



JFA
Purple Orange

JFA Purple Orange Submission

In response to the Department of Social Services National Disability Insurance Scheme (NDIS) - Code of Conduct Discussion Paper

Submitter details

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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.

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1.0 Summary

The National Disability Insurance Scheme (NDIS) is a critical social welfare reform in Australia and presents a genuine opportunity for people living with disability to receive the support needed to deliver transformational benefits. JFA Purple Orange acknowledges that the Australian Government is committed to supporting high quality and safe supports for people with disability. A new NDIS Quality and Safeguarding Framework has been developed to ensure the rights of people with disability are upheld and the services and supports provided through the NDIS are safe.

The NDIS Code of Conduct will be a central element of the Framework. It will encapsulate the rights of people with disability in the NDIS to have access to safe and ethical supports. The Code of Conduct will be overseen by the NDIS Quality and Safeguards Commission. The Commission will have powers to enforce action where providers or workers have engaged in unacceptable behaviours.

JFA Purple Orange raises three key issues in this submission. These are particularly relevant to the implementation of the NDIS Code of Conduct:

- Key Issue 1- The rights of people with disability in the NDIS to have access to safe and ethical supports
- Key Issue 2 –The importance of service provider organisations as ethical organisations
- Key Issue 3 –Informing NDIS participants about the Code of Conduct and the complaints process

2.0 Purpose

JFA Purple Orange welcomes the opportunity to contribute to the Department of Social Services consultation on the National Disability Insurance Scheme (NDIS) Code of Conduct Discussion Paper.

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 well positioned to offer comment.

2.2 Key Values

The work of JFA Purple Orange is anchored on the principles of *Personhood* and *Citizenhood*.

As set out in our Model of Citizenhood Support¹, a good life is characterised by such valued roles (termed Citizenhood) and by the decisions we make (termed Personhood). A good life largely depends on the availability of life chances – the assets and opportunities available to a person.

Unlike formal citizenship of a country, Citizenhood is a dynamic experience: it can rise and fall depending on a person's circumstances. The extent to which any person can naturally take up Personhood and Citizenhood is influenced by 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.

Aside from the need to increase the total amount of funds available for disability support, the two values that have driven the emergence of the NDIS have been

- Each person having *control and choice*, taking up authorship of their own life
- Each person *participating in community life and the economy*, taking up valued roles that bring genuine community membership.

These have an excellent fit with the notions of Personhood and Citizenhood. The NDIS is founded on a framework that promotes empowerment in people living with a disability.² As such, JFA Purple Orange believes that all eligibility and access to services provided by the NDIS must be anchored on principles that will assist people accessing NDIS to feel empowered and supported, to take up valued roles in mainstream community life.

3.0 Approach

This submission is influenced by two main sources of information:

- The Model of Citizenhood Support and
- Previous submissions made by JFA Purple Orange on violence, abuse and neglect against people with disability in institutional and residential settings and on the National Disability Insurance Scheme Quality and Safeguarding Framework.

¹ Williams, R. (2013), *Model of Citizenhood Support: 2nd edition*, Julia Farr Association Inc., Unley South Australia

² *NDIS Values, Capabilities, and Behaviours factsheet*, <https://www.ndis.gov.au/document/our-values-capabilities-and-behaviours>

4.0 Key Issues

Key Issue 1- The rights of people with disability in the NDIS to have access to safe and ethical supports

The NDIS Code of Conduct will be a central element of the NDIS Quality and Safeguarding Framework. It covers the rights of people with disability to have access to safe and ethical supports and reflects the core values and principles set out in the National Standards for Disability Services.

Formal safeguards are not enough, however, to either advance people towards good life chances or to fully mitigate the risks associated with vulnerability.

A Code of Conduct, service standards, mandatory reporting, community visiting, complaints mechanisms, and other elements can all contribute to a quality and safeguards framework but they are not, singularly or collectively, a complete and reliable solution.

The main ingredient for success safeguards is a belief and a connection with each individual as a valued citizen in our communities and the presence of natural networks and valued roles should be the cornerstone of any work with any individual.

JFA Purple Orange believes there must be a balance of investment being focused on developmental safeguards, followed by preventative safeguards, and with the smallest portion spent on corrective safeguards.

Previously JFA Purple Orange recommended that the Australian Government endorse a zero-tolerance approach to violence against, and the abuse and neglect of, people living with disability, such as identified in the National Disability Services Zero Tolerance Initiative.³ Further, JFA Purple Orange recommended the implementation of a national mandatory system for reporting abuse of people living with disability as one element in a comprehensive range of measures.

JFA Purple Orange supports the development of a Code of Conduct and its application to all providers and workers who are funded under the NDIS, regardless of whether they are registered, or whether they receive funding through individual plans or contracted services.

Safeguarding people living with disability is every disability service provider's responsibility and must be built into everyday practice. We believe 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.

