

## Submission

### **Proposal for a National Disability Insurance Scheme (NDIS) Quality and Safeguarding framework.**

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Australian Government Department of Social Services for the opportunity to provide comment on proposal for a National Disability Insurance Scheme (NDIS) Quality and Safeguarding framework.

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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### **Proposal for a National Disability Insurance Scheme (NDIS) Quality and Safeguarding framework.**

This submission is from People With Disabilities (WA) Inc. (PWdWA) in response to the proposal for a National Disability Insurance Scheme (NDIS) Quality and Safeguarding framework.

As part of this process, PWdWA worked with Developmental Disability WA (DDWA) National Disability Service (NDS) and the state Disability Services Commission (DSC) on a consultation program to enable people with disabilities to engage with, raise their concerns and recommend solutions/improvements about the framework. Individual advocates from PWdWA attended these sessions and the feedback is articulated in this submission. It is important to note therefore that comments and recommendation of this submission are based on real life experience of people with disabilities.

#### **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.

### **Recommendations:**

**Ensure that the Developmental Domain is heavily factored into the quality and safeguarding framework as this provides real opportunity to develop and enhance natural safeguards.**

**Ensure advocacy, which plays an important role in all facets of the framework, is highly visible, resourced and accessible in the system.**

**Develop mechanisms including peer support, training and self-advocacy that empower individuals, promote independence and provide options for flexibility.**

**Any system development or modification is co-designed with people with disability. The system will be flawed without the design and input from people who know and live these issues on a daily basis.**

**Find ways to innovate and allow a diversity of providers and ways to self-manage throughout the process and not over burden people or providers with bureaucracy which could limit choice.**

**Work with mainstream safeguards including consumer affairs, police and court systems to ensure people with disabilities can use and access them, information can be shared, and that mainstream safeguards will respond appropriately.**

## Introduction

PWdWA welcomes the opportunity to comment on the current proposal of an NDIS Quality and Safeguarding framework. It is important to recognise that this is a hugely important and relevant issue not only to PWdWA but any organisation or individual who is connected to a person with a disability. This paper provides commentary on the three 'domains' as stated in the consultation and then addresses part 2 of the paper which very much focuses on the regulatory element of this framework.

The Australian Institute of Health and Welfare reports in 'Services provided under the National Disability Agreement 2012–13' that:

*'Users of disability support services are diverse. In 2012–13, 59% were male, 87% were Australian-born, 6% were Indigenous Australians, and 54% lived with their families. The most commonly reported disability groups continued to be intellectual (32%), physical (30%) and psychiatric (27%).'*

This statistic alone shows the very diverse and complex nature of disability. It is important to realise therefore that no 'one size fits all approach' can be adopted in a safeguarding and quality framework. The degree of risk and the need to safeguard will be different. The framework should exist to guide and help people to exercise their rights and freedom as individuals, empowering people and not to over burden and create a multi-faceted cumbersome system that people find hard to access and understand.

It is important to get this framework right, should this consultation exercise provide more questions than answers, time should be taken to ensure all views and ideas are carefully considered even if this means a delay in agreeing the framework. It is not an issue that needs to be completed to satisfy the NDIS timeframe but an issue that will affect the daily lives of many Australians. People with disability will have the most direct impact from such a framework but it will also affect a whole range of organisations and individuals who have a direct or indirect connection to a person with disability.

PWdWA is currently working on the WA Disability Abuse Inquiry. The timeframes of this consultation and the report of the findings from the neglect and abuse project are not concurrent. However, initial analysis of information from the inquiry to date provides some very strong primary evidence that will affect how certain elements of the framework should be addressed. PWdWA strongly recommends that decisions about the framework are made when these findings are reported to the Senate Inquiry in June. Several case studies that have been collated as part of the evidence for the inquiry have been incorporated into this submission. There are many more. It

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is paramount therefore that the issues raised from this inquiry need to underpin the development of the framework and PWdWA strongly advocate for this.

It is important when designing a framework that people with disabilities are instrumental in its conception. A large effort has been made to ensure people with disabilities have contributed and engaged with this consultation. This feedback is paramount when designing a framework; it needs to be given greater credence than feedback from any other individual, service provider, government agency or business community. Co-design can be a difficult and challenging concept bringing together the different facets and recommendations to create a framework that priorities people with disabilities but one that also considers other relevant parties. PWdWA recognises that this is a complex process and would welcome and encourage the opportunity to be involved.

The framework needs to comply with relevant legislation. The United Nations Convention on the Rights of Persons with Disabilities is explicit in the requirement to *'ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability'* and in article 4 states *To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.* Article 16 of the UNCRPD in particular, makes specific reference to the need for independent monitoring of disability specific services and throughout Articles 14 to 17 there is recognition that people with disability should not be treated differently to others in how they are treated. This is a clear recognition that restrictive practices are a breach of human rights. Careful consideration must therefore be given to the framework and in particular the development of the 'corrective domain' to ensure that human rights legislation is not breached.

The NDIS is in 'a trial phase' so it is inevitable that changes and adaptations will be made before the scheme is adopted or rolled out across Australia. As the scheme evolves, it is important that a quality and safeguarding framework is flexible enough to adapt to any changes and have an in built mechanism to reflect any continuous improvement.

