Royal Inquiry into Abuse in State Care –Disability Overview

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Background

Stories and what they tell

GRO-B

GRO-B along with many of his peers from Marylands school have given witness statements reflecting on and bearing witness to the violence, abuse and neglect perpetrated on them at Marylands school and at other state ran institutions including Kimberley and Lake Alice. He, along with these many others tell of a young life being moved from foster care to these institutions on the advice of numerous government departments that deemed these placements were in his 'best interest'. Like many of his peers who have given evidence about Marylands school there are intersecting wrongs underpinning his placements and experiences; racism and colonialist ways of thinking that meant being Māori was a factor used to judge his parents' capacity to care for him; ableism where his physical aggression that he explains as his way of 'express[ing] myself because I was always frustrated', was deemed to be a characteristic of his presumed 'mental retardation' by a system and society that institutionalised and segregated those who were seen as 'not normal'; and the practice of state and religion being 'the one' in the provision of 'State Care' by religious organisations instead of state and religion being separate– GRO-B clearly seeing the irony in this 'because my family was never Catholic'.

GRO-B s story like others told to the Royal Inquiry into Abuse in State Care, goes on to describe horrific sexual, physical and emotional violence and abuse at the hands of the Brothers of St Johns Hospitaller at Marylands. This violence and abuse was

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GRO-B

pervasive – meaning it was ever present. Despite GRO-B and his peers reporting the abuse to teachers, other Brothers and social workers from the Department of Social Welfare, they were not believed and the abuse went unchecked.

Sadly, these stories echo across countries and across time. They tell of systems and organisations – religious, government and nongovernment where violence and abuse were a part of the way these places functioned. In these places this violence and abuse seemed almost 'justified' by the perpetrators. This justification was based on deeply held views that because the children and young people in them were not 'normal' according to society's assessment of their race, mental, cognitive and/or physical ability, and the intersection of these 'identifiers' they could be treated as 'other' and dehumanised to the extent that the sexual, physical and emotional abuse experienced was 'the norm'.

There is not room in any report on violence and abuse of disabled people to share the thousands of stories like GRO-B 's; to acknowledge others' tellings, below I share some others from disabled people who lived and live in Aotearoa New Zealand;

> *In hospitals you get abused: you get hit, and they make you a slave. When I was about 6 years old, I had to help. I never went to school. They wanted me for the work because I was so good at it' (Mavis in Mirfin-Veitch & Conder, 2017 p.18)*

> *Sometimes I'd hide under the mattress in the cold weather - wintertime. I'd also hide under the building because I knew that was a really warm place. The hot pipes would keep me warm" (Avis in Hunter, 1997, p. 12).*

> *I am not impressed with what happened with me, nor am I happy with the actions of my rapists. It has made me very upset and angry. …Because of my abuse, I have found it very hard to live and do things that your average person should be able to do like working, going outside of the house alone for a longer time, socialising, and having a stable mood. My relationship with the opposite gender has been a struggle. I find it hard to trust men because I worry they might hurt me like my abusers did. That is so annoying too because I want a relationship" (Sometimes I write letters in 'Mean As!' Donald Beasley Institute, 2019).*

Well I can start from the very beginning. So pretty much I was bought up in foster care because my parents couldn't look after me. My Mum had sort of a similar experience to me but hers was physically worse…[It was] domestic family violence and us kids kind of had to, me and my brother and my half-brother kind of saw it" (Love yourself pretty much, before you love anyone else in 'Mean As!', Donald Beasley Institute, 2019).

These and many more stories of disabled people like them inform my work on violence, abuse and neglect in the lives of disabled people[2]. Institutions where disabled people were sent to 'protect society' from the 'threat' of physical, cognitive, mental and sensory 'difference' are at the centre of many of these stories. The 'total institution' is a well-known and reported site of violence, abuse and neglect. It is described by Erving Goffman (1968) as a "social hybrid, part residential, part formal organization…of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed formally administered round of life' (p.11). For many this 'round of life' in the 'total institution' was one of servitude, and of survival from regular violence, abuse and neglect that was unrelenting – it was always there and never went away. The stories of disabled people also tell us that there is a lasting impact over their lives where the trauma of violence, abuse and neglect has shaped how they have lived their lives; many like GRO-B s life have been lived out in other institutions and services that continue to segregate and 'other' them living without family contact, education, employment and intimate relationships.

While many of these crimes of abuse took place in institutions and may be seen as 'being of' another time and place, and only of historical significance, more recent reports from the United Kingdom (UK) on abuses of disabled people in the highly publicised cases of Winterbourne View (2012) and Eldertree Lodge (2021), both

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[2] See list of relevant references in Appendix One Frawley

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'specialist' hospitals for intellectually disabled people and people with mental health needs, clearly remind the community and government departments responsible for these modern day institutions, that they are, like their historical counterparts, 'places of violence and abuse'.

> *The abuse revealed at Winterbourne View hospital was criminal. Staff whose job was to care for and help people instead routinely mistreated and abused them. Its management allowed a culture of abuse to flourish. Warning signs were not picked up or acted on by health or local authorities, and concerns raised by a whistleblower went unheeded. The fact that it took a television documentary to raise the alarm was itself a mark of failings in the system"* (Department of Health, UK 2012 p.18).

