



Royal Commission
into Violence, Abuse, Neglect and Exploitation
of People with Disability

Research Report

Something Stronger:
Truth-telling on hurt and
loss, strength and healing,
from First Nations people
with disability

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October 2020

Aboriginal and Torres Strait Islander readers are advised that this research paper may contain the voices of people who may have passed away.

Aboriginal and Torres Strait Islander people are further cautioned that this research contains personal testimony and content that some people may find distressing.

Acknowledgements

The author of this research paper acknowledges the contribution of the Aboriginal and Torres Strait Islander people who participated in the research and thank them for providing their stories and insights. I pay respect to their Elders past, present, and emerging, and of the lands where they are from.

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The author wishes to acknowledge the representatives of the Royal Commission on the Violence, Abuse, Neglect, and Exploitation of People with Disability (herein referred to as the 'Royal Commission') for the opportunity to undertake this research, and their respectful engagement with the researchers during the course of this project.

This report was written on the lands of the Dharawal people and Gadigal people of the Eora Nation.

Terminology used in this report

'First Nations people'

The term 'First Nations people' has been chosen to denote Aboriginal and Torres Strait Islander people to align with the preferred terminology that is used by the Royal Commission. There are nonetheless occasions when other research and organisations are cited using the term 'Aboriginal and Torres Strait Islander people', and is used interchangeably with 'First Nations people' to refer to the same group of people. There are also instances where people interviewed identified themselves as either 'Aboriginal' or 'Torres Strait Islander', and their personal choices have been respected. It should also be noted that the identifier 'First Peoples' is the preferred

terminology of the First Peoples Disability Network (Australia) who have supported this research.

Person-first language (i.e. 'People with disability')

This report has chosen to adopt person-first language when referring to 'people with disability'. This terminology aligns with the cultures and values of First Nations people that are inclusive of people with disability^{1 2 3} and avoids diagnostic labels of disability which can be stigmatising and non-inclusive.

The adoption of person-first language contrasts other research from the First Nations autistic community⁴ that adopts identity-first, such as 'autistic person', which is preferred and less stigmatising within that community. The preferences of the First Nations autistic community in relation to their research are noted and respected.

About the title "Something Stronger"

The phrase "*Something Stronger*" used in the title of this research paper is drawn from the testimony of an Aboriginal man living in a remote part of Australia. His was a story of profound trauma, discrimination and grief, both for him and his community. Reflecting on the sadness that surrounded him and the people around him, he then said: "*there is something stronger in here*", pointing to his heart, "*I've just got to get there*".

The purpose of drawing the title directly from the personal testimony of those First Nations people with disability who shared their story is to link them as the cultural owners of their stories. The phrase "*Something stronger*" resonates as a theme throughout this research paper as despite the traumas they have encountered in their life, First Nations people with disability still carry faint embers of hope and a knowledge that there is a strength in their cultures that they can draw upon.

Disclosure

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The information and any opinions contained in this research were developed independently by the researcher, and not intended to be a statement of the Royal Commission, nor reflect the views held by them or any other Australian government department.

For citation

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Executive summary

About the research paper

This research paper on the discourses of First Nation people with disability was commissioned by the Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability.

The purpose of this research paper is to support engagement with the First Nations disability community that is considerate of their cultural values and beliefs on disability and inclusion, and acknowledges the unique traumas arising from their experiences of social isolation, inequality and discrimination.

This research paper builds upon a comprehensive program of research that was led from within the First Peoples Disability Network, a non-government community organisation established by and for Aboriginal and Torres Strait Islander people with disability. The research program sourced the testimonies of 47 Aboriginal and Torres Strait Islander people with disability which have been used as the data source for this research paper. The community-based principles and findings from this research program have been published as *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*⁵.

This research paper focuses on testimonies that disclosed incidents of violence from within the narrative database that was produced by the research program and contains new content and analysis that has not been previously published.

Research questions

This paper addresses two research questions:

Question 1: How do First Peoples with disability speak about their encounters of violence, abuse, neglect, and exploitation; firstly in direct terms (i.e. In describing the events that they were exposed to), and secondly in relation to the surrounding personal and vicarious traumas that are a legacy of their experiences? and

Question 2: How do First Peoples with disability articulate their aspirations of empowerment, self-determination, inclusion and belonging; and how does this contrast with their description of their reality?

Structure

This research paper is organised into six chapters:

- Chapter one contains an overview of ethical considerations in addressing violence in research;
- Chapter 2 details the research brief, research question, scope and social context of the research;
- Chapter 3 outlines the method that was used to source testimonies from First Nations people with disability, and how testimonies that disclosed violence were identified and reviewed;
- Chapter 4 presents the findings and analysis to the first research question that explores how First Nations people with disability spoke of their encounters of violence;
- Chapter 5 presents the finding and analysis to the second question that explores how First Nations people with disability spoke about empowerment and self-determination; and
- Chapter 6 contains summary reflections.

Key themes in the narrative relating to violence affecting First Nations people with disability

On the ethics of talking about violence:

- There are some First Nations people who will not want to talk openly about their exposures to violence, as their experiences are too raw for them to revisit.
- Some First Nations people with disability will be prepared to speak to their experiences of violence if:
 - they can feel safe when they do so;
 - there is a sense of purpose to them telling their story, namely that they will be believed and what they say will matter.
- People who are secondary custodians to testimonies of violence have an ethical responsibility to respect the personal dignity of the person affected, whilst maintaining integrity to the 'truth-telling' that they have been trusted with.

The connection between personal violence and 'structural violence' (and not 'culture'):

- The encounters of violence described by people were not random or one-off incidents. Instead, people who referred to encounters of violence tended to describe being exposed to violence on multiple occasions.
- In some cases, people who had sustained violence were surrounded by others within their immediate community who had similar experiences, referred to as 'trauma clusters'⁶.
- There is a connection between personal violence and social isolation that generates through structural inequality and discrimination. First Nations people with disability encounter social inequality and multi-faceted discrimination at far greater rates compared to other groups in Australian

society⁷. The relentlessness of their social inequality across various aspects of their life harms their health and wellbeing, through what is alternately referred to as 'structural violence'⁸.

