

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

Thank you for the opportunity to share our views on the NDIS quality and safeguard framework.

### **About the authors:**

We are a collective of organisations committed to building skills, knowledge and confidence of people with disability and families in self direction. We do this in different ways

1. Capacity building: information provision, training, peer support, coaching and mentoring, leadership skill building
2. Tools and infrastructure supports: assistance with HR functions, support package hosting, financial intermediary and management services
3. Implementation and facilitation: planning support, implementing plans, service co-ordination, exploring and developing people's community networks and service options.

In some cases, the people we work with have chosen direct payments (known by the NDIA as 'self management') and/or are directly employing support workers.

This submission and its recommendations reflect our extensive professional experience in the sector and the lived experience of a number of our members as people with disability and family members.

Looked at more broadly, therefore, we are part of emerging responses by people with frontline experience in self direction to addressing areas of possible risk.

We therefore propose it would be more helpful to look to grassroots solutions being developed in the sector around these questions and to ask 'what systemic support could be offered to help these solutions flourish?'

Throughout this submission we use the term "self direction". We have done this to move beyond the narrow expression provided in the consultation paper. We also use this term to acknowledge there are a variety of ways people can self direct. Self directing supports is a safeguard in its own right and we propose that this needs further understanding, enhancement and protection.

The following definition of self direction from Dowson and Salisbury (1999) incorporates the ideas of recognising ability, citizenship, and inclusion in community: "...public funding that is allocated to the individual based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in the community as a full citizen"<sup>1</sup>.

We have used the term 'self management' where it relates directly to descriptions in the consultation paper.

---

<sup>1</sup> [In control Australia](#)

While this submission focuses on "Safeguards for participants who manage their own plans", we believe many of the comments and recommendations are applicable to other areas of the consultation and to all people with disability and families utilising paid supports, whether through disability services or through their own means.

### **Contributing organisations:**

**Community Disability Alliance Hunter Inc.** (CDAH) is a user led disability support organisation, run by and for people with disability and their families. We aim to assist people to get the support they need to live the lives they choose. We are an independent, collective voice committed to full inclusion and active citizenship. <http://www.cdah.org.au>

**InCharge** is a social enterprise that helps people with the 'how' of self direction through the provision of group learning opportunities and programs, as well as individual assistance. It also works with service providers interested in supporting people to take more control of their supports. <http://www.incharge.net.au>

### **Jeder Institute – Pathways to Leadership**

Jeder Institute is a ground-breaking, dynamic organisation who brings people together to realise their full potential and build on their existing networks and community strengths! We believe that everyone has abilities and everyone has something to contribute to their communities because there is no one we don't need!

Jeder Institute's practices are all strengths focused and are as varied as they are interesting. They include a range of methodologies and practices to support individuals, families, communities and organisations to identify and build on their existing strengths.

Pathways to Leadership provides advice, support and services to individuals and families who are self-directing their personal support funding from the NDIS, NSW Government or private funds <http://www.jeder.com.au>

**Mind the Gap: Disability Matters** is a social enterprise and has been working in the disability sector since January 2012 assisting people with disability and families build their skills and confidence to exercise choice and control over their supports and develop a vision and actions to achieve a good life. We are registered with the NDIS to provide *Assistance in coordinating or managing life stages, transitions and supports* and *Management of the funding for supports under a participant's plan*. We also assist a number of NDIS participants to self direct their support and directly employ their support workers. <http://www.mind-the-gap.net.au>

## Bias in the consultation framework

While the principles guiding the development of the quality and safeguard framework are sound, these principles are not evident in the discussion on the self management of NDIS plans. Instead, we argue the concept of self management proposed in this paper has been framed in a highly narrow way, and as an overly risky proposition both for the individual and the scheme. For example, the paper assumes that NDIS registration equates with protection. We can see this in language such as "those who choose to have the NDIA manage plans for them will have the protection of using registered providers..." and that registration automatically brings "additional assurances" to people.

There appears to be a bias. That is, an overly positive view of how disability services are currently organised and protections delivered against a negative view of new ways that could enable people to have greater autonomy and flexibility in having their support needs met.