> *Risks to people's safety [at Eldertree Lodge] were assessed but the actions needed to keep people safe were not always present. Legal authorisations for the use of restrictive practice were missing and guidance was not always clear about what people could or could not do. This meant people were at risk of being unlawfully restricted. Accident and incident forms were not always reviewed although plans were underway to ensure this happened…The governance systems in place had not been effective at monitoring people's care….The service was not able to demonstrate how they were meeting some of the underpinning principles of right support, right care, right culture.* (Quality Care Commission, UK August 2021 p.2)

These reports and others like them including reports from Australia and the cases of abuse revealed at Yooralla, one of the largest nongovernment disability services in Australia, (Ryan & Johnson, 2013) highlight that rather than the issue being about 'rotten apples' acting independently in a system, the issue is 'rotten systems'. These reports make it clear that congregate, segregated services for disabled people are corrupt cultures of violence, abuse and neglect and cover up.

> *Two wheel-chair bound women who had cerebral palsy were raped and a third woman was sexually assaulted in their Box Hill home where residential support was provided by Yooralla. The pants of another resident, a disabled man who walks with the aid of a walking frame, were also repeatedly pulled down in front of other residents…Kumar's offending was not opportunistic or*

spontaneous as he was careful to choose the time and place when committing the offences. He made sure he was the only person on duty and that the three women were at their most vulnerable….Kumar began working on a casual basis at Yooralla in March 2009 as a disability support worker and was counselled in August 2011 after two reported instances of inappropriate behaviour, with one involving Kumar twisting the nipple of a male resident. Kumar applied for a permanent job at Yooralla only months after being counselled and was unsuccessful because of rumours of inappropriate behaviour with residents and staff. Nonetheless, Yooralla continued to engage him on a part-time basis, so he was working practically full time hours, and was often rostered on at times when he would be the only support worker at a residence…The judge said one of Kumar's victims had wanted to swear at him and tell him to "f--- off" but it was "a measure of her level of cognitive functioning that she felt unable to say that because there is a rule against swearing in the residence"…."[The woman] was crying when she went into her room, but the team leader did not ask why before she remonstrated with her, telling her her behaviour was inappropriate with the staff member. "Unfortunately for [the woman] the Yooralla response was less than adequate." (Ryan & Jackson, 2013)

The total institution, whether defined in its historical context, or the more modern-day examples of specialist hospitals like the UK examples, or residential services like the Yooralla examples, is not the only site of violence, abuse and neglect of disabled people. As shared by the story writers who tell of experiences of domestic and family violence in their own and foster families, in intimate partner relationships and in the community at large, families, intimate relationships, paid carer relationships in people's homes, and the community are also sites of violence and abuse of disabled people.

Two recent cases in Australia and New Zealand are tragic stories of the deaths of two disabled women. Ann Marie Smith was an Australian disabled woman who died as the result of years of maltreatment at the hands of a paid carer. Her death led the media to ask about '*The way our society treats the Disabled, in life and in death*' (Cranko, 2022, The devaluation of Disabled Lives, The Saturday Paper, April 2 – 8, 2022., No 393). Ann Marie Smith's story is horrendous and tells of a disability system

that did not care, and resulted in her dying from illness and injuries that were akin to torture. Lena Zhang Harrap a 27 year old disabled woman from Auckland was sexually abused and murdered in Auckland when out on her daily walk in her neighbourhood. A media report of her death notes that Lena '…had Down syndrome and a visual impairment…[and]…that very fact made her more vulnerable to violence" citing the 2021 New Zealand Crime and Victim Survey that reported 16 percent of disabled New Zealanders experience interpersonal violence compared to 7 per cent of the general population. What this media report also noted was that Lena's death did not get the same attention from women or the public as other reported deaths of women in public places, 'Lena Zhang Harrap is far from a household name. Why? Have we grown suddenly apathetic?...Or have we somehow decided that Lena's death is less shocking because she was more vulnerable than most"'. In short, because she was a disabled woman? (Jepsen, B '*The murders of Sarah and Gabby earned worldwide attention. So should Lena's'*. Mamamia, October 1, 2021)

Often, as Lena Zhang Harrap was, disabled people are described as 'vulnerable' suggesting that vulnerability is an embodied characteristic of disabled women in particular and more broadly disabled people. However, as these stories and reports confirm disabled people, and in Aotearoa New Zealand, Tāngata Whaikaha Māori have been and continue to be 'made vulnerable by' the ableist world and systems that have, and continues to discount, dehumanise and 'other' them.

