

Supplementary Submission to the Senate Inquiry

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Introduction

Thank you for the opportunity to provide testimony this week. I am writing this as a supplementary document to my testimony and will provide a letter to answer the questions on notice.

I am providing this short paper as an individual acting in a number of roles, including as subject matter expert in the area of prevention of violence against people with disability, rather than as President of People with Disability Australia.

I believe there are serious issues with this legislation, which I will outline in detail below.

The upcoming consultation around the Safeguarding Framework would be a better opportunity to explore some of the issues inherent in the request for legislation change below.

I hope that the Commission and the NDIA will take up the opportunity to develop a co-production process to ensure that people with disability and their families, as well as our representative organisations and supporters, are better able to participate in legislative processes that may have perverse outcomes or outcomes that may negatively impact our lives.

Background

When disabled people are abused, we are treated differently under the law.

This is because of a number of reasons.

It is because the systems that have been designed for non-disabled people do not work for us, because they were not designed for us. They are often not accessible or inclusive.

It is because often the violence, neglect and abuse that happens to us happens in service systems or in ways that makes the violence look like a complex issue.

It happens because the disability sector, who are often contributors to the reasons that we are abused or direct perpetrators, are left in charge of finding and implementing solutions – a bit like having a fox in charge of a henhouse.

About a decade ago, a group of people in the UK decided to try and find a way to think about developing solutions around keeping us safe. They used a risk framework used primarily around computers and chemical processing¹. They changed it a little to make it centred on disabled people, but it was primarily a safeguarding framework developed for service settings and within systems.

The NDIA used that same framework, but took some key parts out of it, developing the Quality and Safeguarding Framework.

That is what we have today.

But when the NDIA redeveloped that framework, they reduced and redefined one of the most important areas – developmental safeguarding, to make it fit into a predominantly regulatory framework.²

This was always a problem. When frameworks are developed for and by and around regulatory systems and providers of services, when end users are excluded from those processes or participation – things end badly. They did for Ann Marie Smith.

¹ <https://www.informit.com/articles/article.aspx?p=2979062&seqNum=11>

²

https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis_quality_and_safeguarding_framework_final.pdf

Safeguarding

But first, safeguarding.

Originally, the three components of safeguarding were as follows;

Developmental safeguarding, which is about what is around you. People who will notice if you are missing or hurt, or if something is wrong.

Places which are accepting and inclusive and accessible.

Enough support to make sure your rights are upheld. Information and knowledge, so that you know what your rights are.

Peer support.

Preventative safeguarding, which is what people do before something goes wrong.

In a disability context, that might mean police clearances, or a physically safe environment, or staff training.

The third part is **corrective safeguarding**. That is what happens after a crime or incident has occurred and is used to reduce the consequences of that undesirable event.

It could mean the complaints process, justice processes or other ways to respond to things going wrong.

The missing parts would be, people assumed, implemented via the mostly-absent Tier 2 of the NDIS and the mostly-unimplemented National Disability Strategy, while the rest would be carried out in conjunction with the NDIS Quality and Safeguarding Commission.

The idea that we would be safeguarded by one single harmonised system was a sound one in theory, but not in practice. The NDIS registrar would have responsibility for registering providers; managing the NDIS practice standards and certification scheme; leading the design and broad policy settings for nationally consistent NDIS worker screening; monitoring provider compliance; and taking action as required.

They were also supposed to monitor, review and report on the effectiveness of the NDIS market of supports, including anti-competitive

conduct and early indicators of risk of thin markets and market failure. This information is not publicly available.

The senior practitioner was supposed to oversee approved behaviour support practitioners and providers, provide best practice advice; receive, review and report on provider reports on use of restrictive practices and follow-up on serious incidents that suggest unmet behaviour support needs, as well as referring concerns about worker or provider noncompliance to the NDIS registrar.

Restrictive practices, initially planned to be managed by States and Territories, is now managed by the NDIS Quality and Safeguards Commission as well as the States and Territories. And then there was the nationally consistent NDIS risk-based worker screening and the banned workers list.

In the early days of the development of the NDIS, I was involved as one of the original scheme architects, working on the expert group for workforce. Another group was centred on safeguarding and included Marita Walker³, Bruce Bonyhady and Kate Fulton. I have attached a copy of the paper that was drafted to reflect that initial thinking and which was based on ideas about citizens' rights and control.

Decision makers decided to focus on what could be done within a series of regulatory frameworks, while remaining centred on the rights of the individual. They also planned to invest in people with disability themselves, grow and mature the marketplace and make sure disabled people had an active part in safeguarding.

This never happened. And here we are.

And then Ann Marie Smith died.

³ <https://www.centreforwelfarereform.org/uploads/attachment/385/a-personalised-approach-to-safeguards-in-the-ndis.pdf>

The Response to the Killing of Ann Marie Smith

Annie was one of thousands of disabled people who had died in care. But her death was different. She was rich, and white. She lived not in a state or private institution but in her own, very nice home, in a good suburb near Adelaide.

She died of severe neglect after she was neglected by her service provider, Integrity Care. She was left to die in a chair, the public has been told, and died of septic shock, multiple organ failure, severe pressure sores and malnutrition.

It was a death more often encountered by police who attended scenes where informal carers had provided little or no care to elders, not home based care where NDIS funding was provided and service providers were in attendance. There was exploitation and theft, as well as fraud. It was something very different to what is usually experienced by disabled people.

The other difference was the response. The nation was outraged by the way that she had died. What was quickly apparent is that governments rapidly responded – the South Australian government with the fast assembly of a State based task force, the Federal government with an unprecedented appointment⁴ of a retired judge to commission a review into her death, even before the police investigation had concluded.

Although a person has now pleaded guilty to Ann Marie's manslaughter, the investigation has not yet been concluded. Her death was part of a highly unusual set of circumstances – she died at the commencement of the pandemic in what is believed to be a set of circumstances that involved targeted exploitation, fraud and possible organised crime by more than one perpetrator.

