ideas.

Disability Information
Free, Accurate & Independent

IDEAS does information so you can do life.

Submission

Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape

Phone 1800 029 904

or visit ideas.org.au

Our Vision

People with disability live full lives of their own choosing

Our Mission

IDEAS purpose is to provide access to information and opportunities for people with disability, their supporters and the community to reach their full potential.

What we do

IDEAS delivers information to support people with disability via multiple channels including:

- Phone
- 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 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.

Our activities include various means and modes of dissemination of information that meet the needs of all people with disability. Our activities utilise our extensive networks to increase the effectiveness of referrals resulting in stronger links for people with disability in their community.

Improving the NDIS Experience:

Establishing a Participant Service Guarantee and removing legislative red tape

IDEAS is the go to for independent information provision for people with disability, their families and carers and supporters.

There is no properly resourced national information service for people with disability.

IDEAS is the only stand-alone Information provider in the nation and has 35 years of experience and 312 years of combined sector knowledge. People are falling through the cracks and IDEAS is there to help them only until 31 August 2020.

From that time people with disability who are not funded participants of the NDIS will have *nowhere to go* to gain assistance in navigating mainstream options.

Since 2009 people with disability have asked at every opportunity for services and supports in navigating complex systems in the disability specific sector and mainstream.

The ILC response has been late and chronically underfunded. It also has reverted in fact to a largely medical model.

People accessing the NDIS need guaranteed, independent access to information in their ‘ready’, ‘set’ and ‘go’ parts of the pre-planning, access and plan scenario.

The current landscape features:

- Local Area Coordinator churn
- Local Area Coordinator quality and knowledge
- Participants don’t feel valorised in their humanity
- For participants some activities of the NDIA are perceived as threatening
- The more inclusive Australia is yet to grow
- Local Area Coordinators have not been able to deliver their 20% of work time to community development.

IDEAS is better than good enough now to deliver

People talk to real people who listen and give them the information they need and want in formats they want it

Real community engagement to build community awareness.

What should be in the Participant Service Guarantee:

IDEAS recommends

The participant service guarantee include a principle confirming the right to access independent information that supports choice and control for all Australians with disabilities. It must be free and ubiquitous. It must be available in accessible multi modal channels at all times. That is before pre-planning, planning and plan review.

The Standard

That all people with disability can request and receive independent, verified and un-conflicted information in a timely manner that supports their choice for a good ordinary life, wherever they live and in ways that are appropriate to them.

IDEAS recommends

The Information Linkages and Capacity Building arm of the NDIS needs redefining for this pillar of the scheme to be relevant, meaningful and congruent with the Disability Care and Support Productivity Commission Report 2011 and the National Disability Insurance Scheme Act 2013.

IDEAS recommends

The notion of building capacity of people with disability may well sit best in their plan as part of their life goals. In an external program delivery, building capacity can imbue a further sense of "being done to" that is, not being whole as you are. This is antithetical to the social model of disability.

IDEAS recommends

The ILC becomes two components only. The first component is information. The second component is linkages.

*Referrals to services, supports and mainstream options.
*LACS work to build more inclusive communities.

Characteristics required for quality Independent Disability Information

IDEAS' extensive experience tells us a national Information Service is sorely needed, with these critical elements:

- That it is run with and by people with disability or lived experience of disability
- That each person is listened to with respect for their individual circumstances, no matter where they live
- That a real person will answer the phone and deal with the enquiry
- That many channels need to be used including telephone, and live chat with real people, face-to-face, video, SMS, e-mail, social, digital and web interface as well as newsletters and e-news
- That the information is accurate and independent – that is, the organisation is not trying to sell the person anything
- That the information can be provided in accessible formats chosen by the customer

A National Disability Information Service delivered properly will

- Provide unequivocal evidence that all Australians living with disability can be served by a one-stop, multichannel service to get the information they need to make choices for themselves
- Complement the NDIS, support LACS, Support Coordinators and individual intenders, applicants, participants and all Australians with disability
- Increase community confidence in a more inclusive Australia
- Minimise medium and long-term risks for 'unfunded' non-participants of the NDIS who cannot get what they need to lead a fulfilling, ordinary life wherever they live.

