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

Research

Report

Examining language and vocabulary used by people living with disability

Purple Orange

October 2020

About JFA Purple Orange

JFA Purple Orange is an independent, social profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production and includes hosting a number of user-led initiatives.

Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially around policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

Our work is informed by a model called *Citizenhood*.

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Content warning

This report contains information that may be distressing to readers.
It may include accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviour.

The report may contain firsthand accounts of violence, abuse, neglect and exploitation, related accounts of abusive or offensive language experienced or witnessed. Some direct quotes in the report contain language that may be offensive to some people.

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- SMS.

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If you are deaf or have a hearing or speech impairment, telephone the National Relay Service on 133 677 and give 02 6146 1468 as the number you want to call.
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Contents

1. Executive Summary

The aim of this study was to explore the use of language by people living with disability with respect to violence, neglect, abuse and exploitation and explore concepts such as safety, inclusion, belonging and self-determination. This research utilised co-design, focus group and targeted recruitment approaches in order to engage people living with disability from across South Australia. Participants self-identified as living with the following categories of disability types: physical disability, intellectual disability, autism, deaf/hard of hearing, blind or low vision, acquired brain injury and psychosocial disability.

This report describes findings from 13 focus groups representing different disability cohorts held with 83 participants who live with disability. An additional two focus groups were held with 13 family members of people living with disability. The focus groups were held across Adelaide and regional locations of South Australia in January and February of 2020.

The findings from this research highlight that some terms are better understood than other terms by members of the disability community. Participants across different age, gender and disability categories reported that the terms 'neglect' and 'exploitation' were confusing and were not words that many were familiar with. Other terms also brought about confusion, with the term 'abuse' having such broad connections and connotations that some participants felt unsure as to what the Royal Commission would consider to be 'abuse.'

These findings offer insight into how people living with disability make meaning of the key terms being used by the Royal Commission. These terms represent acts of crime against people living with disability that sit in high numbers of occurrence compared to the wider Australian population. Statistics relating to these crimes can offer insight into the number of occurrences, and the prevalence within different parts of the disability community. However, it is only through language that a victim can fully describe these crimes and their impact. Therefore, the findings provided by the current study offer a unique collection of meanings, connotations and interpretations towards the themes that this Royal Commission is tasked with investigating.

2. Introduction

This report provides a final summary and analysis of findings for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability who commissioned research services from JFA Purple Orange to deliver a series of focus groups with people living with disability. The purpose

of the focus groups was to explore the use of language with respect to violence, neglect, abuse and exploitation and explore concepts such as safety, inclusion, belonging and self-determination.

This research was guided by the following research questions:

1. How do diverse groups of people living with disability speak of violence, abuse, neglect and exploitation?
2. How do diverse groups of people living with disability speak of self-determination, safety, inclusion and belonging?
3. Are there discourses particular to certain groups of people?
4. Do these words, descriptors differ/match across disability groupings, across sexes?

3. Background: The need to understand diversity in language and vocabulary within the disability community

The impact of language on the human experience is immense. Certainly, language is significant to most of the phenomena that lie at the core of studies relating to human behaviour, such as attitude change, social perception, personal identity, social interaction, and stereotyping. On writing about language and social behaviour, Krauss and Chiu state "just as language use pervades social life, the elements of social life constitute an intrinsic part of the way language is used[1]." Put simply, the way a person defines a social situation, the way they make meaning about their own and others' identities, and their perception of other people, will all impact on the nature and content of their language and interpretation of language.

This research explored the meaning and understanding of specific terms being used by the Royal Commission and also explored the themes of self-determination, belonging and inclusion within the disability community. One's understanding of these terms, and the vocabulary they use to describe both the terms and the types of incidents that can come within their meaning, can be influenced by a range of factors such as their experience, disability type, age, gender, sex, and cultural background. The use of language can be considered a dynamic process; as such, words have the power to not only reflect attitudes but also to change attitudes and influence behaviour. Therefore, gaining insight into how people with a range of lived experience of disability understand and use language is important for understanding their overall experiences. We also acknowledge that misunderstanding

language associated with value-laden terms and constructs carries the risk of reinforcing negative stereotypes or assumptions with respect to disability.

4. **Methodology**

This consultation utilised co-design, focus group and targeted recruitment approaches in order to engage people living with disability from across South Australia, including regional areas.

4.1 Co-design group

A co-design group was established at the beginning of the project to guide the consultation process. This group had representation across a number of disability demographic categories as outlined below:

Table 1: Description of people who attended co-design workshop by disability type, gender and age

Disability	Gender	Age
Acquired Disability (Neurological including blindness)	Male	50+
Sensory Disability (including deafness)	Non-binary	31-49
Psychosocial Disability	Male	31-49
Physical Disability (including wheelchair user)	Female	18-30
Parent of person living with intellectual disability	Female	50+

The co-design group was utilised by the research team to guide the development of the research approach and the content of the focus group discussions. In particular, the group was used to talk through the planned research approach, the proposed questions for the focus groups and potential scenarios that could be used in the groups. Key feedback was as follows:

1. **Composition of focus groups** – There were suggestions to conduct a focus group for people living with autism owing to potential different communication methods and needs; there were also suggestions to conduct a focus group with people living in supported accommodation, given potential lower levels of engagement and higher levels of vulnerability; since language can be context-specific, group members highlighted the

importance of parents of school-age children and people in employment being represented within the research (e.g. by asking about this as part of the group registration process);

2. **Accessibility and ethics of focus groups** – The co-design group members suggested allowing a short break in the middle of the focus group; where possible request that participants' own support workers leave the room during the group so that participants feel more able to speak honestly; and where possible provide a quiet room adjacent to the focus group room for participants/the counsellor to use;

3. **Terms** – Self-determination' is the most difficult for people to understand, so terms such as 'decision-making' or 'choice and control' should be offered where needed as additional explanation; people living with intellectual disability may need help with descriptions for many of the terms; additional probes will be important to explore the full breadth of terms where people initially interpret them quite narrowly (e.g. a question around safety may initially elicit comments about road safety or fire safety) or where they do not initially associate any behaviours with the term being discussed;

4. **Scenarios** – researchers tested out five general scenarios with the group (1. A person hits and injures a person living with disability; 2. A person ties down a person living with disability; 3. a person living with disability is left in dirty clothes and isn't given any lunch; 4. Someone takes advantage of a person living with disability; 5. a person living with disability isn't allowed to do the same things as everyone else), asking people what the scenarios made them think of (first writing down individually and then discussing), what types of situation they might happen in and how they would define the situations.

    a. It was found that group members somewhat struggled to discuss the scenarios owing to the lack of specific detail, e.g. some simply said that each scenario was not okay and others asked questions such as 'why?' and 'how?'.

    b. It was also found that group members naturally tried to relate the scenarios to their own lives, heightening the risk of disclosure

Having reflected on this, it was decided that general scenarios are unlikely to stimulate the desired conversation because of their artificial nature. It was therefore decided that a likelier more productive approach would be to focus the 90-minute discussion around the 8 terms of interest and allow the terms (plus additional probes) to drive the conversation. The additional advantage of this approach is that it would allow researchers to be more upfront with people regarding exactly what the focus groups will cover.

The co-design group process was an invaluable part of the research methodology. It is recognised that co-design membership did not represent all areas of disability experience, however the variety

of lived experience within the group membership had broad application across a number of considerations for the methodology of this project.

4.2 Recruitment

In order to ensure that a range of disability experiences were represented across types of disability, ages and location, a highly intentional, purposive sampling method was used. Participants were recruited through online advertisements, word of mouth and advertising via a variety of disability organisations, such as service providers and social media disability-specific groups. Eventbrite was primarily used for registration, with researchers personally registering any participant requiring additional support to complete the registration process.

The registration process was designed to screen all participants to ensure that they all directly lived with disability and that they were aged over 18. Whilst this project had few exclusion criteria, it was necessary for researchers to ensure that all participants met the following criteria:

1. Over the age of 18
2. Identify as living with disability
3. Identify as able to take part in a 90-minute focus group as described in the information provided during the registration process
4. Able to provide informed consent for participation in the research

Participants who did not meet these four criteria were excluded from participation. The registration process allowed for researchers to collect some demographic information from participants, enquire about accessibility requirements and was a mechanism for participants to raise any queries or concerns about participation.

Research Participants

83 adults living with disability participated in this research. Participants were screened by researchers to ensure that they directly lived with disability prior to their attendance at focus groups.

Of the 83 participants, 60 were female, 22 were male and one identified as non-binary.

The breakdown of age was as follows:

- 12% of participants were aged 18-30;

- 44% of participants were aged 31-49;

- 43% of participants were aged 50 years and over; and

- 1% of participants preferred not to provide details of age.

Please note First Nations people were not included in this study as the authors understand that a separate study will examine language used by this cohort. A dedicated focus group for people living with disability from Culturally and Linguistically Diverse backgrounds was run, involving representation from the Bhutanese, Afghan, Bosnian and Polish communities. However, owing to the difficulty of different language and interpretation requirements, the required information could not be obtained because of the inability of participants using different languages to converse with each other. A mutual decision between the researchers and DRC was made to approach this cohort via a separate, targeted piece of research at a later stage. The data and participant information from the dedicated CALD session has not been included in this report.

Participants represented lived experience across a range of disability types as detailed in the following table:

Table 2: Participants represented lived experience across a range of disability types

Primary Disability Type (self-identified)	Number of participants
Physical Disability	29.8%
Intellectual Disability	19.5%
Acquired Brain Injury	11.4%
Unknown/Prefer not to say	11%
Autism	9%
Psychosocial Disability/ Mental Illness	8%
Deaf or Hard of Hearing	6.8%
Blind/Low Vision	4.5%

4.3 Ethical Considerations

This project was designed in accordance with the JFA Purple Orange Ethics Protocol tailored for this research study (see Appendix B). All participants gave informed consent prior to taking part in focus groups. The research team provided all participants with information about how the focus groups would be conducted, reminded them that participation was voluntary and that they could leave at

any time and supplied relevant referral pathways to all participants should they experience any discomfort or distress through participation.

Each focus group session was attended by a trained counsellor supplied via the Disability Royal Commission counselling team. A separate, private room was available for use in each focus group session should any participant need to meet with a counsellor during the focus group or debrief following the sessions. The counselling services were utilised by participants as needed across services. These participants were then followed up by counsellors.

All data captured during focus group sessions was stored securely in a password-protected electronic file within the JFA Purple Orange office. Data was stored in a deidentified and confidential format, with only the research team having access to the data.

4.4 Focus groups

As detailed in section 4.1, the co-design group was used to seek feedback on how to approach data collection for this project.

The feedback from this group centered around ensuring that the project was designed in a way that enables people living with disability to provide meaningful input. The focus group sessions were then shaped around the feedback provided.

There were 15 focus groups run throughout January and February 2020. Thirteen of these focus groups included people directly living with disability whilst two focus groups were aimed at family members of people living with disability. This report deals with the two family member focus groups separately as the participants were not people living with disability and therefore findings have been analysed separately.

The 13 focus group sessions consisting of participants living with disability were separated into the categories below. Please note that owing to reasons of confidentiality the researchers will not provide demographic information per category.

Table 3: The 13 focus group sessions consisting of participants living with disability were separated into the categories

Focus group number	Focus group description	Number of participants in attendance
1	Young people living disability (aged 18-30 years)	3
2	People living with disability aged 50 and over	7
3	People living with physical disability	8
4	People living with intellectual disability living in the community	6
5	People living with psychosocial disability	7
6	People living with intellectual disability in supported residential care	6
7	People who are deaf/living with hearing impairment	6
8	People living with autism	6
9	People living with disability (Males-only group)	7
10	People living with disability (Regional South Australia)	6
11	People living with disability (Regional South Australia)	5
12	People living with disability (Regional South Australia)	7
13	People living with disability (Females-only group)	9

Focus groups were predominantly held at a central office in Unley, South Australia. All focus groups lasted for 90 minutes and were led by two facilitators, one of whom had lived experience of disability. All facilitators held current police checks and disability-related employment screening clearances. All accessibility requirements were planned for and met by the researchers, including physical assistance, travel support, Auslan interpretation, language interpretation and live captioning. Most focus groups were held in metropolitan Adelaide with three sessions conducted in regional South Australia.

The purpose of the focus groups was clearly outlined to participants via information embedded in the registration process and via a verbal statement supplied by the researchers at the commencement of each focus group. Please see Appendix A for a copy of the focus group schedule used in all focus groups. Each focus group started with a discussion about safety before going into the four maltreatment types (violence, abuse, neglect and exploitation) and then ended with a discussion around belonging, inclusion and self-determination. By book-ending the discussions about violence, abuse, neglect and exploitation with an exploration of the concepts of safety, inclusion, belonging and self-determination, the researchers aimed to provide a positive introduction and conclusion to the focus groups. This assisted with creating a safe and comfortable environment for participants to engage in conversation. All participants were compensated for their time unless it was their preference not to receive compensation. In alignment with the JFA Purple Orange ethics protocol

developed for this project, a counsellor was present at every session and utilised as needed by participants.

4.5 Analysis

An interpretive, qualitative research design that incorporated focus group methodology was utilised across this study[2]. All data from the focus groups were audio-taped, transcribed and analysed by the research team using a manual thematic analysis framework[3]. In conducting the analysis, the research team implemented a process of data interpretation in which any themes inferred by one researcher were verified by co-researchers before being considered as final themes.