³ National Disability Services (2015), *Zero Tolerance Framework*, <http://www.nds.org.au/projects/article/194>

JFA Purple Orange agrees that the NDIS Code of Conduct should reflect the core tenets of the National Standards for Disability Services: respecting people with disability, listening to and being guided by what a person wants, respecting people's right to privacy and prohibiting behaviours that may cause harm.

We are pleased to see that behaviours that may not constitute a crime such as exploitative or otherwise unethical treatment; neglect; and vengeful or deceptive behaviour in response to a complaint or incident are clearly named as behaviour which is never acceptable in the context of the NDIS.

JFA Purple Orange supports the nine obligations for the NDIS Code of Conduct as listed below and rates them all as 'extremely important'.

- NDIS providers and workers promote individual rights to freedom of expression, self-determination and decision-making
- NDIS providers and workers actively prevent all forms of violence, exploitation, neglect and abuse
- NDIS providers and workers act with integrity, honesty and transparency
- NDIS providers and workers provide supports in a safe and ethical manner with care and skill
- NDIS providers and workers raise and act on concerns about matters that may impact on the quality and safety of supports provided to people with disability
- NDIS providers and workers not engage in sexual misconduct
- NDIS providers and workers keep appropriate records
- NDIS providers and workers maintain adequate personal and professional liability insurance appropriate to the risks associated with the supports provided.

Evidence has shown that people living with disability are at far greater risk of violence than others in the population and that this violence often goes unrecognised or unaddressed.⁴ For example, 18 per cent of people living with disability report being victims of physical or threatened violence compared to 10 per cent of non-disabled people; and people living with intellectual disability are ten times more likely to experience violence than non-disabled people.⁵

People living with disability face significant barriers to reporting abuse:

A consistent theme is the finding that people with a disability are much more likely to experience abuse, including physical and sexual assault, than the general population. At the same time, it is widely recognised in the literature that the available data is unlikely to give the true picture of the level of risk and prevalence of abuse, due to obstacles experienced by people with a disability to reporting abuse, such as fear of losing services or not being believed, reliance on assistance for day to day support,

⁴ See for example, Casteel, C, Martin, SL, Smith, JB, Gurka, KK & Kupper, LL (2008), 'National study of physical and sexual assault among women with disabilities', *Injury Prevention*, vol. 14, no. 2, pp. 87-90.

⁵ Frohmader, C and Sands, T (2008) Fact Sheet: *Violence Against People With Disabilities in Institutions and Residential Settings*, Women with Disabilities Australia and People With Disability.

*language or communication difficulties and lack of awareness of rights and what constitutes abuse.*⁶

Conversations conducted by JFA Purple Orange with people living with disability confirmed support for an NDIS complaints system that is independent from providers of support. They consider that it is very important to have an independent complaints system because it will be autonomous and impartial.⁷ They also pointed out 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.⁸ A further concern related to making complaints directly to a service provider: people may be scared to complain to a service because they are not sure if it will have a negative effect on them.⁹

The independent complaints body should have the ability to investigate all complaints in a neutral role ensuring the participant is respected and heard. A further function of the complaints body should be a reporting role to the NDIS advocating changes to system, funding or guidelines.¹⁰

We believe that protection for the person lodging the complaint is critical. The first priority of the system should be to protect people who are more vulnerable and to be seen to protect the person making a complaint. The NDIS Code of Conduct must

*create a culture where misuse of power (the core of almost all complaints) is unacceptable and lodging a complaint to protect [people who are more]... vulnerable is the normal and honourable thing to do*¹¹

Key Issue 2 –Ethical service provider organisations

JFA Purple Orange supports a Code of Conduct that promotes safe and ethical service delivery to people living with disability under the NDIS. The draft Code of Conduct clearly sets out expectations of providers and workers.

⁶ Coulson Barr, L (2012), *Learning From Complaints, Occasional Paper No. 1, Safeguarding People's Right to be Free From Abuse*. Victorian Disability Services Commission. See also: Office of the Public Advocate (2010), *Violence against people with cognitive impairments*, Melbourne, Victoria, Australia; Bruder, C & Kroese, BS (2005), 'The efficacy of interventions designed to prevent and protect people with intellectual disabilities from sexual abuse: a review of the literature', *The Journal of Adult Protection*, vol. 7, no. 2, pp. 13-27;; Martin, SL, Ray, N, Sotres-Alvares, D, Kupper, LL, Moracco, KE, Dickens, PA, Scandlin, D & Gizlice, Z (2006), 'Physical and sexual assault of women with disabilities', *Violence Against Women*, vol. 12, no. 9, pp. 823-837; Goodfellow, J & Camilleri, M (2003), *Beyond belief, beyond justice: the difficulties for victim/survivors with disabilities when reporting sexual assault and seeking justice*, Final report of stage one of the sexual offences project, Disability Discrimination Legal Service, Melbourne.