Challenging the 'vulnerable victim' narrative: a systemic approach

The work of Dick Sobsey a Canadian disability academic and advocate, and his colleagues from the early 1990's onwards, reoriented our understanding of violence, abuse and neglect in the lives of disabled people. Using a systemic, and intersecting understanding of violence, abuse and neglect this 'ecological' model shifts the 'blame' for violence, abuse and neglect of disabled people from the disabled victim and their perceived 'vulnerability'. The model highlights the inter-relatedness of devaluing attitudes about disabled people, characteristics of their experience of disability, and the disempowered position they have in society, families, services and communities. It questions the power and control 'over' disabled people in these environments and relationships, and sees the interaction of all of these factors as

impacting on risk and experiences of violence, abuse and neglect. It also affirms that all of the factors and how they interact shape the environments in which disabled people live, work and participate, including institutions, families, specialist disability services and the community.
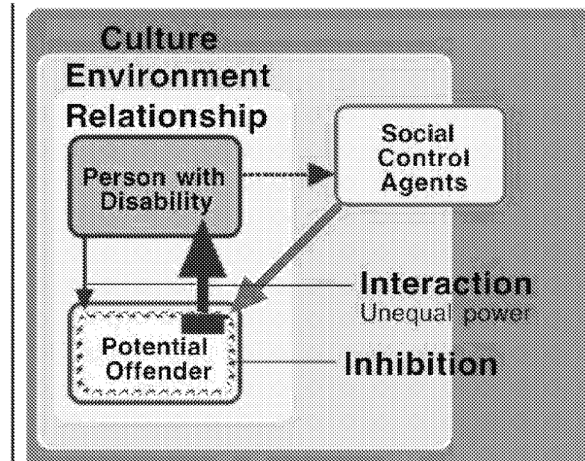

(Sobsey & Calder, 1999)

This model, and variations of it have informed research, policies, practices, programs, and services to understand, prevent and address violence, abuse and neglect of disabled people internationally including; in the U.S (see the work of Nancy Fitzsimons 2009; 2010; 2017; the Olmstead Prevention of Abuse and Neglect Special Committee, 2018 and the work of the Vera Institute of Justice), the U.K (Hollomotz, 2009; 2011; 2013), Australia (see the work of Frawley and others Appendix One and, Our Watch, 2022), and NZ (see Mirfin-Veitch & Conder, 2017 and 'Mean As!', Milner, Mirfin-Veitch, Tikao, & Frawley, 2019). These social-ecological models align well with mainstream (non specialist/ disability services), models, policies and programmes of prevention and responses to violence and abuse.

Integrating disability violence and abuse prevention with the mainstream

The World Health Organisation through its Prevention of Violence Unit informs approaches to interpersonal violence prevention through research and provision of resources. At the centre of this work is an ecological framework for preventing violence and abuse that reflects the model used by Sobsey and others.
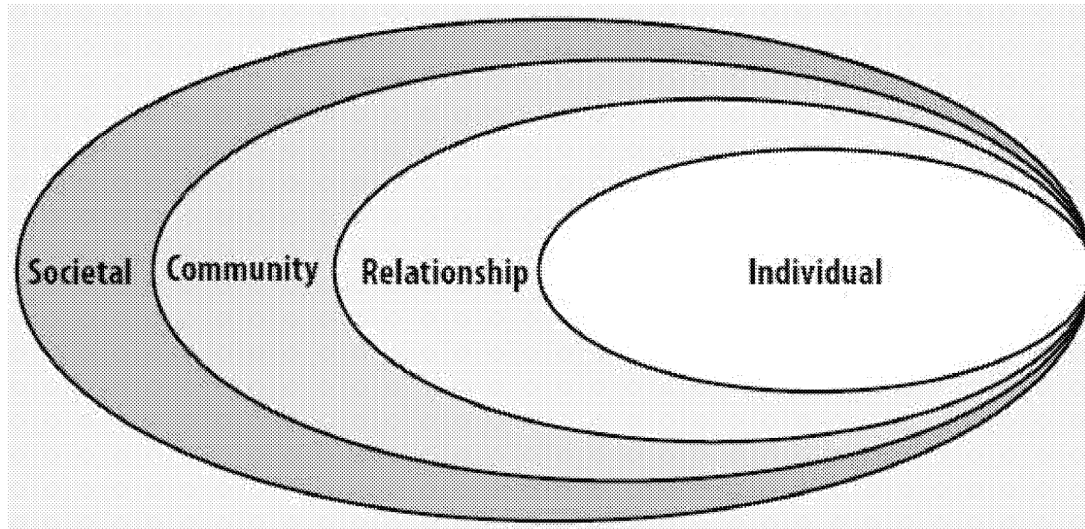
This model is based on evidence that "no single factor can explain why some people or groups are at higher risk of interpersonal violence" (WHO, 2022). This model is used by the WHO to advocate for systemic appraoches to preventing violence by multiple sectors in society that include strategies across sectors that; Address the underlying risk and protective factors that increase or decrease the likelihood of violence including; Ensure violence prevention strategies are active in all organisations and services including schools, disability services, health services, workplaces and community organisations; That all sectors collaborate to change attitiudes that impact violence including sexism, racism, ableism and that cross sector work be coordinated and monitored (WHO, 2022a).

More work is needed to ensure these mainstream models are understood and used when focusing on violence and abuse of disabled people, and in particular they are used in ways that are inclusive of the experiences of Tāngata Whaikaha Māori and in particular Wāhine tāngata whaikaha in Aotearoa New Zealand, given the high incidence and rates of violence and abuse they experience.

