

Analysis - Disabled people

Date: March 2022

Purpose

During May and June 2021, the Joint Venture engaged with people across Aotearoa New Zealand to inform [Te Aorerekura – the National Strategy to Eliminate Family Violence and Sexual Violence](#). A key part of this engagement was the conversation with disabled people. This paper reflects disabled people's experience with the family violence and sexual violence systems and the opportunities for improving how Aotearoa New Zealand work to prevent, respond, heal and recover from these forms of violence. Communities, organisations and individuals were generous in sharing their experiences, and through their insight government agencies have worked to develop a 25-year Strategy designed to achieve the moemoeā, or vision: All people in Aotearoa New Zealand are thriving: their wellbeing is enhanced and sustained because they are safe and supported to live their lives free from family violence and sexual violence.

This paper sets out themes that came out of hui, written submissions and conversations with disabled people and uses, as much as possible, the words and voices of the people who shared their pūrākau (stories) and whakaaro (thoughts). The writing of this paper has been strongly informed by this community.

Our engagement process with disabled people

Our engagements with disabled people were informed by advice from the Joint Venture Disability Reference Group. This advice included that:

- Submissions, information and processes needed to be fully accessible including information being available in alternate formats
- Engagement hui reach people with learning disabilities because they are often at high risk and often overlooked in government consultations
- Engagement hui be held in locations with existing safeguarding services in place.

An important aspect of the Joint Venture's engagement approach involved communities hosting targeted and closed hui. Specialist practitioners were on hand in case discussions triggered personal disclosures.

The engagement materials were made accessible in Word documents and alternate formats were produced in Braille, audio, large print, New Zealand Sign Language (NZSL) and Easy Read.

The Joint Venture partnered with the Personal Advocacy and Safeguarding Adults Trust (PASAT), People First and Safeguarding Vulnerable Adults Taranaki (SVAT) to hold in-person hui in Taranaki and Waitematā. These areas have existing safeguarding pilots and support



services in place, which helped to ensure the safety of participants. The hui format was flexible and able to adapt to disabled people's needs and approaches, including, for example accessible venues (where available), a longer hui time and regular breaks.

The JV also held a number of zoom hui and invited public submissions via Citizen Space online consultation platform. We heard from, and engaged with, service providers, advocates, the Joint Venture Disability Reference Group, disabled people's organisations, disability support organisations and whānau and families of disabled people, including parents of children with Foetal Alcohol Spectrum Disorder (FASD).

Some parts of the disability community were not able to be reached within the timeframes for this engagement, including people with high and complex needs, people with psychosocial disabilities including people with experience of mental illness, disabled children, people living rurally or outside of the areas where safeguarding responses are in place or those in a residential support services and homes. Whilst Māori and Pacific disabled people participated in engagement hui, we acknowledge that more could have been done to reach people in these groups.

What we know about disabled people

The New Zealand Disability Strategy¹ defines disability as:

“Disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments, this is the thing all disabled people have in common. It is something that happens when the world we live in has been designed by people who assume that everyone is the same.”

Not all people captured by this definition will choose to identify with disability-focused language. It is society that disables people, as such disability is a dynamic concept shaped by the way people with impairments are treated by society. The concept will continue to evolve as society changes over time. Disabled people's aspirations to realise their rights is the pou that connects disabled people.

Disability is complex. It includes people with a wide variety of physical, sensory, cognitive, psychosocial and other impairments. People with the same impairment can have different needs and require different responses, therefore responses need to be flexible and respectful of the disabled person's mana. Families, whānau, friends, carers and supporters are an important part of the disability community. In this way, disability also impacts on people without impairments.

The disability sector includes a wide range of groups and organisations providing support, services to, and advocacy with, disabled people. Disabled people's organisations (DPOs) are those that have a mandate to represent their disabled members and have a national focus.

¹ Office for Disability Issues. 2016. The New Zealand Disability Strategy. <https://www.odi.govt.nz/nz-disability-strategy/>

The DPO Coalition is a coalition of seven DPOs established to oversee government's Disability Action Plan and to provide advice to government.

