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Disabled people and cancer: Literature review

Ngā tāngata whaikaha me te mate pukupuku: He arotakenga mātātuhi

Adapted in November 2025 by Te Aho o Te Kahu Cancer Control Agency

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Foreword
He kupu takamua

Tēnā koutou,

I am proud to present the Te Aho o Te Kahu - Cancer Control Agency (the Agency's) literature review on disabled people and cancer across Aotearoa New Zealand.

One in six people in Aotearoa are disabled (Stats NZ, 2023) – and for Māori this is closer to one in five. Disability becomes more common as people age.

When we released *He Pūrongo Mate Pukupuku o Aotearoa 2020: The State of Cancer in New Zealand 2020,* we identified that there was little data available on cancer outcomes for disabled people. At the time, we committed to investigating how cancer affected disabled people. The result is this Literature Review, and a companion report called *The burden of cancer among disabled people: Diagnosis insights - He taumaha te mate pukupuku ki ngā tāngata whaikaha: Ngā kitenga.*

This report summarises current international and national research on the experiences of disabled people in accessing cancer screening, diagnosis, and care. It highlights focus areas for addressing the poor cancer outcomes and barriers that many disabled people experience. Often, these barriers are preventable. Some examples include difficulties accessing appointments or support navigating the health system and a lack of appropriate equipment or clinical awareness to screen or treat a disabled person effectively. But hampering a better understanding of these issues are gaps in international and local evidence available on how cancer impacts disabled people. Other concerning issues highlighted in the literature include when clinicians misattribute a person’s cancer symptoms to their disability, an act we refer to as diagnostic overshadowing; and when disabled people are not offered similar treatment options to someone who was not disabled.

We are grateful to the people and teams across the health and disability sectors who shared their expertise and insights to inform these reports, in particular the advisors with lived experience who shared their insights on being disabled and navigating the system of cancer care.

I believe these reports provide a strong foundation for coordinated planning across the health sector to ensure the national cancer care system becomes more inclusive of and responsive to disabled people. A system-wide response that improves outcomes for all disabled people brings us closer to our vision of ‘fewer cancers, better survival, equity for all.’

Ngā manaakitanga,

Rami Rahal
Tumuaki – Chief Executive and National Director of Cancer Control
Te Aho o Te Kahu – Cancer Control Agency

Acknowledgements
Ngā mihi

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We also acknowledge the many kaimahi (staff) from Whaikaha – Ministry of Disabled People, Health New Zealand – Te Whatu Ora (Screening and Disability teams) and the Ministry of Health – Manatū Hauora (Health of Disabled People, Hauora Māori and Pacific Health teams) who contributed to this work.

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The 2023 New Zealand Household Disability Survey reported that 17% of New Zealanders and 24% of Māori are disabled[1]. We know that disabled people use health services at a higher rate and report poorer health compared with non-disabled people. However, Te Aho o Te Kahu – Cancer Control Agency (the Agency) has identified a need for more data and evidence on the cancer burden and experience and outcomes of care for disabled people. Therefore, the Agency has recognised that this population group is an important area of focus.

This report collates peer-reviewed local and international literature — about disabled people with cancer. It aims to provide insights to support the wider health sector to better understand many of the challenges that disabled people face during their cancer journey. The report also outlines evidence-based ways to reduce barriers to care for disabled people.

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[1] We note these proportions are lower compared to the previous survey, likely due in part to methodological changes that mean these results reflect only people who reported a high level of difficulty with functional tasks. In total, 51% of the population reported at least some difficulty with functional tasks. Source: *customised data from the 2023 Household Disability Survey; provided by Stats NZ in May 2025*

The report has not included a review of literature relating to experiences of people who became disabled because of or following their cancer, or disabled people's exposure to cancer risk factors such as tobacco use. However, we recommend these as future focus areas.

Disability and cancer: inequities and barriers

Overall, there is limited information on the state of cancer for disabled people. What is available in international data indicates that, when compared with non-disabled people, disabled people are likely to have higher mortality and lower survival for some cancers.

Regarding access and barriers to cancer services, much of the international research reviewed focused on breast and cervical screening. These studies showed that disabled people are screened at a lower rate than non-disabled people, placing them at greater risk for delayed diagnosis and cancer mortality. Studies identified multiple barriers to participation, including:

difficulties accessing appointments

- a lack of support to navigate services
- a lack of physical tools that enable participation in the clinic/hospital setting
- inadequate information for patients
- inadequate training for health care workers.

A small but growing number of studies have focused on identifying inequities in cancer treatment and substandard experiences of service provision. These can be broadly grouped into experiences related to specific cancers and those related to disability. Overall, the studies (excluding those for prostate cancer) showed that disabled people are diagnosed later than non-disabled people and are less likely to receive comparable treatments. Limited existing literature also indicates that people with learning disabilities face an additional burden of inequity – that is, they are less likely to receive curative cancer treatment compared to people without learning disabilities. While reasons for these inequities were not a focus of these studies, the authors suggest ableism, diagnostic overshadowing, and failures to acknowledge the diverse needs of disabled people are likely key factors for consideration.

Diagnostic overshadowing describes the misattribution of signs and symptoms to a person's underlying disability or coexisting health conditions. A 2020 study investigated the experiences of 20 patients with mobility disability[2] with the process of cancer diagnosis and found half of them experienced a delay in their diagnosis

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[2] Mobility disability was defined in this study as 'requiring the use of an assistive device and/or assistance performing activities of daily living'.

due to their cancer signs/symptoms being incorrectly attributed to their underlying disability.

Overall, similar patterns of disparities for disabled people have been observed globally across different health care systems, including countries with universal health coverage and public health care that is free at the point of delivery. Most barriers identified were at a systems and process level. This indicates there is inadequate provision being made for disabled people at all levels of clinical and health leadership to prioritise the unique and diverse needs of disabled people.

Improving cancer services for disabled people

Most of the research reviewed was international and focused on specific practical and organisational approaches to eliminating barriers to cancer screening, diagnosis and treatment. However, a clear theme of discussion in key articles was the importance of system-level change. This included removing the costs associated with screening and increasing the awareness of cancer screening in the general public (including disabled people).

While there is limited research available on Indigenous disabled peoples, leading Aotearoa

New Zealand disability researchers urgently want to eradicate discrimination towards tāngata whaikaha Māori (disabled Māori). Experts assert that addressing the systematic and institutional mechanisms that drive inequities for disabled people will require the active dismantling of racist, ableist and disablist systems. This requires disabled people – and tāngata whaikaha Māori in particular – to co-design the systems and services that affect them, echoing the phrase ‘nothing about us without us’.

Literature on practical organisational strategies to improve or remove barriers to screening and treatment have focused on breast and cervical screening, and are often limited to people with physical disabilities or learning disabilities. However, it is likely that the various strategies arising from these studies are broadly relevant across all impairments.

Research indicates that health care providers and health systems can take steps to improve cancer care for disabled people. The recommendations in the literature largely relate to the provision of reasonable accommodations to facilitate high-quality care for disabled people regarding screening and treatment – for example, larger examination rooms, longer appointments, and careful consideration of the physical, emotional and spiritual comfort of the individual and their whānau during a procedure. In addition, it is important to ensure appropriately trained support people are available to help navigate the health system where required.

Health promotion information about screening should be provided in alternative formats to be accessible for all, including disabled people. Health promotion messaging should also be developed to educate the public about disability and raise awareness of the inclusion and accessibility needs of disabled people.

Health workforce training in disability competence was a common theme emerging from literature. Among other benefits, adequate training can enable relatively simple interventions that make a significant difference to a disabled person's experience – for example, discussing a person's needs before an appointment to plan the use of an interpreter or a specific piece of equipment.

Discussion

There are several interventions highlighted in this report that align with the priority areas identified in the *Government Policy Statement on Health 2024–2027*, including equitable access to services, a skilled (disability competent) and culturally capable workforce, and resilience of digital infrastructure.

Most of the international studies reviewed focused on cancer screening. While screening reflects an important phase of the cancer continuum in terms of reducing cancer-related morbidity and mortality, its scope is limited to those cancers with existing screening programmes. There is limited research on treatment and outcomes and palliative care and end-of-life care for disabled people with cancer, internationally and within Aotearoa New Zealand.

Although not specifically reviewed in the literature, the effects of broader determinants of health are evident as they filter down into practical barriers for disabled people. For example, this includes ableism when organisations do not prioritise health professional training or neglect to provide reasonable accommodations during cancer screening or treatment.

The literature suggests system improvement should be co-designed with disabled people – and tāngata whaikaha Māori in particular. In addition, there is a need to further investigate the impact of intersectionality on disabled people, particularly for tāngata whaikaha Māori.

A number of studies discussed the importance of accurate and appropriate data collection for disabled people. The literature also highlighted the variety of ways that disability has been described and categorised, resulting in challenges in the ability to compare data and information reported in different studies.

Accurate, appropriate and consistent collection of disability data is essential to identify equity gaps in the design and delivery of health policy and services. The most streamlined way to achieve this would be to establish ways to collect disability data – both identifier and qualitative information on individual needs - as part of routinely collected data. More frequent survey data could support better understanding and enable data on disabled people to be reflected in policy development.

Indigenous data sovereignty and governance should be incorporated into the improvement of disability data, including infrastructure, quality, collection, protection, analysis and communication.

Conclusion

The research reviewed in this report has shown that specific groups of disabled people are at risk across the cancer continuum, particularly in screening, diagnosis and treatment. Although there was a lack of literature on other parts of the continuum, – it is likely that many other touch points would benefit from targeted action, such as cancer prevention.

Literature suggests that addressing inequities for disabled people requires a multifaceted approach at all levels of the health system. Research identifies specific accommodations necessary to support equitable access to health care and outcomes for disabled individuals. Although there is limited cancer-specific research on opportunities for system-level change, findings indicate the importance of including disabled people in the co-design of services to facilitate change. Additionally, research notes the relevance of considering intersectionality when designing and delivering health care services.

Next steps

We expect the findings of this literature review will support action under several government priorities and plans. It also highlights areas for further research, which will guide action to support disabled people in accessing appropriate care within the cancer and wider health sector.

The Agency will work with health entities and the disability sector to build a shared understanding of inequities in cancer outcomes for disabled people and their whānau, and to identify changes required to improve cancer outcomes for disabled people – and in particular tāngata whaikaha Māori.

Introduction
He kupu whakataki

Cancer is the leading cause of death globally (Union for International Cancer Control 2020). In Aotearoa New Zealand, each year around 26,000 people are diagnosed with cancer and approximately 9,000 New Zealanders die of cancer (Te Aho o Te Kahu – Cancer Control Agency 2021). Over the past 20 years survival has improved to the extent that more people than ever before are surviving their cancer, but our improvements have not been as rapid as other developed countries (Te Aho o Te Kahu – Cancer Control Agency 2021).

In 2021, the Agency identified a lack of research on cancer incidence and cancer outcomes for disabled New Zealanders (Te Aho o Te Kahu – Cancer Control Agency 2021). This population group is a key focus for the Agency. In 2023, 17% of New Zealanders – and 24% of Māori – reported as disabled in the Stats NZ Household Disability Survey (Stats NZ 2023).

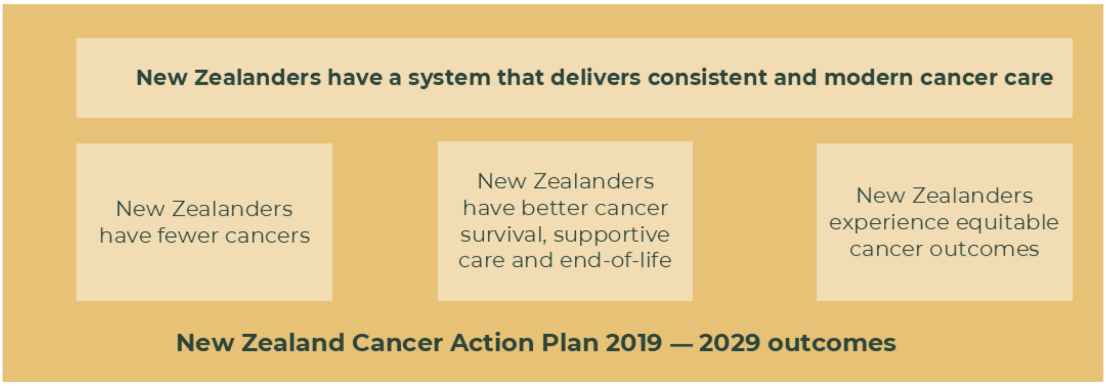
Internationally, disabled people have overall poorer health and wellbeing outcomes and die earlier than non-disabled people (World Health Organization 2011). In Aotearoa New Zealand, disabled people use health services at least twice as much as the non-disabled population (Health and Disability System Review 2020) and consider themselves overall to be in poorer health compared with non-disabled people (Minister of Health 2023a). Cumulative layers of disadvantage, often referred to as ‘intersectionality’, have been shown to disproportionately impact health outcomes for disabled people (Edwards et al 2020; Hughes et al 2022).

This report summarises local and international literature relating to disabled people with cancer. It aims to help the wider health sector better understand the factors that impact disabled people when accessing and navigating the cancer care system. It also aims to highlight ways to mitigate barriers for disabled people so that evidence-based approaches can be incorporated into policy and practice.

The role of the Agency

The Agency was established in 2019 to lead and unite efforts to deliver better cancer outcomes for Aotearoa New Zealand. It is guided by the goals and outcomes in the New Zealand Cancer Action Plan 2019–2029 (Ministry of Health 2019a), as outlined in Figure 1.

Figure 1: Outcomes of the New Zealand Cancer Action Plan 2019–2029



New Zealanders have a system that delivers consistent and modern cancer care

New Zealanders have fewer cancers

New Zealanders have better cancer survival, supportive care and end-of-life

New Zealanders experience equitable cancer outcomes

New Zealand Cancer Action Plan 2019 — 2029 outcomes

Improving what we know about the experience of key population groups across their cancer journeys is a critical step towards achieving these goals.

This literature review is part of the Agency’s Disability and Cancer Project, which also includes:

- data analysis on the burden of cancer among disabled people
- an internal kaimahi (staff) disability responsiveness programme.

