****People with Disabilities WA

individual & systemic advocacy

**Submission**

**National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and other measures) Bill 2017.**

People with Disabilities (WA) Inc. (PWdWA) and Development Disability WA (DDWA) would like to thank the Standing Committee on Community Affairs the opportunity to provide information to the inquiry into the National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and other measures) Bill 2017.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy.

PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

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### People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

**Developmental Disability WA (DDWA)**

DDWA is a trusted source of independent information, advocacy and support which for over 30 years has worked with people with intellectual and other developmental disability, their families and the people who support them.

DDWA’s vision is that people with developmental disabilities and their families live their lives their way.

DDWA provides individual and systemic advocacy and creates lasting positive change by

* Supporting people with developmental disability and their families to have a strong voice
* Partnering with others to develop more connected and inclusive communities, and
* Influencing government and other decision makers

**Introduction**

The National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and other measures) Bill 2017 establishes the Commonwealth’s regulatory responsibilities under the NDIS Quality and Safeguarding Framework. Minister Porter in his speech on May 31 2017 addressing the Bill said that it ‘in large parts forms the basis of the government’s response to the Senate inquiry’ into abuse and neglect of people with disability. Advocacy organisations are concerned with this statement. The Bill covers people who are eligible for NDIS, it does not safeguard people who are not eligible for NDIS and those people who choose to use mainstream providers and/or disability providers that are not registered with NDIS.

We strongly urge the Government to instruct a Royal Commission to investigate into the abuse and neglect of people with disability. People should be afforded the respect to tell their stories in the knowledge that the Government takes these issues extremely seriously and will hold perpetrators to account, address historical abuse, and recommend actions at all levels of government across all sectors of services. We would argue that the Bill is a starting point to address such issues but only when a Royal Commission reports on its findings will the full extent of what needs to be addressed be uncovered.

We welcome that the Bill will establish a Quality and Safeguards Commission to provide national stability for quality and safeguards for people who use NDIS services. We are particularly encouraged that the Commission will be underpinned by the UN Convention on the Rights of People with Disabilities part of which requires that people with disability be protected from exploitation, violence and abuse.

The information contained in this submission provides issues that we feel need further explanation/clarity or information to ensure the role of the Commission is delivered effectively.

**Timeline**

As advocacy organisations that operate in Western Australia (WA), we are concerned with the timeframe for the Commission’s introduction into the State. The Bill would come into effect in 2020 in WA, due to the delay in rollout of the NDIS that puts WA at least one year and compared to some States two years behind the rest of Australia. We advocate for people with disability to have the same levels of safeguarding and quality regardless of which State they reside in and would urge the Government to speed up the process of implementation in WA.

**Development safeguards**

The Commission needs to focus on development safeguards, commit to and invest in areas that build the capacity for natural safeguards to develop. Building natural safeguards is a process that takes time; it is an ongoing process that requires an in depth understanding of a person’s life history, circumstances, choices and aspirations. An individual’s needs are paramount and by empowering a person to feel safe and secure through a natural process will reduce the need for preventative and corrective measures in the future.

Advocacy has an important role to develop a person’s capacity to act with informed choice and control. Independent individual advocacy builds a person’s capacity as the advocate is working alongside a person, helping them to understand their options and ensuring their voice is heard. Advocacy is also a form of independent monitoring as it raises issues from an individual to a systemic level to address systemic abuse and discrimination. The ability to build capacity in terms of knowledge of rights, knowledge of complaints systems, and confidence in self-advocacy are all areas that will develop natural safeguards. Investing in community infrastructure whether it is through advocacy, peer support, education and training, awareness raising and improving the flow of information will all help to develop natural safeguards.

There is concern from advocacy organisations that due to shift towards market driven forces of the NDIS they will be penalised as their outcomes are not geared towards a service delivery model.

**Quality Framework**

It is important that a quality framework is consistent, transparent and easy to understand. Feedback from people suggests that conducting quality audits does not always reflect the actual practice of a provider. Many audits focus on management and operational processes and not the true experience of the individual. In Western Australia, individuals and families are not able to access the results of quality audits – it is up to the provider to make them public. Very few providers ensure that their clients are able to access their quality audits. In a world where people with disability should be making informed choices this lack of transparency by providers puts people in an uninformed position.