What it could look like:

National 1800 number and multi modal access to information

Entry point that is

- Relevant
- Timely
- Accurate
- Verified
- Up to date
- Easy to access
- Free

People have asked for information

There is no meaningful choice without access to independent, reliable information. The thing people first identified in the 2009 *Shut Out Report*, and in every report since, was information, yet it **has not been delivered** in a coherent, personalised, consistent and unconflicted way.[1]

39% of submissions to the *Shut Out Report* referenced access to quality one-stop-shop information was critical to removing barriers for people with disability in the areas of early intervention supports, services, education, health, housing, equipment and employment. This report highlighted that without information services to support decision making, Australia was at risk of not fulfilling her obligations as a signatory to the UNCRPD, the first of whose eight guiding principles is 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.'[2]

Current Status

Information does not exist at the front end and this is a major barrier for people with disability accessing any specialist or mainstream service or support.

Currently, there is no defined policy or program space for people to get independent information before pre planning, before planning, before attending planning meetings. This compounds people with disability's difficulties in engaging with the agency. It compounds a break in trust before any relationship is developed, de-facto providers of information e.g. service providers are filling the gaps (this is a very poor outcome for people with disability as it is conflicted). People don't know what they don't know. People connect less with mainstream inclusive options as they are unknown. People are not given the breadth of options that might be available due to lack of expertise, lack of policy, lack of programming and lack of consistent funding for information delivery.

Without free independent disinterested information provision, the enquiry, paperwork and running around burden falls back on individuals to navigate complex systems without support.

Just like anyone else, the decisions needed to get on with an ordinary life for people with disability, require information to ensure choice and control. That information needs to come before anything else and available in an ongoing way. There is no choice without information.

The ILC program has repeated the siloed approach of producing information sets based on the outdated and discredited medical model of disability. IDEAS takes the social model as our true north. People are people first, and we serve them instantaneously, wherever they are and in a manner which suits them best.

IDEAS predicts a further loss of trust towards the NDIS by participants, and all Australians with disability, their families, carers and supporters. The confusion will *not* be dealt with by the current piecemeal options in a timetable that only meets the budget needs of the Agency itself. The current 2019 ILC National Information Program grant recipients are working on information sets. Again, largely condition based, to form the basis of an as yet unknown, untimed national information program. The technical details of this program are also unknown, the means of keeping data updated is unknown, the data is not predicated on the social model and it is late and slow.

Like the whole of the ILC program the issues of clarity on definition, scope, desired outcomes and accessibility are poorly defined. In short, this equals more confusion in the short term for participants, less collaboration by sector authors and specialists, poorer outcomes for people with disability in a context of rationed fund distribution without obvious social policy rigour.

Current ILC towards the NIP

Guidelines released for 2019 three-year national grants to create a National Information Program by 2022 – 13 years on from the *Shut Out Report*.

The grants are

- Mired in the medical model of disability by requesting information fact sheets and other information resources around disability types and impairment categories.
- The total investment over the three years is a mere $51 million.
- The approach, the amount of funding and timeframe are all inadequate to address the current information needs of people with disability.

Programs for people with disability and their carer's are disjointed, inconsistent and unreliable. This has been exacerbated by the 'pain points' of the NDIS: the Agency's style and means of correspondence, the inability ever to talk with the same person, and different answers being given to different people with the same issues at the same time.

The sector is beset by confusion, mistrust and exhaustion, a situation that is exacerbated for underprivileged and marginalised communities, particularly First Nations people and those whose first language is not English. People in rural, regional and remote Australia are among the least well served.[3]

Risks

This situation risks thwarting the goals of the NDIS which are:

People with disability are granted control and choice, based on the UNCRDP.
The NDIS is financially sustainable and governed using insurance principles.
The community has ownership, confidence and pride in the NDIS and the NDIA.

The ILC is a failure now in reaching and supporting people with disability without NDIS funding.

The inaugural Chair of the NDIA Board warned in his resignation letter that the Scheme would fail if the ILC pillar was not supported properly. In his outgoing report he wrote 'The ILC is a critical foundation stone of the NDIS. If those people with disability who fall just outside the access requirements for the NDIS receive insufficient support, they may need to exaggerate their disabilities in order to become Scheme participants, so as to gain access to necessary supports. *This risks undermining the culture of the NDIS and its focus on maximising opportunity and social and economic participation*.

