



National Disability Insurance Scheme (NDIS) – Code of Conduct

**Submission by Queensland Advocacy
Incorporated**

**Australian Government – Department of Social
Services**

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About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (QAI) is an independent, community-based systems and individual advocacy organisation and a community legal service for people with disability. Our mission is to promote, protect and defend, through systems and individual advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI has an exemplary track record of effective systems advocacy, with thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law and policy reform and by supporting the development of a range of advocacy initiatives in this state. We have provided, for almost a decade, highly in-demand individual advocacy through our three individual advocacy services – the Human Rights Legal Service, the Mental Health Legal Service and the Justice Support Program. Our expertise in providing legal and advocacy services and support for individuals within these programs has provided us with a wealth of knowledge and understanding about the challenges, issues, needs and concerns of individuals who are the focus of this inquiry.

QAI deems that all humans are equally important, unique and of intrinsic value and that all people should be seen and valued, first and foremost, as a whole person. Further, QAI believes that all communities should embrace difference and diversity, rather than aspiring to an ideal of uniformity of appearance and behaviour. Central to this, and consistent with our core values and beliefs, QAI will not perpetuate use of language that stereotypes or makes projections based on a particular feature or attribute of a person or detracts from the worth and status of a person with disability. We consider that the use of appropriate language and discourse is fundamental to protecting the rights and dignity, and elevating the status, of people with disability.

QAI's recommendations

QAI offers the following recommendations:

QAI recommends that:

1. A Code of Conduct should be introduced to safeguard the rights of people with disability and to ensure national standards of conduct for all providers and workers within the NDIS market.
2. A Code of Conduct is not, by itself, sufficient to protect the human rights of persons with disability.
3. Breaches of the Code of Conduct should result in the application of sanctions or remedial action to workers and/or service providers, as appropriate.
4. Reporting requirements should be imposed to ensure the monitoring, recording and reporting on the incidence of allegations under the Code of Conduct, including the unauthorised use of Restrictive Practices.
5. The nine principles proposed should be included in the Code of Conduct.
6. A robust, independent and diverse advocacy sector is essential for the realisation of these principles.
7. A proactive investigative approach to detecting potential violations of the Code principles is essential. Expecting vulnerable and disempowered people whose rights have been violated to take action to protect and defend their rights is unreasonable.
8. There is a pressing need for a change in culture and mindset, particularly among service providers, to ensure respect for basic human rights is normalised.
9. The measures proposed to address violence, exploitation, abuse and neglect of people with disability people are not adequate and should be strengthened.
10. Cultural and attitudinal issues will have a significant impact on the realisation of the Code of Conduct principles and must be addressed.
11. Stringent safeguards must be introduced to protect people with disability from sexual violence, abuse and misconduct.
12. No support worker or service should deny a person the right to make choices about where and how they live, including choices about their personal relationships.

Background

This Code of Conduct is part of the NDIS Quality and Safeguarding Framework which was developed with the stated aim of ensuring that the rights of people with disability are upheld and that the services and supports provided through the NDIS are safe.

The Code of Conduct is described as one of seven 'new national functions', with the other functions including provider registration, a complaints handling system, reportable incident

notification, behaviour support and restrictive practice oversight, investigation and enforcement and nationally consistent worker screening.

The Code of Conduct is designed to be a central element of the Framework and is purported to encapsulate the rights of people with disability in the NDIS to have access to safe and ethical supports, whilst reflecting the core values and principles set out in the National Standards for Disability Services.

Consultation

The Discussion Paper has been released for the purposes of consulting on the development of the Code of Conduct with people, including people with disability. QAI congratulates the Department for releasing Easy English and audio versions of the discussion paper to facilitate this consultation. However, we note that this remains inaccessible to many people with disability, particularly those who lack access to internet technology. We emphasise the need for the Department to take all reasonable steps to engage with people with disability and mental health concerns and relevant organisations in the development of this Code of Conduct. We repeat our comments in earlier submissions to related inquiries by the Department that it is vital that people with disability are driving this process.

