Disaster resilience and disability: Nothing without us

Integrative literature review

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Kōrero Whakamārama: We apply the Kāi Tahu dialect when writing in te reo Māori. This means that the ng is replaced with a k (for example: whakarongo is changed to whakaroko). We have underlined the k whenever this has been applied.

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Kā Whakamārama/Glossary

Co-design: "Co-design refers to a philosophical approach and evolving set of methodologies for involving people in the design of the services, strategies, environments, policies, processes, - that impact them" (Mark & Hagen, 2020, p. 4).

Disability: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNCRPD, Article 1) (United Nations, 2006, p. 4).

Disability Inclusive Disaster Risk Reduction ('DIDRR'): "[T]he process of reducing barriers and strengthening enabling actions (enablers) to ensure meaningful engagement of people with disabilities in community-based disaster risk reduction (CBDRR) programmes, making them more visible and prioritised in disaster mitigation, preparedness, response and recovery initiatives and to ensure all these levels are inclusive of people with disabilities" (Grech, 2022, p. 4).

Disaster: "[A] critical disruption in the functioning of systems and communities, involving widespread human, material, economic or environmental losses and impacts, and which is more than the community can handle to cope using its own resources, and hence requires assistance" (Grech, 2022, p. 4).

Disaster management: "[A]n applied science which seeks, by the systematic observation and analysis of disaster to improve measures relating to mitigation, preparedness, emergency response and recovery" (Basri et al., 2021, p. 40).

Disaster Risk Management (DRM): "Seeks to 'address vulnerability in order to reduce risk and therefore needs to consider the full range of vulnerability drivers…'" (Grech, 2022, p. 4).

Disaster Risk Reduction ('DRR'): "Disaster risk reduction is aimed at preventing new and reducing existing disaster risk and managing residual risk, all of which contribute to

strengthening resilience and therefore to the achievement of sustainable development" (CBM International et al., 2019, p. 7).

Duty bearer: "Duty-bearers are entities or individuals having a particular obligation or responsibility to respect, promote and realize human rights and to abstain from human rights violations. It is commonly used to refer to State actors, but non-State actors can also be considered duty-bearers. Depending on the context, individuals, local organizations, private companies, aid donors, and international institutions can also be duty-bearers" (UNESCO, 2022).

Hazard: "[A] hazard is a potential or existing condition that may harm people or may damage property or the social, economic, cultural or natural environment. Hazards may have many potential consequences including death, injury, illness, and damage to property or the previously mentioned environments" (Ministry of Health, 2015, p. 14).

Intersectionality: "[A]n analytic framework that assumes that harms and violations associated with disability, race and ethnicity, gender, or other identities cannot be understood sufficiently by studying them separately. To see clearly how they [affect] access to resources or create risks for persons with disabilities, it is necessary to see how disability, age, gender and other factors interrelate and to evaluate their overall effect" (Inter-Agency Standing Committee Task Team [IASC], 2019, p. 10).

Resilience: "The ability of a system, community or society exposed to hazards to resist, absorb, accommodate to and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions" (Economic and Social Commission for Asia and the Pacific [ESCAP], n.d., p. 7).

Rights holder: "Individuals or social groups that have particular entitlements in relation to specific duty-bearers. In general terms, all human beings are rights-holders under the Universal Declaration of Human Rights. In particular contexts, there are often specific social groups whose human rights are not fully realized, respected or protected" (United Nations Economic and Social Commission for Western Asia [UNESCWA], n.d.).

Social Model of Disability: "Asserts that existing social policies, practices, and institutions, rather than the individual impairments of people with disabilities, generate barriers and inequitable access" (Stough et al., 2015, p. 405).

Twin-track approach: "A twin-track approach is about making sure mainstream services and supports are inclusive of, and accessible to [disabled people] and that services and supports that are specific to us as disabled people are also available. This approach is not about having to choose between the specific or mainstream option: rather it is about having the right access to the right high-quality support or service, and the right time and in the right place" (Office for Disability Issues, 2016a, p. 21).

Universal Design: "Universal design promotes the development, availability and use of goods, services, equipment and facilities, including housing that are designed to be used by all people to the greatest extent possible without the need for adaptation, and promoting such design in the development of standards and guidelines" (Office for Disability Issues, 2019).

Kupu Māori/Māori word definitions

Aotearoa: Māori name for New Zealand.

Kaupapa: Topic, policy, matter for discussion, plan, purpose, scheme, proposal, agenda, subject, programme, theme, issue, initiative.

Kotahita̲ka: Unity, solidarity, togetherness and collective action.

Marae: Courtyard - the open area in front of the wharenui, where formal greetings and discussions take place.

Taha hine̲karo: One's psychological health relating to thoughts and feelings (Carter, 2013).

Taha Tinana: One's physical wellbeing, relating to how a body feels and moves (Carter, 2013).

Taha whānau: The health of one's close family as well as their extended relationships (Carter, 2013).

Taha wairua: The things that give one meaning in life for example religion or spiritual connection. It can also include celebrating one's own particular journey and self (Carter, 2013).

Tāmaki Makaurau: Auckland.

Ta̲kata Whaikaha: A disabled person.

Tā̲kata Whaikaha: Disabled people.

Te Ao Māori: Māori world view.

Te Tiriti o Waitangi: Te Reo Māori version of The Treaty of Waitangi - New Zealand's founding document (Orange, 2023).

Te Whare Tapa Whā: A Māori model of health, which incorporates spiritual, psychological, physical and familial/relational health, with the land forming the foundation (Carter, 2013).

Tika_ka_: The customary system of values and practices that have developed over time and are deeply embedded in the social context.

Tino Ra_k_atirata_k_a: Self-determination, sovereignty, autonomy, self-government, domination, rule, control, power.

Whakapapa: Genealogy, genealogical table, lineage, descent.

Whānau: Extended family, family group, a familiar term of address to a number of people - the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.

Whenua: Land.

Pasefika word definitions/Kupu Te Moana-nui-a-Kiwa[1]

Aiga: Immediate and extended family.

Fale: A Samoan house with open sides and a thatched roof.

Fonofale model: A Pasefika model of health, which utilises the metaphor of a Samoan house with various parts of the house symbolising a different element of health.

Gafa: Genealogy, family tree, lineage.

Pou: Posts.

Tagata Sa'ilimalo: Pasefika disabled people, aiga and carers/supporters.

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[1] (Pulotu-Endemann, 2001)

Kupu Rāpoto/Acronyms

AEM: Auckland Emergency Management

CBO: Community Based Organisation

CDEM: Civil Defence Emergency Management

DBI: The Donald Beasley Institute

DIDRR: Disability Inclusive Disaster Risk Reduction

DPO: Disabled People's Organisation

DRR: Disaster Risk Reduction

EGL: Enabling Good Lives

ESCAP: Economic and Social Commission for Asia and the Pacific

NZDS: New Zealand Disability Strategy

NDRS: National Disaster Resilience Strategy

NEMA: National Emergency Management Agency

OPD: Organisations of Persons with Disabilities

P-CEP: Person-Centred Emergency Planning

PWD: People with Disability

SDGs: The Sustainable Development Goals

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

UNISDR: United Nations Office for Disaster Risk Reduction

Whakarāpopototaka Mātua/Executive Summary

Instructive conventions, policies, frameworks and models:

- Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disabilities, New Zealand Disability Strategy, social and rights models of disability, Enabling Good Lives, the National Disaster Resilience Strategy, Sustainable Development Goals, Sendai Framework for Disaster Risk Reduction, and cultural models of health and disability are examples of frameworks that can provide useful guidance on the role of disabled people in strategy, policy and programme development in Disaster Inclusive Disaster Risk Reduction (DIDRR).

Background:

- Disabled people experience lower levels of disaster preparedness than the general population.

- Barriers to preparedness include financial access, community connectedness, communication access and education levels, as well as disability-specific barriers.

- The social and rights models of disability assert that disabled people are disadvantaged by socially constructed barriers, and that disabled people have the same human rights as everyone else.

- It is the responsibility of duty bearers (authorities) to remove socially constructed barriers, while implementing disabled people's human rights and justifying the pace and quality of implementation.

Key findings:

Enhancing disabled people's preparedness requires:

- Representation and participation of disabled people during preparedness planning.

- Building trusting relationships between all levels of government, disabled people and their representative organisations, and emergency personnel; at both organisational and individual levels.

- Ensuring all preparedness communications, materials and resources utilise a twin-track approach; are delivered in a way that reflects the diverse needs of the disability community; are available in a variety of accessible formats; and utilise trusted relational networks of disabled people such as Disabled People's Organisations (DPOs) and Community-Based Organisations (CBOs).

- Ensuring DIDRR education and training materials are co-designed with the disability community; are disseminated in accessible formats; and are targeted towards disabled people, emergency personnel, community-based professionals and family and whānau.

Innovative practices:

- All identified innovative practices involved duty bearers working closely with rights holders (disabled people) and their representative organisations to build knowledge of DIDRR; co-design resources and training programmes; train disabled people in preparedness; design disaster response plans; and incorporate accessibility features across the platforms where engagement took place.

- These practices supported key stakeholders to learn from one another and build trusting relationships, which could be relied upon during the response and recovery phases of a disaster.

- Examples include (but are not limited to): a city council hosting inclusive community engagement forums to learn about DIDRR; accessibility features being explicitly incorporated within the development of a DIDRR framework; training disabled liaison officers in preparedness who then share this expertise with their community; and the co-development of a toolkit emphasising the capabilities of disabled people, and giving them agency, choice and control over how they prepare for disaster.

Potential modes of communication:

- All advertisements, invitations, consultations, planning and co-design processes and preparedness outputs and resources must be made available in accessible formats as listed in the Accessibility Charter.

- Digital communication should be provided in accessible formats and according to web accessibility standards. Print formats should be provided through DPOs, CBOs and government services for disabled people who do not have easy access to technology or the internet.

- Under Te Tiriti o Waitangi, the inclusion of all communications in Te reo Māori ensures partnership with tāk̲ata whaikaha.

- Accessible spaces must be intentionally created where relationships of trust can be built. Some examples include public forums, online and in person consultations, disability conferences and disability network and organisation meetings.

- Education and training must take place through a diverse range of forums and in consultation with a wide range of disabled people and representative organisations.

Potential platforms for delivery:

- Potential platforms for engaging with disabled people and increasing their participation and representation in preparedness planning include DPOs, disability organisations and networks, service providers, disability advocates, disability influencers, researchers, family and whānau, schools, utility providers, Whaikaha Ministry of Disabled People, accessible information translators and service providers, access radio, Marae, CBOs and social media channels.

Other findings and future research:

- The response and recovery phases of disaster are inherently interlinked with the preparedness phase and therefore all phases should be considered when planning for disasters.

- Accessible communication, accessible evacuation and accessible shelters are three important factors that can enhance people's resilience during the response phase. All three link directly to the preparedness phase.

- Disabled people must be included in efforts to 'build back better' during the recovery phase. A precedent for inclusion starts in the preparedness phase.

- DIDRR is a new and emerging area of research, with gaps that require further investigation.

1. Whakatakika/Introduction

It is estimated that 16 percent of the global population (more than 1.3 billion people) lives with some form of disability (World Health Organisation, 2023). In Aotearoa New Zealand, 2013 Census figures show that 24 percent of New Zealanders identify as disabled. For Māori, this number is even higher at 26 percent (Office for Disability Issues, 2016). Disability crosses ethnicity, gender, and socioeconomic status, and disabled people are more likely to experience disproportionate disadvantage across key life outcomes such as low education levels, poor health outcomes, high unemployment, and high rates of poverty (World Bank, 2023; World Health Organization, 2023).

Research also shows that disabled people experience greater risk when disasters occur. For example, disabled people are two to four times more likely to die or experience injuries in disasters than the general population (Calgaro et al., 2020; ESCAP, n.d.; Quaill et al., 2019; Villeneuve, 2020; Villeneuve, 2022). Furthermore, not only are disasters likely to create new disabilities, but also exacerbate existing ones (Calgaro et al., 2020; Landry et al., 2016; Lord, 2010).

In 2023 Auckland Council sought the research experience of the Donald Beasley Institute to develop an integrative literature review that could help inform a Disaster Resilience Strategy for Auckland Emergency Management (AEM). The focus of the literature review is disability responsiveness in preparedness, with the aim of identifying potential modes of delivery; platforms for delivering AEM's key messages; and innovative ways to create positive change that enhance the resilience of the disability community.

This report begins by outlining key concepts and values that underpinned the integrative literature review, and how they informed the process of identifying, analysing and summarising academic and grey literature within the context of the brief. The method of the review is then presented, before key findings from the reviewed literature are noted. At the conclusion of each finding is a table of key themes, including how the findings can be applied by AEM, potential modes of delivery and platforms for delivering AEM's key messages, and examples of innovative practice. While the literature emphasised that the different phases of a disaster (preparedness, response and recovery) are interlinked

(National Council on Disability, 2009), this integrative review has primarily focused on the preparedness phase of a disaster. Brief summaries of response and recovery findings have been included in *Part C* to demonstrate the interconnectedness of response and recovery with preparedness.

