

Consultation paper: Proposal for a National Disability Insurance Scheme Quality and Safeguarding framework

Submission: Raelene West, April 2015

In relation to Broader Disability Sector:

•The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) promotes the human rights and dignity of people with disability (pwd). Since 2008, Australia has been a signatory to the CRPD, and as such, is expected to actively pursue the objectives of the Convention framework and meet the reporting requirements of the Convention.

In developing a national Quality and Safety (QandS) framework for the NDIS, greater emphasis on articles contained within the CRPD are required, both in order for government to meet its CRPD reporting requirements, but more importantly, to ensure the human rights of pwd in Australia are fully met. Viewing the entire consultation report through the lens of human rights, rather than just utilising human rights within the segment on Restrictive Practices, should work towards development of a more in-depth and prescriptive QandS framework, where safety and protection elements of the QandS framework are related specifically to CRPD articles.

I am concerned that efforts to reduce regulatory burden and 'red tape' with the new QandS framework will compromise the protections and safetys of pwd in Australia prescribed in the CRPD. I feel certain elements of the QandS framework are bias towards business' in favouring their market flexibility and competitiveness as a service provider rather than adhering to a more stringent QandS framework. Given the government has out-sourced responsibility of provision of disability support services over the last 25 years and harm and abuse of pwd in Australia has continued to occur, I feel government should be mindful of the need for a rigorous QandS framework and not some loose protectionist framework placing onus of the individual to build 'natural' supports (however these are defined). In most cases, pwd are more vulnerable than mainstream users of services, and are often dependent on support staff for basic, life supporting tasks in their homes or residencies. As such, despite the increased time, effort and resources of a more onerous framework, a stringent QandS framework focused on freedoms and protections of pwd, as prescribed by human rights within the CRPD, is required. CRPD articles that relate directly to the NDIS QandS framework include:

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16 - Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 22 - Respect for privacy

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

Provide these health services as close as possible to people's own communities, including in rural areas;

Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26 - Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

- The segment on Restrictive Behaviours for the QandS framework should be remodeled around more contemporary models of Positive Behaviour Support. Please refer to link to WA state government fact sheet for summary:

- <http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Positive%20Behaviour%20Support%20Information%20Sheet%20for%20Disability%20Sector%20Organisations.pdf>

- Where exactly will the QandS framework sit in relation to the National Standards for Disability Services, revised in 2013. This isn't clear. Does the QandS framework sit within or alongside of these standards. Possibly the documents should be merged so there is one clear, national document outlining all requirements for quality assurance and safety requirements so business' have a single and clearly defined framework to operate within. Of note, the National Standards for Disability Services 2013 mentions the CRPD, but utilises a completely different human rights framework inconsistent with the CRPD.

- As a Victorian and pwd, I don't wish to lose the functions and protections of the Victorian Disability Services Commission, with its roles of education and investigative powers, or the Office of the Public Advocate, with its legal expertise and protections related particularly to guardianship, powers of attorney and consent amongst other legal roles. The OPA in particular is crucial in providing many legal safeguards for pwd in clinical health and group home settings in relation to provision of disability support services.

- Will protections and safeguards provided by any external complaints/resolutions body to the QandS framework be available for individuals receiving funding for disability support services through Transport Accident Commission (TAC) or WorkSafe such as with the Victorian Disability Services Commission currently having investigative powers within TAC and Worksafe

- Given evidence of ongoing abuse and harm of pwd in Australia over the last 25 years from current inquiries, and ongoing discrimination of pwd in Australia in various areas such as funding for provision of disability support services and treatment of pwd by service providers and their staff, government should reappoint a fulltime Disability Discrimination Commissioner to ensure protections, safetys and human rights of pwd are embedded into the psyche of both service providers and mainstream Australians.

