Our Voice Australia

There are more than 700,000 Australians with intellectual disability and/or complex and associated needs. There are more than one million family members who support them.

Our Voice Australia is a voice for those who cannot self-advocate.

www.ourvoiceaustralia.org.au

Our Voice Australia - NDIS Code of Conduct Submission

About Our Voice Australia

Our Voice is collaborative disability family advocacy. This means a partnership between family members with disability and the families who support them.

We are a representative voice for the needs of people with developmental/intellectual disability and/or complex needs. To be a full member of Our Voice Australia, you must be a person with an intellectual disability or a person with associated complex support needs or a parent or sibling of an eligible member.

We welcome the outcome from the input of voices from across the nation regarding the NDIS Code of Conduct. We place great hope that peoples' views, passions and deliberations will inform a Code of Conduct that responds adequately, fairly and justly.

Code of Conduct coverage

It is commendable that the contemplated NDISCode of Conduct captures a very broad range of organisations and personnel in its ambit.

Under heading 1.3 "Who will be covered by the NDIS Code of Conduct?" of the discussion paper, providers of every kind and workers are covered, with additional coverage of personnel involved in decision-making within the providers, as in the quote below:

> "The term 'providers' includes key personnel such as any person with responsibility or influence over planning, directing or decisions, including board members and other stakeholders of significance."

Notably absent from the Code of Conduct is the Department of Social Services itself, the NDIA, and key personnel with responsibility or influence over planning, directing or decisions and other stakeholders of significance within these organisations.

Our submission is that the Code of Conduct should apply broadly to ALL workers, providers and paid personnel involved in service delivery and decision-making. Therefore the Code of Conduct should also apply to decision-makers within the NDIA and the Department of Social Services. There may be Codes of Conduct which apply to these workers already, as is already the case with some workers and providers, but a commitment to the NDIS Code of Conduct would impose no additional burden especially when the aims of the Code are so beneficial for the recognition and protection of participant's rights.

This is vital given the transfer of state employees into the design mechanisms and planning side of the Scheme.

Many of these employment transferees or those who have applied and been accepted or were head-hunted into substantive positions within the NDIA, had been ultimately responsible for upholding the rights of people with disability under the state-based systems administered by them. Please see addendum 1 (a not for publication confidential document).

This highly confidential document would never have been written or come to light if those in a position of power and oversight had responded both instantly and comprehensively to claims of sexual assault, and/or neglect and abuse and exploitation of people with complex needs within group homes funded by; and often staffed by, government agencies. These agencies frequently chose to diminish or cover up these claims and to ignore the evidence rather than to investigate and to respond.

It makes little difference if the offender is a person with disability or a staff member. The rights of residents who are offended against to feel and be safe in their home environment should be the prime consideration, not the last consideration. How can such situations continue for years without proper actions when if the person can communicate well, police are called in, the offender removed and charges laid? Or if the family have ‘standing’ in the community the responses are quick and fulsome? The system up to now has exploited the disability in order to to abrogate the responsibility to those citizens who are manifestly vulnerable and powerless.

It was the ultimate responsibility of state bureaucrats to ensure that a minimal standard of oversight, action and resolution was delivered to people within their portfolio brief. It was therefore incumbent on the state bureaucracy to ensure all vulnerable groups under their purview had the right not to be abused and/or neglected and for them to feel safe in their home environment. This oversight is crucial in the implementation of the NDIS. The dismissive attitude of “if we ignore it it will go away or not happening”, had no place in state systems and has even less place in building a responsive, personalised and individualised service system which is the hallmark of the NDIS. Additional to this, we must bear in mind that people with disabilities in accommodation settings are often not there by choice but through circumstances beyond their control, oftentimes because of family crisis.

If bureaucrats, service provides and those responsible for the implementation of the NDIS apply a code of conduct different to that which they would accept for themselves or for their own family members, then that is discrimination at first instance.

When a different code of conduct is applied to people with intellectual disabilities and/or with complex support needs, people who generally cannot self-advocate, complain or communicate to the level required at law, then the issue of equality before the law for people with disabilities does not exist.

The wider application of the Code of Conduct will serve multiple purposes: ensuring that ALL decision-makers, providers and workers understand and abide by the Code of Conduct and are all mandatory reporters, while encouraging mutual responsibility and accountability for the goals of the Code as the policies apply to all decision-makers and workers within the NDIS system, including the Department of Social Services and the NDIA and related organisations.