A quality framework against standards such as the National Disability Services Standards also requires people with disability and families to understand and have access to the Standards. When a person engages a service provider under individualised funding, the contract for service to the individual should adhere to the same quality framework as well.

Section 73T of the Bill details the NDIS practice standards may deal with the following:

* standards to be complied with to become a registered NDIS provider;
* standards to be complied with to remain a reqistered NDIS provider,
* matters relating to assessing compliance with standards
* matters relating to the screening of workers employed or otherwise engaged by registered NDIS providers.

Clarity about these standards needs to be determined. Are the NDIS practice standards in addition to the National Standards for Disability Services (NSDS) or are they a replacement for the latter? If they are in addition to NSDS, what is the difference? It is important to identify the difference in practice to ensure that providers are not duplicating effort on two separate standards. It is also important that people with disability are involved in the co design of such standards.

There needs to be significant investment in funding for training. This includes investing in the people who deliver services, Salaries of staff need to attract people who can deliver services to ensure people have the best access to quality services and access to the best-trained staff. The investment should also include training for people who self-manage to train their staff. A level 4 certificate does not automatically equip someone with the detailed knowledge required to support an individual. Disability is diverse and training cannot be a blanket coverage.

**Benchmarks - quality needs to be driven through with evidence of contemporary practice.**

A proactive, rather than reactive approach to safeguarding would ensure that risks were managed by promoting positive aspects of life and increasing service user involvement in the community, education and training, and in the organisation. Providers can also be proactive by improving key areas of practice like the positive behaviour frameworks and allowing access to independent advocates.

A culture of ongoing learning, collaboration, openness to change and shared responsibility will be required to facilitate the reform process. Government, NFP and service providers will be required to work collectively with people with disability, their families and carers to provide

* innovative practice in service delivery, including the development of new models of support;
* increased flexibility and responsiveness to needs;
* new ways of working across agency boundaries;
* sector capacity building; and
* outcomes for individuals.

It is important to engage a co-design group from peak body and disabled persons organisations that represent the diversity of disability to check the standards meet the expectations people with disability have of staff from their supports and services. This group should explore different contemporary scenarios and the interaction with mainstream systems. It is important that the Bill identifies and incorporates evidence based, best practice models around positive behaviour frameworks to ensure the Commission is working with contemporary methods. The Bill needs to ensure this approach is driven through working practice.

**Restrictive Practices**

The Bill sets out the role of the Commission in monitoring the use of restrictive practices within the NDIS. The Bill states that under the Commission, restrictive practices will only be used as a last resort. It must form part of a behaviour support plan which includes positive behaviour support strategies and which has been developed by a registered behaviour support practitioner. Restrictive practices must also be authorised by the state or territory in which the participant resides.

We would advocate for the elimination of restrictive practices and question the terminology of ‘last resort’. This requires national consistency to create a national approach across Australia. It should not be left for state jurisdictions to determine ‘last resort.’ It is also unclear from the Bill the mechanisms to monitor consistency in the use of restrictive practices given it must also be authorised by the jurisdiction in which the person resides.

We also advocate that restrictive practices should not be the responsibility of one person. There needs to be an advisory panel in making such decisions. Responsible panel members should receive mandatory training in contemporary measures in behaviour support strategies.

**Ensure decision makers are accountable for their actions**

The Bill needs to include legislation to impose clear sanctions, expectations and obligations against persons or organisations responsible for the care of people with disability in the same way that Occupational Health and Safety legislation responds to breaches of duty of care against workers.

**Providing safeguards in ‘thin markets’**

The Productivity Commission released a position paper – NDIS costs in June 2017 in which it identifies ‘thin markets’ as

* living in outer regional, remote and very remote areas
* with complex, specialised or high intensity needs, or very challenging behaviours
* from culturally and linguistically diverse backgrounds
* who are Aboriginal and Torres Strait Islander Australians
* who have an acute and immediate need (crisis care and accommodation).

