



## **Response to the Proposal for an NDIS Quality and Safeguarding Framework**

### **1. Disclosure of Interest.**

- My Voice is an independent for profit social enterprise established in 2011 to provide individualised training, enablement and risk mitigation in self-management. The training is based on content and an approach developed from lived experience, local and international research and experience drawn from our participation in three NSW Government self management pilots.
- My Voice has provided training in self-management to more than 120 individuals along with their families and associates. That training has occurred in the homes of individuals across NSW, with more than 60% of students residing in regional areas.
- My Voice is a registered NDIS provider under the plan management category. This category does not however reflect the nature of the service provided by My Voice, as there was no more appropriate category at the time of registration. My Voice accepts referrals from individuals with disability, their nominees, guardians and financial managers as well government and non-government planners and coordinators.
- The views expressed are those of the Directors of My Voice arising from their experience in self management training over the last four years.

### **2. About the Authors (Founding Directors of My Voice)**

Dr Robert Zoa Manga has been a senior medical practitioner and academic in the area of public health operating at a national and international level. He is a person with disability and has been self-managing using a direct payment for more than seven years.

Deborah Frith has worked in the disability sector for more than 30 years in the areas of behaviour management, guardianship and legal issues, advocacy, policy and service development.

## General Comments

### Safeguards and Quality

1. The creation of a quality system of care for people with disability is an ongoing requirement and it must be determined by the outcomes that matter to people with disability and are informed by their experience.
2. A quality system should be measured by the achievement of the outcomes the NDIS was set up to create: choice, control, autonomy and self determination. We would further suggest that we will know we have a quality system when people with disabilities are able to provide their views directly, can provide feedback and have input into the way the system looks and performs.
3. Safeguards are a component of a quality system and should be determined through person centred planning and practice. People with disabilities who feel safe and experience the choice and control over their lives that they want, may not need to access safeguards at the same level or the same way as other people who are experience more vulnerability for example.
4. For those individuals and their families, they need to be supported to create their own informal safeguards, ones that ensure their security, health and wellbeing, with respect for their ability to do so. Strengthening and enabling informal safeguards such as maintaining family relationships, stability in accommodation, access to health and the community should be the primary focus. Flexibility and creativity in developing these should be encouraged. Formal safeguards are necessary when the informal ones fail.
5. The challenge is how to develop such a system that is co-designed and cognisant of individual experiences, cultural, linguistic and religious background, nature of disability, limitations and specific barriers to participation while at the same time providing a system that is reportable and accountable.
6. Safeguards when needed must be able to be accessed easily and immediately for people with disabilities who do not feel safe or who are vulnerable to neglect, abuse and exploitation. In those instances and for those individuals, knowing where and how to access help is critical as well as knowing what ones legal and human rights are. Education forms a substantial part of safeguarding practice for all of the community.
7. Formal systems need to be able to interact or adapt with informal safeguard and quality systems. All systems, regardless of the level should be open to scrutiny and reflection at any given time. Safeguards need to uphold the dignity of a person and should make it easier to access quality care and support rather than make it more difficult.

## **Balancing the discussion of risks and safeguards with enablement and autonomy**

1. Through our experience we are of the strong opinion that self-management with minimal restrictions is of itself a major safeguard for people with disabilities, and can dramatically improve a person's quality of life and health outcomes.
2. Individual needs, choices, goals and aspirations still need to be able to drive the discussion around what is a reasonable risk for that person in that circumstance and how he or she can ensure their own safety and with what level of support.
3. There needs to be caution involved in any discussion on safeguards that does not give equal weight to the need for autonomy and a presumption of capacity and capability. The concept of 'positive risk taking' should be included in the discussion.
4. Capacity needs to be built into the current system to enable professionals and existing services to support people to experience risk in a dignified and safe manner to build resilience and promote the development of individual safeguarding practices.
1. Trust and knowledge that government is commitment to support are necessary if individuals are to engage in any discussion on risks and safeguards. To date, we have had many individuals report feeling that their lives are being unduly scrutinised and that assessments are used to 'test' them and are based on presumptions of incapacity and incapability rather than the other way around. There is considerable concern amongst the community we engage with regarding apparent subjectivity and use of value bases in the judgements that are being used to determine a persons suitability for self-management.
5. There can be an assumption that the current system of registered service providers and appropriately trained frontline workers already provides safe and empowering services. In our experience there are wide variations and we have personally been involved in the training of individuals who have experienced service delivery behaviour ranging from extreme disrespect to abuse and neglect.

## **Self-Management, Quality and Safeguards**

1. People with disabilities and their families need to be given an opportunity to understand the concepts of risk and safeguards and to participate in the development of their own specific safeguarding practices.
2. The maintenance of safeguarding practice is a separate issue and it requires open, transparent and regular review processes where the emphasis is on supporting the person with the disability and his or her family to develop and grow in their capability and prevent foreseeable risks.