The Disability and Cancer Project team included three disabled people with lived experience of cancer. The experiences represented through our Lived Experience Advisors included wāhine Māori, migrant/refugee, under 25, over 65, rainbow, and a range of cancers. While our Lived Experience Advisors’ perspectives were diverse, we also recognise that each disabled person’s experience is unique. We have consulted with subject matter experts across the health sector in the development of this report and to progress the Disability and Cancer Project.

Appendix A provides a glossary of terms used this report.

Māori health and Te Tiriti o Waitangi

The Agency has identified tāngata whaikaha Māori as a high-need population group for a number of reasons. Māori have been reported as disabled at the highest proportion (age adjusted at 24%) compared with Pacific peoples (21%), European New Zealanders (18%), and Asian New Zealanders (13%) (Stats NZ 2023).

The Pae Ora (Healthy Futures) Act 2022 requires the Agency to focus on achieving equity in health outcomes. The Act specifically requires us to:

- be guided by the health sector principles which, among other things, are aimed at improving the health sector for Māori and improving hauora Māori health outcomes
- maintain systems and processes to ensure we have the capacity and capability to understand Te Tiriti o Waitangi, mātauranga Māori and Māori perspectives of services.

In this context, the Disability and Cancer Project has been guided by the principles of Te Tiriti o Waitangi as set out in the Pae Ora (Healthy Futures) Act 2022, informed by the *Hauora: Report on stage one of the health services and outcomes kaupapa inquiry* (Waitangi Tribunal 2023) (see Appendix B for details). This report provides a valuable Te Tiriti-based analysis of the primary health care system and offers recommendations intended to improve Māori health outcomes relevant to the wider health and disability system. To support ongoing improvements, this literature review highlights evidence relating to tāngata whaikaha Māori. It also notes the evidence gaps and provides some suggestions for further research and system change.

As noted earlier, the Disability and Cancer Project also includes a data analysis on the burden of cancer among disabled people in New Zealand. This second report, He taumaha te mate pukupuku ki ngā tāngata whaikaha: Ngā kitenga – The burden of cancer among disabled people: Diagnosis insights, highlights outcomes for all disabled people with cancer and tāngata whaikaha Māori with cancer.

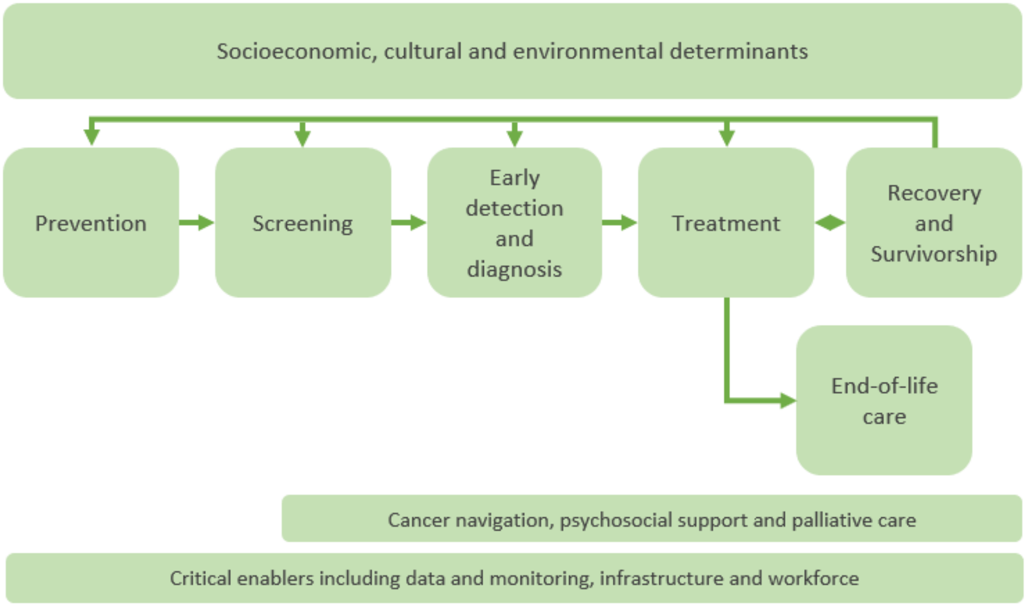
Background
Kōrero o mua

Inequities and the cancer continuum

The cancer continuum is one way to represent the cancer journey (Figure 2). Inequities occur across the cancer continuum, from prevention and the broader determinants of health to cancer screening and treatment and the critical enablers of health services (Sarfati 2019).

Māori, Pacific peoples and other communities experience inequities in the incidence and outcomes of cancer (Te Aho o Te Kahu – Cancer Control Agency 2022). Māori experience inequities in diagnosis of a number of cancers, including breast, liver, lung, pancreatic, stomach and uterine cancers (Te Aho o Te Kahu – Cancer Control Agency 2022). Other groups who experience inequities in cancer incidence and outcomes include Pacific peoples, Asian people, people living rurally, and migrants and refugees (Te Aho o Te Kahu – Cancer Control Agency 2022; Teng et al 2016).

Figure 2: The cancer continuum



This section highlights key touch points along the cancer continuum and gives selected examples of where inequities may arise for certain population groups. This provides context to the literature and evidence reviewed on disabled people and cancer throughout the rest of the report.

Cancer prevention and the determinants of health

As outlined in *Pūrongo Ārai Mate Pukupuku – Cancer Prevention Report* (Te Aho o Te Kahu – Cancer Control Agency 2022), up to half of cancers globally are preventable by reducing exposure to cancer risk factors present in our environments. Modifiable risk factors include tobacco use, alcohol use, poor nutrition, physical inactivity, excess body weight, excessive ultraviolet radiation, workplace carcinogen exposure and chronic infections such as hepatitis B and C viruses. Of note, some risk factors are not modifiable, such as an increased risk of some types of leukaemia for those with Down syndrome.

Some risk factors may impact disabled people more than the general population. For example, disabled people are 1.76 times as likely to be daily smokers compared with non-disabled adults, with 10.2% of disabled people being daily smokers, compared with 6.9% of the total population (Ministry of Health 2024). Smoking is a major cause of lung cancer and cancers of the head and neck in addition to other cancers.

Although reducing exposure to cancer risk factors often may be perceived to involve a level of choice, people are heavily influenced by a range of environmental factors. The environments in which people live, work and play determine many things, such as whether healthy food options are available or whether healthy housing is affordable. In turn, these conditions are determined by wider social, economic, cultural and political factors.

There are many examples of inequities in the determinants of health for disabled people. In education, almost 27% of disabled people aged 16–39 have no school qualification compared with

12% in the general population (Stats NZ 2014, 2015). Further, there is a 56% employment rate for disabled people aged 15–64 compared with 82% in the general population (Stats NZ 2023). Disabled people reported having not enough or only just had enough income to meet basic needs – 53% compared with 33% of the non-disabled population (Stats NZ 2023). Disabled people have also reported having less access to emotional and instrumental support from others, and lower levels of trust in other people and in public institutions (Stats NZ 2018a).

Discrimination is recognised by the World Health Organization (2025c) as a social determinant of health equity. For disabled people, this can be observed in acts of ableism and disablism (Ingham et al 2022). On average, disabled people are more likely to experience discrimination than non-disabled people (Stats NZ 2018a). In addition, Māori are overall 10 times more likely to experience multiple types of discrimination compared with non-Māori (Harris et al 2006). Perry et al (2020) describe the additive effect of discrimination for those who identify as both Māori and disabled. Māori and tāngata whaikaha Māori health outcomes are negatively impacted by this discrimination, highlighting the impact of colonisation and the socio-political and economic environments that sit under this influence (King

2019; Reid et al 2019; Te Aho o Te Kahu – Cancer Control Agency 2021).

Cancer screening and diagnosis

For some population groups, cancer diagnosis can be more likely to be delayed than for others. This can be due to differences in ability to access health care. Higher rates of diagnosis of chronic conditions for Māori and Pacific peoples (including cancer) in emergency departments may suggest barriers exist to accessing primary care (Beatty et al 2009; Lawrenson and Blackmore 2021; Sheridan et al 2024). In addition, Māori with lived experience of disability have a higher proportion of unmet need compared with non-Māori regarding accessing a health professional (21.9% compared with 15.5%; King 2019). Other factors may include differential access to testing in primary care or access to cancer screening.

There are three cancer screening programmes in Aotearoa New Zealand:

- **Cervical screening** uses a test for human papillomavirus (HPV) for women aged 25–69 that can be done by self-testing[3] usually at 5-year intervals.[4]
- **Breast screening** involves mammograms for women aged 45–69 every two years.

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[3] Prior to September 2023, liquid-based cytology was the primary method, without a self-test option.

[4] The other key intervention in the prevention of cervical cancer is the HPV vaccination.

- **Bowel screening** requires a stool test (faecal immunochemical test or FIT) and is currently offered every two years to those aged 60–74.

An extension in the age category for bowel screening to include those aged 58–59 has been recently announced (Health New Zealand – Te Whatu Ora 2025a).

There are inequities within screening programmes (Te Aho o Te Kahu – Cancer Control Agency 2021; Health New Zealand 2022) that are contributed to by barriers that affect some groups more than others. Examples include cost barriers or ability to travel to locations where screening is offered (Carroll et al 2023; Gurney et al 2019; Te Aho o Te Kahu – Cancer Control Agency 2021).

Cancer treatment and support services

Cancer services encompass cancer specialist care, as well as cancer navigation, allied health, ongoing primary care, and psychosocial support. Palliative care and end-of-life care are also a part of these services, alongside specialist palliative care. Cancer treatment can include surgery, radiation therapy, and systemic anti-cancer therapies (such as chemotherapy). Other critical parts of the health system include data and monitoring, workforce sustainability and infrastructure.

Inequities within cancer services could stem from differences in quality of care received, less timely access to treatment, and differences in impact of barriers such as health care facility accessibility, clinician attitudes, communication from secondary services or availability of health services near where a person lives (Gurney et al 2019; Kidd et al 2021; Te Aho o Te Kahu – Cancer Control Agency 2021).

Key population insights

Cumulative layers of disadvantage – often referred to as ‘intersectionality’ – are shown to disproportionately impact health outcomes for disabled people (Edwards et al 2020; Hughes et al 2022). Therefore, it is important to understand the health status of key population groups.
Although not intending to be exhaustive, Appendix C gives an overview of the health status and inequities for seven groups within the disabled community:

- tāngata whaikaha Māori
- Pacific peoples with disabilities
- disabled women
- disabled people who live rurally
- disabled members of Rainbow communities
- disabled older people
- disabled migrants and refugees.

These groups are not always discrete, meaning some people may sit within many of these groups (eg, tāngata whaikaha Māori who live rurally).

Disability

There are different ways of thinking about disability. These ways of thinking, the values that underpin them and the presumptions that flow from them are described in various models of disability, which in turn can inform how society and governments perceive, and seek to assist, disabled people.

Understandings of disability, globally and in Aotearoa New Zealand, have developed over time. They also remain contested by different communities. Below is a summary of some early and contemporary models of disability drawn from Western society followed by non-Western perspectives important in Aotearoa New Zealand.

Early models of disability

Early definitions/models of disability influenced how disability was thought about and responded to historically in Western societies. While these models remain in use in some communities, they are not relied upon in academia, or by governments when designing public policy or services.

The **religious model** viewed disability as an act of God, usually a punishment for some sin committed by the disabled individual or their family. In this model, disability is seen as punitive or tragic in nature. The **tragedy or charity model** framed disabled people as victims of circumstance who deserve pity. In this context, the culture of ‘care’ has threatened the autonomy and agency of disabled people by medically classifying, segregating and institutionalising disabled people.

Contemporary models of disability

The **medical model** sees disability as a medical problem with a person’s body or mind. Under the medical model, the solution to disability is fixing, correcting, treating or curing the problem through medical intervention.

In contrast, the **social model** sees disability as the result of interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. Under the social model, the solution to disability is identifying and removing the social barriers to inclusion and participation for disabled people.

The **human rights model** recognises disabled people are a rich part of the diverse fabric of humanity. Discrimination against disabled people creates barriers that exclude their full participation in society. The solution is to treat disabled people in a fair and equitable way. There are also important ways of thinking about disability that can be found in **Indigenous world views**. Te ao Māori and Pacific perspectives are touched on in the following section.

The **biopsychosocial model** sees disability as neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors, and can occur at three levels:

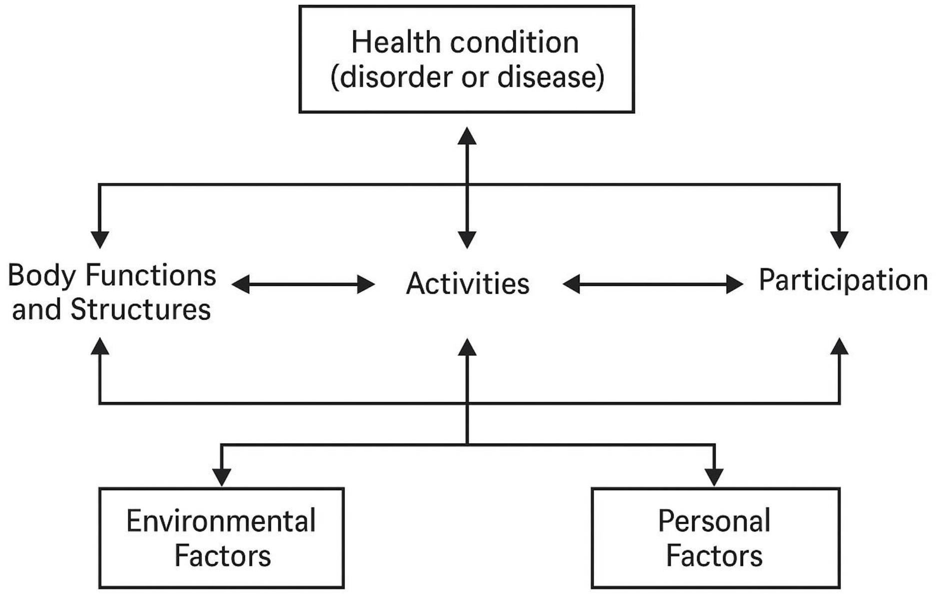
- an impairment in body function or structure, such as a cataract that prevents the passage of light and sensing of form, shape and size of visual stimuli
- a limitation in activity, such as the inability to read or move around
- a restriction in participation, such as exclusion from school.