The report identifies that insufficient supply may lead to higher prices, less variety, lower quality services and unmet demand. In the disability support sector, thin markets can result in poor participant outcomes, increased demand for mainstream services, and greater pressure on informal carers. Scheme costs are also affected while they may be lower in the short term (due to underutilisation of supports), they may be higher in the long term if participants are not receiving the right supports at the right time.

The challenge for the Commission will be to ensure that the appropriate safeguards are incorporated into service delivery in these ‘thin market areas’ and in turn ensure the balance for individual choice and quality service are met.

**Funding decisions having impact on safeguards**

Any person who wants to self-manage their plan is able to do so and should be equipped with the information required to do this. People who choose to self-manage should have access to education, training or mentoring programs that provide them with the skills to effectively manage and direct support staff, and comply with worker rights and other legal requirements. Advocacy support would assist people to make informed decisions about how to choose and screen a provider that is not registered with the NDIA.

There is an opportunity at the point of contact with the NDIA when a person chooses to self-manage to actively connect people to peer support, advocacy and training. Many people with disabilities and families feel there is no training available to them and what they can do to make self-management work. There is also an opportunity here to make people aware of mainstream safeguards like consumer protection laws. Each state has its own department that includes consumer protection with information on contracts. Engaging with these departments to ensure they are aware and able to provide information to people with disabilities and families is another opportunity.

Our feedback suggests that the lack of funding to address these issues is having a detrimental effect on people’s ability to develop these natural safeguards. If the quality of service is compromised through the lack of training, understanding and relevant information then this will have negative implications for safeguarding.

**Complaints**

It is encouraging to note that the Commission will provide information about the complaints process to people with disability and also provide information to providers, on best practice complaints handling. It is also necessary that people are informed about the outcomes made as a result of the complaint not just the process.

The Commission needs to establish a robust, effective and transparent incident reporting mechanism. It is important to identify what is meant by a serious incident, how serious incidents are being reported, how are people being notified, how is the public being notified of decisions. There is currently a lack of transparency. What are the random checks to tease out serious incidents. What are the safeguards to ensure they are being reported?

When a serious incident occurs, there should be mandatory reporting (where a provider is required to report the abuse to police) and when the complaint is received, it needs to be investigated by the Commission. There also needs to be a robust mechanism for collection of data and analysis of trends to drive forward continuous improvement. Currently, the government body requests the provider to develop an action plan about how they will address the issue. This process does not involve the person who is making the complaint or their family, and people are seldom notified of the outcome of an abuse incident. The process relies on the provider to take effective action and there is no timeline for submitting a serious incident report.

Mechanisms for reporting must not be channelled only through the disability sector. It is also important to not forget the mechanisms that every person has such as contacting the police. If a crime has occurred as part of the breach, it must be reported to police. Police must then have the mechanisms and expertise to support the victim to give evidence. It is a disservice to people with disability if we ignore that some breaches are crimes and as such, must be treated as a criminal offence.

The Commission needs to detail at what stage of the process the person with disability is informed about the outcome. It is important that the person with disability is the focus in this system and as such is supported not only throughout the process but are also involved/informed about the final decisions. This will ensure that the person will feel safe, informed and confident that their issues has been resolved to their satisfaction.

There is a concern that the Bill will establish a dual role for the Commission when handling complaints. The Bill details that Commission will support people to be heard and provide protections for victimisation should they make a complaint, there is potential for impartiality to be compromised if the Commission is both interrogator and supporter. There is a strong case for independent advocacy to be available to ensure the rights of people are upheld in an unbiased way.

The Bill needs to determine a set of procedures for emergency support whilst an investigation is occurring. If an allegation has been made, the person with disability is entitled to a safe and secure environment whilst an investigation occurs. It is essential that their support needs are continued to their expected level so that the person is in no way disadvantaged or put at risk during this process.

It is important that the Bill identifies the process for a person with disability to re-engage with services should their service provider’s registration be revoked. The Bill should state whose responsibility it is to ensure that person receives services from an alternative provider in a seamless transition so as not to disadvantage the person with disability. It is important that this process is documented and is available in accessible formats so that the person with disability is confident that their level of support is continued.