3. People should be encouraged to make use of the safeguards that exist in mainstream society before accessing specialised safeguards. For people who are self managing, mainstream safeguards include the ability to access government websites and consumer protection agencies, access information and support telephone lines, access to legal and accounting professionals who understand the nature of self management.
4. To access mainstream safeguards, people with disabilities need access to appropriate technology, accessible buildings, transport as well as strong expectations on mainstream services to respond in accessible ways.
5. In regard to specialist safeguards, case coordinators, planners and other involved in the support of individual plans and the supervision of reporting and outcomes, need themselves to be well trained in how to assist in the development of individual safeguards that also allow for dignity of risk and self determination. Reviewing quality and safeguards should be undertaken in a positive and enabling way rather than as a punitive method or one that seeks to exclude.
6. The ultimate safeguard for many people with a disability is the provision of a quality service that responds to their individual needs, is flexible, cost effective and driven towards the outcomes that enhance a person's participation, health and wellness and autonomy.
7. People with disabilities who we have trained have provided us with consistent feedback that the quality of their lives and their care substantially improves and improves over the longer term when they are able to manage their care and supports in the way that suits their individual circumstances.
8. Individuals who directly employ report that their staff are better trained, are more committed and reliable and maintain long periods of employment. The type of person they are generally seeking has a substantially different profile to the type of person they are provided with when an agency/provider is engaged. There are also early indicators that the ability to dismiss staff or agencies that are not suitable or concerning without unreasonable delay provides individuals and families with considerable comfort.
9. There is some early evidence that people who directly employ may have better health outcomes as their staff are trained to meet their specific conditions and needs and are familiar and work around a person and their families routines and preferences. There may be less family and relationship breakdowns as a result of the stability of these care arrangements.

## Specific Comments

### Possible approaches

#### Option 1: Building capacity of participants to manage their own risks.

1. People need to be given the information and support to be able to identify their own risks and to know what options they have available to them to manage those risks.
2. We are of the strong view that training and mentoring are safeguards in their own right and that such practices can develop the capability of people with disabilities and their families to take greater control of their own care and support and to determine for themselves how to manage the risks involved in their delivery.
3. My Voice provides training in these very specific areas, covering employment options, transition to direct employment, budgeting, risks and responsibilities. We have also developed over time specific competency based approaches so that individuals can put into practice with support the skills they need to manage their own risks.
4. In our experience, when given the information on risks, safeguards, rights and responsibilities, the majority of people act on this information. Generally no one wants to put themselves or their loved ones at risk. However, it is appropriate to expect individuals to undertake continuous improvement activities and to expect external scrutiny of their management of government funding as long as it occurs in a supportive context.
5. There are barriers to the ability of individuals to access mainstream advice and support to assist with safeguards. There is limited understanding of the nature of disability and self-management within a range of professional groups including lawyers, accountants, bookkeepers and insurance professionals.
6. Informed discussion for families around the risks and responsibilities of self-management needs to be inclusive of the risks and responsibilities entailed in *not* self-managing. People with disabilities and their families need to be aware that risks are inherent in any system, with services provided by anyone and that they need to develop the knowledge and skills to determine quality service delivery and to know how to respond to abuse, neglect and exploitation and be empowered to do so.
7. There may be an inherent conflict of interest for traditional disability service providers in increasing access of their current clients to self-management.
8. We have received consistent anecdotal information that people with disabilities and their families are being told that they are not capable of self managing, that it is too hard for them and that the risks are too great by providers who may potentially hold a conflict of interest. This may reduce the capacity of people with disabilities and their families to feel empowered to engage in the design of any new system from the outset.

9. It is crucial that people with disabilities and their families be given access to the same level of 'capacity building' currently being offered to the traditional disability service providers to support the transfer to the new system. People with disabilities and their families have little experience of choice and control and it will take time for people to begin to understand and experience a different approach.

**This option could be further strengthened by:**

1. Approaches that seek to address isolation, poverty, and lack of access to technology and community access.
2. More emphasis on building up the natural and community safeguards that result from a person developing relationships with a range of people not just paid service providers, being able to participate in the workplace, accessing the community, gaining confidence and self esteem by being trusted and having their rights respected.
3. Building the capability of people with disabilities to engage with technology. Most of the My Voice students are too poor to have regular access to the Internet, social media and email. As a result people are generally excluded from information on their general consumer protection and privacy rights, choices, service providers, quality measures, risk and mitigation, unless given it in person.
4. Support for individualised training, mentoring and independent information provision.
5. NDIS facilitating access to police checks on behalf of people where that was required and desired.
6. NDIS facilitating access to reasonably priced insurances for frontline workers.
7. Emphasis on the disability awareness training and discrimination for mainstream and community providers.

**Option 2a and b: Prohibiting and excluding.**

My Voice has no specific comments to make.