Summaries, main findings and quotations from all data collected within the focus groups are presented within the summary of findings in this report. Each section has been written with the following aims:

1. To demonstrate how diverse groups of people living with disability speak of violence, abuse, neglect and exploitation
2. To demonstrate how diverse groups of people living with disability speak of self-determination, safety, inclusion and belonging
3. To demonstrate if this research project shows there are discourses particular to certain groups of people living with disability
4. To demonstrate how these words and descriptors differ or match across disability groupings, across gender identity and across different lived experiences of disability

Wherever possible, raw data such as quotations have been incorporated into this summary of findings in order to capture the essence of the language used by participants and to illustrate the way participants made meaning of the terms being discussed. Please note, any identifying words or names have been deleted to ensure quotations cannot be re-identified. At times this has resulted in quotations being attributed simply to "a participant" with no other details provided.

5. **Summary of Findings**

The following sections provide an overview of eight different terms discussed in the focus groups sessions:

1. Violence;

2. Abuse;

3. Neglect;

4. Exploitation;

5. Safety;

6. Inclusion;

7. Belonging; and

8. Self-determination.

For each term, an overall summary of key findings is provided as well as a table showing examples of phrases, language and terminology used by participants within the focus groups when discussing these terms. Many participants shared personal or anecdotal incidents they believed were examples of the terms being discussed in the focus group at the time. These examples are also included in the tables.

Please note a copy of the discussion guide that was used in each focus group is attached at the end of this report as Appendix A.

5.1 Findings related to the term 'violence'

Summary

The word 'violence' was strongly associated with many other words and terms including physical violence, bullying, verbal violence, harm, rape, sexual assault, murder, controlling, pinching, hitting, and removal of one's agency. Participants also described feeling as though they are at greater risk of experiencing violence than people without disability. Additionally, participants in the regional areas focus groups stated that the type of violence people living with disability experience is the same as other people, however it is harder for the person living with disability to get away from.

Types of violence identified

Physical violence was readily referred to by all groups, with descriptions or stories of people carrying physical acts of harm being shared. Emotional violence was discussed, particularly by people living with intellectual disability who described bullying, discriminating, name-calling and one participant stated, "words can hurt." Female participants as well as people aged 50 and over associated the term 'violence' with sexual assault and for that group the use of the term 'violence' needed to be extended. One female participant stated: "I like the use of the word violence. I think it doesn't even

go far enough. I think when the Commission talks about violence, stop calling it sexual assault, call it rape. Start calling it out for what it is. If someone is being pinched or hit call it assault."

Examples of more subtle forms of violence were also provided. For instance, people living with physical disability spoke of unwelcomed gestures intended to be helpful that can be perceived by the people living with disability as violent, such as not asking before you grab a person's arm to cross the road when they are vision impaired, or pushing a person's wheelchair without being invited to do so.

Key Differences between groups

People living with intellectual disability described difficulties with reporting violence to authorities. One female participant said, "if people living with intellectual disability try to report violence, no one believes them; we are suffering in silence."

Another issue for people living with intellectual disability regarding violence was emotional violence owing to other people "using their IQ to put us down." This was spoken about with reference to doctors, care workers, and professionals providing services.

The Deaf community were able to readily discuss what violence meant to them. Of particular relevance is the way in which the Auslan signs to demonstrate the word 'violence' have evolved over time. One participant supplied a history of this:

> "Back then [30 years ago] it used to be about assaulting people, punching, you know, specifically punching people… the signing for violence has changed, now they talk about someone being assaulted on the face specifically or someone being assaulted and the specific sign for that in terms of a website called Signbank, there are more formalised ways to depict sign language and so they show violence, there's a couple of signs of that, but the deaf community uses it in different way. The older community still finger spell violence, the younger community might use a different way, the middle-aged community a different way. The young people see it and change, but the older community still uses the finger spelt "violence."

This explanation demonstrates the importance of understanding the translation of spoken and written English words for members of the Deaf community who rely on Auslan for the bulk of their communication. As one participant using Auslan said: "the reality is, Auslan is our first or preferred language… it's where we're comfortable."

There was a lengthy discussion around people living with disability (particularly psychosocial disability) being portrayed as violent or being the perpetrators of violence; this was unique as this is a different viewpoint whereby participants spoke of violence coming *from* people living with

disability themselves. This cohort also spoke of gaslighting (a tactic in which a person, in order to gain more power, makes a victim question their reality) and noted the importance of addressing this: "Gaslighting is something that really needs to be addressed – it comes from professionals and mental health sector." Other participants spoke of psychological violence as a form of domestic violence, saying "it should also be acknowledged as a form of violence towards people with disability."

People living in regional areas spoke of feeling somewhat protected from violence owing to the small communities in which they live: "Regional areas provide some protection from violence as there is more acceptance of disability." However, some participants were careful to qualify that this notion cannot be extended to all regional areas: "We are lucky in this region that people living with disability are more accepted and respected, meaning less violence. This isn't the case in all regional areas or in the city."

The following table provides examples of the language and terminology used in the focus group discussions.

Table 4: Examples of language, phrases and terminology used when discussing the term violence

Physical Disability:

- People being idiots in nightclubs, throwing glasses, getting involved in an argument that isn't their argument, king hitting
- "Typical physical violence, but I find being patronised and condescended to extremely violent"
- Sarcasm – saying one thing but meaning another
- Micro-aggressions – not done deliberately, but they have an effect
- Verbal abuse, particularly for people who have difficulty with communication – leave the person frustrated and say they're angry
- "Silent aggression where you become an untouchable because you have a disability"
- "Being vision impaired, standing at a crossing, someone grabs your arm and says "c'mon let's go", and you say "hang on who are you?"
- "That happens to wheelchair users too – people come up behind you and start pushing"
- "My neighbourhood isn't the worst but it isn't the best – you can hear things happening on the street, sometimes my neighbours fight and I get scared I can't look after myself, to the point of being terrified"
- "Safety in my home – I don't feel like I'm protected. I would love to learn self-defence skills. I feel vulnerable, at risk, and I feel like a burden on other people"
- "I don't like how other people, or other support workers, makes decisions for us"

Psychosocial Disability:

- Assault, a person being hit to control their mental illness
- Physical and psychological
- Restraint (mechanical, physical, chemical, environmental)
- Self-harm (headbutting out of frustration)
- In US – battery is not just physical but psychological (which can cause changes in the brain)
- "Bruises heal, cuts heal, but psychologically they're still there"
- "Domestic violence includes psychological, gaslighting, things that don't leave broken bones and bruises – all of those things should be included in concept of violence for People living with disability"
- Blame – "what did you do to ask for that? What did you do first? Are you sure it was that bad?" – those comments are common when you have anxiety
- Police: "what did you do to make that happen to you?"
- "If you are assertive the automatic response is that you're being verbally aggressive"
- "Gaslighting is something that really needs to be addressed – it comes from professionals and mental health sector"
- Gaslighting – done using sympathy and concern, not overt abuse, perpetrator is a martyr, used as a tool to cover abuse
- Perpetrator engages other people in the gaslighting too
- Stigma – it's the media portraying people with mental illness as violent
- "If you see someone get stabbed they'll say there was a history of mental illness, (people think) then they all must be like that". It perpetuates that stigma that everyone with mental illness is violent
- Signs in hospitals about not tolerating violence: "we see those signs, we have mental illness, you are going off your tree with chronic pain… this is not a regular pain… they ask about your depression… it's patronising"
- Overlook the unintended consequences of violence – see patient turn up with five security guards, mouths of other patients drop, conversations are happening in the public
- "There's an equal sign -violence equals lack of services"

Intellectual Disability (living in the community):

- Fist fighting
- Fighting in a mall or nightclub
- People using weapons or saying death threats
- "I think of self defence"
- "I think of people glassing each other"

- Sexual harassment

- Somewhere in public, the setting is often public, outside spaces

- People playing games with your mind, mental abuse

- Assault, people hurting each other

- "I think of blood"

- Physical, mental, psychological

- "People hit you"

- "They spit in your face"

- Intimidation from friends

- People in your space

- Being bullied, being called names

- "Sometimes you bully yourself – you don't trust people, make friends with the wrong people"

- Have to step carefully when you talk to people – say hello, people treat you bad, discriminate

- "I've been in institutions: violence by staff members, manager sticks up for them, frustrating, who do you tell?"

- Emotional side – lack of control, financial decision-making, brought on by carer or family member

- "other people using their IQ to put us down"

- "If care worker is violent and you tell someone, they don't believe you"

- Need to hold people to account

- Suffering in silence

- Isolated physically and emotionally

- When younger, punched in the head and picked on by kids at nearby school. Told the school and they didn't believe.

- Being hit in the head when crossing the road. People walk up behind you and hit you over the head.

- "I was called an AIDS carrier at 6"

- Called "Minda", stupid, moron

- Words can hurt

- Never had any friends

Intellectual Disability (living in residential care)

- Being scared

- "Some people get raped, you have to be careful"

- Fighting

- Everyone just fights with each other

- "We have plenty of that [violence] around here sometimes"
- Violence gets out of hand
- Child abuse
- Violence can happen anywhere
- Teenagers who get really bored, all they want to do is get out and start fights
- Domestic violence
- "Instead of saying violence all the time it could be anything, it could be fear, or scared"
- "Aggression, I saw that (aggression) today at [shopping centre], it was young kids. Because it's school holidays, kids that go to other schools roll up to the shopping centre and start fights"

Deaf community:

- When I was in my 20s violence wasn't really talked about. Used to be about assaulting people, specifically punching. "The signing for violence has changed." Now specific sign for being assaulted on the face etc. Older community still finger spells violence, younger community and middle-aged community use different way"
- "I think now about the tone of domestic violence, I just think about the physical hitting, punching. Now I've learnt that that can also include the financial abuse, those things I mentioned before, social and psychological abuse, whereas before [when I was younger] I thought domestic violence was just physical."
- "I think of deliberate harm"
- There's all sorts of different ways to describe violence in sign language.' E.g. someone choking someone, going at someone with a knife or baseball bad. "The thing with sign language is it's so visual" – it represents what's actually happening, rather than just using the term 'violence.'
- "Just from my own background, my own experience working in disability, working with aged care, I just think about things that I've learnt and that violence is, obvious, neglect and attack, there's the physical, the social, where you cut people off from being a friend, the psychological abuse"
- "Once [the Auslan sign for violence] used to be one way of punching. Now there's equipment e.g. bats and knives "

Female-only session

- Aggressive people on buses (feel scared/uncomfortable, have to get off the bus)
- Aggression within families
- Passive aggressive behaviours (being blocked out, not being acknowledged)

- Emotional aggression

- Violence means lots of things, including situations getting out of control

- "Whatever a person thinks violence is to them should be validated"

- "Violence can be quiet"

- Crossing boundaries

- Feeling helpless

- "People trying to be helpful but are actually invading your personal space"

Male-only session

- Not just physical harm but the threat of physical harm

- Violence can happen anywhere

- Bullying (in schools and workplaces)

- Violence in the home (for example children acting out)

- Verbal abuse

- Unwanted behaviours

- "It depends on whether you feel like you're in a position to voice how you feel about the behaviours and whether you have the means and skills to fight for yourself"

- "There's a middle ground between violence and neglect which is oppression"

Autism

- "The other thing that comes to my mind is being silenced, as a form of violence. From being told to sit down and shut up, being told by other kids "we don't give a shit about what you're saying" or being silenced by the wider community"

- "Squashing our voices. This is so big, silence leads to violence"

- "Emotional violence- I don't realise it is happening"

- "It's normal for me to experience violence, emotional violence"

- "Vulnerability, we are much more vulnerable because we can't read things, like cues. I totally miss stuff that the average neurotypical person would catch. It leaves a massive door open to all sorts of vulnerabilities."

Aged 50 and over

- Physical violence, Bullying, Verbal, Harm, Controlling

- "People who don't have a disability don't know how to interact with people with disability – you don't have to solve all their problems"
- No inclusion
- Frustration at not being included can be perceived as violence
- "People say things like "When did they let you out of Minda?"
- Rape and sexual assault
- "I think of a spectrum that goes from murder and rape back down to pinching, smacking…and everything in between in terms of physical violence"
- Uninvited touching happens to people living with disability a lot… not done with evil intention but it's still an intrusion
- "How you perceive violence is important"
- "Stop prettying the words up. Violence is a good solid word"
- "Removal of one's agency borders on a kind of violence… it's a psychological and social violence"
- Family members who don't treat you as a fully functional adult human being and take advantage of you
- Violence is a bit at the top of the range
- Lack of oversight can lead to violence
- "I like the use of the word violence. I think it doesn't even go far enough. I think when the Commission talks about violence… stop calling it sexual assault, call it rape. Start calling it out for what it is. If someone is being pinched or hit call it assault"
- "No one ever questions when a man has his wallet stolen, but they do question when a woman says she has been raped"
- Range of other words, violence indicates a whole range of things. Violence could be an umbrella term and you can have all those other terms underneath that indicate those violent acts.
- "It's not good for people's self-esteem"

People living in regional areas

- Physical abuse: Bashing, Bruises, someone hitting you, domestic violence
- Support workers or parents yelling at you
- Violence can happen in many ways – mental, verbal
- Verbal violence in the community (calling people a drunk etc.)
- Regional areas are more accepting of people living with disability given they know the people, know their families and accept them for who they are. They are more protected in small towns.
- "Show me your brain size, not your physical size."
- Violence doesn't solve anything.

- You need to stand up for yourself and retaliate when needed, although some people felt like they can't do this.

- "People don't feel like they are at risk –they say, "people aren't going to hit me.""

- Getting bashed at school or workplace

- Mental violence and intimidation

- If we can't access buildings, transport or whatever, that is abuse, we should be able to access that

- "In some instances abuse and violence are the same, in others they are different"

- "Violence is the action, abuse is the long term effect"

- Emotional violence

- "It [violence] is broader than just the bruises"

- Mental health impact of violence stays with you forever

- "We are lucky in this region that people living with disability are more accepted and respected (meaning less violence). This isn't the case in all regional areas or in the city."