2. Ka Mātāpono/Values

The Donald Beasley Institute is an independent charitable trust that conducts disabled-led and inclusive disability research. Ka Mātāpono (DBI Research Values) underpin this important work:

- Whakatinana – Honouring Te Tiriti o Waitangi through our practice
- Whakarakatira – Being Respectful
- Whakawhanaukataka – Being Relational
- Whakamana – Being Ethical
- Whakawhirinaki – Being Accountable
- Whakakotahi – Being Inclusive
- Whānau – Through uplifting whānau, our journey will be one of prosperity.

WHAKAMANA
ETHICAL

WHAKAKOTAHI
INCLUSIVE

WHAKATINANA
HONOUR TE TĪRITI O WAITANGI

WHAKAWHANAUKATAKA
RELATIONAL

WHAKARAKATIRA
RESPECTFUL

WHAKAWHIRINAKI
ACCOUNTABLE

WHĀNAU
FAMILY

Within the tohu, kōwhaiwhai (shapes) depict patterns representing the DBI's whakapapa (history), matāpono (values), mahi (work), and commitment to whānau whaikaha (disabled people and their families).

3. Key concepts

Outlined below are the key concepts and assumptions that informed this integrative literature review.

3.1 Defining disability

While there is no universally accepted definition of disability, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that disabled people include "those who have long-term, physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis as others" (United Nations, 2006, Article 1). This literature review utilises this broad definition of disability because it: recognises the full range of impairments disabled people experience; is inclusive of formally recognised disabilities as well as suspected and/or hidden disabilities; highlights diversity and intersectionality within the disability community; and was developed by disabled people, including disabled New Zealanders, during the UNCRPD's drafting (2001 - 2006). This review therefore includes, but is not limited to, literature referencing a wide range of disabled people, including people with chronic illness, people who are blind or have low vision, people who are D/deaf or hard of hearing, people with psychosocial disabilities, people with learning (intellectual) disability, and people who are neurodivergent.

3.1.1 Person and identity first language

There are many words disabled people use to describe themselves and their community/ies. The UNCRPD uses the term 'persons with disabilities', which some in the disability community prefer as they feel it recognises them as an individual before their disability (person first language). However, in this review the term 'disabled people' is used (identity first language), as it is the preferred term within the context of Aotearoa New Zealand. Identity first language recognises the barriers that exist within society are disabling, rather than characteristics inherent to the person (reflecting the social model of disability). 'Disabled person' is also used by many in the disability community as a source of pride and identity. It is important to note that not all people with impairments discussed

in this review identify as having a disability. For example, Deaf people often identify as being part of the Deaf community rather than as being part of the disability community (Office for Disability Issues, 2016a). Where direct quotes have been used, the original terminology has been retained.

3.2 Defining disaster

There are many definitions of a disaster event. For the purposes of this review, disasters are defined as an event that severely disrupts communities and systems, leading to large scale economic, human, material or environmental impacts, which a community can struggle to cope with, therefore requiring assistance in its response (Grech, 2022). Such an event can have a natural cause, for example, floods, earthquakes, cyclones, pandemics and volcanic eruptions. However, it also includes human made disaster events such as terrorist attacks and war. This definition allows for a broad exploration of disaster literature, while also providing flexibility in the review's discussion.

Within the context of Aotearoa New Zealand, a wide range of disasters have taken place over recent history, such as volcanoes, landslides, earthquakes, terrorist attacks, extreme weather events, and a pandemic. However, flooding is the most common disaster, with earthquakes and tsunamis being the most damaging (Massey University, n.d.).

3.3 Defining resilience

Resilience has been discussed in a variety of contexts, from the resilience of individuals to the resilience of broader structures and systems (Hernandez et al, 2018). The definition of resilience that informed this review was:

> [T]he ability of a system, community or society exposed to hazards to resist, absorb, accommodate to and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions (ESCAP, n.d., p. 7).

This definition has been highlighted due to its broad and systemic view of disaster resilience, and its focus on systems, communities or societal resilience as a whole, rather than individuals. This approach is consistent with the social model of disability, in which individuals with impairments are disabled due to socially constructed barriers which limit their ability to fully participate in society (Oliver, 2013). The selected definition also reflects Te Ao Māori conceptions of resilience - manawa ora - which highlight the communality and collectiveness of indigenous resilience (Maunganui Wolfgramm et al., 2021), as well as disabled people's experiences of resilience, which is largely impacted by insufficient responses at a systemic level (Grech, 2022).

3.4 Defining disaster preparedness

The primary focus of this literature review is disability responsiveness during disaster preparedness. The preparedness phase of a disaster "implies that specific efforts are made to identify potential hazards so as to decrease the number of variables that can lead to disasters, while at the same time increasing the ability of individuals, organizations, and nations to prevent, prepare for, and react to them effectively" (Finkelstein & Finkelstein, 2020, p. 2056). Many actions can be taken as a part of this phase. For example, evacuation drills, training, disseminating materials that teach people how to personally prepare for a disaster and putting together supplies, at both a personal and a community level, in preparation for a disaster (Staupe-Delgado & Kruke, 2017).

It has been argued that the preparedness phase of a disaster cycle has the biggest impact on the toll a disaster takes on a community. This is because it has the ability to shape the disaster response and recovery phases that follow it and to therefore minimise the negative outcomes of a disaster (Landry et al., 2016). For example, a United Nations survey of 5,717 participants (all of whom were disabled) from 137 countries reported that the main reason for the disproportionately high number of deaths of disabled people during disasters was a result of their needs and voices not being considered during the disaster planning phase (The United Nations Office for Disaster Risk Reduction [UNISDR], 2014).

4.   Te Aramahi/Methodology

A literature review is a critical evaluation of what has already been written about a specific topic. As the most inclusive form of literature review, integrative reviews can facilitate a wide understanding of phenomena of concern through the combination of theoretical data and empirical literature of all kinds (Whittemore & Knafl, 2005). Fundamentally, this approach also allows the scope of reviewed literature to extend beyond peer-reviewed and academic articles, to include 'grey' literature. Grey literature includes information produced by governments, academia, businesses, service providers, non-governmental organisations, and industry, that is not commercially published and/or where publishing is not the primary activity of the producing body (Lawrence, 2012).

When using the integrative review method, there are generally four questions that a reviewer seeks to answer while reviewing a body of knowledge: (1) What is known? (2) What is the quality of what is known? (3) What should be known? and (4) What is the next step for research or practice? (Russell, 2005). Given the stated intention of this review is to inform a Disaster Resilience Strategy and improve disability responsiveness during preparedness, this approach was selected for its ability to generate information that has the potential to have practical implications for both policy and practice.

4.1 Literature search method

This integrative literature review was conducted by an inclusive and diverse team of disabled and non-disabled researchers. Initially, the disabled-led team began by searching for both academic and grey literature using Google Scholar, a general search on the University of Otago library website, and Google, which allowed for a broad search of literature across many academic disciplines as well as for grey literature. The research team also drew on established research portals; Academic Search Complete (EBSCO), ProQuest Central and Medline (OVID). A wide range of terms were used during the search, including (but not limited to) disaster management, emergencies, disaster risk management, humanitarian action, disaster response, emergency response, government defence and emergency preparedness, alongside terms such as disability, Māori,

whaikaha, New Zealand and Auckland. Included in this review were articles published in English between January 2005 and July 2022, to encapsulate literature developed since the international establishment of the UNCRPD (2006), the New Zealand Government's signing of the UNCRPD (2008) and its Optional Protocol (2016) and current literature. Both international and New Zealand-based literature was included.

4.2 - Data analysis

Once the core literature was identified, the research team reviewed abstracts and titles and scanned each text for relevance. Literature that was viewed as relevant was read in full. Emphasis was placed on research that utilised a disability lens and prioritised the views of disabled people. Key findings and study details from relevant literature were entered into a data chart, before thematic analysis was undertaken to identify key themes across the literature. Reflecting the structure of identified literature, the literature was also mapped against three main themes: disaster preparedness, response, and recovery. Following this, relevant literature (primarily relating to preparedness) was categorised into separate data sets under each theme, and subthemes were identified.[2]

4.3 - Strengths and limitations

The greatest strength of this research was that it was led by a team of diverse, experienced, disabled scholars, representing a range of identity and cultural groups. This ensured that a variety of perspectives shaped and informed the final review, with the core values (section 7) and accountability to the disability community being prioritised at every stage of the review process. A second key strength was the volume of academic and grey literature in the area of disaster and disability. While this meant it was difficult to include all findings from all of the identified literature, the findings that have been included in this review reflect the views of the disabled research team as being most critical to the work of AEM. A final key strength is that being based in Tāmaki Makaurau Auckland and around Aotearoa New Zealand, the research team have the benefit of living through, and

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[2] Search terms, databases, themes and an example of how the data corpus was coded are provided in Appendix A and Appendix B.

drawing on, the lessons learned from the Christchurch earthquakes (2010/2011), the COVID-19 pandemic, and the 2023 Auckland floods and Cyclone Gabrielle.

There were also limitations to the review process. Even though an extensive search of the literature was conducted, there may be other relevant research that has not been included because it is unpublished; was not available through the chosen databases; was not written in English; was not considered to align with the core values; or for some other reason was not included in the data corpus.

Further to this, the literature often did not provide specific and detailed examples of good practice or tangible recommendations. According to the United Nations, disability best practice must:

- adopt a rights-based approach (systemic implementation of the UNCRPD);

- ensure equality and non-discrimination (inclusion of marginalised disabled people such as people with psychosocial disabilities, learning (intellectual) disabilities; and indigenous disabled people);

- recognise the interaction between gender and disability;

- promote accessibility (physical, mental, sensory, intellectual and developmental accessibility);

- be participatory (enabling the active and meaningful participation of disabled people in forming policies and programmes);

- be accountable to disabled people (through monitoring, evaluation, and complaints processes);

- increase awareness and understanding of disability at organisational, community and institutional levels;

- be results-based and produce measurable change that contributes to the improvement of disabled people's lives;

- be appropriately resourced (financially and in terms of human resources);

- be sustainable (socially, culturally, economically, politically and environmentally);

- be replicable;

- and involve effective partnerships and the full involvement of DPOs (United Nations, 2011).

Given that there are very few examples of best practice according to the criteria above, this review instead discusses 'useful', 'informative' and 'innovative' practice, as it pertains to preparedness and resilience.

It is clear that even though there was a lot of disability, disaster and resilience literature, disability inclusive disaster risk reduction (DIDRR) is a developing area of research, particularly when it comes to literature and practice that is co-designed and led by disabled people. This highlights the importance and value of AEM taking the first steps towards developing their own unique DIDRR approach that aligns with the United Nations's guidance on best practice, Te Tiriti o Waitangi, the UNCRPD and the New Zealand Disability Strategy, by directly engaging with disability communities in Tāmaki Makaurau Auckland.

Other limitations included the timeframe of the scope (2005 - 2022), meaning there may be helpful literature available outside of these dates. In addition, while some literature identified whether it was conducted or written by disabled researchers and/or included the views of disabled people, it was often unclear whether the research and/or practice was endorsed by disabled people themselves. This was particularly relevant when considering the voices of tākata whaikaha (Māori disabled people) and other indigenous populations. The methodology and resources used to develop this review were mainly Eurocentric in origin, and lacked any clear guidance on cultural aspects of DIDRR. However, in order to uphold the values identified in section 7, efforts were made to draw on Māori and Pasefika models of health and wellbeing, as well as Māori- and Pasefika-led research where possible, even when outside the scope of the literature search.

5. Part A: Instructive conventions, policies, frameworks, and models

Throughout the review process, a range of key conventions, policies, frameworks and models were either repeatedly referred to in the literature as being crucial to ensuring that disaster resilience efforts closely align with cultural, human rights and legal obligations, or were regarded by the New Zealand disability sector as being important to policy and strategy development in Aotearoa New Zealand. While these documents are not findings in themselves, they do provide broad guidance on the engagement and inclusion of affected populations during strategy, policy, and practice development.

Outlined below are brief summaries of these instructive conventions, policies, models and legal frameworks that were referenced in the literature. A summary table is provided at the end of Part A, which includes suggested modes of application in the context of a disability responsive resilience strategy.

5.1 Te Tiriti o Waitangi

In Aotearoa New Zealand, Tiriti o Waitangi is the foundational document that affirms the belonging of land to Māori while offering belonging to the Crown and others. It also secures the Tino Rangatiratanga of Māori, which is "the right for Māori to make decisions for Māori" (Matike Mai Aotearoa, 2016, p. 8). Articles contained within Te Tiriti o Waitangi should underpin all strategy, policy and practice development in Aotearoa New Zealand, including disaster management (Ministry of Civil Defence & Emergency Management, 2019). While identified literature did not clearly articulate how disaster management can best uphold Te Tiriti o Waitangi for tāḵata whaikaha (Māori disabled people), Te Tiriti o Waitangi does guarantee tāḵata whaikaha rights, self-determination and, amongst other things, equity in all things that affect them (Ingham et al., 2022).

5.2 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Based on the social and rights models of disability, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international agreement that gives expression to the disability rights slogan "nothing about us, without us". Guided by the principle of equal participation, the Convention sets out what governments must do to ensure that disabled people have the same rights as everyone else (United Nations, 2006). In 2008, the New Zealand Government became one of the first signatories to the Convention, before further indicating its commitment by ratifying the Convention's Optional Protocol in 2016. As a state party to the UNCRPD, both central and local governments have an obligation to progressively realise the human rights set out in the Convention. Article 11 is the most relevant to the reviewed literature, stating that the government "shall take all necessary measures to protect the safety of disabled people in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters" (United Nations, 2006). Local and central governments of Aotearoa New Zealand therefore must take all necessary measures to ensure the safety of disabled people through all phases of a disaster, including during preparedness efforts.