**Option 3: Self-managed participants would be required to use a provider who has been approved or screened by the NDIA**

1. When free to determine who will provide them with their supports, we find that most individuals prefer to draw on immediate and local resources. When allowed the option most of the My Voice students would choose to employ relatives, friends and neighbours. People with whom they feel comfortable

with, trust and often already rely on for a range of care and often emergency care.

2. Having to go through a process of registration and approval by the NDIA for such engagement could potentially create delays, require extra administrative work for the person with the disability and impact a person's ability to cease the engagement when necessary in the event that it is not appropriate.
3. Efforts to exert too much control at this early stage might stifle emerging and tentative moves by some individuals towards self determination, particularly in vulnerable communities such as Aboriginal and Torres Strait Islanders.
4. It could also disrupt the emergence of individual solutions that we are witnessing that are unique, highly flexible and developing in unforeseen ways.
5. There are risks involved in the engagement of any service and it would seem more fitting that people with disabilities and their families were given the benefit of being able to respond in the way an 'ordinary' person might rather than having their arrangements unnecessarily controlled in the interests of 'protecting' them.
6. Our comments hold for 3a and 3b as well.

### **Option 3c**

In our view this is an appropriate and reasonable response.

### **Q Should people who manage their own plans be able to choose unregistered providers of supports on an 'at your own risk' basis or does the NDIS have a duty of care to ensure that all providers are safe and competent?**

1. Asserting the right of individuals with a disability to live and be included as equal members of the community and enjoy the same privileges, opportunities *and risks*, has been a long battle over the years. But real and important changes have occurred in that time. People with disabilities have achieved the right to a mainstream education, to receive equal pay for the work they do, to be recognised in the law, to have their human and civil rights upheld, to receive appropriate medical care, to leave the institutions and live next door and to have their decisions and choices respected. Lets continue this process and remove the barriers people with disabilities and their families continue to experience to live life like everyone else in this community.
2. While protection is important, if it is the primary intent, it can have the effect of isolating people with disabilities, reducing their exposure and opportunities to learn in the same way the rest of the community does and reinforces the notion that this is a group apart, requiring care and paternal assistance and not to be trusted to find their own solutions and direct their own lives.
3. There are already substantial and highly effective systems in place for the protection of people with disabilities, including the guardianship and financial management services existing in every state, alongside the powers of



Ombudsmen, complaint bodies, consumer protection agencies and advocates.

4. While there are legal imperatives for businesses and the community to be more inclusive we still have “special schools” and “special workplaces” and “special buses”. Every year there are people with disabilities are not able to access voting booths and exercise their democratic right, cant go to the dentist because they cannot get into the chair, cant get to or stay in a general hospital. Many people with disabilities will still struggle to enter general premises, to be served and to have requests acted upon.
5. There must be an expectation on mainstream Australia to respond to the needs and demands of people with disabilities. Controlling and limiting the services people with disabilities can access will never transfer the onus for change to the general community.
6. It would be our view that the NDIS has a specific duty of care to act on knowledge that it may receive that a provider is not acting in a safe and competent manner. It would be almost impossible for the NDIS to have a duty of care to ensure all providers are appropriate, if as it should be, the term provider extends to *all services in Australia with whom a person with a disability and his or her family member could purchase from*.
7. It could be argued that the NDIS has a more global duty to ensure that people with disabilities are not discriminated against through actions that prevent people from accessing a range of services or acting in a way that is self-determining.

**Q. What kind of assistance would be most valuable for people wanting to manage their own supports?**

2. The current discussion is limited by the lack of involvement from people who are actually self managing and who could provide rather important and relevant views. My Voice is connected to more than 150 people who are engaged in self-management or the process to move to self-management who remain largely unaware of the discussion.
3. We also hold some concerns that decisions will be made before the majority of individuals who may be interested in self-management even become aware that it is an option for them.
4. However, in lieu of that input and from our experience the following kinds of assistance are crucial for people wanting to manage their own supports:
  - Training to commence and training to maintain self-management opportunities, including the nature of risk and quality
  - Training to understand and develop individually relevant safeguards
  - Clearly articulated indicators of what a quality service should look like and behave like.
  - An emphasis on outcome based service development and delivery



- Mentoring from those with lived experience
- Access to technology
- Community and peer networks
- Access to phone based information and support on quality services
- Access to legal information
- Moral support and encouragement from funding bodies with emphasis on the dignity of risk
- Assumptions of capacity and capability
- Reasonable adjustments
- Disability support equipment
- Access to reasonable costed transport
- Well trained and planners who receive peer supervision which enables them to understand and reflect on their own values and experience and how that impacts on the lives of people with disabilities when they are in a position of decision making about a persons life.

Thank you for the opportunity to provide this response. The Directors of My Voice are available and interested in participating in further discussion.