Submission: Proposal for a National Disability Insurance scheme Quality and Safeguarding Framework

Department of Social Services12 May 2015





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1. Overarching Key Element of framework –

What is not clear within the framework is the broader role of government, both state and federal, once the rollout of the NDIS has occurred. Consideration should be given as to *their* duty of care towards participants of the Scheme and the use of public monies. It will not be sufficient for the responsibility of meeting the individual needs of people with disabilities to only lie with the NDIS. It will not be acceptable for governments to see the NDIA as the sole provider of support services.

Although human rights seem to be underpinning the NDIS it appears to be missing from the Quality and Safeguard Framework. Human rights needs to be strongly articulated in all parts of the framework, influencing both practice and complaints mechanisms to ensure those rights are the overarching determinant in decision making for participants.

Recommendation 1: Human rights have a stronger presence within the Quality and Safeguard Framework.

1. Supporting Individual Capacity

When developing and facilitating the capacity of individuals it should not be assumed that they:

- have an understanding of their rights;
- have the capacity to independently exercise their rights; and
- have established natural safeguards (eg family, other support) that provide them support when required.

An independent information/advocacy service needs to be readily available to assist individuals with decision making. This may include opportunities to discuss issues of concern, consider options available, and support for final decision making processes. These services need to be independent of service provision as well as the NDIA, and be independently block funded. Each individual requesting support needs to be provided with capacity building skills tailored to their requirements. It may take time for an individual to develop such skills, and this should not be restricted by any compulsory adherence to a funding formula.

To support an individual with capacity building, information and supports need to be:

- accessible and in different formats;
- available at a range of venues;
- provided by an independent third party;
- provided via the communication method used by the individual;

- free from influence;
- provided via individual one-to-one sessions when required.

The Framework assumes that people have internet/telephone access but this is not always the case. Less than 50% of people with communication or speech difficulties have access to online services¹.

An outreach component is essential for isolated members of the community. For genuine engagement of isolated and vulnerable individuals, time, effort and understanding need to be provided initially in order to ensure effective support. This is particularly the case for people with complex communication needs, who will either need Communication Support Workers to be involved in information and support services, or workers trained in such communications support directly.

The *one hour planning* meeting provided by NDIS is insufficient for some individuals with complex communication needs/disabilities to be able to receive, question and consider all the information necessary to make an informed decision. Individuals who have complex communication needs may use a communication method that relies on spelling words out letter by letter. All individuals are different. A 'one size fits all' approach is not going to be effective.

For those providing services to people with communication or speech difficulties there must be training of those staff in the participant's method of communication. It is important to keep in mind that one cannot work effectively with a person unless they can communicate with them.

Going back one step, before one can effectively meet the communication needs of people with disabilities, one has to ensure that all persons have been provided with communication. It is highly probable that a percentage of people contacting the NDIS for services will not have ever been provided with a communication method. This, then, will be the highest priority, as it is self-evident that one cannot provide information, ask to receive information or discuss the merits of services, if one cannot communicate.

In cases such as these, it is the NDIA who will need to take on the responsibility of ensuring that individuals have a communication method.

Recommendation 2: Independent Information/advocacy Services be funded to support individuals in their capacity building program.

Recommendation 3: Information provision needs to be accessible, available and meet all individual needs. It is imperative that services that do not rely only on access to technology are available.

¹ Owen, J; Lamb, K; Smith, G; Telecommunication Needs of People with Communication/Speech Difficulties, Deakin University (1998).

Recommendation 4: Community outreach is provided to engage isolated and vulnerable individuals.

Recommendation 5: Ensure capacity building services are not time-limited in order to ensure that people with complex disabilities are provided with equal access to this service.

Recommendation 6: Provision should be made and planned for, to support individuals who require high levels of support and staff with a higher level of skill and scrutiny.

Recommendation 7: The NDIA make communication assessments and the provision of a communication method a priority for individuals who have no communication.

