People with Disabilities WA

individual & systemic advocacy



Submission

Issues paper: Safeguards and quality

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with <u>Disability</u>

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Disability Royal Commission for the opportunity to provide comment about safeguards and quality services.

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.

Introduction

PWdWA welcomes the opportunity to provide comment to the Disability Royal Commission on safeguards and quality services. PWdWA receives both state and federal funding to provide advocacy around issues experienced by the community concerning violence, abuse, neglect and exploitation – including safeguards and service quality. We also have specific funding from the Department of Social Services to provide Individual Advocacy to assist individuals to engage with the Disability Royal Commission and make submissions.

As the peak consumer voice for people with disability in Western Australia (WA), our submission is compiled on the experiences of people with disability, their families, and carers. Our responses are also informed through PWdWA collaboration with other advocacy and disability organisations. We have provided case studies from our individual advocacy work and quotes from a small online survey where appropriate to furnish our statements.

Addressing issues around service provider quality and safeguarding is an important aspect of PWdWA's advocacy work at both a systemic and individual level. Our Advocates have supported people who have experienced violence, abuse, neglect and exploitation as a result of inadequate safeguarding and poor-quality service.

PWdWA supports the statement by the Disability Royal Commission that strong safeguards are created when there is a blend of informal and formal safeguards

tailored to the individual. A human rights approach to safeguarding is crucial to ensure that the systems that are imposed do not restrict choice or control and allow for dignity of risk.

We believe one of the most important ways to safeguard people with disability is to build people's own natural safeguards. As stated in the Behind Closed Doors¹ report:

A person with sound knowledge of their rights and who understands how the system works, and who has support from others in their lives, will always be better protected by these natural safeguards than they could be a safety-net built by governments

The Behind Closed Door report explores the idea of building and investing in peoples 'natural' capital as a developmental safeguard. This natural capital includes:

- Personal capital ability to self-advocate, inner strength, resilience and selfesteem
- Knowledge capital skills, knowledge and the ability to access high quality information and act on that information
- Social capital relationships including family support, friends and community; and
- Material capital community, home and income

We know that those people with a disability who have low natural capital are more at risk and therefore investment in their natural capital will have a substantial impact on minimising their risk of experiencing violence, abuse, neglect and exploitation.

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¹ Connor, S., Keely, B. (2015) Behind Closed Doors: Preventing Violence, Neglect and Abuse against West Australians with Disability.

We also note that WA is just seeing the rollout of the NDIS Quality and Safeguards Commission, so we have not yet been able to gauge the impact of the Commission on the landscape of service quality and safeguards in WA.

Submission Format

This submission will be presented in two sections. Section 1 outlines the issues and gaps PWdWA has seen around safeguarding and quality services. While we have broken this section up, we note that there is intersection between many of the issues identified. Section 2 will discuss recommendations for improving outcomes for people with disability.

Section 1 – Issues and Gaps

Access to Information and Advocacy

Education and access to information is a key part of informal and formal 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 to make informed decisions. Information must be provided in a format that is accessible, considering individual needs and capacity. This includes multiple formats such as Easy English and Auslan etc. We note that while many people with a disability have access to computers and are connected online, the COVID-19 pandemic demonstrated that many are still lacking access. Therefore, we need to actively consider how people will access information.

Providing a person with education about their rights is one way to provide credible information and increase a person's natural capital. Funding for education and training around violence, abuse, neglect and exploitation specifically for people with disability in WA has been ad hoc and there has been limited incentive for service

providers to make it available to the people they support.

Help us know exactly what is available and how to access what is neededin multiple formats to cater for every PWD.

To make them [Safeguards] better people need to know about them, they need them in simple language, they need to be educated on what to do and where they can get support. So far I know nothing because I've been told nothing so the safeguards that are there are useless to me if I don't know about them or know how to access them

PWdWA Online Survey 2020

Many people who contact PWdWA are simply needing access to information about their rights so they can self-advocate. This includes information about:

- Restrictive practices
- Guardianship and Administration Orders
- Choice and control
- Complaints processes
- Violence, abuse, neglect and exploitation

This is in addition to other issues, many of which have an impact on, or are impacted by, safeguarding. Many people who are provided information can go on to resolve their own issues either by themselves, or with help from informal supports. A large number of people, however, still require the direct support of an advocate to resolve their issue.

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.