5.3 2016 - 2026 New Zealand Disability Strategy (NZDS)

The 2016-2026 New Zealand Disability Strategy guides the work of the New Zealand government on all disability issues. The vision of the Strategy is: "New Zealand is a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen" (Office for Disability Issues, 2016, p. 6). The Strategy's three main principles include Te Tiriti o Waitangi, the UNCRPD, and making sure disabled people are involved in the decision-making of all things that affect them. The NZDS sets out eight outcomes, all of which are important in the area of disaster resilience. They are education, employment and economic security, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control and leadership. A key aspect of the NZDS is the twin-track approach, which holds that mainstream services and supports are inclusive of, and

accessible to, disabled people and that services and supports that are specific to disabled people are also available (Office for Disability Issues, 2016).

5.4 Models of Disability

Impairment and disability has existed throughout all of history. Social responses, however, have varied as different meanings have emerged out of specific social and cultural contexts. Models of disability are heuristic devices that represent ways of thinking about disability that can help to generate explanations (Llewellyn & Hogan, 2000). Models are often indicative of underlying structures for large and complex diagnostic and defining systems with significant political, social and financial consequences (Smart, 2009). Individual models of disability, for example, locate the 'problem' of disability within the individual, while explaining the cause of the problem as stemming from functional limitations (Oliver, 1990a; 1990b). The medical model - one of the most common and prevalent models of disability - is an example of an individual model, whereby impairment is considered pathological in nature. That is, disability is an abnormality in function, a disorder, dysfunction, defect or deformity located within the human anatomy (Barnes & Mercer, 2010; Bickenbach, 1993; Goodley, 2011; Oliver, 1990b; Silvers et al., 1998).

Individual models of disability have been strongly rejected by the disability community, in favour of the social and human rights models of disability. The social model of disability addresses disability in terms of social oppression, cultural discourse, and economic and environmental barriers (Shakespeare, 2013). Within the social model, disability is understood as a social creation, where people with impairments are disabled by socially constructed barriers (Shakespeare, 2013). Instead of the emphasis being on the impairment itself, the social model addresses the social conditions that cause disability and the denial of basic civil rights (Olkin, 1999). The human rights model holds that disabled people have the same human rights as non-disabled people (Johnstone, 2001), and emphasises the empowerment of disabled people as active stakeholders, as well as the responsibility of duty bearers (public institutions and structures such as the New Zealand government) to implement disabled people's human rights (as rights holders), and to justify the pace and quality of implementation (Miller & Ziegler, 2006).

5.5 Enabling Good Lives (EGL)

Designed by disabled people, Enabling Good Lives (EGL) is a partnership between the disability sector and government that promotes greater choice and control disabled people have over their lives and the supports they receive. The EGL approach asserts a set of eight principles which should guide decision-making and monitoring, including in the disaster management space. These are self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, and relationship building (Enabling Good Lives, n.d).

5.6 National Disaster Resilience Strategy (NDRS)

The National Disaster Resilience Strategy was published in 2019 by the Ministry of Civil Defence and Emergency Management, and can be found in a wide range of accessible formats on the National Emergency Management Agency website. The NDRS outlines the government's goals relating to civil defence emergency management, and highlights the government's obligations under Te Tiriti o Waitangi and the New Zealand Disability Strategy, stating that all actions taken to reduce risk from hazards must contribute to "reducing vulnerability and pursuing equitable outcomes" for disabled people and other marginalised populations (Ministry of Civil Defence and Emergency Management, 2019, p. 15). Section 4.4.1 of the NDRS specifically addresses disability and resilience, and suggests a twin-track approach to disaster risk reduction and resilience practices. This includes inclusive preparedness design and implementation; including disabled people in emergency management planning and implementation; recognising diversity within the disability community; disability inclusive response, recovery and regeneration; and incorporating universal design into 'building back better' (Ministry of Civil Defence and Emergency Management, 2019).

5.7 Sustainable Development goals (SDGs)

In 2015 the New Zealand government adopted the Sustainable Development Goals (SDGs). The SDGs consist of 17 goals that seek to protect the planet and the environment, to end poverty and to "leave no one behind" (ESCAP, n.d., p. 15). Disabled

people are one of the SDG's target populations, including recognition of the need for specific approaches that ensure disabled people have access to human rights on an equal basis as others (Abualghaib et al., 2019). Disabled people are directly referred to in goals 4.5 (eliminating gender disparities), 8.5 (achieving full and productive employment), 10.2 (promoting social, economic and political inclusion), 11.2 (providing access to safe and affordable transport systems), and 17 (enhancing capacity-building support to developing countries to increase the availability of high-quality data). With regards to disaster, there are 25 targets related to disaster risk reduction in 10 of the sustainable development goals, firmly establishing the role of disaster risk reduction as a core development strategy (United Nations Office for Disaster Risk Reduction, n.d.).

5.8 Sendai Framework for Disaster Reduction 2015 – 2030

In 2015 the New Zealand government became a signatory to the Sendai Framework for Disaster Reduction 2015 – 2030 in (Sendai Framework) (Saunders et al., 2020). The Sendai Framework aims to reduce disaster risk and the impact of disasters (United Nations, 2015). The Framework explicitly discusses the role of disabled people in the disaster management system and guiding principles 19(d) and 36(iii), which emphasise the importance of partnering directly with disabled people when countries are engaging in disaster risk reduction efforts.

5.9 Cultural frameworks

The reviewed literature did not provide any specific details about disability and cultural responsiveness in preparedness, disaster risk reduction (DRR), or resilience strategies. It was recommended, however, that understanding different cultures, customs and beliefs, including about disability, was crucial to best practice in DIDRR (Grech, 2022). Outlined below are examples of the types of models that might be incorporated into preparedness efforts and disaster resilience strategies in the context of Aotearoa New Zealand. Specific models, however, should be determined through close consultation with disabled representatives from those communities.

5.9.1 - Mātauranga and te ao Māori models of wellbeing

As identified in the literature, it is important for DIDRR to integrate cultural understandings of disability. In Te Ao Māori there are two primary models of disability - the whānau hauā model, and the whaikaha model. The whānau hauā model acknowledges the impact of ongoing colonisation and contemporary influences that are oppressive and discriminatory to indigenous disabled people. In this context, whānau refers to family from whakapapa or as kaupapa whānau, and hauā refers to hau - the wind that lifts and assists disabled whānau members. The model acknowledges that disadvantage caused by colonialism and ableism impedes the ability of individuals to have their needs met, including during disaster. Wellbeing is therefore not an individual responsibility, but the collective: working together to restore the equilibrium of whānau and disabled community members (Hickey & Wilson, 2017).

Tākata whaikaha is another disability model that recognises the strengths of Māori disabled people, and has been widely adopted throughout Aotearoa New Zealand, such as in the title of the recently established Whaikaha Ministry for Disabled People. The term whaikaha is closely associated with Matua Maaka Tibble (Ngāti Porou) who, after feeling discomfort with the term 'disabled' and the deficit approach to impairment, suggested that 'Whaikaha' or 'Tākata Whaikaha' was more reflective of people's strengths (Whaikaha - Ministry of Disabled People, n.d.). According to Te Reo Hāpai (2020), whaikaha means to "have strength, to have ability, otherly abled, enabled. A word created within the Māori disabled community."

More generally, Te Whare Tapa Whā is a model that was developed by Mason Durie and is a commonly used Māori model of wellbeing. It seeks to acknowledge the various strands of wellbeing, including physical health as well as spiritual and emotional health. It also emphasises family relationships and cultural practices (Rawson, 2016). The four key elements of this model represent the four walls of a house "with each side complementing the others to ensure strength and balance. Each wall represents a complementary dimension of well-being: taha wairua (spiritual); taha hinengaro (psychological); taha tinana (physical); and taha whānau (familial/relational)" (Carter,

2013, p. 34), all with the whenua (land) forming the foundation. Te Whare Tapa Whā views health and wellbeing in a holistic manner and offers a unique perspective to disability responsiveness, including throughout all phases of a disaster. Tākata Māori have emphasised the importance of whānau within this model. The use of Te Reo Māori as well as tikanga, or protocols, have also been noted as providing a sense of belonging and contributing to positive health outcomes (Rawson, 2016).

5.9.2 - Pasefika models of wellbeing

Much like Te Ao Māori, different Pasefika cultures have various terms and models regarding disability and impairment. The Tagata Sa'ilimalo model, developed by Pasefika disabled people living in Aotearoa New Zealand, is an important example. Tagata refers to a person or people, and sa'ilimalo is the pursuit of success. According to the Tagata Sa'ilimalo Strategic Framework:

> Tagata Sa'ilimalo is an aspirational vision of the pursuit of success underpinned by sheer determination and sustained by the collective vitality of Pacific peoples. It is a vision that reflects the hopes of the disability community to imagine better for their future. The Tagata Sa'ilimalo vision is inclusive of all Pacific peoples in Aotearoa and all disability types (Tōfā Mamao Collective, 2022, p. 5).

There are also many models and approaches that have been developed by different Pasefika communities for Pasefika communities that give expression to cultural perspectives and approaches when working on issues that impact the health and wellbeing of Pasefika peoples. As one of the better known models, the Fonofale model of health was developed by Fuimaono Karl Pulotu-Endemann in 1995 after consulting with a range of Pacific Island communities throughout Aotearoa regarding what they believed to be the most important determining factors in good health. The model encompasses the values of Samoan, Cook Island, Tongan, Niuean, Tokelaun and Fijian peoples. The Fonofale model utilises the metaphor of a Samoan house with various parts of the fale (house) symbolising a different element of health, and altogether supporting the concepts of continuity and holism (Pulotu-Endemann, 2001). In the model, the floor of the fale represents the family, which also connects to gafa (genealogy), and the roof represents

cultural values. In between the roof and floor are four pou (posts) that represent spiritual, physical and mental health as well as 'other', which relates to other elements that can affect health such as sexuality, gender, socio-economic status and age. The fale is also surrounded by other dimensions that can impact health such as the environment, time and context (Pulotu-Endemann, 2001). Mackay and colleagues (2019) have noted that both the Fonofale model and Te Whare Tapa Whā model emphasise "connections with others and giving with reciprocity" (p. 240).

5.9.3 - Incorporating cultural frameworks into preparedness

The Whānau Hauā, Tākata Whaikaha, Te Whare Tapa Whā, Tagata Sa'ilimalo and Fonofale models are a small selection of Māori and Pasefika models that have been drawn on for the purposes of this review, particularly in the context of recognising that disability responsiveness during preparedness must also be culturally responsive to tākata whaikaha (Māori disabled people) and tagata sa'ilimalo (Pasefika disabled people). There undoubtedly are other Te Ao Māori and Pasefika models relevant to developing disability responsive preparedness and disaster resilience, which should be explored with tākata whaikaha and tagata sa'ilimalo and their communities. While the majority of the reviewed literature came from international sources, and therefore did not include discussions of Māori and Pasefika models regarding disaster resilience, the aforementioned models are examples of models that are essential for underpinning strategy, policy and practice that is responsive to and inclusive of different cultures in the disability community of Tāmaki Makaurau Auckland.

5.10 Part A: Summary table

Document / model	Vision	Application[3]
Te Tiriti o Waitangi	AEM's disaster resilience strategy recognises, and preparedness efforts foster, partnership between tākata whaikaha and AEM, according to Te Tiriti o Waitangi.	The rights, will and preferences of tākata whaikaha are identified and integrated into disaster resilience strategy development and preparedness planning, through close consultation and engagement with tākata whaikaha and their whānau living in Tāmaki Makaurau. Tākata whaikaha are supported to have self determination over all matters that affect them, including during preparedness efforts. All preparedness information, communications, and resources are available in Te Reo Māori. Mātauranga Māori and Te Ao Māori models of wellbeing are embedded in disaster resilience strategy development and preparedness planning. This includes, but is not limited to Māori concepts of disability. Appropriate Te Ao Māori models are determined through close consultation and engagement with tākata whaikaha and their whānau.
United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)	AEM takes all necessary measures to protect the safety of disabled people in situations of risk (Article 11, UNCRPD).	The rights, will and preferences of disabled people are identified and integrated into resilience strategy development and preparedness planning, through close consultation and engagement with people with a wide range of disability experiences in Tāmaki Makaurau Auckland (Article 4).

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[3] This table has not been developed from the literature, but is the disabled research team's interpretation of the literature in the context of this integrative review.

| | | All AEM digital and print information and communications are available in accessible formats (Article 9).

AEM's disaster resilience strategy development and preparedness planning identifies and seeks to remove the barriers experienced by disabled people in exercising their rights, will and preferences before, during, and after a disaster. |
|---|---|---|
| **New Zealand Disability Strategy (NZDS)** | Disabled people have equal opportunities in the disaster management space and are involved in all decision-making processes regarding emergency management issues that impact them. | AEM partners with people with a wide range of disability experiences in Tāmaki Makaurau Auckland during disaster resilience strategy development and preparedness planning in a way that considers the rights, will and preferences of disabled people.