- 'Structural violence' also socially isolates First Nations people with disability from others in Australian society, effectively maneuvering individuals in to situations where they are more susceptible to personal violence.
- To reiterate, the social factors that manoeuvre people into situations of vulnerability where they are exposed to violence are structural and not cultural. Personal violence and structural violence against people with disability (see below) has no basis in First Nations culture and should not be conflated as such.

How were the experiences of violence is described by First Nations people with disability?

- The predominant way in which First Nations people spoke about their experiences of violence was in terms of a 'loss', or that someone or something is 'lost'. This focused more on the personal impact of violence, rather than describing what actually happened.
- When First Nations people with disability did describe specific incidents of violence, they most commonly did so in reference to being 'hit'.
- On occasions, other euphemisms were used to avoid talking directly about incidents, such as "my son was 'interfered with'".

How did First Nations people with disability speak about empowerment?

- First Nations people with disability did not speak using the language of 'empowerment', 'self-determination', or 'sovereignty'. No uses of these exact words were recorded.
- The most common narrative from First Nations people with disability who had experienced violence was a 'language of survival' that centred on getting themselves through the day.
- There were some fleeting instances where First Nations people with disability spoke of their aspirations for a more positive future, as reflected in the title of this report, "*Something stronger*".
- More obscured, and only coming with some prompting, some First Nations people with disability said that they wanted to use their experience to help others by giving 'voice' to their experience. Once people started down this path, they tended to grow confidence and returned to an empowering narrative in their testimony.

Summary reflections

- The statements of strength and hope embodied within “*something stronger*” that emerged from a place of entrenched disempowerment are a turning point in the narrative surrounding the violence that affects the First Nations disability community.
- Aspirations of giving ‘voice’ and empowering others are effectively statements of sovereignty and self-determination, even though that language was not explicitly used.
- Taken as a whole, the community narrative points to a progression from trauma to healing, with empowerment and the self-determination of a connected and inclusive First Nations disability community the end destination.

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1. 'Respect the story, respect the person who told it': Ethical pillars to support truth-telling by First Nations people with disability

1.1 *The raw trauma in testimonies of violence*

In a paper on the hurt and loss of First Nations people that has been caused through violence and abuse, it is fitting to give the floor first to someone who has experienced it first-hand.

This opening story is from an Aboriginal woman who lives in an Aboriginal community complex within an inland city. Geographically, the place where she lives is classified as a regional city but living on the outskirts of town gives it the characteristics of remoteness. The sense of isolation becomes stronger once the stories of trauma and discrimination start coming from her and other people living in her community. Each story adding to a foreboding invisible wall that separates their lives from others who live in their town.

Her story is one of immense pain, full of many personal tragedies that include the deaths of people close to her through violence and neglect. She says she doesn't talk to people about her trauma, she cries by herself. When she does decide to talk to people, it is only with people from Aboriginal organisations, as she sees them as more understanding. She specifically mentions that she "*doesn't talk to counsellors or mental health [people]*", because she doesn't want other people "*talking about her business*".

Out of respect for this implied wish, her personal traumas are not detailed any further here. However, that part of her testimony included above teaches important ethical principles on how to speak and write about violence and abuse experienced by First Nations people with disability, particularly when relaying secondary accounts of violence and abuse that are the experiences of others.

That there are First Nations people with disability people do not want others *“talking about our business”* explains some of the reticence that is shown around talking about violence and abuse. At the personal level, these experiences are too raw to talk about. They have also been abandoned at critical moments when they sought help and support, so there is an expectation that nothing will change, and putting words to their story will only remind them of their pain.

1.2 *“Our stories are powerful”*: Creating a space for truth-telling on violence

Despite the traumatising involved in talking about personal encounters of violence, there were First Nations people with disability who were prepared to tell their story within an environment in which they felt safe and could trust. As the Chapter x.x will later detail, a total 47 First Nations people with disability provided recorded testimony across 41 interviews on their experience of living with disability, of which 9 disclosed encounters of violence and traumatic events. These disclosures were captured using voluntary processes in which the participant could opt out at any point. There were some cases where people were active in wanting to tell their story, and in some cases, First Nations people with disability approached the researcher to tell their story, rather than the other way around. In some sites, people lined up in a queue to participate in a personal interview. There were also no issues from First Nations people with disability in gaining their permission to have their voice recorded, as if this was symbolic in having their story 'on the record'. From the same community as the Aboriginal woman who didn't want to talk to other people about her pain came this statement: *“Our stories are powerful”*.

Opening up a discussion on violence affecting First Nations people with disability raises a number of apparently conflicting positions. At the personal level, it is painful and re-traumatising, so there is an understandable avoidance to having to relive their experience over and over again. At the community level, there is an acknowledgement that truth-telling is needed to expose the structural influences on the incidence and impact of violence that otherwise remain unspoken of. There are other cases where witnesses to the suffering of others -caused through violence - are moved by that, but may not know how to act appropriately and ethically without causing further harm.

The message in the active participation First Nations people with disability in this research program is that there is a preparedness within their community to take on the confronting task of truth-telling on the topic of violence. However, there are conditions for their safety that those seeking to support and facilitate the truth-telling process must ethically adhere to. Specific observations on the engagement behaviours of First Nations people with disability to this research can guide what ethical stipulations will support the telling of their stories:

Ethical pillars for supporting and facilitating truth-telling from First Nations people with disability:

- (i) *Providing a safe space for people to tell their story also means allowing them not to tell their story if they do not wish to do so.*

Pressing people to tell their story risks re-traumatising them and can cause them harm.

- (ii) *If people do decide to share their experience of violence and trauma, they should not be required to tell it over and over again.*

The more times people are required to revisit their experience, the greater the chance they will experience trauma from it. This was one of the motivations for publishing the narratives in *Culture is Inclusion*, as it captured the testimonies from First Nations people with disability once and once only, and circumvented a need for them having to repeat their experiences in different forums.

- (iii) *People will be more likely to tell their experience of violence and trauma if they are confident that they will be believed, and not just heard.*

This requires an approach to interviewing that allows the person giving testimony on their terms and without judgement. Once there is a sufficient sample of personal testimonies, the patterns in the data will speak for

themselves, and the community narrative will validate the personal accounts of violence.

- (iv) *People will be more likely to tell their experience of violence and trauma if they believe it will matter for something.*

Specifically, they will be prepared to add their experience to the shared experience of others if they believe that collective experience will address the structural factors that contribute to their personal vulnerability.