PWdWA is concerned with the lack of consideration for cultural diversity and in particular for Aboriginal and Strait Islander people in the proposed framework. There is a great emphasis in the National Standards for Disability Services to design, deliver and promote services that acknowledge and include these cultural aspects. PWdWA is disappointed that the proposed framework does not recognise this cultural identity which is particularly important in the safeguarding arena as service providers need to be fully equipped to offer services to people with differing levels of risk and safeguarding needs.

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The focus of this consultation is about the regulatory arm of the framework, however, it is vital that the Developmental Domain is given an equal amount of attention. PWdWA strongly supports the development of this domain in tandem with the Information, Linkages and Capacity Building (ILC) framework as it encourages capacity building, advocacy and participation with people with disabilities, their families and carers. Frameworks that empower individuals and help them make better choices will ultimately produce natural safeguards from better connections with their community.

There is a missed opportunity in the planning process to identify any risks that relate to that individual. Supporting people with disability to identify their own risks would enable them to think about what they need to stay safe and still enjoy choice, control and flexibility in directing their services. Supporting self-direction is critically important to enable people with disability and their families to be able to take charge of their supports and services. Self-direction is currently not actively promoted as an option or supported well by the provision of tools, training or mentoring.

### **Developmental Domain**

#### **Introduction**

The current proposal for the quality and safeguarding framework focuses on safety and risk management measures and not enabling measures to ensure people have visible and active lives in their community.

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. This is why the developmental domain is a fundamental part of the framework. 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. It is important that this domain is not overburdened or over-regulated to the extent where innovation and different approaches are stifled.

A well supported, skilled and informed person with disability is better able to detect and respond to violence, abuse and neglect by support staff by taking swift remedial action and terminating that person's employment. By ensuring that people with disability and their families are able to understand their obligations as an employer and access information and training readily, an environment is introduced where there is a constant continual improvement system that is personalised to the person's needs and which works in a way that is mutually beneficial to both staff and the person with a disability. People with disabilities and their families, whether self-managing or not, should be able to attend and participate in training on employment recruitment and human resources practices, Occupational Safety and Health, and

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working with staff. It is also imperative that people who are self-managing can access training for the workers they employ.

Advocacy has an important role to develop a person's capacity to act with informed choice and control. PWdWA is disappointed that advocacy whether it be individual, self or systemic is very much understated in the current proposal and would strongly encourage its inclusion in a revised framework. 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 can be 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, 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 developing natural safeguards.

### **Information**

The purpose of the developmental domain is to build individuals' own natural safeguards. It is vitally important that people are given access to credible and relevant information through a variety of channels to ensure an acceptable level of choice of to make informed decisions.

A 'one stop shop' is not the only answer for an information system. People with disabilities, organisations and government have tried setting up one stop information portals or phone lines and even with marketing it does not get to everyone and many people still find it difficult to get information. Information must be available to people on their terms, must be available in a variety of accessible formats and must be delivered in a range of ways.

The amount of information requests and 'signposting' to other organisations that PWdWA receives is in the region of 380 per year. The nature of these calls range from a simple one of phone call to more complex calls where more research is required to provide an informed response. PWdWA anticipates that as the NDIS gains momentum that the numbers for this type of request will increase and appropriate advocacy support and resources need to be factored into the framework to accommodate this.

A highly accessible information system is required which is available in different formats including Easy English; and in different places. In designing such a system, PWdWA recommends co-designing with people with disabilities; looking at best

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practice internationally and in other sectors/industries. It also means making information less bureaucratic and recognising the range of ways people currently get information, and maximising those current mechanisms.

A system similar to that of 'trip advisor' has been suggested often by people with disabilities and families as there is a higher level of trust in word of mouth information from people with lived experience. This system will enable service users to rate the quality of the experience of a provider and share this knowledge with other users. 'Clickability' which currently operates in Victoria works off this premise. This is a relatively new system which is about to be rolled out across Australia. Its conception was initiated from the purple orange project which sought the views of people with disabilities on the main elements of an online information system. A review of 'Clickability' based on this blueprint, its successes and challenges of implementation could be initiated and modifications made in occurrence with the findings. This would negate the need to develop a separate system which will ultimately hold similar information. Importantly 'Clickability' has been developed by people who have seen the need and are independent of government and service providers. This independence is what ensures its authenticity.

PWdWA also acknowledges that online communication should not be the only mechanism for providing and sharing information. There are many people with disability who are not digitally connected, mechanisms to ensure these people are able to access information needs to be developed. This is clearly evidenced by empirical research, for example, the Survey of Disability, Ageing and Carers (SDAC) 2009, shows that 70% of people with a disability had access to a computer at home; this was lower than the 78% recorded for the Australian population in 2008-09. Access to the internet was also lower for people with a disability (61%) than for the Australian population (72%).

It also needs to be acknowledged that access to computer technology does not necessarily equate to actual use. In 2009, only 57% of people with a disability aged 15 years and over reported having actually used a computer in the 12 months prior to interview. In the same time, just over half of people with a disability, 53% had used the internet. Therefore online technology is not reaching 47% of people with disabilities and should be addressed.