A twin-track approach to disaster resilience strategy development and preparedness planning is utilised. |
| **Social and rights models of disability** | AEM's disaster resilience strategy is based on the social and rights models of disability. | AEM's disaster resilience strategy recognises that people are disabled by socially constructed barriers. The strategy seeks to remove those barriers.

AEM works in collaboration with the disability community to identify and remove barriers to preparedness.

AEM works in collaboration with the disability community to implement disabled people's human rights, and to justify the quality and pace of implementation. |
| **Enabling Good Lives (EGL)** | Preparedness efforts and AEM's resilience strategy give disabled people and their | The eight EGL principles are considered and applied during disaster resilience strategy development and preparedness planning. |

	families greater choice and control over their lives and the supports they receive.	
National Disaster Resilience Strategy (NDRS)	Actions taken to reduce risk in Aotearoa New Zealand are inclusive of all people.	The views, experiences and expertise of disabled people are utilised and valued throughout efforts to reduce risk in Tāmaki Makaurau Auckland.
Sustainable Development Goals (SDGs)	Disabled people are not left behind in disaster management.	Disabled people are engaged as agents of change in disaster management spaces and processes. Disabled people are given opportunities to be leaders in sustainable development actions.
Sendai Framework for Disaster Reduction 2015-2030	Disabled people are directly engaged during planning for disaster risk reduction.	Disabled people are engaged as agents of change in disaster management spaces, planning and processes.
Mātauranga Māori and Te Ao Māori models of wellbeing	Mātauranga Māori and te ao Māori models of disability and wellbeing are embedded in AEM's disaster resilience strategy and preparedness efforts.	Tāk̲ata whaikaha and their whānau are consulted about what te ao Māori models should be applied in AEM's disaster resilience strategy and preparedness efforts.
Pasefika models of wellbeing	Pasefika models of disability and wellbeing are embedded in	Tagata sa'ilimalo and their aiga are consulted about what Pasefika models should be applied in

	AEM's disaster resilience strategy and preparedness efforts.	AEM's disaster resilience strategy and preparedness efforts.

6.   Part B: Preparedness findings

Having identified key conventions, policies, frameworks and models that can be used to inform AEM's development of a disaster resilience strategy, the next part of this review delves into literature specifically related to disabled people's experiences of disaster preparedness, and how being disability responsive can improve disaster resilience for the whole community.

Part B begins with literature pertaining to the levels of preparedness disabled people experience, as well as barriers to preparedness. This provides important context for the four broad key themes that were found interwoven throughout the literature that can enhance disabled people's preparedness for a disaster event. The four themes are: representation and participation; strong and trusting relationships; accessible communication; and education and training.

At the end of each theme potential modes of communication and platforms of delivery are noted, as well as suggestions on how to apply the findings in the context of AEM's work with the disability community in Tāmaki Makaurau Auckland, with examples of innovative practice provided.

6.1 Levels of preparedness

Globally, research shows that disabled people are underprepared for disaster events (Smith & Notaro, 2009; 2015; Wolf-Fordham et al., 2015). For example, in an international survey conducted by the United Nations that sought to investigate disabled people's experiences of preparedness processes, it was found that 85.57 percent of the respondents had not participated in any community preparedness processes. A further 72.2 percent stated they did not have a personal plan in place to prepare for a disaster (UNISDR, 2014).

Disabled people's lack of disaster preparedness has also been noted in the context of Aotearoa New Zealand (Phibbs et al., 2014; Dunn et al., 2017). A study utilising both a survey and face-to-face interviews found that disabled people living in Christchurch prior

to the 2010 earthquake were unprepared for disaster (Phibbs et al., 2014). Only five of 25 survey respondents noted they had sufficient emergency equipment prior to the first large earthquake (September 2010), and only three reported they had a preparedness plan. Even though the sample size for this study was small (N=23 for the face to face interviews and N=25 for the survey), the findings are reflective of international research.

The literature also noted that there are many different factors that influence a disabled person's level of preparedness. For example, some studies linked positive preparedness behaviours with having already experienced a disaster (Phibbs et al., 2014; Ronoh et al., 2015): "the lived experiences that disabled people have from previous disasters are instrumental in developing accessible solutions and practices, enabling actors to better prepare for and respond to future disasters" (Engelman et al., 2022, p. 1500).

Another important finding was reported by Dunn et al. (2017), where it was noted that out of all of the participants, tākata whaikaha (Māori disabled) participants were better prepared for disaster than other cohorts of disabled people. While the literature did not provide details on how this group was more prepared, this finding indicates that cultural belonging and practice have the potential to impact preparedness levels and actions. Drawing on Kenney and Phibbs (2014), Dunn et al. (2017) discuss Māori cultural practices, stating that "the cultural concepts of whakapapa (genealogy) and whānau (family) provide 'a stable emergency management infrastructure for Māori' and that the marae (Māori community) has, for centuries, been able to rapidly mobilise support at times of adversity" (2017, p. 9). In their report, Dunn et al. (2017) also suggest that it is possible that Māori participants relied more on a collective preparedness plan than an individual one.

Other studies have focused on the structural barriers disabled people experience as impacting on their level of disaster preparedness.

6.2 Barriers to preparedness

As articulated by the social model of disability, disabled people are not disabled by their impairment, but instead by socially constructed barriers (Oliver, 1990a). Throughout the

reviewed literature, there was a clear and consistent message that in order to respond to underpreparedness, it is important to first identify barriers to preparedness. In this section of the findings some of the more common barriers are explored, as well as the underlying reasons why disabled people are generally less prepared than non-disabled people.

6.2.1 - Financial access

One of the biggest barriers to preparedness was reported to be financial access. Research shows that families with disabled members are more likely to experience low educational levels, low incomes and higher rates of poverty (Stough et al., 2017). For example, in Aotearoa New Zealand, disabled people under the age of 65 are almost 2.5 times more likely to state that they do not have enough income than non-disabled people under 65 (Murray, 2019).

Discussions around both preparedness processes and preparedness resources typically encourage disabled people to take personal responsibility for preparing for a disaster, including stocking up on resources that might be needed, such as torches, first aid kits, water, food, and medications. Take, for example, the Disaster Preparedness Guide for People with Disabilities (Bay of Plenty Emergency Management, n.d.), the Waikato Disabilities and Disaster Preparedness Guide (Waikato District Health Board, 2012), and the Get Ready website (National Emergency Management Agency [NEMA], n.d.b). While guides such as these can provide useful information for assisting disabled people who have the financial ability and capacity to self-manage their own preparedness, when reviewed alongside the United Nations criteria for best practice (section 9.3) they did not meet the requirements.[4] Furthermore, while all three examples recommended disabled people plan an alternate place to stay, such as with friends or family during an emergency, Blake et al. (2017) note that disability preparedness guides such as these do not examine

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[4] Most notable was the lack of clarity around what role disabled people played in co-designing and informing these guides; the density of the information provided; the high level of responsibility placed on individual disabled people to self manage preparedness; the absence of the full range of accessible formats; a lack of guidance on how to support people with learning disabilities and people with psychosocial disabilities; the absence of cultural frameworks and references to tākata whaikaha, tagata sa'ilimalo, other cultural groups, and harder to reach populations; and the lack of clarity around periodic disability-led evaluation and monitoring of the guides.

how emergency planners can support people without the means or ability to take these steps, or people who find it challenging to do so: "[g]reater socio-economic privilege and social capital can equate to increased preparedness behaviour because these people are able to take the necessary steps required to 'get ready' and be prepared" (p. 286).

In a study by Dunn et al. (2017) it was noted that for many disabled people, cost was a barrier to preparedness (almost a quarter of participants). Cost being a significant barrier to preparedness has also been identified in international studies (Phibbs et al., 2014; Kohn et al., 2012; Smith & Notaro, 2009), with socio-economic status experienced by the disability community often correlating to low preparedness levels (Dunn et al., 2017).

6.2.2- Community connectedness

A second barrier to preparedness is the widely cited recommendation to connect with neighbours and community, build a network, and have an evacuation plan in place for when a disaster occurs.[5] While social connections are often promoted as a positive preparedness strategy, many disabled people can find this a challenge. A history of institutionalisation and deeply embedded ableist ideologies means that disabled people often have reduced networks. For example, research conducted by the Helen Clark Foundation showed that disabled people are four times more likely than non-disabled to report feeling lonely most or all of the time - 11.3 percent compared to 2.8 percent (Walker, 2021). As a result, many disabled people find it difficult to reach out to others due to the perception that their needs are too high and that they are a burden (Villeneuve et al., 2021; Chang et al., 2022).

Reflecting these research findings, many existing preparedness discourses are not currently framed in a way that considers the socially constructed barriers disabled people experience when trying to connect to community. For example, the literature contained little information about what to do when someone has difficulty with preparing for a disaster due to existing discrimination, social isolation and lack of social capital. When

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[5] For example, the Bay of Plenty Disaster Preparedness Guide for People with Disabilities; Waikato Disabilities and Disaster Preparedness Guide; and Get Ready government website.

reflecting on their lack of preparedness for a disaster, disabled people have expressed the view that they are in a "state of emergency" in their everyday lives, which makes preparing for a theoretical disaster that may never take place a challenge as well as an unheld privilege (Finkelstein & Finkelstein, 2020, p. 2060).

6.2.3 - Communication and education levels

Another barrier referenced in the literature was communication. It was consistently noted that emergency information and resources provided during the preparedness phase were not available, not accessible to disabled people, or difficult to understand (Park et al., 2019). For example, Phibbs et al. (2014) reported that fifteen out of thirty-five disabled survey participants stated that emergency information was not adequate for their needs. While 20 participants reported that emergency information was readily available, it was clear from the survey responses that information was frequently viewed as inaccessible. Twenty-six out of thirty-three participants either 'strongly disagreed' or 'disagreed' that emergency information considers the needs of disabled people.

In another study Cooper et al. (2021) reference the 'Information Deprivation Trauma' (Schild & Dalenberg, 2016), which describes a "negative event that is experienced as traumatic or more intensely negative because information or knowledge about this event is limited or not available, preventing the person from fully assessing the threat" (Cooper et al., 2021, p. 3). The Information Deprivation Trauma framework highlights how good quality and accessible disaster communication can enable disabled people to know what is going on around them, enabling them to engage in protective behaviours.

The lack of accessible information for the Deaf community was specifically discussed in a study that engaged key informants from community-based organisations (CBOs) (Neuhauser et al., 2013). The study found that 53 percent of the CBOs serving D/deaf or Hard-of-Hearing individuals as well as older adults did not provide emergency preparedness materials to their clients. These materials appeared to be mainly available from public health departments and when they were available, the emergency preparedness materials intended for D/deaf and Hard of Hearing clients tested above the

recommended 4th grade reading level, making it inaccessible to many. The study concluded that emergency preparedness materials should be more commonly distributed by CBOs, be easier to read, written in simpler language and be accessible in alternative formats such as sign language. Engaging with the people who are the intended users of emergency preparedness resources in a genuine co-design process was noted as a solution to the identified issues, because such groups are on the "cutting edge of communication approaches that can be used to help all populations" (Neuhauser et al., 2013, p. 9). Though the study only engaged with key informants at CBOs rather than disabled people themselves, it identifies key barriers to preparedness resources - an issue also frequently raised by disabled people.

6.2.4 - Disability specific barriers

Alongside financial, community connectedness, educational and communication barriers, the literature showed that disabled people face additional demands that non-disabled people do not. When reviewing literature on disability and disaster, Villeneuve (2020) documented disabled people's perspectives across multiple public forums. At the conclusion of the review, Villeneuve (2020) urged duty bearers to recognise the disproportionately high responsibility placed on disabled people to prepare for a disaster. For example, disabled people are required to update their preparedness plan every time their support needs change. In addition, because disabled people receive support from a range of services they must engage in constant negotiation as to how their support will be managed during a disaster (Villeneuve, 2020). Many disabled people also rely on service and/or support animals, the needs of which must also be included in the support plan (Kelman, 2021). Villeneuve (2020) noted that this context is what disabled people are referring to when they say emergency preparedness is "overwhelming, messy and confronting" (p. 14).

6.2.5 - Addressing barriers: Whose responsibility is it?

Based on the literature, many preparedness efforts and processes are typically underpinned by deficit and individualised understandings of disability. For example, the

medical model of disability sees disability as a 'problem' located within an individual and is therefore the individual's responsibility. Therefore, when the responsibility to prepare for a disaster is placed on an individual (rights holder) who already experiences disadvantage, the responsibility of duty bearers to address the barriers that exist in society can become diluted. Alternatively, a social and rights model approach to disabled people's preparedness would see duty bearers actively working to remove barriers to preparedness. This might include reframing messaging around whose responsibility it is to prepare for a disaster (for example, when preparing kits and establishing personal support networks); resourcing disabled people to adequately prepare and adapt their plans over time as their needs change; ensuring planning guides and emergency resources are considerate of the magnified disadvantage disabled people experience; communicating in accessible formats; and working directly with disability communities to identify disability-specific barriers to preparedness, and working together to remove these barriers.

6.3 - Enhancing disabled people's preparedness and resilience

Having established the low levels of preparedness amongst the disability community as well as some of the common barriers disabled people experience, the literature was then analysed for ways in which AEM can work towards reducing barriers and improving preparedness levels for disabled people in Tāmaki Makaurau. Through this process, four important themes emerged: representation and participation; trust building and relationships; accessible communication; and training and education.