This can only work with both a ‘top down’ ***and ‘***bottom up’ approach, which means those in the lowest link in the chain of command do not bear all responsibility while those with the power to make decisions and thereby change the circumstances, are not held accountable if they are aware and fail to act.

Providers of last resort

The NDIA has not to date released a position paper on supporting those who will need a provider of last resort if service providers reject those in need of service and support who are deemed too difficult, dangerous or unmanageable.

To date, states have always been the service provider of last resort. Therefore we envisage that the NDIA will need to become the provider of last resort if financial issues or service provision cannot be resolved with respect to costs of and resources for servicing and support this highly expensive group requiring extensive and expensive support on multiple fronts.

Ultimately, it is the Commonwealth that now bears responsibility for provision of services to those people with disabilities which are difficult, complex and supra-intensive. This means the Commonwealth agency with oversight of the NDIS will be responsible to ensure the safety of all concerned, while affirming and protecting the human rights of the participants in the NDIS and the front-line staff providing hands on service and support.

Accordingly, we believe the Commonwealth agency with oversight of the NDIS must be brought within the ambit of the NDIS legislation with specific reference to any decision-making role which would ultimately affect the circumstances of the participant in the NDIS.

We submit and strongly recommend that the Code of Conduct must be applied to all decision-makers and employees of the NDIA and the Commonwealth agency with oversight of the NDIS, as well as service providers and staff.

Code of Conduct Application

The ability of “anyone” - “participants, family members, friends, providers, workers and advocates” to make a complaint to the Commission under the Code (with first recourse to the provider and their complaint systems) is a very sensible approach ensuring the participant and the whole community around a participant can hold providers and decision-makers accountable. This is especially important where a participant lacks the ability to effectively advocate for themselves.

However, the discussion paper lacks some important details regarding:

1. Anticipated timeframes for investigation and action
2. Process of follow-up and reporting back to complainant
3. Escalation if complaint is not resolved in a timely manner or if dissatisfied with outcome
4. Maintaining anonymity of complainant and privacy of participant throughout process

Our submissions regarding each heading in turn follow.

1) Anticipated timeframes for investigation and action

Investigation and resolution of a complaint in a timely manner is essential for effective protection of the rights of participants the Code of Conduct seeks to uphold. If complaints regarding the essential rights of participants are not dealt with within a minimum period, serious abuses may continue for weeks or months longer than tolerable or acceptable.

Our submission is that the Commission must establish a clear timeframe for timely investigation and action so that participants and complainants can know when matters shall be either resolved or dealt with.

2) Process of follow-up and reporting

Alongside expectations of a timely investigation and subsequent action, there is no detail in the Discussion Paper as to how investigation, action and outcome is reported to the participant and the complainant. The Discussion Paper creates obligations for providers to report incidents to the Commission, but does not discuss the form of reporting to the participants or complainants regarding the process or outcome of the complaint.

Our submission is that the Commission must establish a clear process for reporting to the participant and complainant regarding the process, action and outcome of any investigation.

Without a clear process, a complainant or participant may remain unaware if any investigation or action was taken at all regarding their complaint, which certainly does not serve the aims of the Code.

3) Escalation

Every scenario in the discussion paper seems to conclude with all parties satisfied, which, with all due respect to the authors, does not often correlate with the reality of complaints regarding the basic rights of participants.

This begs the question, if a participant or complainant is not satisfied with the timeliness, the reporting or the outcome of an investigation, what process is available to appeal or escalate the matter? Is it the Ombudsman, the Minister or the courts? What support is triggered to assist the participant to take their complaint further if it becomes moribund within the system as has been the case under state-based legislation? The Discussion Paper does not contemplate or foresee any such scenario, although the necessity of finding a process is a certainty, as having all complaints resolved perfectly satisfactorily is only possible in fictional scenarios.

Our submission is that the Commission must establish an escalation or appeals process for when participants or complainants are not satisfied with the outcome of a complaint.

4) Maintaining anonymity, whistle-blowing and privacy of participants

Anonymity

Scenario 2.5.2 clearly contemplates the ability to make complaints anonymously, which is a laudable aim allowing participants, workers or anyone in the community to protect the rights of participants without risking employment or identification where that may be sensitive or have negative repercussions.

Maintaining anonymity is a worthy goal but the discussion paper neither discusses nor makes any detailed proposal for a potential process to maintain anonymity. This is essential especially where following-up and reporting back is concerned. Our submission is the Code and the Commission needs a clearly established and detailed procedure to not only make complaints anonymously, but also maintaining anonymity in subsequent reports and follow-ups.

