



Submission to consultation on National Disability Insurance Scheme Quality and Safeguarding Framework

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Summary of Recommendations

1. That supported decision making to be internalised in the NDIS culture and staff training in a systematic way. A training module for NDIA Planners should be produced in partnership between a reputable inclusion organisation and university.
2. That capacity building organisations are funded ongoing to support people with disability (and, where appropriate, their families) more intensively with visioning and decision making. This will assist people to develop capacity to understand context and interpret information in order to make decisions about their lives.
3. That research is commissioned to assess this training for NDIA staff and the work of supported decision making in capacity building organisations.
4. That information, linkages and capacity building funding is ongoing and considered in any quality and safeguarding framework.
5. That the next round of funding for ILC include specific funding for several organisations in all States and Territories to support people to develop the skills to self direct and self manage their funding.
6. That funding directed to support people to develop the skills to self direct and self manage their funding should be researched and evaluated accordingly.
7. That the Quality and Safeguarding Framework recognise advocacy as a key safeguard, and focus on improving the opportunities for people with disability, as well as independent advocacy, information and representative organisations, to provide ongoing feedback to government through structured mechanisms.
8. That the Quality and Safeguarding Framework recognise families as a key natural safeguard for people with disability, and focus on upskilling and developing their capacity and advocacy skills to safeguard their family member.
9. That the framework contains a recommendation that a right to independent advocacy, representation and information for people with disability to be enshrined in legislation.
10. That registration should be minimal for low risk services and differentiated according to the type of service.
11. That quality evaluation does not focus solely on qualifications but recognises the importance of value and role based employment.
12. That an independent national complaints agency for the disability sector be established under legislation and that it address individual issues and document systemic level issues.
13. That a complaints body should have responsibility for promoting access to advocacy and supported decision making.
14. That a national Working with Vulnerable People Check be established. This check should look at a wider range of information including AVOs, child protection orders,

lapsed charges and work history. It should be national and harmonise with checks in other industries.

15. That where people with disability and their families choose to self-direct payments, they have some flexibility as to the performance of the checks.
16. That capacity building organisations be funded to provide self-managing participants with assistance when hiring and managing of support staff, including optional checks and registration,
17. That NDIS participants be empowered to self-manage their funding by having the option to choose to use unregistered providers whilst taking responsibility for the risks.
18. That information is provided to all participants, and where appropriate their families, about how they can access self-directed and self-managed options, including the risks and safeguards associated with this option as with any service based option.
19. That the NDIA support options whereby the management of and payment for support staff is shared between participants and service providers and brokers or intermediaries.
20. That the NDIA consider contracting support for those participants who choose to employ people directly, by making a bulk purchase of employment support from Jobs Australia or a similar provider.
21. That the NDIS adopt a restricted practices safeguarding policy which includes authorisation measures from Option 4.
22. That the NDIS adopt a restricted practices safeguarding policy which includes monitoring measures as in Option 2.
23. That the NDIS implement training in any community visitors scheme which ensures visitors can identify when restraints are having flow on effects for others if the person subject to restraint is in a congregate environment.
24. That if a person with no family or friends able to assist them is subject to restrictive practices, they should have an independent, fully funded advocate allocated.

Introduction

Family Advocacy is a state and federally funded disability advocacy organisation in New South Wales (NSW), founded by families of people with disability. Our goal is to advance and protect the right of people with developmental disability to achieve meaningful lives and enjoy the same opportunities and living conditions as the majority of Australians. The organisation has a high presence and profile across the State:

- building the capacity of families to undertake an advocacy role;
- auspicing a successful ongoing capacity building project, called Resourcing Families;
- developing leadership skills in families;
- making representations to Government regarding legislation, policy, funding, monitoring and practice and the extent to which they reflect the needs of people with developmental disability;
- and providing advocacy related information, support and advice.

Accordingly, the focus of our submission is on the impact of quality and safeguards on participants and their families.