However, there is an ethical dilemma in asking people who have experienced traumas to re-open their wounds, then having their stories ignored, as this may do more damage than not hearing them in the first place.

- (v) *People will be less likely to tell their experience of violence and trauma if they feel they will be further isolated or shunned.*

The courage to truth-telling is accompanied by a personal risk that they will be ignored, ostracised or even vilified for drawing attention to an issue that society in general doesn't know how to deal with. 'Strength based discourse', which is the prevailing fashion in Aboriginal and Torres Strait Islander policy discourses, poses a peculiar threat to truth-telling by people at the edges of society, as it erases those experiences that cannot be framed in a positive light, which in turn can amplify their sense of social isolation.

The impact of violence is of a magnitude that obligations are imposed upon second-hand witnesses to act with integrity to the other people's first-hand disclosures. The obligations cover secondary recipients of other peoples' testimonies to violence, such as researchers and policy-makers, must be constantly asking themselves "what do I have permission to tell and retell?" as guided by advice from First Nations disability community. These pillars that guide ethical conduct in the handling of testimonies of violence can be summarised as 'respect the story and respect the person who told it'.

These ethical parameters have been placed as a preface to the research content so that people who rely upon it are aware of the conditions of use by which First Nations people with disability gave their testimony. The remainder of this paper will present testimonial evidence and analysis for two research questions: first, how do First Nations people with disability speak and violence, abuse, neglect and exploitation; and secondly, how do First Nations people with disability articulate their aspirations of empowerment, self-determination, inclusion and belonging.

2. What is this research paper about?

2.1 *Background to the research brief*

This research paper on the discourses of First Nation people with disability was commissioned by the Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability. Established in April 2019, its terms of reference lists the “particular situation of Aboriginal and Torres Strait Islander people”⁹ as an item for special consideration for the inquiry, noting further the multifaceted experiences of violence that intersect, amongst other things, with age, gender, sexual orientation and intersex status.

There is an established body of research that looks into violence against First Nations people^{10 11} that is developing further in relation to violence against women and its resulting trauma^{12 13}. Whilst the broader body of research on violence affecting First Nations people is relevant in piecing together a range of factors that might affect people with disability within First Nation communities, the purpose of this paper is to elevate the issues that specifically affect First Nations people with disability. In that respect, there is little that has been currently published in the way of prior research and evidence that specifically focuses on violence as it affects the First Nations people with disability. A number of human rights advocacy organisations¹⁴ and academic researchers and scholars¹⁵ have acknowledged the need for a dedicated investigation of violence, abuse, neglect and exploitation on the issues and impact affecting First Nations people with disability. There was one Victorian based study that investigated how Aboriginal women and children with disabilities got their ‘voices’ heard in a service setting. Having undertaken interviews and focus groups with 60 Indigenous and mainstream service providers, their conclusion was:

“the reality often is that governments and service providers find Indigenous victims of violence with disabilities as a group ‘too hard to handle’”¹⁶

Otherwise, there has been a general lack of empirical research that has taken an intersectional approach¹⁷ to understanding the incidence and impact of violence affecting First Nations people with disability as marginalised groups intersecting two marginalised communities. As it stands, the issue of violence is a great unspoken area of research and social policy, and the First Nations disability community have been silenced because of it.

The absence of a prior research base presents a problem to the Royal Commission in initiating an engagement with First Nations people with disability around the violence that they have encountered. Sensitivities around the topic are high, and the goal is to avert retraumatising a community whose suffering has already been too great. The engagement approach needs to consider their cultural values and beliefs on disability and inclusion, as well as acknowledge their unique traumas that emerge once race-based and disability-based discrimination connect and manifest into violence. The purpose of this research paper is to be a precursor to what might be expected once First Nations come to the Royal Commission, so they can be afforded a safe environment in which to tell their story.

2.2 *Leveraging community-based research from the First Nations people with disability*

The testimonies from First Nations people with disability are drawn from a research program that was conceived and directed from within the First Peoples Disability community. Hosted by the First Peoples Disability Network, the aim of the research was to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability in research and policy to support advocacy for the human rights of the community. The findings of this research were initially published in the research monograph *Culture is Inclusion*¹⁸.

The study was an open-ended and comprehensive study on the experiences of First Nations people on their experiences of disability. The study allowed participants to share their personal story on their terms, and covered what barriers they face in their lives, what keeps them strong, and what matters to them in their future. Intended as

a comprehensive study across all social policy areas and issues, it was not designed to explicitly focus on experiences of violence. Nonetheless, participants could voluntarily disclose any issue that they chose to, and this flexibility generated ample testimony on their experiences of violence that were both personal and structural in nature. More obscured within the testimonies, as Chapter 6 will show, were expressions of empowerment and self-determination.

There are attributes in the philosophy and design of the research that align with what the Royal Commission is aiming to achieve. Firstly, the research program was inclusive of people who identified as being Aboriginal and Torres Strait Islander people with disability, taking an intersectional approach. Second, in keeping with the principle of promoting the voices of First Nations people with disability, it excluded the perspectives on their situation from intermediaries such as service providers, carers, or other people working in a professional capacity supporting people with disability. Third, it enabled First Nations people with disability to self-direct their testimony in which they could disclose as much or as little as they chose. Taken together, these principles aimed at creating an authentic program that was led and owned by the community.

The methodology of how the testimonies were sourced to produce a master database of narratives from First Nations people with disability are detailed further in Chapter 3, along with the methods used within this research paper to identify and analyse testimonies that relate specifically to accounts of violence.

2.3 *Research questions*

There are two questions that are addressed in this research paper:

Question 1: How do First Peoples with disability speak about their encounters of violence, abuse, neglect, and exploitation; firstly in direct terms (i.e. In describing the events that they were exposed to), and secondly in relation to the surrounding personal and vicarious traumas that are a legacy of their experiences?

The methods for locating testimonies referring to the encounters of violence within the master narrative database are described in Chapter 3.5. The findings for the first research question are presented in Chapter 6.

Question 2: How do First Peoples with disability articulate their aspirations of empowerment, self-determination, inclusion and belonging; and how does this contrast with their description of their reality?

Addressing this question required a review of all testimonies within the narrative database. The findings for the second research question are presented in Chapter 6.