The full investigation may reportedly take some years to be brought before suspects are brought before the courts.

The appointment of Alan Robertson AO was carried out the month after Ann Marie had died, before the circumstances of her death had even been ascertained. The inquiry would be careful not to focus on any of the particulars of her death in order to avoid compromising the police

⁴ <https://www.theguardian.com/australia-news/2020/may/26/former-judge-to-investigate-death-of-adelaide-woman-ann-marie-smith-in-full-time-care>

investigation, Mr Robertson advised. The SA State Task force made the same commitment.

With limited information about the death of one woman in highly irregular and unusual circumstances, two discrete reports made a series of recommendations based solely on perceptions about the death of a woman whose circumstances remained unknown due to an ongoing police prosecution.

The report⁵ for the SA Task Force was handed down in July, 2021, the report from Alan Robertson in September, 2020. Annie's support worker, Rosa Maione, pleaded guilty to manslaughter just five days ago.

As someone who studies the deaths in care of thousands of disabled persons, I submit that Ann Marie's death had components of the types of violence often experienced by disabled persons, elders and women who experience violence – but the manner of her death was not typical. I am happy to provide extraneous material about this and would strongly suggest that you speak independently to the investigating detectives from the South Australian police.

This is important, because developing legislation which will address issues for a large population of Australians should encompass the usual systemic issues that those Australians are subjected to, not the highly unusual circumstances of one victim. Developing laws to keep people safe should not be developed in isolation, a co-production process with people with disability and their families, nor by people with no experience in the area of violence, abuse and neglect. This is a serious issue that may result in serious adverse outcomes for disabled people, especially disabled women and girls and those who have extremely complex needs.

My belief is that the changes to the legislation are being made to facilitate other planned changes to systems that we may or may not know about, including payment systems and desired changes to the NDIS and other government systems. They are changes which will almost certainly impact on our rights, including potentially the right to freedom of movement, freedom of association and right to privacy.

They are changes which have serious potential to make us less safe.

⁵ <https://dhs.sa.gov.au/latest-news/safeguarding-taskforce/safeguarding-task-force-report-july-2020>

On Vulnerability

Ann Marie Smith's case is still with the police and public commentary may still compromise ongoing investigations.

But there are other areas that require addressing within the disability sector, including the release of public information regarding the role of statutory authorities in failing to keep Ann Marie Smith safe.

The proposed amendments to this legislation are seriously flawed and should not pass. They are premised on the idea that disabled people are inherently vulnerable, rather than marginalised.

This arises from the prevailing attitude that when a disabled person dies as the result of violence, neglect and abuse, the issue lies with the disabled person, rather than the perpetrator.

This attitude is brought about by four factors. They are;

- Ableism and societal attitudes which stereotype disabled people as weak or 'vulnerable' rather than marginalised;
- othering, and an inability to see a disabled person as a human with inherent rights rather than a care recipient, commodity or user of services;
- an inability to understand complex or 'non-traditional' forms of violence, abuse or neglect when it is presented in a disability context with co contributory factors; and
- the reluctance of funding bodies, service systems and aligned systems (including justice and police) to place blame squarely with the failure of responsibility by those charged with a person's care, especially given stereotypes around charitable attitudes and the perceived qualities of caregivers.

Disabled people are very rarely treated in the same way as traditional victims of crime. This is seen at all layers of safeguarding responses within disability service systems. The attribution of 'cause' (rather than 'blame') to a disabled victim's supposedly inherent 'vulnerability' means that the fault is placed with the disabled person in a way that implies victim blaming.

Nobody would suggest that women were more often victims of sexual violence because of their inherent biological attributes, nor men rapists because of theirs.

This attitude of assigning qualities of ‘vulnerability’ rather than ‘marginalisation’ means that any proposed solutions are inevitably centred on processes which often restrict or reduce the disabled persons’ rights or freedoms rather than around the perpetrators.

Violence, neglect and abuse against disabled people should not be regarded purely as the outcome of a transactional service agreement, or a breach of administrative duties and responses should be informed by best practice within trauma informed response systems.

The only consultation on this legislation, a privately commissioned exercise by Discourse Consulting, was carried out in April of this year. I was one of the stakeholders interviewed during this consultation.

The report was not publicly released but an interim report was provided to the Disability Royal Commission a few months ago in connection with this matter. In the interim report, it is clearly shown that the consultation reflected views which do not align with either the current approach by the agency or the approach proposed by these legislative amendments.

On the idea of ‘vulnerability’, the report provided⁶ the following commentary;

‘Stakeholders near unanimously prefer the language of risk to the concept of vulnerability.

Two long-time disability campaigners and advocates who live with disability and are NDIS participants had this to say about vulnerability:

“The term ‘vulnerable’ should not be used, but ‘at risk’ is preferable. For example, at greater or higher risk...”

Another experienced advocate added:

"Vulnerable? At risk is preferable terminology".

A person with lived experience of disability and CEO of a small service provider said:

“Vulnerable people is a term used in legislation to refer to disabled and elderly people. People who are disabled and not inherently vulnerable.”

A senior advocate said:

⁶ <https://disability.royalcommission.gov.au/system/files/exhibit/CTD.7200.0016.0388.pdf>

“The word vulnerable does have some difficulties as it can fall foul of the international treaty on the rights of people with disabilities.

We need to understand that some participants may need more support than others but that is a question of risk mitigation not an inherent fault in the person.”

An example of the issues can be shown within the NDIA’s current approach.

In May of this year, in response to direct questioning, NDIA CEO Martin Hoffman described the process that has been developed to keep NDIS participants safe.⁷

It is as follows;

‘Question 5

With reference to Recommendation 1 in the Robertson Review and Safeguarding Gap 1 in the Safeguarding Task Force Report:

(a) does the NDIA identify vulnerable participants?

(b) If the answer to 5 (a) is yes:

(i) What criteria are used to determine whether a NDIS participant is vulnerable?

(ii) When, and in what context, were the criteria established?