Family Advocacy performs a combination of family and systemic advocacy in NSW. “Family advocacy is an independent, community-based model that usually involves family members acting on behalf of a son or daughter or sibling” (Weafer, 2003, p.39), and “systems advocacy lobbies for reform and change of social systems and structures that discriminate against, abuse and neglect people with disabilities” (Seymour and Peter, 2004, p.12). Advocacy is a cornerstone in the lives of people with disability and those that love and support them, ensuring that their rights are protected and they have natural safeguards.

Family Advocacy helps families to advocate on behalf of their child for a good life with the things most of us would expect in Australia: education in a regular classroom at a local school, a place in the community amongst friends and family, and the supports, informal and paid, necessary to make that happen.

Case study

A mum may call Family Advocacy because she is facing difficulty at her son or daughter’s school when asking the classroom teacher to make reasonable adjustments to the curriculum for her child with disability. Adjustments are needed so that he or she can continue to be included in the regular class at the local school. Family Advocacy staff would work through her options; provide her with information about her child’s rights; support her to be assertive in asking for her child to be included, and to look for a mutually workable solution in dialogue with the school.

Family Advocacy supports the National Disability Insurance Scheme (NDIS) view that quality and safeguards are imperative for the wellbeing of participants in the NDIS, and for the longevity and functioning of the NDIS itself. Therefore we welcome the *Consultation Paper: Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework* (henceforth, the consultation paper) and the dialogue it enables. Following the format of the consultation paper, this submission is in two parts, dealing firstly with the overall framework and secondly with the detailed proposals.

Overall framework

The advent of the NDIS Quality and Safeguarding Framework presents an opportunity to further unravel what choice means in a practical sense, especially for those whose whole lives have often been subject to control by others. Family Advocacy suggest that creating infrastructure and culture within the NDIS, services and wider community that supports people to have high expectations for their lives, to make decisions for themselves where at all possible, to think outside the congregate or segregated service model, and to challenge decisions or options that limit them, will be the strongest safeguard. The three things most imperative to this outcome are supported decision making, capacity building, and a strong advocacy sector to assist people in ensuring their rights are practiced and promoted within disability systems and in broader society.

Supported Decision Making

The knowledge that we have the right, and responsibility, to make decisions that affect outcomes in our lives, is something that many people take for granted. However, making decisions is a skill, and like most skills, it requires practice. For many people with disability, particularly intellectual disability, this is an area where they may have limited experience. Assumptions about a person's capacity, as well as limitations such as literacy, or other cognitive impairments, may mean that a person with disability has not had the opportunity to practice this skill, and indeed, that all aspects of their life might be controlled by others. For parents of kids with disability, they may find that professionals and medical specialists dominate decisions about their child.

Unfortunately, there is little research on supported decision making for people with intellectual disability; however, it is regarded as best practice within the sector. The supported decision making model fits well with the NDIS's focus on choice, control, and individualised options. The process of supporting people with disability to make choices has been well documented in a series of resources by Inclusion Melbourne, available online and attached as an appendix to this submission.

Supported decision making is, in essence, a process of supporting people whose capacity may be in some way impaired, to have choice and control over some or all aspects of their lives. In practice, there are numerous and sometimes conflicting definitions (Dinerstein 2012). Inclusion Melbourne helpfully explains choice by dividing it into every day, lifestyle and pervasive choices. They argue that choices at one level should not conflict with choices at the other levels, if a person is to have a satisfying life experience. Therefore support for people's choices must be present in capacity building but also throughout the NDIS and broader services. For example, if a parent wants the pervasive choice of an included life for their child as an adult, where possible, it will be best to avoid congregate and segregate environments in childhood, in everyday and lifestyle choices. They will have more capacity to make these choices if the school system supports this. Inclusion Melbourne notes that "personal experiences may be limited by money, experience or what is possible. Nobody is completely free to choose and pursue any choice they wish. What is important is whether the limitations experience[d] are reasonable or not" (2013 p. 6). Supporting people to gain knowledge of contextual factors and their own preferences is what supported decision making is about. It works with broader systemic inclusion.

Family Advocacy encourages supported decision making to be internalised in the NDIS culture and staff training in a systematic way. We consider that this would support NDIS's goal-based planning, which already uses a strengths-based approach and "seeks to maximise your choices and your independence" (NDIS 2015). We also suggest that due to the limited time participants have with planners, that capacity building

organisations are funded to work more intensively with participants and families regarding decision making, as well as natural safeguards and supports.

