Seniors Information Service Inc.

Submission
Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework

Seniors Information Service

Seniors Information Service is a registered charity. We improve the physical, social and emotional wellbeing of people disadvantaged by disability or age by providing information, training programs, case management and opportunities for learning and social connection. We support people to be self-directed and exercise choice and control in their lives.

Programs developed and run by SIS are inclusive, promote engagement and improve social and emotional and health and well-being.

SIS is particularly known for its digital literacy training that supports people with little or no experience with devices to become confident using mobile devices, search for information, and be safe online. SIS provides training at a pace that builds confidence and capability, with one on one support to solve specific issues or build new competencies.

SIS has for many years supported older people with a disability find appropriate services and navigate mainstream systems - 50 % of people >65 have a reported disability[1].

With the closure of the disability specific information and resource centre in South Australia in 2014, SIS has taken responsibility for disability specific information and promotion.

Seniors Information Service (SIS) appreciates the opportunity to consider, and make comment to the National Disability Insurance Scheme on the Proposal for a National Disability Insurance Scheme Quality and Safeguard Framework (February 2015).   SIS would also like to acknowledge the quality of the discussion paper provided by the NDIS and the thoroughness of the options canvased in relation to each element of the framework.

SIS fundamentally supports the paradigm shift reflected in the NDIS model; from policies and practices based on 'what a person can't do' to self-directed and managed assistance enabling people with disability to rightly assume and enjoy full citizenship.

SIS has provided a response to the following sections, where we can add to the discussion.
-       Providing information for participants
-       Building natural safeguards
-       System level safeguards & provider registration
-       Handling Complaints.

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[1] ABS Cat 4430 Table 30_1

Providing information for participants:
What are the most important features of an NDIS information system for participants?
How can information system designed to ensure accessibility
What would be the benefits and risk of enabling participants to share information, for example through online forums, consumer ratings of providers and other means?

As outlined in the framework SIS agrees that the NDIS information system needs to:
- Give participants the tools to choose the best providers of their supports.
- Ensure participants know what they are entitled to expect and what they can do if these expectations are not met.
- Drive quality improvement in the system.
- Harness, not depend on the internet or social media to build empowered communities.

The later point is particularly important. A functional website and social media strategy that reflect the diversity of needs, issues and capabilities of people with a disability as outlined in the Framework will be important tools to build empowerment. However evidence repeatedly demonstrates that the most vulnerable people in our community (whether they be poor, older, disabled, with limited ability to communicate/in English or otherwise, or living regionally/remotely), are also the community that is offline, either through lack of physical access to technology, lack of capacity/ digital literacy or lack of desire.

Experience in the United Kingdom with '0digital by default' policies suggest that a reliance on digital engagement further marginalizes and isolates already vulnerable people.
http://www.social-policy.org.uk/wordpress/wp-content/uploads/2015/04/39_yates-et-al.pdf
http://www.theguardian.com/technology/2014/jun/23/when-the-uk-goes-digital-by-default-who-will-be-left-behind

The SIS experience over many years validates this research. That is, high quality online information for families, carers, older people and people with disability is a good start but insufficient to ensure that citizens have sufficient information to exercise choice and control in their lives. Citizens need access to phone based services and face to face support, to help understand the system, understand eligibility criteria and processes , understand their rights and obligations, help to complete forms and to know where to get help from.

The SIS experience is there is value in people having access to and building a relationship with an independent source of advice that can provide information on a

range of issues, particularly when they "do not know where to go." This is particularly so for people who are socially isolated and do not have other supports to rely on.

Example
A couple living independently, one with a brain injury and able to speak clearly and the other with affected speech has communicated with SIS via telephone, post and email over several years. They have limited mobility and financial resources and find that in times of stress it is difficult to determine where to get support from. They have also found their communication difficulties have prevented them from getting help from service providers. Being able to get advice, information and support from SIS in various forms on a range of different issues, as and when they need it, gives them the confidence to ask for help from government and other relevant service providers and remain living independently.

The Disability Information and Resource Centre (closed 2014) ran the Disability & Lifestyle Expo on annual basis for over 10 years. This highly successful expo, which will be run by SIS in 2015, brings together exhibitors from aged care services, advocacy, disability support services, education, employment, entertainment, equipment, mobility, physio, recreation, rehabilitation, sport, wellbeing, youth services and more. It provides one-stop-shop for disability-related information, and provides a place to interact with potential service providers and to gather information about support services and opportunities that are available. The expo has performances by artists with disability, as well as sport and recreation demonstrations and last year had presentations on equipment, the NDIS, acute care strategies, employment, Australian Standards, grief management and a wide variety of other disability-related topics. The expo both informs people with a disability and their support networks of what is available and raises the profile of disability within South Australia.

With DIRC closing last year, Seniors Information Service is carrying forward this important event for the disabled community in South Australia. This Expo provides a great opportunity for the NDIA to support this event and with financial support take the Expo to regional areas.

Recommendation
NDIS information system includes face to face and phone information services from independent sources, to provide people with a disability and their families, carers and supports access. This services need to have local and specific knowledge of service providers.

Specific effort, beyond translation of written information, into other languages is required to inform and engage disabled people (and their social supports) from CALD backgrounds of the NDIS, their rights and obligations, service provider standards and complaints systems.

The NDIA supplement existing activities and events to promote information about the NDIS and disability awareness more broadly. We encourage the NDIA to support and promote the Disability and Lifestyle Expo in Adelaide and regional areas.

> **Building natural safeguards**
> **Are there additional ways of building natural safeguards that NDIS should be considering?**
> **What can be done to support people with a limited number of family and friends?**

Community awareness and supports are crucial natural safeguards for individuals. These can take a variety of forms, including general level of community awareness and understanding and inclusion by individual and community groups towards people with disabilities. A high level of general awareness can enable and encourage community members to befriend and connect, potentially socially isolated people to a point of support and/ or referral.