The safeguards given the most weight in the consultation paper rely on a regulatory framework of registered services and vetting of staff. We must highlight that reliance on such regulation does not ensure safety and wellbeing.

Most recently we have seen the failures of the "system" and regulatory frameworks being documented in the Royal Commission into institutional responses to child sexual abuse<sup>2</sup> and Senate Inquiry into violence, abuse and neglect of people with disability in institutional settings<sup>3</sup>.

This is not old news. The Bolshy Divas' submission, "the uncounted"<sup>4</sup>, to the above mentioned Senate inquiry documents forty examples of violence, abuse and neglect that occurs in a wide variety of settings and many continuing to this day. Less than a fortnight ago Max Jackson, in *the Age*, highlighted that "despite rapes, deaths and neglect in care, the disability sector is obsessed with self-protection"<sup>5</sup>.

In short, these regulatory frameworks on their own often fail people with disability and we therefore consider it folly to focus on these alone.

Secondly, we are concerned that the discussion on self management does not address this need for safeguards and quality assurance in the broader context of self-determination and citizenship. If this was the case, the consultation paper would be more focussed on the principles of dignity of risk, how to support genuine choice and control (for example by asking how self direction could be further supported as a choice of equal weight), the presumption of capacity and a developmental framework, rather than on regulation and administration.

The paper takes a 'one-size-fits-all' approach to safeguards without due emphasis on developmental investments in people, building citizen capital and the development of individual safeguarding capacity.

---

<sup>2</sup> [Royal Commission into Institutional responses to child sexual abuse Resource Centre: people with disability](#)

<sup>3</sup> [Senate Inquiry into violence, abuse and neglect of people with disability in institutional settings 2015](#)

<sup>4</sup> "The Uncounted": Bolshy Divas. Submission to the Senate Inquiry into violence, abuse and neglect of people with disability in institutional settings, 2015

<sup>5</sup> [The Age \(20 April 2015\), Max Jackson: "what has changed in disability care since the 1980s and 90s"](#)

Thirdly, the paper does not outline the merits and benefits of self direction including, what we consider are some of its inherent safeguards.

There are a number of ways a participant can self direct their NDIS plan, including using a combination of options. Participants can use their funds to engage support workers from a registered service provider, non-registered provider or contractor or they can become an employer themselves (or a combination of both). They can use a plan manager, service co-ordinator, incorporated circles of support or any number or combination of innovative responses.

The diversity of different ways people are self directing should therefore be protected and enhanced, as these are ways people are finding, for themselves, to create better lives and citizenship.

## Safeguarding is having a good life

The primary function of safeguarding is not only protection from harm but also to promote a person's wellbeing. This means people receiving the support they need to achieve "a good life, to be active and equal citizens, to reach their potential AND to promote their safety"<sup>6</sup>.

Increased safety does not come from continuing to be segregated. It does not come from only having paid support and disability service providers in your life. In fact, the very opposite. This means people spend most of their lives in the role of client as a passive recipient of services. Therefore having a system of registered providers and vetted staff, many of whom could still be segregating people (even with individualised funding packages) and not supporting participants to take more control of their supports, ultimately leaves people more vulnerable.

We make people safer by connecting them to a wide range of other people, making sure they are visible and present in their local communities, building confidence and self-esteem, sharing knowledge and information about rights, developing advocacy skills and having access to advocacy support.

It was difficult to see what the consultation paper was offering as safeguarding propositions in this area of long term, highly nuanced capacity building and community development work?

Increasing numbers of people are finding that self direction offers ways of getting these things - choice and control and connection and presence in communities - in part, because they have not found these outcomes through traditional disability service providers. Self direction supports people to move from the role of client to contributor.

This is not to suggest that self direction is without risks or challenges, or that it is a panacea<sup>7</sup>. No system is; including a system of 'registered providers' and 'vetted staff'. Rather, when well supported, self direction brings many benefits a number of which are safeguards in their own right.