The role of the new NDIS Quality and Safeguards Commission

This Commission is empowered to enforce action where providers or workers have engaged in 'unacceptable behaviours'.

Part 1 of the Discussion Paper

Why do we need an NDIS Code of Conduct?

QAI supports the Department's view that national standards of conduct for all providers and workers are important to ensuring the safety, quality and ethicality of supports within the NDIS market. However, we qualify this by noting that, in the case of vulnerable people with disability, a Code of Conduct alone will not be sufficient to ensure the Australian Government honours its commitment to ensuring the human rights of people with disability are protected and promoted. This is particularly so given Australia's lack of a bill or charter of human rights to provide baseline protection of the basic rights all people should enjoy, and Australia's reticence to implement the obligations to which it agreed by signing and ratifying international treaties including the *Convention on the Rights of Persons with Disabilities*.

QAI supports the proposal to apply sanctions or remedial action to workers and/or service providers in circumstances where the Code of Conduct is breached. It is important that there is a real and effective means of enforcing the policy, to ensure it is complied with.

QAI also notes the importance of properly and authentically monitoring, recording and publicly reporting on the incidence of allegations under the Code of Conduct, including the unauthorised use of Restrictive Practices. We are concerned that people who live with Restrictive Practices in Queensland and who, with the assistance of family or friends, are currently self-directing their supports are being coerced into relinquishing their choice and control. People who have gained control in their lives will inevitably experience decreased

quality of supports and services if forced to move to traditional service delivery. Moreover, attempts to coerce them to live in group homes may give rise to abuse. Denying people the right to self-direct their supports will result in many new participants failing to disclose the use of Restrictive Practices in their homes in order to retain independent support staff and avoid traditional services. The analysis of complaints data will help to inform, educate and raise awareness of the vulnerabilities of people with disabilities and help to identify points where additional safeguards must be implemented. It will enable systems advocates to inform law and policy makers about the required changes necessary for continual improvement.

What is proposed to be included in the NDIS Code of Conduct?

QAI is pleased to see that the Code of Conduct has been developed with consideration of broader policy, legislative and regulatory environments including the CRPD, the National Disability Strategy (which is purportedly the conduit for the Government's implementation of the CRPD) and disability discrimination legislation.

It is proposed that the Code of Conduct will require workers and providers delivering NDIS supports to:

1. Promote individual rights to freedom of expression, self-determination and decision-making;
2. Actively prevent all forms of violence, exploitation, neglect and abuse;
3. Act with integrity, honesty and transparency;
4. Provide supports in a safe and ethical manner with care and skill;
5. Raise and act on concerns about matters that may impact on the quality and safety of supports provided to people with disability;
6. Respect the privacy of people with disability;
7. Not engage in sexual misconduct;
8. Keep appropriate records;
9. Maintain adequate personal and professional liability insurance appropriate to the risks associated with the supports provided.

The principles designated as the building blocks of the Code of Conduct are laudable. These principles reflect the obligations Australia has assumed at international law.

Building upon our earlier submission on the NDIS Quality & Safeguards Framework, we note that advocacy is critical to ensuring the realisation of any rights contained in the Code of Conduct. As noted in our earlier submission, QAI has not sought the inclusion of advocacy within the NDIS and supports its separation:¹

When advocacy is independent it is free to promote the rights and welfare of people with disability without conflict of interest. Social institutions that have the potential to

¹ See Queensland Advocacy Incorporated submission to Department of Social Services – *NDIS Quality and Safeguarding Framework*, 7.

inflict harm on vulnerable people ought not to have a say in whether advocates can act to challenge them. Any organisation that already provides a service to people with disability - accommodation, support, legal services - must not also be responsible for advocating on their behalf. Inevitably there will be conflict between service needs and those of people with disability. The police should not police themselves, and nor should service systems, government or insurance schemes. The National Disability Insurance Agency must not fund disability advocacy. Funding should remain separately funded under the National Disability Advocacy Program.