- "The same violence there is for anyone, it's not specialised to the disabled world. There's nothing that happens to us that doesn't happen to people with no disabilities. We are a bit more vulnerable to it because for instance you can't get away… people are isolated and they don't want to lose the one person"

- "people living with disability are seen as an easier mark. Violence is everywhere but the vulnerable will be picked on."

- "Isolation can lead to violence. There's nowhere to escape to"

- "You can't have one without the other. You can't abuse someone without some form of violence"

- Violence can be happening around them that's not appropriate (e.g.: watching television with violence, or watching abuse between mother and father, a fight out on the street) – "violence doesn't have to happen to them but it can affect their mind"

- "Abuse at the hands of companies and government departments – "you can't change your disability to fit into their boxes"

- "[violence is] when you're excluded"

5.2 Findings related to the term 'abuse'

Summary

The word 'abuse' was given broad meaning by the focus groups. It went further than physical acts and was applied to situations where a person's psychological, emotional, financial and mental wellbeing was adversely affected. Abuse was also understood to occur in a variety of settings, including in private and in public. Perpetrators of abuse could be individuals as well as institutions, leading to mistrust by people living with disability to report abusive behaviour. The difference

between violence and abuse was generally understood to be one based on the longevity of the behaviour: violence was a one-off occurrence whereas abuse was the longer-term pattern of violent behaviour. Words associated with the term abuse included violence, domestic violence, control, power, gaslighting, vulnerable, rape, hitting and ignored. The words rape and sexual assault were more strongly related to the term abuse than violence by focus group participants.

Abuse is a broad term
There was consensus among the focus groups that the word 'abuse' was broad and included not just acts resulting in physical harm, but also harm to a person's financial, emotional, mental and psychological health and wellbeing. The Males-only focus group started the discussion by stating "abuse is a big term". The word 'abuse' was described by some focus groups as an umbrella term for violence, neglect and exploitation, with a regional-based focus group saying "all the words can be classed as abuse of some sort." A participant of the Deaf community focus group noted that "there are thousands of modes, methods of abuse, particularly in this online world." Another focus group noted that exclusion can also be a form of abuse. Abuse was also characterised by one participant as a "catch all" word that could be used by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to describe behaviours that may "fall through the cracks" of the language in the terms of reference.

Abuse could be experienced by people living with disability in a variety of settings, including the home, the workplace, school and other public settings. According to one focus group abuse can "be kept secret" when it occurs in private settings. Another participant noted that "abuse is normal" in the disability sector and that "it happens every day".

Gaslighting as a form of abuse
Focus groups did not often engage in in-depth discussions about physical abuse, with conversations instead turning to other behaviours that resulted in harm to people living with disability. For example, gaslighting was understood to be a form of abuse, particularly by the Female-only and Psychosocial Disability focus groups. Gaslighting was described by participants as a way in which an individual exerts control over a person living with disability through manipulating them to make choices that aren't in their best interests and having the person living with disability believe those choices are what they wanted all along.

Abuse of power

Abuse was strongly associated with abuse of power by the Regional, Males, Females, Physical Disability and Psychosocial focus groups. Abuse of power could be perpetrated by individuals as well as institutions.

A participant in the Males-only focus group stated, "abuse starts at the top… the government is abusing the trust of Australian people". Participants across a number of focus groups shared examples of where they felt abused by institutions including the NDIA and Centrelink. Abuse in this context was not physical acts of violence, but rather attitudes of staff and the perception that the system was working against the interests of people living with disability. Using the NDIA as an example, one participant expressed the belief that the cycle of NDIS plans and appeals was a form of financial abuse.

Some focus group participants also shared examples of where individuals who should occupy positions of trust, such as families, support workers and the police abused their power to the detriment of the person living with disability. Abuse of power could be experienced through subtle and gradual changes in behaviour of the "trusted" person. For example, one participant stated that support workers can initially act like they have the best interests of the person living with disability in mind, however over time the person living with disability finds the support worker is exerting more and more control over their life and pushing them to make choices that suit the support worker rather than themselves. The abuse of power by persons in positions of trust often had a negative impact on a person living with disability being willing and able to report the abuse.

Non-reporting of abuse
Many participants living with intellectual disability agreed that their intellectual disability was used against them when reporting abuse. One participant said they were told "you don't know what you're talking about" by police when they tried to report abuse. The perception they will not be believed as well as not knowing how to report abuse has a strong impact on a person living with disability being willing and able to report abuse.

The following table provides examples of the language and terminology used in the focus group discussions.

Table 4: Examples of language, phrases and terminology used when discussing the term abuse

Physical disability

- Physical, verbal and emotional
- Body language, control
- "Often really subtle, how it can start out being subtle until someone feels like they have more power
- Domestic violence is an example
- "It's [abuse] a hidden thing"
- Using positions to have power
- "Support workers – sometimes you have someone who might seem ok, but over time they start to push you in directions they want you to go. You find overtime they are exerting more and more control over your life"
- Victimisation
- Patronising behaviour, "we're doing you a favour by turning up"
- "We get disempowered"
- "Gaslighting – happens all our lives, we get told we're not as good as, so we believe that, therefore we (doubt ourselves), think we're overly suspicious but we're not"
- Other people blame you when something goes wrong – "scapegoating – everyone can blame the cripple"
- "There are no DV houses for people living with disability – it makes us more vulnerable, put up with abuse situations"
- Told you're being difficult if you stand up for yourself

Psychosocial Disability

- Abuse is something ongoing
- Abuse is systematic
- Anything that traumatises someone
- Abuse can be one off
- Something that is hierarchical (neglecting people's needs)
- Misuse of restraints and seclusion
- Self-abuse
- "Excluding someone is abuse"
- Abuse of position and abuse of power
- People on the ground are too scared to speak up in case they lose their job
- "There are so many different ways you can abuse someone"
- Someone who is vulnerable is more likely to be abused
- Legal definitions of abuse, what about other definitions

- "Something coming to you that's not meant to come to you that's not nice"
- Societal culture about what is acceptable behaviour towards other people
- Human beings like to hurt other human beings, it shouldn't happen, but it does
- "Not just about the definition of abuse, it's going to keep going on, it's going to keep happening, how do you mitigate it?"
- Recognising that a lot of things we have become desensitised to ('that was just a joke')
- Children or people living with disability won't speak up or aren't able to speak up
- Social media/online abuse
- The most insidious form of abuse is sexual abuse

Intellectual Disability (living in community)

- Rape, being raped, kids being raped
- Anyone can be an abuser
- "Normal people don't do this sort of thing"
- It is scary
- Can happen anywhere- pubs, malls, toilets, work, home, through video games, forums
- Emotional, social, physical, mental, financial
- "Rape you, they win, make you feel like you're the perpetrator. I was raped. Was treated like I wanted it. Made me feel guilty, feel so sick"
- Blame the government and the police
- Raped, scared to speak up. Who will you believe? If you have a disability, hard to tell people who don't have a disability
- At police station, "they say you don't know what you're talking about"
- Who to tell? Lawyer is expensive. Service providers stick up for their staff
- "They [services] treat us like dogs"
- "I don't trust cops at all. Told the police about a man who abused her in her home, he laughed and said he's allowed to live there"

Intellectual Disability (living in residential care)

- Someone hitting someone
- Someone being drunk
- Bashing people up
- Some parents abuse their kids
- Some fathers and men can be violent

- "It can be kept secret, not spoken about"
- People threatening you
- "Telling you to do what you don't want to do"
- Being broken into
- "I don't think about it much"
- Arguments at work
- Some people take drugs
- "If you don't say no people can take advantage of you"
- Violence is abuse
- Forcing people to have sex (sexual abuse)
- Physical abuse
- When people are mean to you
- You can be abused at work
- When I'm working people tend to give me shit about everything
- Police can be involved in abuse

Deaf community

- Not only one [Auslan] sign; it has to be context-driven
- "I picture physical abuse, punching, kicking, all sorts of that stuff, just throwing a chair and nearly hitting someone"
- "It is not only physical abuse, there's emotional abuse. There's mental health abuse, emotional abuse et cetera, psychological, and there are different signs that you would use to associate with that."
- "Someone walked past a deaf-blind person, with a badge saying, 'I am deaf and blind', knocked them, the deaf-blind person yelled out and they were just like "ugh", and walked off. But the person got a cut and bled. Again, is that abuse? "
- "I'm looking at that, if I was in the other situation and having this happening, exactly the same, would I think "You abused me"? I wouldn't think that way. I would see it in a different sense. I don't know that I would term that "abuse". I've never seen it happen. I don't know that that person abused my client. Again, it's got to be – the way I see it, it has to be a deliberate act. That was a bit of an accident walking past. I don't see it as abuse because I see abuse differently. "
- "I think there is violence and abuse, but abuse I feel as though it is more ongoing. That is where it becomes abuse, if it is an ongoing nature. Violence can potentially be a one off, but abuse, it depends on the line. Whether it's deliberate and recurring."
- "I think it can be anywhere and everywhere. There's so many different types of abuse, and I kind of see the word "abuse", as being the umbrella overall those other terms discussed"

- "I see that being the umbrella. It happens at work, school, family, people you don't know, people you know, even online abuse, Nigerian scams. Yeah, anywhere. "
- "There are thousands of modes, methods of abuse, particularly in this online world."
- First exposure to abuse at school: kids would slap their hands around in front of us as a way of teasing us "
- "There's a difference between intentional and non-intentional. I think that was an accident. Does it still fall in within the definition of "abuse".

Female-only session

- Abuse of power, psychological abuse
- "Gaslighting is making people doubt themselves – manipulating a person to believe that's what you wanted all along"
- People gaslighting about you to others
- Parents gaslighting their children living with disability
- Parents being verbally violent to kids
- People staring and you don't know why (and it's not always positive)
- Other people blaming their actions on your disability (e.g.: "I was speeding because of my daughter")
- "Other people using your situation to get support for them"

Male-only session

- Abuse is a big term
- Physical and financial abuse
- The NDIS itself is a form of abuse
- "The cycle of NDIS plans and appeals is financial abuse"
- "Abuse is normal in the disability sector, it happens every day, it happens every minute"
- Abuse stems from a lack of respect
- Being ignored or being dismissed
- Abuse starts at the top – the government is abusing the trust of Australian people
- Abuse and neglect are linked

Autism

- "[Abuse is] not always malicious"
- Abuse can come from miseducation, from misguidance
- "Communication is so important. Trust is so important. These are safeguards against abuse"

- "[Autism] Spectrum is a communication-based disorder. It is so hard because I can talk well but I can't always advocate for myself. People don't get that"
- Being silenced by being ignored is abuse
- "I think of violence"
- "I call it abuse when you are neglecting the needs of disabled people in your care"
- With abuse, it is actively choosing to do something to someone that is going to hurt them, whether it is emotional or physical
- "Neglect is not always deliberate. People aren't always aware or have understanding. They aren't trained properly so they do a form of neglect or a form of abuse, so it isn't always intentional"
- "Other people need to try to come to my world"

Aged 50 and over

- "Violence is abuse, bullying is abuse, exploitation is abuse"
- Seems to be a way to bring in sexual abuse
- "I take it to be a useful word in the terms of reference because it's a catch-all for anything that falls between the cracks… it broadens the ability of the DRC to consider anything that might be outside the strict meanings of other words"
- "It is highly abusive if you can't include people"
- Not recognising the people directly
- Using someone or something for your own gain over and over again and not giving back
- "If you don't understand the culture and diversity of this country, you are going to make huge mistakes"
- Ignorance is not abuse (in a cultural context)
- Abuse of power, the government, agencies

People living in regional areas

- "All the other words [talked about in focus group] can be classed as abuse of some sort"
- Abuse of power – happening more now that NDIS has come out. Huge issue trying to find appropriate support workers. E.g. trying to make everyone from a shutdown mill become support workers
- Hard to get male support workers who are not power hungry or want to lauder of someone
- Lack of understanding about disability
- Making environments inaccessible is a form of abuse
- By living in a small town, your options are limited in where you can go and once you can't go to some places, the number of places you can go to are very few (and therefore increased isolation).

- People living with disability that are verbally abused, don't go to those places anymore. This restricts where they can go. This rules out more places in this small community that people feel they can go.

5.3 Findings related to the term 'neglect'

Summary

Many participants described terms such as "people not caring" or "needs not being met" as being linked to their understanding of the term 'neglect'. The concept of being vulnerable was also discussed at multiple sessions in reference to neglect. There was also discussion in some groups of how neglect is different to other terms discussed and one participant said that for her "abuse is doing something, neglect is not doing something." Words and phrases associated with neglect by participants included not caring (about something or someone), lack of (something), isolation, discrimination, not looking after something or someone and being left out.

Limited understanding of the term neglect

Participants living with intellectual disability tended to have limited or rudimentary understanding of the term neglect. One participant stated, "It isn't a word I really know" and others at the focus group agreed with this. Facilitators had to supply examples or prompts relating to the term neglect in order to encourage more discussion. For some participants, they more readily understood a description such as "not taking care of people living with disability" and for others the strongest association with the term neglect was around children being neglected, such as being left in a car on a hot day or not being fed properly. For participants living with intellectual disability who are based in residential care the discussion kept coming back to neglecting pets and animals which was distressing for some. It was clear that for this cohort, the term 'neglect' as related to people living with disability was not a familiar or recognisable term.

Neglect from services

For other groups, discussion of the term neglect led to conversations around feeling neglected by government agencies, welfare systems, the health system and services. For people living with psychosocial disability neglect was viewed as a lack of services or funding (for individuals and for systems like hospitals and considered through examples such as a lack of access to basics like food and shelter).