2.4 *Connecting structural violence and personal violence in the scope*

The Terms of Reference for the Royal Commission to investigate violence, abuse, neglect and exploitation experienced by people with disability are broad and expansive. It is not the intent, to replicate the breath of inquiry within this research paper, nor was it possible to do so.

Defining the scope has meant some judgement on what aspects of violence, abuse neglect and exploitation were included for a more detailed analysis. *Culture is Inclusion* published findings that First Nations people with disability experience multi-faceted social inequality and discrimination related to both their race and disability, across all aspects of their lives, and interaction with social support systems. The pervasiveness of social inequality and discrimination produces a form of social isolation that dehumanises those who are affected, through what some writers have defined as 'structural violence'^{19 20}. The ongoing effects of colonisation are a factor²¹²², which dispossess First Nations people with disability from both Country and body²³. There is a direct connection between structural violence and exposure to personal violence. The structural disempowerment of being 'out of sight, out of mind' manoeuvres people into socially isolating situations where they become vulnerable to personal incidents of violence.

Whilst the impact of structural violence and colonisation must be acknowledged, the intent of this paper is to hear the voices of people directly affected by violence in their own words. Without seeking to diminish the impact of micro-aggressions that are encountered on a daily basis, this paper has focussed its scope on the serious incidents and events of violence that were disclosed by First Nations people with disability in their testimony.

Sourcing testimonies on violence through trauma informed interviewing

2.5 *A research program based in the First Nations disability community*

This chapter outlines the principles and research methods that were used to generate the narrative database of First Nations people with disability. It then outlined how testimonies that were specific to violence, abuse, neglect and exploitation were drawn from the narrative database, and the research approach to identify and present the key themes in the narrative.

The testimonies on violence, abuse, neglect and exploitation that informed this research paper were sourced from First Nations people with disability through a research program that was based in the First Nations disability community. This research program was hosted by the First Peoples Disability Network (Australia), a non-government disability organisation established and governed by First Nations people with disability acted as the host for the research program. Having the research led by a First Nations disability community organisation, and the research embedded in that organisation, was critical to forging a connection with members of the First Nations disability community who were interviewed as participants in the study.

The research program resulted in the publication of *Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander people with disability*²⁴. This research monograph contains a comprehensive narrative on the social inequalities and multi-faceted discrimination that First Nations people with disability experience, and contrastingly an Indigenous cultural value of inclusion and community participation of people with disability. Included within the narrative are some specific references to violence, abuse, neglect and exploitation²⁵ within the broader context of their life experiences. The details of violence within the testimony was redacted from *Culture is Inclusion*, due to the nature and intended tone of this publication, and concern over the inadvertent traumatising of Aboriginal and Torres Strait Islanders who read it. Whilst the risk of traumatising is still there in this research paper, the focus on violence is explicit and transparent in its title. Hence, references to violence and abuse are able to be expanded upon within this as a self-contained research paper,

with the inclusion of additional narrative content and analysis beyond what was previously published in *Culture is Inclusion*.

2.6 *Principles of trauma informed and participatory research methods*

Culture is Inclusion also detailed at length a community-based philosophy of research, and how principles and values that came from the First Nations disability community were operationalised as participatory research methods²⁶. The key principles relevant to this in-depth focus on violence and abuse are summarised as:

- A. The research drew upon established principles of grounded research methodologies²⁷. This was applied in the collection of testimonies by asking participants the overarching question “what is your story?”, then allowing the participant to guide their testimony to wherever they wanted.
- B. The research anticipated that the participants that were interviewed would likely to have been exposed to trauma and multi-faceted discrimination (i.e. racism and/or ableism) that could be either personal, structural, or both. Consequently, care was taken to establish a safe and supported place in which First Nations people with disability could share their story. Safety and distress protocols were established aimed at circumventing distress from escalating during the research processes.
- C. In acknowledging the cultural dimensions to disability and inclusion for First Nations people, the research incorporated Indigenous research methodologies, including an Indigenous narrative approach to ‘yarning’ as a research method^{28 29}.
- D. A vocabulary was created to convey technical research terms and concepts that the First Nations disability community found alienating into language that they would understand and engage with. As an example, the purposive sampling methodology^{30 31} used to recruit participants was described to the community as ‘rock up recruitment’³². This term described an approach the

researcher would 'rock up' to talk with First Nations people with disability on their terms and in their local community, once assent from the Elders and leaders in that community had been obtained.

These methods formed part of an encompassing philosophy of community-based research. The application of this philosophy across all aspects of the research elevated the voices of First Nations people with disability to the forefront.

2.7 *Composition of the narrative database*

The narrative data used for this research came from 41 interviews with 47 people who self-identified as being First Nations people and who live with disability. Interviews were conducted with participants in the Australian states of New South Wales, Northern Territory and South Australia. The interviews generated 21 ½ hours of audio testimony at an average of 31 minutes per interview. The audio interviews were later transcribed into text form.

Data was collected using a trauma-informed grounded research methodology which allowed participants to self-select into the study and provide testimony on their experiences of living with disability to a level of disclosure that they felt comfortable with. The interview technique was designed alert to the discrimination and trauma that the interview group may have experienced as both First Nations people and people with disability. All interviews were conducted by a researcher identified with the First Nations disability community. Gender sensitivity was maintained by having a support person of the same gender as the person being interviewed present alongside the researcher. The interviews were conducted in:

- Metropolitan Sydney (principally from First Peoples Disability Network's Redfern office);
- Three regional locations and one remote location in New South Wales;
- Remote locations in Northern Territory from Alice Springs to Tennant Creek; and

- a cohort of Deaf Aboriginal people in Sydney and Adelaide, who self-identify as a discrete social networking group within the First Nations disability community as the 'Deadly Deaf Mob'.

The participant group contained a gender balance, with 25 females participating (53.2%) and 22 males participating (46.8%). The profile of First Nations participants who contributed their testimony is contained the table below.

Table 1: Participant profile contributing to the narrative database, by gender and cohort.

Total number of participants	47
Total number of interviews	41
Non-verbal participants (accompanied by parents as carers)	3
Average length of interview	31.01 minutes
Participants by gender:	
Female	25 (53.2%)
Male	22 (46.8%)
Participants by cohort:	
Deadly Deaf Mob (NSW and SA)	11
Metropolitan – NSW	11
Regional and remote – NSW	15
Remote - Northern Territory	10
TOTAL PARTICIPANTS	47

The interviews were initially recorded in audio format with the consent of the participant. The audio format was then transcribed into text form, then de-identified to remove any personal markers. The texts were then stored in a secure narrative database that could be accessed for further in depth analysis on particular topics, such as in this inquiry into narratives of violence and empowerment.