### **Peer support**

PWdWA purports that in order to access information; people must first know where to access it. Peer support networks, including online forums, enable people to connect with each other. There are many different ways to do peer support and in remote and regional communities people often connect in different ways, such as through sporting clubs. Online forums have presented new opportunities for people

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with disability and their families to connect, share and learn. One such example is the NDIS Grassroots discussion page. This is an online group open to anyone wanting to talk about issues related to the NDIS and is moderated by people with disabilities as a group independent of the NDIS.

### Online Peer Support

*It presents an opportunity for collective wisdom to grow - and to my mind has been the best place for that over the past few years. One of the biggest challenges for people with disability and their families is genuine information based in experience, which has always been one of the best ways to find out about options, evaluate choices and build networks. Information here is grounded in experience and reality rather than the salesmanship of those that promise and design things but don't live it. Through this page my networks and sources have certainly gotten a great deal wider. I have valued the chance to both learn from others and share with others. I think often about the many people with disability who are not able to use the internet - independently or at all, and how difficult it continues to be for them to be connected to others. – NDIS Grassroots Discussion Page feedback.*

### Access to relevant information for the most vulnerable

The information that is going to assist people with disabilities as a natural safeguard must be relevant and able to be put into context. People with disability who live in institutional settings are often so immured to violence, abuse and neglect that it is not easy for the person with disability to recognise it or understand their rights. In an institutional setting getting information becomes difficult and peer support can be limited. Many people live in continued isolation from sources of support or advocacy, especially those who live in enforced cohabitation conditions in group homes or institutions. It is critical that people who are isolated and segregated have access to strong, independent advocacy and accessible information about their rights, as well as sexual education and education about respectful relationships and rights based assertiveness training. Providers need to view access to advocacy and training for people with disabilities who they support as an opportunity for continuous improvement and as a natural safeguard.

### Case Study

*Rape just became a normal part of her life, to be honest. She was sexually abused when she was in care from a very young age and then it became normal. She'd go up to people and say 'do you want to have sex with me'...and then others knew that she was a target. And at the group home they couldn't bring men back so she would have sex with men at the park. Like a dog under a tree. There was no chance of her ever having an actual relationship with a man because of what had happened to*

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*her. Never a chance to learn how respectful relationships actually work in the real world.*

*Nobody ever believed her when she is raped, so she stopped telling, after a while. And who would believe her if she told someone she'd been raped by a support worker?' – WA Disability Abuse Inquiry*

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 fundamental element in building the capacity of people with disability and families is education and training, this is integral at any stage of the process. In the developmental domain there needs to be an emphasis on raising awareness in the community, awareness training in schools and training for people with disabilities into how and where to access the appropriate information. People with disability and their families and carers need information and access to training to recognise abuse and potential threats.

Staff training is also a significant issue. The ability of staff to recognise and reduce risk is vital. There needs to be robust management arrangements and training supports within organisations to ensure staff can do this with confidence and knowledge. It should be part of an individual's personal development that they receive adequate and appropriate training so they can determine 'safe' practice and are equipped with appropriate knowledge and training to act upon any breaches in quality and safeguarding issues

People living in institutionalised settings without informal or family supports are often more at risk of violence, neglect and abuse than other people with disability. In addition, disadvantage and marginalisation can be compounded by being a person who is from a CALD background, a person living in a regional or remote community or a person who is Aboriginal. It is a mistake to assume that the presence of family confers an automatic developmental safeguarding – the current Senate Inquiry has documented many cases of violence, abuse and neglect which have resulted in death after family abuse. (Kate Therese Bugmy, <http://www.smh.com.au/breaking-news-national/health-services-fatally-failed-woman-20100826-13t0v.html> - Kyla Puhle <http://www.abc.net.au/news/2013-08-22/mother-spared-jail-over-malnutrition-manslaughter/4905964> )

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There is strong evidence to continue investment in supportive infrastructure around people who are disconnected, especially those who are institutionalised or who live in regional and remote settings. That infrastructure may include further investment in peer support networks, developing and sustaining circles of support or 'microboards' around people with disability, or developing ways for people with disability to be able to easily access advocacy and information services. For people who only have paid supports in their lives, it is important that they are able to access the same rights and freedoms as people with informal supports. New organisations are emerging in other states that are providing services like financial intermediary and other business services so people can self-manage and direct their services. Supporting people who are marginalised because of lack of informal support to access that emerging infrastructure will also play an important role in ensuring that people can access all parts of the NDIS.

### **A Positive Image**

There may also be a role for the NDIA to play in addressing public hostility or indifference to people who live with a disability by ensuring that people with disability are at the forefront of marketing campaigns and that people with disability are employed within the Agency itself. People with disability are often seen as 'other' to the normal range of expectations the community has, and so it is then easier for people with disability to be treated differently. What we see as neglect or abuse in the general population, (such as being in a locked cupboard at school) is seen as being necessary management of disability. To counteract this tendency to see people with disabilities as 'other' there needs to be a more natural inclusion of people with disability across all media and all aspects of the community.

### **Preventative Domain**

Both the preventative and corrective domains are addressed in detail in Part 2 of the consultation paper which considers specific measures of the quality and safeguarding framework. This section provides an overview of the key messages and issues for development that will assist in safeguarding before it becomes a corrective issue.