Other participants spoke of neglect when reflecting on their time in educational settings, both school and tertiary settings. For people living with autism, discussion of school and examples of neglect was a significant focus of the conversation. One participant from this group described her experience in high school:

> "The school was completely neglecting for me to have a safe space to go to the toilet, people would slide under the doors and do all kinds of things, no teachers in the toilets so kids can get away with a lot more stuff. This is a form of neglect."

Another participant spoke of a lack of understanding or specific training from her high school teachers as contributing to what she had perceived as neglect during her schooling, now some years ago. She described both broader issues but also everyday issues that over time had a significant impact on her experience with schooling: "So many times my sandwich got thrown out by my teacher because no one used to get that I eat slowly, I pick, it is a spectrum thing."

Neglect of Sensory or Social Needs

Some participants spoke of social or sensory needs not being met and this was considered by them as neglect. In particular, members of the Deaf community provided the following examples of neglect:

- deaf people neglected by the wider community as they can't communicate
- people don't take the time to understand
- being excluded through lack of communication access
- being isolated in the workplace
- pressure to use spoken voice even if a person can't do so/is not comfortable to do so

One Deaf participant who uses Auslan stated:

> "I think that in the workplace, people might initially start off being excited about a new deaf colleague or make an effort when it comes to communication, but it can only be a matter of weeks that that connection interest wanes, and deaf people, I think, feel very isolated in the workplace and then it starts a bit of a divide. That's certainly been my experience in the workplace."

Impact of neglect

The impact of neglect was discussed by participants at several focus groups, with people living with intellectual disability stating that they thought they weren't on the same footing as non-disabled people and that this "plays with my mental health." Other participants from this cohort discussed neglect in terms of things not getting done, or not receiving what one needs, people not listening and the impact of this: "[I] don't have freedom and control, depend on others. People make me feel guilty for wanting my needs to be met. They [care workers] make you feel like you're using them."

Participants living with autism also discussed the impact of neglect for them. One female participant said:

> "I feel that on a whole our needs, our sensory needs are really neglected. I worked at a workshop, in a steel and concrete packaging factory. I installed a sound and decibel measure on my phone, and it was very high, it was overwhelming to deal with. I was constantly exhausted from sensory overload but no one at the job thought it should be a problem for me. No one cared."

The following table provides examples of the language and terminology used in the focus group discussions.

Table 5: Examples of language, phrases and terminology used when discussing the term neglect

Physical disability

- "I think of my life"
- People not caring
- Not being told about services that are available
- Vulnerability goes hand in hand with neglect
- "We are not inherently vulnerable, we are vulnerable because we are neglected"
- Family, friends forgetting about you
- "Being left, and you're just on your own"
- People having a low care factor
- Emotional detachment
- Neglect by the whole of society – if you listen to the media – we either get totally ignored, totally stared at or patted on the head
- Inspiration porn
- Minorities – women, "blacks", LGBTQI, elderly, indigenous – indigenous will always get mentioned as a disenfranchised minority but not us
- Hospitals treat sickness, not disability   "Charities portraying us as poor, incapable"
- "Public health system, the way people living with disability are treated – not entitled to surgery because I'm 64 not 70"
- "When you're in hospital with a physical disability you get entirely neglected"
- Neglect in group homes
- Assumptions being made about your condition

- Not being allowed to take your carers into hospital – the staff barely even know how to use a lifter
- Discrimination is a form of neglect
- Neglect happens on a lot of different levels, private public, medical commercial, charitable, but probably happens the most with support workers at home. Not having the training or capacity to help me with my personal care, or not making me feel comfortable enough to trust them to help me with my personal care.
- Carers doing personal things when they are supposed to be helping
- We never get any training in how to be a boss to support workers, this is neglect

Psychosocial Disability

- Lack of services, Neglect by services
- Lack of funding (for individuals and systems like hospitals)
- Turning a blind eye
- Lack of access to basics like food, shelter
- Agency, owning your own life
- Neglect is psychological as well
- If basics aren't being met, that person is being neglected
- Neglect comes with a lack of compassion or empathy
- "Neglect = someone chooses to neglect you"
- You can be neglected from having a social life because of disability
- Systemic and organisational neglect
- Abdication of responsibility, lack of duty of care
- Lack of access to complaint processes

Intellectual Disability (living in community)

- "It isn't a word I really know"
- Parents not taking care of children
- Spending money on cigarettes instead of on what people need
- Leaving children or dogs in the car on a hot day
- Old people not being taken care of
- When you feel alone
- Things not getting done
- "I can't read, people make fun of me"
- "Mum neglected me"
- "People not listening to you"
- Not getting what you want e.g. clothes and money
- Live in a house with others living with disability, one person left, had damaged house, people won't fix it
- Housing Trust neglects to fix the bathroom
- Governments do neglect you – doctors, health and safety

Intellectual Disability (living in residential care)

- "Special schools, I think of special schools"
- Suffering

- "If I don't feel like walking, my care worker says "you're using us for petrol", calls me lazy. "I don't have freedom." They make you feel like you're using them."
- "Neglect through ignorance", lack of action e.g. campaigning for more cab vouchers, had to cut back on appointments and can't have a normal social life. No one is listening.
- Not asking for handouts, put on same level as an able-bodied person.
- People neglect whatever pet they have, they should actually be more responsible
- " I don't know what neglect means"
- Keeping people locked up for hours
- "Abusive is another word for neglect. Neglect can be abusive, offensive, racist to Aboriginal people""
- Violence against women and children
- People with walkers and wheelchairs – people ignoring them, they might need help to cross the street or get somewhere
- "When you care for each other that's not neglect"
- "Adoption is neglect, I was adopted and then given up"
- "Neglect happens all the time"

Deaf community

- "There are various signs to depict neglect. It depends on context. Again "it is painting that picture about neglect". I don't think there's one sign. "it's story driven"
- "You might say "I'm getting engaged". I will go "I don't care". Does it mean I'm neglecting? Maybe not, maybe so. It's just varied. "
- "Like forgetting something. I've neglected to do something. Or not even thinking. Not even thinking about that particular situation. I normally neglect things because I don't think of things."
- "I think a violent act is more than likely deliberate, but neglect can be uninformed and not intended"
- "when I'm in a deaf community, a deaf party, a deaf workplace or something like that, I feel a part of it, I feel normalised, but when I'm in a hearing community, hearing only with not much sign at all, things like that, if I sit for an hour, like, for example, if there were no interpreters here, I feel that would be neglect, I would be neglected because everybody else is able to have a good time, et cetera. … You feel like you're not part of what's going on and you want to get out. … You can't blame the hearing community, because not everyone knows sign, it's not their fault, but at the same time you still have those emotions.… We go through the same thing. It's the same experience. So that neglect is there."
- "Not looking after your children. That could be anyone, not necessarily disability, not feeding or clothing them properly. That could be neglect or there's social neglect what you're talking about."
- "I think that in the workplace, people might initially start off being excited about a new deaf colleague or make an effort when it comes to communication, but it can only be a matter of weeks that that connection interest wanes, and deaf people, I think, feel very isolated in the workplace and then it starts a bit of a divide. That's certainly been my experience in the workplace."
- "Maybe another thing is I think that when deaf people don't speak, so people don't use their voice, either because they can't or they don't want to, they're not feeling comfortable doing it, then I feel like those people who don't speak are given even a harder deal or a really raw deal. People expect that if you can use your voice that you will because it will remove the responsibility of that person to have to learn how to communicate with deaf people. "
- "I think everyone experiences neglect in a different way and when it comes to our interactions with the broader community, it is very frustrating. You think why are they not taking time to understand us? Why are they not taking time to understand the way we do things. So much so that you get the impression that they're thick heads, that it's just not getting through.So I think the broader community

not taking the time to learn about us, to understand us [deaf community] and so I feel like the broader community neglects us, neglects people with a disability. "

Female-only session

- Social isolation
- People neglect your independence and abilities
- "People could be there physically but in reality they aren't supporting you"
- Not caring about your physical or social needs
- Neglect can be the assumption that another person/department will take responsibility for something (creating gaps)
- Neglected by agencies or systems
- Slow processes make it feel like you are not being heard
- "You can't get better otherwise you'll lose your financial and other supports"
- Neglect can be lack of access to education around services ("knowledge is power")

Male-only session

- Discrimination is a form of neglect
- Oppression
- Psychological intimidation
- Indirect discrimination (treating people the same when they're not)   Systemic neglect (e.g.: lack of appropriate infrastructure)
- Neglect relates to safety
- Neglecting to take into account impact of initiatives like electric scooters on footpaths

Autism

- Lonely and left out
- "The school was completely neglecting for me to have a space safe to go to the toilet, people would slide under the doors and do all kinds of things, no teachers in the toilets so kids can get away with a lot more stuff. This is a form of neglect."
- "If I pulled my pants all the way down [at school in bathroom], people would pull them. I stopped pulling my pants all the way down so I could hide from the kids knowing which toilet I was in."
- "Mental health needs can be neglected. There were very little services when I was in school, maybe if there has been more services they could have picked up on my trauma issues "
- "That [neglect] is why I am PTSD. There is so much that has happened, it has been neglect by hospital staff when I have been in institutions, and by GPs. "   "So many times my sandwich got thrown out by my teacher because no one used to get that I eat slowly, I pick, it is a spectrum thing That [trauma] is my whole life."
- "I feel that on a whole our needs, our sensory needs are really neglected. I worked at a workshop, in a steel and concrete packaging factory. I installed s sound and decibel measure on my phone, and it was very high, it was overwhelming to deal with. I was constantly exhausted from sensory overload but no one at the job thought it should be a problem for me. No one cared"
- "I got to the point where I was so scared of going to the toilet. I used to catch a bus at 7:30 am and go to bathroom near bus, go to school and not go to toilet all day and then go back to bus stop and go to toilet at shops again. Because if I went to toilet at school, I'd get beaten up"

Aged 50 and over

- "people living with disability don't get what they need to achieve in life"
- "Promising something and not following through"
- "Not having needs met, whether it's physical, social or emotional"
- Neglect is "missing the voices of people with disability"
- Failing to engage someone, failing to have a mechanism to give someone meaningful input
- Leaving someone out of the conversation
- Support workers missing a shift lead to people lying in their own shit for 12 hours
- "Lack of will to meet the needs"
- "When you need something and it's not followed up"
- People not having patience
- Discharging someone from hospital without the help they need
- Governments spending money on re-fitting planes, that money could pay for a lot of support workers
- "Neglect covers a lot, it's not just governments, it can be families "
- Young children looking after parents who have disability
- "Omission is neglect "

People living in regional areas

- We are all human, so we all have a human response
- Getting something taken away from you (such as a car)
- Need to be tolerant when you are feeling neglected because otherwise you will react?
- Taking away your independence.
- Neglect is when we don't do what is most important
- Neglect is about the disabled person "neglecting" things, such as jobs around the house.
- Lack of money can lead to neglect. You don't have as much money to do everything on "their list."
- Lack of control over money is a form of neglect.
- Professional people (i.e. GPs etc.) don't give enough time for what you need – this is neglect.
- People don't get the same level of support when they are on Medicare as people with private health (or other "public services")
- "Can't always say what I need to say due to brain injury, which leads to lack of services or being "thrown around."
- People are asked to sign documents they don't understand.
- Financial independence taken away from people
- Child neglect (not feeding them etc.)
- "Neglect at schools = missing out on education"
- Neglect in hospitals. Drs not having enough time to communicate with people that can't keep up.
- Lack of equipment funded through the NDIS
- Lots of neglect in country towns due to closure of services. (government services are being closed down before new NDIS services are available).
- "Quite often disabled people neglect their own physical and emotional health, and so do carers because they don't have the time or the training"
- "The neglect of ppl you're supposed to providing a service for, neglect in the community, not looking or for making provision for people that need different things"
- "To me neglect is something not being done that needs to be done so that someone can live a normal, healthy life"

- "Abuse is doing something, neglect is not doing something"
- "It's a broad term and when you start to dig down, there are more layers"
- "Neglect is the inverse of abuse, where you're deliberately looking over details because you don't care about the person"
- "Sometimes it's how you were raised… if you don't know any different"

5.4 Findings related to the term 'exploitation'

Summary

Similar to the term neglect, not all participants understood the term 'exploitation'. In fact, this was considered to be the trickiest of all terms discussed with one participant living with intellectual disability saying, "I've heard of the word, but I don't know what it is." Another participant who also lives with intellectual disability and is in residential care said, "unless you've had a problem with it you don't know the word."

Across all focus groups, exploitation was discussed using language such as people being used, taken advantage of or being preyed on due to their circumstances or vulnerabilities.

Exploitation by services and systems

There was a lot of discussion around service providers and individuals using people living with disability for their own benefit, be it money or praise, to feel better about themselves or some other motivation. This was particularly the case for people living with physical disability. One participant said: "we are seen as an easy mark, because we have a need for them [services] they can take advantage of us."

For other participants, there was consensus that the word "disability" allows people to charge more for goods and services: "The 'commercialisation' of disability is exploitation – [disability] has become a mega industry." For other participants, the term "exploitation" was associated with exploitation by charities, situations where people living with disability are being portrayed as "cripples" or "poor" just to encourage more donations. For members of the Deaf community, examples were given whereby including a person who is deaf can occur with disingenuity: "related to the deaf community, I'm thinking of being on a Board and they try and get people on a Board but do they really want to use their expertise? No. They're exploiting them to say they've got deaf people on the Board. It is a tokenistic thing."