Information Sharing:

•I strongly agree that the federal government should contribute block funding to capacity build credible, robust information exchange systems that allow NDIS participants to seek and share knowledge to inform decision making. I agree government should actively support participants to develop their self-advocacy and decision-making skills to increase understanding of human rights and how they will be operationalised within the NDIS. This will be vital to ensuring participants make well-informed choices and that their human rights of protections and freedoms are met within the NDIS framework

•In developing information exchange systems, I feel a 2 page summary of each service provider organisation to support participants in their decision-making tasks should be developed. This summary could include a history of each service provider organisation and how long it has been operating, the philosophies, the ethics of the organisation, the size of the organisation and the number of clients it has (whether it is a boutique or large-scale service provider), a summary of organisational safeguards, a summary of accreditations/quality audits/recognised industry standards, details of training frameworks for staff, unit costs for services, geographic area that organisation services, and any specialisations the organisation may offer for example cultural awareness training. Further, NDIS participants could be provided with independent reviews and outcomes-based quality information to help them make choices about providers, similar to that of trip-advisor for travel. All information would be provided in a range of accessible formats, online and in print copy, and like the yellow-pages, would be updated every 12 months.

Peer support

•Peer support mechanisms are an excellent mechanism in bringing-in isolated pwd who are members in our community with a limited number of family and friends, and peer support can act as a mechanism to ensure the social inclusion and safety of pwd in our community. Many benefits are obtained in enabling participants to share information, lived experiences and challenges they may be facing in their current living situation as a pwd (both in relation to provision of support services and life in general). Peer support can provide a mechanism through which individuals discuss issues and become informed of mechanisms and strategies to manage various situations, including situations where safety may be compromised. The distance and independence from family carers or support service staff also provides a safer space from which a pwd may wish to voice a situation related to safety/neglect/abuse and discuss possible safety and reporting strategies available in a less compromised environment.

In particular, group members with mental health issues appear to have gained significant benefits of friendship, understanding, advocacy, information sharing and moral support from weekly face-to-face peer support group meetings.

Peer support could occur in various formats including face-to-face group meetings weekly/ fortnightly, online forums, webinars including pwd, blogs, facebook and social mediums

A reference on peer support and individualised funding of note is: State of Victoria, Department of Human Services-Disability Services Division, 2012 *Peer Support: A guide to how people with a disability and carers can help each other to make the most of their disability supports*. It recognises that:

the potential of peer support to make a valuable contribution to the overall wellbeing and empowerment of people with a disability and their carers

that peer support between service users can encourage people to try new things outside of their traditional service, and be prepared to respond to this.

A further reference for parents of pwd peer support is:

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), 2013, *MyTime Peer Support Groups for Parents and Carers of Children with Disability or Chronic Medical Condition Program (MyTime)*.

NDIA Service Provider Registration

•The key aim of the new NDIS QandS framework is to prevent all forms of neglect, abuse, financial or sexual exploitation, harsh or rough treatment, depriving a person of food, sleep or basic needs, bullying, or intimidation and/or vengeful behaviour in response to a complaint. These are all serious and prevalent issues for pwd in Australia as the Productivity Commission Disability Care and Support 2011 report highlighted, the NPWDACC, 2009, *'Shut Out: The Experience of People with Disabilities and their Families in Australia'* detailed and as the current Senate inquiry into violence, abuse and neglect against people with a disability in institutional and residential settings, 2015, of abuse in residential care settings is now examining. Also recent charges against support workers at Yooralla and investigative segments on ABC's Four Corners on abuse and mistreatment of pwd ALL demonstrate that lack of safety and protections for pwd in Australia, provision of poor service standards and lack of service provider and staff accountability. The evidence from inquiries suggests that abuse and mistreatment of pwd may be on a larger scale than is currently estimated. The Australian Human Rights Commission access to justice inquiry culminating in the release of the report Equality Before The Law, 2014 (<https://www.humanrights.gov.au/our-work/disability-rights/publications/equal-law>) found significant problems for pwd to even access the justice system, let alone in having offenders prosecuted and convicted. It found 'tragic stories of where the criminal justice system had failed people with disabilities, and had compounded disadvantage'. It seems evident that the Human Rights of pwd in Australia are not being fully met, and that despite Australia being a signatory to the UN CRPD since 2008, pwd are being subjected to abuse despite existing safeguards and quality frameworks.