A consensus exists in the literature that the risks of abuse are exacerbated by:

- public hostility or indifference to people who are visibly different;
- institutional cultures, regimes and structures in which direct care staff have low skills, status and pay; where there is resistance to change and a closed community; unequal pay, conditions and training opportunities for qualified and unqualified staff;

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- repeated exposure to multiple carers for those in receipt of personal assistance and intimate care;
- ignorance and poor training of staff who work with people who have complex needs and/or challenging behaviours;
- lack of regulation or strong accountability to an independent agency/department. (Safeguarding adults and children with disabilities against abuse, Professor Hilary Brown in co-operation with the Working Group on Violence Against, and Ill-treatment as well as Abuse of People with Disabilities, 2003)

Evidence from the WA Disability Abuse Inquiry and other inquiries into violence, abuse and neglect against Australians with disability supports many of the above findings.

### **A quality framework**

It is important to indicate that although PWdWA supports the development of a quality framework for providers, how this is implemented, monitored and reviewed needs to be carefully considered with the person with disability at the centre. Current consultation feedback shows 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.

### **Whistleblowing**

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.

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Although WA has reputedly the strongest whistleblowing legislation in Australia, it extends only to the public service. Whistleblowing is not encouraged in the disability sector and workers can be penalised for reporting abuse.

This is illustrated by the story of WA disability support worker, who relocated to WA to find work after he was 'unofficially blacklisted' in Victoria for blowing the whistle on a high profile abuse case at Yooralla.

### Case Study

*Mark, a casually employed male support worker, worked at Yooralla and developed a good rapport with the residents of one house. He worked with a man later charged with rape. Mark says that the rapist confided in him that the disabled women were 'easy'.*

*After the man was arrested, he emailed the management to raise his concerns about the welfare of the women assaulted by the rapist and management's subsequent treatment of them. A month later, he was told by his recruitment agency that he was to be placed on an 'exclusion list' because of a change in policy by Yooralla that meant only females could work there. Mark then learned that despite the 'female only' policy, Yooralla still had three male support workers at the house.*

*Some months later, he received a phone call from a lawyer representing Yooralla, who told him there had been a breach of an email account involving information from Yooralla's internal report into the Kumar case had been sent to Mark's private email address and to the parent of a Yooralla resident. He was told that Yooralla believed he was a computer hacker.*

*He was stood down and charged with unauthorised access to Yooralla's IT database. He avoided a conviction by agreeing to a program for first time offenders which requires a person to acknowledge their offence.*

*Mark believes that it has been difficult for him to find agency employment in WA and he has been asked about his involvement in the Yooralla case by HR managers in interviews. He is successfully working as a private support worker on the basis of his very strong personal references. Mark states that it was 'bizarre' being 'put up in flash hotels by the police to testify against this rapist, and at the same time being charged as a computer hacker'.*

PWdWA believes that legislation must be adopted that provides protection for 'whistle blowing' beyond just the public sector to all jurisdictions. Where appropriate,

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help and support can be provided through advocacy to allow whistleblowing to happen.

### Advocacy

Advocacy plays an important role in the 'preventative domain' whether it is informal advocacy provided by family and/or friends, or formal advocacy from an advocacy organisation. For example informal support for a person with disability in the planning process will give that person the confidence and ability to assert their rights and ask questions. Knowledge of quality mechanisms, complaints and knowledge and understanding of the system will build on the developmental domain and build and develop natural safeguards.

Advocacy services are often called upon when a person does not feel that their voice or issue is being heard or understood. Where people know they can access advocacy it can often be a way of getting to problems before they become issues. Advocacy also supports people who are most vulnerable to get increased supports and a diversity of supports which then reduces the person's risk and vulnerability. Advocates will stay involved until safeguards are in place.

#### Case Study

*Sue is a person with intellectual disability and co-occurring psychosocial disability. She lives in the community by herself and for many years had the support of a social trainer who went above and beyond her job description in providing social and emotional support. The social trainer programme was closed by the funding body and Sue's social trainer, although wanting to stay involved in her life, was burnt out and needed to move to other paid work.*

*Sue has no family or friends in Perth and although she was living in the community she was isolated and her health and mental health deteriorated with this change. She experienced a psychotic episode and had a small stay in hospital but was not given access to long term support after being discharged and so deteriorated again. Sue contacted an advocate for help.*

*The advocate contacted Sue's LAC and helped the LAC understand the full impact of what Sue was going through after the sudden ending of her only support. The advocate worked with the LAC and helped Sue apply for funding. The advocate also listened to Sue throughout the process and helped to ensure that Sue had services and people in her life that she wanted, and that support was long term and not emergency relief or short term respite. A large part of the advocate's role was helping Sue to make choices and have her voice heard on issues of what she wanted. – PWdWA case study*

### **Corrective Domain**

Many of the issues that are captured in this domain such as complaints and restrictive practices are explored in greater depth in part 2 of this consultation paper. What is apparent is that advocacy in the corrective domain is about assisting people in their access to corrective measures. Many people are overwhelmed and confused about the systems that are created to “safeguard” their interests. Advocates help people through these processes.