The biopsychosocial model incorporates the medical and social models of disability and is based on the **International Classification of Functioning, Disability and Health (ICF)**, which is a framework used by the World Health Organization (2025b) to support consistent and comparable measurement of disability. The ICF considers disability as an umbrella term for impairments of body systems, activity limitations and participation restrictions.

As outlined in Figure 3, the ICF brings together the relational elements of health, components of function, and context (environmental and personal factors). It integrates aspects of the social, medical and human rights models of disability. There is general support for the ICF as described by Kostanjsek (2011) because it anchors the concept of disability largely in the sociocultural aspect of our lives rather than purely attributing it to the individual.

Figure 3: Interactions between the components of the International Classification of Functioning, Disability and Health (ICF)

A flow cahrt



Source: Kostanjsek (2011)

This approach and the human rights approach are consistent with the understanding of disability embodied in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Aotearoa New Zealand ratified in 2008 (United Nations 2006). The UNCRPD definition of disability states that ‘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’ (United Nations 2006, Article 1).

In Aotearoa New Zealand our understanding of, and approaches to, disability are still evolving. There is still a lot of debate on the relevance of models of disability. For example, the medical model is critiqued for its limited scope for considering the full spectrum of issues related to living with disability, placing the focus on the individual and the care they receive. Conversely, criticisms of the social model are that its focus on the social causes of disability de-emphasises the person’s impairment.

Many disabled people live with impairments or conditions that may require significant medical care and input as well as disability support. Thus, to support the co-existing health, disability and cultural needs of disabled people, approaches that integrate the strengths of multiple models are often required.

Disability in Aotearoa New Zealand

> ‘Disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments, this is the thing all disabled people have in common. It is something that happens when the world we live in has been designed by people who assume that everyone is the same.’
> (Office for Disability Issues – Te Tarī Mō Ngā Take Hauātanga 2016, p12)

Disability is not uniformly defined in Aotearoa New Zealand. The predominant view of disability in Aotearoa New Zealand remains grounded in a Western individualised context that does not reflect culturally based collective/holistic models of health and wellbeing found in many Indigenous cultures, including in Aotearoa New Zealand (King 2019). Some te ao Māori perspectives and themes from Pacific peoples’ perspectives on disability are summarised here.

Te ao Māori perspectives

Many tāngata whaikaha Māori identify as Māori first (Shivas 2022; Whaikaha – Ministry of Disabled People 2023). Therefore, cultural identity is central to how tāngata whaikaha Māori move through both te ao Māori (the Māori world) and te ao Pākehā (the Western world). Cultural identity incorporates language, tikanga (customary system of values and practices), whānau (family), and a whānau-centred approach, which can differ from traditional Western concepts of family and disability (Office for Disability Issues – Te Tarī Mō Ngā Take Hauātanga 2016).

The term ‘disability’ was introduced to Māori through early European colonisation. The introduced concept was characterised by deficit framing of disability as a ‘curse’ or ‘abnormality’ that needed fixing and was at odds with traditional (albeit diverse) Māori concepts of disability, in which historically Māori valued the abilities and strengths of tāngata whaikaha Māori as a gift or tohu (sign) of significance and importance to iwi/hapū (Hickey and Wilson 2017; Jones et al 2023).

In an article for *Altogether Autism Journal*, Tūraukawa Bartlett (Ngāti Whātua Ōrākei) speaks about being an autistic father of an autistic child:

> ‘He Māori ahau, he tangata whai takiwātanga ahau, he kaitiaki au mō taku tamati, he taonga ia, he taonga te takiwātanga i waiho ai e ngā tūpuna ki a tātou. Mauri Ora!
> I am Māori, I have autism, I am a father of a child with autism, and they are precious gifts left to us by our ancestors.’
>
> (Bartlett 2019, p5).

Two Māori phrases are now commonly used to describe disabled people. The term ‘tāngata whaikaha Māori’ is used to describe two or more Māori people with a disability. It was coined by the late Maaka Tibble MZNM (Ngāti Porou) and designed to move away from Western deficit framing of disability:

> ‘Tāngata whaikaha means people who are determined to do well, or is certainly a goal that they reach for. It fits nicely with the goals and aims of people with disabilities who are determined in some way to do well and create opportunities for themselves as opposed to being labelled, as in the past.’
>
> (Maaka Tibble, as quoted in Ministry of Health 2018a, p4)

Whānau Hauā is a model presented by Hickey and Wilson (2017) to describe an alternative Indigenous approach to disability. The term was gifted by Donny Rangiahau (Tūhoe) to Te Roopu

Waiora (an Auckland Māori disability agency) – the word ‘hau’ meaning wind and ‘ā’ referring to ‘the drive or urge that propels this wind’ (Hickey and Wilson 2017). The model itself is aligned[5] to the social and human rights models of disability. It also adds a cultural dimension that is inclusive of collective responsibility and acknowledges the environment of change and systemic barriers.

Pacific perspectives

There are diverse Pacific cultures in Aotearoa New Zealand that hold diverse perspectives on disability. As for the general population, these perspectives continue to evolve.

Many Pacific peoples highly value collectivism, connection with culture, and the importance of family and community. Disability can therefore be understood from a social model perspective – as an effect of living and/or interacting with the individualistic Western system that differs from this (Ministry of Health 2008).

Like the general population, many Pacific people understand disability from a biomedical perspective, where a disabled person is someone

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[5] An important distinction here is that ‘aligned to’ does not mean ‘the same as’. Neither the social model nor the human rights model has been based on or explicitly include Indigenous world views or perspectives (Jones 2023).

with a physical, sensory or intellectual impairment. In addition, some may attribute the reason the person came to be disabled to religious or cultural reasons, which may differ from typical medical explanation (Ministry of Health 2008).

In Aotearoa New Zealand, the Samoan term ‘tagata sa‘ilimalo’ refers to people in pursuit of success and is sometimes used to describe disabled Pacific peoples, their families, and carers (Tōfā Mamao 2022).

Defining disability for data purposes

The New Zealand Disability Strategy 2016–2026 (currently being refreshed) recognises that disabled people are often not counted, recognised or understood, and when they are, their needs are often not responded to (Donald Beasley Institute 2023; Office for Disability Issues – Te Tarī Mō Ngā Take Hauātanga 2016).

Research shows that accurate, appropriate and consistent collection of disability data to understand inequities and to inform policy and service design. Collecting high-quality disability data requires careful consideration of the complex, multifaceted nature of disability. When we discuss methods of ‘counting’, it can seem that a population is easily divided into disabled and non-disabled groups. However, all people have different functional abilities, and how they are defined as ‘disabled’ depends on context (Abualghaib et al 2019; Mont 2019).

The choice and method of categorisation for data purposes depends on what the information is intended for. Many of the studies cited in this report use categorisations of disability based on a medical model to create data and statistical comparisons – however, for other purposes it is more appropriate to ask individuals to self-identify (Dirth and Branscombe 2018; Nario-Redmond et al 2012).

To address this, the Washington Group Short Set (WGSS) has been integrated into censuses and national surveys, allowing for a more comprehensive and nuanced understanding of disability across the population. The WGSS is a brief questionnaire designed to identify individuals with difficulties in basic activities leading to restriction in social participation. This measure is not as comprehensive or accurate as some disability surveys but represents a credible alternative where access to more detailed data is not possible (Office for Disability Issues – Te Tarī Mō Ngā Take Hauātanga 2021; Stats NZ 2017; Webber et al 2022).

Currently, national health administrative data links a person’s health information together at both an individual and population level, and can be disaggregated by demographics such as age, gender, ethnicity and deprivation. However, national administrative data are do not consistently identify disability status, which limits the health system's understanding of health inequities for disabled people at a population level. The health system is progressing key data work to improve information about disabled people, including identifying disability status in administrative data and recording disabled people's reasonable accommodation requirements for accessing health services.

In addition to challenges in disability data, we also know that Māori have been systematically undercounted in health and disability data (Cormack and McLeod 2010; Harris et al 2022; Reid et al 2016; Te Aka Whai Ora 2023). There is a similar issue of under-representation of Pacific peoples in population estimates (Sonder et al 2024). This undercounting is likely to impact tāngata whaikaha Māori and disabled Pacific peoples – for example, by limiting the ability to accurately monitor health status and plan required health services.

Aotearoa New Zealand disability policy

Aotearoa New Zealand's disability policy is shaped by obligations to international rights-based conventions, such as the UNCRPD, and national documents such as the Human Rights Act 1993, Te Tiriti o Waitangi and the Pae Ora (Healthy Futures) Act 2022.

A health system consistent with a human rights approach ensures everyone has the same rights to accessing health care and receiving treatment. This means health care that is accessible, inclusive and equitable. This is an important focus because we know from recent health system reviews this has not been the experience of our health system for disabled people.

The 2020 Health and Disability System Review found that the system did not adequately serve disabled people. The review identified several areas for improvement, including:

- **Accessibility:** The health system should be accessible to disabled people and their families.
- **Involvement:** Disabled people should be involved in the design of services and the system.
- **Workforce:** The health workforce should be inclusive and culturally safe.

- **Data:** The health system should have a robust database that identifies the accessibility needs of disabled people and tailors support accordingly.
- **Partnership:** The review recognised the importance of true partnership with Māori and leadership by disabled people (Health and Disability System Review 2020).

The following strategic documents are key vehicles that give effect to the rights and protections afforded to disabled people in a health context:

- The **New Zealand Disability Strategy 2016–2026** is the cornerstone of the wider disability system across government. Outcome 3 (Health) directs the Ministry of Health and other key health entities to deliver improved health outcomes for disabled people. It outlines that access to mainstream health services should be barrier-free and inclusive, and services that are specific to disabled people should be high quality, available and accessible (Office for Disability Issues – Te Tarī Mō Ngā Take Hauātanga 2016). The refreshed New Zealand Disability Strategy is likely to strengthen accountability for achieving results across all outcome areas, including health, for disabled people.
- Section 44 of the **Pae Ora (Healthy Futures) Act 2022** legally authorises the requirement for a Health of Disabled People Strategy.
- The **New Zealand Health Strategy 2023** sets the direction for improving the health of all New Zealanders. The strategy highlights the need for the

health system to be more responsive to disabled communities (Minister of Health 2023).
- The **Health of Disabled People Strategy 2023** informs the direction and long-term priorities for the new health system to move towards achieving equity in disabled people's health and wellbeing outcomes (Minister of Health 2023a).

The current **New Zealand Health Plan – Te Pae Waenga** recognises the need to address how our health system approaches and understands disability and includes actions on improving data collection, incorporating consumer and whānau voice, and designing and implementing the disability model of care (Health New Zealand – Te Whatu Ora 2025b).

Pae Tu – Hauora Māori Strategy 2023 supports the health system to uphold Te Tiriti o Waitangi and improve equity and long-term health outcomes for whānau Māori (Minister of Health 2023c). An updated strategy is due to be released in 2025.

The **Government Policy Statement on Health 2024–2027** sets out the Government's priorities for health and the health system (Minister of Health 2024).

The Agency applies a Te Tiriti o Waitangi informed, mixed model approach to disability that broadly aligns with the strategy documents above. This approach draws on, and at times integrates the strengths of, current models, including Aotearoa New Zealand Indigenous, human rights, social and biopsychosocial models.

Disabled people and cancer literature review
Ngā tāngata whaikaha me te mate pukupuku me te arotakenga mātātuhi

Approach and scope of literature review

Within this literature review we sought to answer the following questions:

What do we know about the incidence of cancer, the experience of the cancer journey and the cancer outcomes for disabled people in Aotearoa New Zealand?

What does the international research tell us?

A keyword search of peer-reviewed journal articles, government reports, and grey literature was performed in the Medline, Scopus, Embase, PubMed, Google Scholar and Europe PMC databases, as well as in the Analysis & Policy Observatory (APO) and King's Fund grey literature databases. Further detail is provided in Appendix D.

It was beyond the scope of this report to address the following specific areas of interest:

People who are disabled because of, or following, their cancer
This is a consideration for future research, but our current focus is on understanding the end-to-end experience of people who were disabled before their cancer diagnosis.

Disabled children with cancer
For this foundation piece we have chosen to focus on adults with cancer. We acknowledge the importance of adding to the knowledge base for disabled children experiencing cancer, and this may be an area of focus in the future.

Disabled people's exposure to cancer risk factors such as tobacco use, alcohol use, excessive ultraviolet radiation, poor nutrition and physical inactivity
While this report does comment on the contribution of risk factors to the development of cancer for disabled people, a detailed review of the literature on the broader aspects of cancer prevention and risk has not been included.

Disabled adults supporting people, including children, who develop cancer

Incidence of specific cancer types associated with specific genetic and developmental

conditions are not captured in this literature review, however it is assumed that a number of studies included will incorporate people who develop a cancer that is associated with their impairment or difficulty.

Mental wellbeing

While mental wellbeing is out of scope of this report, we acknowledge the link and overlap with disability, and this may be an area of focus in the future.

While this report aimed to capture research from both Aotearoa Zealand and international sources, we found primarily international peer-reviewed literature. Where research is from Aotearoa New Zealand, this is noted.

We acknowledge this report will raise additional areas of interest, highlighting future research opportunities. We also anticipate that findings from this work will inform system-, organisation- and individual-level changes that could benefit a wider group of disabled people than those included in this literature review.

Terminology in this section

The way words are used and how information is presented can shape the perceptions and attitudes of a reader. Language shapes culture and is used to influence how we think about people and situations. This is evident in the evolution of language used to describe disabled people within different models of disability.