6.3.1 Representation and participation

The first and most prevalent theme found throughout the disability and disaster literature concerned disabled people's representation in preparedness planning. This finding was illuminated by an overwhelming number of negative and positive examples, whereby the exclusion of disabled people had negatively impacted their preparedness levels, coupled with examples of improved preparedness levels when disabled people were represented during preparedness planning. The importance of including disabled people in decision-

making that affects them is highlighted by the New Zealand Disability Strategy, which argues that when disability inclusive decisions are made, it results in better quality outcomes (Office for Disability Issues, 2016, p. 19).

There are many reasons why disabled people may be excluded from preparedness planning. For example, access barriers, attitudinal barriers, or because they simply were not invited. Regardless of the reasons, disability exclusion creates a significant loss of critical knowledge and expertise from preparedness planning. In a scoping study by Abbott and Porter (2013), exclusion was a key factor in preventing disabled participants from being able to grow towards having the status of 'expert' or 'active contributor' in the area of environmental hazard preparedness (Abbott & Porter, 2013). The authors argued:

> [I]t is a waste of resources to marginalise the knowledge contribution that comes from the margins of lived experience of disability" and hypothesised that "disabled people's intricate, daily negotiations with risk, hazard and barriers make them extremely well placed to be at the heart of such forums" (Abbott & Porter, 2013, p. 840).

An example of the negative impact of exclusion can be found in Aotearoa New Zealand, where tākata whaikaha reported that their voices were not included in preparedness and response efforts during the global pandemic. When asked about the COVID-19 health response, tākata whaikaha noted that they were not engaged in any meaningful way from the outset of the pandemic. This was despite the fact there were existing pathways for consultation and engagement with other groups to take place (Independent Monitoring Mechanism, 2021). Even so, tākata whaikaha were amongst the most at risk of the adverse impacts of Covid-19, as well as the measures that took place to slow the spread of the virus (Jones et al., 2020).

More positively, it was reported that when there is a conscious shift in attitude from disabled people being perceived as passive recipients of care (medical model of disability) to being recognised as capable agents and experts (social and rights models of disability), then preparedness efforts were enhanced. The reviewed literature confirmed this by consistently highlighting that the aforementioned barriers could be

ameliorated by including disabled people early in preparedness decision making processes. For example, there were a small number of reports where disabled people were provided with opportunity, funding, training, resources and information to actively contribute to DRR and preparedness planning (Pertiwi et al., 2019; CBM International et al., 2019; Grech, 2022). When reviewing current good field practices in DIDRR, Grech (2022) spoke with CBM office representatives and partners from Haiti, Niger, Zimbabwe, Bangladesh and the Philippines. Drawing on their field experience, participants believed in the importance of disabled people having a strong platform and voice in this area. One of the factors noted as being essential for successful practices in DRR was strengthening Disabled People's Organisations (DPOs) to lead inclusive practice, in conjunction with disabled people, and their organisations owning the process from the very beginning: "overall, this requires a shift towards a genuinely bottom-up, ground-driven approach to DIDRR, and where people with disabilities are leading the whole process" (Grech, 2022, p. 15).

Another example of good practice was reported by Pertiwi et al. (2019) while documenting the work of DPOs in the area of DRR. One study involved three DPO case studies; each organising and leading successful disaster preparedness activities in Indonesia. Findings showed that through their activities, DPOs could increase awareness of the experiences of disabled people, influence policy, while preparing disabled people for disasters. Three key factors impacted the success of these initiatives: funding for preparedness activities, DPO confidence in the activities, and support from experts in the DRR field. The DPOs also noted the importance of identifying established mechanisms within government where DRR was already being coordinated. The participating DPOs would then strategically embed themselves within these established spaces to ensure that disability was considered in mainstream DRR efforts (Pertiwi et al., 2019). This ensured a twin-track approach to DRR was implemented.

As summarised by the United Nations global survey, when it comes to disaster management disabled people's main priority is to simply be involved in disaster risk management and reduction activities (UNISDR, 2014). Involvement in these processes

accords with target 10.2 of the Sustainable Development Goals, which promotes the social, economic and political inclusion of all people, including the disability community.

6.3.1.1 - Summary table

Theme	Key findings	Potential modes of communication	Potential platforms for delivery[6]
Representation	Excluding disabled people from preparedness planning represents a loss of critical knowledge and expertise. A conscious shift away from disabled people being perceived as passive recipients of care to capable agents of change, is needed. Disabled people and their representative organisations (including tākata whaikaha) should contribute to preparedness planning as early as possible. Funding and resources should be made available to disabled people and their organisations to participate in designing and co-designing preparedness planning and activities.	All invitations, consultations, planning and co-design processes, as well as preparedness outputs/resources, should be made available in a range of accessible formats at the same time they are made available to the general public. According to the Accessibility Charter, this includes: - New Zealand Sign Language - Easy Read - Braille - Large print - Audio - Captioned and audio described videos Under Te Tiriti o Waitangi, the inclusion of all communications in Te reo Māori ensures partnership with tākata whaikaha.	Disabled People's Organisations Disability organisations Disability service providers Disabled influencers Disabled experts Disability experts and researchers Family, whānau, aiga and close supporters of disabled people Human Rights Commission Whaikaha - Ministry of Disabled People Access radio Iwi Marae Pānui AEM's social media channels

Examples of innovative practice:
- Following the 2010 earthquake, learning (intellectual) disability advocacy organisation IHC led a series of workshops on disaster preparedness with people with learning disabilities across Aotearoa New Zealand. The workshops were co-developed and co-delivered

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[6] Potential modes of communication and platforms for delivery throughout this review were primarily developed in consultation with disabled research team members, as the literature did not provide specific details on these subjects.

with people with learning disabilities. As a part of these workshops IHC supported participants to develop an Earthquake Reflection Group. This group developed survival strategies and put together preparedness kits. They also formed relationships with various stakeholders such as the New Zealand Red Cross and the Christchurch City Council. This enabled them to contribute to the recovery and rebuild process after the disaster event had taken place, as well as ensure people with learning disabilities were prepared for any future events that may occur (CBM International et al., 2019, p. 12).

● In Urakawa Town, North East of Japan, the local government worked with community members and in particular people with psychosocial disabilities to design best-case scenarios for planning disaster response. When the Great East Japan Earthquake and tsunami occurred in 2011, authorities were able to respond effectively and quickly, whereby a group of residents with psychosocial disabilities were evacuated first thanks to the training they had received as part of their social skill development programme and the multimedia training manuals that were designed to be accessible by all in the community (Inclusive Disaster Risk Management - Governments, Communities and Groups Acting Together, 2015).

6.3.2 Trust building and relationships

The next key theme related to trust building and relationships. In broad terms, this encompassed networking and building trusting relationships between disabled people and all levels of government (for example, Auckland Council and AEM), as well as between emergency personnel, disabled people (individuals) and their representative organisations. As highlighted in the literature, this process requires all disaster preparedness stakeholders to connect, build relationships, talk to one another, collaborate and work together to prepare for a disaster (ESCAP, n.d.; Putera et al., 2018;). In doing so, in the circumstance of a disaster, the response phase will likely be more effective if "cross-sector learning, training, and capacity building" has already taken place (World Bank Group and Global Facility for Disaster Reduction and Recovery, n.d.).

However, research shows that disabled people often do not feel a strong sense of trust towards authorities, including during disasters (Finkelstein & Finkelstein, 2019). Disability responsiveness during the Covid-19 lockdowns in Aotearoa New Zealand provides a strong example of the importance of trust. When reviewing the implementation of disability rights during Covid-19, disabled people reported that "they preferred to receive and/or had greater trust in COVID-19 information provided by local groups and organisations. This information was perceived as more applicable, trustworthy, and relevant than official COVID-19 information from central Government, which could be 'Wellington-centric'", and that "representative DPOs and community organisations worked hard to ensure they received trustworthy, timely, and relevant information about COVID-19 in a way they could understand. Some disabled people reported that they got most or all of their information from a community organisation or DPO" (IMM, 2021, p. 42).

In an Australian study that took place over a five year period (2015-2020) exploring multi-stakeholder collaboration, emergency managers were brought together with disabled people and their community-based support services to work on multiple shared preparedness activities such as co-designing tools and approaches to DIDRR (Villeneuve, 2021). The knowledge gained from these collaborations led to the development of the DIDRR Framework and Toolkit, which provides practical suggestions

for how disabled people, disability support services and local disaster management can work together to create DIDRR:

> [R]aising the critical consciousness of individuals with disability about their rights and responsibilities in DRR, helping them to form collectives ... and linking them up with emergency managers, DIDRR identified and addressed visible, hidden and invisible forms of power through behavioural changes, collective agency and local institutional reforms. Together, people with disability and emergency managers are combining local knowledge, networks and resources to increase their collective impact (Villeneuve, 2021, p. 10).

Importantly, Villeneuve (2021) noted that two key factors of the success of this collaboration was the regularity of interactions and the variety of groups involved. That is, providing frequent opportunities for different stakeholders to come together and talk and learn together was considered essential.

A further example of how pre-disaster collaboration and relationship-building can positively impact the response and recovery phases of a disaster was detailed by McDermott et al. (2016), who analysed the response to the '1000-year flood' in South Carolina, USA. The authors concluded that the disability response to the disaster was fast and effective due to the strong collaborative network created by the Emergency Preparedness Committee for People with Functional Needs. The Committee consists of a large variety of members including groups such as the American Red Cross, Protection and Advocacy for People with Disabilities Inc., the Salvation Army, and others. As a result of the preparedness efforts of the Committee, the State was able to quickly coordinate resources and to effectively respond to the disaster.

However, as highlighted by Finkelstein and Finkelstein (2019, p. 9), trust building is not only important at an organisational level, but also on an individual level, which requires one-on-one engagement with disabled people:

> [E]mergency preparedness of people with disabilities requires gathering detailed information about the individual's daily life, experiences, practices, habits, and

needs. Their embodied way of managing time, space, and speed in the realities of daily living need to be taken into account in the planning of the timing and spaces in the context of preparing for emergencies. Another aspect that the study revealed is that people with disabilities already have an array of means and strategies which they employ in their everyday routines. These too should be mapped, so as to harness them for use in an emergency. There is reason to believe that the one-on-one encounters that the collection of such precise information would entail could help strengthen the interpersonal relationships and establish trust between community figures and the individuals with disabilities. Such an interpersonal relationship is likely to have positive repercussions during an emergency, as well.

The theme of trust building and relationship is also reflective of Te Ao Māori and Pasefika world views. Take, for example, the value of kotahitanga (unity and solidarity), which can be seen in the communal and collaborative responses to disasters that have been carried out by Māori communities in Aotearoa New Zealand. It also reflects the importance of Te Tiriti o Waitangi - whereby the crown and Māori agree to act in partnership with each other. Respecting and embedding the intent of Te Tiriti o Waitangi into emergency management response makes it critical that local and national governments and tākata whaikaha build strong relationships during the preparedness phase (and throughout all phases of a disaster).

Trust building and relationship are also key aspects of Pasefika models of wellbeing, as highlighted by the four interconnected pou in the Fale Fono model. The importance of relationship is further expressed in the Yavu Foundations for Pacific Engagement, which presents four key principles that should be applied during engagement with Pasefika communities, including tagata sa'ilimalo:

- Principle 1 Understanding Context - Know who Pacific peoples are
- Principle 2 Understanding Environment - Make time to connect
- Principle 3 Understanding Responsibility - Recognise Pacific peoples' contribution
- Principle 4 Teu le va - Build, nurture and strengthen relationships (Ministry for Pacific Peoples, 2022)

Theme	Key findings	Potential modes of communication	Potential platforms for delivery
Relationships and trust building	Building strong and trusting relationships includes, but is not limited to: all levels of government, disabled people and their representative organisations, and emergency personnel. Disabled people do not feel a strong sense of trust towards authorities. Disabled people have a stronger sense of trust in DPOs and CBOs. Response and recovery phases can be enhanced by building strong and trusting relationships between key stakeholders during the preparedness phase. Trust building should happen at both an organisational level and at an individual level. Relationship building must recognise and actively deconstruct power imbalances between disabled people and authorities.	Public forums Online and in person consultations Surveys and qualitative research Disability network and organisation meetings Disability conferences Public campaigns Webinars Workshops	Disabled People's Organisations Disability organisations Disability service providers Disabled influencers Disabled experts Disability experts and researchers Family, whānau, aiga and close supporters of disabled people Human Rights Commission Whaikaha - Ministry for Disabled People Access radio Marae Pānui AEM's social media channels Disability sport organisations Funding providers Auckland Council Disability Advisory Panel National Disabled Students' Association (tertiary institutions)

	Trust building requires regular interactions over time, with a wide and diverse range of disabled people. Both Te Ao Māori and Pasefika models of wellbeing centre the importance of relationships, and should be utilised in preparedness efforts.		