(iii) Does any assessment of vulnerability occur in person?

The identification of vulnerable participants has always been part of the NDIS planning process. The NDIS Quality and Safeguarding Framework (the Framework), as agreed by the former Disability Reform Council in December 2016, noted that participants will take part in a formal risk assessment during the plan development process. They will be asked a range of questions about their personal perceptions of their own safety, their informal safeguards and the level of assistance they need.

The NDIS Framework, like the NDIS, starts from a presumption that all people with disability have the capacity to make decisions and exercise choice and control. Strategies for reducing harm need to be weighed-up against the likelihood of harm occurring and its severity, and the impact this will have on choice and control.

⁷ <https://disability.royalcommission.gov.au/system/files/exhibit/STAT.0355.0001.0001.pdf>

The South Australian Safeguarding Task Force Report (SA Task Force Report) and the Robertson Review were released on 31 July 2020 and 4 September 2020 respectively. At the time, the NDIA's focus was appropriately on ensuring that participants could continue to access their essential disability supports during the COVID-19 pandemic, including participants who were considered to be vulnerable. As such, there was already a focus on ways to better or more proactively identify and safeguard vulnerable participants which aligns with the recommendations of the SA Task Force Report and the Robertson Review.

The NDIA also conducted its own review into the circumstances surrounding the death of Ms Smith.

The culmination of this work is discussed further at paragraphs 30 to 64 below. The responses should be read in the context of this work, not solely the Robertson Review or the SA Task Force Report.

The NDIA identifies, categorises and monitors vulnerable participants in several ways through a range of data sources and analysis. These include:

- (a) a risk streaming method;*
- (b) the Participant Risk Assessment Tool (PRAT), a copy of which is attached to this statement as Exhibit MH3-1 (CTD.8000.0013.0334);*
- (c) Customer Relationship Management (CRM) system risk alerts and profiles;*
- (d) Participant Dashboards;*
- (e) the Participant Critical Incident (PCI) Framework; 9*
- (f) the Complex Support Needs (CSN) Pathway; 10 and*
- (g) the Participant Check-In model.*

Risk streaming

The NDIA applies a risk streaming method for all participants as they enter and interact with the NDIS.

Streaming refers to the predicted level of assistance or support a participant may need to navigate the NDIS pathway. Streaming doesn't impact the level of reasonable and necessary supports a participant receives.

When a person meets access to the NDIS, an NDIA access delegate will make an initial streaming decision depending on the participant's individual circumstances. Participants may be streamed into one of four streams (General, Supported, Intensive, and Super Intensive).

The factors considered when determining a participant's stream are outlined in the 'Standard

Operating Procedure: Update Participant Streaming' (Standard Operating Procedure), and include (relevant to the question):

(a) Where a participant has very minimal/no known informal or community supports;

(b) Where a participant is currently in or will be moving into a shared supported accommodation;

and

(c) Where a participant has a history of abuse or neglect.

A copy of the Standard Operating Procedure is attached to this statement as Exhibit MH3-2 (CTD.8000.0013.0389). Based on how the participant is streamed, they will be provided with the appropriate level of support to engage in the development of their plan. Participants streamed 'general' and 'supported' are allocated to Local Area Coordinators (LACs), while participants who are streamed 'intensive' or 'super intensive' are allocated to an NDIA Planner, to begin the planning process.

Streaming can be updated at any time, and is reassessed during the plan monitoring and plan reviews processes, as well as when new information becomes available.

Some streaming factors may result in a referral to the CSN Pathway. This is for participants who may be streamed as 'complex'. A CSN Planner will decide whether a participant is streamed to the CSN Pathway. Further information about the CSN Pathway is discussed at paragraphs 51 to 53 below.

Participant Risk Assessment Tool

The PRAT is used to evaluate participant risk during a planning meeting (after streaming) and is completed with details of the vulnerabilities or risks relevant to a participant's current circumstances.

The PRAT identifies whether a participant is:

- (a) vulnerable to physical harm;*
- (b) vulnerable to mental harm;*
- (c) vulnerable to financial harm;*
- (d) vulnerable to undue influences;*
- (e) unsafe in the home;*
- (f) unsafe in the community; or*
- (g) vulnerable to exploitation.*

The PRAT also requires a planner or LAC to confirm whether the participant has a reliable support network (for example, friends or family), and whether the participant is able to advocate for themselves or requires someone to advocate on their behalf.

The PRAT is designed to alert a planner or LAC if there was anything previously identified through the streaming activity that could be considered a vulnerability (i.e. the participant was involved in the justice system, child protective services, and/or has a history of abuse/neglect).

The planner or LAC must record details of safeguards that need to be considered for the participant where risks are identified while completing the PRAT. The 'Practice Guide - Safeguarding the participant's interests' (Practice Guide), provides guidance to planners and LACs about how to safeguard a participant's interests on a day to day basis as they engage and connect with the NDIS.

The Practice Guide considers safeguards and risk identification at all stages of the NDIS pathway, from access to plan implementation and monitoring.

Customer Relationship Management system risk alerts and profiles

The NDIA's CRM system has an 'alert' functionality that allows the NDIA to record an alert against a participant's record. Each time a participant's record is accessed in CRM, the alert will be made visible to the relevant NDIA staff member or LAC via a pop-up screen or a tool bar. The alert signals to the NDIA staff member or LAC that there is important information, including risk factors, relating to the participant which must be acknowledged before the record can be viewed.

Alert data comprises a high-level alert category, a detailed alert type, start and end dates, and a 'free text' information field which is used to capture specifics of the alert. There are a number of different alert categories in the CRM system, including:

- (a) 'Home Visits Only';*
- (b) 'Interpreter required';*
- (c) 'Participant to attend office';*
- (d) 'Contact preferences'; and*
- (e) 'Priority access request'.*

43 The CRM also has the capability for NDIA staff and LACs to input free text to allow for more detailed/personalised alerts. The free text alerts provide NDIA staff and LACs with the ability to provide individualised information regarding a participant's vulnerability and individual situation or circumstance.