Calling an independent information service can be a safe way for socially isolated people to establish contact outside their current environment. Expanding the scope of information services, to be able to, for example provide a follow up phone call to see if the person has resolved their issue, to provide a regular phone call check in, or a once a week social chat , can help to build rapport and confidence that enables people to gradually expand their social connections. Information services can also be a safety net for people to ask questions or check where they have concerns for example about their service provider, separately to the people they maybe dependent on for their daily living.

Latest data[2] available shows that over 40% of people with a disability did not access the internet AT ALL in the last 12 months. By definition this 40% excludes any person with a disability who accessed the internet once in the preceding 12 months and therefore is a very narrow definition of digital accessibility. In practical terms the level of digital exclusion is likely to be much higher.

Of the people who did access the internet, most did at home, with only 4.8% accessing the internet solely outside of the home. Internet lounges and community centres that provide access to PC's rarely provide support to actually use the technology (eg how to search online) or support to explain information and online forms. People in general also feel less comfortable dealing with private information in a public facility, even if it is only entering data into an online form.

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[2] ABS Cat 4446.0 - Disability, Australia, 2009

SIS provides a staffed internet lounge for free public use. This means that users can get help, advice and support as they need it. If they have a query about other issues related to services or accommodation, relevant staff can also help them with these inquires.

Community centres and group activities are an important way to build relationships, social connections and provide support to people who would otherwise be socially isolated. Over the last 6 months an increasing number of service providers have reported to SIS that they are ceasing to provide group activities and/or removing disability as an eligibility criteria. A key driver is the change of the Home and Community Care program to the Commonwealth Home Support Program (CHSP) model which clearly targets frail aged participants.

There is no source of funding to operate social based activities on a sustained basis to address the social isolation of vulnerable people. While both the NDIS (when fully operational) and Department of Social Services CHSP and Home Care packages do allow for payments for social and community based activities there is a short term funding gap as these models are implemented (i.e. no short term funding for adult disabled clients to replace HACC funding). Also there are people with disability or otherwise vulnerable and socially isolated not able to access these funding sources. An additional core issue is that the funding that is available is marginal not average cost of providing services which challenges organisations ability to provide sustained community and group support.

Recommendation
NDIS provide funding for self-advocacy training to help build peoples natural safeguards prior to the full role out so that eligible people are equipped to participate. The positive changes being driven in the NDIS will only be effective if individuals are confident and capable of advocating for themselves.

NDIS promotes disability awareness more broadly within Australian community.

System level safeguards

While provider registration is an important part of system level safeguards it is equally important to address the interaction between NDIS and the Aged Care system.

There is a significant risk that as people with a disability age and move from the NDIS to Aged Care, that the changes to the level and nature of the care provided significantly impacts their ability to maintain choice and control and social connections.

For example
A middle aged male was living in a supported residential facility and with a medical and allied health program to manage his mental illness. Unfortunately his physical status

deteriorated to the point where he needed a higher level of care and he was moved to an aged care facility. Aged care facilities are not required to support residents or provide transport to attend medical appointments. As the man had limited social supports to help him attend these appointments, and people in aged care facilities are not eligible for transport support, his participation/attendance at these appointments significantly declined. As a result his mental illness deteriorated in the aged care facility.

People with early onset dementia, who are physical well, but are unable to live independently may seek access residential aged care facilities.   As outlined in the Fact Sheet (Younger people in residential aged care) the NDIS will not fund daily living expenses or accommodation charges (as these are funded through the Aged Care system). However the structure of Commonwealth subsidies for aged care places mean that mobile people with conditions such as dementia are not attractive to aged care providers and the providers are very reluctant to accept people with early onset dementia over other potential clients. Even when providers accept people with early onset dementia, they are not required to provide support to attend appointments or participate in activities outside of aged care facilities.

Recommendation
NDIS needs to implement safeguards to protect people with disabilities as they transition between social service systems to ensure they are able to maintain as much independence, control and social connection as possible.

NDIA provider registration
Which option would provide the best assurance for providers, for participants?
Should the approach to registration depend on the nature of the services?
How can the right balance be reached between providing assurance and letting people make their own choices?

Given the risk to clients as a result of poor, unacceptable or inappropriate service delivery SIS supports a registration model that requires:
- adherence to the code of conduct
- providers to meet additional conditions that reflects the nature of the services and supports they provide to disabled people.
- provider of higher risk supports to participate in independent quality assessment of their services and supports, with outcome information publically available.

Systems for handling complaints
Should an NDIS complaints system apply only to disability-related supports funded by the NDIS, to all funded supports, or to all disability services regardless of whether they are funded by the NDIS?
What powers should a complaints body have?
Should there be community visitor schemes in the NDIS and, if so, what should their role be?

SIS supports a complaints system that applies to the disability related supports that are funded by the NDIS. This system also supports people with disability to access the complaints systems for mainstream services. This ensures:

- a mechanism for those services that are not currently covered by existing complaints system
- information to maintain the integrity of the core NDIS services
- mainstream complaints systems are required to support complaints by disabled people
- a back-up mechanism for failure within mainstream systems and/ or support when there are barriers to accessing the mainstream system.

SIS supports the implementation of a community visitor scheme for those participants without informal social networks or advocates or those whose capacity to self-advocate is limited. The community visitor scheme could be complemented by a community calling scheme that makes contact with participants more regularly than visitors are able to attend and provides another safeguard for participants who are able to communicate by phone. SIS would be interested to discuss these options with the NDIA.