In the 2019-20 financial year PWdWA supported over 1000 people with advocacy issues across many different areas. The increasing level of demand being experienced by the advocacy sector had required us to focus on providing detailed information and advice to people experiencing non-urgent issues so that we have capacity to provide one-to-one advocacy to those persons with a disability who are vulnerable and have urgent issues requiring support. This has meant that many people who would have previously had access to advocacy support have either been placed onto waitlists or have had to self-advocate without an advocate being available to walk alongside them and build their capacity. This means that advocacy services in WA are essentially acting as crisis support services and have limited ability to provide the capacity building supports they have previously provided.

We need LOTS more Advocates, especially for those of us who have ZERO informal supports!!

Increased funding for advocacy organisations to be able to shorten waitlists, and assist people in a timely manner. Advocacy organisations should also be increasing people with disabilities self advocacy skills and increasing family members advocacy skills. Advocacy organisations should assist people with finding the correct information, achieving an outcome and guiding people to become their own advocates.

PWdWA Online Survey 2020

PWdWA are encouraged to see the WA State Government acknowledging the need for additional disability advocacy funding and including it in its budget. However, funding is still short term, with no guarantee of ongoing funding over the long term. We have also not seen an increase in the federal funding for advocacy services in the last 3 years despite the NDIS being overwhelmingly the most pressing issue.

Insufficient funded supports

NDIS

While NDIS has improved the lives of many people, as an advocacy agency we see where it is failing to meet the needs of the people it was designed to support.

Reviews for insufficiently funded NDIS plans form a large part of the advocacy

support that PWdWA provides. We know that having adequate access to quality funded supports can ensure that more heavy-handed safeguards such as restrictive practices are not required. For example, having properly funded behavioural therapy supports, and sufficient funding to help a behavioural support plan to be implemented, is paramount to success in reducing or eliminating the need for restrictive practices. There is also the opportunity to access supports which build natural capital such as community relationships and friendships, and supported decision making. Additionally, without sufficient funded supports you put carers at risk of burnout and risk the breakdown of informal relationships, both of which increase the risk of violence, abuse, neglect and exploitation.

The difficulty in accessing funding for safeguarding and capacity building supports such as Microboards and Circles of Support is a clear example of how the NDIS is failing to invest in capacity building safeguards. Most of us have family, friends and other informal networks that we can seek support from when we need help. For some people with disability however, these connections and relationships do not naturally exist and need facilitation. We know that there are many individuals in WA whose only point of contact is their paid support staff. In some circumstances the individual is at further risk because they only have a single service provider.

Mechanisms such as Circles of Support or Microboards are a way of building connections outside of paid supports. They can provide support for a person to understand and make decisions about their lives and services. They act as a safeguard as they ensure there are numerous people who know the person with disability well enough to recognise when issues are occurring and help the person speak up if needed. However, it is not always an easy process to create and run these supports. For some individuals there will need to be funding provided to facilitate this process. For those who are especially isolated there will likely be a need for a long-term and intensive coordinator². While some individuals have been able to successfully include circles and microboards concepts in the NDIS plans, many other have not had success. There is no mention of Circles of Support or

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² Bigby, C.,& Araten-Bergman, T. (2018). Models for forming and supporting circles of support for people with intellectual disabilities.

Microboards on the NDIS website and no guidance from the NDIA on how a person might go about having these kinds of supports included in a plan. Despite Circles of Support and Microboards being a valid option to assist with supported decision making our experience has been that NDIA has been very reluctant to fund them.

Hannah's Story

Hannah is person with an intellectual disability. Hannah has complex communication and support needs. Hannah has a few people in her life who have volunteered to form a Microboard to support Hannah to make decisions and to ensure that she has a voice about the supports she is receiving. As a safeguarding option it would have helped build the Hannah's natural capacity. That is:

- it would ensure Hannah has access to information, advice and support to make decisions
- it would help Hannah understand the supports available to her and her rights regarding those supports
- it would ensure Hannah has access to trusted people who know her communication style and preferences
- it would ensure Hannah has support available to help her with any issues or complaints she has

Hannah asked for the NDIS to help pay for her to set up her Microboard. It takes up to two years for a Microboard to be set up and there are costs associated with this process including formal facilitation to create the Microboard and the cost of incorporation. The NDIA said they would not fund the establishment of Hannah's Microboard. They said that if Hannah needed supported decision making it was most appropriately provided by her Support Coordinator under the funded supports available and through her existing informal networks. They stated that if Hannah needed additional support to make decisions a Legal Guardian should be appointed to make decisions on her behalf.

PWdWA believes this presents a failure on several levels regarding person centred safeguards. Firstly, the suggestion that a person who needs a high level of supported decision making should just be given substitute decision making is the antithesis of a human rights approach. It should be the absolute last resort where there is a means of facilitating substitute decision making, such as a Microboard. The cost of the Microboard in this case was also less than the cost of funding 25 hours of Specialist Support Coordination and would provide ongoing support past the initial cost of set-up.

