JFA
Purple Orange

JFA Purple Orange Submission

National Disability Insurance Scheme Quality and Safeguarding Framework Consultation

A conversation with people living with disability

Submitter details

JFA Purple Orange
104 Greenhill Road
Unley SA 5061 AUSTRALIA

Telephone: + 61 (8) 8373 8333
Fax: + 61 (8) 8373 8373
Email: admin@purpleorange.org.au
Website: www.purpleorange.org.au
Facebook: www.facebook.com/jfapurpleorange

Contributors

Kerry Telford, Research Officer
Jackie Hayes, Leader Social Policy and Initiatives

We gratefully acknowledge the contribution of the participants who gave their time to this report. We do not have their permission to print their names here.

About the Submitter

JFA Purple Orange is a non-government, social profit organisation. Anchored on dialogue with people living with disability, their families, service providers, government and other stakeholders, we seek to identify policy and practice that has the prospect of advancing peoples chances of a good life. Our work is anchored on the principles of Personhood and Citizenhood. Our work includes research, evaluation, capacity building, consultancy, and hosted initiatives.

Contents

1.0 Summary

The National Disability Insurance Scheme (NDIS) is to be commended on the development of a NDIS Quality and Safeguarding framework. JFA Purple Orange and the people consulted regard this as critical in ensuring people living with disability are effectively safeguarded as they make choices and decisions about NDIS funded supports. This submission is based on the perspectives of people living with disability. The key themes emerging from the submission are:

- The importance of good, quality, accessible information that enables people to make informed choices
- The need for highly trained support workers
- An independent oversight body for the NDIS
- Guidance and guidelines about what's involved in managing own supports
- Mandatory reporting on the use of restrictive practices
- Clear accountability for the decision to use restrictive practices.

2.0 Purpose

This submission is based on the voices of a small group of people living with disability. It is a summary of their collective views on the NDIS Quality and Safeguarding draft policy framework. JFA Purple Orange works alongside people with lived experience of disability and wants to help ensure their voices are considered and represented in the framework.

2.1 Introduction

JFA Purple Orange is the social policy agency of the Julia Farr group, a trio of social profit, non-government organisations based in South Australia, working to improve the life chances of people living with disability. The Julia Farr group (JFA Purple Orange, Julia Farr Housing Association, and the Julia Farr Trust and Julia Farr MS McLeod Benevolent Funds) and its predecessor organisations have been involved with the disability community, older people and other vulnerable groups for more than 130 years.

We are an independent, non-government organisation that fosters innovation, shares useful information, and promotes policy and practice that support and improve the life chances of people living with disability.

JFA Purple Orange is not a service provider – we deliver research, evaluation and information services anchored upon the stories and experiences shared by people with a lived experience of disability and others in their lives. As such, we feel we are ideally positioned to offer comment.

2.2 Context of a Good Life

Given key elements of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (the Convention)[1], and the values underpinning the development of the NDIS, it can be asserted that a good life might be characterised by the presence of the following:

- authorship of our own lives (often described as control and choice)
- having valued roles in community life and economy (often described as inclusion).

As set out in JFA Purple Orange's *Model of Citizenhood Support*, a good life is characterised by such valued roles (termed Citizenhood) and by the decisions we make (termed Personhood)[2]. Unlike citizenship, Citizenhood is a dynamic experience: it can rise and fall depending on the person's circumstances. The extent to which any person can naturally take up Personhood and Citizenhood is influenced by the degree to which that person lives with vulnerability. For the purposes of this submission we define vulnerability as the presence of circumstances that can adversely impact on the person's capacity to build authorship of their own lives and the person's capacity to take up valued roles in community life and the economy. We believe any formal response to the NDIS Quality and Safeguarding Framework needs to be anchored upon supporting the person into roles of citizenhood and personhood.

Many people living with disability, who live with increased vulnerability, are at increased risk of abuse, harm and neglect. Safeguarding people living with disability is every disability service provider's responsibility and must be built into everyday practice. A policy of zero tolerance is critical to the effectiveness of successful prevention of abuse, harm and neglect.

2.3 Behaviours of concern

People living with disability feel uncertainty and confusion along with powerlessness when faced with abuse or restrictive practices. In line with the Convention (2006)[3], JFA Purple Orange does not support restrictive behaviours.