2. NDIA Provider Registration

It is essential that under the framework no NDIA registered provider discriminates when providing services for 'more complex needs' individuals, where higher levels of scrutiny and skills are required. The monitoring body must be mindful that *there be no indirect or direct discrimination* against individuals who require:

- staff to have a higher level of skill and scrutiny;
- Communications Support Workers/Interpreters;
- longer and/or more appointments.

A Code of Practice may be sufficient for people working in house maintenance or gardening, but anyone having direct contact with vulnerable clients requires a 'vulnerable persons check'.

Given the high rates of neglect, abuse and exploitation of people with disabilities in the disability service sector, an external quality evaluation is necessary, which is focussed on receiving feedback directly from clients not chosen by providers.

When we refer throughout this document to "vulnerable persons check" we recommend that the suggestions made to the Royal Commission into Institutional Responses to Child Sexual Abuse² be adopted as set out below:

"The pre-employment screening practices other than criminal background checks (often referred to as sources of 'soft information' in the literature) that evaluation authors identified as necessary components of a comprehensive pre-employment screening procedure included (in order of most frequently to least frequently mentioned):

a) Scoping Review: Pre-employment screening practices that aim to prevent child sexual abuse

² 'Scoping Review: Evaluations of pre-employment screening practices for child-related work that aim to prevent child sexual abuse' February 2015

- b) Conducting thorough reference checks (for example, those obtained directly from previous employers by asking direct questions about any concerns regarding the applicant's suitability to work with children)
- c) Holding employment interviews that focus on determining the applicant's suitability to work with children (such as value-based interviewing; for more information, see Erooga, 2009)
- d) Checking suspected or substantiated child abuse against other sources of information, such as child-abuse registries, children's court decisions or disciplinary body proceedings
- e) Critically examining an applicant's employment history and/or written application (to identify gaps in their employment history and thus clarify their cause, or to explain ambiguous responses to direct questions about criminal history)
- f) Verifying the applicant's identity using methods such as photo-based documents or fingerprinting
- g) Verifying the applicant's education or qualifications (in order to determine if they are qualified to undertake child-related work)."

We endorse Option 4.

Recommendation 8: The highest level of scrutiny is required for staff working with people who are vulnerable and marginalised. A 'vulnerable person's check' (see above) needs to be developed nationally, and mandatory.

Recommendation 9: A national registration program needs to be established to audit services.

Recommendation 10: An independent external evaluation monitoring body is required.

3. Ensuring staff are safe to work with participants

For staff working with people who are vulnerable and marginalised it is essential that the highest level of scrutiny is administered. This requires a *national registration* and 'vulnerable person's check' (see above). Each staff member should be responsible to keep their own registration current and not be reliant on service providers to maintain their records. Registration should be required every year, ensuring that such checks are not imposing a financial hardship on the worker or the service provider. These checks should also include international criminal records checks for overseas workers, and the establishment of an 'exclusion list' for those not to be employed.

Casual staff need to also maintain their registration.

Service providers need to sign onto the National Disability Standards and Quality Frameworks with at least two external auditors involved in their registration and accreditation. For those providers whose staff are not in direct contact with vulnerable individuals, a lower level of registration could be negotiated. Given the high rates of neglect, abuse and exploitation of people with disabilities in the disability service sector the external audit must be focussed on receiving feedback directly from clients not chosen by providers.

Any proposed national registration body needs to be mindful of those participants who wish to employ family members and the potential risk attached. Some form of monitoring needs to occur to ensure there is no abuse. This is particularly the case for vulnerable and marginalised clients.

Participants should have access to independent advocacy services to assist them with staff complaints. Not all people have the skills or confidence to access complaints processes independently.

All service providers should be providing services with staff that have the highest level of clearance possible in order that individuals who are vulnerable can have the access to the same variety of service providers as other people with disabilities.

We endorse Options button 3 & 4

Recommendation 11: Staff must be responsible for their own registration.

Recommendation 12: Self-managed participants need to have staff registered to ensure no abuse and appropriate levels of training.