However, as also noted in that submission, there is a vital need for:

- alert points for the appointment of independent individual advocates;
- recognition of the importance of systems advocacy;
- the instigation of new or expanded services in local communities, particularly for people with heightened vulnerabilities.

Advocacy is of great importance in helping any individual, and particularly a vulnerable individual, navigate a complaints system established by a Code of Conduct.

Who will be covered by the NDIS Code of Conduct?

QAI supports the proposal for the Code of Conduct to have broad application, including to all providers and workers funded under the NDIS, irrespective of whether they are registered or receive funding through individual plans or contracted services.

While we appreciate that the intention is to ensure that NDIS participants who self-manage will, with encouragement, provide information about the Code of Conduct to any unregistered providers they engage, we are concerned that the reality of the power imbalance between service providers and recipients will challenge this.

We are concerned about the translation of the principles of the Code into practice, as the power imbalance between individuals, particularly individuals with recognised vulnerabilities including a disability, and service providers is significant, and can silence the making of complaints.

Further, QAI holds significant concerns about the vulnerability of people with disability who do not receive an individual NDIS package. With the focus and resources directed towards the NDIS, those that are outside the Scheme are already facing heightened vulnerability and the overriding assumption that the NDIS is a panacea in the disability space increases the risk of abuse and neglect. This is prevalent for many people with disability who live in boarding houses and hostels at the behest of the manager or owner and who often exert unreasonable restrictions and control over the person's life.²

² Code of Conduct Principle 1.

How will the NDIS Code of Conduct be Applied?

QAI supports the broad standing proposed to be provided – ie anyone will be able to make a complaint about breaches of the Code of Conduct, including participants, family members, friends, providers, workers and advocates.

However, we consider the proposed application of the Code of Conduct to be deeply problematic in that the first step in the complaints process is defined as contacting the relevant service provider to make a complaint (internal review). This is a deeply unsatisfactory approach having regard to the noted power imbalance between a person with disability and a service provider.

The approach of permitting a complaint to be made directly to the Commission, not only in circumstances where the complaint is unresolved after notifying the service provider, but also in circumstances where a person does not feel comfortable to approach the provider about the problem arguably has merit. However, the onus remains on the individual person to instigate and prosecute a complaint. This is a significant burden for many individuals, and many of the most vulnerable people with disability will lack the support they may require to proceed down this avenue.

QAI recognises that other aspects of the complaints handling process helps to overcome these limitations, as it requires notification of reportable incidents by registered providers. This is an important safeguard, and will help to introduce greater accountability and safety into this area. However, this does not protect people that receive services from unregistered providers.

Further, we note that terming an allegation of violence or abuse a ‘complaint’ acts to trivialise and demean the conduct.

QAI supports the proposal to vest the Commission with ‘own motion’ powers, to empower the Commission to commence an investigation as a result of any information it receives. We caution that the efficacy of this measure will significantly depend on the funding provided to the Commission for this work. We emphasise that it is vitally important that Commission is adequately funded, to ensure it is sufficiently resourced to fulfil its role as a safeguard.

Part 2 of the Discussion Paper

Part 2 of the Discussion Paper provides further detail, including fictional scenarios, to illustrate the proposed application of the Code of Conduct.

We will briefly comment on each of these principles in turn.

1. Promote individual rights to freedom of expression, self-determination and decision-making

QAI strongly supports the inclusion of this principle.

The rights to freedom of expression, self-determination and decision-making are recognised as fundamental human rights and are asserted in key international human rights instruments

including the UN *Convention on the Rights of Persons with Disabilities* and indeed, the Code of Conduct includes express reference to the CRPD for the rights basis.

While QAI strongly endorses the non-discriminatory principles expressed in the Code of Conduct, we note that challenging the root causes of the discrimination faced by people with disability requires a systemic and holistic response.