The following data is taken from the 2013 New Zealand Disability Survey². This is the most comprehensive source of information on disabled people in Aotearoa New Zealand. There has not been another survey since 2013.

The 2013 survey found that disabled people represent almost a quarter (24%) of the population - 1.1 million people. 26% of the Māori population were identified as disabled. The main impairment type for disabled adults and children was a physical impairment (47%). Disease or illness and accident or injury are leading causes of impairment for disabled adults and children. Aotearoa New Zealand has an ageing population which will result over time in an increasing proportion of people experiencing disability. In 2013, 59% of people over 65 identified as disabled. Disabled people are also living longer, and there will be an increasing number of people with age-related impairments. This is a global trend and is drawing greater attention to disability and the actions required to enable the full participation and wellbeing of people. Meeting the needs and challenges of our ageing population is a significant issue now and will continue to be over coming decades.

New Zealand Sign Language (NZSL) is an official language of Aotearoa New Zealand used by some 20,000 people, approximately 4,500 of whom are deaf people who use sign language as their first or preferred language.

According to the New Zealand Crime and Victims Survey³ adults with disability are significantly more likely to experience crime across all offences – personal offences, household offences, burglary, and interpersonal violence offences. The risk of interpersonal violence for adults with disability is twice as high as the New Zealand average, after accounting for age differences. This is reinforced by research published in 2021⁴ which found that people with disabilities report experiencing a significantly higher lifetime prevalence of intimate partner violence compared with people without disabilities.

Along with people living with disability, whānau Māori are more likely to be victims of crime, including family violence and sexual violence, compared to other people.⁵ The higher rate of disability among the Māori population could indicate higher risks of family violence and sexual violence for Māori disabled people. This is an important consideration for intersectional policy and service design in the National Strategy.

² Statistics NZ. 2013. *New Zealand Disability Survey*. <https://www.stats.govt.nz/information-releases/disability-survey-2013>

³ Ministry of Justice. 2021. *New Zealand Crime and Victims Survey. Key findings. Cycle 3. October 2019 – November 2020*. <https://www.justice.govt.nz/assets/Documents/Publications/NZCVS-Cycle3-A5-20210611-v1.0-fin.pdf>

⁴ Fanslow, J. Malihi, Z. Hashemi, L. Gulliver, P. and McIntosh, T. 2021. *Lifetime prevalence of intimate partner violence and disability: results from a population-based study in New Zealand*. *American Journal of Preventive Medicine*.

⁵ Human Rights Commission. 2021. *Acting now for a violence and abuse free future. And Honour the Treaty, Protect the person*.

https://www.hrc.co.nz/files/5516/3830/6276/Executive_Summary_Acting_now_for_a_violence_and_abuse_free_future_FIN_AL.pdf

Emerging themes from engagement with disabled people

The family violence and sexual violence system is not accessible and does not work for disabled people

Generally speaking, our society and services are not designed with, or for, disabled people, as a result they are not accessible and difficult to navigate. Disabled people and their family or whānau lack choice and control over supports and services, due to service gaps and inconsistencies across supports. Reporting, complaints processes and systems are most often not accessible or supportive of disabled people's needs, with reporting data and information presenting a very limited picture of people's experiences. The experience of being a marginalised and under-served group contributes to low levels of trust within the disability community that systems/services can work for them, which in turn further contributes to isolation and under-reporting of family violence and sexual violence.

Disabled people report experiences of state systems, institutions and services where practices have been abusive and failed to adequately uphold their human rights. For example, disabled women have been presumed to be unfit mothers because of their disability and have had their children removed from their care. Health decisions have been made based on misunderstandings and discrimination against disabled people, including forced sterilisation. And in the everyday experiences of people with disabilities, the lack of responsive support and accessible services can lead to further systemic or inter-personal abuse.

The low levels of knowledge and awareness about disability across society contributes to the high level of discrimination experienced by disabled people, including within the family violence and sexual violence response systems.

There is a need to address ableism and barriers to services and support

Society creates many barriers for disabled people, including barriers to accessing family violence and sexual violence services and supports. There are few services designed by and for disabled people, and multiple barriers to disabled people being able to report and to being heard when they do report family violence and sexual violence.

