risk and safeguarding plan is undertaken that it is not a set and forget, and is not nimble enough to have effective safety for a person should an emergency situation or life event take place. If these situations are thought about within the planning process then the safeguards can have personalised integrity, be as light touch as possible and actually contribute to the enhanced capacity, self-confidence and community engagement of the person.

A question we think appropriate to grapple with is that suggested by Michael Kendrick in his discussion paper "Self Direction" in services and the emerging Safeguarding and Advocacy Challenges that may arise, June 2005. In part of this paper Michael Kendrick behoves us to look into the future as we may have looked at the past. That is when designing new settings and policies to be alive to the proponents and detractors of what was hard fought for, won, implemented and then re-questioned. He proposes this with a view to group homes replacing institutions. *"As we now know from examining any number of complaints lodged annually by advocates in many jurisdictions, group homes have not always been implemented in optimal ways, and many shortcomings have emerged that were minimised as being likely by the original advocates for them This is not meant to suggest that the original advocates were fundamentally incorrect in their assertions ,but rather that many valid options may not, in reality be implemented in ideal terms in regards to quality and sound practice, thus opening the door to shortcomings, vulnerabilities and perversities.* He goes on to argue *"By adding the presence of thoughtful safeguards of various kinds well in advance of their use only once something has gone wrong, it may well be that such intentional safeguards will actually increase the likelihood of success; they might actually enrich the potential viability and vitality that may be present in such arrangements."*

## **AGENCY IN CO-DESIGN**

Mr Kendrick also underlines the good sense proposition that in relation to the individualised nature of needs and vulnerabilities of a person, it makes good sense for those people to have a hand in contributing their own sense of the relative priority of needs and concerns in their own lives, and therefore play active and defining roles in designing and testing safeguarding and support strategies that might help them. Heavy handed and de-personalised prescribed remedies can be said to re-institutionalise the same paternalism that brought about the need for self-direction in the first place. A co-design simply makes people with disability agents in their own lives.

IDEAS is a supporter of the universal safeguards available to people with disability as for all citizens in Australia. There is here too, another role for information services both to people with disability and also within the services designed for remedy. These include of course, the police, consumer protection law, health legislation, building codes, human rights legislation public advocates, disability advocacy, complaints commissioners and Ombudsmen. This specific information and its distribution and knowledge gaining needs a similar framework to other information services proposed earlier in this document. Placing information actions around accessing these services in a carefully rolled out and continuous framework will have increased natural safeguarding for all people. The intent is to be fully accessible to people with disability.

## **OVERSIGHT for the NDIS**

IDEAS support the discussions in the consultation paper about the oversight body possibilities for the NDIS. The Model similar to the Telephone Ombudsman looks fruitful, and add to that the market oversight functions.

## **SUMMARY**

**Independent information provision to highest standards at a national level which is nimble enough to be place and person perfect is a precursor to meeting the objectives and scope of the national quality and safeguarding framework:**

- **To advance the rights of people with disability**
- **Minimise the risk of harm**
- **Maximise the choice and control they have in their own lives.**

*More information about IDEAS can be found here: <https://youtu.be/phjdgH5ijg4>*

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