Fanslow, et al (2021) when reporting on findings from the 2019 New Zealand Family Violence Study note, "Those who identified as Maori were over-represented among those with any disability (26.3%) compared with European New Zealanders (20.3%) and those of other ethnicities" (p. 322). The authors of this study go on to say that because Maōri have a higher experience of disability than people of other ethniciites, and considering the gendered nature of violence where "...women are subjected to more severe and frequent IPV [intimate partner violence]" (p. 326), there is a need to

take an 'intersectional' lens to violence and abuse of disabled people. This means looking at specific lived experiences, and across multiple lived experiences that are intersecting to increase risk and experience of violence, including the lived experience of Tāngata Whaikaha Māori and Wāhine tāngata whaikaha. This study found that "women with any disability reported significantly higher rates of experiencing IPV (16.9%) than men with any disability (5.0%) (p. 323). Further research by this research team (Malihi, Fanslow, Hashemi, Gulliver, & McIntosh, 2021) also looked at prevalence of nonpartner physical and sexual violence using this same population-based study. When looking at nonpartner physical and sexual violence AND disability they found that "15.4% of women with disabilities experienced lifetime nonpartner physical violence and 11.1% experienced lifetime nonpartner sexual violence…For men with disabilities, 56.2% experienced lifetime nonpartner physical violence, and 5.6% experienced lifetime nonpartner sexual violence" (p. 330). Importantly this study found that all perpetrators were men, and that 43.5% of disabled women in the study and 60.0% of men never sought help.

These studies provide clear evidence that all forms of violence are being experienced by Tāngata Whaikaha – disabled people in Aotearoa New Zealand at a higher rate than for non-disabled people living in New Zealand, that gender, race and disability are intersecting in ways that increase risk of all forms of violence and abuse, and that this is a significant social issue for New Zealand.

Changing the story: prevention of violence, abuse and neglect 'for all'

> *"To be successful in this kaupapa requires us to embrace a decolonised and critically conscious orientation" (Tricia Keelan in Whakamanahia Te Tiriti, Whakahaumarutia te Tangata (HRC, 2021)*

In 2021 in Aotearoa New Zealand reports were released on the social issue of violence and abuse – two focusing on disability violence and abuse - *Whakamanahia Te Tiriti, Whakahaumarutia te Tangata – Honour the Treaty, Protect the Person – Violence and abuse of tangata whaikaha in Aotearoa New Zealand Evidence and Recommendations* (NZ Human Rights Te Tika Tangata Human Righs Commission, December 2021) and *Whakamahia te tūkino kore ināianei, ā muri ake nei - Acting now for a violence and abuse free future - Violence and abuse of disabled people in Aotearoa New Zealand Evidence and recommendations* (NZ Human Rights. Te

Kāhui Tika Tangata, December 2021); and one looking more broadly at the issue of violence and abuse across Aotearoa and across lived experiences of all people *Te Aorerekura – The enduring spirit of affection: The National strategy to eliminate family violence and sexual violence* (Te Kāwanatanga o Aotearoa - New Zealand Government, December 2021). These reports, and in particular the National Strategy, provide comprehensive information about the issues impacting on the risk and experiences of violence and abuse in New Zealand, and the intersecting issues impacting on experiences of violence and abuse of Tāngata Whaikaha Māori, and Wāhine tāngata whaikaha. They provide a strong justification for a multi-sectoral approach to preventing violence and abuse and to responding to violence and abuse when it does occur. All three reports read together offer important guidance on how this can be done and align under the six 'shifts' that the National Strategy offers:

- Shift One: Towards strengths-based wellbeing
- Shift Two: Towards mobilising communities
- Shift Three: Towards skilled, culturally competent and sustainable workforces
- Shift Four: Towards investment in primary prevention
- Shift Five: Towards safe, accessible and integrated responses
- Shift Six: Towards increased capacity for healing (NZ government, 2021 p. 5)

The two reports from the Human Rights Commission – co-developed with and informed by Tāngata Whaikaha sit underneath this overarching national plan and reflect the mainstream and disability focused ecological models presented above. They also outline the interconnecting Te Tiriti of Waitangi and International Human Rights framing for the transformational change they outline is needed to prevent and address violence and abuse of Tāngata Whaikaha. These reports are based on the following positions: Violence is a Te Tiriti and human rights issue; Tāngata whaikaha Māori rights have been breached; Disabled people's human rights have been breached; Violence is an abuse of power; Gender based violence is an epidemic: a gender lens is critical to adequately address violence; Violence toward disabled people is also an epidemic as disabled people experience even higher rates of violence (NZ Government, 2021 p. 1).