Prevention of any opportunity of mistreatment or abuse of pwd must therefore be paramount. Stringent and onerous quality and safety frameworks will need to be implemented as the current standards within state-by-state frameworks currently in place are not effectively preventing abuse or mistreatment of pwd, and safety of pwd appears to be based on luck and not on effective monitoring capacities. Ensuring support workers and any individual providing services funded by the NDIA are of a good character, come to work in a fit state (i.e. unaffected by drugs or alcohol), are not engaged in bullying or criminal behaviour, respects personal boundaries and individual property are paramount.

As stated in consultation report, the framework is intended to be risk based - there is risk that pwd could receive poor quality supports that do not help them achieve their goals, and risk that people with disability could be harmed in some way. I am concerned however that with the extent of abuse and lack of protections currently in the disability sector, that now is not an opportune time to be implementing a QandS framework with reduced protections. Given the significant amount of regulatory and policy movement in the sector, pwd are looking for assurances that they will be safe when utilising support services. Many participants may be using support services for the first time within the NDIS, or conversely have negative experiences and anxieties related to poor standards/abuse/mistreatment during receipt of support services over the years. Pwd are looking for a QandS framework that delivers on safety and protections, that genuinely provides solid and robust safeguards and protections from abuse, that effectively demonstrates strategies and mechanisms to deter and prevent harm and abuse, and implements regulatory approaches that are effective and thorough in ensuring pwd are free of harm, abuse, exploitation or violence.

Any risk-based framework must target not just those areas where the dangers are greatest, where abuse has 'traditionally' occurred such as in group homes, family members or isolated pwd in the community, but must encompass all support service provision. All consequences of harm for pwd are severe. Abuse of pwd is often cumulative, occurring in many different forms over many years. Confidence in the safeguards within the system are currently low, and anxieties of many pwd are high related to numerous experiences of poor treatment and/or abuse related to provision of support services across Australia. All service providers operating within the NDIS must be made to comply with a strong QandS framework.

Although language in the consultation report notes there is a need to 'achieve a balance between ensuring quality support provision and minimising unnecessary barriers', it is evident that these barriers are required as high levels of abuse, human rights violations and abuse are being reported across the system. Providers of support services have a responsibility to ensure the safety of pwd,

however it would appear this responsibility is not currently being met by many service providers, despite existing safety frameworks. Abuse and harm of pwd is occurring within service provider organisations, such as Yooralla, that have supposedly met national disability service standards and auditing processes within current QandS frameworks. These mechanisms failed pwd in preventing the occurrence of abuse, and these individuals suffered abuse because current safety frameworks failed. As such, I feel the development of a new national QandS framework should force all service providers operating within the NDIS to comply with a strong and stringent elements within the QandS framework. The 'terms of business' of a service provider must prioritise safety and prevention of mistreatment.

Tiered System?

•Suggestions of a tiered system of safety frameworks has been suggested within the consultation report - 'support types where there is potentially a greater risk to participants will have to comply with a stronger regulatory framework than providers in low-risk areas like home handy person services'. The consultation suggests differing arrangements may be put in place between differing providers offering various supports, based on 'potential to pose a higher risk of harm to participants', and that these service provider organisations would require less regulation because there is less risk of harm to participants. That 'alongside traditional disability support providers, there will be greater numbers of registered health professionals and providers of transport, household cleaning and gardening services'.