For other participants, there was discussion of people living with disability being exploited by disability services and systems in relation to much-needed equipment. Many participants agreed that the cost of disability equipment could be seen as exploitation. One participant who uses a wheelchair described her view: "As soon as 'medical' or 'disability' is put before a product it adds double if not more to the cost of a product. It's like weddings, except with weddings at least the bride might have a nice time. We [people living with disability] don't have a nice time."

Emotional exploitation

Some participants spoke of emotional exploitation, giving examples such as exploiting kindness and taking advantage of a person living with disability's situation of having "a lack of real friends". Participants described scenarios such as other people promising to pay money owed, but then this never eventuating.

For people living with intellectual disability, participants described "being used in your own home (for example) people staying over (and) using (your) phone." One participant said, "People see what they can get out of you."

For one participant who has experienced a brain injury he described having memory issues and how he is not always aware that he is being exploited: "Sometimes I don't know they're doing it."

In contrast, other participants described being aware they are being exploited, but stated that they let it happen as they don't have other friends, they are lonely, and they want to fit in. Several participants agreed that this happens but they are "used to it."

Exploitation of rights

There was discussion of exploitation in terms of wages paid to people living with disability. More broadly than that, there was a discussion in many groups around exploitation of people living with disability being a human rights issue. An example was provided by people living with intellectual disability who explained that, for them, exploitation can be linked to their disability, such as being short-changed in shops, or people assuming they don't understand official processes.

Participants with autism discussed exploitation of their human rights, including disrespect of their needs in relation to employment or contribution to organisations. One participant described her experience in relation to this:

"When I was young, I was a peer educator for a program, I was always compensated but then there was a set up within a hospital where they wanted to use us to help but they don't want to give us anything for it. It is exploitation to just expect that because you can do you will do. They wouldn't try this with neurotypical people."

The following table provides examples of the language and terminology used in the focus group discussions.

Table 6: Examples of language, phrases and terminology used when discussing the term exploitation

Physical disability

- "As soon as medical or disability is put before a product it adds double if not more to the cost of a product. It's like weddings, except with weddings at least the bride might have a nice time. We don't have a nice time"
- Commercialism is disgusting, they take advantage, it's major exploitation of disability
- "Need a $200 OT assessment for a ramp you can get from Bunnings for $50 '
- "Charities exploit us. Now most charities have volunteer workers… but they have CEOs, staff that are paid well, exploit us by portraying us as pitiful… they get the money off the people and they make sure their asses are well padded before we get any of it. They'll use the most terrible exploitive advertising to get money"
- "They [disability systems/government bodies] commercialise us"
- "[Disability] has become a mega industry"
- "People exploit disabled people to make them feel better about themselves"
- Taking advantage of someone
- Greed (causes exploitation)
- Abusing our funding, e.g. the cost of OTs
- Government making decisions about what you can and can't have
- "Unless you have lived experience or knowledge and knowhow, they [systems, professionals] come into our world and they don't understand"
- "People living with disability are seen as an easy mark because we have a need for others they can take advantage of us"
- "See that [exploitation] in schools where young people are bullied, even we are bullied"
- People have a power, warm, fuzzy addiction– they control disabled people, get warm fuzzies through praise from other people or money
- "The NDIS, they are taking over our lives so they can earn the money. It's a money-making scheme"

Psychosocial Disability

- Taking advantage of someone
- NGOs – profit for purpose – conflict of interest – danger of them exploiting people with disability for profit
- "[exploitation] was happening even before the NDIS"
- Exploitation – using inside knowledge to get financial benefits from government
- Being used as a medical subject by doctors

- Exploitation can be the long-term consequences of neglect that happened in the past
- "Exploitation is dangerous, it's a silent assault"
- Lawyers exploit disabled people – "your case costs a lot because they had difficultly dealing with you because of your depression"
- "I couldn't stop it (exploitation)" because advocates weren't available (6 months wait list for disability advocate)"
- "Unconscionable conduct "
- Plan managers, service providers. Only need to look at NDIS Grassroots Facebook page to see the exploitation
- "If a bank takes advantage of you they are liable for $1.2m in fines, but if you're taken advantage of by a payday lender (who take advantage of people who are stressed)"
- "Support workers persuading disabled people to hand over money, make them a beneficiary in a will"
- Support workers who keep talking about being a person's friend, not that they're there to help them find friends, it opens the door to people thinking that 'well I give my friends presents'
- "NDIS saying we'll provide support if you do our programs"
- "Can't do anything about medical exploitation by doctors"

Intellectual Disability (living in community)

- Money being taken from you (financial exploitation)
- I don't understand that term, I don't use that word
- Sexual abuse
- Taking things
- Using/Taking advantage of the vulnerable
- Taking things out of your house
- "Someone uses you up e.g. money "
- Someone comes to house and stays there i.e. exploiting my kindness
- Manipulation
- People talking about you behind your back e.g. on Facebook
- "People use your disability against you"
- "I can see she's doing it [exploitation [, let her. I'm used to it. " "Alcoholics and drug addicts stay at my house and it's hard to get rid of them. Have a crush on one guy, he is exploiting me emotionally"
- Wasting your time
- Use your food
- Drunk people using phone
- Using washing machine, fridge. People say they will give money (e.g. for washing machine, food) but they don't
- "Sometimes I don't know they're doing it"
- "I try to make friends, kind heart, want to fit in. No family and no friends, too lonely, make the wrong friends."
- "When shopping, try to get right change, I am not good at maths. I just assume it's [the change I get] right. "

- People see what they can get out of you.

Intellectual Disability (living in residential care)

- "I've heard of the word but I don't know what it is"
- Taking advantage of you [using you] for money
- Use people for getting what they want
- "I've been blackmailed"
- Making a disability person do all their [someone else's] housework
- "You need to tell someone if you are being taken advantage of" "Unless you've had a problem with it you don't know the word "
- Take advantage of a person's colour (race)
- Ignore the people who are nasty to you
- Take no crap
- "Taking advantage of", or "using", these are better terms than "neglect"
- Getting cheated on by a partner

Deaf community

- "For me when you say that word, I think of taking advantage of people. Like, for example, you do something for me and that means I don't have to do it, or you might say "You go and do this, but I will take the rewards from it", like money, for example. Overseas you see child exploitations, they get dolled up and the exploiter is taking the rewards from it, taking the money from that.
- "Related to the deaf community, I'm thinking of being on a board and they try and get people on a board but do they really want to use their expertise. No. "They're exploiting them to say they've got deaf people on the board. It is a tokenistic thing."
- "It's difficult to explain for many reasons, but I feel as though there's a barrier to it. I don't think there's enough information around that word that the deaf community would understand that word." "I think personally speaking, I don't use that word. I don't use it in my normal vocabulary. I wouldn't use it. I might have in my 20s but not now I'm over 50. I haven't used that sign for a long time. "
- "The light way [of thinking of exploitation] – kids ask mum for some money. But there is a serious way [of thinking of exploitation] that can be harmful."
- "With the NDIS, people are being taken advantage of e.g. support worker claim for shifts they didn't do or an allied health worker, OT or physio. OT claiming for more travel than they actually did. "knowing that, someone on a disability, they get this money on NDIS, thinking of ways of how can I get my hands on that money. That's what I think about with "exploitation."

Female-only session

- "Exploitation leads to violence "
- People using you for your disability to get something for themselves
- Exploitation takes lots of forms

- People suggesting things for you that actually make things easier/more profitable for them
- Sheltered workshops are a form of exploitation
- Employers might get grants to employ people living with disability but when the grant money runs out the job disappears
- People living with disability exploited by employers who are seeking to have building modifications made and once the modifications are done the job disappears
- "It's expensive to be me"
- Taking advantage of someone's misfortune
- Charging heaps of money for a disability item or service
- Sneaky service providers not disclosing when they will start charging more
- People living with disability being used as "inspiration porn"
- Journalists not being careful with the language they use around people living with disability
- Charities using the sympathy of others for their own benefits e.g. making gains though pity"
- Employers say they can only employ you if you go through DES provider

Male-only session

- Taking advantage of people living with disability
- Australian Disability Enterprises are just cheap labour
- "Being paid $2 an hour is not good for anyone" No opportunities for advancement
- Exploitation of people with disability by "self-serving" organisations working in the disability/homelessness sector ("they are only concerned about keeping the organisation open")

Autism

- "When I was in high school, people could do something or say something that would upset me and I would have a meltdown and they'd do it on purpose "
- "I try very hard to not let people know what my vulnerabilities are "
- "Exploitation of our humans right, disrespect of our needs and our rights, it is exploitation"
- "When I was young, I was a peer educator for a program, I was always compensated but then there was a set up within a hospital where they wanted to use us to help but they don't want to give us anything for it. It is exploitation to just expect that because you can do you will do. They wouldn't try this with neurotypical people"
- Poorly paid wages for people living with disability
- "I remember one of my old workplaces, one job I did was dismantling old electronics for recycling and they told me I should be able to dismantle a certain amount of kilos per hour but who were they comparing me against?"
- "The government thinks that people who are intellectually disabled are getting social benefits so they don't pay them properly "
- "Sometimes when you get asked to do something, you don't get offered anything for your time. People want to exploit your intellectual property, your lived experience but they don't want to pay "

Aged 50 and over

- Taking advantage of someone's naivety
- You don't have to have a disability to be exploited
- Employment arena
- People in receipt of funds and people who take advantage of that and use the funds for their own purposes
- People living with intellectual disability are vulnerable, rely heavily on family and friends to make sure they're not being ripped off
- "If you have a disability and you're doing a job a person without a disability could do you should be paid equally"
- Bullying associated with exploitation (exploitation is a form of bullying)   Sheltered workshops – workers are "appallingly exploited"
- People living with disability might let (bad behaviour/exploitative behaviour) escalate by not speaking up
- "Not knowing where to go to raise concerns can make exploitation worse"
- "You don't have to actively take something from someone to exploit them"
- "The system in and of itself creates a situation where exploitation of people's busy-ness, capacity to move, lack of education or knowledge of services, constitutes a kind of exploitation"
- "Creating a system that doesn't work by not being available after hours or online… is in and of itself a kind of exploitation

People living in regional areas

- "The vulnerable people are exploited – people see anyone in community that's vulnerable and exploit that, especially people with intellectual or physical disability"
- "A disabled person can exploit something. I sort of do it as a joke because the things I can get away with in a wheelchair is hilarious"
- "I've seen other people guilt parents or carers into feeling sorry for them, suck the life and energy out of those other people"
- "Services and products we can get access to in community – I can get it for free, I don't need it but give it to me anyone – makes it hard for other people because services getting clogged up with requests they don't need"
- Employment – hourly rates (underpaid), not given the same amount of hours as someone without a disability "You've got a disability, you're a liability, we don't want you"
- Being asked to do things for nothing [council asking participant to join committee but not offering payment]
- "You get over being expected to do something for nothing. There is such an assumption that people living with disability have all this free time"
- People living with disability are seen as an "easy target."
- They are more likely to have people hit on them
- It can go the other way – people living with disability may be extremely smart and people exploit that as well   "It's not the carers but the people who organise stuff, their exploitation is just astonishing. The client feels they should be grateful for things, but they don't realise they are actually paying for the service and they have the right to choose their carer."
- "Exploiting people who don't have the support network to back them up"

- When you've taken on someone else's job they're supposed to be doing because you have a disability
- People are judged based on the way they look
- "I can't remember who I have lent money to, so people take advantage of this. I overhear people saying, "he won't remember, so don't worry about it.""
- People exploit the fact that people living with disability aren't able to do something, by charging more.
- There has been a shift towards people living with disability being treated more equally in regional areas over time (participants think things are getting better).
- "You can exploit someone without knowing you've done it, but more often than not it's done without a guilty conscience"
- People make assumptions about people living with disability (in particular, what they can afford)

5.5 Findings related to the concept of 'safety'

The term 'safety' was readily associated by participants with themes of safety in one's home and while out in public/community settings and strategies that are important for people living with disability to keep themselves safe. Words associated with safety included protected, certainty, stability, family, police, communication, familiarity, vigilant and understanding. The term safety was heavily connected to themes of abuse and maltreatment. As such, discussion of safety led to discussion of abuse and related topics.

Different types of safety identified

Participants viewed and discussed safety in various ways, including physical safety, emotional safety, psychological safety and environmental safety. Environmental safety tended to be discussed in terms of accessibility in the community. Participants spoke of emotional aspects to safety including feeling unsafe, experiencing emotional abuse and feeling vulnerable in relationships, community settings and workplace settings. People living with psychosocial disability discussed psychological safety and the concept of 'gaslighting', which is considered to be manipulation by psychological means into doubting their own sanity. This term was discussed with reference to potential manipulation by people in positions of trust in medical and legal settings.

Key differences between groups

There were differences in the way safety was discussed between the groups included in this project. For instance, participants living with intellectual disability tended to speak of other people or

services providing safety or helping them to feel safer. For example, they referred to calling police, using emergency services and reliance on family members or other close supporters ("I just call my mum"). For many people living with intellectual disability, safety was discussed in terms of physical environment factors such road safety and water safety and being safe when you are out as a group ("if we get lost, we have a contact number, a phone").

In contrast, people living with physical, acquired or psychosocial disability tended to discuss safety in terms of needing to keep safe from the actions of other people or from systems. They talked about safety in familiar environments and being at greater risk to the actions of others owing to living with a disability ("Safety is certainty, people living with disability live with uncertainty, like not knowing if you can get out of bed in the morning if your support worker doesn't turn up").

In addition, participants representing the deaf community associated safety with having access to information: "For deaf people, it's also about access to information, being able to communicate with people. That makes me feel safe, and you're much less vulnerable if you have that access. Obviously, access in sign language for deaf people makes me feel safe."