### **Monitoring Oversight**

PWdWA recognises the need for an independent oversight body for the NDIS. It is important that people with disabilities are confident and secure with a system that is equitable, transparent and person centred. It is vital that strong and inclusive support mechanisms for people with disability are in place from the very grass roots of the developmental domain such as peer support, advocacy and training right through to the regulatory domain.

PWdWA also acknowledges that implementing an overburdened regulatory system will not necessarily provide safeguards for individuals or improve the quality of services. A heavily audited, bureaucratic system could have the opposite effect to its intention. It is important that processes are incorporated into the design that empower individuals and provide options for service improvements without fear of retribution or provider alienation. The focus of monitoring needs to be on people’s experiences through processes such as community visitor schemes, independent and transparent complaints handling, safe and secure mechanisms for ‘whistleblowing’ and serious incident reporting. People with disabilities and their families need to know they can go to independent bodies and be heard, respected, acknowledged and believed.

In Western Australia, serious incidents are reported only as part of a funding agreement between the government body and the service provider. When a serious incident occurs, there is no mandatory reporting that occurs (where a provider is required to report the abuse to police) and when the complaint is received, there is no investigation carried out by the government agency, nor any collection or analysis of trends. Rather, the government body requests the provider to develop an action plan about how they will address the issue. This process does not involve the abuse survivor 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.

Many of the accounts currently received through the WA Disability Abuse Inquiry reflect a culture that imposes the burden of investigation and proof on the family,

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rather than police or justice systems. The following case study illustrates the circumstances in which family members with children who do not use spoken language are often faced.

### Case Study

*Caleb went to a riding class for disabled children and was taken by staff to ride as a treat for his eleventh birthday. He fell off the horse, but nobody reported it. His mother states, 'They put him back on the horse, then made him go round and round. He was screaming, but they thought he was just having a behaviour. He went on a bus, went back to school, went back home, screaming blue murder the whole way. We just thought he had a really bad day, we had no idea, nobody told us. And then when we took his shirt off his shoulder was swollen and blue.' Caleb was taken to hospital, where he was x-rayed for a broken arm. The family was told that they were being investigated for abuse unless they could prove that Caleb had fallen off a horse. The family contacted the school, who said that there is always a person beside the rider and another holding the reins. Fortunately, there were photographs taken of Caleb on his birthday, which clearly showed a single person at the head of the horse and staff members sitting under a pagoda drinking coffee and smoking cigarettes.*

*Once confronted, the nurse left her place of employment or was terminated. The onus was clearly on the family to carry out their own investigation into what had happened to Caleb. In another incident (involving Caleb, where he received a broken shoulder and collarbone) in a disability service setting, the alleged perpetrator of neglect went on stress leave for a week, delaying any investigation that may have been carried out by the provider, who was unable to contact the person during that time because of their obligations as an employer. – WA Disability Abuse Inquiry*

There is no national, statutory authority in Australia to take, investigate and act on complaints. A 'disability abuse hotline' was set up some years ago, but the data is not accessible to anyone but government and people reporting abuse in government settings are not able to access the service – the person who has been abused is told to make an internal complaint to the government agency. Without widespread legislative change or an independent, national statutory body, it is difficult to understand how additional layers of regulation will address the issues.

### Advocacy

The corrective domain is where the biggest need for independent advocacy lies. People with disability trying to have their voice heard and have their allegations and complaints taken seriously need someone who can be at their side speaking on their behalf and addressing the power imbalance faced by dealing with large organisations and government.

Advocacy is the process of standing alongside individuals to ensure that people are able to speak out, to express their views and to uphold their rights. It is vitally important that advocacy is independent of service providers and government so that people can trust that the advocate is on their side.

#### Case Study

*A service provider asked a PWdWA client, Peter to sign a service level agreement. Peter felt that the service agreement benefited the service provider and could be used to withdraw services for him at any-time. He believed that the service was not in line with the National Standards for Disability Services. Peter was assigned an advocate from PWdWA who was able to assist Peter in negotiating the terms of his service agreement. By talking through the issues and indicating where the service did not comply with standards an arrangement was agreed where Peter had his needs and choices met. This is just one example, where individual advocacy can resolve a situation by giving the person with disability the confidence and knowledge to challenge a provider's decision. It is also important as a preventative measure before the situation was escalated into a formal complaint which would become more distressful and more complicated to resolve. – PWdWA Case Study.*

### **Part 2 - Detail of key regulatory elements of the quality and safeguarding framework**

#### **NDIA provider registration**

PWdWA supports in principle a provider registration scheme, however care must be taken to ensure a tempered approach and not blanket coverage. There are many variables to consider in designing a registration scheme such as nature of service, geographic location, specialised services and cultural diversity.

PWdWA also acknowledges the potential limitations to choice by creating a mandatory provider registration. A concern with registration of services is around how much detail is required to become registered. For a new service that may be providing something different, the requirement to prove they have been viable for a period of time for example prior to registration will make it difficult to be registered and be a disincentive for new providers. This will then stifle the market and limit choices for people with disability either unable or unwilling to self-manage. In a rural or remote area there needs to be the opportunity for new local services to develop which should not be hampered by a burdensome registration process. Also providers of lower risk services should not be expected to provide high levels of registration information and conditions, and mainstream businesses should not be required to go through any lengthy registration process.