Recommendations from these reports include:

Whakamanahia Te Tiriti, Whakahaumarutia te Tangata - Honour the Treaty, Protect the person	Whakamahia te tūkino kore ināianei, ā muri ake nei - Acting now for a violence and abuse free future
- Value Indigenous worldviews ensuring programme design, implementation and evaluation are informed by Tikanga and Te Ao Māori - Prioritise tino rangatiratanga, self-determination and autonomous decision-making by tāngata whaikaha Māori as part of whānau, hapū and iwi - Move from an individual focus to a focus on whānau, hapū, iwi and communities - Ensure solutions reflect the aspirations and elevate the voice of tāngata whaikaha Māori - Ensure parallel responses to simultaneously address context and violence against tāngata whaikaha Māori - Partner with whānau, hapū, iwi and communities to emphasise primary prevention of violence - Allocate appropriate resourcing including capacity building of whānau, hapū, iwi and communities and Kaupapa Māori approaches - Realise the promises of Te Tiriti and rights for tāngata whaikaha Māori under UNDRIP and UNCRPD	- A twin track approach [mainstream and specialist together] is needed [that is underpinned by Te Tiriti and Human Rights] to address gaps in services, knowledge and practice - Mainstream prevention initiatives, services and processes need to be accessible [to tāngata whaikaha and in particular Wāhine tāngata whaikaha] - Tāngata whaikaha Māori and disabled people must lead solutions - Disabled people's organisations and tāngata whaikaha Māori must be resourced to participate [in informing these solutions] - Ableism must be challenged - Service responses [disability services and violence and abuse services] need to rapidly improve – [informed by research and co-developed models] - Support public education of Te Tiriti and human rights, including the UNCRPD. - Enhance disabled people's tāngata whaikaha Māori access to justice [and to be recognised as competent decision makers under the law as per Article 12 UNCRPD]

A coordinated, multi-sector approach underpinned by the National strategy and resourced through the action plan of this strategy using the evidence, information and insights in these two reports, transformation and importantly recognition of violence and abuse that has occurred, and holistic approaches to healing are possible.

Challenging ideas of inherent vulnerability of disabled people
There is a need also to situate this transformation in an overall approach to strengthen the rights of disabled people to "have safety' in their lives. This includes all areas of life that all citizens seek and expect safety, including in the community, neighbourhoods and homes and in interpersonal relationships. For many disabled

people this also means in their day to day lives where they are supported by formal supports and services..

The term 'vulnerability' is often used in relation to experiences of 'safety' or 'unsafety', and in the context of disabled people's lives there is a sense that being 'a disabled person' is to 'be a vulnerable person'. This is despite the existence of equal citizenship and legal rights that allow all people to make decisions about how they live their lives, including managing risk. For disabled people this is enshrined in the CRPD in particular in Article 12 – Equal recognition before the law. This article situates all disabled people as being recognised as persons before the law and as being recognised to have legal capacity 'with others in all aspects of life'.

Article 12 s4 refers to 'safeguards' being available to 'prevent abuse in accordance with international human rights law' noting that the 'rights, will and preference' of disabled people are paramount and central to their decision making and that any 'safeguards' are "proportional and tailored to the person's circumstances, apply for the shortest time possible….and be proportional to the degree to which such measures affect the person's rights and interests' (UNCRPD, Article 12). It is important to acknowledge this use of the term 'safeguard' as it clearly refers to practices that are required to be developed and applied specifically because they are 'restrictive' in some way to rights, will and preference to prevent abuse of rights. In relation to prevention of violence and abuse in the lives of disabled people the term 'safeguarding' has been used to refer to programs and approaches that have a focus on 'teaching people how to be safe'. US academic Nancy Fitzsimons refutes the notion that people 'can be safe' and that there is a way to 'safeguard', instead advocating for the use of the concept of 'safer'. In using this she is drawing on the work of the late Dave Hinsburger a disability sexuality and relationships rights researcher and advocate who proposed ' a ring of safety as the antidote to the prison of protection and the dehumanising indignity of safety (Hinsburgher, 1994). This 'ring of safety' has at its centre acknowledgement and articulation of personal rights of disabled people and 'transferring the power and responsibility' of their lives to them. It is within this context that the idea and use of 'safeguarding' within prevention of violence and abuse work with disabled people is contested as the term is clearly related to the practice of intervening to restrict or change autonomous decision making based on a presumption of inherent 'risk, vulnerability and incapacity'. For

this reason, it is important to challenge ideas and practices based on 'safeguarding' and instead focus on and use a rights approach.

As the NZ Disability Commissioner Paula Tesoriero notes in her address to the 2022 forum on independent monitoring of the UNCRPD note, there is a need for full scale and urgent adoption of legislation, policy and practice led by the lived experiences of disability and embedded in a human rights model of disability. Below are the key recommendations of the Disability Commissioner to enable this transformation.

- Establishing sustainable mechanisms between government and tāngata whaikaha to ensure the voices of tāngata whaikaha Māori are formally included in all disability-related policy and legislative development, and any Crown–Māori partnership initiatives.
- Enact genuine and properly resourced partnership with disabled people. This extends to establishing mechanisms to suit the diversity of disabled people and include specific experiences such as those of the disabled children, disabled women, disabled people of diverse ethnicities. And
- Embedding the Disability Convention in Legislation and ensuring the public service accessed education about the disability convention led by disabled people. (Disability Commissioner Paula Tesoriero, March 29 2022, HRC)

Addressing key questions

In this section I address the questions framing this brief. The background information presented in the previous section provides the conceptual framing that underpins these brief and focused responses.

   a. How do disability, gender, age, culture, mental illness and race intersect in relation to experiences of abuse (including neglect)?