Recommendation 1

That supported decision making to be internalised in the NDIS culture and staff training in a systematic way. A training module for NDIA Planners should be produced in partnership between a reputable inclusion organisation and university.

Recommendation 2

That capacity building organisations are funded ongoing to support people with disability (and, where appropriate, their families) more intensively with visioning and decision making. This will assist people to develop capacity to understand context and interpret information in order to make decisions about their lives.

Recommendation 3

That research is commissioned to assess this training for NDIA staff and the work of supported decision making in capacity building organisations.

Capacity Building

Family Advocacy supports the inclusion of information, linkages and capacity building (ILC) in the NDIS architecture. Given the limited time that participants will have with NDIS planners, capacity building will remain important through the life of the NDIA. Family Advocacy encourages the NDIS to view safeguards in the broadest sense of creating infrastructure that connects, supports and strengthens people with disability and their families to manage risk.

The need for investment in capacity building for people with disability and their families has been well understood and documented well before the earliest stages of the NDIS. The Productivity Commission report into disability care and support explicitly stated that initially, most people with disability going through the shift from a service model to a model based on personal choice and decision making would need support to do so in a way that the NDIA itself cannot provide. The report also quoted Pave the Way, noting:

... whole of life and succession planning is vastly different from service planning ... Services might play a role in assisting individuals to achieve some goals, for example, those concerning home, work, recreation, communication and education, but are unlikely to play a role in many other aspects of the individual's life, such as personal security, financial security, decision making, relationships and friendships, health, spirituality and developing individual passions. Services can assist people to have a good life; they do not constitute a life (sub. 528, p. 9).

The Productivity Commission report also noted that capacity building organisations face lower 'search costs' for services and supports than most people with a disability due to their knowledge and experience, thus lowering the costs of the NDIS for participants and consequently helping to contain the overall costs of the NDIS.

There is significant funding in the disability service system to assist services to transform and build their capacity to deliver individualised services. This investment must be matched with an investment in the capacity of people with disability and families, ongoing, both for the inherent value of such investment as well as in order to ensure demand for the changed paradigm as a safeguard to regression to the old service centric system. Many families of people with significant disability who have been associated with Family Advocacy (and its capacity building arm Resourcing Families) over many years, have experienced the benefits of capacity building. Here is just one example.

Case Study

Mac Wilson-Burns was once described as the 'most disabled child ever to be mainstreamed'. Mac is now in Grade 4, working at grade level using a combination of partner assisted foot switches, typing in Morse code, using auditory and visual scanning and his 'old faithful' yes/no foot switches.

His mother Gina is actively involved with Family Advocacy as Mac (age 10) pursues an inclusive education in a regular setting, with his friends, despite his multiple, severe disabilities.

See more at <http://inkyed.wordpress.com/>

In particular, Family Advocacy encourages capacity building organisations to be funded to assist people to self direct and self manage their funding packages and for some ILC funding to be directed explicitly to this purpose. It should be researched and evaluated accordingly. Employment support organisations in England and Sweden have been using this approach successfully for some time and may provide a helpful model (Goodwin 2014 p.68-69). Self direction and self management allow for unprecedented levels of control and independence over one's life, however, they also involve skills that

few people with disability will have previously developed. Thus, specialised support will be necessary to ensure the success of such approaches.

Recommendation 4

That information, linkages and capacity building funding is ongoing and considered in any quality and safeguarding framework.

Recommendation 5

That the next round of funding for ILC include specific funding for several organisations in all States and Territories to support people to develop the skills to self direct and self manage their funding.

Recommendation 6

That funding directed to support people to develop the skills to self direct and self manage their funding should be researched and evaluated accordingly.

Advocacy

Currently the Commonwealth and New South Wales (NSW) Governments fund advocacy organisations, information services and representative bodies to ensure people with disability have a voice in the actions of government that affect their lives. Family Advocacy provides the NSW government and Commonwealth government with feedback regarding issues as they relate to people with disability. We also provide families with information and advice about how to make the voice of their family member with disability heard to government and to both disability-specific and broad-based service providers.