2.8 *Compliance with ethical standards in collecting narrative data*

The narrative data was collected in compliance with accepted standards of ethical research practice involving Aboriginal and Torres Strait Islander people and communities³³. Ethics approval for the collection of testimonial data from First

Peoples with disability has been obtained from the relevant Aboriginal Health and Medical Research Ethics Committees with responsibility for research ethics in the jurisdictions in which the narrative data was collected in New South Wales (Aboriginal Health and Medical Research Council Ethics approval number:1157/16), Northern Territory (Central Northern Territory Aboriginal Research Ethics Committee approval number: HREC-16-435), and South Australia (Aboriginal Health Research Ethics Committee approval number: 04-16-693). The PhD research also received ethics approval from the University of Technology Sydney Human Research Ethics Committee (Approval number: ETH16-0966).

2.9 *Locating testimonies on violence within the narrative database*

Within the narrative database, 9 of the 41 participants (22 per cent) voluntarily disclosed an exposure to violence or acute traumatic episode. These were described in a variety of ways. The types of violent and traumatic episodes included: references to close family members who had been murdered or 'lost'; women alluding to seeking respite from gender based violence; being subjected to a violent attacks with a weapon; deaths by suicide; a young child dying because of medical neglect; and an extensive and detailed account of being exploited by a human trafficking ring. Whilst there was no apparent gender bias in the participation in the study, there was an apparent gender bias in the disclosures of exposure to violence, as 7 of 9 participants disclosing experiences of violence were women³⁴.

These disclosures from this cohort of research participants enable a depth of focus in addressing the first research question on how they have described their experiences, and the context in the narrative that led up to the disclosures in the course of the interview. While a description of these events have been redacted in publications to date, the full transcribed testimonies of these events were collated for a targeted narrative analysis specific to violence and abuse.

This method of identifying and collating testimonies on violence enabled addressing the first question of this research paper. However, as Chapter 5 will later show, extremely few people who had encountered severe experiences of violence limited

their narrative to basic survival, and very rarely engaged in talk on their personal empowerment. Hence, addressing this second part of the research power on empowerment, self-determination, inclusion and belonging required going back to the entire narrative database.

2.10 *Narrative analysis*

The core analytical approach used was critical discourse analysis of the texts. Critical discourse analysis is a research technique that has been applied in narrative based research that explores empowerment and marginalisation for certain social groups^{35 36}.

The critical discourse analysis was undertaken over a number of steps. The first step was to use Nvivo software to first identify, then to collate, the testimonies from First Nations people who had disclosed an encounter of violence. These were then read as a complete narrative to identify key themes in the language that was used by the people, initially in how they described the encounter of violence; then how they described the impact.

This initial thematic analysis generated number of keywords. These included 'loss' or 'lost', and 'hit'. Once these keywords were identified, NVIVO software was used to undertake a keyword search of these terms and like terms to further identify any other uses and the context in which they were used.

As mentioned in Chapter 3.5, these methods facilitated an analysis in relation to how First Nations people with disability spoke of their exposure to violence but were not able to identify how they spoke of empowerment, self-determination and belonging. For this latter question, a more expansive approach was needed going back through the complete narrative database. A keyword search for words including 'self-determination', 'power', 'sovereignty' or '(de)colonisation' did not yield any findings, although there were instances where 'voice' was used in the context of empowerment.

The results of the critical discourse analysis are presented in Chapter 4 in relation to how First Nations people with disability described encounters of violence and its impact on their wellbeing; and Chapter 5 presents the result in relation to how they spoke about empowerment (or not, as was mainly the case).

2.11 *Preserving the voice of First Nations people with disability in the presenting of their testimonies*

Consistent with the overarching aim of elevating and promoting the voices of First Nations people with disability in research and policy, and number of strategies were taken to preserve the integrity of their testimony and the context in which their words are used to illustrate themes and concepts. Presenting the narrative was a careful balancing act. On one hand, the use of their testimonies had to maintain integrity with what the First Nations person with disability conveyed on their sensitive topic. On the other hand, this needed to be presented in a form that did not inadvertently invade their expectation of privacy, nor be presented in a tone that was unnecessary gratuitous or voyeuristic. This required additional measures beyond the de-identification processes that were outlined in Chapter 3.3.

The first measure to preserve the personal integrity of the participant was to present these accounts as a community narrative. This approach is to highlight the patterns in the narrative, rather than create an intense focus on certain individual experiences through a few select case studies. In balancing the need to present case examples to illustrate key points with creating the effect of a community narrative, no names of individuals have been included in this report, nor were any pseudonyms created as a proxy for a person's real name.

As a second measure, case examples were converted to a gender neutral form where possible. This was not always possible however, as it was deemed from the surrounding context in some of the case examples that the person's gender was likely a relevant factor in their experience, and hence the gender reference was retained.

As a third measure, great care was exercised to preserve the participants' testimony in the exact manner as narrated by them. To avoid inadvertently altering the message and tone of the participants' testimony, the researcher refrained from editing the transcribed text of the interviews by paraphrasing, changing words or editing the syntax and grammar, other than for the removal of pauses, consecutively repeated words, and occasional instances of casual swearing.

As a fourth measure, a draft report was subjected to a community review and validation processes that was convened by the First Peoples Disability Network (Australia) and comprising representatives of the First Nations disability community who were not involved in the production of the report. The purpose of the community review was to confirm the interpretation of testimonies and negotiate any sensitive issues in the presentation of the narrative prior to its final publication. The community review and validation process was in addition to a separate peer review process organised by the Royal Commission which reviewed the academic quality and integrity of the research.

3. Discourses on violence: How did First Nations people with disability directly affected by violence talk about these events?

NOTE: This chapter contains personal testimony and content describing violent events that some people may find distressing.

3.1 *Themes in descriptions of violence by those directly affected*

This chapter addresses the first research question of how First Nations people with disability described incidents of violence, abuse, neglect and exploitation. As stated in the research brief in Chapter 2, whilst abuse, neglect and exploitation were pervasive in their lives of First Nations people with disability, this section focuses on detailing the most serious incidents of violence and abuse that they disclosed in their testimony.