Education

Our submission to the 2020 Review of the Disability Standards for Education 2005³ highlighted the issue that parents face in WA in relation to accessing appropriate supports for children in primary and secondary settings. PWdWA have seen the following outcomes due to a lack of funded supports in the education setting:

- Children's unmet needs resulting in 'behaviours'
- Children being suspended or expelled
- Children being voluntarily withdrawn from schooling
- Children self-harming and experiencing mental distress
- Children being bullied
- Children not achieving academic success

Having adequate supports to successfully engage in early childhood education is one of the keys to building confidence and lifelong skills that have an impact on a person's natural capital. It is vitally important that we invest in children early to build their natural safeguards.

Crisis Support and preventative educations services

PWdWA would like to draw the Disability Royal Commissions attention to a submission by SECCA to the Joint Standing Committees enquiry into General

³ PWdWA. (2020) Submission: 2020 Review of the Disability Standards for Education 2005 https://www.pwdwa.org/documents/submissions/DSE2020ReviewPWdWASubmission.pdf

issues around the implementation and performance of the NDIS.⁴ This submission explores the issues around current funding for crisis supports that can appropriately meet the needs of people with a disability, as well as funding for developmental safeguards such as protective behaviours. PWdWA support the recommendations made by SECCA in this submission.

Safeguards that restrict choice and control

As touched on in the Issues Paper there is a tension between dignity of risk and duty of care with service providers. In some cases, this is tied to prevailing paternalistic attitudes which assume that a person without a disability is better placed to make decisions in the 'best interest' of the person with a disability. It is also related to the focus of service providers on risk mitigation and liability. Often these decisions or actions are couched in the terminology of safeguarding and duty of care but in reality can unnecessarily restrict a person's choice and control.

When asked how people can maintain choice and control if safeguards are needed, respondents to the PWdWA online survey overwhelming stated the importance of listening to the person with a disability and ensuring adequate independent supports such as advocacy are available.

Include the person in the decision making process and find efficient ways of communication if person is non-verbal.

By assigning an independent advocate to make sure that the person with a disability is given space and facilitation to communicate their experiences and their decisions. If a person is unable to communicate, then an independent advocate would be able to assess whether their best interests are being served by service providers.

PWdWA Online Survey 2020

⁴ SECCA, General issues around the implementation and performance of the NDIS Submission 24 https://www.aph.gov.au/DocumentStore.ashx?id=a8e59b8a-fdfd-4f70-afd4-a8ef3cdde077&subId=685593

Restrictive Practices

We know that Restrictive Practices are a Safeguard that are often misused. Further information on how restrictive practices are misused and impact on choice and control can be found in our submission to the Restrictive Practices Issues Paper.

A recent issue regarding Restrictive Practices and safeguarding has come to light in WA since we submitted our Issues Paper. The WA State Government is introducing a new policy on the authorisation of Restrictive Practices. A key part of the policy is around gaining consent from the person with a disability as part of safeguarding measures to ensure choice and control. There is no requirement under the policy for a legal threshold for consent to be reached or a legal Guardian to be appointed if there is a question around capacity. The issue of how a person can be supported to provide consent is still being explored by Department of Communities - Disability Services. It is concerning however, that service providers have already informed families and carers that they must have Guardianship Orders in place to consent to restrictive practices. PWdWA are aware of at least one order being granted. We are concerned that this will be used as a mechanism to circumvent the effort required for supported decision making, overrule a lack of consent from persons labelled as 'difficult' and may have a suit of unintended consequences that limit a person's choice and control.

Guardianship and Administration / Substitute Decision Making

Another Safeguard system that PWdWA regularly interacts with is Guardianship and Administration Orders under the WA *Guardianship and Administration Act* 1990. PWdWA has aided with over 200 issues involving Guardianship and/or Administration Orders since 2012. This system is one that applies substitute decision making, meaning it inherently restricts choice and control. The United Nations Convention on the Rights of People with Disability is clear that substitute decision making is not in line with the purpose of the Convention. We have seen

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⁵ MS [2020] WASAT 146

service providers and families seek Orders for individuals under the rationale of safeguarding where PWdWA believes that the orders are really designed to:

- Make it easier for services to deal with a 'difficult' individual
- Prevent the loss of income to services where an individual wishes to change providers
- Prevent a person making decisions that have an adverse impact on family
- Mitigate risk and liability

In many of these cases, alternative safeguards have not been explored. This includes safeguards that would build natural capital.