As part of the business improvement work underpinning the NDIA's new CRM system, the NDIA will use data and intelligence to create 'risk profiles' in the background of the system. These risk profiles will identify vulnerabilities and risks for individual participants and guide an NDIA staff member or LAC with the appropriate action to effectively discuss and document the mitigation approach to manage these risks.

In 2020, a CRM enhancement was made to provide an 'errors and alerts' indicator which is permanently visible on the tool bar at the bottom of the display for a participant's record. This indicator enables NDIA staff and LACs to identify if any errors and alerts apply to a participant's record irrespective of the method of access.

Participant Dashboards

A Participant Dashboard (Mydashboard) is available to NDIA staff and LACs through PANDA Live (PANDA Live is a real time reporting view which provides visibility of participant information from CRM) which is an internal view of participant information drawn from CRM data. This dashboard identifies some risk factors and alerts and raises their profile to staff involved in managing the case such as LACs, Planners and National Contact Centre staff.

The MyDashboard is designed to include follow-up activities, including some which are generated in response to risk factors (such as when

funding in a participant's plan is under/over-utilised), for prioritisation and response.

The NDIA is continuing to explore opportunities to better target the risk monitoring and use of PANDA Live to trigger frontline activity. PANDA Live currently includes reports on safety risks and considerations, participant check-in monitoring, and implementation of plans to monitor participants' access to supports. Where applicable, the logic defining these risks is continuously monitored and improved.

Participant Critical Incident Framework

The PCI Framework establishes the process for NDIA staff and partners to effectively and consistently manage participant critical incidents, including:

- (a) unexplained death of a participant that occurs in connection with the provision of NDIS supports or services;*
- (b) serious injury of a participant;*
- (c) abuse or neglect of a participant;*
- (d) unlawful sexual or physical contact with, or assault of, a participant;*
- (e) sexual misconduct committed against, or in the presence of, a participant, including grooming of the participant for sexual activity;*
- (f) unauthorised use of a restrictive practice in relation to a participant;*
and
- (g) a participant threatening or attempting self-harm.*

The PCI Framework sets out NDIA staff and partner responsibilities when receiving notification of an alleged participant critical incident, which may include:

- (a) reporting to responsible state authorities, where incident circumstances indicates disclosure may be necessary to prevent or lessen a serious threat to an individual's life, health or safety;*
- (b) notifying the NDIS Quality and Safeguards Commission (NDIS Commission) for further involvement; and*
- (c) considering any implications for a participant's NDIS plan (having regard to the scope of the NDIS legislation and the obligations of other service systems as agreed by governments).*

Complex Support Needs Pathway

The CSN Pathway provides specialised support for participants who require additional support to engage with the NDIS. The CSN Pathway has dedicated planning teams and a network of skilled planners with experience working with specific complex support cohorts.

NDIS Act, s 60(2)(e).

The relevant situational factors or criteria that lead to referral to the CSN Pathway include:

- (a) voluntary or involuntary involvement in other government service systems, in particular health, child protection, guardianship orders, mental health and justice;*
- (b) transitional supports for returning to the community (for example, leaving hospital or incarceration);*
- (c) an immediate unmet need for targeted support or a crisis situation due to a sudden unexpected change in the participant's circumstances;*
- (d) extraordinary challenges concerning market or services;*
- (e) insufficient formal (for example, advocate, guardian, nominee) and informal (for example, family member, carer, friend support) support to assist with decision making or engaging in planning.*

This includes in the context of informal supports;

- (f) minimal or no informal supports resulting in service and support related risks;*
- (g) multiple family members with disability or a parent/carer with disability;*
- (h) at risk of entering residential aged care;*
- (i) homelessness; and*
- (j) child in voluntary or statutory out of home care, or at risk of requiring accommodation outside the family home.*

The relevant personal factors or criteria leading to referral to CSN Pathway include:

- (a) identified behaviours of concern and/or regulated restrictive practice;*
- (b) deterioration in behaviour/creating a risk to self and others;*

- (c) hard to reach/difficulty engaging (including a significant psychological disability or someone who is itinerant);*
- (d) multiple diagnosis;*
- (e) clinical complexity of disability;*
- (f) a history of trauma or abuse having a significant current impact; and*
- (g) limited or no expressive communication.*

Participant Check-In model

I described aspects of the Vulnerable Participant Outreach Contact (VPOC) Program in a statement provided to the Royal Commission and dated 25 September 2020 (STAT.0173.0001.0001).

From March 2020, the NDIA made a number of changes to ensure participants could continue to access services and supports during the COVID-19 pandemic. Both NDIA staff and partners in the Community (which includes LACs) contacted more than 70,000 vulnerable participants across all states and territories, to check-in with them during this uncertain time.

The NDIA criteria used to determine whether an NDIS participant is 'vulnerable' during the COVID-19 pandemic, including vulnerable to the virus itself or particularly vulnerable should their services be discontinued or disrupted, include:

- (a) living alone;*
- (b) receiving high levels of 'core daily activities' supports (e.g. assistance with self-care activities during the day or evening);*
- (c) single service provider;*
- (d) streamed 'super-intensive' or already in the CSN Pathway;*
- (e) receiving Disability Related Health Supports (including community nursing, assistive technology for personal care/safety, and diet management);*
- (f) receiving behavioural supports;*
- (g) over 55 years;*
- (h) in remote Indigenous communities;*
- (i) due for a scheduled plan review within the next three months; and*

(j) living in vulnerable housing (i.e. hostels).

These criteria are now being considered by the NDIA and the NDIS Commission and have been refined based on outcomes from the VPOC and findings from the Robertson Review and SA Task Force Report. The NDIA continues to work with the NDIS Commission and the Department of Social Services (DSS), together with state and territories, in formulating a definition of vulnerability as it relates to both proactive responses and reactive response to incidents and events impacting on people with a disability across multiple service systems.