Some of the studies included in this literature review draw from a medical model of disability, rather than the social or human rights models. This is most noticeably reflected in the language used in studies that have been reviewed. We acknowledge the tension between language used to describe disability in different settings – that is, in research, in government policy, and in the disabled community. In this report we have therefore chosen to replace two terms that are not preferred by the disabled community in Aotearoa New Zealand: 'intellectual/developmental disability' and the word 'severe' relating to the impact of a person's impairment.

In most cases we use the term 'learning disability' in place of references to 'intellectual disability' or 'developmental disability'. While the latter terms are often used in medical studies, for the purposes of this review the term ‘learning disability’ is to be understood as inclusive of ‘intellectual disability’ and/or ‘developmental disability’, as set out in the glossary (Appendix A).

Several studies in this section use different ways of categorising impairments, often including a category called ‘severe’. The term ‘severe’ has a negative association, which is inconsistent with our approach. Where possible, we have replaced the word ‘severe’ with words such as ‘most significant category of impairment’. This issue is noted in the glossary (Appendix A) under the term ‘impairment’.

The definition of a ‘significant disability’ can vary depending on the categorisation being used. We suggest considering a significant disability as one that is most likely to affect a person’s ability to participate in daily activities like work, self-care and social interaction in a significant way. However, readers citing any references used here are encouraged to look up individual studies to consider the accuracy of replacement terms.

Cancer incidence, survival and mortality

What the literature tells us

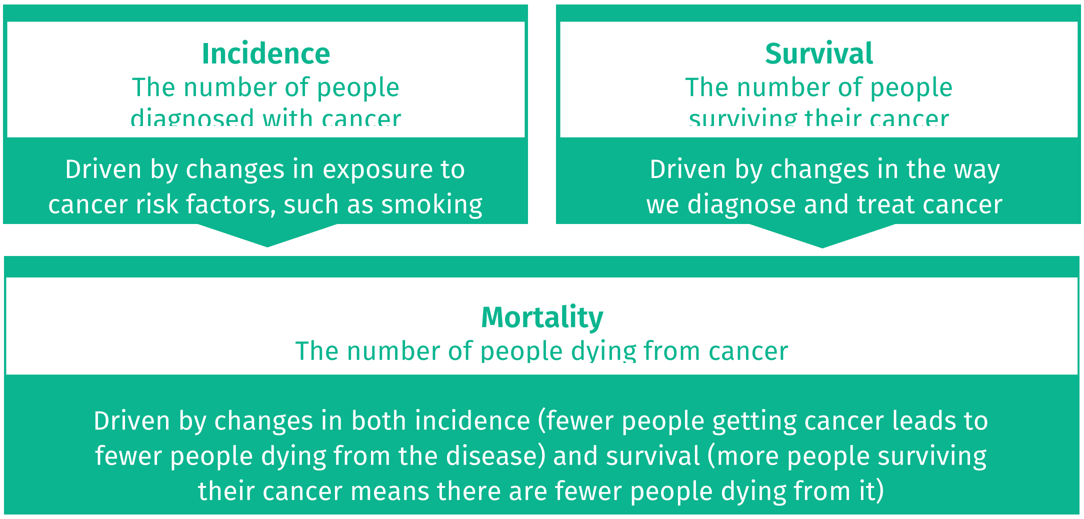
There is limited peer-reviewed literature on the cancer incidence, survival and mortality of disabled people as a population group.

While it is difficult to draw conclusions, the literature available indicates that when compared with non-disabled people, disabled people may be more likely to be diagnosed with some types of cancers and may have poorer survival from some types of cancer.

This section gives an overview of the literature we reviewed that discusses cancer incidence, mortality and survival for disabled people.

Cancer incidence, mortality and survival are different measures to help us understand the patterns of cancer. As outlined in He Pūrongo Mate Pukupuku o Aotearoa 2020 – The State of Cancer in New Zealand 2020 (Te Aho o Te Kahu – Cancer Control Agency 2021), these measures are interlinked but give us different information, as seen in Figure 4.

Figure 4: The relationship between cancer incidence, survival and mortality



Incidence
The number of people diagnosed with cancer

Driven by changes in exposure to cancer risk factors, such as smoking

Survival
The number of people surviving their cancer

Driven by changes in the way we diagnose and treat cancer

Mortality
The number of people dying from cancer

Driven by changes in both incidence (fewer people getting cancer leads to fewer people dying from the disease) and survival (more people surviving their cancer means there are fewer people dying from it)

Source: Te Aho o Te Kahu – Cancer Control Agency (2021)

International

Incidence and prevalence

There is little information available on cancer incidence and prevalence for disabled people. However, there is some indication that the prevalence of some types of cancer in disabled people is higher compared with non-disabled (Hughes et al 2022; Iezzoni 2022).

Iezzoni et al (2020) analysed national health survey data in the United States, focusing on the association between two categories of disability – movement difficulties and complex activity limitations[6] – and four cancer types: bowel

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[6] The categories in this study were derived from United States National Center for Health Statistics algorithms and are outlined further in the article.

cancer, non-Hodgkin lymphoma, prostate cancer and ovarian cancer. The study found that disabled people had higher proportions of self-reported diagnosis of all four cancer types. This is likely to be at least in part explained by higher exposure to risk factors for cancer, for example age, smoking and socioeconomic status. However, for some cancers, these differences remained after adjusting for age, ethnicity, education, body mass index, income, smoking and health insurance. The analysis found that those with movement difficulties and complex activity limitations were more likely to have a diagnosis of bowel cancer compared with non-disabled (adjusted odds ratio (aOR) 1.5; 95% confidence interval (CI) 1.2–1.9 and aOR 1.9; 95% CI 1.5–2.4, respectively. People with complex activity limitations were also more likely to have a diagnosis of non-Hodgkin lymphoma (aOR 1.5; 95% CI 1.1–2.1). They did not find similar associations for prostate and ovarian cancers. The authors note that there is no clear explanation for this finding, and it highlights the importance of vigilance in diagnosis and screening for disabled people.

Iezzoni and colleagues also looked at United States national health survey data specifically relating to breast and cervical cancer diagnosis (Iezzoni, Rao, Agaronnik, et al 2021). They found that 3.5% of people with pre-existing movement disorder and 3.6% with complex activity limitation had a diagnosis of breast cancer compared with 2.2% for non-disabled people. They also found that 0.8% of people with movement disorder and 1% with complex activity limitation had a diagnosis of cervical cancer, compared with 0.6% for non-disabled people. They found that disabled people had lower screening rates and so they then adjusted for screening status as well as similar variables as in the previous study. They found that people with complex activity limitations were more likely to have had a diagnosis of breast cancer (aOR 1.21; 95% CI 1.01–1.46) and cervical cancer (aOR 1.43; 95% CI 1.04–1.99) compared with non-disabled people. The differences were not statistically significant for people with movement difficulties.

Kwon et al (2020) used Korean national databases to analyse the association between disability and multiple myeloma diagnosis. In contrast to the above reports, they found that disabled people had a lower rate of diagnosis (29.1 per 100,000) compared with non-disabled people (39.4 per 100,000). The authors discuss the possible contribution of underdiagnosis in the disabled population. They noted that disabled people diagnosed with multiple myeloma were more likely to have renal failure sooner after diagnosis which is associated with later stage disease.

Mortality

Some research shows that disabled people with cancer are more likely to die from cancer compared with those without a disability (Hughes et al 2022; Iezzoni 2022). However, few mortality-related studies have been conducted.

For cancer overall, Cuypers et al (2022) compared cancer-related mortality patterns between Dutch people with and without a learning disability and found that cancer was noted as the cause of death approximately 1.5 times more often among people with a learning disability in comparison with the general population.

Some studies looked at mortality for specific types of cancer. Shin et al (2021) carried out a retrospective cohort study in South Korea using disability registration data linked to Korean National Health Insurance and national cancer registry data. While the authors found that overall mortality was significantly higher in disabled people than in non-disabled people (adjusted hazard ratio (aHR) 1.20; 95% CI 1.15–1.25), prostate cancer specific mortality was only slightly higher in disabled people (aHR 1.11; 95% CI 1.04–1.18).

Choi et al (2021) performed a retrospective cohort study using Korean registry and administrative data and found that disabled people with cervical cancer had higher overall mortality compared with non-disabled people (aHR 1.36; 95% CI 1.25–1.48). This difference was more pronounced for disabled people with the most significant category of disability (aHR 1.72; 95% CI 1.52–1.95). Similarly, Kim et al (2020) demonstrated that disabled people with gastric cancer had a higher mortality risk compared with non-disabled people. Research also indicates that disabled people are more likely to die from breast cancer than non-disabled people (Iezzoni et al 2008; McCarthy et al 2006; Satgé et al 2014).

Survival

Data relating to survival, as for incidence and mortality, was sparse in the literature examined in this review. However, there were several studies that found disabled people had poorer survival compared with non-disabled people.

Shin et al (2019) and Kwon et al (2020) both demonstrated that disabled people had lower survival rates compared with non-disabled people for different cancer types (lung cancer and multiple myeloma, respectively).

A recent Canadian study by Hansford et al (2024) found that people with learning disabilities had poorer survival from breast, bowel and lung cancers.

For those with breast cancer, five-year survival for people with a learning disability was 61.5%, compared with 81.7% for people without a learning disability.

For those with bowel cancer, five-year survival for people with a learning disability was 34.2%, compared with 56.6% for people without a learning disability.

For those with lung cancer, five-year survival for people with a learning disability was 11.9%, compared with 19.7% for those without a learning disability.

Aotearoa New Zealand

This review did not identify any published data on cancer mortality or survival among disabled people in Aotearoa New Zealand. However, there is some information on cancer diagnosis.

The *Māori Health Disability Statistical Report* (Ministry of Health 2019b) linked data from the

2013 Adult Disability Survey to the Ministry of Health cancer registration dataset, chronic condition dataset, and public hospital discharge dataset.

The report showed that after age standardisation, tāngata whaikaha Māori had an approximately 1.47 times higher likelihood of having a cancer diagnosis of any type compared with disabled non-Māori (rate ratio (RR) 1.47; 95% CI 1.08–2.01). Additionally, the analysis specifically reported breast cancer, finding that tāngata whaikaha Māori women were more than twice as likely as disabled non-Māori females to have a diagnosis of this cancer type (RR 2.22; 95% CI 1.12–4.39).

The 2023 IHC report titled *From Data to Dignity: Health and Wellbeing Indicators for New Zealanders with Intellectual Disability*[7] performed an estimate of cancer prevalence by identifying people who were entered into the New Zealand Cancer Registry and those who received specialist cancer care or treatment from 2016 to 2018. The report found that those with an intellectual disability had an age-standardised rate of 4.33 (95% CI 4.08–4.58) compared with

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[7] IHC New Zealand uses the term 'intellectual disability'. The term 'intellectual disability' has not been replaced with 'learning disability' here because it is central to how the publishing organisation identifies.

those with no intellectual disability at 4.04 (95% CI 4.02–4.06). This resulted in a statistically significant rate ratio of 1.07 (Beltran-Castillon 2023).

Disparities

What the literature tells us

Disparities in cancer screening

The majority of cancer studies looking at disparities between disabled people and non-disabled people focus on screening.

Disabled people are screened at a lower rate than non-disabled people.

Screening rates appear to be even lower for disabled Indigenous populations.

People with learning disabilities are screened at a lower rate than those without learning disabilities.

Disparities in cancer diagnosis and treatment

A small but growing number of studies have identified inequities in cancer diagnosis, treatment and service provision for disabled people.

There is evidence of later-stage diagnosis for disabled cancer patients, especially for those with significant disabilities.

Literature suggests that people with learning disabilities are more likely to be hospitalised, more likely to have prolonged stays, and less likely to receive curative treatment for some cancers, compared with people without learning disabilities.

This section presents the literature we reviewed in the following structure:

What were the disparities in cancer screening for disabled people?

- Overall screening disparities
- Breast screening
- Cervical screening
- Bowel screening

What were the disparities in cancer diagnosis for disabled people?

What were the disparities in cancer treatment for disabled people?

What were the disparities in cancer screening for disabled people?

The majority of studies on disparities for disabled people and cancer were related to cancer screening.

A growing body of literature indicates lower participation in cancer screening for disabled people, placing them at greater risk for delayed diagnosis and cancer-related mortality. There is evidence this affects a wide range of disabled people, including people with physical impairments (Sakellariou and Rotarou 2020), D/deaf people (Kushalnagar et al 2019) and people with learning disabilities (Osborn 2012; Stirling et al 2021).

In North America, the difference appears more pronounced among Indigenous groups with learning disabilities compared with non-Indigenous people with learning disabilities (Armin et al 2023; Williamson et al 2021).

In Aotearoa New Zealand there is no known screening data for tāngata whaikaha Māori as a group, but we do know that screening rates for Māori across available screening programmes are lower than rates for other[8] ethnicities (Health New Zealand – Te Whatu Ora 2024; National Screening Unit 2024a, 2024b).

More detailed research relating to cervical, breast and bowel screening is outlined below.

Cervical screening disparities

Disabled women have lower participation rates in cervical screening[9] compared with non-disabled women (Armour et al 2009; Chan et al 1999; Cheng et al 2001; Choi et al 2021; Drew and Short 2010; Iezzoni, Rao, Agaronnik, et al 2021; Ramirez et al 2005).

Shin et al (2018) reported that the age-standardised cervical screening rate of Korean women was 54.1% in non-disabled women and only 29.8% in disabled women with more significant impairment. Similarly, a report published on the use of cancer screening among US women looked at the ability to perform a

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[8] 'Other' is defined as non-Māori non-Pacific non-Asian for the National Cancer Screening Programme and the National Bowel Screening Programme, and non-Māori non-Pacific for Breast Screen Aotearoa.

[9] When discussing cervical screening, the studies referenced in this section refer to Papanicolaou (Pap) testing and/or liquid-based cytology (LBC screening). The accessibility of this testing method differs from that of HPV primary screening, which was adopted by the New Zealand National Cervical Screening Programme in late 2023. This may affect the applicability of these studies in the current New Zealand context.

number of activities[10] and found that women with limitations in these activities were significantly less likely to have received cervical screening within the preceding three years (Centers for Disease Control and Prevention 1998).