⁷ JFA Purple Orange (2015), *A Conversation With People Living With Disability. Submission in response to the NDIS consultation paper, Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework*,.p.9

⁸ Ibid, p.9

⁹Ibid, p.10

¹⁰ Ibid .p.10

¹¹ Homan, J (2011), *From Charity to Equality: Supplementary Submission*, Response to the Productivity Commission Draft Report on Disability Care and Support. p.6

However, clearly more is required than a NDIS Code of Conduct that sits on a shelf next to all the other Acts, statements of national standards and codes of behaviour. Ethical behaviour must underpin the work of NDIS service providers at each layer of the organisation. According to Webley and Werner and numerous other authors:

*“having a code of ethics without creating an ethical culture and a comprehensive ethics program is like having a Ferrari without wheels—i.e., it looks good, but you’re not going anywhere”.*¹²

An ethical culture:

*is created and fostered by top management (including the board of directors), who manifest their commitment to ethical practice in their attitudes and behavior. You can’t create an ethical culture if employees and other stakeholders believe the company ...does not value or safeguard human lives. You can’t have an ethical culture if employees don’t feel comfortable discussing ethical issues or if unethical behavior is not questioned*¹³

Further:

*A well-designed ethics code should inspire and promote ethical values, and not just consist of a set of constraints, rules, and violations. It should focus on all stakeholders who are affected ...as well as the community in which the organization operates*¹⁴

McMillan suggests that ethics training should be integral to the organisation so that when an employee is faced with an ethical dilemma as well as asking themselves whether it is legal and ethical and whether it is consistent with policy and the Code of Conduct, they should also reflect on whether they could explain it to their family and friends and would they be comfortable if it appeared in the newspaper.¹⁵

JFA Purple Orange believes that ethics training should be undertaken on a regular basis across the whole organisation and not just a topic covered in orientation for new workers. Effective implementation of the NDIS Code of Conduct, must be a part of a learning process that requires training, consistent enforcement, and continuous measurement and improvement. Managers should not rely on a one-off briefing on the Code of Conduct.

Service providers need to ensure that workers can understand the Code of Conduct and will continue to remember it. As Webley and Werner point out:

¹² McMillan, M (2012), ‘If you adopt one, will they behave?’, *Enterprising Investor*, CFA, 20 February <https://blogs.cfainstitute.org/investor/2012/02/20/codes-of-ethics-if-you-adopt-one-will-they-behave/>

¹³ Kerns, C (2003), ‘Creating and sustaining an ethical workplace culture’, *Graziado Business Review*, vol. 6, no. 3 <http://gbr.pepperdine.edu/2010/08/Creating-and-Sustaining-an-Ethical-Workplace-Culture/>

¹⁴ McMillan, op. cit.

¹⁵ Ibid

“it is not sufficient to send a booklet to all staff and expect them to adhere to its contents”.¹⁶

Further, providers should ensure that values and ethics are embedded in the organisation in a way that leads to adherence to the NDIS Code of Conduct. *“An ethics code is like a marriage license: unless the participants make a serious commitment, it is only a piece a paper”*.¹⁷

JFA Purple Orange believes that ethical conduct *must* include strict adherence to the responsibility to notify the Commission of reportable incidents, including incidents involving abuse, neglect, violence and/or exploitation. Failure to notify should be treated as a breach of the Code of Conduct. Providers should be required to identify the actions they have put in place to ensure that such incidents will not reoccur. This needs to be specifically stated in the Code of Conduct. Acquiescence, turning a blind eye, seeing and witnessing but not reporting are all acts that place a person in danger and are tantamount to neglect.

Key Issue 3 –Informing NDIS participants about the Code of Conduct and the complaints process

JFA Purple Orange recognises that people living with disability may not feel confident to raise issues of concern or to make a formal complaint.

NDIS participants must be provided with information about the Code of Conduct and the complaints process and empowered to use this. Information on the Code of Conduct and the complaints process must be easily accessible, in a wide variety of formats to accommodate a diverse range of people living with disability.

Some NDIS participants, particularly people who are more vulnerable and who receive services in institutionalised residential settings largely away from the eyes of the community, and where the main people in their lives are paid to be there¹⁸ are likely to require additional support to identify unacceptable practices, to be empowered to raise their concerns and to navigate the complaints process. Training for people with disability, which could be done through peer support networks, should include but not be restricted to:

- Self-confidence, assertiveness and self-esteem
- Communication skills
- How to manage and supervise their staff (support workers)
- How to manage their support agencies
- Their rights and responsibilities
- The laws that protect them i.e., DDA, Disability Services Act, OH&S etc.
- How to make a complaint

¹⁶ Webley, S & Werner, A (2008), ‘Corporate codes of ethics: Necessary but not sufficient’, *Business Ethics: A European Review*, vol. 17, no.4, p.407

¹⁷ McMillan, op. cit.