From August 2020, the NDIA expanded the VPOC (referred to now as the 'Participant Check-In model') by delivering ongoing check-ins with participants, beginning with those considered vulnerable or at risk. This occurs outside of a participant's regular plan review cycle and forms part of the broader planning process.

An important feature of the ongoing check-ins is to support participants' welfare, and ensure they understand how to use their NDIS plan to meet their goals. The purpose is to reassure participants that they are well supported and connected with the NDIA, and that the NDIA and partners are responsive to their needs. It also aims to help the NDIA identify any risk or potential safety concerns for the participant.

Under the NDIS, people with disability are presumed to have capacity to make decisions that affect their own lives. Participants' choice is a pillar of the NDIS, including the choice for their preferred method of planning (face-to-face, phone or virtual). However, where a 'home visit only' or 'participant to attend office' flag exists on a participant's record in CRM, planners and LACs are expected to meet face-to-face with the participant and their representatives.

Regardless of the channel of communication, NDIA staff reconsider a participant's streaming and complete the participant risk assessment at each planning conversation (for new plans and plan reviews) and use guidance about safeguarding a participant's interests to make appropriate referrals, discuss strategies to reduce risk or to escalate as appropriate.

The 'Conversation Style Guide' sets out that staff should always try to speak with the participant directly if there is a nominee or family member who is also part of the conversation. Staff will ensure a participant's nominee/representative relays questions and clearly provides unfiltered

responses from the participant. A copy of the Conversation Style Guide is attached to this statement as Exhibit MH3-3 (CTD.8000.0013.0316).

The NDIA assesses vulnerability in the context of planning conversations, either in person or over the phone.

During planning conversations, planners or LACs gather detailed information about a participant's situation, including mainstream, informal and community supports and the impact of their disability on their daily life.

As part of these conversations, planners or LACs complete risk assessments that enable them to identify risks and safeguards in participants' lives. From these conversations, they gather information to determine any risks associated with the participants and their support networks. They also identify strategies to mitigate risks to the participants and build their capacity to choose and manage the supports in their plans.'

You can read the rest of his submission [here](#).

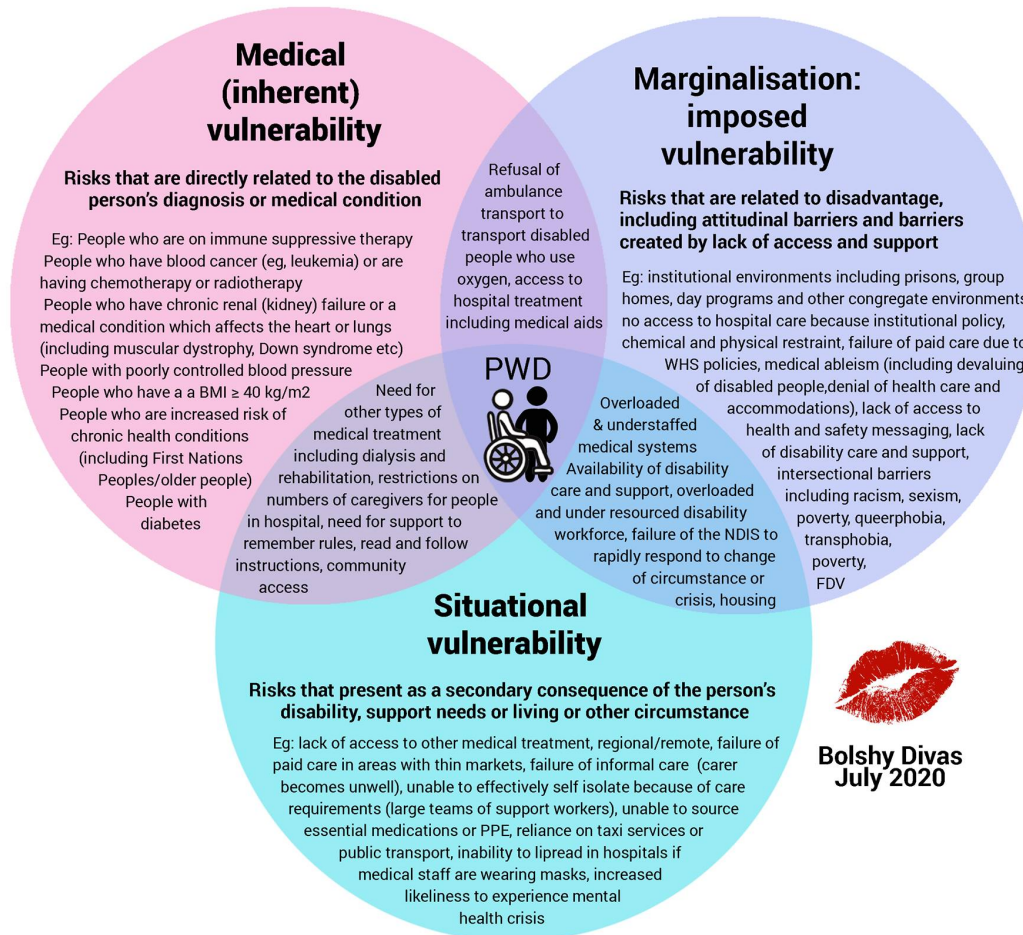
In our community, participants report that these measures are either not implemented, do not work, are inconsistently applied or are not trauma informed. The majority of disabled people believe that there is no consistent or coordinated approach to safeguarding. The above measures are *not in line with any form of evidence based decision making tools currently used in the prevention of violence*, especially in gender based spaces, but are administrative risk management tools designed to mitigate risk for bureaucrats rather than eliminate harm for disabled people.

The process outlined above for Ann Marie Smith, who was transferred over from the old SA state system, in all likelihood never met with a member of the NDIA nor an LAC and who was segregated and isolated by her abusers in the same manner that most perpetrators control their victims, would not have worked.

What would have worked is ensuring that her rights were upheld – that she had real choice in her life, including choices about who supported her – that she was treated as a woman experiencing abuse in the home rather than an inherently vulnerable 'participant' in a transactional arrangement between funder and provider.