Strategies related to safety

Many participants discussed what is important for them to feel safe. For many, this was about familiarity, such as being in familiar settings or with familiar people. This was especially the case for people living with physical or mobility-related limitations as they tended to focus on being aware of physical access issues or trip hazards as a key strategy to ensuring their own safety. This was a key focus for people living in regional areas where local councils are being lobbied to attend to community access issues. For others, having trusted relationships with people in their life was identified as a key strategy around safety, particularly around paid support workers.

The following table provides examples of the language and terminology used in the focus group discussions. These have been separated into categories reflecting the focus groups we ran:

Table 7: Examples of language, phrases and terminology used when discussing safety

Physical disability

- Knowing your environment, having your environment protected – so you can see if there are any changes, things happening that shouldn't be happening
- "Having people let you know who they are when they knock at the door"
- "You need to have certainty and stability"
- Something has happened that has made you feel unsafe even if you can't pinpoint it

- "I want to know I can leave somewhere – I've had a few situations where I have felt very unsafe and because of my disability I don't know if I can leave"
- Being able to genuinely depend that people will do what they say in a way that you have explained what you want

Psychosocial Disability

- Safety is often thought of in the physical sense, and psychological safety is ignored or not considered
- Safety risk can be overt – put downs, but it can also be more subtle
- Environment or social situation impacts safety
- No one can understand (mental health) unless they go through it, it's not recognised ("oh cheer up, at least you haven't got it as hard as people in Africa")
- Feeling safe enough to feel listened to, and not put down or ridiculed
- If co-workers and managers persistently using negative language about mental health/disability, then the worker feels inadequate or not doing their job properly. This makes workplace unsafe
- Workplace safety – psychological safety isn't part of that agenda
- The nature of safety depends on the nature of the disability
- "Even if the language isn't directed at you, you can still be impacted by it"
- Flippant comments threaten safety like "have you taken your meds lately?"
- Stigma is alive and well
- Medical arena – gas lighting that occurs after you have a long-term doctor patient relationship with specialist – don't tell truth, get paranoid about litigation – no access to justice as legal aid doesn't give advice or cover it
- Access to justice: "feeling safe is to be respected when you're going through that process"
- No one will believe you
- Doctors bullying patients
- Safety from suicide ideation

Intellectual Disability (living in community)

- Being taking advantage of
- Don't talk to strangers
- "I feel safe at home with people I know"
- "I feel safe in my bedroom"People without disability use you
- "I've been locked up when I was younger"
- "My children were taken away, it's happening still"
- "My family shamed me, they say cruel things, ignore me"

Intellectual Disability (living in residential care)

- When you go out you should go as a group
- "If we get lost, we have a contact number"
- "The police make me feel safe, and the firies and ambos"
- "Staff look after us, make us feel safe"

Deaf community

- "Auslan is the language of the deaf community… the reality is, Auslan is our first or preferred language… it's where we're comfortable"
- "For deaf people, it's also about access to information, being able to communicate with people. That makes me feel safe, and you're much less vulnerable if you have that access. Obviously, access in sign language for deaf people makes me feel safe."

Female-only session

- "Safety means having strategies to help make you feel secure"
- "Being educated on your rights and processes to use if your rights have been violated"
- Safety in the home, including doing things for yourself safely
- Feeling more unsafe if your disability isn't visible
- Feeling safe by having access to information
- To contribute to safety there needs to be more community education
- In reality, people with disability experience violence in high numbers

Male-only session

- Feeling safe in your own home
- Living on your own makes you more vulnerable
- Safety in the workplace, not just physical safety but safe from emotional stress
- "My dog helps me feel safe"
- "Society is getting worse because people are angrier and putting others at risk"
- You rely on others to help you feel safe (like workmates) but they can leave

Autism

- "Multiple levels of safety for myself; for my family the biggest factor is emotional safety. When I am in the throes of a shutdown, I am not capable of attempting to explain it, all I can hear is my blood pumping"
- "How you feel is disregarded and trampled on, especially by therapists or friends who don't understand, this is a safety issue"
- "When I was a little girl, my mum's voice and the words she used were the only real safety I had, especially when I was having a meltdown. She'd use the same words and it would bring me back"
- "Creating education creates safety"
- "Having an understanding and to be educated within what a person's needs are and looking at why the behaviour is happening rather than to just squash the behaviour, this will stop it becoming an unsafe situation"
- "It is so important for children with autism at school to feel safe. I had many instances at school where I didn't feel safe, neither physically or emotionally. There were so many times I got locked in a room, or pinned down"

Aged 50 and over

- "Being able to communicate with your support worker… because it helps me to communicate what my needs are and how it would benefit them in keeping us both safe"
- Vulnerability

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- An awareness of your self
- "The need for regular, constant vigilance about what it's like to be a woman moving through the world and even when it comes to living in your own home I lock my doors when I'm at home and lock the back gate"
- "I'm hypervigilant… every time I step out the door I'm anxious and fearful"
- You don't ever feel safe
- "You don't want to get knocked over"
- All these issues are solvable by common sense and civic courtesy
- "The need for vigilance is heightened because prior to having a disability… I felt it was likely I could fight back… but now I'm less confident about that"

People living in regional areas

- Do things slowly
- Need to be aware of your own capabilities
- Councils need to understand what makes things accessible and safe for people living with disability – concerns around architects not being aware of these things.
- "Disability workers – if you're a carer you have to show people can trust you and you respect their boundaries, but if you're a client you've got to show that back too, that you respect them as an individual and show that you're gonna do your best to make sure they're safe too"
- Knowing your limitations
- "There's plenty of people out there to con you, whether you have a disability or not, but people with disability are often looking for relationships and friendships and they're offered on a plate but they're not actually what they seem"
- All the advertising online "buy me buy me" – it is very hard to filter and know what is a good thing and what isn't
- There should be set rules around how to build accessible facilities.

5.6 Findings related to the concepts of inclusion, belonging and self-determination

Summary

The last section of each focus group was dedicated to exploring participant understanding of the terms 'inclusion', 'belonging' and 'self-determination.' These terms were not always readily understood by focus group participants, in particular, the term self-determination. While on the face of it these concepts have positive meanings, the focus group discussions were often characterised by negative feelings owing to the absence of inclusion, belonging and self-determination in the lives of people living with disability. These terms were often seen as aspirations rather than reflective of participants' current realities.

Inclusion

Summary

Words associated with inclusion were acceptance, welcoming, friendly, equality, accessibility, positive. Inclusion was generally understood by all focus group participants and was discussed in terms of what it means but also what it does *not* mean.

What inclusion isn't?

For many focus groups, the discussion of the term 'inclusion' started with examples of what inclusion does not mean. The focus group of people living with disability aged 50 and over remarked that inclusion means "not being treated any differently" and "not being ostracized." This cohort, together with the regional focus groups also felt that inclusion means "not being discriminated against." The regional focus groups also highlighted that inclusion means "not just accommodating someone's physical needs." The female-only focus group commented that inclusion does not mean equality: "Inclusion means everyone getting what is appropriate to their needs, not everyone getting the same thing."

What inclusion is

The focus group discussions revealed that inclusion could be both felt and physically demonstrated. For example, the focus group of young people living with disability (aged 18-30 years) noted that feeling "accepted" was a form of inclusion. Participants living with an intellectual disability discussed how "being part of a team" led to feelings of inclusion and that being included makes them "feel happy".

Inclusion was physically demonstrated when the design of buildings, footpaths and signage has considered the needs of people living with disability. Practices such as "quiet hour" in supermarkets were also understood to demonstrate inclusion. Participants in the regional focus groups noted that inclusion can be more difficult to achieve in rural areas, although they did not go into detail as to why that is so. Members of the Deaf community described how hearing loops, lighting and visual fire alarms in buildings demonstrated inclusion of people living with hearing impairments. A member of the females-only focus group stated, "inclusion is the opposite of segregation".

Inclusion is being part of the community

Inclusion with the community, rather than activities or programs designed specifically for people living with disability, was fundamental in achieving a feeling of inclusion. For example, a member of

a focus group of people living with intellectual disability said that "getting involved with the local community" was a form of inclusion. Supports offered through the NDIS were also seen to help someone be part of the community and thus achieve inclusion. For example, a member of the Deaf community said "if the government decided tomorrow to take away those (NDIS) funds, I think that I would be feeling like I was taking a giant leap back to the bad old days. Whereas now I feel like I can make my own path, I feel like the community is more accessible because I have access to the funding and interpreters."

Belonging

Summary

Words associated with belonging were love, family, respect, comfortable, connection, peer networks, and valued. The word 'belonging', while similar to inclusion, was given its own discrete meaning by some focus groups, with the difference between the two terms resting on whether respect was present in the situation.

Belonging = inclusion + respect

Belonging was seen as similar to but separate from inclusion. For example, a person living with intellectual disability remarked "belonging means people give you respect." This sentiment was echoed by a member of a regional focus group who said "sometimes I feel like there's inclusion but there's not belonging. Inclusion (is) helping out someone but belonging is where the respect comes in." Another participant in a regional focus group highlighted the distinction between inclusion and belonging when they said "belonging is the emotional side; inclusion is more the physical side. Not just letting people in, it's thinking about how people can actually participate."

Where you feel like you belong

Belonging was strongly associated with group settings such as family, peer networks and teams. Participants in one of the intellectual disability focus groups used expressions like "love", "being needed" and "feeling like you fit in" when describing situations where they felt like they belonged.

A member of the Deaf community explained that "shared experiences" help you to feel like you belong in the community. A participant in a regional focus group said they believed being seen as a

productive member of the community, even if you might not be able to do everything others are able to, was important in order to achieve a sense of belonging.

Belonging and empowerment

"A big thing in belonging is feeling like you've got a voice. Because if you're not heard how can you feel like you belong or are accepted or valued?" This comment was made by a participant in one of the regional focus groups and demonstrates the importance of being empowered in order to feel as though you belong. The same focus group went on to discuss how perceptions that people living with disability are not able to make their own decisions works against achieving belonging.

Self-determination

Summary

Of the three terms explored in this section of the focus groups, 'self-determination' was the term least understood by the focus groups. Participants living with intellectual disabilities and one of the regional focus groups understood it to mean a person being determined to do something and not giving up. Other focus groups highlighted the importance of choices and decision-making when exercising self-determination. When the term was familiar to participants, words used in association with self-determination were voice, choices, goals, decisions, independence, informed decisions, control and determined.

Self-determination and decision making

Self-determination was strongly associated with decision making by many of the focus groups. Focus groups identified three main prerequisites to achieving self-determination through decision making: access to information, choices and being trusted to make decisions.

Access to information and choices

A member of the Deaf community said, "talking about self-determination means I know I have all the information I need and I know how to ask for information." The importance of access to information in relation to self-determination was highlighted by a member of the Deaf community when discussion turned to recent bushfires. One participant noted that interpreters and captions on TV allowed the Deaf community to "make their own informed decision about when they need to leave the home, if it's safe to stay and protect their home or if they need to leave." Having choices when making decisions was highlighted by a participant in one of the regional focus groups who said that

having choices helped them to feel like they had control. A focus group participant with a psychosocial disability said that "choice and control" were essential to self-determination. This comment highlights that way that NDIS discourse may be influencing language used by people living with disability.

Being trusted to make decisions

Being trusted to make decisions and being treated like adults was connected to self-determination, particularly for people living with intellectual disability. One participant recalled how friends and family objected to him playing contact sports and how this attitude showed they did not trust him to make good decisions. Another participant living with intellectual disability said that she wanted to have children but that her parents won't let her. As a result, she felt they didn't trust her, and they weren't treating her like an adult. A member of a regional focus group commented "I'm allowed to use my voice, I have it for a reason. I'm capable of making decisions."

6. Input from family members of people living with disability

Two focus groups not included in the above analysis were undertaken, both involving family members of people living with disability. The first focus group was aimed at parents of young children. This was attended by five people, all female and all of whom had school-aged children. The second focus group was aimed at family members of adults living with disability. This was attended by eight people (six females and two males) and included parents, spouses and siblings of adults living with disability.

As these sessions did not directly involve participants living with disability the data has not been included in the main analysis. However, these focus groups offered the valuable viewpoint of family member perspectives towards the same set of questions used throughout this project. Therefore, analysis of the data captured within these sessions was performed and the main findings described below.

Parents of young children

Parents of young children were primarily concerned about the concept of safety as it relates to children living with disability and the various forms of abuse that can occur to these children.

In relation to safety, several parents agreed that a key factor was assumptions of safety made by other people in their children's lives that may be misunderstood or misguided. For example, the

mother of a young boy who lives with autism explained that his teachers do not understand that he can run out into a carpark or a road, or even harm himself if something triggers him. One mother explained "People don't understand how unsafe children with disability can be until they see it." Other parents agreed with this, adding that a key issue can often be that a child living with a disability is not always able to communicate around issues of safety, so parents, teachers or other adults involved in caregiving may not always know about safety issues.

Another family's experience related to safety was described as "all-consuming." As the mother of two children living with disability, this mother stated, "We live and breathe safety" adding that family life was dictated by the efforts necessary to keeping her two sons with autism safe. Examples given included making sure that teachers or caregivers did not leave sharp objects within reach across the course of a school day and also educating anyone providing care to her sons that they cannot be left alone despite their chronological age. Another participant echoed these statements, saying that for her family "safety is about knowing if they [children] have the support and skills to keep them safe in the environment."