## Benefits

- People with disability and family members who self direct their support report improvements in the quality of their lives. This view is supported by numerous peer reviewed studies<sup>8 9 10</sup>

---

<sup>6</sup> Walker, M. Fulton, K. and Bonyhady, B. (2013) "A personalised approach to safeguards in the NDIS" .  
<http://www.centreforwelfarereform.org/uploads/attachment/385/a-personalised-approach-to-safeguards-in-the-ndis.pdf>

<sup>7</sup> Knebdrick, M. (2005) "Self Direction In Services And The Emerging Safeguarding and Advocacy Challenges That May Arise: A Discussion Paper For An Exploratory Study Session June 9, 2005, Hartford, CT., Hosted By The Connecticut Office Of Protection And Advocacy"

<sup>8</sup> Glendinning, Caroline, David Challis, José-Luis Fernandez, Sally Jacobs, Karen Jones, Martin Knapp, Jill Manthorpe, Nicola Moran, Ann Netten, Martin Stevens and Mark Wilberforce, *Evaluation of the Individual Budgets Pilot Programme: Final Report*, York: Social Policy Research Unit, University of York, 2008, <http://www.york.ac.uk/spru/pubs/1119>

<sup>9</sup> Riddell, Sheila, Linda Ahlgren, Charlotte Pearson, Victoria Williams, Nick Watson and Hazel MacFarlane, *The Implementation of Direct Payments for People Who Use Care Services: Report to the Scottish Parliament Health Committee*, (Scottish Parliament Paper 624), Scotland: Scottish Parliament,

- Self direction by its very nature is person centred and tailored to the individual based on their needs, preferences and circumstance.
- Self direction can more easily bring people into the heart of the community. Because people are no longer only connecting with disability service providers they are finding themselves freer to direct their resources to pursuing their own interests, to work, volunteer and contribute in myriad ways that make sense to them.
- Self directed funds can be used to encourage, enhance and complement informal support arrangements.
- Individuals who self direct and/or recruit their own support find that their staff are better trained, are more committed and reliable and maintain long periods of employment.
- With the freedom to recruit and employ support, people with disability and families generally seek support workers who have a substantially different profile to that of support workers employed by a service provider. Self direction enables a better match between person with disability and support.
- There is early evidence of better health outcomes when people directly employ as staff are trained to meet their specific health needs.
- Similarly there is evidence that families continuing capacity to provide informal support as a result of the stability of direct employment.
- Recruiting and directly employing support means that the individual support workers have lesser conflict of interest. Their commitment lies with the person they are supporting who is their employer rather than their commitment being divided between the person(s) they support and his or her employer.
- People who self direct are able to recruit support particular to their specific lifestyle, circumstance, interests, culture and values
- People who choose direct employment often do so because service providers have been unsatisfactory at meeting their support needs. This may be because of cultural and linguistic reasons, geographic remoteness, the need for flexibility in the provision of support or the experience of abuse, neglect and exploitation from traditional providers.

---

<sup>10</sup> Purcal, C., Fisher, K. R., & Zmudzki, F. (2014). *Direct funding trial for attendant care support: Evaluation Plan (SPRC Report 6/2014)*. Sydney: Social Policy Research Centre, UNSW Australia.

## **Creating fruitful conditions, not imposing conditions**

Option 1. of the consultation paper- *participants who manage their own plans* - proposes that if a participant chooses a non NDIS registered provider that the NDIS could provide some information on how to go about hiring a provider.

While we support this option, this is a very low level role being offered here. There is so much more that can be done.

## **Supporting a personalised approach to risks, vulnerabilities and safeguards**

People actually vary significantly in their safeguarding needs. Factors that influence it include our age, preferences when it comes to risk-taking, culture, family practices, mental health, availability of advocacy and support, presence of informal networks and the services we are supported by.