David's Story

David is a gentleman with an intellectual disability who received services from one provider. David was unhappy with the services that he had been receiving from his provider and had been thinking of changing providers. Although he had made complaints to his provider about the services he had received, his complaints had been dismissed offhand by the staff and were left unresolved. When David began expressing a desire to change service providers, he found himself on the receiving end of an application for Guardianship and Administration Orders under the WA Guardian and Administration Act 1990. David's provider had made the application based on the reasoning that he was unable to manage his money or his support services. Some of the arguments they made for the order included: that David used his income to provide expensive gifts to the children of his ex-partner; and that his best interests would not be met by the new service provider David wanted to engage. There was no medical or other evidence to support the idea that David was unable to manage his own life or make his own choices. His bills were always paid on time, he managed his medical appointments, and with the help of services would easily be able to manage his daily affairs. Essentially the service had decided that they were better placed to make decisions about how David spent his money and who should be supporting him. This is a clear example of how attitudes and culture around capacity, dignity of risk and best interest can lead to decisions about safeguarding which undermine a person's human rights and their right to choice and control. An advocate was able to work with David to have the application for orders overturned but the process caused David considerable stress.

Francine's Story

Francine is a young woman with a psychosocial disability who moved into an apartment as part of her goal to live independently. Francine and her mother were distressed to learn that Francine's service provider had made an application for a Guardianship order. The service provider was alleging that Francine was not safe in her accommodation. The service provider had not spoken to Francine or her mother about their concerns, or what steps could be taken to safeguard Francine. In fact, the service provider had implemented restrictive practices such as putting locks on cupboards without Francine's consent. A PWdWA advocate supported Francine and her mother during the State Administrative Tribunal process. It was evident that the concerns regarding Francine's safety would be easily addressed by ensuring Francine had adequate supports funded in her NDIS plan. It was also clear that Francine was able to make her own informed decisions and choices with adequate support that took into account her communication needs. While the order was ultimately not granted, it demonstrates all to frequent occurrence of service providers applying for orders as a quick fix to safeguarding issues.

In addition to restricting choice and control, substitute decision making can increase the risk of violence, abuse, neglect and exploitation.⁶ Advocates have seen many examples of family or friends, acting as legal substitute decision makers, who have acted in their own best interest at the expense of the person with a disability. This includes both where a person has been coerced into signing an Enduring Power of Attorney⁷ or an order has been granted under WA's *Guardianship and Administration Act 1990*.

⁶ Law Commission of Ontario. (2014). https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship-discussion-paper-2/i-the-problem-of-abuse-and-misuse-of-substitute-decision-making-powers/">https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship-discussion-paper-2/i-the-problem-of-abuse-and-misuse-of-substitute-decision-making-powers/;

⁷ A person does not have to have legally lost capacity for an Enduring Power of Attorney (EPoA) to be used. An EPoA does not have to be registered anywhere. There is no formal process for validating the currency of the document and it is difficult to repeal without knowing exactly where it has been provided. For more information on the powers granted under an EPoA see:

https://www.publicadvocate.wa.gov.au/E/enduring power of attorney.aspx

The Aged Care Royal Commission received many submissions outlining the misuse of substitute decision making powers⁸ and we recommend that the information available from this process be considered to inform recommendations around safeguards.

Service Provider Education and Training

PWdWA often receives calls from service providers where instances of violence, abuse, neglect or exploitation have occurred. We also receive contact from people with a disability themselves or their family/friends to seek assistance of an advocate. In many of these instances the service providers have not taken appropriate steps to respond to the situation. This includes failure to:

- Notify line manager of incident
- Notify police where appropriate
- Complete a Serious Incident Report as per funding arrangements
- Ensure safeguarding measures have been reviewed and safety plans are put in place for person with a disability
- Refer person with a disability to other appropriate services such as Domestic Violence supports

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⁸ Senior Rights Victoria. (2019). Submission to the Royal Commission into Aged Care Quality and Safety https://seniorsrights.org.au/wp-content/uploads/2019/07/2019-05-13-SRV-submission-to-Aged-Care-Royal-Commission.pdf

Joe's Story

Joe had recently moved from Host Family Care to living independently with support. Joe's service provider called PWdWA because his father had applied for Guardianship and Administration Orders without his knowledge. Joe's father wanted Joe to stay with his Host Family. Joe was very clear about his desire to remain living independently. The service provider suspected that the Joe's Host Family was behind this action as they did not want to lose the income they received from hosting Joe. Joe had been taken to a State Administrative Tribunal (SAT) hearing by his father and Host Family Carer but had been told he was being taken out to lunch. At the time of contacting PWdWA the service provider had not taken any action in response to the situation, other than seek an advocate for Joe. The PWdWA advocate had to guide the service provider to complete a Serious Incident Report which was a requirement under the service provider's funding. The advocate was able to support Joe through the SAT process and ensure that his father and Host Family were not appointed substitute decision makers and that Joe's preferences were supported to the best extent under the law.