Several studies compared cervical screening uptake between adults with learning disabilities and those without (Brown et al 2016; Cobigo et al 2013; Havercamp et al 2004; Havercamp and Scott 2015; LP Lin et al 2010; Reynolds et al 2008; Xu et al 2017). All but one (LP Lin et al 2010) observed significantly lower participation among adults with learning disabilities.

Breast screening disparities

As with cervical screening, a number of studies show that disabled people have lower rates of breast screening compared with non-disabled people (Armour et al 2009; Clark et al 2009; Courtney-Long et al 2011; Gurney et al 2017; Iezzoni, Rao, Agaronnik, et al 2021; Sakellariou

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[10] The specific activities used for this study were as follows: lift 10 pounds, walk up 10 steps without resting, walk a quarter of a mile, stand for approximately 20 minutes, bend down from a standing position, reach up over the head or reach out, use fingers to grasp or handle something, and hold a pen or pencil.

and Rotarou 2019; Shin, Yu, et al 2020; Wei et al 2006; Weir et al 2011; Yankaskas et al 2010).

This research generally centred on women with complex physical impairments (Armour 2009). The Centers for Disease Control and Prevention reported that women 65 years old or older with three or more functional limitations[11] were less likely to have ever had mammograms than non-disabled women of a similar age (Centers for Disease Control and Prevention 1998). More recently, Shin, Yu et al (2020) utilised linked administrative datasets to explore the impact of disabilities on breast screening in South Korea, including adjustment for age, sex, income level and place of residence. The authors found that disability was associated with slightly lower breast screening rates (aOR 0.824; 95% CI 0.820–0.828). Breast screening rates were especially low in women with the most significant category of impairment and among women with autism, brain injury and learning disabilities.

Notably, a small number of studies have challenged the above findings (Andresen et al 2013; Diab and Johnson 2004; Liu and Clark 2008;

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[11] The specific activities used for this study were as follows: lift 10 pounds, walk up 10 steps without resting, walk a quarter of a mile, stand for approximately 20 minutes, bend down from a standing position, reach up over the head or reach out, use fingers to grasp or handle something, and hold a pen or pencil.

Steele et al 2017). For instance, a US national survey-based study by Ahmed et al (2009) found that women with more significant physical impairments were more likely to have mammograms than non-disabled women.

Several studies found that people with learning disabilities were less likely to have breast screening compared with those without learning disabilities (Cobigo et al 2013; Havercamp et al 2004; Havercamp and Scott 2015; Xu et al 2017). A study of people with learning disabilities in community group homes found that of surveyed women (*n* = 58), only 52% received an invitation to mammography, and 46% reported attending a mammography appointment (Davies and Duff 2001). Another study (Chicoine et al 2015) observed that 62% of eligible women with Down syndrome in a single institution (*n* = 684) received a mammogram, and the majority of those who did not have a mammogram did not have an explanation recorded detailing why it was not completed (Chicoine et al 2015).

Bowel screening disparities

Compared with breast and cervical screening studies, few studies have examined disability disparities for bowel screening (Merten et al

2015). Those studies that have compared bowel screening for disabled and non-disabled populations have produced inconsistent findings (Iezzoni et al 2020; Littman et al 2012; Wei et al 2006).

There was variation in the tests used for bowel screening across studies. Studies based in the United States commonly used either a stool test (faecal occult blood test or FOBT) or lower gastrointestinal (GI) endoscopy, such as flexible sigmoidoscopy.[12] This difference may impact on access to testing for disabled people. However, studies based in other countries only involved a stool test, which is aligned with Aotearoa New Zealand bowel screening practice. A newer stool test called the faecal immunochemical test (FIT) is now used in Aotearoa New Zealand, which has also been adopted by other countries to replace the FOBT. While the test differs in the laboratory process, the impact on this change to the person undergoing screening is minimal and therefore not likely to alter findings.

Of the studies that found lower bowel screening rates for disabled people compared with non-

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[12] These studies' definition of bowel cancer screening generally followed the United States Preventive Services Task Force recommendations (available at **www.uspreventiveservicestaskforce.org/uspstf/recommendation/colorectal-cancer-screening**).

disabled people, only one study included lower GI endoscopy as a screening method (Gofine et al 2018). The remaining studies included stool samples only, either FIT or FOBT (Floud et al 2017; Liao et al 2021; Ouellette-Kuntz et al 2015; Shin, Chang, et al 2020). Among these studies, one Canadian study found that the odds of having a FOBT in the previous two years were 32% lower for those with learning disabilities (Ouellette-Kuntz et al 2015). Floud et al (2017) found lower rates of FOBT for disabled people overall, with lower rates for those with self-care difficulties, physical impairment and vision impairment. Similarly, a Taiwanese study assessing screening for disabled people using the more up-to-date FIT found that disabled people were less likely to be screened compared with non-disabled people (OR 0.88; 95% CI 0.87–0.89; Liao et al 2021).

In contrast, there were also several studies that used lower GI endoscopy or a stool test that found roughly equivalent screening rates for disabled and non-disabled people (Diab and Johnston 2004; Iezzoni et al 2020; Littman et al 2012), aside from lower rates for more significantly disabled people in one study (Diab and Johnston 2004). Of note, one of these studies was in a war veteran population in the US, who are likely to have better access to health care than the general population overall (Littman et al 2012). In one study by Wei et al (2006), they found that disabled people were more likely to have screening compared with non-disabled people.

In general, studies also showed that those with more than one impairment (eg, difficulties with self-care, vision and mobility; Floud et al 2017) and those with more significant impairment (Diab and Johnston 2004; Gofine et al 2018; Shin, Chang, et al 2020) were even less likely to receive bowel screening.

What were the disparities in cancer diagnosis for disabled people?

We found few studies that compared stage at diagnosis for disabled people and non-disabled people. Of those, most found that disabled people are diagnosed at a later stage compared with non-disabled people.

Kim et al (2020) found that when compared with non-disabled patients with gastric cancer, disabled patients tended to be diagnosed at a later stage (localised stage 53.7% vs 59.0% or stage unknown 10.7% vs 6.9%), especially those with the most significant category of impairment (*P* < 0.001). Similarly, later stage at diagnosis for disabled people compared with non-disabled people has been seen in studies looking at lung cancer (Shin et al 2019) and cervical cancer (Choi et al 2021). Choi et al (2021) found that more significant communication and physical/brain disabilities were strongly associated with later stage of cancer at diagnosis for disabled people with cervical cancer.

Shin et al (2021) found that disabled people with prostate cancer did not have a later stage at diagnosis compared with non-disabled people. However, people with more significant impairment were more likely to be recorded with an unknown stage at diagnosis compared with non-disabled people, raising the possibility of later stage that had not been accurately measured or recorded.

What were the disparities in cancer treatment for disabled people?

A small but growing number of studies have identified inequities in cancer treatment and substandard experiences of service provision for disabled people (Bone et al 2014; Gibson and

O'Connor 2010; Iezzoni 2022; Iezzoni et al 2008; Sakellariou and Rotarou 2020).

Literature indicates that disabled people are less likely than non-disabled people to undergo treatment for cancer. Shin et al (2019) conducted a large retrospective cohort study in Korea and found that disabled lung cancer patients underwent fewer staging workups and fewer treatments compared with age-matched controls. Similarly, Choi et al (2021) found that disabled women with cervical cancer, especially those with severe disabilities, received less treatment than non-disabled women. Kwon et al (2020) reported that compared with non-disabled people, disabled people with multiple myeloma may be less likely to undergo autologous stem cell transplantation, although this difference did not reach statistical significance (37.5% vs. 43.7%, $p = 0.072$).

A study looking at early-stage breast cancer indicated that disabled women were less likely than other women to receive standard therapy[13] following breast-conserving surgery and experience higher mortality (McCarthy et al 2006). More recently, one study observed women with learning disabilities were more likely to

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[13] Standard therapy in this study referred to either radiation therapy or axillary lymph node dissection.

have a mastectomy instead of breast-conserving surgery (Shinden et al 2017). Similarly, Ansmann et al (2020) and Groß et al (2020) reported that women with physical disabilities were more likely to undergo mastectomy than breast-conserving therapy, even after accounting for differences in age and socioeconomic status. Acknowledging need for further research in this area, the authors speculate that reasons for these disparities likely include:

inequitable access to treatment options

preferences such as a desire for a briefer treatment process without radiation

individual difficulties such as limited transportation to clinics for radiation therapy

complex coexisting health conditions and other medical difficulties.

Shin et al (2021) used linked administrative data to determine if disparities exist in the treatment of disabled and non-disabled prostate cancer patients. They found a difference in treatment for prostate cancer according to the presence or absence of disability. Disabled people were less likely to undergo surgery than non-disabled people (33.1% compared with 38.6%, respectively). Further, disabled people were slightly more likely to receive androgen deprivation therapy (ADT) than non-disabled people (57.9% vs. 55.0%). People with more significant cognitive impairment, learning disability and neurodivergence were much less likely to undergo surgery and much more likely to receive ADT instead. The authors suggested the decreased likelihood of this group receiving curative surgery could stem from difficulties in obtaining informed consent and/or the perception that people with a disability might benefit less from curative treatment. They also acknowledged that overall, such inequities are likely driven by ableist views on the value of disabled people, including views held by health professionals.

Disparities specifically for those with learning disabilities have been noted. For instance, two studies have found that women with learning disabilities are admitted to hospitals more frequently and had longer hospital stays for cancers of the uterus, breast, cervix, ovaries and other female genital organs than women without learning disabilities (Parish et al 2018; Sullivan and Hussain 2008). Notably, Parish et al (2018) attributes the increased rate of hospitalisation to cancer progression.

Barriers

What the literature tells us

Cancer screening barriers

Studies focus almost exclusively on breast and cervical screening.

Overall, barriers can be attributed to pain and discomfort; physical barriers; attitudes, knowledge and training of health care workers; understanding of cancer screening; the role of family and care workers; and cost.

Prior experiences of sexual assault are an important barrier to cancer screening for some disabled people. This is especially relevant given the increased risk of sexual and physical violence faced by disabled people in multiple settings.

Diagnosis and treatment barriers

Barriers to accessing appropriate treatment are often a mixture of environmental barriers (such as lack of accessible information and facilities and lack of appropriate equipment) and interpersonal barriers (such as bias, diagnostic overshadowing, and lack of flexibility, empathy, knowledge and training).

Disabled people encounter providers who fail to acknowledge their disability-related needs and provide disability-related accommodations and who disregard cancer signs and symptoms as emotional responses to a chronic health condition.

In some instances, physical signs and symptoms of cancer are incorrectly attributed to the underlying disability (diagnostic overshadowing).

Overall

Ableist attitudes at societal, institutional, and interpersonal levels are noted in the literature as underlying many of the barriers to cancer screening, diagnosis and treatment faced by disabled people.

This section gives an overview of the literature we reviewed that discusses barriers to cancer screening, diagnosis and treatment for disabled people. The literature we reviewed is presented in the following structure:

What were the barriers to cancer screening for disabled people?

What were the barriers to diagnosis and treatment for disabled people?

What were the barriers to cancer screening for disabled people?

Some caveats should be noted when reviewing this section on barriers to cancer screening experienced by disabled people. Firstly, barrier and facilitator- focused studies have often failed to distinguish between factors that affect access to cancer screening and factors that affect the actual uptake of screening (Chan et al 2022; Edwards et al 2020). Next, the majority of studies we found relating to access to screening were focused on people with either physical or learning disabilities. Further, the studies have almost exclusively focused on experiences of breast and cervical screening.

Barriers to cancer screening for disabled people that were identified in this literature review fall under six primary themes:

1. Pain, discomfort and distress
2. Physical barriers

3. Health care workers' attitudes, knowledge and training
4. Understanding of cancer screening
5. The role of family and care workers
6. Cost and transport barriers

1. Pain, discomfort and distress

The pain, discomfort and distress associated with screening procedures was identified in the literature as a key barrier to cancer screening for disabled people. People with physical disabilities are more likely to experience considerable pain, discomfort and a sense of powerlessness during mammograms and cervical screening than non-disabled people (Kilic et al 2019; Peters and Cotton 2014; Poulos et al 2011).

Notably, participants in Peters and Cotton's (p568, 2014) qualitative study of 12 women with physical disabilities in Australia likened their experience of breast screening to 'one of pain, torture and humiliation' as health care professionals handled their breasts and bodies to better position them for mammography. Similar accounts of discomfort were reported by Poulos et al (2011), who conducted an observational study of 13 Australian women with physical disabilities undergoing a mammogram.

Of the nine participants who were wheelchair users, five were unable to keep the required position for successful mammography as they were unable to stand or sit up and lean into the machine. Eight out of the thirteen participants did have successful diagnostic images taken, but four of these women reported that they would not return for future screenings due to undesirable levels of physical handling, anxiety, pain, discomfort and diminished dignity they experienced during the procedure.

People with learning disabilities described experiences of pain during and after cervical and breast screening (Broughton and Thomson 2000; Willis 2016). The pain was attributed to the speculum in cervical screening and the mammography machine in breast screening being cold and applying pressure to the breast.

In addition to these discomforts, Aotearoa New Zealand researchers Mirfin-Veitch et al (2016) found that for women with learning disabilities, embarrassment with the screening procedure was a significant barrier. Pain and discomfort experienced during screening therefore becomes a barrier due to the negative impact on the individual’s future participation in screening (Chan et al 2022; Edwards et al 2020; Peters and

Cotton 2014; Piotrowski and Snell 2007; Poulos et al 2011; Yankaskas et al 2010).

2. Physical barriers

Studies of disabled people in breast and cervical screening have shown that people with physical disabilities experience physical barriers in accessing venues where screening services are provided (Choi et al 2021). People with physical impairment also reported difficulties in arranging transportation to the clinic providing the screening service. As reported by Angus et al (2012), participants found that possible delays in the arranged transportation would make them late for their appointment, and long waiting times at the clinic would also make them miss their arranged transportation back home.