PWdWA has found that for some people who have been considered complex with behavioural issues it is only smaller private (non-registered) providers which are willing to provide support. These can often be providers which are run by families as a business that don't have the resources to implement the full bureaucracy to meet registration but meet the very human requirements of caring and understanding needed to provide a positive environment.

Registration alone will not provide safeguards. It is the information that is afforded to people and how this is achieved, such as through peer support and 'Clickability' and independent advocates, that will ultimately empower people to make their own decisions and choose their preferred providers. As the amount and quality of this information improves so too will the building blocks for natural safeguards. The links between this regulatory mechanism and the developmental domain are strong. A provider registration system will be ineffective without an accessible and transparent system for the transfer of knowledge and information.

### **System for handling complaints**

It is fundamental that a complaints system is independent from service providers and PWdWA strongly supports a complaints system that applies to all disability services and includes those not funded by NDIS.

PWdWA encourages that as a minimum, service providers are required as part of their funding arrangements to have a robust and transparent complaints system that is accessible in different formats, actively promoted and the use of independent mediators/advocates is encouraged when required. An issue often experienced by advocates is that people did not know they could have an independent advocate because services have not told them or given them information about advocacy. As an advocacy organisation PWdWA is consistently asking Government bodies and service providers to ensure that people with disabilities and families know they can access advocacy, and often we hear that brochures are put aside and advocacy is not mentioned in information sessions. Both providers and government bodies need to recognise that there is an inherent power imbalance when a person with disability makes a complaint. Having an advocate is one step towards addressing that power imbalance.

In Western Australia, The Health and Disability Services Complaints Office (HaDSCO) is an independent statutory body that operates under a number of legislative frameworks, the primary Act being The Health and Disability Services (Complaints) Act 1995 which determines the legislative framework for HaDSCO's functions, operations and powers.

Consultation with people with disabilities suggests that this system is not working effectively. Some people were unaware of HaDSCO's existence and the name itself causes confusion. There was also the perception of HaDSCO being a 'toothless giant'. Despite the legislative framework being robust and thorough HaDSCO rarely uses its full range of powers to investigate a complaint and there is a real notion that complaints are rarely actioned. Mediation is seen as being the preferred option by complaints bodies and we have experienced people leaving this process feeling that their voice has not been heard. We are also concerned that mediation and resolution to close an issue by paying someone out with confidentiality clauses means that issues are hidden and not taken up systemically.

PWdWA recommends a review of the current system to ascertain the reasons for its inadequacies and improvements adopted to create better usage and confidence in people using the system.

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

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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.

It is clear from consultation activity that there is a real fear of retribution from people with disabilities by service providers when complaints are lodged. **The onus needs to be on the service provider to obtain an outcome that is satisfactory for the complainant.** When a service goes on the defensive and does not give any legitimacy to the person's complaint they are further disempowering the person and creating a culture of mistrust. There should be a shift away from the emphasis of 'blame' to one that supports continuous improvement. Service providers should value complaints as a way to improve and develop systems making their services more in line with consumer's needs. Consumers need to feel confident that complaints will be taken seriously, actioned accordingly and that processes are introduced to minimise these issues arising in the future.

Feedback from providers indicates that complaints are often not upheld or reported because of fear of industrial relations reprisals or being found guilty of breaching workers' rights. Accounts from the WA Disability Abuse Inquiry support that feedback.

### Case Study

*John, a young man with an intellectual disability and cerebral palsy, was living in a rented unit with significant support. The family employed a qualified psychiatric nurse through an agency, with appropriate checks and police clearances. References were provided and checked. For three months, the worker was regarded as a superb support person, but after the probationary period was up, 'the wheels started falling off'. Abuse was suspected and after some weeks, a series of incidents occurred which resulted in the family terminating the workers employment. The worker tried to argue that he was unfairly dismissed, but there was significant evidence to support the family's claims.*

*After the support worker left, another support worker alerted the family to some written material that had been left on the computer at John's unit. The support worker had been using the computer to write a rebuttal to an unfair dismissal complaint, for 'throwing a woman with an intellectual disability up against the wall and smashing her face in'. The woman had allegedly assaulted the worker. The family contacted the man's previous workplace and they substantiated that he had just lost the case and had been dismissed for abuse.- WA Disability Abuse Inquiry*

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Another mechanism for providing both preventative safeguards and a complaints process is Community Visitors Schemes. PWdWA supports a streamlined national community visitor scheme. It needs to be based on the protection of individual's rights and expressed wishes. It must be properly funded and resourced, easy to access and readily available to people with disabilities. It should also have, in conjunction with an independent complaints vessel, statutory powers to investigate with or without service provider consent.

A community visitor scheme is essentially a legislated scheme where independent people can drop in both unannounced and planned to any institutional setting or service provided to people with disability to check that people are ok. A person (with disability, family member, support worker etc.) could request for a visit to happen or visits are randomly scheduled. Community Visitors can take complaints from people directly and refer people to advocacy and formal complaints process. Visitors can also raise systemic issues of abuse and neglect they may see. In Victoria there is a scheme which visits people in supported accommodation (group homes) and in WA there is a scheme, the Council of Official Visitors, which visits people in Psychiatric hostels and hospitals. Visitors are independent and concerned with the protection of individuals rights.