Advocacy promotes rights, positive systemic change, and the voice of people with disability. This cannot be done effectively by an organisation that provides services, because there is a fundamental conflict of interest. For people with disability, the NDIS is only the beginning of social change and one piece of the puzzle, and advocates want to ensure that when people with disability face barriers within the NDIS and within broader society, they have an independent, effective and experienced voice behind them.

At present the agreement between NSW and the Commonwealth Government signs over all disability funding from Ageing, Disability and Home Care (ADHC) to the NDIS by 2018. This includes funding for advocacy.

Family Advocacy considers that rights to independent advocacy should be written in to legislation in Australia as in England's *Care Act 2013*. Similarly in Scotland a person with disability has a legal right to independent advocacy under the *Mental Health (Care and Treatment) Act 2003* (Goodwin pp. 49-50).

While Family Advocacy provides both family and systemic advocacy, we also argue that there is a critical need to engage people, who may not have personal connection to a person with disability, in advocacy in order to create more advocates, more relationships and more movement toward inclusion. Therefore citizen advocacy programs should be valued and funded. Hindle states that:

Citizen Advocacy happens when a valued and competent citizen who is unpaid and independent, with the support of an independent Citizen Advocacy office, represents the interests of a person who has a disability as if those interests were her or his own (1993 p.29).

Funded programs for family and citizens, that support unpaid individuals with intrinsic motivation to advocate for people with disability, are efficient, long-term and strategic. In addition, some people without natural supports or in particular cases, will require more intensive individual advocacy, and this is also a critical safeguard, as in the case of restrictive practices (see p. 15 of this submission).

Case study

In the mid-nineties when thousands of parents of children with disability were being refused enrolment in the regular class of the local neighbourhood school, advocacy agencies campaigned to change education policy and education infrastructure so that students with disability could expect a quality education together with their peers.

While initial advocacy efforts led to the physical presence of students with disability, teaching practice and school attitudes kept them marginalised. In response, advocacy organisations worked both outside government (through campaigns, letters, articles and discussion papers) and inside government (on working parties and advisory groups) to enable children and young people with disability to have the same opportunities as their peers without disability.

Recommendation 7

That the Quality and Safeguarding Framework recognise advocacy as a key safeguard, and focus on improving the opportunities for people with disability, as well as independent advocacy, information and representative organisations, to provide ongoing feedback to government through structured mechanisms.

Recommendation 8

That the Quality and Safeguarding Framework recognise families as a key natural safeguard for people with disability, and focus on upskilling and developing their capacity and advocacy skills to safeguard their family member.

Recommendation 9

That the framework contains a recommendation that a right to independent advocacy, representation and information for people with disability to be enshrined in legislation.

NDIA provider registration

Family Advocacy recognises the tension represented in the consultation paper regarding provider registration i.e. that of balancing safety with the most choice and control possible for people with disability.

Family Advocacy looks at this problem through the lens of the question ‘What will assist people to get the supports they need to have a normal life?’ In answering this question, it becomes clear that not all services required by people with disability, and paid for from NDIS funding, for example tradespeople, should require registration with the NDIA. If registration is required for these types of everyday services, it should be the lowest barrier possible whilst meeting universal legal requirements. Differentiated registration would allow regulation to be targeted to the type of service provided. Thus personal care or social support provision would be subject to far greater regulation than, for example, gardening. In terms of the options provided in the paper, Option 2 (pp. 34-35) appears to provide the balance of potential for quality evaluation with legal requirements and also to allow swift entry where participants may wish to make new arrangements.

Additionally, while the paper focuses on quality evaluation and assessment, it is imperative that the disability sector pursues value based and role based employment, rather than more qualifications, if people are to be assisted to lead normal lives. Value based employment means that people with disability will be supported to lead included, ordinary lives by those with appropriate skills and values. People with these skills and values may be better sourced from the full diversity of people in the community, perhaps through family or school networks, rather than solely from the pool of those with disability or medical qualifications. Role based employment means that support staff may be selected partially based on roles they fill in the community that may directly benefit a person with a disability due to that person’s interests or goals.