Both of the fictitious scenarios provided by way of example in Part 2 required vigorous and sustained self-advocacy, and the matter was only progressed and resolved in both cases following a complaint made by the person with disability on their own behalf (albeit with the 'encouragement of a family friend' in Scenario 2.1.1).

This shows that there is a pressing need for a change in culture and mindset, particularly among service providers, to ensure that respect for these basic human rights is normalised. Unless and until this occurs, the Code of Conduct can only, at best, perform a similar function to the anti-discrimination legislation that exists at both a state and federal level in Australia. While laudable, the anti-discrimination legislation has been widely regarded as a toothless tiger that has had little impact in ensuring the rights of vulnerable people are protected and defended. Key problems, which we have discussed indepth elsewhere,³ include the individualistic approach taken, which require individuals aggrieved by discriminatory treatment to take action to assert the violation of their rights and pursue an appropriate remedy. This is highly inappropriate having regard to:

- the vulnerability of people with disability and their relative lack of power when compared with a service provider;
- the focus on negative action (rather than a positive duty to promote equity);
- the exceptions, exclusions and exemptions narrow the scope of anti-discrimination law; and
- the lack of effective remedies and sanctions.

This principle of the Code of Conduct must be safeguarded against a similar fate.

2. Actively prevent all forms of violence, exploitation, neglect and abuse

This principle is very timely, given the recent Senate inquiry into violence, abuse and neglect of people with disability in residential and institutional settings, and the current calls amongst civil society for a Royal Commission into violence, abuse and neglect of people with disabilities.

QAI supports the requirement that all providers and workers must commit to eliminating violence, exploitation, neglect and abuse against people with disability and that they must have appropriate systems and procedures in place to prevent violence, exploitation, neglect and abuse from occurring. We also support the proposal to ensure staff have appropriate supervision and training to enable them to identify, monitor and act when potentially harmful situations arise. Further, we endorse the mandatory reporting requirements proposed.

³ See Queensland Advocacy Incorporated. Submission to the Legal Affairs and Community Safety Committee. *The Appropriateness and Desirability of Legislating for a Human Rights Act in Queensland*. April 2016.

QAI submits that these steps must be accompanied by a change in culture and mindset that elevates the status of people with disability. Recognition is an important first step, yet experience has shown it is not sufficient – signing and ratifying the CRPD has not had effect that its principles are translated into practice, nor has the development of the Council of Australian Governments' National Disability Strategy (purportedly the means by which the CRPD is to be implemented in Australia) resulted in widespread knowledge or respect for the fundamental rights of people with disabilities.

The fictitious scenario provided to exemplify this principle has a satisfactory outcome because of the presence of a dedicated and concerned advocate who made a complaint and persisted in following it through to a reasonable resolution. Not all people with disability have access to a legal (or non-legal) advocate. Indeed – this will become increasingly rare in the context of the erosion of the support for the advocacy sector in Australia. For many people, a matched citizen advocate could assist, providing decision-making support and improving quality and safeguarding of people.

Further, the harm experienced by these residents until the situation was resolved was entirely preventable. QAI has long advocated for the necessity for people with disability to have choice and control over where and with whom they live. There were many key factors about this housing arrangement that were highly unsatisfactory and should never have been in place to begin with. We consider choice and control is fundamental to avoiding these types of situations in the first place. QAI is concerned that many of the situations in which a person with disability may be exposed to violence or abuse occur in a person's home, where they are forced to cohabit with another person for the purposes of sharing care provided by a service provider. Historically in Queensland, many people with disability, particularly those with high or complex support needs, have been forced to live in institutional or group settings, where they are denied choice about where and with whom they live. As QAI noted in our submission to the Senate Inquiry into violence, abuse and neglect of people with disability:⁴

Queensland, like every other state in Australia, has a history of abuse in institutional settings such as hospitals and large and small congregate residential arrangements... the dark chronicles of abuse have been echoed through the halls of several institutions...