Disabled people are less likely to report, or have the violence they experience identified or addressed, due to a number of factors. This can include being dependent on the family members, carers or organisations who are using violence. There are limited support options or accessible, safe places to go and some disabled people face communications and language barriers.

Communication barriers can include not having access to communication equipment or New Zealand Sign Language interpreting services. The shortage of accessible housing means disabled people may be unable, or reluctant, to leave their accessible homes when exposed to violence. People in the disability community talk openly about not being taken seriously, or being blamed, for the abuse when they do disclose. Disabled Māori, who are disconnected from whānau and whenua, can be more vulnerable to harm, due to having fewer support networks and safety nets.

Ableism⁶ acts to minimise the needs and concerns of disabled people, and must be addressed through education and capability building so disabled people can confidently speak up and/or complain if they experience violence or discrimination. Workforce development and social change campaigns are required to build understanding of disability, and respect towards disabled people, across Aotearoa New Zealand. Other ways to improve understanding, policy and practice include:

- raising community awareness of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁷ and disabled people's human rights
- progressing the 'Accessibility for New Zealanders legislation' with a clear timeline for introduction of a bill to Parliament, followed by investment in implementation in communities.

Better data collection and research is required

More and better data, including qualitative research, is needed to better understand the nature and extent of violence and abuse experienced by disabled people. Commissioning of research must include funding more specific disability research, carried out with, by and for disabled people. Data also needs to be collated about disabled peoples' experiences in the care-carer relationship and carers' experiences of violence.

Data collected by agencies should be able to be disaggregated by, for example, impairment, access and support needs, gender, ethnicity, and type of violence or abuse. This would allow more accurate recording and analysis of the needs of disabled people.

Disability responsiveness training should be provided to agencies collecting this data, including for example, the importance of self-identification and not making assumptions.

Better data collection requires an understanding of the limitations of administrative data based on service use to inform policy and practice, and agreement to improve our knowledge-base so that we can learn and monitor.

Across the family violence and sexual violence system, better, safe, information sharing is needed.

Finally, investment decisions should be informed by improved data and research, as our understanding of how family violence and sexual violence occur within the disability community increases.

There are service and support gaps for 18 to 65-year-olds

There are almost no services or organisations providing services and support to disabled people aged between 18 and 65 who have experienced family violence and sexual violence. This leaves a significant, long-unaddressed gap for people needing services between young adulthood and into older ages.

⁶ Ableism is discrimination and social prejudice against disabled people based on the assumption or belief that disabled people are inferior because of their impairment/s.

⁷ United Nations. 2006. *United Nations Convention on the Rights of Persons with Disabilities*.
https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

There is very little resourcing for targeted education and awareness raising for disabled people about what violence is, how to keep safe, their rights, and where to seek help. This is critical for raising the capacity and capability of disabled people.

Little interaction between the disability sector and family violence and sexual violence sectors

There is growing awareness and discussion on the disconnection between the disability sector and the family violence and sexual violence sectors. Disability services often do not have the capacity and capability to support people who have experienced family violence and sexual violence. Equally, the family violence and sexual violence sectors often do not have the capacity and capability to respond to the specific needs of disabled people.

Violence by carers and violence towards carers are related issues

Abuse in the care of others, whether within the family, in a shared disabled people's home and/or when living with disabled people is acknowledged. It should also be noted that most carers are women.

There is often a significant power imbalance between disabled people and the carers who come into their homes who are often undertaking very private and personal tasks with the disabled person. Ableist attitudes and some poor carer support systems and employment conditions can result in disabled people experiencing abuse from carers. This is exacerbated by a lack of best practice or monitoring of support workers and carers leading to unsafe situations. Abuse by carers is often not identified or reported.

Disabled people want to have control and choices in carer staff, employment contracts and organisations providing carers.

In Aotearoa New Zealand, the dynamic of violence towards carers was raised during consultation on Mahi Aroha: Māori perspectives on volunteering and cultural obligations.⁸ Some carers are managing very complex care situations and experiencing violence and aggression from the disabled person they were caring for with few or poor support services.