Whistle-blowing

The Discussion Paper alludes to “whistle-blower protections” in the legislation establishing the Commission without specifying any details of how those laws will be drafted or function.

In Australia whistle-blower protections in the private sector are not sufficiently robust. The *Public Interest Disclosure Act 2013* only applies to Commonwealth Public Sector employees, and in the private sector, which would be the entirety of workers and providers in the “NDIS market”, legislated whistleblower protections in Australia in both State and Federal law are worryingly scarce and if there are any they are weak and ineffective.

Our submission is that the Code requires full and detailed disclosure of proposed whistle-blower protections for public scrutiny and consultation before implementation; in order to scrutinise their scope, efficacy and ultimate effectiveness.

Vexatious complaints under the guise of whistle-blowing

The Discussion Paper does not address the possibility of vexatious complaints being brought anonymously against the NDIA, service providers or support workers or by any of the above as well as participants of the Scheme or their agents. This possibility should be given due consideration and a penalty regime applied for false and vexatious allegations.

Privacy

The privacy of participants is paramount, and yet clearly aspects of their lives will be discussed as part of complaints. An open system of complaints from “anyone”, including anonymous complaints to allow protection of participants’ rights is difficult to balance with protecting the privacy of participants and others during the process, and this is not adequately explored in the Discussion Paper. Acknowledging this difficult balance and how it will be managed is crucial to the integrity of any investigation.

Our submission is that a detailed process for how privacy will be protected during a complaints process is required.

Furthermore, a detailed outline of processes and legislation that enable anonymous submissions, whistle-blowing protections and privacy protection must be made available by the Commission before a Code that intends to uphold all these elements is implemented..

Guardianship

Additional barriers are presented for NDIS participants whose Guardianship has been awarded to their accommodation service providers who, allocate their funding expenditure, sign off on funds usage and manage the use of their NDIS funding and their Disability Support Payments. The conflict of interest in this scenario is manifest. There must be clear guidelines regarding this very poorly considered application of State Guardianship Tribunal decisions and the alarming conflict of interests that can arise in such circumstances. While bearing in mind that many participants will have no family and no significant others to ensure their interests are advanced and protected. This requires independent oversight and review.

We submit that a national Tribunal that takes over such guardianship applications for NDIS participants, given that the NDIS is a national Scheme to remove human rights conflicts. Currently the state-based guardianship systems can actively work against the human rights of participants by tying decision-making to providers of services and requiring no evidence being put forward in order to make decisions on guardianship.

Our submission is that NDIA makes itself aware through audit of all participants whose financial and decision-making authority sits with a funded service provider or their staff who have all authority across an individuals whole-of-life domains. This audit is to ensure that the conflicts of interest that come with such authority, are carefully reviewed and that funds are spent exactly as nominated, with the agreed staffing levels within the participant’s Plan.

Service providers, finances and allocations of staff

We submit that audits of organisations that provide accommodation supports should look at staff ratios, roster systems provided to ensure they synchronise with the dollars claimed for support hours across the individual service. We recommend that each participant supported by an accommodation service provider, has a detailed cost sheet that shows staff ratios for dollars spent.

The only way to ensure the accuracy of expenditure and ensure that people are not being exploited is to review the staff ratio funding plan alongside employment data and to ensure that required staffing levels were/are provided. We have provided a copy of a plan that should be the standard to ensure that each participant is provided with ***meaningful*** funded support for hours that they have been invoiced (please see addendum 2). This should be consistent with the dollars claimed for service provision across each accommodation model.

Inaction as neglect and abuse

Neglect and abuse are not always actions, they can also be causal factors such as inaction. We submit that the Code of Conduct also should include under-servicing. People with intellectual disability do not always make the best choices for themselves.

For example: a participant spends 80% of their life either in bed or the couch. This can be construed as 'individual choice' as they choose to do this. However, if the participant does not understand the outcomes of their choices – i.e. of poor health, obesity, social isolation, to allow such choices as a lifestyle when you are funded to provide that person with supports to enhance their life and grow their independence is tantamount to neglect and abuse.

Additionally, people with intellectual disability are more likely to make poor choices regarding diet. The onus must be placed on the service provider to ensure the participants for whom they provide service are encouraged to shop, cook and in the main eat healthy nutritious food . Poor nutrition and obesity without an organic reason is another form of neglect.