### **Ensuring staff are safe to work with participants**

PWdWA supports the prerequisite that staff are safe to work with participants and agrees that a national system is required to achieve this. Many organisations support option 3 of the framework: working with vulnerable people clearances. PWdWA agrees in principle with this option but **NOT** with blanket coverage. As previously stated, people have a varied range and type of disability and by enforcing such stringent measures may hinder some people's decisions and choices. These extra layers of regulation can have unintended consequence of penalising other people with disability who may not have the same safeguarding needs as others. For example, the requirement to hold a card will impact upon university students who require a short period of support during a break at university. The current timeframe for receiving a working with children's card in WA is between three and six weeks, which is not feasible for most people requiring immediate care and support.

PWdWA considers these checks should be part of a much bigger and flexible arrangement which allows for informed and considered decisions based on individual circumstances and an understanding that the degree of risk will fluctuate greatly between people.

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Evidence currently being reviewed as part of the WA abuse and neglect senate inquiry demonstrates that working with vulnerable people clearances would not stop abuse and neglect happening to people with disabilities. The evidence suggests that it is a much broader and systemic failing that can happen at any point and at any stage of the process. The mechanisms for reporting are weak and many people are disempowered and threatened by a system that currently favours the service providers and not the individual. If people do not have complaints and issues against workers reported or registered it will not be on the persons record. This then negates the whole purpose of a vulnerable people's clearance if there are not robust, supported and independent mechanisms to make a complaint.

There are no guarantees that reactive approaches like 'blacklists' and 'vulnerable persons' cards' are effective in preventing violence, neglect and abuse – in fact, the WA abuse and neglect senate inquiry research team has been unable to establish a single incident where a worker who has been charged with a criminal offence has been employed and has reoffended. There are many examples of occasions where a worker has been 'moved sideways' or not employed as a permanent staff member because he or she was found 'not to be suitable', but in some cases, this has meant that the person has been employed as a casual 'emergency' support person and has been tasked with providing sleep shifts or isolated care and support, exacerbating the chances of risk (Vinod Johnny Kumar vs State of Victoria).

We believe there also needs to be some employer discretion as there is the possibility of the folly of youth impacting on peoples' future career. This may be especially significant in remote and rural areas and in indigenous communities, as in the example below.

### *Case study*

*A man living in a country town, who was self-directing, wanted to employ an indigenous man from the same region to support him. The man had a criminal conviction – some years ago, he had been charged with drink driving and had some other offences recorded against him. The man's agency said that they would not have employed the man, but the man had proven to be one of the best support workers in the region. His criminal convictions occurred at an early period in his life when he was young and when he made bad decisions as a consequence of a bad home environment. Some twenty years on, he is a role model in the community for young people.- WA Disability Abuse Inquiry*

### Organisational Accountability

PWdWA strongly supports the stance taken by Alan Blackwood as quoted below. It puts a greater emphasis for accountability on the governance of organisations being aware of the issues and potential of abuse and neglect occurring, and taking responsibility for its prevention.

*Care workers must be carefully vetted, but by focusing only on workers, the scheme is a piecemeal response that merely plays to the "bad apple" tune and does not fully address the larger issues that have allowed this crisis to fester. The scheme is also limited to disability residential services, meaning other types of services where the risk of abuse is just as real, such as community or aged care and those receiving care at school, are not covered.*

*People with a disability are most likely to be abused in segregated service environments, where abusive practices go unrecognised and unreported and where client and family participation in services is devalued. Delivering safe, open and accountable services that respond to individuals with capable staff and comprehensive accountability must be the minimum expectation, not only in Victoria, but nationally. It is unacceptable to rely on weak regulation, the occasional criminal convictions of carers or compensation claims by abuse victims to deliver the change individuals with disability and their families are seeking. Legislated obligations are needed to underpin this change, to both prevent abuse and neglect and to deal strongly with it when instances occur.*

*We already have a successful system of legislated safeguards and sanctions in our occupational health and safety system (OHS) that locates responsibility for workplace safety with boards and management. Legislated civil and criminal sanctions for breaches of OHS duty of up to \$600,000 in fines or five years' jail for individuals for serious breaches have materially changed the behaviour of directors and companies.*

*The cultural change needed to incorporate the OHS framework in the life of organisations has taken time and hard work. This would never have occurred without legislation to drive the change and establish clear expectations, obligations and sanctions. It is telling that, like all company directors in Australia, board directors and senior officers of disability organisations have legislated liability for breaches of financial, corporate and OHS regulations, but face no comparable liability or established sanctions for serious breaches in their duty of care to clients. This is what we need to fix.*

*Alan Blackwood, Young Persons in Nursing Homes National Alliance*

### Multiple Strategies

PWdWA strongly recommends that a whole raft of measures are incorporated or strengthened within the system to ensure the bias is in favour of the person with disability. Overarching legislation pertinent to disability which covers international, national and state imperatives such as the UNCRPD, Disability Discrimination Act 1992, and Disability Services Act 1993 (WA) needs to be upheld and enforced where appropriate. There needs to be strengthening of legislation such as the Public Interest Disclosure Acts to include all service providers and anyone receiving funded support. There must be a review and strengthening of legislation and process that enable people to make complaints to ensure complaints are taken seriously and upheld. There must be adequate resourcing and promotion of independent advocacy so people with disabilities know they have someone on their side. Complaints legislation must ensure that Boards and CEO's of providers are held accountable and punitive actions are enforced where there has been a breach of human rights. There needs to be a cultural shift away from prejudice of service providers to one where the rights and choices of the individual are prevalent.