Recommendation 13. A national registration program needs to be established to register, monitor and remove inappropriate staff.

4. Handling complaints

Most registered service providers will have a documented complaints handling process. To date the experience of some people with communication or speech difficulties is that these processes have structural barriers, as they rely on telephone, online systems or having a requirement to negotiate with a person who may not understand their method of communication. It is often not possible for people with complex disabilities to access someone who understands their method of communication to make a complaint. Many people require support from an independent advocate to make a complaint to service providers for a range of reasons, including fear of retribution, communication barriers, inaccessible complaint systems and/or not having the confidence to independently lodge a complaint.

If the complaints process leads to an individual making a legal complaint, that individual needs to be able to provide clear direction to a lawyer. If a person's communication method is not clearly understood by the legal representative, s/he will not accept the individuals' instructions. They then act 'in the best interest' which may be contrary to the wishes of the person.

There is a need for an independent communication support system or 'Intermediaries', as found in United Kingdom³. This will allow an individual to access professionals trained in a variety of communication methods, and therefore allow them to have a voice. While not necessarily the responsibility of the NDIS, such issues need to be resolved in order that all people with disabilities can access complaints systems and make decisions.

A national and independent complaint body is required to investigate and take action on behalf of the participant. A consistent method of dealing with any complaint including the provision of support for individuals during the process is essential. Advocacy agencies could be funded to take on this role.

The complaint body should have the right to inspect records and fully investigate a complaint with the right to call for any relevant information. A streamlined documented process needs to be developed, published and followed thus allowing all parties to have an understanding and clear expectations of the process.

The complaint body should not be a mediation body. Mediation can be entered into as part of an overall process, but not directed by the complaints handling body.

Information gathered by Community Visitors can also provide important information to inform investigations, remembering that Community Visitors do not take complaints.

Independent advocates are best placed to support individuals to make complaints as they already have a relationship with the community and a good understanding of consumer and disability rights. For people with communication or speech difficulties, advocacy services require expertise in alternative and augmentative forms of communication to assist individuals to participate. There must be a requirement for complaints body to allocate the time, skills and resources to liaise with individuals with complex disabilities when necessary.

To provide a contemporaneous example, the existing Disability Services Commissioner in Victoria has been not provided people with disabilities with an effective complaints mechanism, and has caused significant dissatisfaction for individuals and advocates attempting to address complaints with service providers. The complaints about the ODSC from advocates include:

complex complaints registration process;

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³ http://www.theadvocatesgateway.org/intermediaries

- not disability friendly in terms of access to the office;;
- it does not investigate complaints despite having the power to do so;
- when an advocate is involved ODSC staff relied too heavily on the advocate to facilitate the process;
- little understanding of complex cases;
- the limitation on only providing mediation services.

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Recommendation 14: Establish an 'Independent Communication Support' system that gives people with communication/speech difficulties the same rights as those who are Deaf and can currently access Auslan interpreters.

Recommendation 15: A national complaints handling body needs to be independent of government, NDIA and the service system.

Recommendation 16: Access to independent advocacy services to be made available for people with complex communication needs/disabilities to ensure access to complaints processes.

Recommendation 17: The complaints handling body is required to have the powers to investigate and direct.

5. Monitoring and Oversight

A national system with monitoring and oversight for the operation of the Scheme is essential. The body should be independent of the NDIA, the government disability Department, and of service providers. It should have the capacity to collect data, respond to market failure, and identify trends/gaps for future planning of the scheme.

Recommendation 18: The complaints handling body should also collect data, and identify trends and gaps within the service system.

6. Safeguards for self-managing participants

For those who choose to self-manage their packages it is essential that their staff have some form of registration, as packages are it is public money. There have been a number of cases where families have decided to assist their young adult to manage their package only to find that the individual has been disadvantaged by this

structure. There always needs to be checks and balances to protect the rights of the individual and public money.