The people we know who choose self direction are often heard to say that the potential risks and the safeguards employed to avoid them are of far less significance to people with disability and their families than the flexibility, freedom and quality of life that self management enables. In addition, many people say that, while they have made mistakes, and things don't always go right, self direction offers people the immediate power to be able to act to rectify that situation. For example, one of the authors remembers never being able to get to the bottom of situations, or to find out where the responsibility lay in multiple instances where their family member was harmed whilst living in congregate care. This contrasts to a situation once they began self directing. For example, they were more quickly able to discover and fire a worker who had been drinking on shift. Yes they hired that person (who 'passed' all relevant employment checks). But self direction meant they had the power to take decisive action.

We argue the planning process should be used as an opportunity for the identification of risk and vulnerability that relates directly to that individual. This would initiate a process that allows discernment of that person's fundamental needs and requirements, to complement the focus on goals and aspirations. It would also support people (alongside trusted others whether it be family or other) to identify their own vulnerabilities and risks.

Our organisations work in this way with people and have developed successful processes around it. We find most everyone we work with inherently know the areas of their lives where they are more vulnerable. What they often lack are processes and supports which enable them to articulate these and then ways to turn those into practical and empowering strategies to minimise that risk.

This approach would allow for targeting of safeguards and supports (rather than broad brush approaches) and therefore minimise investments in things that offer little specific value. This methodology is more consistent with the principles espoused in the consultation paper, supporting a personalised approach, autonomy and negotiation rather than imposed solutions.

### **Example:**

One of the authors recently worked with an individual in receipt of a package of support to enable him to move out of the family home. While this was exciting, there was much trepidation by

his family. The parents were supported to practically work on these issues. The organisation suggested that they form a small group with some current support workers and interested family members. Led by the man's mother, they created a 3 page list of "What If's" which ranged from "What if the house key is lost" to "What if the housemate is a bad person". This had the effect of enabling the mother to articulate all her fears in a supportive environment, and therefore not continue to be held back by them. It enabled others to understand those fears and take them seriously. The group then set about together addressing each one of those issues and creating simple solutions, preventative measures and ways of dealing with it in the event it did happen. They set about creating their solutions, in crucial part, by contacting other individuals and families who had already put successful strategies in place. The role of the supporting organisation is an example of third party assistance to people to do these things themselves, seek relevant information and link with others.

#### **Vignette:**

One author of this paper attending the NDIS quality and safeguards consultation session heard concerns raised as a scenario of the risk to a blind person engaging a cleaner who steals from them. Being blind herself, she found it unhelpful and impertinent that someone else would make such assumptions about risks and vulnerability.

Supports and safeguards that are negotiated on an individual basis can then evolve as circumstance requires. These strategies and safeguards become part of a person's plan and help to support 3 things:

1. A personalised and therefore proportionate approach to risk
2. A potentially powerful developmental approach
3. An assumption of knowledge and capacity by the person

These principles are articulated in the consultation paper.

In addition, we argue that this is equally necessary regardless of whether a person is managing their own plan (or part of it) or using agency registered services.

## **Investment in Tier 2: Information, linkages and capacity building (ILC)**

Borrowing from Walker, Fulton and Bonyhady (2013) we believe an approach that invests in the citizen capital of individuals and their families will create the strongest and sustaining safeguards.

If there were real commitment to promoting and supporting self direction as a genuine choice for people in the NDIS, the question below would become a key part of developing a safeguarding framework:

"What are the key supports that people in self directed situations ought to **routinely** have available to them?"



## **1. Ongoing investment in peer mentoring**

There has been some welcome investment in the development of peer networks around Australia. We believe this should be an ongoing investment.

We are committed to the belief that peer guidance and mentoring are safeguards in their own right. They are essential to people with disabilities and their families taking greater control of their own support and determining for themselves how to manage the risks.

Peer support is a critical starting point for people learning to direct their own supports, manage their funding and identify and find strategies to mitigate risks.

As people with disability and families navigate significant changes to the management and provision of support, peer support provides highly practical information, reassurance and working strategies to those 'What If' questions. Through peer support people with disability and families are empowered to try new approaches and strategies, particularly when they encounter someone who has previously experienced similar changes.