People who are employed in the disability sector are often poorly paid, poorly trained and poorly resourced, and working in systems that are not well monitored. Improving the pay and professional development of this workforce requires a significant shift if the workforce is fully resourced and supported to deliver care, alongside family and other carers working in the sector.

There is a need to protect staff who face abuse. The Family Violence Act 2018⁹ (section 14), outlines that a recipient of a care-carer relationship can constitute a close personal relationship and the violence may cause cumulative harm.

Robust procedures and practices are needed to encourage disclosure by any party and to correctly determine the primary victim and perpetrator in the care-carer situation. Monitoring

⁸ Office for the Community and Voluntary Sector. 2007. *Mahi Aroha: Māori perspectives on volunteering and cultural obligations*.

⁹ Ministry of Justice. 2020. *Amended Family Violence Act 2018*.

<https://www.legislation.govt.nz/act/public/2018/0046/latest/DLM7159322.html>

structures and a process and list of people who have been barred from working with disabled people and vulnerable adults would provide greater accountability. Reforming the audit process to be on a surprise basis would enable more accurate record keeping between client and service providers. It's important that abuse against disabled people is treated as a crime – not an "event". The complaints process should be handled appropriately and independently, with a process of reporting assault to Police.

Gendered patterns of violence experienced by disabled people need to be understood

The gendered nature of family violence and sexual violence observed in the general population can look very different for disabled people. For example, a significantly higher proportion of disabled men experience violence when compared to non-disabled men, as indicated in the 2021 research by Fanslow *et al.*¹⁰ This trend is also seen in terms of who is accessing safeguarding services in the Waitamatā, which is almost equally accessed by disabled men and women.

However, family violence and sexual violence services are primarily designed to respond to intimate partner violence involving men using violence against women. Services are needed that respond to disabled people's experiences of violence including services for disabled men who experience family and sexual violence.

Twin-track services are required

The New Zealand Disability Strategy¹¹ promotes the twin-track approach: ensuring mainstream services and supports are inclusive of, and accessible to, disabled people and ensuring there are specialist services and supports specific to disabled people, including for disabled children and whānau of disabled people. People's needs for either or both can change over time too. This should include specialist prevention, response and restorative/healing services and initiatives developed to specifically meet the needs of disabled people, including for example counselling and recovery services.

Ensuring that mainstream services and supports are inclusive of disabled people requires the provision of reasonable accommodation¹² and incorporation of universal design.¹³ Reasonable accommodation can often cost very little or nothing at all. Because it is specific to a situation; what it looks like in practice can vary significantly. Accessibility audits should be conducted of mainstream family and sexual violence prevention and response services (including those provided by third parties) to identify the improvements needed. This would ensure that they

¹⁰ Fanslow, J. et al. *ibid.*

¹¹ Office for Disability Issues. *ibid.*

¹² Reasonable accommodation is defined in the Convention as "... necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms." (Article 2).

¹³ Universal design is good design that works for everyone. It is about making sure everything is accessible to, understood by and used to the greatest extent possible by everyone, with little or no adaptation required. Incorporating universal design early on is cost-effective. Universal design is often referred to in relation to the built environment, but it applies to services, supports, the curriculum and technologies as well. Universal design is distinct from accessible design. Accessible design represents the minimum accessibility requirements in built design, whereas universal design seeks accessible design outcomes that work for everyone.

are inclusive and accessible, and staff have access to appropriate training. These audits should be led by disabled people and approved technical experts. Priority should be given to supporting disabled people to remain in their accessible home (adapted to their needs) and in the community where they have supportive networks and services.

All information about family violence and sexual violence support and services, including information about legal processes, must be available and easily accessible in alternate formats to a range of disability communities.

It is necessary to build workforce competence

Specialist workforce competencies regarding disabled people's experiences of violence and abuse must be developed, with family violence and sexual violence response providers, Police, Justice and Health workforces trained to respond safely and appropriately. Workforce frameworks and training must be provided to wider justice sector personnel, including Police, judges and lawyers to ensure all disabled people can access safe and appropriate supports and have equitable access to justice.