Case study

*For a teenaged boy needing support to attend age-appropriate social activities, a young man with sporting **roles** in a local club or team, a social network in the area, and who has inclusive **values**, may be more appropriate as a support person than someone with qualifications in disability studies.*

Recommendation 10

That registration should be minimal for low risk services and differentiated according to the type of service.

Recommendation 11

That quality evaluation does not focus solely on qualifications but recognises the importance of value and role based employment.

Systems for handling complaints

Family Advocacy always recommends that people attempt to resolve complaints internally or informally in the first instance. However, we know from experience that this is not always possible, and that the results of abuse, neglect, and other breaches of trust and professionalism can be devastating for people with disability and remain alarmingly common. Unresolved, systemic issues for people with disability are ongoing and highlight the need for an effective complaints system in the disability sector. A credible complaints system will be independent, address individual issues and document systemic level issues.

As the consultation paper suggests, an industry self-regulation approach such as Option 1 (p. 52) does not empower consumers to make change. Further likely problems with this approach include lack of capacity to identify systemic issues, and disempowerment of participants. In the same vein, an external industry-led complaints function as suggested in Option 2 (p. 53-54) may not have sufficient credibility with consumers or incentive to make change.

Option 3a (p.55), while providing the protection of a statutory authority, does not provide independence from the NDIA, which represents a potential conflict of interest. Option 3b (p.55), which canvases a complaints office independent to the NDIA, is Family Advocacy's preferred option as this can provide the strongest protections for participants. It will be important that in any such option, the complaints agency has its independence protected by both statutory security of tenure for the head of the agency, and regular public reports. If established, the independent complaints body should also be resourced to report on issues within the sector and document evidence regarding participants' experiences. This evidence should have a direct pathway to the NDIA that allows for gaps to be addressed.

Family Advocacy also note that the Disability Complaints Commissioners group has recommended that a complaints body should have responsibility for promoting access to advocacy and supported decision making (2014 p. 3).

Recommendation 12

That an independent national complaints agency for the disability sector be established under legislation and that it address individual issues and document systemic level issues.

Recommendation 13

That a complaints body should have responsibility for promoting access to advocacy and supported decision making.

Ensuring staff are safe to work with participants

Family Advocacy's view on a safeguarding system focused on staff is that it needs to recognise that staff working within services, not just those attempting to gain employment, may also pose a risk to vulnerable people. This is demonstrated by the ongoing Royal Commission into Institutional Responses to Child Sexual Abuse. Therefore systems should also apply to existing staff. For example, if a Working with Vulnerable People Check were to be in place, an automatically renewed check each year or several years that a person continues employment in the sector could be mandated. With the exception of proscribed offences, there could then be some flexibility or discretion for employers.

Similarly to our above discussion regarding decision-making supports, which assist people to practice decision-making, it is imperative that rights based training for people with disability and their family is available. Recent evidence from the Royal Commission into Institutional Responses to Child Sexual Abuse shows that child sexual abuse prevention programs for pre-schoolers appear to be effective and may provide a model for capacity building in this area of risk (see Selected References on p. 16 of this submission).

A Working with Vulnerable People Check, identified in Option 3 (p.62) of the consultation paper, is not only more comprehensive, but also avoids the problematic and unintended possible categorisation of all people with disability as children under the Working With Children Check options. While this check applies to services that support children, many services for people with disability support both children and adults, and thus confusion can occur about the labels applied to those being safeguarded. This is a problem when people with disability are often vulnerable to being seen as eternal children. As the consultation paper identifies (p. 57), state based checks are also "problematic given that workers may move interstate" and Family Advocacy supports a national system.

Additionally a balance must be struck between safeguarding people with disability and not controlling the choices of participants and their families if they choose to self-direct their funding. The barred persons list suggested in Option 4 (p.65-66) will not provide people with disability and their families with this choice. It is important that where people with disability and their families choose to self-direct payments, they have some flexibility as to the performance of the checks, whilst accepting responsibility for this, as discussed on p. 14 below.

Recommendation 14

That a national Working with Vulnerable People Check be established. This check should look at a wider range of information including AVOs, child protection orders, lapsed charges and work history. It should be national and harmonise with checks in other industries.