Approximately one-quarter of First Nations people who were interviewed in the research described encounters of violence in their lives, although it should be noted that the research program through which these testimonies were sourced was not designed as prevalence study. Furthermore, once an experience of violence was referred to within an interview, it was likely that the person interviewed would speak of other experiences of violence and abuse that they had encountered. The vast majority of descriptions of violence were from First Nations women, reflecting a distinct gender bias in report of violence within this study.

Some of the violent events that were described over the course of the interviews included: multiple references to deaths of close family members or people within their community who had died as a result of violence, including direct or implied references to murders, accidental deaths, and suicide; a person who had been attacked with “*a long knife*”; a young child who had died as a result of an untreated tooth infection; and a woman who had been coerced into a sex trafficking ring in her youth³⁷. There were also occasions when a woman made indirect references to

having problems accessing respite housing to escape violence, without making a direct reference to the violence itself.

Turning to the first-person discourses on violence, or how First Nations people with disability who were directly affected talked about violent events, there was one predominant theme to their narratives which was around 'loss'. This recurrence of the references to 'loss' had the effect of fore fronting the personal impact of violence, more so than detailing the occurrence of the actual event.

Within the prevailing narrative on 'loss', there were occasions when the people described the actual occurrence of violence. These events were most regularly cited by the person as being 'hit', although there were a small number of occasions when the person used euphemisms to describe violent event(s).

These themes and their significance are detailed further in the remainder of this chapter.

3.2 *Something is "lost"*

The predominant way that First Nations people with disability spoke of their encounters of violence in their narratives was around 'loss', or that someone or something was 'lost'. The spoken word on 'loss' was delivered with sadness through a non-verbal presentation that was typically sombre and mournful. A notable contrast to the sadness and grief in the manner in speaking about 'loss' was an absence of a visible anger, barring a few exceptions.

Examples from the testimony:

The expression that someone was 'lost' was regularly used when referring to people from their family or community who had died. There was one case which directly mentioned the death of a young child who had died due to an untreated tooth infection. There were multiple references to relatives who had been 'murdered'. In one of those cases, the person mentioned that the murder had not been solved and that this injustice had left them with a lingering grief. There were other occasions where people spoke of relatives who had been 'murdered' without going into further detail.

There was one case where an Aboriginal woman spoke of her son who had been 'lost', and the impact that it had on her family one another of her children who has a disability. She did not elaborate on the circumstances of her death but implied within her testimony it was sudden and tragic.

"Because he, you know, when he lost his brother, he's – he was pretty – pretty – well, I mean, it traumatised all of us."

Her expression of loss in relation to the death of her son was repetitious, with the word 'lost' or its derivative appearing 7 times in a 25 minute interview.

Other references from another case speak to the pervasiveness in the trauma of First Nations people dying at relatively young ages. This, from one case:

"My brother died three years ago, you know. I struggled so much after his loss and I wasn't coping very well";

And this from a separate case:

"And, what happened was my godmother lost her daughter. A truck hit the bike and she was on the bike, and she was deaf – [name deleted]. A really good friend. She passed away when she was eight"

Another Aboriginal man described being attacked by a *"long knife"*. His description of the attack was frantic, reflecting the rawness of the trauma that he still felt, repeating *"I lost a lot of blood"* 8 times in the space of a few minutes. He then said that the attack had left him unconscious and when he woke up he had 'lost' a leg which had been amputated as a result of the attack. He spoke of his grief at losing his leg, mentioning it another 4 times in the interview.

The expression that something was 'lost' also came up in relation to an acquired disability in relation to hearing 'loss'. There were multiple references, and usually spoken of casually, for example, *"I lost my right ear"*.

One final context in which 'loss' was referred to was in relation to a loss of identity. This sense of loss was explicitly spoken about in one testimony from a deaf Aboriginal person who had experienced sustained discrimination over their life, and that a traumatic event had triggered a spiral in their wellbeing, saying:

"So, I think that's where I lost my identity";

and later in the interview:

"And, I feel a bit lost".

3.3 *Being 'hit'*

Whereas the narratives on 'loss' placed the impact of violence at the forefront, what was less frequent were description of the actual event of violence. When people were prepared to speak directly to what happened, the most common expression that was used was in reference to being 'hit'.

Much like the way that expressions of 'loss' were repeated by people in quick succession, so were references to being 'hit'. In other words, when people spoke of being 'hit' the first time, they followed up by saying it again and again in quick succession. As with 'loss', the repetition in use of these words is a sign of the

intensity of the trauma that the person was reliving at the moment that they were speaking to it.

Examples when used in the testimony:

The first case example is from a Deaf Aboriginal person. In the testimony, leading up to the person had mentioned that they had been transitioned from dedicated Deaf Schools to 'mainstream' schools. The use of sign language was actively discouraged as a form of communication, and the person said they were punished when they used sign language at the 'mainstream' school that they attended:

"I signed my hands were hit all the time";

and later:

"and my hand would get hit again and again".

There were other cases where First Nations persons with disability spoke repetitiously of being hit, including these two separate cases of Aboriginal women who whilst living in different States, both spoke to a shared experience of violence whilst in foster care:

"the woman that was flogging me, you know... [section deleted].... she would be in the middle of strangling me and bashing my head against the wall and the phone would ring. And, she would hit you with anything she had in her hands, anywhere on your body. Like, she liked the face a lot and the head. She used to hit our heads a lot."

and in a separate case:

"She [the foster carer] used to fill up the bath and put me in, hit my head against the side of the bath and hold me under...[section deleted]...And, then she would pull me out and start hitting me with toaster cords cause it hurts more when you're wet."

As a qualifying note, the word 'hit' was used in a different context by others in a colloquial sense that was unrelated to violence, for example, "*I've just hit 50*" when referring to age, and "*I just hit the wall*" referring to fatigue. This is different to the narrative of 'loss' which was consistently used within the same context.

3.4 *Other euphemisms and indirect inferences of violence*

Outside the predominant patterns in the narrative, there were euphemisms and exceptions.