Analysis papers on the experiences of LGBTQIA+ communities; Ethnic, migrant and former refugee communities; Children and Young people and Disabled people supplement Te Aoreerekura - the National Strategy to eliminate family violence and sexual violence (Te Kāwanatanga o Aotearoa - New Zealand Government, December 2021). These analysis papers read together are a story or intersecting experiences that the WHO model of violence, and abuse and the disablility focused

ecological models recognise as being factors that act to increase risk of abuse of people who identify as and across these identities.

Intersectionality and ableism have been introduced in the background to this paper. These concepts, along with the ecological models outlined provide a way of seeing and understanding how the lived experience of disability and the lived experience of violence and abuse are linked through oppressive socio-cultural, ableist structures including systems that privilege dominant power positions of gender, race and ability. This is highlighted in this quote from the Human Rights Commission;

"The disadvantages experienced by tāngata whaikaha Māori as Māori disabled persons is compounded by the structural and institutional disadvantage they face as tangata whenua" (Whakamanahia Te Tiriti, Whakahaumarutia te Tangata ,HRC 2021).

> b. How does the human rights framework you use in your work uphold the rights of disabled people? In what ways do you see it benefiting disabled people abused in care?

Disability rights are human rights; this is the main premise of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), as it was developed to promote the human rights of disabled people not develop additional rights. Pinto (2016) highlights however that despite the obligations to recognise the human rights of disabled people, "…international human rights law has not been applied in ways that redress the disadvantages that [disabled people] experience (Pinto, 2016 p 211). The development of the UNCRPD "..reaffirms that *all* persons with *all* types of disabilities must enjoy *all* human rights. One of these rights is the right to be safe from violence and abuse as articulated in the UNCRPD *Article 16 – Freedom from exploitation, violence and abuse.* (United Nations, 2022). While it is important to see and use the Convention as a whole to reform legislation and policy, it is also important to highlight key articles that can provide a clear platform for reform and redress. Article 16 along with Article 12 – *Equal recognition before the law* are key to both informing prevention of violence and abuse AND framing how experiences of violence and abuse of disabled people are recognised and responded to. In my work in primary prevention of violence and abuse of disabled people (see Appendix One – Sexual Lives and Respectful Relationships) these

rights are interpreted through the stories told by disabled people and used in group and individual work with disabled people so they are aware of and can relate these rights to their lives.

An imporant part of this work is to reframe experiences of violence and abuse as crimes, and as human rights breaches. This is particularly relevant where experiences of 'abuse in care' have been framed by disability services as 'incidents' in workplaces rather than breaches of law. Using a rights approach in prevention of violence work with disabled people, and ensuring access to the law as it applies to all members of society for when violence and abuse occur, does reframe and offer opportunities to reform, and reclaim the human right to be safe from violence and abuse.

> c. Specific to your area of expertise, how can the sexual rights, including health education, of people with learning disabilities be supported and promoted? Are there other ways you are aware of by which sexual rights of people with other disabilities can be supported?

1.Sexuality is inherent to being human. For disabled people sexuality is not always acknowledged by others as being such an important part of their lives. Gill (2015) in his aptly titled book *Already Doing It,* highlights that those who mediate the lives of people with an intellectual disability have created an 'extraordinary sexuality' that does not line up with more commonly understood and held ideas about adult sexuality. This notion of an extraordinary sexuality restricts and 'removes' those aspects of sexuality that are determined to be unachievable and inappropriate for people with an intellectual disability; including reproductive sex, self-authored sexual identity and often privacy and intimacy (in Frawley & O'Shea, 2020 p, 413).

2.If the Convention on the Rights of Persons with Disabilities is to be used to enable equality of rights for people with disability, then being silent on sexual rights, in particular as they are perceived within the lives of people with intellectual disabilities, also silences advocacy about sexual rights in the disability movement and weakens opportunities for people with intellectual disabilities to engage with the broader social movement on sexual rights (Frawley & O'Shea, 2020, p. 415).

3.In the Sexual Lives and Respectful Relationships model (Frawley & O'Shea, 2020) disabled people are positioned as "owners, developers and facilitators of knowledge'

of and about their sexuality". This positioning challenges ideas about 'inherent vulnerability' and 'incapacity' to *be* sexual which are used in some 'specialist' approaches described as 'safeguarding' programs.

4.There is a need (and an opportunity) to engage in community awareness raising about sexuality and relationships in the lives of disabled people that draws on the mainstream 'sex positive' approach. This is promoted within mainstream (Nimbi, et al., 2021) sexuality education and sexual health and "promotes the importance of being open-minded with respect to sexual and gender expressions, being nonjudgemental and respectful of personal autonomy, giving centrality to the need for asking/obtaining consent for any sexual behaviour, discussing different sexual expressions and behaviours, emphasizing the validity of a person's sexuality and focusing on health care and education consequences" (Nimbi, et al., 2021).

> ### d. What can be done to support LGBTQIA+ people with learning disabilities to explore healthy sexual lives and respectful relationships?