Some people living with disability may have behaviours that can obstruct other people and breach a person's right, dignity and/or quality of life. These behaviours may also represent a serious risk of physical harm to themselves or others. In these situations JFA Purple Orange advocates the use of positive behaviour support. This is a rights-based approach that involves the development of a positive action plan, outlining the best ways to support

---

[1] *United Nations Convention on the rights of people with disability. Accessed 20/4/2015* *http://www.un.org/disabilities/convention/conventionfull.shtml*

[2] *Williams, R. (2013), Model of Citizenhood Support: 2nd Edition, Julia Farr Association Inc, Unley South Australia*

[3] *United Nations Convention on the rights of people with disability. Accessed 20/4/2015* *http://www.un.org/disabilities/convention/conventionfull.shtml*

people in managing their behaviour. Legislation is in place to support a positive behavioural support approach. The new laws also make it easier for service providers to meet their legal obligations while increasing their accountability around the use of restrictive practices[4].

JFA Purple Orange believes the NDIS must be able to show that it can build and maintain meaningful environments that respect, protect and meet the requirements of individual rights. NDIS practices must also place a person living with disability at the centre of service provision and enhance quality of life along with community inclusion. JFA Purple Orange considers that these are the conditions in which personhood and citizenhood will thrive.

3.0 The Consultation

The proposal to develop an NDIS Quality and Safeguarding framework based on consultation is to be commended. It will establish and maintain systems that are designed to safeguard people living with disability as they make decisions about supports funded by the NDIS. This will ensure the scheme provides high-quality supports, thereby increasing the choice and control that participants experience. In addition, this framework will be critical to ensuring protection of the rights of people living with disability. The focus of this framework seeks to reinforce the culture, systems and mechanisms that provide effective and reliable safeguards for people living with disability. Safeguarding is an important component of the *Model of Citizenhood Support* and a good life.

3.1 The Consultation process

This submission is based on the perspectives and experiences of a focus group of people living with disability. Seven people living with disability offered their perspective and experience on the NDIS Quality and Safeguarding framework. Four participants were interviewed by telephone and three participants completed the survey. Two people did not complete all the questions in the survey. The participants who contributed to the submission are:

- A 43 man living with multiple sclerosis related disabilities including total vision loss who lives independently
- A 50 year old person living with muscular dystrophy related disability. This person lives independently and uses a wide range of support services
- A person living with Muscular Atrophy who has worked most of his life
- A person living with Cerebral Palsy (CP) and lives with a significant level of disability including communication difficulties
- A 60 year old woman living with Multiple Sclerosis (MS) related disability
- A young man living with MS related disability and
- A woman living with significant Cerebral Palsy including communication difficulties.

---

[4] *Bourne, C.(2013). Positive behaviour support framework. Accessed 23.4..2015: https://www.google.com.au/#q=Positive+behaviour+support+South+Australia*

The participants of the focus group considered the questions posed in the Consultation paper: *Proposal for a NDIS Quality and Safeguarding framework.*

Each of the above conversations has been transcribed and anonymised. We invite the Department to contact us if it wishes to access this raw data.

3.2 Consultation questions

Q1 What are the most important features of an NDIS information system for participants?

The overwhelming response to this question from the perspective of people living with disability is that the information must be easily accessible, in a wide variety of formats to accommodate a diverse range of people living with disability.

Participant N placed emphasis that the process be a two-way information flow. They suggested that a system of networks could be set up across Australia to communicate about issues associated with the NDIS. This would be easily accessible and local. Where it was necessary, they suggested face to face communication should be organised.

Q2 How can the information system be designed to ensure accessibility?

People living with disability provided a number of suggestions for ensuring accessibility. They suggest information should be provided in a variety of formats including large text, attention to contrast ensuring the text stands out from the background, easy to understand text and online access to text. It would also need to include access to information in an auditable format.

Some people may require a support person to work through the information with them, providing the opportunity for clarification, discussion and questions. Participant G considered it to be important to avoid service jargon, to provide information both online and in hard copy, and develop lots of factsheets to download with 'easy to understand' guidelines. In addition to this Participant T suggested a helpline and financial assistance would be useful to people living with disability. Participant N suggested it would be necessary to have a combination of technologies such as computers, telephones, etc. in order to communicate to people living with a wide range of disability. It is important that the language of communications from the NDIS reinforces a culture of positive values and opportunity for people living with disability. Any communication about information needs to be based on the development of a relationship whereby people can seek clarification and ask questions.