Examples of innovative practice:
- In 2019, Ipswich City Council in Queensland Australia partnered with the Disability Inclusive and Disaster Resilient Communities project team to host inclusive community engagement forums that brought together disabled people, community, health and disability service providers, emergency personnel, and government workers to learn about Disability Inclusive Disaster Risk Reduction (DIDRR). Forum participants learned directly from disabled people about the challenges they face before, during, and after disasters in Ipswich and surrounding communities. Reports were shared back to participating Councils and findings from seven forums held in four Local Government Areas were used to build the Queensland DIDRR Framework and Toolkit, which the Ipswich City Council committed to implementing. Within 18 months, Ipswich City Council had delivered a number of important DIDRR actions, including: reviewing all emergency management documents for accessibility and adding alt text to images and figures; adding Auslan and closed captioning to existing videos and making a transcript of all available videos available; hosting workshops on Person-Centred Emergency Preparedness in partnership with disabled people; ensuring disability representation in the Local Disaster Management Plan; and inviting a disability representative to speak to the Local Disaster Management Group about DIDRR. When reflecting on the relationship between disabled people and Ipswich City Council, and what she would recommend to other councils, Kristie McKenna (Ipswich City Council Emergency Management Officer) advised, "Just get out and talk to people with disability. Find out what it's like. Find out how you can make things easier." McKenna emphasised that councils have many touch points into communities, whether it is through their community development programs or their disability and inclusion committees. She recommended reaching out through them. "Honestly, attending the QDN [Queenslanders with Disabilities Network] meetings has probably been the best insight and the best way to build trust and relationships, which I think will help us to keep this going moving forward. You can't unlearn this [...] we'll now consider disability inclusion as 'business as usual' in our emergency management work" (Collaborating4Inclusion, n.d.).

- In 2015 a research project took place in the Philippines led by the Deaf Disaster Assistance Team-Disaster Risk Reduction (DDAT-DRR), a Deaf persons organisation. The result of the research was that humanitarian actors did not appear to be able to communicate effectively with the Deaf community. In response to these findings DDAT-DRR connected with the Philippines Red Cross and partnered with the local government. The goal of this cross-sector collaboration was to train leaders in the Deaf community, as well as sign language interpreters, about DRR and first aid. The Deaf leaders then connected with their local Red Cross groups to conduct joint first-aid training for the local Deaf community and volunteers for the Red Cross. This collaborative project built relationships between the Deaf communities and actors in the Disaster Risk Reduction space and it supported Red Cross members to better understand the lived experience of Deaf people and their needs during disasters (CBM International et al., 2019).

6.3.3 Accessible information and communication

The next key factor that enhanced disabled people's preparedness levels was ensuring that information and communications were both accessible and easy to understand. Specifically, there were three accessibility sub-themes that improved disaster preparedness: ensuring the availability of a wide range of accessible formats; considering the impact of socio-economic status on access; and taking a twin-track approach to accessibility and content.

The first and most prevalent accessibility theme in the literature concerned the diversity of disabled people's communication and access needs. As highlighted by a participant in a study by Villeneuve et al. (2021), information must be delivered in a way that reflects the diverse needs of the disability community:

> The other thing, which is an eye-opener for me, as well, is that you tend to put disability in one group. But I spoke to three different people who had three different disabilities, and you realise that the communication has to be targeted. Because those three people required completely different things. And the information they got was not in a mode that they could use (Villeneuve et al., 2021a, p. 4).

Globally, researchers and disability advocates have recommended that all disaster preparedness information be provided in accessible formats (Dai & Hu, 2022; Neuhauser, 2013). For example, in 2018, a Caribbean study surveyed disability advocacy organisations about their views on disaster risk management information and assistance. All seven participating organisations reported gaps in the availability and accessibility of disaster risk management information for disabled people. The organisations recommended strategies for filling these gaps including: all information being available in sign language and Braille; media policies that require all disaster related information on television to be communicated in sign language and closed captions; training programmes targeted at disabled people to inform them about what information is available; and disaster management programmes being designed specifically for disabled people (Carby & Ferguson, 2018).

This directive is also reflected in New Zealand's Accessibility Charter, which states:

> [All government] forms, correspondence, pamphlets, brochures and other means of interacting with the public are available in a range of accessible formats including electronic, New Zealand Sign Language, Easy Read, Braille, large print, audio, captioned and audio described videos, transcripts, and tools such as the Telephone Information Service (Ministry of Social Development, n.d.).

The purpose of the Charter is to improve disabled people's access to information provided by national and local governments to the public; provide disabled people with a consistent experience when accessing central and local government information; and to meet New Zealand's international human rights obligation under the United Nations Convention on the Rights of Persons with Disabilities (Ministry of Social Development, n.d.). Accessible information and communication are also central to the Sendai Framework for Disaster Risk Reduction, which states that: "Disaster risk reduction practices need to be multi-hazard and multisectoral, inclusive and accessible in order to be efficient and effective," which is achieved through the inclusion of "women, children and youth, persons with disabilities, poor people, migrants, indigenous peoples, volunteers, the community of practitioners and older persons in the design and implementation of policies, plans and standards." As summarised by Cooper et al. (2021), when people have access to information the resilience of populations is enhanced, and post-disaster trauma is reduced.

A second aspect of accessible information is the consideration of issues linked to poverty and technology. Reviewed literature consistently emphasised the higher rates of poverty and lower socio-economic status experienced by disabled people than the general population (Donald Beasley Institute, 2020; 2022; Independent Monitoring Mechanism, 2021; Murray, 2019; Stough et al., 2017). Technology disadvantage must be considered when providing preparedness information to disabled people, given they are more likely to experience lower access to internet (Grimes & White, 2019) and a "digital divide" due to the unaffordability of the internet and technology (Independent Monitoring Mechanism, 2021, p. 40). It is important that strategies to increase disabled people's access to

technology and the internet are developed, while also using a wide variety of modalities to communicate preparedness information. For example, digital information dissemination should be coupled with hard-copy communication, utilising trusted relational networks of disabled people such as DPOs and CBOs.

A third aspect of accessible information referenced in the literature was the twin-track approach to information and communication. The twin-track approach is a well established framework for ensuring that mainstream services and supports are inclusive of, and accessible to, disabled people, while also ensuring there are services and supports that respond to the specific needs of disabled people (Office for Disability Issues, 2016). Given that disasters impact disability groups in different ways, information and communications intended for the general population should be delivered in the accessible formats identified above (track one), while also providing information and communications that are targeted towards different disabilities (track two). The twin-track approach recognises that "no one measure, policy, practice or organisation will do on its own," and that there will be times when disabled people require targeted services and support (Grech, 2022, p. 16). For example, in their work on inclusive information and communication technologies during the COVID-19 pandemic, Dai and Hu (2022) demonstrated how information targeted at different disability groups was achieved by forming multiple disability sub-committees, each of whom developed guidance relating to COVID-19 for specific groups of disabled people.

6.3.3.1 - Summary table

Theme	Key findings	Potential modes of communication	Potential platforms for delivery
Accessible information and communication	All information and communications that are made available to the general public must also be made available in accessible formats at the same time. Information should be available in both digital and hard copy, to ensure that disabled people who do not have access to the internet or technology can still receive the information. A twin-track approach to preparedness information ensures that mainstream content is accessible, and that disability-specific content is also available.	Digital and print accessibility: - Alt-text - Image descriptions - Large print - Plain text - New Zealand Sign Language - Closed captions - Audio descriptions - Braille - Te Reo Māori - Easy read Web Accessibility Standards	In addition to the potential platforms listed in table 11.3.2.1, trusted organisations for the delivery of accessible information and communication include (but are not limited to): Make it Easy (People First) Deaf Aotearoa Blind Citizens NZ Blind Low Vision NZ Deaf Radio Accessible Information and Communications Limited Able Seeflow Relay Services
Examples of innovative practice:			

- In 2015, at the Third United Nations World Conference on Disaster Risk Reduction (WCDRR) in Sendai, Japan intentionally and explicitly incorporated accessibility features whilst developing a disability-inclusive disaster risk reduction framework and its implementation. For example, venue and conference sessions were accessible to both disabled participants and disabled speakers in attendance. Closed captioning in English and Japanese were provided at main venues and sign language interpretation was available across various sessions. Wheelchair accessible transportation was provided to and from conference venues. Documents were in accessible format and blind participants were provided machines that displayed documents in Braille. As a result of these accessibility features, more than 200 disabled people were able to actively participate in the WCDRR proceedings as either delegates, speakers, panellists, or contributors, and participate in the planning of the disaster reduction framework (Stough, 2015).

- The New Zealand National Disaster Resilience Strategy is an example of inclusive and accessible information delivery. Through the National Emergency Management Agency (NEMA) website, the full Strategy is available in PDF, Te Reo Māori, and New Zealand Sign Language. A summary of the Strategy is also available in digital format, PDF, Braille, large print, audio, Easy Read, and other languages (NEMA, 2019).

- In Queensland, Australia, the Gladstone Fire and Rescue Service Station developed autism sensory trauma kits specifically designed to help firefighters communicate with people with Autism Spectrum Disorder (ASD) or other communication challenges during emergency situations. Each kit contained visual and hearing protection, sensory objects and communication boards. As highlighted by one of the firefighters, "Having these kits on the [fire] truck can help us calm people down if they are experiencing distress from the situation. It also prompts us to think about whether anyone around is showing signs they might need some extra help or might be at risk. It's something that's very easy but helps us do our job better by serving the community better. It helps us to consider people who have specific needs or who might otherwise be overlooked" (Queensland Fire and Emergency Services, 2020).

6.3.4 Education and training

Disaster education and training are important factors in preparedness. Often a disaster takes place quickly and suddenly, so it is important that disabled people are educated on how to respond. It is also important that disaster management personnel and people who support disabled people are trained in how to support them in a disaster event. Throughout the literature disaster education was intertwined with the need for accessible information and communication, and covers a wide range of activities such as school-based programmes, public information campaigns, adult education, popular culture and community learning exercises (Carby & Ferguson, 2018).

6.3.4.1 - Training of disabled people (rights holders)

Training disabled people in DRR is a new area of research that appears to have gained traction over the last four years, most notably in Australia. Most widely-cited is the work of Associate Professor Michelle Villeneuve and colleagues from the University of Sydney who have worked in collaboration with DPOs, advocacy organisations, service providers, state and territory government departments, and funders to co-design the Person-Centred Emergency Planning (P-CEP) toolkit. The P-CEP toolkit helps guide disabled people on how to talk about disaster preparedness with their networks and how to develop a preparedness plan. Importantly, the P-CEP is holistic in its approach to DIDRR, and is inclusive of three key components:

- A capability framework setting out eight elements to support disabled people's ability to self-assess their strengths and support needs in the context of disaster preparedness;

- Three principles to help guide joint efforts of stakeholders leading to tailored emergency preparedness planning for the disability community; and

- Four process steps to enable the developmental progression of preparedness actions and facilitate linkages between disabled people, their support services and emergency managers (Villeneuve, 2020).

Importantly, the P-CEP toolkit is based on the social and rights model of disability, and takes a strengths-based approach to DIDRR, rather than a disability as deficit approach (also in alignment with the whānau hauā, whaikaha and tagata sa'ilimalo models of disability). As highlighted by Villeneuve (2020, p. 14), "with the right tools and supports, people with disability can self-assess their risk and tailor emergency preparedness to their individual support needs and situation."

The P-CEP toolkit has been delivered in a number of locations across Australia and with specific cohorts of disabled people, including people from culturally and linguistically diverse communities (CALD) (Crawford et al., 2021). Specifically, P-CEP Peer Education Programmes have been identified as being an important aspect of training disabled people in disaster preparedness, whereby P-CEP-experienced disabled people are contracted and resourced to host workshops in their local communities and support other disabled people to learn about P-CEP. Numerous evaluations of the P-CEP toolkit and peer education programmes have shown significant improvements in disabled people's emergency preparedness following the peer-led workshops. However, evaluation findings also caution that preparedness education and training requires significant time, planning and trusting relationships. Reaching disabled people who are not involved in formal disability service systems is also an ongoing challenge (Chang et al., 2022).[7] Importantly, the P-CEP toolkit and P-CEP Peer Education Programmes appear to give expression to the key findings of this review within the cultural context of Australia (representation, trusting relationships, accessible communication, and disability-led and co-designed training).

Another example can be found in the Get Ready programme in New South Wales, Australia, which aimed to increase the preparedness of d/Deaf, d/Deafblind and hard-of hearing community members and promote greater inclusion in DRR processes (Calgaro et al., 2020). In line with universal design principles (as outlined in the UNCRPD), the collaborative project focussed on fostering inclusive community development and

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[7] The Collaborating 4 Inclusion website provides in-depth detail on the P-CEP toolkit and P-CEP Peer Education Programme, as well as evaluation reports detailing how the trainings were delivered, and their strengths and limitations.

capacity-building. When analysing the successes of the Get Ready programme in advancing d/Deaf people's preparedness and inclusion and collaboration in DRR practices and processes, researchers noted that the biggest wins came from the training of nine d/Deaf Liaison Officers (DLOs) with strong community links in emergency management and preparedness training. As a result, the DLOs were able to provide a culturally appropriate and active bridge between emergency services and the d/Deaf community; provide a platform for greater d/Deaf-led leadership in DRR through the upskilling of motivated d/Deaf individuals; and offered DRR actors a grounded blueprint for greater inclusion for minorities in DRR processes through cross-cultural collaboration and a shared understanding.