1.Challenge the 'single story' of sexuality and learning disability that is as Gill (2015) notes 'extraordinary' in that [the sexuality of learning disabled people] is framed as being without agency, without diverse expression and without intimacy. Marks, O'Shea, McVilly, Frawley, & Despott, 2020) add, it is also framed as heteronormative, which impacts the extent to which a disabled LGBTQIA+ identity can be claimed by disabled people.

2.Use the lived experiences and 'told stories' of learning disabled people to challenge these views, and engage learning disabled people in the telling and sharing of these stories. In Australia, the self advocacy movement has been an important space for learning disabled LGBTQIA+ people to claim their identity, advocate for their rights and partner with mainstream LGBTQIA+ organisations in research and advocacy (see Rainbow Rights Australia https://www.voicestogether.com.au/wp-content/uploads/2019/02/Rainbow-Rights-and-Arts.pdf)

3.Through this partnered research and advocacy promote opportunities to celebrate, research, educate and advocate together (see Rainbow inclusion https://rainbowinclusion.org.au/ a community partnered research initiative LGBTIQA+

Intellectual Disability information project – Inclusion Melbourne, Thorne Harbour Health & Deakin University; LGBTQIA+ Disability advocacy at the intersections– Queerspace Victoria https://www.queerspace.org.au/advocacy-intersections/ and; Switchboard UK https://www.switchboard.org.uk/what-we-do/disability-and-neurodiversity-group/)

> e. How can access to domestic, family and sexual violence services for disabled people (particularly disabled women) be improved?

Understand the barriers and enablers to access to domestic, family and sexual violence services for disabled women/Wāhine tāngata whaikaha, and work with them to co-develop solutions.

There is a strong commitment by government and disabled people to address access and inclusion to domestic, family and sexual violence prevention and response services and strategies in NZ (see *Te Aorerekura – the National Strategy to Eliminate Family Violence and Sexual Violence;* Whakamanahia Te Tiriti, Whakahaumarutia te Tangata – Honour the Treaty, Protect the Person – Violence and abuse of tangata whaikaha in Aotearoa New Zealand Evidence and Recommendations). This strong base needs to be built on through connecting domestic, family and sexual violence, disabled people led organisations and researchers in shaping transformation that has begun with the recent research that underpins these reports.

The NZ Disability Strategy and the *Te Aorerekura – the National Strategy to Eliminate Family Violence and Sexual Violence* advocate for a 'twin -track' approach to ensure prevention and response services and strategies are accessible to disabled people and in particular disabled women and Wāhine tāngata whaikaha.

The term 'twin-track approach' has been adopted in international disability policy and practice to "…address double discrimination" (Gupta, 2011, para 11). It is an approach that advocates for 'general provisions [of services, funding]' to be inclusive of, and accessible to disabled people AND advocates for 'specialist provisions [of services, funding etc]' to respond specifically to barriers that are not addressed by generalist approaches. Dhanda (2008) suggests this translates to having access to

'the same and different' [services, funding etc]. The approach is used particularly in relation to addressing double discrimination of marginalised disabled people including women, those marginalised by poverty and social disadvantage in particular in developing countries, marginalised cultures/race, and diverse sexualities, for example.

A twin- track approach has been adopted in disability policy in NZ being one of the two approaches articulated in the NZ Disability Strategy 2016 – 2026 (ODI, 2016). While there is no direct reference to or description of how this approach was adopted in NZ disability policy it is an approach embedded in Convention on the Rights of Persons with Disabilities, "The CRPD requires States Parties to incorporate disability-sensitive measures into mainstream service delivery, and to provide disability-specific services that are necessary to support the inclusion and participation of persons with disabilities [also referred to as a twin-track approach' (UN Development Group, 2011 p. 16).

Applying this approach to address gaps in provision of violence and abuse services for disabled people has been recommended in a recent report by Te K`ahui Tika Tangata – the NZ Human Rights Commission (Human Rights Commission, December 2021). In this report the justification for this approach is premised on the inclusion of a twin-track approach in the NZ Disability Strategy, "The NZ Disability Strategy developed by disabled people to operationalise the UNCRPD in a domestic context includes a twin-track approach" (Human Rights Commission, Dec 2021, p. 39). It recommends that 'Twin track one' should address gaps in accessibility of all relevant mainstream services and processes. Referring to research undertaken by Debbie Hager (2011) this section notes that , "…there are almost no mainstream services available that respond to violence against disabled people" (p. 40). The report continues by stating that 'Twin track two' should focus on the development of 'specialist services' highlighting that there are "..no violence prevention and response services that are responsive to, or that incorporate, disability-specific intersectional cultural needs" (HRC, Dec 2021, p. 43).

This approach to date has not been implemented in NZ in violence and abuse prevention and response policy and services. The National Strategy to Eliminate Violence and Abuse commits to this twin-track approach noting "Te Aorerekura also

sets out a commitment to work towards what some communities refer to as the 'twin-track approach'…this will include, for example, specialist disability-focused services informed and led by disabled people themselves, and culturally and linguistically appropriate models of intervention for ethnic communities" (p. 60). The strategy notes that building these services will take time. As such there there is no research evidence about the efficacy or efficiency of this model in NZ. Research needs to be undertaken in NZ to investigate the current situation given the lack of available current research, and to co-develop approaces with disabled people – in particular women Wāhine tāngata whaikaha.