### **Example:**

Community Disability Alliance Hunter's peer support meetings are a regular get-together where individuals can bring an issue they are having with directing their support. The group work together to problem solve and support the person resolve their issues. This might involve group members sharing their own knowledge and skills and/or referral to specialist services.

## **2. Training and mentoring**

A personalised approach to identifying vulnerability and safeguards should support people to then be able to do something about that.

Having been assisted to identify risks, gaps in knowledge and skills, people should be assisted to then access training and information on addressing these, including peer support.

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.

Our work shows that the way to assist people to be safer is to support them to be both part of the identification of vulnerability AND the implementation of practices to mitigate that risk.

For example, if people who are seeking to hire staff can be supported in the vetting and management of staff, if they can be supported to know how to fire them, then those individuals whose behaviour is abusive and malevolent are likely easier to detect. An abusive or otherwise unsatisfactory support worker can more easily circumvent detection if they are working with unsupported, unskilled and disconnected individuals with disability.

### **Example:**

One of the authors is currently supporting an individual who is using an NDIA registered provider, but has continually indicated a strong dislike for a support worker who he is intimidated by. This case is a perfect example of how registration alone provides little safeguard in a situation where the man feels unable to complain and has little skills or support to take action.

### **3. Supportive infrastructure**

What is needed is continued investment in the development of supporting infrastructure around people. This is also a crucial aspect of a safeguarding framework for people managing their own plans, and indeed for the safeguarding framework generally.

In our experience, people do not put themselves or their loved ones at unreasonable risk and when given the information on risks, safeguards, rights and responsibilities, they act on this information.

The people and families we assist have also found innovative ways to manage risks by utilising mainstream services such as lawyers, bookkeepers, community colleges and so on which becomes a further safeguard as they increase their level of community engagement.

It is important to us that a national system has the fundamental belief in people's capacity to make decisions about their own safeguards, to provide a system that is simple and flexible in its structure yet robust in accountability.

So such infrastructure support could include investment in developing:

1. Networks around the person like circles of support and microboards.
2. Consumer or family governed collectives, which are ways that people can pool their resources to support each other and have assistance to develop their own solutions, as well as collectively manage a number of supports. Examples of such networks include Kalpana in Brisbane, Supported Living Network in Sydney, and Living Distinctive Lives in Victoria.
3. As mentioned there are organisations emerging which seek to support people with the business side of their arrangements through payroll and other financial intermediary services. There are organisations that can assist people learn their responsibilities as employers, manage and mitigate the risks they identify. The authors of this paper, for example, are all involved in providing such assistance.

### **4. Access to independent advocacy**

Individual, self and family advocacy are a priority to ensure people know their rights and have their rights respected. Advocacy is also vital for when things go wrong. People need access to prompt and efficient advice to help them resolve problems.

## **Being able to come back to the NDIA**

It may greatly assist people who have chosen to manage some or all of their plans, to know that they could come back to the NDIA should they hit a difficulty or potential area of risk they feel unsure how to deal with. The NDIA would not be charged with its resolution, but rather with re-directing people to places where they can gain assistance.

## **Looking to the evidence and deciphering best practice**

There is little information in the consultation paper on the benefits of self direction including a lack of references to peer reviewed literature produced internationally and in Australia.

Direct payments and self direction, although relatively new, still has a history in Australia worth investigating. Canada, Sweden, England and Scotland have had direct payment options since 1990s. They have grappled with these issues so it is worthwhile to look to these experiences to see what works well, what is needed to be in place for people to self manage and lead good lives.

Many jurisdictions in Australia have shared management options, where an eligible service provider holds the funds but allows people to recruit and manage their own support. The NDIS could develop a consultation process that seeks to discern the best practices that have emerged in Australia and internationally, including those things found not to have worked well.

The NDIS could be a mechanism for innovation by helping people to build their ideas and develop flexible and tailored support arrangements - driving innovation and responsiveness from service providers as well as promoting support to genuinely include within the community as an active and value citizen.

This is surely the foundation upon which to protect, enhance and enable self direction to flourish. We would happily provide a list of organisations and key individuals of influence in this area.