Q3 What would be the benefits and risks of enabling participants to share information, for example, through online forums, consumer ratings of providers and other means?

All people living with disability who were interviewed could imagine there would be benefits and risks involved in online forums, community ratings of providers, etc.

- The potential benefits were described by people living with disability as the sharing of ideas that would occur and sharing of people's experiences. This was seen to facilitate communication around what works well and what does not. Participants demonstrated a strong value on sharing of the experiences of people living with disability with one another. Participant N thought that this would promote awareness of what was possible and what was helpful (sharing of resources).
- Participant G raised that it would be a good source of information for the NDIS about what is helpful and what is not.
- A risk was seen to be that particular people may dominate conversations and seek to influence others. This was an acknowledgement of the impact of people participating in a shared conversation. Similarly, one-sided information and misinformation could be shared. Participant G thought that if people are negative this may reinforce their anxieties and fears. Participant T mentioned that privacy may be compromised.

Q4 Are there additional ways of building natural safeguards that the NDIS should be considering?

Three participants suggested the development of an online support group to discuss issues such as their experience of the NDIS. Some participants thought the NDIS would need to understand more about natural supports, including what an important part of the person's life they are and why. They suggested that the NDIS be referred to the circles concept. Accessed 26.4.2015: http://www.purpleorange.org.au/news-links/links/building-networks-useful-links/
This places a strong emphasis on natural supports. Meaningful natural relationships that come from being part of the community and being regarded as a fellow citizen are important components in the lives of people living with disability

Q5 What can be done to support people with a limited number of family and friends?

People living with disability regard isolated or lonely people as requiring quick access to support at the time when they need it. For example, at the end of phone number. Most participants expressed the importance of having access to the type of support that would include clarification, discussion and questions.

Participant G suggested the use of independent advocates to monitor issues such as person centred interaction and rights based service. Participant T suggested that more volunteers of a similar age would be helpful to support people who had a limited number of family and friends. However, we are unsure of their understanding of the question and the concept of natural safeguards.

Q6 . What kind of support would providers need to deliver high-quality supports?

People living with disability regarded this issue as related to training. Clearly well-trained support workers are seen to be more likely to deliver high-quality supports. Participant T expressed that people living with disability would need to have an understanding of the worker's perspective. That might occur through training. Additionally, support workers would be familiar with person centred practice, supported decision-making and safeguarding for people living with disability.

Q.7 Should there be an independent oversight body for the NDIS?

All people living with disability consulted considered that an independent oversight body for the NDIS is a good idea. The reasons for this judgement included:

- To make the NDIS accountable for decisions and changes
- To give people the confidence of transparency
- To ensure participants and service providers are treated fairly
- To avoid situations such as misused funds
- Participant N suggested it could be a national body with members from each state, including a professional person and a person living with disability. Participant N would prefer it is elected for three years (half of the panel would move on after three years and half would remain so that there was some consistency). He expressed a concern that people wait too long for their issues to be heard.

Q 8. What functions and powers should an oversight body have?

From the perspectives of people living with disability the functions and powers ought to be:

- To be able to question the NDIS
- To be able to investigate concerns or complaints
- To ensure changes are for the right reasons
- To advocate for participants or services
- Monitoring of complaints and humans rights issues
- Management
- Ability to provide advice to people living with disability about complaints
- Accountability to people living with disability and their families/NDIS.

Q.9 Considering the options described above, which option would provide the best assurance for:

- **Service Providers**: A system of registration was regarded as beneficial for providers in that people could easily see what different providers offer. In other words it is a promotion of their services. Participant N thought a national database for providers, linked to Centrelink, would be helpful in that information would be readily available. Participant N also suggested a national database would provide protection for both providers and participants.

- **Participants**: Most people living with disability thought that service registration would work well for them because it would make decisions and comparisons between services easier.

Q.10 Should the approach to registration depend on the nature of the service?

Amongst people living with disability, seven participants thought that registration should not depend on the nature of service, but rather pertain to the range of services funded by the NDIS. Participant N regarded registration as a tool with which to address other forms of discrimination in the person's life. In other words, it could be a reference point for the person living with disability to receive advice.