Broad systemic change is needed that engages disabled people - tangata whaikaha, in particular disabled women Wāhine tāngata whaikaha across the lifecourse, across cultures (Māori, Pasifika, other ethinic groups) and across and diverse sexualities, in challenging the socio-cultural attitudes and practices that position them as vulnerable victims. Research that uses a critical disability studies and culturally responsive approach to to inform community awareness raising and advocacy is needed to inform this work. In particular through this work co-development of resources will be available be in multiplesectors to respond to disabled people who experience violence and abuse (see for eg 'One Size Does not fit all' Frawley et al (2017) https://20ian81kynqg38bl3l3eh8bf-wpengine.netdna-ssl.com/wp-content/uploads/2019/02/Whatever-It-Takes-Access-Resource-FINAL.4.pdf; Making Rights a Reality – South Eastern Centre Against Sexual Assault, Victoria, Australia; VERA Institute for Justice, Center on Victimisation and Safety Brooklyn New York; Deaf Health Charity Signhealth Domestic Abuse Service, UK and WWILD, Queensland Australia.

It is important to acknowledge that this work requires funding that affirmatively enables disability focused research as has been the case in Australia through the Australian National Research Organisation on Women's Safety and funding by the US Government for the work of the VERA Institute for Justice 'Equal access for people with disabilities' suite of research and programs. https://www.vera.org/projects/equal-access-for-people-with-disabilities

f. In response to questions (c), (d) and (e), do you have any specific recommendations that relate to survivors of abuse in care, including how to prevent abuse in care?

Survivors of abuse in care:

An important first step is hearing from disabled people who are survivors of abuse in care as is happening through the Royal Inquiry into Abuse in State Care [ensuring adequate support for engaging in this see for eg 'Your story legal support' – Australia https://yourstorydisabilitylegal.org.au/Home). Following from this a program of analysis of these stories and reports is needed to identify and use the key themes to:

- Offer an apology and provide redress to individuals/whanau/family
- Enable and support justice outcomes
- Inform legislation, policy and practice in the provision of disability supports and services including all segregated services (education, residential etc)
- Support a Royal Inquiry into abuse of disabled people with a broader scope

Prevention of abuse in care is addressed earlier in the paper.

g. What are the barriers that prevent disabled people from reporting incidents of abuse and neglect?

Paula: First of all, they should believe you. Second, they should give you choices of where to go from there. And then support you in what you want to do, which may be just going to psychologists to help. It may be, "I want to report it to the police." It may be, "I am not safe where I am living," so we need to find a way to either move the person – move one or the other (Maher, J. M., Spivakovsky, C., McCulloch, J., McGowan, J., Beavis, K., Lea, M., … Sands, T. (2018). Women, disability and violence: Barriers to accessing justice: Final report (ANROWS Horizons, 02/2018). Sydney: ANROWS.)

Research continues to highlight that disabled people, and in particular disabled women who have experienced violence, abuse and neglect in state funded, private and community spaces, places and relationships face significant barriers to justice beginning with 'not being heard and believed'.

A full-scale review of laws and practices for enabling access to justice – including reporting to police for victims of violence, abuse and neglect is needed. There has been very good work undertaken in NZ on access to justice for disabled people (see for example 'Developing a responsive legal service' (Mirfin-Veitch, Gates, Diesfeld, & Henaghan, 2014) and 'Benchmark' 2022 an online resource to assist legal professionals working with people who may be vulnerable in the New Zealand legal system https://www.benchmark.org.nz/); and research to inform implementation of Article 12 of the CRPD (Mirfin-Veitch 2016). This work needs to be built on with a focus on the experiences of victims of violence, abuse and neglect.

Co-development of accessible resources for disabled people, disability support providers, disability advocates, domestic, family and sexual violence services, the policy, judiciary and health providers is needed (see for example Making Rights a Reality suite of resources https://www.secasa.org.au/programs-and-services/making-rights-reality/#:~:text=Making%20Rights%20Reality%20is%20a,sexual%20assault%20or%20family%20violence.), along with accessible legal support and advocacy for using victim support services including eg ACC and justice based victim support.

> **h. What supports or safeguards are required to uphold the rights and safety of disabled people in care?**

(See background section for overarching approaches)

While agencies/roles such as the Health and Disability Commissioner and the Human Rights Commission are in place and perform important roles in responding to, and to some extent developing preventative advocacy for disabled people, a focus on service system transformation is needed. This includes:

- Redevelopment of disability services to ensure they are 'disabled people led' – this includes transforming the way disability services are funded to ensure the funding agreements reflect this principle in practice
- Continual work to ensure disabled people are aware of their rights through partnerships between these safeguarding entities and disabled people (see for example the work of the HRC and disabled people in the development of the two 2021 reports -

'Acting now for a violence and abuse free future' and 'Honour the Treaty, Protect the person')

- Challenging the concept of 'safeguarding' as it is currently applied in the disability sector, and align approaches to rights including the UNCRPD with particular focus on Article 12 and Article 16.

i. What needs to change to prevent the abuse and neglect of disabled people in care?

(See background section of this paper for a comprehensive response to this question).

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