While we are encouraged that some services are seeking the help of an advocate for the person with a disability, their lack of knowledge about their own policies and requirements on how to respond to these types of incidents is concerning. We believe this is due to a lack of education across all levels of service providers on how to respond to violence, abuse, neglect and exploitation. Without an appropriate response the violence, abuse, neglect or exploitation will not be addressed, safeguards to ensure it do not occur again will not be implemented, and the lack of reporting means there is a dearth of evidence available about the experiences of people with disability in regards to these issues. A respondent to the PWdWA online survey had this to say regarding service provider education:

My brother's Service Provider Management knows very little of their own policies or what they are being to deliver under the NDIS. We regularly have to send through NDIS guidelines to them. It certainly doesn't filter down to the grassroots staff that just continue to do what they have always done without any supervision or direction.'

PWdWA Online Survey 2020

Additionally, education is lacking around when and how it is appropriate to implement safeguards and how to support decision making. This includes education about what constitutes a restrictive practice. As identified in previous case studies services providers are often quick to apply for Guardianship and Administrative Orders where there are no grounds for an order, and other less restrictive options have not been explored. A quality service that understands how to support decision making and knows how to work well with a person to meet their individual needs is one that will be less likely to engage in restrictive practices and more likely to achieve positive outcomes for a person with disability.

There needs to be robust management arrangements and training supports within organisations to ensure staff can respond to risk 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.

Matt's Story

Matt called PWdWA because he wanted help saving for a holiday. While PWdWA cannot provide financial advice, the advocate told Matt they could help him connect to a financial counsellor and understand how his service provider could help him achieve his goal. In working with Matt, it was identified that there were a number of irregular expenditures and that support workers were not diligently maintaining records of Matt's expenses per the advice from Matt's financial counsellor. The financial counsellor and advocate spoke to both Matt and his service provider about the importance of keeping good records as a safeguard against financial abuse. They also spoke about options such as Centrepay which would be a good financial safeguard. Matt agreed to both these actions. The financial counsellor requested copies of bank statements and expense records so that they could help Matt create a budget and help him work towards his savings goal. The service provider failed to support Matt to get copies of these items and failed to support Matt to keep proper records of his spending. As a result, Matt's risk of financial abuse had not been addressed. The service provider suggested applying for an Administration Order as an alternative safeguarding measure. Matt did not want to make a complaint about his service provider, so the advocate was unable to provide any further help. The matter was referred to the service providers funding body and PWdWA are unaware of whether any action was taken to address the quality of supports provided.

Complaints processes

People with a disability need to understand their rights and know where to go for help in order to make a complaint. Some people with a disability have difficulty accessing information or may rely on formal supports providing information to them. Many people with a disability will need support to make a complaint. This includes not only informal supports such as family and friends, but also formal supports such as independent advocates. For those who do not have informal supports knowing

that advocacy is available and how to access it can be crucial to successfully navigating a complaint outcome.

The PWdWA Behind Closed Doors report identified that:

People who were isolated – whether it was in a hospital, supported employment agency, aged care facility, prison, residential care facility, day centre or school – were less likely to be able to access complaints mechanisms and more likely to experience violence, abuse and neglect.

The report also found that complaint systems were underutilised, considered ineffective and fear of retribution was common. For example, not all people are easily able to access complaints bodies such as HaDSCO⁹, Ombudsmun, Australian Human Rights Commission or police. There can also be confusion as to which complaints body has jurisdiction over certain matters and in some cases, people are referred from place to place without ever finding a resolution.

I was not aware of any systems and services when the abuse occurred, although I now am, but as it occurred in private, I still feel very helpless.

PWdWA Online Survey 2020

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 crimes and must be treated as a criminal offence. We know of instances where people have had difficulty making a complaint to the WA Police. In one instance an assault by a support worker was reported to the police by a family member. According to the family the police claimed they could not do anything as the person was an

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⁹ Health and Disability Services Complaints Office

unreliable witness due to their intellectual disability. In other cases, police have not identified where a person may require support to interact with the criminal justice system either as a victim or a perpetrator. The PWdWA Independent Support Person Program Feasibility Study provides further information on the difficulties faced by people with intellectual or cognitive disabilities who come in contact with the WA Justice System.¹⁰

PWdWA has supported persons where service providers have failed to make the appropriate referrals or provide supports to help them access these systems. In many cases the people we have supported have found internal complaints mechanisms to be adversarial, cursory, and lacking any real resolution pathway.¹¹

It is exhausting when the complaint is not acted upon or just met with a million excuses. We have become so selective about the frequency and types of complaints we raise as we worry about possible repercussions on our brother when we are not with him.