It is also important to understand the fine balance between regulation and choice for the individual. Over regulation could in turn have the opposite effect and restrict choice. Developing transparent mechanisms which may improve activities and relationships will be more effective. The community visitor scheme for example is likely to have a better impact on quality and safeguarding than a standardised quality framework.

It is also important to not forget the mechanisms that every person has such as contacting the police. Another strategy in the corrective domain must be that the police are supported to hear evidence from people with disability. At any level through the complaints or reporting process, if a crime has occurred 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 abuse and neglect are actually crimes and must be treated as a criminal offence.

### Safeguards for participants who manage their own plans

*Option 1: Building the capacity for participants to manage their own risks'* would be the most suitable option for people choosing to manage their own funds.

PWdWA strongly believes that 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

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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.

### **Reducing and eliminating restrictive practices in NDIS funded supports**

The use of restrictive practices to manage 'challenging' behaviours constitutes a very high risk to breaches of the human rights of people with disability. Often challenging behaviours can be a response by an individual with disability to his/her environment, a way that a person communicates their unhappiness or distress. Changing services, systems and environments should be the starting point for changing behaviour as opposed to implementing restrictive practices.

More research needs to be undertaken to better understand 'challenging' behaviours and developing supports for people with disability that maintains their human rights.

#### *Case Studies*

*Michael is a forty year old man with Prader-Willi syndrome. He has sleep apnoea, and uses a CPAP machine and mask to ensure that he does not stop breathing during the night. Michael is a sturdily built man who has an intellectual disability and uses a motorised wheelchair.*

*Michael's family was contacted by staff who asked if Michael could be fitted with elbow splints to stop him removing the mask at night. His family agreed, as they were concerned for Michael's safety. However, the elbow splints were costly and not readily available, so the staff tied him to the bed by his hands. The family protested and were told that they had agreed to the practice as they had agreed to use 'elbow splints or other means'.*

*It took a long time to get the restrictive practice lifted, but in that time the family noted that Michael was being put to bed at six pm at night. Other residents in the group home needed care and medication, so his bedtime schedule was changed to suit the provider. Consequently, he was bored by 1pm and was taking apart his CPAP mask*

*fittings. Now, Michael has a usual bedtime for a man of his age and is no longer fitted with restraints. – WA Disability Abuse Inquiry*

*'My child was removed from our care because they thought we were using restrictive practices. She was twelve years old. None of the service providers would accept her because of her behaviours, so she went into government emergency accommodation. There was one place that she loved, a respite place, they would have taken her, but they weren't registered so she couldn't use her funding there. So she went into a house by herself with only one staff member, there were no other clients – they opened the emergency accommodation for her, she was there for more than a year. The staff members were mostly men and when we said that we didn't want men showering her, they said we had no choice. There have been police reports and incidents and as for restrictive practices, that's a joke. They can do whatever they want as long as it is in a 'plan'. They just tell you that you have to sign off on it and they can do whatever they want.'* - WA Disability Abuse Inquiry

PWdWA is also concerned about the lack of clarity as to what constitutes a 'restrictive practice'. In WA for example there is a voluntary code on elimination of restrictive practices that defines these terms but it is not legislated. This is a start but PWdWA strongly supports that this code becomes mandatory. The differing interpretations of what this means across the sector will have an impact on people with disabilities. There is an urgent need to clarify this terminology and then provide effective awareness and training initiatives to support this.

Until such a time when restrictive practices are deemed illegal, PWdWA strongly supports limited use of restrictive practices as a last resort only and for a minimal amount of time. It is essential that approval involves an independent body/person to represent the individual particularly when the person has limited decision making capacity or communication. It is important that the decision should not come down to one individual but an informed decision made by a panel with an appropriate level of expertise. A planned review is essential to prevent indefinite use once the restrictive practice has been placed. It is also essential that different types of restrictive practices require different levels of authorisation, such as containment and seclusion.

Mandatory reporting of restrictive practices need to be enforced with stringent review dates as part of the safeguards to provide greater monitoring and ability to measure the reduction or elimination of a practice. Further consideration needs to be given to an appropriate body to monitor and intervene where necessary should there be concerns about inappropriate use of restrictive practices.

### Conclusion

A quality and safeguards framework should enable people with disabilities to express freedom of choice with service providers who are transparent, flexible, and over all accountable. The framework advocates for increased control and choice. However, a significant amount of support and work is needed to ensure that this translates to practice as traditionally, people with disabilities 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 funding 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 development domain which building natural safeguards includes.

It is imperative that an independent statutory complaints body and a mandatory reporting system for the elimination of restrictive practices are created. We must not forget to include and upskill mainstream systems like consumer affairs and 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 for people to access the right information to make these informed choices.

Importantly, people with disabilities must be engaged as designers and co-designers in aspects of the framework. People will only feel confident with a framework that has been developed by people who use services and whose lives will be severely affected if this framework does not succeed!

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