Those consulted considered registration to be a safeguard for people living with disability. However, it does not support safeguarding that diminishes the choice of the individual person living with disability. People need to be safe in the context of person centred support and personalisation, with individuals empowered to make choices and supported to manage risks[5]. Rather than preventing bad things happening (through restrictive practices), measures are needed that positively build a person's capacity and maximise the good things in the person's life will provide natural safeguards for them. It must not be about being over paternalistic or denying people living with disability opportunities to negotiate risk.

Q 11 How can the right balance be reached between providing assurance and letting people make their own choices?

People living with disability are naturally concerned about being able to make the right choices for themselves rather than have other people make the decisions for them. Participant T suggested that a care plan needs to be developed in conjunction with the consumer. They felt it was important for the NDIS to realise the consumer is independent in making choices (that will vary depending on the nature of disability they live with). Participant N suggested the NDIS should maintain a database of professionals who may not be "top-notch" but have at least some of the indications that the person is safe.

Q 12 How important is it to have an NDIS complaints system that is independent from providers of supports?

People living with disability consider it to be very important to have an independent complaints system because it will be autonomous and impartial. It is important to note that people living with disability have not been encouraged to complain and typically, do not possess the skills or confidence to effectively make a complaint. Participant G makes the point that people may be scared to complain to a service because they are not sure if it will

---

[5] Faulkner, A. & Sweeney, A.(2014), *Prevention in Adult Safeguarding. Social Care Institute for Excellence, UK in JFA Purple Orange (2015). JFA Purple Orange submission. Accessed 25.4.2015:* *http://www.purpleorange.org.au/files/4714/2889/9883/Senate_submission_on_violence_abuse_neglect_in_residential_settings_FINAL_130415.pdf*

have a negative effect on them. They also make the point that people may not know where they can access support to approach a service to complain. People living with disability consider the NDIS would have an important role in guiding and supporting people and their families to make complaints. There is a strong emphasis on the importance of having complaints managed outside the service. Participant N regards it as important that there is a feedback loop from the complaints body to the NDIS and even to a legal body (if appropriate) that recognises the barriers to a person living with disability making the complaint formally.

Q 13 Should an NDIS complaints system apply only to disability-related supports funded by the NDIS, to all funded supports, or to all disability services regardless of whether they are funded by the NDIS?

People living with disability were mostly a little confused about this question. In terms of common sense they expressed that a complaints system should apply to all services and supports whether they are funded by the NDIS or not. Participant N thought that a complaint service should apply to all funded supports by the NDIS but also be able to provide advice on the quality of support provided by other services. Participant T suggested they ought to be able to represent the consumer in every situation, including during legal proceedings. Participant N suggested that if we are going to place people living with disability in a position of strength then complaints need to relate to all aspects of service provision. Participant N went further to suggest the NDIS needs to be aware that some people are abused by family members and a complaints system needs to be able to provide some safety for the person living with disability in the family.

Q 14 What powers should a complaints body have?

People living with disability referred to the following powers and functions:

- Receive the complaint
- Make an action plan to address the complaint
- Refer to the most appropriate body or service
- Ability to investigate all complaints in a neutral role ensuring the participant is respected and heard
- To report to the NDIS advocating changes to systems, funding or guidelines
- Provide feedback to the NDIS about aspects of service
- Ability to represent the consumer in legal proceedings.

Q 15 Should there be community visitor schemes in the NDIS and, if so, what should the role be?

Four of the people living with disability consulted felt clearly that a community visitors scheme would be beneficial for the NDIS. They referred to their role as monitoring that people get a fair go. Participant N suggested that a community visitors scheme would need to have standards which would hold visitors accountable and visitors would need thorough knowledge of what it means to live with disability – but they do not necessarily need to live with disability themselves.

Participant G referred to the usefulness of an independent advocate who regularly monitors the support people are receiving and how it relates to their plans and goals. This person felt that families ought to discuss with the person on a regular basis what is working and what isn't.

Q 16 Should people who manage their own plans be able to choose unregistered providers of supports on an 'at your own risk' basis (Option 1) or does the NDIS have a duty of care to ensure that all providers are safe and competent?