The difference between vulnerability and marginalisation, using the COVID environment, is illustrated within this framework.

A Better Framework for Thinking About Risk, Disabled People and COVID-19



If you use the same framework to consider the issues surrounding Ann Marie's death, her medical (inherent) vulnerability was her inability to independently mobilise because of cerebral palsy and a mild intellectual disability which may have caused her to rely on others for more support. This would generally have been mitigated by the provision of adequate support. The imposed and situational factors were far more pertinent to her death. I suggest these factors are considered within the context of a discussion with the South Australian police and after ascertaining the current status of the investigation.

Some of the factors which should be considered as situational or imposed vulnerabilities in a scenario like this might include the following examples;

Situational	Imposed
<p>Lack of access to built environments including churches, community centres, clubs and other community facilities as well as neighbourhood homes</p> <p>Aging parents and carers who are easily targeted, ‘attitudes of compliance’ experienced by disabled people as a result of care systems, a lack of exposure to business practices and safeguarding measures</p> <p>No regular access to doctors, dentists or allied health professionals because of access or other barriers</p>	<p>Ableism – reluctance of non-disabled people to become friends or have much contact with disabled people, especially if they have an intellectual disability</p> <p>Targeted abuse and exploitation via the grooming of wealthy parents or caregivers (or directly to a person with a disability)</p> <p>Not enough support or inadequate safeguarding via the NDIS or other funding systems</p>

Disabled people should never be considered a ‘risk’, just as women should not be considered a risk when developing responses to violence, neglect and abuse.

There needs to be a balance between the idea of ‘risk’ and the implementation of it, including ensuring that we are not subjected to punitive measures as a result of our disabilities and ensuring that providers are not hamstrung by administrative burdens.

Here is an example of how this has already recently gone wrong. It is from a fitness company who has published their risk management matrix on their website.

‘In November 2020 the NDIS Commission introduced requirements for providers of Assistance with Daily Personal Activities supports including: enhanced participant risk assessments; regular communication with

participants; face-to-face in-person monitoring, and; supervision of support workers. This document is an effective way to:

- map identified participant risks to establish appropriate monitoring programs,
- clearly organise information to support participant understanding,
- attach all required data to the Service Agreement and ensure compliance,
- manage monitoring and supervision tasks and generate evidence of compliance.

This document is designed to ensure compliance with the NDIS Commission's objectives and requirements:

The NDIS Commission recognises that any NDIS participant who is provided with personal support in their own home may experience a level of risk if those supports are provided by the same individual NDIS worker for any extended period of time. This risk is likely to be greater where the NDIS participant lives alone.

The NDIS Commission wishes to be satisfied that NDIS providers are ensuring that the provision of personal support to NDIS participants who live alone and are supported by the one individual worker have worked with the participant to assess any risks to them, have established appropriate arrangements for monitoring the quality of those supports and to monitor the participant's satisfaction with them.

The new condition concerns the delivery of personal supports to participants who live alone only. It is designed to ensure that participants choosing to be supported by a single individual NDIS worker can continue to exercise that choice.'

Bear in mind that this is a fitness service and this has been introduced prior to any change in legislation. Presumably, a legislative change is not required – or this would not be compliant with the legislation and should not have been introduced by the Commission.

It goes on to say this;

'ON-SITE MONITORING: The NDIS requires that a procedure is in place to monitor the implementation of the Service Agreement (including this risk assessment and monitoring plan). The NDIS does specify the kind of procedure but says it "must include someone other than the support

worker checking directly with the participant.” They must visit the participant in their home to, with appropriate frequency, and determine “the participant’s level of satisfaction with the type, quality and frequency of personal support being provided.” We assume that the ‘someone other’ should have appropriate qualifications or experience.’⁸

As disabled people, we do not want John from the gym casually dropping in to ‘supervise’ us. This would actively make many disabled people less safe.

John from the gym is also apparently going to assess whether our peers are ‘anti-social’, ask us if we lose our handbags a lot, determine if we are socially isolated or brush our teeth enough, work out if we are nice to our cats and then determine our supports on this basis.

Ms Taylor talked about the introduction of this ‘compliance activity’ – that is, the requirement for some providers to introduce this risk matrix and additional measures - on Monday. The transcript reads as follows;

‘I’m happy to go to that. Discourse Consulting was engaged by the commission in the earlier part of this year to undertake a consultation around Mr Robertson’s second recommendation. He, in that recommendation, talked about how, to use his term, no vulnerable NDIS participant should have a sole carer, and that, in removing that option for people with disability, the relevant statutory instrument should be amended to provide for that.

Last year, from May through to October, the commission started an extensive compliance activity to understand the extent of the types of arrangements that were in place that were similar to Ms Smith’s arrangements, and to assess providers’ compliance with standards around the management of risk to people who were living at home alone, their oversight of any arrangements where the number of workers supporting a person was limited, their supervision of those workers and other matters.

The upshot of that compliance activity was to implement a new condition for 2,500 providers delivering personal care to people with disability in their own homes. That condition is available on our website. It requires a number of things of providers. It also goes to assist providers in understanding the types of risks that might present themselves for

⁸ <https://www.definefitness.com.au/wp-content/uploads/2020/11/Participant-Risk-Assessment-Revised.pdf>

people who are living at home alone and make them more vulnerable to harm than others, such as reliance on equipment to communicate, equipment for mobility and limited other social networks.’

This serves to illustrate the integrity gap between the actions of government – even if they are well intended – and the way that policy is implemented. I know what this process looks like, because I was one of the people who was consulted by John Della Bosca from Discourse Consulting. John did not suggest to me that this could be an outcome from that consultation – nor did I know that this would inform legislation. It was just a consultation from the NDIS Quality and Safeguarding Commission, asking broad questions about a range of topics.

I would have objected fiercely to these measures, because they are based on an incorrect premise – that providers will keep us safe and that additional regulatory measures that impact on our choice and control and fail to help uphold our will and preference will be a positive measure that will protect us from harm.