Discussion of the terms 'violence' and 'abuse' led to many examples being shared, most of which had occurred to young children living with disability in a school setting. Some parents were angry that issues of violence and abuse towards children living with disability occur frequently and go without formal investigations. One mother stated "If any of the incidences that happen in a special school happened in a mainstream school, you would know about it." Parents were concerned that incidences around violence and abuse are "dulled down" in a disability setting within schools when they should have been seen as "critical." There was discussion about the violence that might come from children living with disability owing to the nature of their disability. It was agreed that there is much stigma around explaining violent or abusive behaviour that may be exhibited by children living with disability. One participant said "if you say, 'my son's violent', you are automatically ostracised, but if you say 'he's autistic and he has meltdowns', this is ok." It was agreed that the language and descriptions used were critical for how other people accepted and tolerated violence or abuse from a child living with disability.

This discussion of language led back to talking about safety and strategies for families around safeguarding vulnerable children. Participants agreed that it was difficult to know what constituted issues of 'abuse' and 'neglect' and 'exploitation' with one participant suggesting "these words all need something else under them to explain what this could mean to me and my family." Other participants felt like they were unsure if they were "eligible" to tell a story of violence, abuse, neglect

or exploitation to the current Royal Commission because they felt uncertain that the issues experienced by their children would be of significance. It was agreed that the four terms being used were not always clear and one mother said "if you can find all the smaller words, rather than the "big" words, people will engage a lot more."

It is interesting to note that parents were also reporting confusion with the terms being used by the Royal Commission, alongside people who themselves live with disability. This suggests that the terms being used have levels of complexity for a variety of cohorts across the Australian community.

Family members of adults living with disability

Summary

The family members of adults living with disability focus group explored the concepts of safety, inclusion and self-determination. The impact of the behaviours of others on the lives of adults living with disability was of interest to this group, with support workers in particular being discussed. This focus group also recognised the importance of adults living with disability being at the centre of decisions they make and of decisions made about them. Having genuine choices was considered essential by family members to a person living with disability achieving inclusion and self-determination.

Safety

Safety was discussed in a predominantly physical sense during this focus group. According to family members, risk factors affecting the safety of an adult living with disability include their surroundings and the suitability of support workers. During this focus group, the surroundings that were discussed included places where the adult living with disability lives and works. With the exception of a comment in relation to travelling by car, the discussion did not turn to safety in the context of a person living with disability being in a public place. This may be due to the fact that homes and workplaces are often less visible to others and therefore family members may believe the safety of people living with disability may be at greater risk in those environments.

One participant gave the example of supported disability accommodation settings which would require two exit points from a workplace fire safety perspective, however often only one exit would be open for resident-related security reasons. In this sense families of adults living with disability included the safety of others when they considered the concept of safety in relation to their family member.

According to family members, support workers were deemed a safety risk when they lacked the necessary qualifications to care for the adult living with disability. The lack of ongoing monitoring of the suitability of support workers was also considered a safety concern to participants. Concerns were also raised about whether support workers prioritise safety risks appropriately, together with the belief that there needs to be greater accountability of support workers' responsibility to keep their clients safe.

Family members also highlighted that equipment designed to help keep adults living with disability safe (such as mats and hoists) can turn into a safety hazard. For example, floor mats can be tripped on and adults living with disability could get stuck if a hoist malfunctions.

According to one focus group participant, negative experiences with government departments such as Centrelink can lead to an adult living with disability feeling unsafe, resulting in them later "falling through the cracks" and not being visible in systems or services. The focus group of family members of adults living with disability did not spend as much time discussing the relationship between government departments and a person's safety as other focus groups. Family members also believed that knowing how to raise safety concerns, having the ability to raise safety concerns and the confidence to raise safety concerns were important determinative factors for adults living with disability to achieve safety.

The majority of this focus group's discussion on the concept of safety centred on safety risks, rather than how an adult living with disability might keep themselves safe. It was recognised that having the knowledge, ability and confidence to raise concerns assisted adults living with disability keep themselves safe, however, family members were most concerned about factors external to the person living with disability, such as their surroundings, equipment and other people.

Comparison with other focus groups

As with the focus groups of people living with disability, the family members focus group strongly associated the word safety with the physical environment and supports provided therein. Unlike the focus groups of people living with disability, this focus group's discussion did not turn to the concept of emotional safety, or practices like gaslighting that may affect a person's psychological and emotional wellbeing. This could indicate that family members felt more concerned about, or responsible for, ensuring the physical safety of a person living with a disability which is consistent with findings from the focus group with parents of children living with disability.

Inclusion

The family members of adults living with disability focus group associated the concept of inclusion with the words belonging, self-determination, consultation, choice, decision making and control. One focus group participant commented "inclusion is making the person (living with disability) a part of the choices and including them in decision making." Another participant noted "inclusion is a person living with disability participating in an activity at the level they want to participate." This second comment suggests that this family member believed that inclusion could be achieved through activities being modified to enable more meaningful participation by the person living with disability.

According to family members of adults living with disability, grooming behaviour can also be masked as inclusion. This can occur when a person living with disability is only given choices that suit the other person. An example of this was given by one participant who said a support worker could ask their client "you want to eat your dinner at 5pm don't you?" In this case the support worker could claim they included the client in the decision-making process about mealtimes, however in reality the client was not given a choice. Behaviours like this led the focus group to be concerned about the appearance of inclusion, which can occur when inclusion is approached as a "box ticking exercise". The example above also highlights the importance of genuine choice as an element of inclusion. One focus group participant noted how the presence of a family member can potentially reduce a person living with disability's inclusion in decision making about themselves. The focus group participant recounted a time when a support worker asked him "what would you like to do with your brother today?" to which the focus group participant replied "you should ask (my brother)." This suggests that family members are attuned to people living with disability being overlooked or underestimated by others when it comes to making decisions for themselves, and the impact this has on their family member being included in decisions that affect them.

Comparison with other focus groups

For the family members focus group the concept of inclusion was most strongly associated with a person living with disability being included in decisions made about them. Words like consultation, decision making and control were used by this focus group. Conversely, focus groups of people living with disability used language with positive feelings associated with it to describe inclusion, such as acceptance, welcoming, friendly and positive. Focus groups of people living with disability took a much broader approach to understanding and applying the concept of inclusion, with discussions

extending not just to choice and decision making, but inclusion in the community through social activities and inclusion in the design process for public places.

Self-determination

The words choice, agency and decisions were associated with self-determination by the focus group of family members of adults living with disability. Factors that could lead to a person exercising self-determination included information, knowledge, experience, supports, coaching and mentoring. The focus group of family members of adults living with disability strongly associated self-determination with a person living with disability having choices and being able to make decisions for themselves. One family member used the example of a person living with a disability exercising self-determination through being able to decide when they have paid support and how it is delivered. Another family member commented that choice is "knowing all the options but not being overwhelmed by choices either." However, the simple presentation of a list of activities or options to a person living with disability was not necessarily considered to be indicative of self-determination by family members, reflecting the belief that self-determination requires more than just to ability to choose.

Family members also recognised that they (and others) can undermine the self-determination of adults living with disability by "stepping in to do things because you are being helpful." However, family members also acknowledged that in order to exercise self-determination, people living with disability may require support "which can be from other people or even technology." This demonstrates the need for family members to strike the right balance between supporting a person living with disability to exercise self-determination without that support unintentionally reducing the person's capacity and ability to exercise self-determination.

Comparison with other focus groups

When compared to the information provided by focus groups of people living with disability, the information provided by the family members group about self-determination was consistent insofar as both recognised the importance of choice in self-determination. However, the family member focus group did not use the word control in this context, whereas the other focus groups did. The family member focus group also did not touch upon the issue of trust as it relates to self-determination. Participants in the focus groups of people living with disability recognised that trust from other people was required for them to exercise self-determination, however family members viewed this issue from the perspective of being careful not to be too "helpful."

7. Limitations of the Current Study

There are several limitations that the researchers readily acknowledge, and all findings must be inferred in recognition of these limitations.

Firstly, we wish to make a note about our chosen sampling technique. Purposive sampling allows for the study sample to be disproportionate as it is selected to include all groups targeted for consideration within a study. As such, in the present study there was a gender disparity in the sample size as the final *n* included significantly less men than women. Therefore, findings need to be interpreted cautiously as this sample is not representative of the typical Australian disability community. Similarly, a disproportionate age spread can be seen in this study's population; the majority of participants were drawn from the age categories of 31-49 and 50 years plus respectively, leading to fewer younger participants being represented. We therefore acknowledge that many examples of meanings and interpretation of language and vocabulary provided in this report belong to a generation of people aged between 30 and 50 plus years of age.

We further recognise that focus groups were only held with members of the disability community and that the requested research scope did not extend to any examination of how non-disabled members of Australian communities consider and make meaning of the same terms. We therefore recognise there is no data for comparison between that produced in this study and the wider Australian community. As a result, we are not able to fully determine how much of the language and vocabulary found in the current research can be attributed to participants' lived experience of disability or how similar these findings would be to the same study being run with participants who do not have lived experience of disability. For instance, it is interesting to note that family members were also reporting some confusion with the terms being used. This confusion suggests that the terms and/or language may be quite complex for large cohorts of people across the Australian community. Should funding permit, perhaps the DRC could initiate a second wave of the current study to ascertain similarities and differences between the population involved in the current study and the wider Australian community.

Furthermore, we wish to acknowledge that the sample size of family members in the current study is small (n=13) and we therefore hasten to add caution to inferences drawn from this group of participants. Whist the findings collected in these focus groups were insightful and informative, we acknowledge that this sample is too small to be representative of the wider community of family members of people living with disability in Australia.

Lastly, it is important to note that identification of living with disability relied on self-report from participants with no external validation from researchers. Whilst this is accepted practice within research recruitment strategies, it is worthy of acknowledging that participant disability status within the study population is therefore self-identified and not researcher-identified. As a result of this there is little data collected on the detail of participants' disability, for example the duration of time they have identified as living with disability and/or any specific information about the disability beyond the categories participants were asked to select from during the registration process. Future work in this area could aim to ascertain greater understanding of these details in order to identify to the extent to which participants' narrative or discourse around language is impacted by the length of time they have lived with disability or by specific aspects of the disability.

8. Addressing the research questions

As stated upfront in this report, the current research set out to answer several research questions relating to the language and vocabulary used by people living with disability in regard to themes of violence, abuse, neglect and exploitation. A brief summary is offered below against each research question.

1. How do diverse groups of people living with disability speak of violence, abuse, neglect and exploitation?

This research identified that people living with disability interpret violence, abuse, neglect and exploitation broadly, with interpretation of behaviours that extend beyond physical actions and include mental, emotional, psychological and financial acts.

The word 'violence' was strongly associated with many other words and terms including physical violence, bullying, verbal violence, harm, rape, sexual assault, murder, controlling, pinching, hitting, and removal of one's agency. Participants also described feeling as though they have a greater risk of experiencing violence than people without disability. Participants in the regional areas focus groups also pointed out that the type of violence people living with disability experience is the same as other people, however it is harder for the person living with disability to get away from.

The word 'abuse' was given broad meaning by the focus groups. It went further than physical acts and was applied to situations where a person's psychological, emotional, financial and mental

wellbeing was adversely affected. Abuse was also understood to occur in a variety of settings, including in private and in public. Perpetrators of abuse could be individuals as well as institutions, leading to mistrust by people living with disability to report abusive behaviour. The difference between violence and abuse was generally understood to be one based on the longevity of the behaviour: violence was a one-off occurrence whereas abuse was the longer-term pattern of violent behaviour. Words associated with the term abuse included violence, domestic violence, control, power, gaslighting, vulnerable, rape, hitting and ignored. The words rape and sexual assault were more strongly related to the term abuse than violence by focus group participants.

Many participants described terms such as "people not caring" or "needs not being met" as being linked to their understanding of the term 'neglect'. The concept of being vulnerable was also discussed at multiple sessions in reference to neglect. There was also discussion in some groups of how neglect is different to other terms discussed and one participant said that for her "abuse is doing something, neglect is not doing something." Words and phrases associated with neglect by participants included not caring (about something or someone), lack of (something), isolation, discrimination, not looking after something or someone and being left out.

Similar to the term neglect, not all participants understood the term exploitation. In fact, this was considered to be the trickiest of all terms discussed with one participant living with intellectual disability saying, "I've heard of the word, but I don't know what it is." Another participant who also lives with intellectual disability and is in residential care said, "unless you've had a problem with it you don't know the word."

2. How do diverse groups of people living with disability speak of self-determination, safety, inclusion and belonging?

These terms were not always readily understood by focus group participants, in particular, the term 'self-determination'. While colloquially these concepts have positive meanings, the focus group discussions were often characterised by negative feelings owing to the absence of safety, inclusion, belonging and self-determination in the lives of people living with disability. These terms were often seen as aspirations rather than reflective of participants' current realities.

The term 'safety' was discussed in the first section of each focus group. The term was readily associated by participants with themes of safety in one's home and while out in public/community settings and strategies that are important for people living with disability to keep themselves safe.

Words associated with safety included protected, certainty, stability, family, police, communication, familiarity, vigilant and understanding.

Words associated with 'inclusion' were acceptance, welcoming, friendly, equality, accessibility, positive. Inclusion was generally well-understood by all focus group participants and was discussed in terms of what it means but also what it does *not* mean.

Words associated with 'belonging' were love, family, respect, comfortable, connection, peer networks, and valued. The word belonging, while similar to inclusion, was given its own discrete meaning by some focus groups, with the difference between the two terms resting on whether respect was present in the situation.

Of the terms explored in this section of the focus groups, self-determination was the term least understood by the focus groups. Similarly to their struggle with the term 'exploitation', participants living with intellectual disabilities and one of the regional focus groups understood 'self-determination' to mean a person being determined to do something and not giving up. Other focus groups highlighted the importance of choices and decision-making when exercising self-determination. When the term was familiar to participants, words used in association with self-determination were voice, choices, goals, decisions, independence, informed decisions, control and determined.