Recommendation 15

That where people with disability and their families choose to self-direct payments, they have some flexibility as to the performance of the checks.

Safeguards for participants who manage their own plans

It is an essential tenet of the design of the NDIS that people who self-manage their funding have the option to choose to use unregistered providers whilst taking responsibility for the risks. Options 2a through 3c in the consultation paper (pp. 70-74) appear to restrict participants, or in the case of proposed negative licensing in 2a, subject them to refusals of service. We note that evidence suggests that there may be no greater risk to those who self-direct payments than service users (Goodwin 2014: 4). We also note that those in congregate or segregated settings are more vulnerable to abuse and neglect.

Family Advocacy considers that Option 1, which allows people who self-manage their funding to make choices whilst building their capacity to manage risk, is the least restrictive option for people with disabilities. Ways in which we propose that people with disability and their families can best be supported to manage risk include:

- Funding some capacity building organisations to help participants with hiring and managing of support staff, including optional checks and registration, applications, taxation, payment etc.
- Providing all participants, and where appropriate their families, information about how they can access self-directed and self-managed options,
- Training NDIA planners, as discussed in 'Decision Making Support' above, to help participants understand options, and the risks and safeguards associated with each.
- Supporting options wherein the management of and payment for support staff is shared between participants and service providers and brokers or intermediaries.
- The NDIA could contract support for those participants who choose to employ people directly, by making a bulk purchase of employment support from Jobs Australia or a similar provider.

Recommendation 16

That capacity building organisations be funded to provide self-managing participants with assistance when hiring and managing of support staff, including optional checks and registration,

Recommendation 17

That NDIS participants be empowered to self-manage their funding by having the option to choose to use unregistered providers whilst taking responsibility for the risks.

Recommendation 18

That information is provided to all participants, and where appropriate their families, about how they can access self-directed and self-managed options, including the risks and safeguards associated with this option as with any service based option.

Recommendation 19

That the NDIA support options whereby the management of and payment for support staff is shared between participants and service providers and brokers or intermediaries.

Recommendation 20

That the NDIA consider contracting support for those participants who choose to employ people directly, by making a bulk purchase of employment support from Jobs Australia or a similar provider.

Reducing and eliminating restrictive practices in NDIS funded supports

Family Advocacy approaches the notion of ‘challenging’ behaviour from the perspective that all human behaviour can be interpreted as communication. When the communication is coming from someone in a vulnerable position or role, as with a person with disability, measures should be in place to ensure that person’s communication is heard and valued. Otherwise, as the consultation paper rightly notes (p.75), restrictive practices may result in death, harm either psychological or physical, or just as tragic, wasted lives and missed opportunities. The National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector (henceforth, National Framework) is a positive step to build upon in the implementation of the NDIS Quality and Safeguards framework.

Family Advocacy note that as well as use of psychotropic medicines, physical restraints, mechanical restraints and seclusion, restrictive practices include confining a person at home or in parts of their home, restricting devices such as mobile phones, as well as physical, mechanical and chemical restraint.

Authorisation

We consider that Option 4 (p.82) would provide the best safeguards. Option 1 (p. 80) does not provide adequate protection for people with disability from restrictive practices. Family Advocacy’s view is that a voluntary code of practice is inadequate to incentivise support providers to reduce and eliminate these practices, and that there must always be an external authority authorising (or not authorising) the plan. In Option 3 (p.81), whereby providers would be authorised to make decisions under specific conditions, independent oversight is missing.

Recommendation 21

That the NDIS adopt a restricted practices safeguarding policy which includes authorisation measures from Option 4.

Monitoring

We consider that for the National Framework to have the desired effect, all positive behaviour plans, which include a restrictive practice, must be reported, as in Option 2.

Recommendation 22

That the NDIS adopt a restricted practices safeguarding policy which includes monitoring measures as in Option 2.

Recommendation 23

That the NDIS implement training in any community visitors scheme which ensures visitors can identify when restraints are having flow on effects for others if the person subject to restraint is in a congregate environment.

Recommendation 24

That if a person with no family or friends able to assist them is subject to restrictive practices, they should have an independent, fully funded advocate allocated.

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