Although in theory, the opportunity to consider new ways of ensuring the suitability of provision of support services by providers while not creating unnecessary costs or regulatory barriers for providers within the NDIS, such as Options 1 and 2 that are presented, is progressive, it is evident that provision of services to pwd that just meet business and consumer law do not meet enough safety criteria for pwd. As noted earlier, pwd are generally more vulnerable than mainstream service users. Pwd have increased vulnerabilities where individuals are coming into their homes and residencies, and as such need assurances that individuals entering their homes to carry out any support service have been screened, are of known good character and have awareness of the specific needs of pwd, such as the increased need for reliability, anxieties around personal safety and security of property (i.e. a cleaner moving things around may have more impact), need of increased privacy or clarification of service provision, and/or varying communication needs.

As a case study from Victoria, taxi services are provided by mainstream service providers who also provide taxi services for pwd. It became evident in recent years that there was wide-scale corruption and fraud related to use of the subsidised disability taxi scheme, and further that abuse, mistreatment (physical, financial and verbal) and discrimination were being experienced by pwd utilising taxi services. No safeguards or protections were put in place on these mainstream service providers in providing services to pwd, and as such, many pwd experienced harm, abuse and mistreatment as a result. Alongside of a widespread inquiry into the fraud, a criminal investigation was required to target the worst offenders, and the system needed to be re-built using card-based technologies to reduce the incidences of fraud. Of note to the development of the NDIS QandS framework, a training program for all taxi drivers was introduced, whereby all taxi drivers were funded by the state government to complete a 10hour training module on disability awareness and effective strategies in providing a good and safe service for pwd. In addition, all drivers were re-screened for criminal histories and in some cases, visas status'.

As such, in addition to meeting business and consumer law, compulsory training and screening of staff was required by a service provider providing a mainstream services to improve the safety and protections of pwd. Where no safeguards existed, such as would exist under Option 1 and 2, pwd experienced abuse, harm and mistreatment. The mainstream service provider was ill equipped to provides support services that fully met the needs of pwd, and the vulnerabilities of pwd were exploited. Although strategies have now been put in place to address these issues, it does not retrieve or lesson the harm incurred by pwd who experienced harm and mistreatment, and demonstrates that increased protections are required in providing mainstream services to pwd.

Sanctions

•A particular issue for pwd under current QandS frameworks is that current service providers have no sanctions or receive no punitive action when standards are not met and/or when there is a breach of the QandS frameworks.

Similar to WorkSafe in Victoria, if a service provider does not meet a safety standards, and a client (pwd) is proven to be harmed and mistreated, service providers should be made to pay damages to the pwd and potentially have sanctions, fines or penalties (or deregistration for repeat offenders) from NDIA or independent external authority imposed on them. Criminal charges should obviously be made against any support staff involved in any harm or abuse.

•Further, although the use of a Code of Conduct is discussed in the consultation report, just listing expected behaviours in a document is not enough to ensure safety and protections for pwd by service providers. My experience is that business statements and codes of conduct are normally only presented and referred to by businesses at auditing time, and that they are used as rhetoric of safety and quality. The Code of Conduct listed in the consultation report appears aspirational and does not appear to be a strong enough mechanism to ensure real protections and safety of pwd unless sanctions are real and evident . What would be an example of 'conditions imposed' and would these apply to each single breach, or only where it was deemed serious enough by the NDIA or an external authority, that a serious breach had occurred? Further, for pwd harmed by a breach of code of conduct, where does it leave the individual? Is there opportunity for the equivalent of crimes compensation or any other form of redress?

•If an independent oversight body was established, such as the Victorian Disability Service Commission at a national level, it should have strong investigative powers where it is viewed there has been a breach conditions of the Code of Conduct or disability service standards. It should have powers to make binding decisions about service providers which would be legally binding and which service providers would be obliged to implement. They would hold powers to award compensation if crimes compensation of pwd is not available, impose fine and sanctions, and support participants in having their complaints resolved quickly and effectively.