The number of people living in care with poor oral health is alarming and it is clinically proven that poor oral health impacts adversely on physical and psychological health. It is incumbent on the provider to ensure that oral health is a priority in service provision. We submit that lack of support in ensuring hygienic oral care and providing medical assistance in a timely manner to people with complex needs who cannot self advocate, should also come within the ambit of the Code of Conduct.

Decision making - Choice and Control

Decision making is not straight forward for people with moderate to severe intellectual disability. Who are the arbiters of good and bad decisions? When we talk about dignity of risk we are really referring to people who have the capacity to calculate the risk. At what point does risk become undignified? The capacity to consider the ramifications of a decision whether good or bad and thereby make an informed choice is too often beyond the ken of people who are moderately to profoundly intellectually disabled.

Decision-making remains a very contentious issue. We were bemused to read the newly expressed contradictions by some advocates and academics on this subject.

We note in the CRC NDIS briefing paper the very notion of choice and control is challenged and viewed as a discriminatory process for people with mild and borderline intellectual disability who have been in contact with the criminal justice system; however the same people that posit this view, claim that ALL people with disabilities even people with severe to profound intellectual disability are deemed capable of making their own major life decisions.

This premise is inconsistent. It is a dichotomy. How can people with borderline or mild cognitive impairment have less ability to make valid decisions due to the effect of disadvantage, than those with moderate to profound intellectual disability? The disadvantage of both groups is glaringly obvious. The reality is that both groups often engaged in behaviours that place them at serious risk to themselves and others, including non-compliance with medication, impulsivity, aggression and criminal behaviour except the latter group do not have the legal capacity to be charged for their actions whilst being deemed by the same advocates and academics as having decision making capacity. Those deemed to have the capacity to be charged by the law, are considered by the same advocates and academics as not having decision making capacity. It beggars belief…

What exactly does this paper say?

Page 4 Choice and control: The need to reconsider 'capacity'

"The founding principles of choice and control central to the NDIS premises a particular conception of the disability experience, which at its foundation excludes the majority of the target group. **By assuming all individuals with disability have the capacity to make positive life choices, the schemes founding principles present significant concerns for this group** (criminal offenders with mild or borderline disability)".

Quote:

"The very notion of choice and control that drives the NDIS has created a discriminatory process for so many of our clients. It all sounds good in theory, however goals and plans for our client group are usually developed via a long process. This involves staff developing a close working relationship with the client, which is possible under CJPs OSSL (On-Site Supported Living) framework. By spending time together (which we do a lot of in the OSSLs), workers are able to identify certain things over time that clients might bring up in a conversation. We can then reflect that back to them in terms of a goal or strategy. It's a process that takes time but is often very effective. But if we were to sit with them and ask 'what are your goals?' we would inevitably draw a blank". (CRC_NDIS_Briefing Paper_Jan2017 Page 15 -)

We submit that those that posit these views are doing people with significant intellectual disability a disservice. If you do not have equal capacity before the law, you cannot be viewed as having greater capacity to guide your own life choices with regard to major legal and lifestyle decisions than those who are deemed to have capacity before the law…

In closing

We would like to express our appreciation that finally there is action with regard to the systemic neglect, exploitation and abuse of people with disability within the social care arena. We look forward to seeing protections finally being put in place that can advance the rights of all people, no matter their disability, to be safe in their living environment, to reduce exploitation, and to offer a degree of certainty that actions will be taken to stem the current two-tiered system where neglect and abuse of vulnerable groups is viewed as acceptable by some in positions of power.

To live a life of fear of violation is an unacceptable anywhere, but specifically in a first world country. There are none so vulnerable as those who cannot articulate their distress. There are none so vulnerable as those whose lives and needs are considered to be of less importance to the needs of those who can articulate their fears and their pain and;

There are none so vulnerable as those whose rights are secondary to that of their perpetrators.

We hope that this review and the subsequent positioning of legislative protections, will provide some certainty that our sons and daughters have equal access to the right to be safe, to be free of exploitation, abuse and neglect, and if that fails, a right to justice.

This legislation MUST have teeth. It must have a bite strong enough to punish perpetrators and to give them pause for thought before they act. It must be strong enough to prevent exploitation and enable a care system that acknowledges the needs of all as being of equal value; a system that embraces change, encourages innovation, and provides the impetus to realise the individual potential of all participants to the fullest extent possible, irrespective of the degree of disability.

With regards

Nell Brown
Marylou Carter
Maree Buckwalter

Our Voice Australia