Guardians who make the decision on behalf of their family members need to have some understanding as to the potential areas of risk for their family members if they employ people outside the system. A Code of Conduct may not necessarily work unless it is monitored.

Recommendation 19: Self-managed participants require a risk management strategy.

7. Reducing and eliminating use of restrictive practices

If participants display challenging behaviour the least restrictive practice must be the response. Challenging behaviours must be addressed through evidence-based psychological interventions. A national regulator needs to be established that works subject to the National Framework For Reducing the Use of Restrictive Practices in the Disability Sector. All restrictive practices should be mandatorily reported to this body.

A Positive Behaviour Plan must be developed based on a Functional Behaviour Assessment performed by a professional with qualifications in behaviour analysis. A compulsory process similar to that required by Department of Health and Human Services in Victoria in its dealings with people with disabilities pursuant to the *Disability Act* 2006 through the Office of Professional Practice in Victoria needs to be established. Staff working with people with disabilities who display challenging behaviours must receive appropriate guidance and training to competently deal with such behaviours without the need for restrictive practices. Currently, the abuse of people with disabilities in care is so widespread that a National Senate Inquiry is currently on foot. This indicates that current service provision is flawed.

Our strong position is that to subject people with disabilities to restraint and seclusion, (practices which can and have caused injury and death), when evidence based psychological interventions based on behaviour analysis can be used in preference to such interventions, is abuse.

No family member or guardian should be making decisions about whether restrictive practices can be used against a person with disabilities, as they do not have any

qualifications in behaviours to make such a judgement. An independent regulator must determine such things. A Code of Practice is completely inadequate to protect people with disabilities from restrictive practices.

The only instance where a service provider should resort to a restrictive practice is in an unplanned emergency situation. Such a situation could only be deemed to be the first time an individual demonstrated a challenging behaviour.

All Positive Behaviour Plans need to be registered and monitored by an external body to ensure the appropriate expertise is being applied.

While the system to regulate restrictive practices in Victoria can be used as a starting point, it is important to look at the **current failings** of that system in order to build a superior national system.

- ♣ The Office of Professional Practice is not fully independent as it sits within the Department Of Health And Human Services.
- ♣ Positive Behaviour Plans do not need to be developed from a Functional Behaviour Assessment, and any staff member, despite having no qualifications in Behaviour Analysis, can undertake a behaviour assessment and develop a Positive Behaviour Plan.
- ♣ It can only be inferred, due to the quality of Positive Behaviour Plans being collected by the Office of Professional Practice, that there is no real monitoring and evaluation of the quality of such plans.
- Currently, the Office of Professional Practice does not regulate seclusion.

The above has resulted in ineffective behavioural strategies, the continuation of challenging behaviours, ineffective monitoring and evaluation, and a misunderstanding about what constitutes best practice assessment and data collection. It is recommended that independent behaviour teams be responsible for Functional Behaviour Assessments and Positive Behaviour Plans. Service providers have a conflict of interest in the development of such plans.

It is particularly unhelpful when the NDIS propose rewarding service providers who are using restrictive practices. While ostensibly, "Development of behaviour support plans that temporarily use restrictive practices, with intention to minimise use of these practices", 4 we are concerned that such a higher hourly rate will serve as an inducement to use restrictive practices, and reward incompetence. Instead, funding should be put in place for independent behaviour support services.

We endorse Option 4.

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⁴'Support Clusters Definitions and Pricing for Victoria' 19 December 2014 Item 11 004 p46

Recommendation 20: All service providers who use restrictive practices against people with disabilities must comply with the National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector, and be audited for doing so.

Recommendation 21: A completely independent body led by senior staff who have the highest level of recognised expertise in behaviour analysis/restrictive practices regulate restrictive practices and register all Positive Behaviour Plans after careful scrutiny.

Recommendation 22: Each service provider needs to develop policies and practices that are compliant with the National Framework to Reduce the Use of Restrictive Practices.

Recommendation 23: There should be no loading incentive to use restrictive practices.