In that submission, we noted the particular vulnerabilities of people with disability in institutional arrangements and called for additional and separate safeguards and supports to protect and defend the rights of people with disability who may be subject to violence, abuse or neglect within an institutional environment. While the de-institutionalisation movement has resulted in the closure of certain institutions in Queensland, many people with disability are still denied choice and control with respect to where and with whom they live and who provides their care. For many people, this can mean that they are forced to co-habit in situations where they can be at risk of violence, abuse and neglect. In this situation, many people with disability can live in domestic relationships, often spanning many years or

⁴ Queensland Advocacy Incorporated. *Submission to Senate Inquiry into Violence, Abuse and Neglect of People with Disability*.

decades, which are not recognised as ordinary domestic relationships for the purposes of the domestic violence legislation.

While we congratulate the Department for recognising the problems in this area and taking steps to address them, we are concerned that the measures are not sufficient to allay the need for safeguards of the nature provided in the examples, and therefore many people with disability will remain vulnerable to experiencing violence, abuse and neglect.

3. *Act with integrity, honesty and transparency*

QAI supports the inclusion of this principle in its entirety. Again, its effectiveness will depend on the proactive measures taken to ensure it is implemented and abided by, as the fictitious case studies demonstrate.

4. *Provide supports in a safe and ethical manner with care and skill*

QAI supports the inclusion of this principle. We note our concerns that workers engaged by service providers are largely disempowered workers, who often provided with minimal training and supervision, are paid minimum wages and often experience devalued work status. This scant respect for the vital work being performed by support workers has a significant impact on the quality of work performed by this sector.⁵ For people who live in boarding houses and hostels, their support, food, medication, outings and money is managed and controlled by the owner or manager with little regard for personal freedoms, privacy or safety.

5. *Raise and act on concerns about matters that may impact on the quality and safety of supports provided to people with disability*

QAI supports the pro-active approach to the identification of quality and safety concerns by providers and workers.

We emphasise that care needs to be taken to ensure that the environment in which complaints can be made by individual workers is honest, transparent and accountable, and that workers do not experience a fear of reprisals that may discourage them from notifying their concerns.⁶

Again, the cultural and environment is vitally important. People must feel safe to provide an honest account of any concerns. Fear of reprisals by those working within the institutions who witness the infliction of abuse has been recognised as a significant deterrent stopping staff members from reporting. The legislative protection provided by the *Public Interest Disclosure Act 2010* (Qld) (which replaced the *Whistleblower Protection Act 1994* (Qld)) has not proven very effective in dampening this fear of reprisal. As QAI noted in our submission

⁵ The devaluing of caring professions, including nursing, childcare and support work, is an issue that has received significant scholarly attention. See for example: P England, M Budig & N Folbre. (2002) 'Wages of Virtue: The Relative Pay of Care Work'. *Soc Probl* 49 (4): 455-473; J. Bigo. (2010) 'The Care Paradox: Devaluing and idealising care, the mother and mother nature'. *Int J of Green Economics*. 4(2).

⁶ Fear of reprisal is recognised as a significant deterrent to whistleblowing, and one which continues notwithstanding safeguards introduced to address this.

to the Senate Inquiry into violence, abuse and neglect of people with disabilities in institutional and residential settings:⁷

Of particular relevance for people with disability who have experienced violence, abuse or neglect within a residential or institutional setting is the power imbalance that exists and the fear of informal reprisal. Recent concerns about the misuse of executive power and lack of accountability under the Newman government have reignited concerns about the proliferation of inappropriate conduct and the potential for reprisals in Queensland, notwithstanding the public interest disclosure protective legislation. There remains in Queensland a climate of fear and reluctance to report official misconduct, particularly by vulnerable persons.

6. *Respect the privacy of people with disability*

Respect for privacy is a fundamental human rights that is protected at international law (including in the CRPD, Article 22), as well as in relevant federal, state and territory legislation.

QAI supports the inclusion of respect for the privacy of people with disability as a core principle of the Code of Conduct. We submit that privacy must include confidentiality.