It was challenging for wheelchair users to access and move around the building due to the lack of wheelchair-friendly facilities, sufficiently wide hallways and barrier-free paths (Armour et al 2009; Kilic et al 2019; Mudrick et al 2012; Poulos et al 2011). In the examination room, people also perceived difficulties in getting onto the examination table without assistance from others, as the examination tables had no disability-friendly features, such as suitable handles (Armour et al 2009; Kilic et al 2019; Mudrick et al 2012; Poulos et al 2011).

Consistent with these findings, a higher severity of physical impairment was associated with lower cervical screening utilisation (Choi et al 2021).

3. Health care workers’ attitudes, knowledge and training

Health care workers’ attitudes, knowledge and training around the unique inclusion and accessibility needs of disabled people have been identified as important barriers to screening. Providers may devalue disabled people, possess negative perceptions and stereotypes about disabled people, and lack disability-specific training and knowledge needed to accommodate disabled patients (Horner-Johnson et al 2015; Iezzoni, Rao, Ressalam, et al 2021; Merten et al 2015; Nosek et al 2004; Peters and Cotton 2014; Piotrowski and Snell 2007; Poulos et al 2011; Ramjan et al 2016; Roguski et al 2022; Yankaskas et al 2010).

Mele et al (2005) conducted a study that surveyed 20 women aged 21–65 with motor or sensory disabilities about their experiences with breast screening. Some of the negative experiences the participants described were:

providers failing to make necessary accommodations

ignoring and failing to advocate for their non-disability health and preventive needs

spending insufficient time with the individual

showing their lack of knowledge and discomfort with the individual’s disability

failing to provide adequate and appropriate information

communicating poorly with the individual.

A key barrier is health care worker ableist attitudes and the failure to provide patient-centred care (Greenwood et al 2014; JD Lin et al 2010; Willis et al 2015). Cervical screening may not be offered because of an assumption that disabled people are not sexually active and therefore cervical screening is not required due to a lower level of risk (Lloyd and Coulson 2014; Parish et al 2013). Health care workers may have inaccurate perceptions of disabled people that lead them to view disabled people as genderless and asexual and hence not in need of breast or cervical screening (Armour et al 2009; Choi et al 2021).

Some studies have also shown that health care professionals may not recommend or offer breast screening to eligible people with physical disabilities (Yankaskas et al 2010), including in an Aotearoa New Zealand context (Pearson et al 2022). Cooper and Yoshida reported that people being told by a doctor that they did not need cervical screening was one of the most common reasons why those with physical disabilities did not undergo testing (Cooper and Yoshida 2007).

Limited health care provider knowledge and training was identified as a significant barrier (JD Lin et al 2010; McIlfatrick et al 2011; Sullivan et al 2004; Taggart et al 2011). Health professionals who cared for people with learning disabilities described a lack of knowledge about cancer, and those with a clinical focus on cancer described a lack of knowledge about learning disabilities (McIlfatrick et al 2011; Sullivan et al 2004; Taggart et al 2011).

A number of studies that included health care providers' experiences and perspectives identified a belief that screening was important for adults with learning disabilities. However, due to numerous barriers, adults with learning disabilities may receive less or lower quality screening, including a decreased tendency for health care providers to follow screening guidelines (JD Lin et al 2010; McIlfatrick et al 2011; Sullivan et al 2004; Taggart et al 2011).

Primary care providers have been reported to focus on the person's disability to the exclusion of other preventive health matters (Iezzoni et al 2000; Mele et al 2005). One potential consequence of this is that disabled people are less likely than non-disabled people to receive a recommendation from a physician for mammography screening (Yankaskas et al 2010).

Closely linked to ableism and limitations in knowledge, not making necessary accommodations is an important barrier for disabled people accessing health care, including screening. This includes a lack of easily comprehensible invitations, time pressures limiting the length of appointments, lack of specialist equipment, or a failure to meet communication requirements (Byrnes et al 2020; Donald Beasley Institute 2022; McIlfatrick et al 2011).

Importantly, the accommodations necessary to facilitate equitable access for disabled people also vary, depending on the type of disability. For example, Payne et al (2023) emphasised the importance of pre-consultation on communication preferences, the use of New Zealand Sign Language (NZSL), staff knowledge, and visual aids as essential accommodations for New Zealand Deaf women accessing breast and cervical screening. Parish et al (2013) found that clinicians may not offer cervical screening to those with learning disabilities because of the time and preparation required to support them to understand the procedure. In a recent qualitative study (Hughes et al 2022), a woman with a physical disability reported that her doctor asked her how she expected to be examined if she could not get up on the table. Another participant shared that she could ‘see it in their eyes’ as they looked at her in the wheelchair, looked at the height of the exam table, and then changed their minds about doing a cervical screen.

Sakellariou et al (2020) highlight that disabled people are among the most disadvantaged population groups. Disabled people face systemic disadvantages such as poverty, lower literacy, and unemployment compared to the general population. These structural disadvantages are compounded by ableism – discrimination directed at disabled people – which often manifests in healthcare as the expectation that all bodies should conform to non-disabled standards. This combination of structural barriers and discrimination limits access to healthcare and can lead to reduced use of cancer services. Sakellariou reminds us that:

> ‘Behind the statistics of cancer screening underuse are human stories: men and women with disabilities who—worried about new, unfamiliar symptoms—try to get screened but whom doctors are reluctant to refer, possibly due to diagnostic overshadowing; wheelchair users being asked to stand up; and healthcare professionals not exploring ways to adapt processes to make them disability-inclusive, exemplifying a general lack of disability inclusiveness in the provision of health care services.’
>
> (Sakellariou and Rotarou 2020, p1144)

4. Understanding cancer screening

A lack of clear, appropriate information about screening purpose and procedure in a way that addresses concerns is a barrier to screening for disabled people.

Kilic et al (2019) found that people with physical disabilities did not have sufficient knowledge of breast and cervical cancer prevention or how to access screening services. In their review of barriers to cervical screening faced by physically disabled individuals, Chan et al (2022) found that limited awareness of the importance of undergoing regular cervical screening can be a primary barrier to accessing cervical screening.

For those with learning disabilities, limited knowledge and understanding about prevention and what cancer screening entails are also important barriers (Lloyd and Coulson 2014; Truesdale-Kennedy et al 2011; Wilkinson, Deis, et al 2011; Wilkinson, Lauer, et al 2011; Willis 2016; Willis et al 2015) and studies outlined the need for better understanding about the benefits of screening (Swaine, Parish, et al 2013).

It should be noted that limited awareness of the importance of cervical screening has also been reported to be one of the impeding factors to cervical screening amongst individuals without disabilities (AL-Hammadi et al 2017; Chorley et al 2017). Therefore, this factor is likely to be a broader barrier to all people rather than exclusively preventing people with physical or learning disabilities from undergoing screening.

However, some disabled people have specific information needs. Cervical and breast screening programmes may inadvertently exclude people with learning disabilities due to having challenges with health literacy. Of note, even among adults without a learning disability, 42% are unable to understand or make use of standard health information and are therefore less likely to act upon preventive health measures (Byrnes et al 2020; McIlfatrick et al 2011; Scott et al 2002).

Studies reported that some people with physical disabilities who were eligible for screening did not perceive a need for breast or cervical screening, as they believed that not being sexually active or having a normal-feeling body meant that regular screening was not necessary (Kilic et al 2019).

A number of studies highlighted that concern about the process was a barrier for those with learning disabilities. This included anxiety associated with cancer screening procedures – not knowing what they would experience or what to expect, including possible pain (Broughton and Thomson 2000; Connolly 2013) – and anxiety associated with waiting for the cancer screening results (Byrnes et al 2020).

Connolly (2013) found that embarrassment can be a barrier for some with learning disabilities. A number of studies discussed that a prior sexual assault history is an important barrier to screening for some people with learning disabilities (Brown and Gill 2009; Mirfin-Veitch et al 2016; Swaine, Parish, et al 2013; Swaine, Dababnah, et al 2013). This is particularly salient given the increased risk of physical and sexual violence faced by disabled people in multiple settings, including state institutions and health care settings both internationally and in Aotearoa New Zealand (Mirfin-Veitch and Conder 2017; Mirfin-Veitch et al 2022; Robson 2016; Roguski 2013).

In Aotearoa New Zealand, Mirfin-Veitch et al (2016) reported that although their participants were clear and accepting about the purpose of screening, they indicated that they found it difficult gaining comprehensive and accessible information about breast and cervical health care, particularly information that reduced their anxieties and fears.

5. The role of family and care workers

A common theme across learning disability literature is a reliance on family or paid care workers to adopt a primary role in the health of those they support (Barber 2011; Hanna et al 2011). However, it is reported that support people may not perceive cancer screening as important or appropriate (Barber 2011; Hanna et al 2011; Kopac 2002; McIlfatrick et al 2011; Parish et al 2013; Truesdale-Kennedy et al 2011).

Studies have described a challenging balance between supporting adults with learning disabilities to participate in screening and the family member or caregiver's concerns surrounding comprehension and decision making (Greenwood et al 2014; Willis et al 2015). Within this context, family and paid care workers were positioned as those who either facilitated or hindered access to screening and reportedly made decisions on behalf of the individual, perhaps without evidence of previous discussion with them (Byrnes et al 2020; Greenwood et al 2014; Swaine, Dababnah, et al 2013; Willis et al 2015).

It is noted, however, that the studies referred to above were conducted in the context of a health care system and culture that centralises Western world views that frame disability in an individualised manner. Consequently, these findings are unlikely to apply to all disabled people and their families and caregivers.

6. Cost and transport barriers

The barriers to breast and cervical screening discussed above may be compounded by the fact that disabled people have higher rates of poverty and poorer access to education and employment opportunities than non-disabled people. Disabled people are also less likely to be covered by private health insurance, which impedes their access to breast screening programmes in countries where private health insurance often funds access to screening. (Chevarley et al 2006; Liu and Clark 2008; Mele et al 2005; Wollin and Elder 2003).

In nations with free cervical and breast screening, costs associated with transport and parking (Armour et al 2009; Kilic et al 2019; Mudrick et al 2012; Poulos et al 2011) and the need for assistance may be a considerable disincentive for disabled people to attend (Jan et al 2012). In Aotearoa New Zealand, Pearson et al (2022) reported that among disabled people, having insufficient income was significantly associated with a lower rate of ever having a mammogram. Barriers to accessing health care are exacerbated in rural settings (Hamilton et al 2020). For example, rural disabled people in the United States who travel some distance to cancer screening providers may be less likely to receive breast and cervical screening than those who live in urban settings (Horner-Johnson et al 2015).

What were the barriers to diagnosis and treatment for disabled people?

Disabled people experience barriers to receiving an early cancer diagnosis, which impacts their chances of long-term survival (Hughes et al 2022). Despite many cases of cancer being diagnosed outside of screening programmes, there has been limited research on the specific barriers disabled people face accessing cancer diagnosis outside of screening pathways. There is also limited research on the barriers disabled people face accessing cancer treatment.

In the literature reviewed, the barriers discussed earlier relating to cancer screening are often also barriers to diagnosis and treatment. These barriers include health care professionals' attitudes and knowledge, and poor physical accessibility. The literature also discusses the impact of diagnostic overshadowing.

1. Health care workers' attitudes and knowledge, and physical barriers

Reports from disabled people with lived experience of cancer in Aotearoa New Zealand reflect important challenges, including ableist attitudes and lack of acknowledgement of disability-related needs. For example, Dairne Kirton, a tangata whaikaha Māori woman with a physical impairment and lived experience of breast cancer, describes her experience:

> 'I was diagnosed in 2008. By 2010 the cancer had spread significantly, which resulted in a double mastectomy, chemotherapy, and reconstruction.'
>
> 'There was very little consideration and support as a disabled person. If I had been listened to respectfully about my impairment, and this had properly been taken into consideration, the surgery would have likely turned out different.
>
> I tried to get people to listen to me and point out disabled people were not being properly consulted or considered, but I was met with many closed doors.'
>
> (Dairne Kirton, as quoted in Livingston 2023b)

Similar themes are seen in a qualitative study by Sakellariou et al (2019). This research explored barriers experienced by adults with pre-existing physical disabilities who have had the additional experience of being diagnosed with and treated for a potentially curable cancer. The overall theme that emerged from the study was that participants experienced a lack of adequate preparation both from health care professionals and health care facilities (ie, at the level of the clinical encounter and at an organisational level) to respond to their needs. This theme is illustrated through the following interrelated subthemes:

Participants perceived a lack of acknowledgement among health professionals about their disability-related needs, including an inability to be flexible and innovative about the best way to support those with a disability.

Participants recalled the lack of ability of professionals to empathise with the lived experience of living with a disability, which translated into an unwillingness to adapt their usual practice.

Most participants experienced challenges related to the physical accessibility of hospital buildings and facilities (Sakellariou et al 2019).

Agaronnik et al (2021) also noted the absence of suitable medical equipment (eg, scales and hoists), which in some cases were barriers that led to delayed diagnosis of cancer.

2. Diagnostic overshadowing

Diagnostic overshadowing describes the misattribution of signs and symptoms to a person's underlying disability or coexisting health conditions. Agaronnik et al (2020) investigated the experiences of 20 patients with mobility disability[14] with the process of cancer diagnosis and found half of the participants experienced a delay in their diagnosis due to their cancer signs/symptoms being incorrectly attributed to their underlying disability. In some cases, participants themselves thought symptoms were disability-related; in other cases, it was the patient's own clinician that made these assumptions. In some situations, these delays had severe consequences.

For example, a woman with cerebral palsy had trouble swallowing, a recognised complication of her disability. She later developed a cough and was given cough suppressant. She was concerned about seeking follow-up 'because they attribute it to my disability, and they don't really pay attention' (Agaronnik et al 2020,

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[14] Mobility disability was defined in this study as 'requiring the use of an assistive device and/or assistance performing activities of daily living'.

p1254). She was subsequently diagnosed with thyroid cancer, which she believes contributed to her swallowing difficulties and cough.

Improving cancer services for disabled people

What the literature tells us

There is limited research on ways to improve cancer inequities experienced by disabled people. Most of it focuses on increasing access to breast and cervical screening.

System-level improvements

Disabled people – in particular, tāngata whaikaha Māori – must co-design research, policies and programmes that affect their lives. These collaborations should be proactive and take an intergovernmental 'health and disability in all policies' approach.