¹⁸ JFA Purple Orange (2015), *Submission on Violence, Abuse and Neglect Against People With Disability in Institutional and Residential Settings*, p.18

- Self-advocacy or how to find an advocate or peer support¹⁹

JFA Purple Orange's discussion with people with a lived experience of disability highlights the importance of education in empowering individuals to know when abuse is occurring. Fundamentally, a person needs to know that what is occurring is wrong, before they know to report it.²⁰ People with lived experience of intellectual disability have suggested that Information about how they can be supported to keep themselves safe could be presented in a variety of ways such as DVDs and comics²¹ or as accessible resources for people who use alternative and augmentative communication.²² Peer educators could also play a role, for example, peer-to-peer story-telling and role playing power relationships.²³

JFA Purple Orange is pleased to note that anyone (participants, family members, providers, workers and advocates) will be able to make a complaint about NDIS funded supports, including breaches of the Code of Conduct. This provides additional protection to people who are more vulnerable who may not feel confident in making a complaint.

We support the requirement that providers must have a clear process in place to address complaints or disputes. Concerns about internally administered complaints systems have been noted elsewhere:

People understand conflict of interest, and they understand that whistle blowers are seen as a threat, rather than an avenue to address misuse of power, unfairness or other failings in the system²⁴

The Commission should have oversight of the provider's internal processes to ensure that people with disability feel safe to make a complaint or provide negative feedback. Any adverse consequences or loss of services should be treated as a serious breach of the code of conduct.

JFA Purple Orange recommends that there be a public register of providers who have been found to have breached the NDIS Code of Conduct by acting unethically or unsafely. This should cover unregistered providers as well as registered providers.²⁵ It makes sense that a person would want to know a service provider's record against a Code of Conduct prior to

¹⁹ JFA Purple Orange (2015) *Submission in response to the NDIS consultation paper, Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework*.p.12

²⁰ JFA Purple Orange (2015), *Submission on Violence, Abuse and Neglect Against People With Disability in Institutional and Residential Settings*, p.28

²¹ Northway, R, Bennett, D, Melsome, M, Flood, S, Howarth, J & Jones, R (2013), 'Keep safe and providing support: A participatory survey about abuse and people with intellectual disabilities', *Journal of Policy and Practice in Intellectual Disabilities*, vol. 10, no. 3, p.239

²² For example: www.speakupandbesafe.com.au

²³ Meltzer, A, Robinson, S, Proud, Y & Fisher, K (2017), *Literature and Practice Review: Support to make decisions that promote personal safety and prevent harm*, Sydney, Social Policy Research Centre

²⁴ Homan, op. cit. p. 5

²⁵ JFA Purple Orange (2015), *A Conversation With People Living With Disability. Submission in response to the NDIS consultation paper, Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework*. .p.11

making a decision to use that provider. This information should be made readily available to NDIS participants.

5.0 Conclusion and Recommendations

The key points emerging from the submission are:

- 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.
- Ethical behaviour must underpin the work of NDIS service providers at each layer of the organisation. Effective implementation of the NDIS Code of Conduct by service providers must be a part of a learning process that requires training, consistent enforcement, and continuous measurement/improvement.
- JFA Purple Orange recommends the code of conduct include each service provider taking a proactive approach to rights-based, inclusion-based, induction and staff development practices, where the centre of gravity and investment is on developmental safeguarding.
- JFA Purple Orange believes that ethical conduct must include strict adherence to the responsibility to notify the Commission of reportable incidents, including incidents involving abuse, neglect, violence and/or exploitation. Failure to notify should be treated as a breach of the Code of Conduct.
- NDIS participants must be provided with information about the Code of Conduct and the complaints process and empowered to use this. Information on the Code of Conduct and the complaints process must be easily accessible, in a wide variety of formats to accommodate a diverse range of people living with disability.
- JFA Purple Orange recommends that there be a public register of providers who have been found to have breached the NDIS Code of Conduct by acting unethically or unsafely. This should cover unregistered providers as well as registered providers.

In summary, if a battery of measures (including a Code of Conduct) focuses on compliance only then we will make limited progress, because compliance is not an enduring influencer of behaviour. A more enduring influencer is the heartfelt connection with why something is important, in this case the place of people living with disability as valued citizens in our communities. We believe that any formal supports, including arrangements designed to safeguard the person in relation to risks, should be anchored on the goal of measurably advancing the person's journey to valued roles in community life, and therefore any

'safeguarding' arrangement but cannot demonstrate this should have no place in the framework.

6.0 Request to meet

We would welcome the opportunity to provide additional information as required. We would also value the opportunity to meet with the Department to discuss the submission contents in more detail.

For further information about this submission, please contact:

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