People living with disability clearly regarded NDIS funded supports as "safe" and delivered by people "having received proper training". People living with disability thought that people should be able to access information about the service provider to make their own judgement about whether the providers are safe or not. They make the point that some people will be able to assess whether a service provider behaves safely or not, depending on the nature of the disability. They also state that different tasks require different skills and abilities. Therefore, it might be important to be able to check the service providers, employment history if the participant has the capacity to decide if a provider is safe to support them. People living with disability believe they should be encouraged and supported to make these decisions for themselves. There is a sense that the person can make the judgement about whether or not a provider is right for them.

Q 17 What kind of assistance would be most valuable for people wanting to manage their own supports?

People living with disability related this to the nature of disability involved. Some people made the comment that people may need someone to support them with information and the steps to take in recruiting a support worker and setting up a working environment.

Participant G and H emphasised the need for people with living with disability to be prepared for the different roles and tasks involved in managing their own supports. Participant G suggested the assignment of a planner to help people navigate the NDIS system and research all options. Participant G also suggested the planner would need to be trained in person centred planning. They would need to be supportive and imaginative to assist participants to get the best life.

Participant N suggested having access to people who could guide them or signpost them through the steps involved in managing their own support would be beneficial. For example, if I was going to employ somebody I would need to work out what I would pay them, how I would pay them, what conditions they would work under - there is a lot of advice I would require. If I'm about to enter a contract with somebody there should be a way of entering that information on the national database. If I have employed somebody and they don't live up to my expectations of the contract then somebody should be able to help me make that person or organisation accountable to the contract.

Participant H went further in her response as she explained her lived experience and provided examples:

People living with disability themselves must be provided with all sorts of training and empowerment so they can safeguard themselves because that is the natural way humans operate. Specifically people living with disability may need training in:

- Self-confidence, assertiveness and self-esteem
- Communication skills
- How to manage and supervise their staff (support workers)
- How to manage their support agency/agencies
- Money management (both personal and NDIS related)
- Their rights and responsibilities
- The laws that protect them i.e. DDA, Disability Services Act, OH & S etc.
- How to make a complaint
- How to navigate the system, what is the NDIS and how does it work?
- Self-advocacy or how to find an advocate or peer support
- Everyday socialisation and community participation.

Participant H explained people living with disability have a different experience of life so far, which may not have prepared them properly. She explains:

> Traditionally people living with disability are oppressed and disempowered. They are not allowed to manage their own lives in relation to the support they may need in relation to their disability. They are told what supports or equipment that they can have. They are denied supports or equipment due to limited government funding. They are denied a proper (equal) education. They are shunned and shut out of society, shut in institutions and disconnected from everyday life in many ways. They are denied fulfilling work. They are deemed stupid, incapable, unteachable or unable to learn. They are treated as “other” and as less than human. So of course they do not have the skills to lead an ordinary life. This is often not because of their impairment or disability but due to restrictions of all kinds imposed on them by “able-bodied” people.

Q 18.Who should make the decision about whether employees are safe to work with people with disability?

Participant T expressed that an independent assessor coupled with an impartial consumer (if possible) could make these decisions. Participant N and participant L emphasised that the person living with disability would be the most appropriate person to make this decision.

They advocate a system of registration whereby information is available about each provider. This information would indicate for example whether the provider has employment experience with disability, knowledge and skills about providing care, a history involving criminality, etc. If a provider is found to be problematic then this information could be investigated and provided on the database with a recommendation that the person should be monitored. Of course, some people can decide not to employ that person. Participant N also emphasised that all persons living with disability should be on a national database to make it easy to access information.

Q 19 .How much information about the person's history is required to ensure they are safe to work with people with disability?

Most participants considered that police checks, education status and history of employment would enable a decision to be made as to whether a person is safe to work with people with disability

Q.20 Of the options described which option or combination of options you prefer?

Most participants referred a combination of options. Most favoured registration because it would make choosing a provider less difficult and it would ensure access to information about people.

Q.21 Who should decide when restrictive practices can be used?