3. Are there discourses particular to certain groups of people?

In particular, one example of a discourse particular to women is that of the word 'rape.' For some female participants, the words 'rape' and 'sexual assault' were more strongly related to the term abuse than to the term violence by focus group participants. Similarly, as stated previously, several women spoke about their preference for the term 'rape' over other descriptions of sexual violence.

Additionally, specific to participants living with intellectual disability was a preference for simple, descriptive terms. For example, these participants preferred to use phrases such as 'not looking after', 'taking advantage of' and 'making decisions' to refer to 'abuse', 'neglect', and 'exploitation'.

There was a lengthy discussion around people living with psychosocial disability being portrayed as violent or being the perpetrators of violence; this was unique as this is a different viewpoint whereby participants spoke of violence coming *from* people living with disability themselves. This cohort also spoke of gaslighting and noted the importance of addressing this: "Gaslighting is something that really needs to be addressed – it comes from professionals and mental health

sector." Other participants spoke of psychological violence as a form of domestic violence, saying "it should also be acknowledged as a form of violence towards people with disability."

4. Do these words, descriptors differ/match across disability groupings, across sexes?

For people living with autism, discussion of school and examples of neglect was a significant focus of the conversation, with participants pointing out how important understanding the use of and meaning from language is because Autism is a "communication-based disorder."

People living in regional areas spoke of feeling somewhat protected from violence owing to the small communities in which they live: "Regional areas provide some protection from violence as there is more acceptance of disability." However, some participants were careful to qualify that this notion cannot be extended to all regional areas: "We are lucky in this region that people living with disability are more accepted and respected, meaning less violence. This isn't the case in all regional areas or in the city."

9. Conclusion

We recognise that better understanding how people living with disability use and make meaning of the language relating to themes of violence, abuse, neglect and exploitation allows others to gauge greater meaning from the storytelling and discourse around these terms. This meaning is critical to examining the experiences of the disability community and analysing the data that is brought forward as part of the current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. However, it is not just the Royal Commission who we feel will be a beneficiary of these findings. Rather, the Australian community as a whole can benefit from better understanding, sharing in and recognising the stories from people living with disability in regard to the topics being explored. A national effort is needed to make the necessary changes to transform the experience of people living with disability and their families, as has been the intention of the National Disability Strategy. Widespread acknowledgment and understanding of these experiences from the broader Australian community is a necessary step towards this.

10. Appendix A: Focus Group Discussion Guide

Introduction

- *Acknowledgement of country and disability community*
- *Introduce moderators and Purple Orange*
- *Explain project*
- *Explain format of focus group*
- *Explain confidentiality*
- *Discourage personal disclosure and identify support available*
- Housekeeping

Ice breaker

Safety

We'd like to start by talking about safety. Thinking about people living with disability, what is important for safety?

> *Probe as necessary:*
>
> - What comes to mind when you hear the term "safe"?
> - What is important for people living with disability to be safe from **physical** harm?
> - What is important for people living with disability to be safe from **emotional** harm?
> - What is important for people living with disability to be safe from harm from the **environment**? (i.e. not just from people)
> - Why is safety important?
> - What makes people feel safe?

Violence and Neglect

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability wants to hear from people about their experiences of violence, abuse, neglect and exploitation. They want to make sure that when they're talking to people, and when they make their recommendations, they use language that is meaningful and easy to understand.

We won't be talking about your personal experiences of violence, abuse, neglect or exploitation today, but we do want to hear how you talk about these things in general. Please say anything that comes to mind. Don't worry about whether it's relevant or whether it answers our questions exactly. We want to hear all of your thoughts and get a conversation going.

What do you think of when you hear the term 'violence'?

Probe as necessary:

- What is 'violence'?
- What types of situation do you think of when you hear the term 'violence'?
    - Where can it happen?
    - When can it happen?
    - Who might be involved?
- Thinking about the situations you have named, are there any other words or phrases you would use to describe them other than 'violence'?

What do you think of when you hear the term 'neglect'?

Clarify if necessary: someone ignoring or failing to take care of someone living with disability or failing to do something for them.

Probe as necessary:

- What is 'neglect'?
- What types of situation do you think of when you hear the term 'neglect'?
    - Where can it happen?
    - When can it happen?
    - Who might be involved?
- Thinking about the situations you have named, are there any other words or phrases you would use to describe them other than 'neglect'?

BREAK (5 mins) *Remind participants that they can use the quiet room and/or speak to the counsellor if they need to*

Exploitation and Abuse

What do you think of when you hear the term 'exploitation'?

Clarify if necessary: Someone taking advantage of a person living with disability, using them, or treating them unfairly for some kind of benefit

Probe as necessary:

- What is 'exploitation'?
- What types of situation do you think of when you hear the term 'exploitation'?
    - Where can it happen?

- When can it happen?

- Who might be involved?

- (if the group is really struggling) You might like to think about different types of exploitation e.g. physical, sexual, financial, labour

- Thinking about the situations you have named, are there any other words or phrases you would use to describe them other than 'exploitation'?

What do you think of when you hear the term '**abuse**'?

Probe as necessary:

- What is 'abuse'?

- What types of situation do you think of when you hear the term 'abuse'?

  - Where can it happen?

  - When can it happen?

  - Who might be involved?

- Thinking about the situations you have named, are there any other words or phrases you would use to describe them other than 'abuse'?

Inclusion, Belonging and Self-determination

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability wants to make sure it doesn't focus only on negative things. It therefore wants to also understand the language people living with disability use to talk about some positive terms.

So, thinking about people living with disability, what is important for **inclusion**?

Clarify if necessary: People living with disability being included

Probe as necessary:

- What are some examples of people living with disability being included?

- What does inclusion look like?

- Thinking about the examples you have named, are there any other words or phrases you would use to describe them other than 'inclusion'?

Next, thinking about people living with disability, what is important for **belonging**?

Clarify if necessary: People living with disability feeling like they belong

Probe as necessary:

- What does it mean to belong?

- What helps people to belong?

- What examples come to mind of people living with disability belonging?

- Thinking about the examples you have named, are there any other words or phrases you would use to describe them other than 'belonging'?

Finally, thinking about people living with disability, what is important for **self-determination**?

Clarify if necessary: People living with disability making their own decisions and living life the way they want to

Probe as necessary:

- What does 'self-determination' mean?

- What do people need to be able to make their own decisions?

- What examples come to mind of people living with disability having self-determination?

- Thinking about the examples you have named, are there any other words or phrases you would use to describe them other than 'self-determination'?

Close

1. *Thank people for participating*

2. *Distribute referral sheets, gift cards, taxi vouchers.*

Follow up group by emailing out referral sheets.

Disability Royal Commission

research project: ethics approach

Background

All research undertaken by JFA Purple Orange is conducted in a manner that promotes the core values of the organisation. JFA Purple Orange recognises that applying ethical guidelines in research is a process involving judgement and research practice. Ethical responsibilities continue to arise throughout the research process.

Our ethics policy has been developed through consideration of best practice within Australia and internationally and adheres to the National Statement on Ethical Conduct of Human Research.

The following will guide all members of the JFA Purple Orange team who are responsible for conducting research as part of the DRC research project.

Values

General values

The following values underpin all research work undertaken by JFA Purple Orange:

- respect for the human rights, dignity, equality and diversity of all people involved in the research process;
- promotion and advancement of social justice for marginalised groups particularly people with disability within the wider community;
- enhancement of well-being and avoidance of harm to those people involved in the research process and to the wider community;
- facilitation of access to participation in research for people living with disability through provision of appropriate support;
- maintenance of highly professional, legal and ethical standards and competencies;
- anonymity, privacy and confidentiality must be ensured at all stages including the final stage of data storage/disposal.
- (National Health and Medical Research Council, NHMRC 2007, National Disability Authority NDA 2009)

Core values

The core values of JFA Purple orange are to be reflected in all research decisions, these being:

1. Personhood: respect for the individual's personhood including inherent value and potential, self-identity and decision-making
2. Citizenhood: respect for the individual's place as an active member in community life
3. Capacity building: facilitation of support to strengthen the person's capacity (and that of others, including the wider community) in relation to the above two values

The research team

All researchers involved in conducting this research project have an appropriate level of expertise and awareness with respect to equality, diversity and disability, in addition to having experience and skills in conducting high quality research.

The research team includes one member who lives with disability. A co-design group of people living with disability has been established to provide advice throughout the project. A consultant living with disability with expertise in addressing gender-based violence has also been engaged.

Research merit and integrity

Upholding JFA Purple Orange's commitment to research merit and integrity throughout the DRC research project will entail:

- Acting in accordance with recognised principles of honest research conduct;
- Using a fair process for the recruitment of research participants;
- Avoiding placing an unfair burden of participation on particular groups;
- Protecting participant wellbeing and avoiding exploitation of participants in the conduct of research;
- Treating all participants with dignity, regardless of ability, gender, sexual orientation, age, race, ethnicity, religion and culture;
- Advertising the research project widely through a wide range of networks to avoid further marginalisation, discrimination and exclusion of under-represented social groups;
- Making clear to all prospective participants that JFA Purple Orange will meet any accessibility and/or communication needs, to avoid people being excluded; and
- Ensuring that the final report and short report are accessible and are shared with focus group participants at the completion of the project.

Anonymity, privacy and confidentiality

The researchers will take steps to protect the anonymity, privacy and confidentiality of research participants at all stages of the research process. This will include the following:

- The researchers will ask all support staff to leave the room during the discussion. If a participant feels uncomfortable without the presence of their support worker, the researchers will seek the support worker's agreement to abide by the principle of confidentiality.
- At the start of each focus group discussion, the researchers will explain the JFA Purple Orange approach to confidentiality and ask all participants not to disclose information shared by others.
- The researchers will not discuss the information provided by participants with anyone outside the Policy and Research team.
- The research findings will be presented in a way that ensures individuals cannot be identified.

Payment of individuals

All focus group participants will receive a $60 Coles Myer gift card. The researchers will make it clear to participants that this is a token of gratitude for their time and does not create any expectation with respect to the information they provide during the focus groups.

Informed consent

Ethical research practice requires that participants are included based on informed and voluntary consent. JFA Purple Orange will take all steps necessary to ensure that each participant understands the aims and nature of the research (including how their input will be used) before confirming their participation, in line with our ethics protocol. We will obtain informed consent, orally or in writing, from each participant prior to commencing any consultation process with that person. The provision of informed consent will be documented.

In practice, the research team will do as follows:

- We will explain consent and confidentiality on the Eventbrite registration pages, and detail how the information prospective participants provide will be used. We will make it clear that by registering through Eventbrite, participants are consenting to the information they provide being used in the specified way.
- We will contact each participant who registers for a focus group individually, using their preferred method of communication (they will provide this information on Eventbrite). We will ensure that they have fully understood the nature and purpose of the project and how

the information they provide will be used. We will provide information about the project in whichever form the individual may require such as in hard copy, electronically in a format compatible with screen readers, verbally and/or using images. We will confirm that they have provided their informed consent.

- At the start of each focus group, we will reiterate that everyone has given their informed consent to participate. We will again explain how the information they provide will be used and invite anyone to ask questions or withdraw from the research if they desire. We will emphasise that participants can withdraw from the research at any time.

- We will involve people who have existing professional relationships with prospective participants in explaining the project and seeking consent. For example, the project officer supporting our peer network for people living with intellectual disability will contact network members and seek their consent, as she has an established relationship and is familiar with their communication needs.

Proxy consent

In order to respect the autonomy of individuals, the use of proxy consent should be minimised. In line with Article 12 of the UN Convention on the Rights of Persons with Disabilities, people living with disability should receive the support necessary to enable them to make the decisions that affect them (Supported Decision-Making), rather than seeking consent from a substitute decision-maker such as a legal guardian.

In situations where there is uncertainty as to whether a prospective adult participant has given genuine informed consent, it may be prudent to seek additional consent from a next of kin or legal guardian. However, it remains imperative to determine the participant's own position, and to only proceed where he or she has also given consent.

Disclosure and distress

During focus group discussions, participants living with disability may disclose information which indicates that they are at risk. For example, they may disclose that they are being abused or mistreated. If this occurs, the researchers will do as follows:

1. Pause the discussion and ask if the participant would like to take a break and/or speak to the counsellor about their situation;
2. Provide referral pathways to further counselling, support or advocacy groups if appropriate;

3. Provide information about how they can give evidence to the Royal Commission, should they wish to do so.

During focus group discussions, participants living with disability may display signs of distress, owing to the nature of the subject matter. If this occurs, the researchers will do as follows:

1. Pause the discussion and ask if the participant would like to take a break and/or speak to the counsellor;
2. Provide referral pathways to further counselling, support or advocacy groups if appropriate;
3. Document that the participant showed signs of distress and confidentially lodge this information with their line manager; and
4. If possible, follow up with participant after the focus group to assess their wellbeing and determine if distress has continued.

Data storage and protection

All research data collected during the project will be stored in a secure site at the Julia Farr Group, 104 Greenhill Road, Unley, South Australia, for a period of seven years from the completion of the research. Access to the data will be restricted to the research team and the staff at the Royal Commission who commissioned this research. Participants will be sent the publicly available final report and short report upon completion of the project.

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[1] Krauss, R & Chiu, C, (2016) In D. Gilbert, S. Fiske & G. Lindsey (Eds.), *Handbook of social psychology* (4h ed.),Vol. 2. (pp. 41-88). Boston: McGraw-Hill.

[2] *Stewart DW, Shamdasani P. Focus Groups: Theory and Practice. Los Angeles, CA: Sage; 2015.*

[3] *Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101.*

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