7. *Not engage in sexual misconduct*

QAI supports the inclusion of this principle. As QAI has noted in other submissions, violence and abuse, including sexual violence, against people with disability is a significant problem, and the rates of violence disproportionately high as compared with people without disability. In our submission to the Senate Inquiry into violence, abuse and neglect of people with disability in institutional and residential settings, we provided the following statistics on the incidence of sexual abuse or assault:

- Sobsey and Varnhagen suggest that most people with disabilities will experience some form of sexual assault or abuse.⁸ Sobsey estimates up to 80% of people with a disability are sexually abused.⁹
- Muccigrosso suggests that the incidence of sexual assault against people with an intellectual disability is at least four times higher than in the general population.¹⁰
- The incidence of sexual abuse (regardless of age) among people with developmental disabilities was estimated in 1985 by the California State Department of Developmental Services to be 70%.¹¹

⁷ Queensland Advocacy Incorporated. *Submission to Senate Inquiry into Violence, Abuse and Neglect of People with Disability*, 9. See that submission for a fuller discussion of this issue.

⁸ 'Sexual abuse and exploitation of people with disabilities: Toward prevention and treatment'. In M. Csapo and L. Gougen (eds) *Special Education Across Canada* (pp.199-218). Vancouver: Vancouver Centre for Human Development and Research.

⁹ Sobsey, D. 1994. *Violence and abuse in the lives of people with disabilities: the end of silent acceptance?* Baltimore, MD: Brooks Publishing.

¹⁰ Muccigrosso, L. 1991. 'Sexual Abuse Prevention Strategies and Programs for Persons with Developmental Disabilities'. *Sexuality and Disability*, Vol. 9. Pp. 261-272.

While we do not have access to current figures, anecdotal evidence suggests that the situation in this regard has not markedly improved for people with disability.

This is an area where urgent attention is required.

8. Keep appropriate records

QAI supports the inclusion of this principle requiring providers and workers to maintain accurate, legible and up-to-date records. We emphasise that these records must be used to ensure they inform better service provision and help to protect people with disability. It is also important there is national consistency and relevant sharing of information, to protect against situations where a person found unsuitable to work with people with disabilities in one jurisdiction obtains employment in another jurisdiction.

9. Maintain adequate personal and professional liability insurance appropriate to the risks associated with the supports provided

QAI supports the proposal to include a requirement that both registered and unregistered providers must hold adequate and appropriate insurance.

Conclusion

While QAI supports the development of the nine principles, we emphasise the need to ensure that these principles are grounded in the cultural change necessary to ensure their authentic realisation. Further, it is important that the Commonwealth ensures that the Quality and Safeguards Framework, Code of Conduct and the National Framework for the Use of Restrictive Practices are safeguards and do not restrict people with disability from enjoying the same rights and opportunities as other citizens. QAI is concerned that the National Framework for Restrictive Practices is aligned with Queensland legislation which has essentially become an enabler for services providers while eroding some of the protections for people with disability. If the nation follows the Queensland trend, it will reduce the opportunities for vulnerable people who live with Restrictive Practices to exercise the same rights and opportunities available under the NDIS as other participants.

The message that overwhelmingly emerges from the scenarios provided in the Discussion Paper is of the vital importance of appropriate support and advocacy in helping vulnerable people to recognise and realise their rights. Without this support, people remain disempowered, irrespective of their rights on paper.

This is of critical concern to QAI in an environment in which support for advocacy is dwindling. QAI submits that there is a vital need to ensure that all people with disability have access to the support and advocacy they require.

¹¹ Abuse Prevention Strategies in Specialist Disability Services Commissioned by National Disability Administrators on behalf of Commonwealth, State and Territory Ministers responsible for disability services in Australia. 2002; Baladerian, N. 1991. 'Sexual abuse of people with developmental disabilities'. *Sexuality and Disability*, 9(4), 323-335.