In one case, an Aboriginal woman living in a regional location spoke of their difficulties in accessing disability support services for her two sons, both of whom have intellectual disability, across their spectrum of need. As a precursor to this part in her testimony, she spoke of her distrust of the police, and of being "*scared*" for sons because of their disability. At this point her demeanour changed to one of discomfort, as she then directed her testimony to one of her child experiences at school.

*"another kid was [pause] was **interfering** with my boy in the school system".*

She did not go further to say what she meant by '*interfered with*', and nor was she asked to elaborate, but the clear inference was that her son had been sexually abused at school. This inference was by way of a euphemism, rather than speaking to it directly. She did say further that she had taken up the matter with the school and the police but they had done nothing. As a consequence, she had withdrawn her son from the school, and at the time of the interview, her son was not receiving any schooling or education.

Another Aboriginal woman wanted it known that she had experienced abuse as a moment that gave her life story significant context, without wanting to disclose any details:

"I was abused badly by her [her mother] – her boyfriends and all of that. I'm trying to summarise here, I don't want to give you too much information, but I'm just kind of trying to paint a picture as to what happened in my childhood."

3.5 *Exceptions to the patterns in the narrative*

Whilst rare, there were a very small number of times when someone made an occasional reference to a violent event or death within the general course of their conversation, speaking in a way that this were normalised or expected within their life and/or community. For example, there was one reference to a person who had been murdered, and another who had been attacked, without surrounding context. The rarity of these references in the pattern of the testimony makes them an exception as opposed to a pattern.

4. How First Nations people spoke of empowerment, sovereignty and self-determination

NOTE: This chapter contains personal testimony and content describing expressions of trauma that some people may find distressing.

4.1 *A progression from trauma to empowerment*

This chapter addresses the second question of how First Nations people with disability articulated their aspirations of empowerment, self-determination, inclusion and belonging. The purpose of this inquiry was to look at whether there is an alternative narrative to the one of their suffering and “loss” that was mournfully conveyed in reflections to their exposure of violence.

Unlike the disclosures of violence and abuse which were unsolicited, First Nations people with disability did not tend to raise sentiments of empowerment and belonging without being prompted. Expressions of empowerment, inclusion and belonging tended to come in response to a question “what matters to you in regards to your future?”, if at all. The main sentiment that was expressed by First Nations people with disability was one of daily survival. When offered an opportunity to consider more about their future, there were a number who expressed surprise that they were even being asked this, reflecting a lack of expectation they held in others caring about what they had to say. However, when they did come to reflect on their aspirations, they held out optimism for a brighter future, although they were faint. Some even went further to say that they wanted to use their experience to support others. Hence whilst the bulk of testimony was shrouded in negative experiences of violence and abuse, the aspirations that a positive future was still possible points to a progression or pathway from their trauma and into personal and community healing.

4.2 *What First Nations peoples with disability did not say in relation to their empowerment and inclusion*

Addressing the question is how First Nations people with disability did speak about empowerment and inclusion is firstly an observation in what you do **not** see in their testimony. The First Nations people with disability did **not** speak about 'self-determination', 'power', 'sovereignty' or '(de)colonisation' using that language or words. There were no references to any of these words or terms in the individual interviews. Instead, they defaulted to a language of survival, from which they only hesitantly moved on from when they were encouraged to do so.

The omission of a naturally formed narrative of empowerment and inclusion is reflective of the psychosocial impact that sustained exposure to structural violence has upon those who are affected by it. The personal and emotional resources that it takes in doing what they need to survive for this group of people leaves little left for future-oriented thinking. Instead, they are focused just getting through the day, and when they pause to give thought to that instinct, it is a 'language of survival' that flows through their testimony.

4.3 *A 'language of survival'*

A 'language of survival' that filtered through the testimony is characterised by phrasing that was a frequently despondent and occasionally desperate description of what it took to get them through the day. Intrinsicly linked to their mental health and wellbeing, some First Nations people with disability spoke of the depressing effect of the daily reminders of their traumas and discrimination. This is shown in this frank admission from an Aboriginal woman with profound mobility impairment on her daily battles just to get out of bed:

"There are days when I don't want to face the day. I'll just get up, have my shower and I'm going back to bed. I'm under the covers. I don't care about the rest of the world."

and later in her testimony;

“You have your ups and downs but there’s more ups than downs, which is good. Good side to it, you know? Just when, you know, there’s people that I’ve worked with and interact with, it’s like, and it’s okay. Life’s good. Yeah. Because, as I said, there’s some days you wake up and say, “Fucking life is shit. I’m out of here. I want off this planet.””

In another example, an Aboriginal mother of two living in a remote region was asked what the most important thing in her life was, and without hesitation replied *“my two babies, my two girls”*. In the midst of this mother-daughter devotion, she also spoke of a relentless battle navigating health and disability systems to get one of her daughter’s adequate care and supports for her disability that was profound and compounded by her remoteness. She was on taking these battles as a single mother, hammering home the sheer hardness of a life for her and her daughter that was without structure and support. She says:

“But, then me family’s here. I don’t know, we just got to work around it.

When asked about what mattered to her and her daughter’s future, she said she didn’t want to think about that as that made her upset and worry. And with that, her testimony promptly ended.

4.4 *“Something stronger”: Glimpses of a positive future*

There were occasions when some First Nations people with disability pierced through the ‘language of survival’ with utterances that held hope for a positive future for themselves and their community. These were rare examples of wistful statements that defied the remainder of their story that covered a harsh life.

A seminal example of this of this came from an Aboriginal man living on the outskirts of a regional centre, in a community where he was surrounded by people who had experienced severe trauma and violence. His story followed immediately after

another member from his community, an Aboriginal woman with a hearing impairment and an intellectual disability. Her sister's son had died through medical neglect at the age of 2 years old. The child's death was an unresolved trauma for the entire community, and she mentioned that one of her relatives had died by suicide not long after. She was feeling guilt that she could have done more to help her sister.

The Aboriginal man's story seamlessly picked up the litany of incidents of violence, abuse, neglect and exploitation that surrounded his community. He spoke of having to walk a number of kilometres into town to see a counsellor as part of a work training program that he had signed up to, then, being subject to vile racial abuse from people who drove by in their car as he walked home. He says that *"family is everything"*, but all of his family has 'problems', and he wonders:

"how can I fix my problems for I'm helping everyone else?"

He speaks of his feeling of disempowerment, again using the narrative of 'loss':

"Before I had loss, I was in control".