Alternatively, this group will not receive the essential supports they need and will become more disabled, entering the NDIS at a later stage at higher cost and so undermining the objective of the NDIS to minimise lifetime costs. Currently $132 million has been allocated to the ILC. This is not sufficient and means that one of the key foundations on which the NDIS is being built is weak.' He went on to highlight that if the funds for ILC activities were not able to be more flexible, then there would be no mitigating strategy to avoid unnecessary medium- to long-term cost increases.[4]

Models

The idea of generalist information provision is critical to meet the aspiration of choice, control and personalisation in the evolution that Australia seeks as a nation for her citizens with disability. Just as a general practitioner is the hub in stewardship of health and wellbeing for patients, so too is generalist disability-related information a hub for referrals to disability peaks, support networks, and inclusive mainstream services, supports. It is also the gateway to specialist care as well as assisting navigation with state providers of health, education, housing, employment, leisure, travel and advocacy services. Steve Dowson referred to the Emprise Model in ‘Who Does What’ [5] to identify which parts of the system should be separated to ensure independence for the individual, and identified information as a separate function to planning, advocacy support and service provision.

Key Considerations

The existence of a generalist independent information provider is critical in creating true inclusion in any community for people with disability, their families, carers and supporters. This model – IDEAS’ model – removes stress and alleviates the burden for people requiring information e.g.

- when a child is struggling at school
- when an appropriate health specialist can’t be found
- when you need to find some respite.

80% of barriers for people with disability are shared. So, just like a great general practitioner who is a trusted steward of one’s health, disease prevention and wellbeing, so is IDEAS a trusted information clearing house, curator and disseminator.

People with disability will have access to a trusted source of information that uses a listening model to enable people with disability to exercise their right to choice and control.

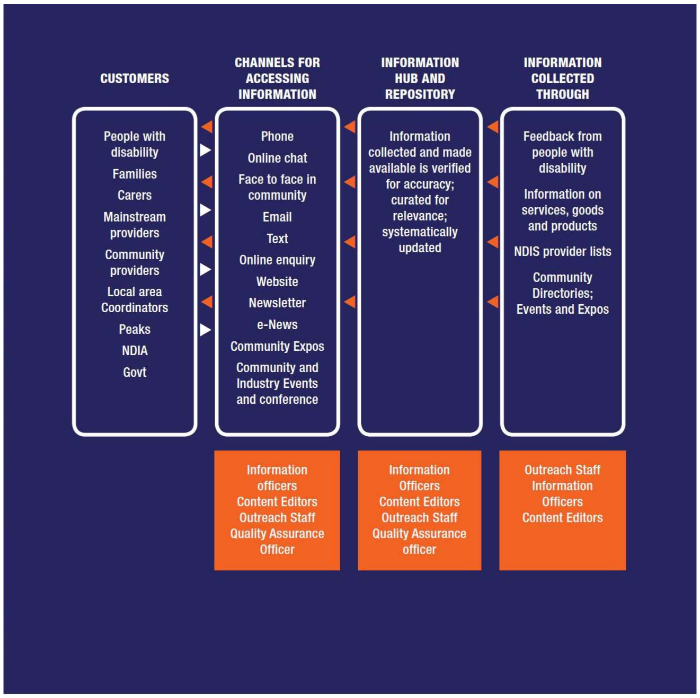

Diagram 1 Information on Disability – Human

Conclusion/Recommendation

IDEAS recommend

An immediate investment of resources for independent information to support choice and control for all Australians with disability. This is urgent and acute.

This would represent a ground-breaking act of inclusion as any person with disability or their families, carers and supporters could access the information and navigation support they need by whatever means suits them best, whether NDIS participants or not. People with disabilities will be empowered, in control and granted true choice.

IDEAS is ready to deliver for the nation now. Our model is already better than good enough now and can scale to serve the nation. A commitment to a five-year time frame to establish and embed a national service with scope for face-to-face connections across the country

IDEAS is:

- Independent
- Trusted
- Heritage provider – 312 years sector knowledge
- 80 % of staff have with or have lived experience of disability
- Innovative
- Has a proprietary listening model
- Has accurate, fact checked data and service finder
- Multi-platform in reach and out-reach including personalised community engagement
- A national toll-free phone line to our Contact Centre
- Live Chat (not Chabot)
- Operating hours 8am-8pm which serves all time zones across Australia now

This would mirror the launch of the National 1800 Respect line in 2009 by Tanya Plibersek, costing $9 million, which was a marker of a loved and trusted access point for assistance to Australians needing it.

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