Barriers - Feel like your complaint makes no difference. Not getting a response to your complaint. Having to make a complaint about your complaint.

PWdWA Online Survey 2020

In some cases, complaint systems failed to make reasonable adjustments for persons with a disability. For example, requiring a complaint to be made in writing by a person who could not write and had limited access to a computer.

Need to be much easier for the paperwork is difficult for complaints.

PWdWA Online Survey 2020

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¹⁰ Arazi, A., Jenkinson, S. (2017) Feasibility Study: Independent Support Person Program for People with Intellectual or Cognitive Disability who come into contact with the WA Justice System. Retrieved from https://www.parliament.wa.gov.au/publications/tabledpapers.nsf/displaypaper/4011001cf589109c9392a16f 482581f00013ce27/\$file/tp-1001.pdf

¹¹ For example a detailed discussion of the issues faced by people with disabilities and their carers making complaints under the WA Education System can be found on page 14 of the PWdWA submission on the *2020 Review on the Disability Standards for Education*

Nathan's Story

Nathan was verbally abused by his family member in front of support workers had requested assistance from the support workers to lodge a police report as he feared for his safety. He was told by the support workers that he would need an advocate to assist him with this as they could not help. The support workers did not report the incident to the service provider and did not help the gentleman to make any kind of report. This incident should have also been reported to Disability Services Commission under the Serious Incident Report guidelines. A PWdWA advocate was able to support Nathan to make a complaint to the service manager who arranged for staff to assist him to make a report to the police, and for staff to provide witness statements. It was not clear if the issue was also raised as a Serious Incident Report.

Service provider culture around complaints also plays a key part in how complaints are handled and is often an indicator of the quality of a service. Since 2012, PWdWA has provided information and advocacy for over 700 issues relating to disability service complaints. This includes complaints about lack of appropriate safeguarding, as well as overly restrictive safeguarding. In a number of cases the service provider has viewed the complaints process as an opportunity to improve practice. In these instances, the process is very conciliatory, and advocates are viewed as adding value to the complaints process. However more often than not PWdWA advocates find complaints processes to be very adversarial. We have had instances of service providers refusing to provide the person with a disability, or their advocate, with a copy of their complaints policy. Service providers have refused to engage with advocates, and in some circumstances, complaints have been followed by service providers withdrawing their services on 'supposedly' unrelated grounds. On many occasions PWdWA has also seen persons who make numerous complaints to service providers being subject to Guardianship Order

applications.¹² It is no wonder then that some people with a disability still fear retribution for making a complaint.

The introduction of the NDIS Quality and Safeguards complaints mechanism is a great step forward. We are encouraged by the NDIS Quality and Safeguards Commissions drive to be truly accessible to people with a disability and take an approach that places the wellbeing of the person with a disability at the core of its response. The data collection function that will enable the Commission to look at patterns of complaints both generally and for individual providers will also be crucial to ensure systemic change occurs. The ability to refer through to investigative and compliance areas within the Commission will also hopefully mean that direct action can and will be taken to address concerns raised. However, the scope of the Commission is limited to services funded under the NDIS. PWdWA has previously found when consulting with people with a disability that the state disability complaints body HaDSCO is considered to be relatively ineffective. 13 There is a widespread perception within the disability community of HaDSCO being a 'toothless tiger'. Despite having powers to investigate complaints PWdWA has rarely seen this power used and many people we support feel as though they have not been heard through the complaint's resolution process. HaDSCO is likely to continue to be the primary complaints mechanism for people receiving disability supports outside of the NDIS.

Service Quality

PWdWA has engaged with many difference services providers across WA in the course of providing advocacy support. The quality of supports varies across a continuum with some providers being innovative and person centred, and others failing to provide adequate supports leading to serious consequences including injury and lasting mental health concerns.