Then comes a shift in his demeanour, switching from despondency to a defiant statement of strength and resilience:

"I know something stronger is in here, [pointing to his heart], I've just got to get there. There's a strength and energy inside me burning to get out."

Then, after the momentary flicker of aspiration, he goes back to punishing himself:

"I'm depressed with myself for not being stronger...I can't see in front of me, I'm walking blind."

Despite reverting, the single statement of strength and hope that emerged from a place of entrenched disempowerment is a turning point in that community's narrative, pointing to a potential pathway from trauma to healing. This next section looks at what the next stage in the progression in the healing pathway might look like, where

First Nations people with disability draw strength from their personal experiences of surviving trauma and discrimination to support and foster empowerment in others.

4.5 Giving "voice", empowering others

There is an adage that goes 'preach from your scars, not your wounds'. This was evident in the survival stories of a number of First Nations people with disability, who said that they wanted to use the knowledge and strength that they gained through survival as a way to help others in their community.

This carries the legacy of the Aboriginal Elders of the disability community. One Elder who was interviewed described a lifetime of advocacy in various organisations, bringing people together for collective action against systemic discrimination. He said that he has spent a large part of his life:

"trying to find other Aboriginal people with disabilities. Because I remember one Aboriginal person who had a disability who's paraplegic. And, he said, "Look" – he said, "I don't have a disability. I just can't get a job.""

The next generation of the First Nations disability community described this vicarious form of empowerment to others through sharing their survival story as giving "voice". One Aboriginal man spoke of his desire to lead change in this way when, after giving a lengthy account of his struggles accessing health care and coming up against other people's social phobias to his quadriplegia, said:

"Because I'm Indigenous and I do have a disability and, you know, I just want to be that voice on behalf of our people."

This reaction was not always instinctive, and others came to 'giving voice' as a purpose in their life only after a period of consideration. This was shown in the story of a Torres Strait Islander woman with cerebral palsy, who had encountered prejudice right across her life, from going to the doctor to trying to get a job after.

Initially she stumbled when asked what matters to her in her future, unused to being asked that question:

"What matters to me? Probably – I don't know. That's a hard one. Probably just – just like, achieving my goals and just not giving up and just like, if I don't get there, keep going. Just keep plodding along and just, yeah. To stay strong and not to give up and that's all I hope."

Then later as the interview was winding down, she opened up on an issue that was important to her, speaking of a close friend who had died by suicide. It was her response to this incident that was painful to her and that motivated her to be a voice for systemic change:

"It really did show me that, like, instead of letting it, like, ruin me with sadness, I just really want to use it to, like, to use it to change peoples' lives and to motivate me to get my degree and to get out there and to make change happen and to improve the system, and to prevent this from happening to other people."

Members of the 'Deadly Deaf mob', a self-named community of Deaf Aboriginal people articulated their desire for a voice for their tightly bonded community - that existed within the larger First Nations disability community. An Aboriginal woman from the Deadly Deaf Mob said what was important to her was;

"Advocacy, and doing that until I die. That's important for me, no matter what. It's important to, you know, raise our voices, to not allow myself to be silent anymore. I want us to be heard. I think it's the right time."

Having opened up on speaking about her future, her confidence and momentum gained sometime later in the interview:

"Okay. I'm just thinking about my future. I'm hoping that there will be a deaf organisation out there working with deaf Aboriginal organisations one day. I'd love them to work together as a team to provide the right services for deaf

Aboriginal people in Australia, because at the moment it feels like it's segregated, and part of their identity sits in one organisation and the other part sits in another organisation, so that's what I would love to work towards, and I think that that's important to me and I'd love to see that."

This statement, and without expressly using the exact words, is articulating the aspirations for sovereignty and self-determination of the First Nations person with disability community.

5. Summary reflections

Coming together as a community help them tell their story

There are two parts to the narratives of First Nations people with disability. The first narrative that was presented in Chapter 4 is a frank and mournful narrative on the traumatic impact that violence that affects them, their families, and communities has upon their lives. As painful as telling these stories was to them personally, their attendance at the interviews shows that they wanted their voices heard, as this was the way they could contribute to changing things for the better. It was the act of coming together as a community and telling their story alongside others with a similar experience that imparted a strength that they could draw from to help them through their truth telling. This is the first reflection in the narratives.

There stories are fundamentally about recovery and healing

The testimonies that described encounters of violence were framed as a 'loss' to the person that was affected. There is a significance to how 'loss' is part of their narrative. 'Loss' infers that something has been taken away from them, 'it' is now gone and cannot be reclaimed. Their accounts of violence were told mournfully, and rarely showed anger. There were no thoughts expressing vengeance against the person who inflicted the violence, even if a dark cloud of injustice lingered over their stories. Their stories were trying to find a way towards recovery and healing from their pain, more so than seek restitution for their 'loss'.

There is a progression from trauma to healing

The second part in the narrative, presented in Chapter 5, gave insights to how First Nations people with disability dealt with the trauma of violence at a personal and community level. Most people used a 'language of survival', describing that their goal in life was to get themselves through the day. Occasionally, there were glimpses of a positive future that they held out for. Reflected in the "something stronger" sentiment that emerged from a place of entrenched disempowerment, these expressions represented a turning point in their narrative. Then there were others who said that

they wanted to use their survival story as a way to help other that were going through a similar experience to what they had been through.

These narratives, combined with their narrative of loss and trauma, are not separate unconnected stories, but taken together form a linear narrative. The narrative of First Nations people with disability shows there is a progression that starts in trauma, makes its way through survival, starts to impart some hope for a positive future, then builds momentum as people start finding empowerment - first in themselves, then as an agent for empowerment others in their community.

Coming together as a community is how First Nations people with disability will find healing and empowerment

Taken as a whole, the community narrative points to a progression from trauma to healing, with empowerment and the self-determination of a connected and inclusive First Nations disability community being the end destination. This is shown by an assertion of self-determination from a Deaf Aboriginal person in the testimony that is the culmination to these chapters. This statement of self-determination of the First Peoples disability community was the outcome of an going process. Fundamental to this process was generating a sense of belonging to a community of people that shared a similar experience. This community supports them with a message that they do not have to deal with their traumas alone. The coming together of people who have experienced trauma is the way by which First Nations people with disability will find their healing and empowerment.

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