More generally, when analysing good practice DIDRR in Haiti, Niger, Zimbabwe, Philippines and Bangladesh, CBM at-risk country offices and partners noted that disability inclusive community mapping and risk assessments are effective tools for documenting where disabled people are located and what their needs are (and the needs of their families), but can also be a way of "awareness-raising and also building of knowledge and training among families and communities to understand the risks, as well as the strengths and resources, and to know when and how to react" (Grech, 2022, p. 45). Furthermore, community mapping can serve to identify the "[a]vailability of support to people with disabilities, be they family members or community members who can assist before or during a disaster and ensure to document and map those who have no support" (p. 46). Ideally, community mapping is "designed, coordinated and executed by people with disabilities and OPDs and the community itself." Further recommendations from CBM and IDEA's good practice analysis suggested:

- Strengthening and training DPOs in basic research methods, as well as using indicators to monitor and document the inclusion of disabled people in DRR;

- Ensuring disabled people, families and caregivers are included in any training on early warning systems, how they work, what the warning signals mean and what actions should be taken;

- Using schools as a platform for educating about disasters, DRR and also disability and disability rights from a young age;

- Teaching disabled people how to monitor news and other alerts before and after disasters and to do this consistently;

- Providing training on contingency plans at a household level;

- Conducting regular drills to check how efficient early warning systems are, and importantly identifying accessibility gaps, with involvement from DPOs.

- Approaching needs assessment of disabled people and their family as fluid and evolving, and an opportunity to see where the gaps are in service provision.

6.3.4.2 - Training of duty bearers

The second education theme identified in the literature was the training of duty bearers - that is, anyone in a position of authority or power who is responsible for delivering human rights through their work. In the literature, duty bearers primarily referred to emergency personnel.

Following the implementation of the Sendai Framework for Disaster Risk Reduction, there has been a noticeable uptake of disability inclusion material in mainstream DRR. However, as argued by Kusumowardoyo and Tamtomo (2021), the approach taken by DRR organisations to disability inclusion is often different from the approach taken by DPOs, in that disabled people tend to focus on a broader range of issues relating to inequity:

> [M]ainstream approaches to DiDRR tend to start from a DRR-based perspective through additional disability inclusion. They are inclined to emphasise the mainstreaming of DRR-based activities to include persons with disabilities. In contrast, OPD-led [DPO-led] innovations focus more on improving the general rights and resilience of persons with disabilities (including their livelihoods) as a broader social baseline so that they can participate in DRR and other aspects of social life (p. 873).

While there were a variety of examples of duty bearer training in DIDRR literature, the most effective approaches were those that were developed by, and in collaboration with, disabled people and their representative organisations; led by disabled people and their representative organisations; and on subjects that were identified as important by the disability community. For example, Wolf-Fordham et al. (2015) discussed the results of an online training programme developed specifically for emergency responders to increase their knowledge of emergency planning and response for disabled people. During the development of the programme, first responders, geographic information system mapping specialists, instructional designers, and disabled people and their families were consulted. The programme was a scenario-based online course where the user experiences a storyline, role-play, and game-like features which simulate the person interacting with disabled people prior to and during emergency situations. The study found that the online course was successful in transferring knowledge and skills about the needs of disabled people in emergency situations (Wolf-Fordham et al., 2015).

In Queensland Australia, researchers conducted interviews with emergency personnel about their experience of engaging in a DIDRR project centred on the P-CEP toolkit (Collaborating4inclusion, n.d.a). All participants acknowledged that the inclusion of disabled people in emergency management is regularly filed in the "too hard basket" (p. 3) resulting in negative consequences during disaster events. Disability inclusion resources were seen as fluffy documents that lacked applicability in real life. On the other hand, after being trained in the co-designed P-CEP toolkit, emergency managers felt like they finally had a practical tool that allowed them to "think beyond the end of the hose" (p. 4). In particular, taking a strengths-based approach to disability engagement had shifted how they thought and talked about disability. However, perhaps the greatest learnings came from being directly engaged with the disability community. When asked about tools and training for emergency personnel, many participants reflected on the "immersion experience" that the DIDRR project had provided, "I found that workshop to be very enlightening. Talking with people with disabilities and everything like that and not realising how much some people didn't understand about how emergency response works" (p. 5). All participants said that emergency personnel would benefit from "disability

awareness training" and cited first-hand interactions with different disabled people and listening and learning from the experiences of disaster-experienced disabled people as being the most effective form of education (Collaborating4inclusion, n.d.a, p. 5).

6.3.4.3 - Training of community-based professionals and service providers

The third theme relating to training and education concerned community-based professionals that provide services to the disability community. For example, disability support workers, general practitioners, occupational therapists and social workers. Researchers have argued that these roles share a common focus in that they support disabled people and/or people with chronic health conditions to be self-sufficient and independent, with the potential to help improve disabled people's disaster preparedness levels (Subramaniam & Villeneuve, 2019). In Aotearoa New Zealand, community-based professionals are also responsible for promoting and upholding the Enabling Good Lives Principles, the New Zealand Disability Strategy and the UNCRPD.

Other community-based professionals that have been identified as important stakeholders in helping to develop disabled people's self-management of disaster preparedness are health practitioners, such as disability support workers, general practitioners and allied health professionals (Subramaniam & Villeneuve, 2019), and even animal organisations and animal-related networks in which disabled people are involved (such as assistance animal trainers). For example, a small number of disabled people rely on service and support animals to alert them to danger. Service and support animals have also been found to increase disabled people's social, psychological and emotional wellbeing and to increase their feelings of independence and companionship (Thompson et al., 2014). Disabled people have noted that they often feel anxious that they will lose their service and support animals during a disaster and have also experienced resistance when attempting to bring their service/support animal with them to an evacuation shelter (Finkelstein & Finkelstein, 2020). As a result, it is important that assistance animals are included in disaster planning, utilising animal organisations and animal-related networks as a pathway for generating discussion on disaster preparedness. This can take place through increasing knowledge of identification tags for service/support animals, which can

be used to identify an animal as a disability assist animal (NEMA, n.d.a) and through preparedness plans such as the P-CEP toolkit.

However, while disability service providers (Villeneuve, 2019) and other community-based service providers (Subramaniam & Villeneuve, 2019) are often an existing part of disabled people's support network, it is important to recognise that not all disabled people engage with formal support services or community-based professionals. For this reason, initiatives such as disability inclusive community mapping can help to identify and engage harder to reach populations who do not have networks they can easily draw on.

6.3.4.4 - Training of family, whānau, aiga and close supporters

Despite family, whānau, aiga and close supporters being important natural and paid supports in the lives of many disabled people, there was little focus in the literature on their involvement in preparedness or DRR for disabled people. One possible reason for this is that the social and rights approach to disability is primarily focused on the empowerment of individuals to self manage DRR. However, it is also important to acknowledge that many disabled people rely on family members for support and advocacy (Finkelstein & Finkelstein, 2020). As articulated in the Preamble of the UNCRPD:

> [F]amily is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities (United Nations, 2006).

Therefore family, whānau and aiga should be included as key stakeholders in disability responsive preparedness.

When reviewing good DIDRR practice, CBM and IDEA note that where possible family should be involved in, and identified during, needs assessment and community mapping (Grech, 2022). For example, many of the DRR preparedness planning templates used in Aotearoa New Zealand recommend that disabled people identify a family member or

friend who can be a contact person in the case of an emergency. As noted in section 11.2.3, however, social capital is an unheld privilege for many disabled people, making this aspect of preparedness a challenge (Blake et al., 2017; Finkelstein & Finkelstein).

It is clear that the role of family, whānau and aiga in DRR, and their training in DIDRR, is an area where further research is needed. While the literature was not forthcoming with recommendations on how to include family in DIDRR, it is, however, possible to draw on the previously referenced cultural models of disability, health and wellbeing for guidance. For example, the literature noted several examples where collective iwi, hāpū and whānau-led initiatives (Wikaire-Lewis, 2022; Waatea Team, 2022; Cram, 2021; Kenney, 2019; Kenney and Phibbs, 2015) had led to significantly better preparedness for local communities, including tākata whaikaha:

> Our marae are a safe haven, and we know that when disaster strikes, with one phone call, they will be there; Omaka Marae demonstrated this last year during the July floods when over 50 people were stranded on State Highway 1. In the space of half an hour they had opened the marae, the heaters were on, beds were ready, and kai prepped. This is what our marae do, manaaki and care for people (Waatea Team, 2022).

Another important finding came from Dunn and colleagues (2017), where tākata Māori and tākata whaikaha participants were identified as being amongst the most prepared for disaster in Aotearoa New Zealand:

> [T]he cultural concepts of whakapapa (genealogy) and whānau (family) provide 'a stable emergency management infrastructure for Māori' and that the marae (Māori community) has, for centuries, been able to rapidly mobilise support at times of adversity (Dunn et al., 2017, p. 9).

While the research does not specify the ways in which tākata Māori and tākata whaikaha were more prepared, the authors argue that it is possible that Māori participants rely more on a collective preparedness plan rather than an individual one. Likewise, the tagata

sa'ilimalo model of disability seeks to grow the worldview of collectivism, by recognising the role of family and community in disabled people's lives:

> In practice this means that a sector built around assumptions of a nuclear family with individualistic aspirations is less able to accommodate the collectivistic needs of a community with larger families that rely on extended family and community support to sustain their daily lives (Tōfā Mamao Collective, 2022, p. 8).

These examples are indicative of the important contributions that Te Ao Māori and Pasefika world views can contribute to enhancing resilience in the disaster management space. Such values and strategies also have the potential to enhance DIDRR processes (Ministry of Civil Defence & Emergency Management, 2019), considering the emphasis that disabled people and other stakeholders have placed on building trusting relationships between stakeholders and ensuring synergy between actors.

6.3.4.5 - Summary table

Theme	Key findings	Potential modes of communication	Potential platforms for delivery
Education and training	There were three aspects to this finding - training of rights holders (disabled people), training of duty bearers (authorities) and the training of community-based professionals. While the training of family was not identified as a key theme in the literature, it was noted as an area for further research, drawing on cultural models of disability and wellbeing as reference. All forms of preparedness training and education should be co-designed with disabled people, and led by disabled people. The P-CEP toolkit, disability inclusive community mapping and disability inclusive risk assessments have been noted as effective ways of improving the preparedness levels of disabled people, including harder to reach disability populations. Community-based professionals are an effective pathway for improving preparedness levels of disabled people.	School-based programmes Public information campaigns Adult education Popular culture and community learning exercises Inclusive and accessible mainstream training and education (track 1) Targeted training and education for disabled people (track 2) Disability-led community mapping Disability-led needs assessments Disability-led online and in-person training for public servants and emergency personnel (including evacuation services) Co-designed resources for community-based professionals and family Webinars	Family, whānau, aiga and close supporters of disabled people Schools Iwi Community groups Community based organisations (CBOs) Religious groups Public servants Emergency personnel Disabled Persons Organisations Disability organisations Digital media Print media Co-designed resources

	To achieve this, co-designed training materials must be funded, resourced and provided.	Apps/online games	Utility companies (power, water, and so on)

Examples of innovative practice:

- Established in NSW, Australia, the Get Ready initiative trained nine d/Deaf Liaison Officers (DLOs) with strong community links in emergency management and preparedness training. The DLOs were then supported to deliver emergency preparedness workshops to children and d/Deaf and hard-of-hearing people in collaboration with emergency services personnel; advised emergency services on appropriate preparedness resource content and form; disseminated preparedness information to their community through established networks; and led eight d/Deaf Awareness Training sessions for emergency services, which provided 245 personnel with the skills and cultural awareness needed to effectively communicate and work with d/Deaf people (Calgaro et al., 2021).

- Co-designed with disabled people, the Person-Centred Emergency Preparedness P-CEP emphasises the capabilities of disabled people and the roles of multiple stakeholders in reducing disaster risk, consistent with Australia's national Emergency Management and Disability Strategies. The P-CEP toolkit is person-centred in that it focuses on the disabled person, their specific needs and abilities, and gives them agency over their decisions regarding preparedness. A short version of the toolkit specifically focused on COVID-19 was also published

(Villeneuve et al., 2018; 2022).

- An online training programme was designed for emergency responders in order to increase their knowledge of how to plan and respond to the needs of disabled people. Disabled people and their families were consulted while the scenario-based programme was being developed. It was found that the online course was successful in increasing responders' knowledge of the needs of disabled people in emergency situations (Wolf-Fordham et al., 2015).

7. Part C: Other findings for consideration

While the purpose of this literature review was to identify potential modes of communication, platforms for delivery and innovative practice that can enhance disabled people's disaster preparedness and a disaster resilience strategy, the reviewed literature also consistently indicated that efforts to increase preparedness should be considered alongside other phases of a disaster (response and recovery), with synergy between stakeholders throughout all phases of a disaster (Grech, 2022). As summarised by the USA National Council on Disability (2009, p. 265), "What emergency management and people with disabilities require is a concerted, comprehensive, interdisciplinary research effort to systematically address the full life cycle of emergency management." To this end, outlined below is a brief but broad overview of response and recovery findings, as they specifically relate to disability responsive preparedness.

7.1 Response phase

The emergency response phase is defined as the "actions taken a short period prior to, during, and after disaster impact to reduce casualties, damage and disruption and to respond to the immediate needs of disaster victims" (Tierney et al., 2002, as cited in National Council on Disability, 2009, p. 85). Actions taken during this time may include saving people from immediate danger, evacuating people from their homes, and preventing property damage. The efficiency of this phase is impacted by preparedness levels, which shapes how the recovery phase of a disaster unfolds.