¹² See Case study 'David's Story'

e%20Amendment%20bill%20submission.docx

¹³ PWdWA, DDWA. (2017) Submission: National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and other measures) Bill 2017. PWdWA. Retrieved from: https://www.pwdwa.org/documents/submissions/170811%20National%20Disability%20Insurance%20Schem

As outlined above, service provider education and culture play a large part in the quality of supports being provided. A quality, person centred service is more likely to actively build a person's natural capital as part of the supports they provide. We know that many people who receive Social and Community Participation funding as part of their NDIS plan are not being supported to truly become part of their community. For example, their support worker will take them to the shop for coffee, or they will attend a prescribed activity as part of a disability specific group. These kinds of supports are generally easier for service providers but do not necessarily build a person's connections in the community. In many cases people do not know any different as they come from a lifetime of living in institutional settings with limited choice and control. A quality service would be one that supports a person to explore their interests, engage in activities that build connections and skills and as a result builds their natural capital.

One respondent to the PWdWA survey had this to say about the quality of supports they received from Local Area Coordinators:

Having experienced a vast difference in quality between LACs of different agencies, some who leave a client to fend for themselves or who lack training in the area of disability their client experiences, there needs to be some quality control for those who are employed to coordinate a person with a disability's care (LACs through NDIS for example). While an effective service coordinator can facilitate access to vital services that improve quality of life and reduce social isolation, an ineffective coordinator acts as a barrier between the disabled person and the supports they need to live an equitable life

PWdWA Online Survey 2020

When asked what a quality service that safeguarded against violence, abuse, neglect and exploitation looked like another PWdWA survey respondent provided the following example:

They assist the client to empower them with the ability to make their own decisions, on a developmental level that is consistent with their own personal, cultural and educational principles, they would be encouraged in their daily activities to facilitate their needs, based on achieving goals set for their own future, lifestyle choices, daily requirements and responsibilities that we are each required to perform on a personal level, and makes them feel understood when communicating taking the time to discuss what is important for the client in living their life and completing their daily activities.

PWdWA Online Survey 2020

Additionally, the small number of people who responded to the PWdWA survey highlighted their preference for services to have independent oversight and quality monitoring as a form of safeguarding. The introduction of the NDIS Quality and Safeguards Commission in WA will vastly change the regulatory, compliance and monitoring landscape for NDIS funded services and will increase the level of oversight and scrutiny on registered providers. Respondents to the PWdWA online survey want to see providers who are not delivering value for money and tangible outcomes held accountable by the NDIS Quality and Safeguards Commission.

However as highlighted in the previous section the NDIS Quality and Safeguards Commission it does not cover non-NDIS services who may interact with and provide support to people with a disability. It also has limited oversight over non-registered providers unless a complaint or issue is raised directly with them. As one respondent to the PWdWA survey pointed out:

Safeguards can only work if there is power associated to the extent that perpetrators are held accountable, can be prosecuted or reprimanded and subject to education protocols.

PWdWA Online Survey 2020

As such educating people with a disability about their rights and having access to effective complaints mechanisms and remedies will still be critical to ensuring service quality.

People who are isolated and vulnerable

As noted above, people who are isolated are more likely to experience violence, abuse, neglect and exploitation. This risk is increased where a person has only one service provider involved in their supports. Being isolated makes it far more difficult to access information and make complaints, especially if the person with a disability is reliant on the perpetrator for their supports. Additionally, many people who are isolated come from a history of institutional settings where they had limited choice and control. They may have difficulty recognising violence, abuse, neglect and exploitation or understanding their rights. Many people continue to live in isolated settings such as group homes and have limited access to sources of support or advocacy. It is critical that people who are isolated and segregated have access not only information and education, but also independent advocacy and supported decision making.

Independent advocates should be assigned to people in vulnerable positions, who couldn't otherwise advocate for themselves. Advocates would need to be independent of the service providers themselves and not employed by the same companies.

PWdWA Online Survey 2020

PWdWA have previously seen instances of people with no informal supports having a service provide act as plan nominees with the NDIS. There is a clear conflict on interest in this case as the service provider essentially has control over requesting a review for additional funding and appointing their own service to deliver supports. In some instances, we have heard of planning meetings occurring where the person with a disability was not present, did not participate, and therefore was not able to raise any issues about the provider.

Ultimately it should be a person's choice if they receive supports from a single provider, but this must be a truly informed decision. For example, we know that many NDIS providers in WA state that they will only provide supports if a participant engages them to provide all the supports in their plans. This clearly brings up safeguarding issues for people who are already isolated, especially those who

require supported decision making. More work needs to be done to ensure that people who have historically been supported by a single provider or who are isolated/vulnerable have access to independent mechanisms such as an independent Support Coordinator, an independent advocate or other supported decision-making models to help them make supported decisions about who provides their services as well as other decisions they may need to make.

Respondents to the PWdWA Online Survey suggested home or consumer visits or regular check-ins should be introduced as part of safeguarding measures.