On the contrary, it has the direct potential to act in exactly the opposite way. It has the potential to cause enormous harm to individual participants, to remove their rights to support and limit us even more when accessing life opportunities.

The policy response from that fitness service, a small gym in Canberra, demonstrates it well. It is a business that is clearly trying their best to comply with an onerous regulatory burden imposed by a government body. What is being missed here is that in the case of the death of Ann Marie Smith, she would not have been at the gym in the first place. Abusers segregate and isolate their victims, which is what happened to Ann Marie.

And ironically, the people who would have been required to fill out this form would be Integrity Care, who subcontracted their staff, who didn’t ever require them to have police clearances and who in all likelihood made her less safe. <https://www.definefitness.com.au/wp-content/uploads/2020/11/Participant-Risk-Assessment-Revised.pdf>

What keeps us safe is having our rights upheld and having the same choices and opportunities as any other Australian.

The Alan Robertson Review Recommendations

On this set of recommendations, I have a number of comments to make.

Recommendation (1)

The Commission should act to identify earlier those people with disability who are vulnerable to harm or neglect. Every stage of decision-making, including corrective regulation, should be alive to factors indicating that a participant may be vulnerable to harm or neglect. (Although not within my terms of reference, the NDIA should also so act in the planning process and continually.) The Commission and the NDIA should have a freer and two-way flow of information for this purpose.

This approach cuts a person with a disability entirely out of the process and is entirely subjective. The 'tools', including the PRAT, cited by Martin Hoffman are not evidence based tools which are used in contemporary practice and have the potential to cause harm, as well as overlook real risks to participants.

Identifying participants as 'vulnerable' will depend entirely on the context (for example, COVID) and machine learning cannot be applied to this. Participants should have the opportunity to identify their own risks and requirements at the point of pre planning and should be given additional support to escape violence, neglect or abuse.

(2) No vulnerable NDIS participant should have a sole carer providing services in the participant's own home. The relevant statutory instruments and guidelines should be amended to provide expressly for this.

This will depend on the participant, their region, a number of other variables. For example, what if this is an Aboriginal person in a region where only one interpreter is available? If there are risks that are inherent here, then the person should be given the opportunity to mitigate them. A change of legislation is not required to do this.

(3) For each vulnerable NDIS participant, there should be a specific person with overall responsibility for that participant's safety and wellbeing. That individual should be clearly identified by name and, ideally, introduced in person, to the vulnerable NDIS participant.

(Although not within my terms of reference, that individual should be identified in a participant's plan.)

This is paternalistic and undesirable for many disabled person. The idea of a case management approach was initially floated and in response, support coordination was developed (as well as specialist support coordination). Although the CEO of the NDIA says that 25% of participants have CoS, he does not indicate how many of those participants are happy with that level of coordination, nor how it is carried out. The response to independent assessments should give the Committee some idea about how disabled people regard the idea of having paid government friends coming into their homes.

(4) Consideration should be given to the Commission establishing its own equivalent to State and Territory based Community Visitor Schemes to provide for individual face-to-face contact with vulnerable NDIS participants. Such contact is also important in emphasising the personal values necessarily involved in providing services to individuals with disability. The NDIS Act should be amended to provide explicitly for this function. Until that happens, the Commission should continue to support the State and Territory Community Visitor Schemes and any doubt about State and Territory powers under those schemes in relation to NDIS participants should be resolved between the law officers of the Commonwealth and of these States and Territories. The State and Territory Community Visitor Schemes will of course continue to apply directly in relation to those with disability who are not NDIS participants.

There are Official Visitors, Community Visitors and other mechanisms which vary from state to state. There has til now been no work to implement any of the various recommendations around this. Visitor Schemes should be opt in for people living outside institutional settings and provisions should be made for unannounced visits for institutional settings.

(5) Because of the inherent limitations in record based systems in preventing harm or the risk of harm to vulnerable participants, the Commission should conduct occasional visits to assess the safety and wellbeing of selected individual NDIS participants, whether or not a complaint has been made or a "reportable incident" notified. The Commission should miss no opportunity for face-to-face

assessment of vulnerable participants. (Although not within my terms of reference the NDIA should also so act.) The Commission and the NDIA should have a freer and twoway flow of information for this purpose so that the NDIS Commission's selection of participants to visit is an informed one.

This is of concern and the proposed response in the amendment is the same. It is also of concern that Mr Robertson is making recommendations outside the ToR. There is nothing to say that the persons doing this assessment would be qualified to do so, especially in a trauma informed way. There are also significant concerns about information sharing for those who are at risk of being abused.

(6) The statutory definition of "reportable incident" in s 73Z of the NDIS Act should be amended to make it clear that it includes a real or immediate threat of one of the listed types of harm. The word "complaints" in s 73X of the NDIS Act should be defined to remove any doubt that it includes concerns and observations in relation to the provision of supports or services by NDIS providers.

The amendment does not reflect this recommendation and it is unclear why the term 'serious threat' is being removed, as well as using past and future threats. I hold concerns that this will be used to obtain information about a participant using the cover of COVID. Our information should be subject to real protections and there is potential to breach our data privacy during the pandemic. There should be additional scrutiny and oversight mechanisms put in place to ensure there are no further data and privacy breaches for Australian citizens, but especially those who have more data collected against their lives and who are potentially easily exploited. This could easily be done on a Federal level in the same way that [Victoria](#) is managing COVID legislative changes at present.

(7) The Commission must at all times be able to know whether a person is or is not an NDIS participant. The Commission should also have readily available access to information held by the NDIA concerning what supports a participant is receiving and the provider of such supports. The Commission should not depend on providers to provide it with such information only after a request.

This is relatively uncontroversial if the Commission is using it for the purposes of protection rather than information gathering.

(8) There should continue to be improvements to the exchange of information and more formal lines of communication between those running the State and Territory emergency services (including police) and schemes for people with disability and the Commonwealth agencies, being the Commission and the NDIA, and vice versa.