Financial barriers to accessing care should be minimised. This may include the provision of financial support for disabled people undergoing cancer treatment.

Public awareness of cancer screening should be increased.

Organisational improvements

Health care staff, whānau and attendant carers should receive training on how best to support the diverse needs of disabled people.

Health care providers must ensure reasonable accommodations are made to facilitate provision of quality care, such as more time for appointments, sign language interpreters, attendant carers and accessible sources of information on diagnosis and treatment.

Psychosocial support should be offered to help to alleviate anxiety or fear during appointments.

Accessible facilities and appropriate equipment should accommodate the diverse needs of disabled people.

Information must be provided in accessible formats.

Disabled people, their whānau and health professionals should receive education on the benefits of cancer screening and inclusion criteria regardless of perceived risk.

There is limited literature available that examines the improvements required to improve cancer services for disabled people. Of the proposed improvement strategies, most studies have centred on the reduction of associated screening barriers to ensure early diagnosis and treatment (Hughes et al 2022).

The comparatively few system-level interventions discussed reflects the small body of literature available on this topic. Some improvements in cancer outcomes for disabled people are likely to sit at the prevention end of the cancer continuum. However, the literature we reviewed focuses primarily on cancer services.

We refer the reader to consider the broader context presented earlier, where the experience of disabled people intersects with the social determinants of health. Inequities are magnified for those who, in addition to being disabled, identify with other disadvantaged groups.

This section outlines approaches to addressing disparities in screening, diagnosis and treatment, from both a system perspective and an organisational perspective.

How can we reduce inequities in cancer services?

The majority of research on disabled peoples' experiences of cancer services has been focused on screening, therefore many of the recommendations for system improvements relate to screening. However, some of these recommendations may also be applicable in other areas of cancer service delivery. Chan et al (2022) notes that further studies are required to determine the degree to which a number of these findings might generalise to people with sensory disabilities, such as those who are low vision, blind, D/deaf, or deafblind.

The following approaches have been identified as enhancing breast and cervical screening utilisation, and can be separated into suggestions for system change and organisational initiatives (including health care worker training).

System-level improvements

1. **Include tāngata whaikaha Māori in decision making and co-design of services.**

Public sector responsiveness to Māori generally does not include tāngata whaikaha Māori; and when the public sector responds to the needs of disabled people, this does not usually include tāngata whaikaha Māori (King 2019). King (2019) asserts this effectively renders them an 'invisible' group across public sector policy, service planning and monitoring.

Ingham et al (2022) outline that interventions are needed that include tāngata whaikaha Māori in decision-making structures, comprising all policies and practices and equal partnership rights, when it comes to designing systems and services that impact their lives. To enact change, the authors recommend proactive, multi-agency collaborations using an intergovernmental 'health and disability in all policies' approach.

2. Improve access to kaupapa Māori primary health care services.

Ingham et al (2022) note the limited availability of kaupapa Māori health services specifically for tāngata whaikaha Māori. The authors discuss the importance of high-quality, culturally safe care that is non-disabling and accessible.

3. Improve research for disabled people.

Ingham et al (2022) note the lack of available analysis of data for tāngata whaikaha Māori and call for this to be improved, ensuring leadership and governance of Māori. This issue is discussed further on page 53.

4. Remove costs associated with screening and treatment.

Mirfin-Veitch et al (2016) note the importance of removing financial barriers for Aotearoa New Zealand disabled people. Internationally, Chan et al (2022) recommend the provision of free transportation to and from cancer screening clinics.

In Aotearoa New Zealand, the cervical screening programme is not fully funded and therefore requires a payment by the person seeking screening when conducted in primary care settings. Some groups can access free routine screening tests, although being disabled is not currently a criterion.[15]

Stirling et al (2021) recommend removing economic and transport-related barriers and increasing the provision of social support for disabled people undergoing cancer treatment. The removal of such barriers acknowledge the

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[15] Eligibility criteria for free routine cervical screening tests can be found on the Health New Zealand website: **info.health.nz/keeping-healthy/cancer-screening/cervical-screening/eligibility-for-cervical-screening**.

role social determinants contribute to differences in cancer outcomes and experiences.

5. Increase public awareness of cancer screening.

There is a need for increased public awareness of health information on the importance of cancer screening presented in an effective way. Chan et al (2022) outline that a key aim of increasing public awareness is to increase knowledge amongst those with physical disabilities.

Organisation-level improvements

1. Improve health care worker training and communication.

Studies commonly noted the need for appropriate health care provider training on the unique needs of disabled people (Angus et al 2012; Follette et al 2009; Kilic et al 2019; Mele et al 2005; Sakellariou et al 2019).

Training of health care staff on how to support disabled people should be provided to health care professionals and families. The UNCRPD mandates that health care providers offer reasonable accommodations to ensure that disabled people have the same access to services as non-disabled people (Roguski et al

2022). Such accommodations include, but are not limited to, provisioning of sign language interpreters, training staff about patient positioning and developing and providing easily understood sources of information about diagnosis and treatment.

For example, a recent Aotearoa New Zealand study (Payne et al 2023) on the experiences of Deaf people accessing breast and cervical screening reported that:

effective communication during screening encounters is essential, including staff being able to communicate effectively with Deaf women and the use of NZSL interpreters

Deaf people need to be consulted on their communication preferences before their cancer screening encounters

communication is enhanced by using visual aids along with NZSL.

Education for health care workers is also essential to ensure they understand the needs of people with learning disabilities and screening inclusion criteria, regardless of perceived risk (Byrnes et al 2020).

Particularly for those with learning disabilities, screening and treatment should occur in a positive and encouraging environment. Health care workers should acknowledge the individual’s preferences, such as the gender of the person carrying out the procedure, using appropriate language and mannerisms to help build rapport (Broughton and Thomson 2000). Further, staff need to be mindful that their demeanour can have a facilitative effect and their engagement with, and encouragement of, the individual can reduce the individual’s anxiety and fear (Byrnes et al 2020; Lloyd and Coulson 2014; Truesdale-Kennedy et al 2011; Wilkinson, Lauer, et al 2011).

Clinician engagement and delivery of patient-centred care to adults with learning disabilities and cancer had a positive impact on the treatment experience (Tuffrey-Wijne et al 2009).

Oncology nurses reported that training to help support adults with learning disabilities and experience providing this care improved their own ability to identify and meet the needs of adults with learning disabilities going through cancer treatment (Flynn et al 2018).

2. Have longer appointments.

An increase in the duration of screening appointments provides more time for physically disabled people to get into position for the screening tests to be performed, enabling them to be screened more comfortably (Angus et al 2012).

Increased appointment times have been shown to be beneficial for those with a learning disability as well. This increase can accommodate specific needs such as communication and use of specialist equipment (Byrnes et al 2020; McIlfatrick et al 2011).

Longer appointments are also recommended by Payne et al (2023) in their study of Deaf women and their experience of breast screening in Aotearoa New Zealand.

3. Ensure adequate support.

For people with physical disabilities, studies have shown the benefit of the availability of a specialised support person to assist a physically disabled individual to undergo the screening procedure. This could include accompanying a physically disabled individual to the examination room and remaining throughout the screening procedure. The provision of support was also noted as possibly combatting the negative impact of some health care professionals' attitudes when working with physically disabled individuals (Angus et al 2012; Chan et al 2022).

For people with a learning disability, research highlights the importance of psychosocial support to help alleviate the individual's anxiety and/or fear towards screening. Notably, anxiety, fear and pain have been found to greatly affect whether the individual attends subsequent appointments (Byrnes et al 2020). In Aotearoa New Zealand, women with learning disabilities were reported to also share the importance of having a close and supportive person accompany them to mammography and cervical screening appointments (Mirfin-Veitch et al 2016).

4. Ensure facilities are accessible.

The use of accessible facilities and larger examination rooms for screening has been found to be important to assist physically disabled individuals to undergo screening more easily, including the development of strategies for optimal patient positioning and comfort during screening (Angus et al 2012; Chan et al 2022; Kilic et al 2019; Magoon and Meadows-Oliver 2011).

5. Provide accessible information.

Accessibility to screening can be increased by providing information in the most appropriate methods, such as using Easy Read information, photo stories and videos to maximise understanding. Further, the individual should be given the opportunity to become familiar with the screening environment and the equipment used before the actual screening appointment. Such provisions can be beneficial to help the individual understand, demystify, and reduce fears around cancer screening (Lloyd and Coulson 2014; Mirfin-Veitch et al 2016).

Byrnes et al (2020) suggest that women with learning disabilities would benefit from family and health care workers alike having education on cancer screening. It is important that all relevant parties involved with the individual know about screening and have informed attitudes towards it (Byrnes et al 2020; Greenwood et al 2014; Rutter 2000; Swaine, Parish, et al 2013; Willis et al 2015).

For those with a cancer diagnosis, one study found that uniquely adapted cancer treatment resources increased the understanding and ability of adults with learning disabilities to cope with a family member's cancer diagnosis, and it facilitated their ability to discuss their own cancer treatment experiences (Tuffrey-Wijne et al 2006). This study involved resources such as the *Getting on with Cancer* booklet, which uses pictures instead of words to describe the cancer journey (Tuffrey-Wijne et al 2006).

Summary and discussion

This section gives an overview of the main findings of the literature review and discusses the findings, including limitations and opportunities for future research.

Disability and cancer: inequities and barriers

There is little existing information on the state of cancer in Aotearoa New Zealand for disabled people. International data indicates that when compared with non-disabled people, disabled people are likely to have higher mortality and lower survival for some cancers. Some research indicated the possibility of a higher incidence of some cancers for disabled people compared with non-disabled people.

In Aotearoa New Zealand, tāngata whaikaha Māori face a high burden of poor health outcomes compared with other groups, even within the disability community. Tāngata whaikaha Māori are reported as being more likely to develop any cancer compared with disabled non-Māori (Ministry of Health 2019b). In addition, tāngata whaikaha Māori women were more than twice as likely as disabled non-Māori females to develop breast cancer (age-standardised RR 2.22; 95% CI 1.12–4.39).

Outcomes can also vary according to disability type. For example, a 2023 study suggested that in Aotearoa New Zealand, people with learning disabilities are more likely to develop any cancer than those without learning disabilities (Beltran-Castillon 2023).

The above examples demonstrate the interplay of ethnicity and disability as independent factors that cumulatively affect equitable cancer outcomes in Aotearoa New Zealand. This is compounded by inequitable access to determinants of health and wellbeing (Hickey and Wilson 2017; Ingham et al 2022; Ministry of Health 2018a), including inequitable access to health and disability care and differential quality of health and disability care received (Hickey and Wilson 2017; Ingham et al 2022).

With regard to access and barriers to cancer services, much of the international research that we reviewed focused on screening, particularly breast and cervical screening. These studies showed that disabled people are screened at a lower rate than non-disabled people, placing them at greater risk for delayed diagnosis and cancer mortality. Studies identified multiple barriers to participation, including:

difficulties accessing appointments

a lack of support to navigate services

a lack of physical tools that enable participation in the clinic/hospital setting

inadequate information for patients

inadequate training for health care workers.

A small but growing number of studies have focused on identifying the existence of inequities in cancer treatment and substandard experiences of service provision. These can be broadly grouped into experiences related to specific cancers and those related to disability. Overall, the studies (excluding those for prostate cancer) showed that disabled people are diagnosed later than non-disabled people and are less likely to receive comparable treatments. Limited existing literature also indicates that people with learning disabilities face an additional burden of inequity – that is, they are less likely to receive curative cancer treatment when compared with people without learning disabilities (Parish et al 2018; Shinden et al 2017; Sullivan and Hussain 2008). While reasons for these inequities were not a focus of these studies, the authors suggest ableism, diagnostic overshadowing, and failures to acknowledge the needs of disabled people are likely key factors for consideration.

Overall, similar patterns of disparities have been observed globally across different health care systems, including countries with universal health coverage and public health care that is free at the point of delivery.

Most barriers identified were at a systems and process level. This indicates there is inadequate provision being made for disabled people at all levels of clinical and health leadership to prioritise the unique and diverse needs of disabled people.

Improving cancer services for disabled people

Most of the research we reviewed was international and focused on specific practical and organisational approaches to eliminating barriers to cancer screening, diagnosis and treatment. However, a clear theme of discussion in key articles was also the importance of system-level change. This included removing the financial costs associated with screening and increasing the awareness of cancer screening in the general public (including disabled people).

There was limited research on disabled Indigenous peoples, including tāngata whaikaha Māori. However, leading Aotearoa New Zealand disability researchers urgently want to eradicate discrimination towards tāngata whaikaha Māori, in line with the obligations under Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities, and the Declaration on the Rights of Indigenous Peoples (Hickey and Wilson 2017; Ingham et al 2022).

Experts in Aotearoa New Zealand such as Ingham et al (2022) assert that addressing the systematic and institutional mechanisms that drive inequities for disabled people will require the active dismantling of racist, ableist and disablist systems. This requires disabled people – and tāngata whaikaha Māori in particular – to co-design the systems and services that affect them, echoing the phrase ‘nothing about us without us’. This approach is consistent with the *Code of Expectations for health entities’ engagement with consumers and whānau*, which sets the expectations for how health entities must work with consumers, whānau and communities in the design, delivery and evaluation of health services (Te Tāhū Hauora Health Quality & Safety Commission 2022). It would also support other recommendations discussed, such as improving access to kaupapa Māori health care services (Ingham et al 2022).

Practical organisational strategies to improve, or remove barriers to, cancer screening and treatment have focused on breast and cervical screening, and are often limited to people with physical disabilities or learning disabilities. However, it is likely that the various strategies arising from these studies are broadly relevant across all impairments.

Research indicated that health systems and providers can take steps to improve cancer care for disabled people. The recommendations in the literature largely revolve around the provision of reasonable accommodations to facilitate high-quality care for disabled people regarding screening and treatment – for example, larger examination rooms, longer appointments, and careful consideration of the physical, emotional and spiritual comfort of the individual and their whānau during a procedure. In addition, having appropriately trained support people to help with system navigation is very important for many disabled people.