Need to actually send monitors out there and not just wait for the complaints and concerns to come in. How does a single person living on their own, who might have communication difficulties, submit a complaint about their Service Provider? How do they tell anyone that they don't feel safe or are being abused and/or neglected? Maybe they don't even realise that they are being abused or neglected. It is all back to front.

PWdWA Online Survey 2020

In Victoria, the Office of the Public Advocate oversees a Community Visitor program which empowers volunteers to visit disability accommodation services, supported residential services and mental health facilities. Anyone can request a visit from a Community Visitor, and they have the ability to make unannounced visits to services where individuals are isolated or vulnerable without invitation. Community visitors:

- Observe the environment and how staff treat the people they support
- Inspect documents and make enquiries
- Speak with the people being cared for about their experiences
- Identify issues with service quality including suspected violence, abuse, neglect or exploitation

Section 2 - Recommendations

Recommendation 1: NDIS should fund Circles of Support, Microboards and other capacity building safeguards

PWdWA recommends that the NDIA work with people with disability, there family and carers to develop guidance material around including Circles of Support, Microboards, or similar mechanisms that build individual safeguards, in a person's NDIS Plan. This should include guidance around when the NDIA *must* provide funding to help establish these types of supports. This should be implemented in conjunction with training and education for participants, LAC's and NDIA planners.

Recommendation 2: Embed Supported Decision making into law

PWdWA believes that Australia should look at embedding supported decision making into law in accordance with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities.

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.

https://www.bclaws.gov.bc.ca/civix/document/id/lc/statreg/96405 01

¹⁴ Representative Agreement Act 1996

Recommendation 3: Review and amend the WA *Guardianship and Administration Act 1990* to replace substitute decision making with supported decision making

In line with Recommendation 2 we would like to see the WA *Guardianship and Administration Act 1990* amended to be in line with international human rights standards. The Commission might look to legislation introduced in Victoria in 2019 which moved their Guardianship and Administration legislation from a substitute decision making process to a supported decision-making process.

Recommendation 4: Ensure adequate funding and education for supported decision making

We know that supported decision making is not well understood in WA. Being able to embed supported decision making in everyday practice will require a concerted effort to educate and upskill services, as well as family and carers. We believe the NDIS Quality and Safeguards Commission should have a role in providing education in the disability sector but there also needs to be investment in other areas such as health, justice and education.

In addition to education of services and informal supports there needs to be adequate funding available for supported decision making in a person's NDIS plan if it is needed. This could include additional hours under Specialist Support Coordination, or as outlined above specific mechanisms such Microboards and Circles of Support.

Recommendation 5: Introduce a Community Visitor Scheme in WA

Our 2015 Behind Closed Doors report made a clear recommendation for introducing a Community Visitor Scheme as part of a suite of safeguarding measures to eliminate violence, abuse, neglect or exploitation. We strongly recommend that a similar program to the Victorian Community Visitor program be made available nationally.

Recommendation 6: Adequately fund of disability advocacy organisations to build and maintain capacity and capability.

Disability advocacy services need long term adequate funding to ensure that they have capacity to provide timely advocacy support to anyone who requires it.

Additionally, we would like to see this funding include provisions for advocacy organisations to provide education to the community and people with disability. At present, PWdWA has sought additionally funding to run community education under grants such as the Information, Linkages and Capacity Building grants. We believe that this type of education should be a core ongoing function of advocacy.

For example, providing education is a key activity for which advocacy services are funded under the National Aged Care Advocacy Program. This education is designed to support people who use aged care services to understand their rights and how they can get help. In WA, Advocare also includes information about Elder Abuse in their information sessions. While it is not mandatory for services to provide these educations to staff and clients, they do play a role in meeting accreditation requirements. This means there is incentive to engage with the advocacy services to provide education as a means to ensure their service is meeting national standards.

Recommendation 7: State based complaints mechanisms be reviewed and strengthened to ensure they are accessible and provide robust outcomes for people with a disability.

Although a number of avenues for complaints already exist, many people in the community are unaware of them. As part of efforts to educate service providers, community and people with disabilities, information about how and where to make complaint must be accessible. We must ensure there is a no wrong door approach to complaints and that if a complaints body does not have jurisdiction all reasonable effort is made to help a person access the appropriate complaints body. Where appropriate agreements to share data should also be in place to ensure that a full picture of the issues experienced by people with disabilities is available.

Recommendation 8: 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.

Recommendation 9: Investing resources into peer support, training and selfadvocacy that empower individuals, promote independence and provide options for flexibility.

Investment in systems and programs that build 'natural capital' will have a substantial impact on minimising the risk of experiencing violence, abuse, neglect and exploitation.

Any system development or modification must be 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.

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