There are concerns about the use of information if data matching is undertaken. For example, we understand that the Federal Government intends to attempt to introduce Cashless Debit Cards for all people who receive income support. If there is data matching carried out between State and Federal authorities, including having access to our payment information, employment and education status, health and justice information (as is intended) there is vast potential for misuse.

For example, a disabled woman who has been abused by her partner may have her identity revealed despite protective status – punitive measures may potentially be introduced on the basis of a person’s health status or addiction status.

The concern here is not just that punitive laws are introduced, but that a subclass of citizens will be further reinforced by the introduction of these laws. Social control is a real concern. There is also the potential for decision makers assigning funding to make moral and character judgements based on additional information about a person’s life or lifestyle – this is already an issue and these biases can be hardwired into algorithmic responses.

(9) To this end, s 67A(1)(e) of the Act should be amended so that the word “serious” is deleted. A threat to an individual’s life, health or safety should be enough to authorise the use of the protected Commission information. Also the word “necessary” should be replaced with a word such as “needed” so that the information may be used even if it is not essential to preventing or lessening a threat to an individual’s life, health or safety. Consideration should also be given to defining the word “threat” in the expression “prevent or lessen a threat” so that it includes preventing or lessening for the future a threat which has passed.

There does not appear to be a harmonised definition around the use of the term serious, and different states have different legislative terminology around this within their own jurisdictions. This requires

serious consideration and consultation within our sector, as (as mentioned above) a 'past threat' may be someone who had experienced domestic violence, a person who had been exposed to COVID, a number of things which could be considered 'serious' but which would ordinarily for an individual citizen remain private.

(Corresponding amendments should be made to, or considered for, s 60(2) (e) for protected NDIA information.)

This is of concern. The reason this is in place is to protect women who have experienced violence and those whose partners or others may work within the NDIA and should not be given access to this information.

(10) The Commissioner should have statutory power to ban a person from working in the disability sector even where that person is no longer so employed or engaged.

This aspect is the subject of the National Disability Insurance Scheme Amendment (Strengthening Banning Orders) Bill 2020 currently before the Commonwealth Parliament. The Commissioner should have the same power in relation to NDIS service providers, that is, to include as subject to the power to ban those entities no longer providing those services.

This is in my opinion uncontroversial. It should extend across jurisdictions like health and mental health and should include an interface which enables government funding contracts to be canceled if a provider is found guilty of serious harm.

If there were real penalties introduced in the same way we have with WorkSafe, that a provider's management were fined 600,000 or went to jail for five years when someone died or was sexually abused because of a breach of duty of care, we would see real change be driven in the sector.

The Proposed Amendments and Consultation

Regarding the legislation, the following should be noted.

That initially, government planned to pass these amendments, which will significantly impact upon the rights and freedoms that are currently held by disabled people, within an hour and with no consultation. This is unacceptable.

There is a very low number of submissions to this process, especially by individuals. This is due primarily to the complexity of the issue and the inaccessible way that it has been presented to the public, without a discussion or issues paper, without a lengthy consultation period and without support for disabled people to be able to engage with this process, let alone understand complicated legislation. This is unacceptable.

The Robertson Review is cited as the sole rationale for changing the Act and the proposed amendments will have serious repercussions for participants. To carry this out without any lengthy and widespread consultation is unacceptable. This has caused disabled people further stress, during a pandemic, at a time when our community should be supported.

I support the calls from the rest of the sector to halt this process and further call for a process to be introduced for legislation which will potentially negatively impact disabled people and communities of disadvantaged people who may be adversely affected by a legislative change.

This should include;

- A clear and accessible process which includes accessible language (plain and easy English as well as issues papers if required)
- A lengthy consultation process which includes key decision makers, peak bodies and which allows sufficient details to allow for informed feedback
- A 'rights based lens' developed to ensure legislative changes are scrutinised for impact upon the rights and freedoms of people who will be affected by the legislative change – in this case, the CRPD

- Tiered decision making which give weight to the feedback of the affected community members – it is not good enough that time after time, community feedback is that there will be serious harm caused by a measure that is introduced into legislation, then the feedback is ignored, and it costs years, time, and money in reversing that poor decision making
- An active co production process with affected communities for all statutory bodies who are introducing new measures which will significantly impact a community

As previously stated, I do not believe these amendments will significantly protect any disabled person from harm. That is with the exclusion of information sharing from the Agency to the Commission – I believe the Commission should be able to access the NDIA's information and treat it in the same way they would any other private information. I do not see this as being something that is unusual between two statutory bodies who are working in the same space.

I further believe that the Committee should be provided with details of the internal investigation into Ann Marie Smith's death, as referred to by Martin Hoffman at the Disability Royal Commission, to investigate the circumstances more fully. I believe Ms Maione has pleaded guilty now and there should be no barriers to doing so.

The Alan Robertson review was carried out the month after her death, was not allowed to investigate the circumstances of her death because of the potential of prejudicing a police investigation – the same applies to the SA Task Force. Both reports were delivered mid to late last year, just a few months after Ann Marie died and without any detail being released other than in newspapers. It makes no sense to develop policy responses built on a series of recommendations loosely developed around the unusual death of one individual.

As one of the NDIS participants who was consulted by Discourse Consulting, I was not provided with a copy of the report, nor given any indication that there would be a change in legislation, nor that my views were being given about that matter. My views did not differ from those given in this paper. I find it difficult to believe that the reason for this sudden legislative change is anything to do with safeguarding or Ann Marie Smith.

The way we are kept safe is when our rights are upheld and respected, when our will and preference is upheld, when people are looking out for our interests, not their own, work with us to develop comprehensive strategies to help keep us safe. We are not kept safe by being wrapped in cotton wool, nor by patriarchal, paternalistic models of care.

We fought for an NDIS that would help us get what we want to be who we are. That includes the right to live in safety without fear of abuse.

Samantha Connor
5th August, 2021