People living with disability stated it is important that the responsibility to decide when restrictive practices can be used rest with someone who has professional qualifications, such as a medical practitioner (three people). Participants G and participant L said that it was important that the person living with disability and/or family members, guardians make this decision. There was a strong sense among all participants that people should not be coerced into using restrictive practices. However, there was some acknowledgement that they may be needed as an option in certain situations, i.e. where people were putting themselves or others at risk of harm. Participant K and participant I referred to a medical practitioner as being an appropriate person. Participant T regarded a care manager from the service provider organisation as suitable to make this decision.

Participant N believed that with restricted practices an independent body was needed. They would need to endorse and monitor the practices that are put in place. There may be local bodies that do this, e.g. associated with Medicare. There may be local behaviour management practitioners who would be on this panel along with people living with disability. These people may visit the person who is submitted to restrictive practices to ensure that they are physically and mentally well.
A positive behaviour support plan which incorporates an individual, evidence based approach**,** and a person centred approach is more acceptable. JFA Purple Orange believes that where the person has capacity for making decisions regarding the use of restrictive practices the decision should be deferred to them, their family/guardian. Supported decision-making may be a useful model in this case.

Q 22 What processes or systems might be needed to ensure decisions to use restrictive practices in a behaviour support plan are right for the person concerned?

People living with disability expressed that a regular review process which was outlined in an action plan and reviewed by a professional panel, including people living with disability would ensure the behaviour support plan was right for the person and not left in place for an unacceptable length of time. This was the perspective of most people living with disability. Participant T suggested a family conference would be necessary to ensure that a behaviour support person is right for the individual.

Q 23 Are there safeguards that we should consider that have not been proposed in these options?

Only three people living with disability answered this question which may indicate that they did not see it as a question for them to answer. The three participants that did respond made the following suggestions:

- A regular monitoring function such as a community visitor scheme was seen as an important adjunct to the panel
- A register of restrictive practices is maintained, monitored and updated
- At an organisational level, a policy on restrictive practices must be exist along with monitoring of the effectiveness and usage of the policy**.**

Q 24 For providers, what kinds of support are you receiving now from state and territory departments that you think would be helpful if it was available?

Most participants considered this question not applicable to them. Participant T suggests a wider variety of tasks which were funded would be helpful to him.

Q 25 Would you support mandatory reporting on the use of restrictive practices? Why/Why not?

There is national recognition, through the ratification of the UNCRPD by Australia in July 2008, that all people living with disability have the right to live their life free from any form of abuse or restrictive practices. Most people living with disability were clear about this question: they said they would support mandatory reporting on the use of restrictive practices. The reason given related to the need to avoid any practices that were not acceptable, such as restraining people for a long period. Participant T suggested that mandatory reporting should be required for some restrictive practices. Participant N thought that restrictive practices must be monitored and endorsed and registered by a dedicated panel including specific professionals and people living with disability. These panels could be established in local areas to maximise access.

Q 22 If you support mandatory reporting on the use of restrictive practices, what level of reporting do you believe should occur (based on one, or a combination of, the options above)?

Several people said mandatory reporting on the use of restrictive practices should be reported to a legal panel or body which was independent of the NDIA. This panel/ body would be made up of professionals and people living with disability. Participant N stated that restricted behaviours needed to be documented, monitored, reviewed and endorsed by a dedicated panel of people, including people living with disability who would be responsible for decisions and review of the use of restrictive practices.

Participant G expressed clear ideas about restrictive practices documentation when she says: Clear guidelines need to be drawn up and documented in the person's plan. It must direct supports at each step of the way and be least restrictive and respectful at all times. Reporting use of restrictive practice should be done at a service level. This ensures they are not being used untowardly and that NDIS supports are also protected with the reporting. NDIS planners or independent advocates should regularly check with participants, families and services to ensure reporting is correct, that it is still current and to support with disputes or changes when needed.

4.0 Conclusion

The NDIS is to be commended on the development of a NDIS Quality and Safeguarding framework. JFA Purple Orange and the people consulted regard this as critical in ensuring people living with disability are effectively safeguarded as they make choices and decisions about NDIS funded supports. This submission is based on the perspectives of people living with disability. The key themes emerging from the submission are:

- The importance of good, quality, accessible information that enables people to make informed choices
- The need for highly trained support workers
- An independent oversight body for the NDIS
- Guidance and guidelines about what’s involved in managing own supports
- Mandatory reporting on the use of restrictive practices
- Clear accountability for the decision to use restrictive practices.