Workforce Training and Working with Vulnerable persons

•As noted above, provision of support services within the NDIS need to be embedded with human rights protections for pwd. The consultation report appears to take the view that 'people said they did not think that training and qualifications were necessarily so important for support workers. Instead, they wanted to choose their workers because they had the right attitude for the job'.

In terms of human rights, although having 'the right attitude' is an important component in choosing a support worker, I think training is essential for all support workers in the field to engage support workers in human rights and safety frameworks. A neighbour, family member and/or friend can easily learn tasks of support quite quickly - making someone's dinner, assisting with personal care tasks, assisting with house cleaning. However when employed as a support worker, they often then do not have understanding of broader knowledge of human rights concepts, or safety frameworks, privacy issues, personal boundaries, oh&s, social inclusion engagement, person centred practice, disability awareness, varying communication needs or complaints/feedback frameworks. These are elements that are taught with VET training such as Cert III's and Cert IVs. Knowledge of these broader elements contribute to a better provision of support services for pwd overall in providing understanding and knowledge of protections, expectations, industry standards, best practice, barriers facing pwd and discrimination frameworks. As such, there is more likely hood that a pwd's human rights will be met and that support outcomes will be improved.

Understanding of these frameworks and boundaries can reduce the difficulty of pwd in having to 'negotiate' support with people known to them - say if the support worker is continually late or wishes to borrow money, or is not completing tasks to standard, it can be difficult to negotiate these difficulties with a known person and may jeopardise the friendship /family relationship if you complain about these matters or wish to remove them from a roster and cease the support work-relationship. Pwd may feel obliged to keep known people working and on roster even if they are

not effectively meeting proper work standards because it is someone known and the pwd feels obliged to continue with them. Lack of knowledge of human rights and safety frameworks by a known person could mean breaches of human rights or safety are more likely to occur, and these may not or may be less reported because of the pwd feels compromised in the support worker / friendship-family dichotomy and overly dependent on their help if they are not aware of formal support options. Fear of retribution when putting in a complaint is difficult enough for any pwd, but fears and anxieties may be increased in putting in a complaint about a known person who is in a close social position also.

VET training such as Cert III's and Cert IVs provided in class, not online, also provides a screening mechanism of support workers. In-class training provides an opportunity for support workers to be screened in-depth by trainers, who can assess values, attitudes, knowledge, persona, communication skills and reliability in addition to ability to complete competencies while completing training. This may be particularly relevant for internationals moving into the disability field where there is no local community knowledge of their persona.

- Re building an individuals own natural safeguards -why should it be up to the individual pwd to establish safeguards? Pwd should not be policing or having to establish independent safeguards. Many pwd are isolated in the community and have no natural defense networks.

- In relation to a national disability support worker exclusion list, I agree this should be implemented. I have concerns re the following:

How are support workers placed on it, and on who's word and authority?

Can support workers move off it, and what is the criteria for this?

Would a separate organisation control this register?

Are support workers/individuals notified if they are put on an exclusion list?

What are the implications of defamation if the exclusion list becomes known in the community (particularly where pwd are themselves employers under the direct payment model)?

Community visitors:

- I feel there should be an expansion of the Victorian community visitor program - see details at <http://www.publicadvocate.vic.gov.au/services/107/> . I feel the community visitor program is a good mechanism whereby the system comes to pwd, rather than pwd always having to instigate action and move towards the system (if they can) following an incident. The community visitor program should also be expanded to pwd in their own homes, if individuals agree, where there is a risk of abuse/mistreatment and the pwd is compromised in reporting. In particular, the community visitor program should continue in group house residencies where there are often underlying cultures of abuse and mistreatment, and an independent person may be required to establish if abuse is occurring. Further pwd in group houses may have fear of retribution in reporting abuse about regular support workers in the house, and need the assistance of a visitor to report a matter. This may be particularly relevant where pwd are not independent enough to physically get to a police station to report abuse/mistreatment, or may not be able to use a phone to report abuse/ mistreatment without carer sitting next to them, further risking the chance of retaliation by support workers.