The emergent themes from submissions on disabled people's experience were:

- Inaccessibility – the family violence and sexual violence system is not accessible and does not work for disabled people
- Ableism – there is a need to address ableism and barriers in services and support
- Data – better data collection and research
- Gaps – there are service gaps for 18 to 65 year olds
- Silos – there is little interaction between the disability sector and the family violence and sexual violence sectors
- Carers – violence by carers and violence towards carers are related issues
- Gender – gendered patterns of violence experienced by disabled people need to be better understood
- Twin-track – twin-track services are required
- Workforce – it is necessary to build workforce competence.

What the National Strategy needs to include

A programme of work is needed to address data and research gaps, design services and work with disabled people towards implementing the twin-track approach, providing support and services to all disabled people.

The Strategy needs to:

- Include clear action areas for disabled people
- Ensure disabled people are visible from vision right through to the Action Plan

- Recognise people with disability as a population group and culture, rather than a health issue
- Ensure disabled person-led accountability
- Acknowledge the systemic discrimination of disabled people, including ableism
- Be strengths-based, taking a human rights approach and including principles related to Enabling Good Lives, the United Nations Convention of the Rights of Persons with Disabilities (UNCRDP) and United Nations Declaration on the Rights of Indigenous People (UNDRIP).

Actions for eliminating family violence and sexual violence for disabled people

A number of actions were proposed through hui discussions and submissions. These include:

- **Person-centred policies:** All policies and services should be person-centred. Disabled people must be involved in decisions that affect them, including decisions about their support services, where they live, and in the design, implementation and monitoring of services and support
- **Disability-led:** Developments should be disability-led, with disabled people at the table designing, implementing and monitoring policies. Disabled people should be actively consulted on the development and implementation of legislation and policies concerning justice, violence and abuse prevention, and human rights. Resources must be co-designed with disabled people for all family violence and sexual violence awareness and prevention initiatives. This could also include establishing a Ministry for Disabled People (run by disabled people) and having the Disability Commissioner look after disabled children under the care of Oranga Tamariki
- **Capacity-building:** There should be increased capacity-building for disabled people and the disability community including a focus on rights and keeping safe. This could include a national roll-out of the Keeping Safe Feeling Safe programme
- **Accessible formats:** All government communications, especially concerning family violence and sexual violence, must be fully accessible, including in alternate formats
- **Safeguarding Framework:** The Safeguarding Framework and service approach should be implemented nationally, which would include the twin-track approach to services and support and could also include a disability abuse helpline run by disabled people and trained counsellors
- **Independent advocates:** Other supports needed include learning disability social services, a nationwide independent advocacy service and coordinators. Advocates need to be trusted, have legal and policy backing and be able to communicate with disabled people
- **Legal changes:** Legal protections should be reviewed for their efficacy in safeguarding disabled people and adults at risk, along with raising people's awareness of what legal protections exist and how they should be applied. This should include better guidelines

around guardianship, assessment pathways, advanced care planning, Enduring Power of Attorney, supported decision making and informed consent. This includes the ability for disabled people to speak for themselves in court. The Protection of Personal and Property Rights Act review needs to include definitions of vulnerability

- **Shared understanding:** A shared understanding and language should be developed including definitions related to disability and violence. This would include implementing legislative change to ensure definitions and understandings of family violence and sexual violence are inclusive of the experience of disabled people. It should be made clearer that the definition of family violence can include child-to-parent violence. The term 'support' should be considered in place of 'carer' to better reflect the experiences of disabled people
- **Integration:** The mental health and disability sectors should be better connected and integrated to remove service siloes. There should also be closer interaction with between the mental health and drug addiction sectors. Different agencies and services need to work more closely together to enable integrated, effective responses to people's needs
- **Whole family approach:** A whole of family approach needs to be taken with increased support (including financial support) for families with a disabled child to reduce stress and help them stay together – and do so earlier. This is particularly needed for families with children with FASD. Better understanding is needed by professionals of the role of parents and families in terms of their knowledge and caring capacity
- **Safe housing:** Disabled people and their family need housing that is safe (i.e. social housing where neighbours are respectful of disabled people and there is not violence around them).