The response phase is important because many lives can be saved if it is effectively planned for, and executed according to the preparedness phase. The trauma people experience can also be reduced if this phase is efficient, inclusive, accessible, and well-coordinated. Disabled people have spoken of their fears of being deprioritised or left behind during this phase of the disaster cycle, leading them to feel vulnerable (Quaill et al., 2019). For example, losing power when it is needed to operate a wheelchair lift or other specialised equipment, the challenges of environmental changes experienced by people who are blind or who have vision impairments, and worrying about whether

evacuation shelters will be accessible, receptive of assistance animals and responsive to disability specific needs (Quaill et al., 2019; Thompson et al., 2014).

The reviewed literature identified three main factors that can enhance disabled people's resilience during the response phase, all of which link directly back to preparedness. These were: accessible communication; accessible evacuation; and accessible shelters. The first key factor concerned the implementation of early warning systems that distribute important information about imminent threats, delivered in a format that is both accessible and inclusive. An early warning system is the first signal to the community that a disaster has occurred. This early warning allows people to take action to protect themselves, and others, as quickly as possible. It is crucial that any public warning system both reaches, and can be understood by, disabled people. An important priority for disabled people is having access to early warning systems that utilise multiple ways of warning people and that are cognisant of the needs of disabled people (Carby & Ferguson, 2018; Grech, 2022; UNISDR, 2014).

For early warning systems to be considered accessible, it is important that they are co-designed by disabled people and their representative organisations in order to ascertain what disabled people require from the system; to understand the multiple formats and modalities that are needed to deliver the system (including communications that utilise both sight and sound); to ensure that the disability community have the capacity to respond to early warnings; and to train disabled people on how to use and respond to the system (Carby & Ferguson, 2018; Chisty et al., 2021; Grech, 2022; Miller, 2020).

The second key factor, communication, is another important aspect of both disaster preparedness and response. Research shows that disabled people consistently experience a lack of accessible communication during the response phase of a disaster (Cooper et al., 2021; Good et al., 2016). While it has been noted that social media can be a positive platform for disaster messaging, even the most widely-used social media platforms are not completely accessible for disabled people (Kent & Ellis, 2015). Accessible communication methods during disaster response can be established during the preparedness phase, in consultation with members of the disability community. This

includes, but is not limited to, the provision of mainstream information in multiple accessible formats across a wide range of formal and informal platforms (track one, see table 11.3.3.1); the provision of information that is related to specific experiences of disabled communities in accessible formats (track two), recognising the heterogeneity of disabled people; and inclusive web-based spaces (Dai & Hu, 2021).

Evacuation, the third factor identified in the literature, is one of the main tools for preventing injury and harm to people during a disaster. The literature showed various experiences of disabled people relating to evacuation, many of whom felt left behind, anxious about evacuating, underprepared and abandoned during disasters (Good et al., 2016; UNISDR, 2014). Research also showed that disabled people evacuate at a lower rate than other groups (Stough, 2015) and often require more assistance to evacuate (Elisala et al., 2020).

The literature regarding evacuation primarily focused on the experiences of physically disabled people. There is a gap in the research about the experiences of other disabled people such as people who are neurodivergent, who have a psychosocial disability, and people with a learning disability. This gap is likely due to physically disabled people having such a clear, visible and urgent need for assistance during a disaster and what has been referred to as their privileged status in the disability hierarchy (Smith, 2022). However, barriers experienced by disabled people during evacuation included the lack of a government mandated disaster management system for disabled people, buildings that lack accessible evacuation routes (Park et al., 2019) and a lack of support to evacuate (outside of family and friends who may or may not be present when the disaster takes place) (Elisala et al., 2020).

Identified barriers to evacuation can be directly linked to the training of disabled people and emergency personnel in evacuation processes during the preparedness phase. For example, emergency responders in Nepal reported that they had not previously assisted in the evacuation of disabled people and that when a disaster occurred (earthquake) there was no specific plan to guide their safe evacuation. In particular, they did not have a record of where disabled people lived and therefore could not target assistance to those

in most need, and there was a lack of specialised evacuation equipment (Bista et al., 2018).

As highlighted in section 11.3.4.2, disability responsive evacuation processes can be actioned successfully when disabled people are supported to train emergency responders regarding accessible evacuation processes (Uzair et al., 2022); when accessible evacuation routes are pre-planned in collaboration with the disability community (Boyce et al., 2017; Butler et al., 2017); when disabled people are trained to practise evacuation processes prior to a disaster taking place (Butler et al., 2017); and when accessible modes of evacuation, such as vehicles, are planned in collaboration with the disability community (Apte et al., 2015).

The final key element of the response phase is evacuation shelters, also known as 'rescue camps', 'welfare centres' or 'emergency shelters'. People are often evacuated to shelters in the very early stages of a disaster, though use of a shelter can continue for many months after a disaster has taken place. Shelters provide disaster-affected community members with a safe space, water, food, sanitation and healthcare (Bashawri et al., 2014). At a bare minimum, disabled people require shelter that can accommodate their needs. This includes but is not limited to: accessible transport to and from the shelter; physical access in and out of buildings and structures; storage for medications and equipment; food that caters to dietary requirements; disability rights trained health care workers; private spaces for intimate care; accessible bathrooms and facilities; accommodations for support people and assistance animals; specialised equipment; and accessible signs and communications (Finkelstein & Finkelstein, 2020; Malpass et al., 2019; Park et al., 2019; Phibbs et al., 2012; Quaill et al., 2019; Thompson et al., 2014; Twigg et al., 2011; Villeneuve et al., 2021; Winarno et al., 2021).

The literature noted that a lack of preparation for the response phase often leads to staffing limitations as well as challenges around shelter management. For example, many shelters do not have staff who are trained to work with disabled people and fail to engage with disabled people and their organisations when planning community shelters (Malpass et al., 2019; Twigg et al., 2011). As this literature review has demonstrated, many of these

barriers can be successfully navigated by implementing the key findings of Part B. That is, ensuring the representation and participation of disabled people during preparedness planning; building trusting relationships between key stakeholders; ensuring all communication is accessible; and by training and educating disabled people, public servants, emergency personnel, community-based professionals, and family on disability rights and responsiveness.

7.2 Recovery phase

The recovery phase of a disaster takes place after the immediate danger of a disaster has subsided. It refers to the "coordinated efforts and processes to bring about the immediate, medium- and long-term holistic regeneration and enhancement of a community following an emergency" (NEMA, n.d.b, para. 2). This definition is appropriate as it provides a focus beyond just physical reconstruction of damage caused by the disaster and has the potential to extend to the regeneration of community networks, physical and mental health, as well as broader infrastructure such as the employment sector and service delivery.

The recovery phase has been described as following a "blurry timeline" (Bourke et al., 2022, p. 1), as there is no clear end point for this phase, with many in the community feeling the impact of a disaster for many years. Studies have found that disabled people have been frustrated with the length of time that recovery has taken and have experienced disadvantage caused by disaster for as long as six months to four years, and in some cases even longer (Bourke et al., 2022; Mörchen et al., 2020; Stough et al., 2015). This finding emphasises the need for long-term follow up and support for disabled people after a disaster. The recovery phase is important as the decisions made and actions taken shape how the community moves forward, who is provided appropriate support in order to recover physically, mentally and financially, and whether the community is rebuilt and reorganised to be accessible to, and inclusive of, all people.

Barriers to recovery for disabled people included failed infrastructure such as a lack of housing and accommodation; a lack of employment and financial hardship; and

challenges accessing services in order to receive much needed support (Stough et al., 2015; Zayas et al., 2017). Disasters were also found to have a profound impact on the mental and physical health of disabled people (Bourke et al., 2022; Stough et al., 2015).

As with the response phase, ensuring disabled people are included in co-designing preparedness efforts and DRR sets a powerful precedent for ensuring that disabled people are present, participating in, and leading the recovery phase as well. As highlighted by Bourke et al. (2017, p. 175):

> [T]he recovery period is not just an opportunity to rebuild for people who experience disability, but of crucial importance, to rebuild *with* people who experience disability. Indeed, research examining the meaning and implementation of 'building back better' during disaster recovery highlight that community involvement is essential to develop recovery initiatives which understand the realistic needs of community members.

7.3 Future research

As noted in section 9.3, there were limitations to this literature review, including the challenges of balancing the volume of DIDRR literature with brevity and clarity. As such, not all relevant literature could be included, but instead was prioritised for its usefulness to the brief.[8] A second limitation is that despite the large volume of literature, DIDRR very much remains a new area of research, and one that still has gaps (Holden et al., 2019; Quail et al., 2018). Some of the more noticeable gaps include:

- Disability-led auditing, monitoring and evaluation of DIDRR processes

- Accountability and reporting to the disability community

- Employment of disabled people in DRR duty bearer roles

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[8] For a full list of reviewed literature beyond that which is included in this report, please contact the DBI.

- DIDRR and indigenous people and other ethnic minorities

- Cultural approaches to DIDRR

- DIDRR and gender

- DIDRR and intersectionality

- DIDRR and neurodiversity

- DIDRR and learning (intellectual) disability

- DIDRR and psychosocial disability

- DIDRR and people with chronic health conditions

- DIDRR and people with multiple and complex disabilities

- DIDRR and co-existing disabilities

- DIDRR and disabled people from the LGBTQIA+ community

- DIDRR and family, whānau, aiga and close supporters of disabled people

While literature on these subjects was limited, this report included literature from beyond the brief, in order to begin to address some of these important issues. However, further work is needed to understand what a Te Tiriti o Waitangi and rights-based approach to DRR means for disabled people and tākata whaikaha in Tāmaki Makaurau Auckland.

8. Kupu whakamutuka/Concluding remarks

This integrative literature review has been an important first step in learning about the different factors that should be considered when developing a disability responsive resilience strategy, particularly during the preparedness phase of a disaster. The review began by outlining key concepts and values that informed the review process, and the assumptions that underpinned the integrative approach. The review method was then discussed, before findings from the literature were presented. In *Part A*, the role of key conventions, policies, frameworks and models in preparedness, DRR and resilience strategies were noted. These documents were either referenced in the literature as providing important guidance on disability responsiveness, or were noted by the research team as being crucial to ensuring that disaster resilience efforts closely align with local and central governments' cultural, human rights and legal obligations in the context of Aotearoa New Zealand. A summary table outlined the vision of these documents in relation to the aims of the literature review, as well as potential pathways of application.

Having established the key instructive documents, *Part B* presented the findings of the reviewed literature, specifically in relation to disability responsiveness during preparedness. *Part B* began by discussing disabled people's levels of preparedness and barriers to preparedness: a lack of financial access, community networks, accessible communications, as well as disability-specific barriers. This provided important context for discussing key themes found in the literature that enhanced disabled people's preparedness levels.

According to the literature, enhancing disabled people's preparedness requires representation and participation of disabled people and their representative organisations during DRR planning; building trusting relationships between key stakeholders; ensuring information and communication outputs are accessible to disabled people and are available at the same time as they are to the general population; and ensuring rights holders (disabled people), duty bearers (government, emergency personnel), community-based professionals and family are trained in matters that are important to disabled people, as defined by disabled people. At the conclusion of each finding a summary table

was presented, including how the findings can be applied by AEM through potential modes of delivery, potential platforms for delivery, and examples of innovative practice.

While the purpose of this review was to analyse literature pertaining to the preparedness phase of a disaster, a further key finding was the fluid nature of all phases of a disaster, and the compounding impact the different phases have on each other. In *Part C* a broad but brief overview of findings relating to the response and recovery phases was provided, specifically as they related to the preparedness phase. Areas for further research and gaps in the literature were also identified.

This integrative literature review demonstrates that for preparedness, DRR and resilience strategies to be responsive to disabled people, it is necessary to both acknowledge and respond to the systemic ableism that disabled people experience in their everyday lives, while also ensuring that disabled people are supported to lead any and all planning, strategies, policies and programmes that affect them. In order to achieve this, a shift in thinking is required, whereby disabled people are no longer considered recipients of care, but are instead understood as experts of their own experiences (Abbott & Porter, 2013). This shift in thinking is not an additional 'burden' or 'add-on' to mainstream responses, but instead comes from the recognition that when the most affected are placed at the centre of preparedness, DRR and strategies, then all people affected by disaster will benefit and the resilience of the whole community will be lifted. In the words of Tāmaki Makaurau Auckland disability advocate, Martine Able-Williamson, we have moved on from the decades-old rallying cry of disabled people "Nothing about us without us!". We are now simply saying, "*Nothing* without us!" (United Nations, 2022).

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10. Appendix A: Databases and terms

Databases searched

- Google scholar
- The University of Otago library website
- Google
- Academic Search Complete (EBSCO)
- ProQuest Central
- Medline (OVID)

Examples of search terms used

- Disaster management and disability
- Disaster management and disability New Zealand
- Disability and disaster and New Zealand
- Emergencies and disability
- Emergency preparedness and disability
- Disaster preparedness and disability
- Disaster Risk Management and disability and New Zealand
- Disaster Risk Reduction and disability
- Disability Inclusive Disaster Risk Reduction
- Auckland and emergency preparedness and disability
- Humanitarian action disability inclusive
- Government defence and disaster and disability
- Disaster response and disability and co-design

- Māori and disability and emergency response and New Zealand
- Māori and whaikaha and disaster management

**Whakarakatira te tākata,
ahakoa ko wai, ahakoa nō hea.**

Respect and treat all with dignity,
irrespective of who they are and
where they come from.