**Stronger protection needed for whistleblowing legislation**

The National Public Interest Disclosure Act 2013 (PID Act) facilitates disclosure and investigation of wrongdoing and maladministration in the Commonwealth public sector, and for other purposes, likewise the Public Interest disclosure Act 2003 (WA) facilitates the disclosure of public interest information, and provides protection for those making disclosures and those who are the subject of disclosures.

Whistleblowing is not encouraged in the disability sector and workers can be penalised for reporting abuse. The Corporations Act 2001 provides protection for corporate whistle blowers albeit limited in scope. Legislation must be adopted that provides protection for ‘whistle blowing’ beyond just the public sector to all jurisdictions.

It is important to realise the fine line between regulation and choice for the individual. Too much regulation may in turn make workers too guarded in their approach to supporting a person with a disability and in turn limit choice. This is important when considering the range and diversity of disability. A one size fits all approach should not be adopted and flexibility in the system should take precedent.

The introduction of third party mechanisms such as the community visitor scheme would have far more positive impact on quality and safeguarding than would an over-regulated Code of Conduct standing on its own. This also provides another person or authority to disclose information to without fear of retribution from either the person with disability or their staff.

**Need for local based offices**

Whilst it is important that a national system will create consistencies in reporting and evaluation, it is also important that the local presence is developed. Evidence from other sectors shows that staff that have a good appreciation of local knowledge and local issues are more effective in their ability to respond to local complaints through action. Advocates should be freely and readily available to assist people with disabilities through the complaints system.

**Stewardship role - the responsibility for implementing change.**

The Bill must ensure that any ongoing and future developments of the Commission are co-designed with people with disability, and provide financial investment to support the mechanisms for this to be achieved effectively.

The Commission must provide and encourage training on the safeguarding for both people who self-manage and unregistered providers they choose to engage. This training should include developing mechanisms for peer support, and self-advocacy that empower individuals, promote independence and provide options for flexibility.

**Supported Decision Making**

The monitoring and regulation of quality and safeguarding is extremely important for people who have supported and substitute decision-making arrangements. Advocates would strongly encourage the Commission to work within contemporary practice as stated in the UNCPRD article 12 that supports people’s right to legal capacity and recognition as a person under the law. In Canada for example, the approach is a move away from a presumption of incapacity to a presumption of capacity that may need support to become evident. This has been enshrined in legislation as supported decision making and provides a legal obligation to explore alternatives with the person and ensure that they are supported to be able to express decisions as much is possible. There is a duty to accommodate placed on service providers such as health professionals, financial institutions and legal services. Examples of duty of care may include, Easy English material; extra time to process information; gauging of preferences through behaviour, and accepting the role of support people who know the person very well in the decision making process.

**Interface with Government Departments and other agencies**

It is important to recognise that people with disability, their families and carers use a wide range of services both mainstream and disability services. It is therefore hugely important that the Commission develop strong links with services outside the NDIS to ensure there is a seamless service for people with disability. The responsibility to provide services to people with disability remains a shared responsibility between all levels of government and it is important that people with disability know about the different ways to maintain quality standards and safeguards in other departments and organisations for example links with Australian Competition and Consumer Commission.

**Conclusion**

The Quality and Safeguards Commission should enable people with disability to express freedom of choice with NDIS service providers who are transparent, flexible, and over all accountable. The Commission will provide the oversight to allow this to happen. However, a significant amount of support and work is needed to ensure that this translates to practice and more importantly contemporary practice. Traditionally, people with disability have had little control over who provides services, information and support and how their service is delivered. The role of advocacy will therefore have an enhanced role in this system and should be recognised accordingly and funded appropriately.

Advocacy will support individuals to prevent and resolve issues; it will provide feedback for continuous improvement and ultimately reduce the need for corrective measures through a better resourced and more effective Commission through the development of natural safeguards.

The Commission’s role will encompass an independent statutory complaints body and a mandatory reporting system for the elimination of restrictive practices. There is also a much needed role to include and upskill mainstream systems like consumer affairs, the police and court systems. It is also important that the balance between regulation and market choice is considered, people should be able to choose their own providers and the system should allow people to access the right information to make these informed choices.

Importantly, people with disabilities must be engaged as co-designers in all aspects of implementing the Commission. People will only feel confident with a Commission that has been developed by people who use services and have lived experience of what a quality and safe environment actually entails in practice.