Health promotion about screening should be provided in alternative formats to be accessible for all, including disabled people. Health promotion messaging should also be developed to educate the public about disability and raise awareness of the accessibility needs disabled people have.

Also mentioned were relatively simple interventions that make a significant difference to a disabled person's experience – for example, discussing a person's needs before an appointment to plan the use of an interpreter or a specific piece of equipment. This requires awareness and processes to facilitate change. An essential component of this is to ensure adequate training of health care workers so they become more aware of the diverse needs (including psychosocial considerations) of disabled people. Such training was a common theme across the literature available, highlighting the importance of widespread competence across health care professionals.

These findings, and those relating to reducing screening barriers, are consistent with Aotearoa New Zealand's commitment to the UNCRPD, which mandates that health care providers offer reasonable accommodations to ensure disabled people have the same access to services as non-disabled people.

Applying international evidence to Aotearoa New Zealand

International evidence should be carefully interpreted for the Aotearoa New Zealand context. Internationally, there is a pronounced lack of research relating to Indigenous disabled people, and this is also the case in Aotearoa New Zealand, where there is very little research relating to tāngata whaikaha Māori. The application of any international research therefore must consider this – for example, the inclusion of cultural safety education within health care worker disability training. Disabled people - particularly tāngata whaikaha Māori -

should be involved in the co-design of system improvements.

There are other specific points that should be considered regarding interpretation of findings for the Aotearoa New Zealand context. Of note, the studies on cervical screening described in this review all used liquid-based cytology, which was the usual process in Aotearoa New Zealand until September 2024 – at which point we moved to HPV primary screening. HPV primary screening can now be done by the person themselves, and if done by a health professional does not usually require a speculum, therefore may be less of a barrier for some disabled people accessing this test. However, many of the findings on cervical screening will remain relevant and should not be dismissed. The complexities highlighted relating to emotional comfort, decision making around requirement for screening and the need for accessible information are particularly relevant.

However, there is some alignment between actions and opportunities identified in the literature we reviewed and our government priorities in health. For example, there are several interventions highlighted in this report that align with the priority areas identified in the Government Policy Statement on Health 2024–2027. This includes equitable access to services, a skilled (disability competent) and culturally capable workforce, and resilience of digital infrastructure. There are also key alignments in the Provisional Health of Disabled People Strategy and the disability actions in the New Zealand Health Plan – Te Pae Waenga 2024–2027.

Limited research on disability and cancer across the cancer continuum

Most of the international studies reviewed in this report focused on cancer screening, with some additional studies focusing on diagnosis and treatment. While screening reflects an important part of the cancer continuum in terms of reducing cancer-related morbidity and mortality, it does not apply to most cancer types. We note limited research on treatment and outcomes for disabled people both internationally and in Aotearoa New Zealand and very little on palliative care, end-of-life care and survivorship for disabled people with cancer.

Primary care is a cornerstone of cancer care in Aotearoa New Zealand. The recent New Zealand Health Survey found that disabled adults reported more barriers to accessing primary care compared with non-disabled people (Ministry of Health 2024). These barriers included costs of appointments and prescriptions, access to transport, and lack of an available support person. These findings mirror the literature we reviewed that specifically related to access to appointments relating to cancer and cancer screening.

While this report did not intend to focus on people who have become disabled because of cancer, this is an important area of interest and future research.

Social determinants of health and intersectionality

We recognise that there will be relevant literature on disability and health that may link to a person's cancer journey that our search strategy was not designed to capture. A key example of this is cancer prevention, where factors contributing to cancer risk (eg, tobacco use or physical inactivity) will not be specific to cancer or to disabled people. This was not included in our literature review and is an opportunity for future research and collation of information to support initiatives in cancer prevention for disabled people. The environments in which we live, work and play are essential to incorporate into consideration of cancer prevention for disabled people, including the structures that contribute to ongoing colonisation, ableism, disablism and racism within the health system and broader society. Although not specifically reviewed in the literature, we can see the effects of these broader influences as they filter down into practical barriers for disabled people, such as organisations not prioritising disability-specific health professional training or not providing reasonable accommodations during cancer screening or treatment.

There is a need to further investigate the impact of intersectionality on disabled people, particularly for tāngata whaikaha Māori. The need for investigation with an intersectional lens is also required for other key groups, including but not limited to Asian people, women, people who live rurally, Rainbow communities, older people, migrants, and refugees. For example, Edwards et al (2020) note that limited research has been conducted on the experiences of disabled men. This may be because most studies are on cancer screening and two of the most common screening programmes are for breast and cervical cancer.

Disability data

A number of studies discussed the importance of accurate and appropriate data collection for disabled people. The literature we reviewed also highlighted the variety of ways that disability has been described and categorised and the complexity that this creates when comparing information. This has also been our experience in a companion project which has attempted to analyse quantitative data on disabled people with cancer in Aotearoa New Zealand. This is discussed further in *He taumaha te mate pukupuku ki ngā tāngata whaikaha: Ngā kitenga – The burden of cancer among disabled people: Diagnosis insights.*

Studies that used national administrative datasets provided the most rigorous and conclusive findings and have been able to document inequities across the cancer continuum. Given the rigour demonstrated in these studies (eg, research from South Korea), Aotearoa New Zealand should explore how we might adopt similar approaches to collecting and analysing disability data.

Accurate, appropriate and consistent collection of disability data is essential for identifying equity gaps in policy and service design. There is work underway to identify disabled people in Aotearoa New Zealand health administrative data. This will create a better understanding of inequities at a population level. Ongoing collection of regular and robust survey data also supports inclusion of disabled people in policy development. Partnering with disabled people in the leadership and design of data systems is paramount.

Indigenous data sovereignty and governance should be incorporated into the improvement of disability data, including infrastructure, quality, collection, protection, analysis and communication (Kukutai et al 2023).

Conclusion

To our knowledge this is the first compilation of literature in Aotearoa New Zealand specifically relating to disabled people and cancer. The purpose of this report was to explore the information available on inequities in cancer care and outcomes for disabled people, particularly tāngata whaikaha Māori.

Given how little is known about the experiences and outcomes for disabled people with cancer in Aotearoa New Zealand, this literature review has focused only on people who identified as disabled before their cancer diagnosis.

The literature review shows that specific groups of disabled people are at risk across the screening, diagnosis and treatments parts of the cancer continuum. While there was a lack of literature on other parts of the continuum, it is likely that other areas such as cancer prevention would also benefit from targeted action.

Literature indicated that addressing inequities for disabled people should be multifaceted and at all levels of the health system. The research highlights specific accommodations that are required to work towards equitable access to health care and equitable outcomes for disabled people. While there was less cancer-specific research concerning system-level opportunity for change, there were strong themes on the need for including disabled people in the co-design of services to drive meaningful change. Research also noted that the cumulative effects of intersectionality should be considered when designing and delivering health care services.

Next steps

We anticipate the findings of this literature review will support action under several government priorities and plans. It also highlights areas for further research, which may guide action to support disabled people in accessing appropriate care within the cancer and wider health sector.

The Agency will work with health entities and the disability sector to build a shared understanding of inequities in cancer outcomes for disabled people and their whānau, and to identify changes to improve cancer outcomes for disabled people – and tāngata whaikaha Māori in particular.

Appendix A: Glossary
Āpitihanga tuatahi

Ableism. Discrimination against disabled people in favour of non-disabled people. A form of discrimination that defines people by their disability and classifies disabled people as inferior or less than. Ableism prioritises the needs of non-disabled people over those of disabled people. Like racism and sexism, ableism can look like:

microaggressions, such as dismissing the need for accessible parking or workplace accommodations like a permanent workstation tailored to an individual's needs in a hot desk office environment

offensive stereotypes that cause people to view disabled people as victims or treat them like children

systemic ableism, where buildings are designed without accessible ramps, lifts or quiet spaces, and playgrounds are not built or upgraded to reflect universal design principles (Whaikaha – Ministry of Disabled People nd).

Age-standardised rate. Age standardisation enables data from two or more population groups with different age profiles to be compared – for example, the relatively young Māori and Pacific populations and the relatively older New Zealand European/Pākehā population. Age standardisation adjusts for the differing age profiles of the groups by applying age-specific rates to a standard population and producing a single, age-adjusted rate for each group (Ministry of Health 2018b).

Cancer continuum. The cancer continuum is a term used to describe the various stages of intervention associated with cancer – that is, identifying genetic, environmental and health behaviour factors, through to prevention, early detection, diagnosis, treatment, survivorship, and end-of-life care. It is a useful framework that can be applied at a system level to develop plans, review progress and prioritise resources. The cancer continuum helps to identify research gaps, opportunities to collaborate, and inequities (National Cancer Institute at the National Institutes of Health nd).

Coexisting health condition. Sometimes referred to as comorbidities. Where an individual has more than one illness or medical condition at the same time.

Deaf. 'Deaf' with a capital 'D' signifies a cultural identity shared by those who use sign language and identify with the Deaf community. The terms hard-of-hearing and deaf (with a small 'd') are commonly used to describe people with hearing impairment. These identity groups are not mutually exclusive and deaf children and deaf people can move between these.

Deafblind. A combination of vision and hearing loss (dual sensory loss) that impacts a person's ability to communicate, access information and navigate their environment.

Developmental disability. Refer to 'Learning disability', listed below.

Diagnostic overshadowing. When a healthcare provider wrongly attributes a patient's symptoms to their mental health or disability, leading to delayed diagnosis or inadequate treatment.

Disability. According to the UNCRPD, 'Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (United Nations 2006, Preamble).

Disablism. Discrimination against disabled people grounded in a belief that disabled people are inferior to others. It is a more direct conscious act of discrimination than ableism and could look like:

abuse, such as using an offensive slur to refer to someone who is disabled

discrimination, such as assuming a disabled person is not capable of doing something (Scope nd).

Impairment. An impairment can be intellectual, psychiatric, physical, neurological or sensory, and may be temporary, intermittent or ongoing. People may acquire an impairment through an accident or illness and/or a person may be born with an impairment. Multiple impairments are common, especially with increasing age (Whaikaha – Ministry of Disabled People nd-b).

Note: We have been careful throughout this document to avoid using words that associate the term impairment with negative things – for example, we have replaced the phrase ‘severe impairment’, which is found in some medical studies, with ‘most significant category of impairment’. This decision is consistent with our approach to employing respectful terminology within an Aotearoa New Zealand context.

Institutional racism. Discriminatory policies and practices within organisations and institutions. See also ‘Structural discrimination’.

Intellectual disability. Refer to ‘Learning disability’ listed below.

Intersectionality. The way various aspects of a person’s identity – such as gender, ethnicity, sexual orientation, and disability – interconnect and influence their lived experiences. These overlapping aspects can shape how someone is treated, and when a person belongs to more than one marginalised group, they may face deeper and more complex forms of disadvantage.

Learning (intellectual and/or developmental) disability. The terms ‘intellectual disability’ and ‘learning disability’ are often used interchangeably.

A **learning disability** refers to difficulties a person experiences with their ability to master specific skills, rather than their capacity to learn (Specific Learning Disabilities of New Zealand nd).

An **intellectual disability** affects a person's ability to learn and function at levels considered typical for their age. These are challenges that are typically picked up before the age of 18.

> There are different ways to talk about intellectual disability, and not everyone in Aotearoa New Zealand agrees on a single definition (Bray 2023).
>
> In Aotearoa New Zealand, 'intellectual disability' is the term most used in the health system. However, People First NZ – Ngā Tāngata Tuatahi prefers the term 'learning disability' believing it to be a more respectful reference to their community (Johns 2022).

A **developmental disability** is often used in a broader way to describe challenges that may be intellectual, physical or both.

Morbidity. A medical term that refers to having a disease or symptom of disease, or amount of disease in a population.

Mortality. Is a measure of deaths in a population (usually expressed as a rate – eg, 35 deaths per 1,000 persons) during a given period, usually a year.

Rainbow. An umbrella term used to cover a diverse range of sexual orientations, gender identities/expressions and sex characteristics.

Acronyms also commonly used as umbrella terms are:

LGBTTQIA+ – Lesbian, Gay, Bisexual, Transgender, Takatāpui, Queer, Intersex, Asexual or Ace. The + recognises there are other identities not listed.

SOGIESC – Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (Public Service Commission 2024; United Nations 2021; World Health Organization 2025a).

MVPFAFF+ – describes a range of Pasifika rainbow identities, including Mahu (Hawai‘i and Tahiti), Vaka sa lewa lewa (Fiji), Palopa (Papua New Guinea), Fa‘afafine (Samoa), Akava‘ine (Rarotonga), Fakaleiti (Tonga) and Fakafifine (Niue) (Department of Human Services, nd).

Structural discrimination. Also known as structural inequality or systemic discrimination and institutional racism, it occurs when an entire social system inclusive of the institutions within it operate policies, practices and norms that create and perpetuate inequalities. (Braveman et al 2022)

Takiwātanga. ‘*In your own time and space*’ – a te reo Māori term describing autism (Bartlet, 2019).

Tāngata whaikaha. People with disabilities (Moorfield nd).

Note: The current preference and generally accepted term is ‘disabled people’, rather than ‘people with disabilities’ or ‘person with disability’.

Tangata whaikaha Māori. A Māori person with a disability.

Tāngata whaikaha Māori. Two or more Māori people with a disability.

Whaikaha. To have strength, be strong. Whaikaha is a positive, future-focused, enabling term. It was the te reo Māori kupu (word) selected in naming Whaikaha – Ministry of Disabled People (nd-a).

Whānau hauā. An ‘umbrella’ term gifted by Donny Rangiahau (Tūhoe) to Te Roopu Waiora (an Auckland Māori disability agency). It is a term explored by Māori disability advocates in work that reframes disability from an Indigenous perspective that emphasises the disabled individual as firmly located within the collective, as part of a wider whānau. Disability and oranga are collective issues for the whānau and not just for the individual (Hickey and Wilson 2017).

Appendix B: How we applied the principles of Te Tiriti o Waitangi to the review

Āpitihanga tuarua

Te Aho o Te Kahu - Cancer Control Agency has a responsibility to contribute to the Crown meeting its obligations to the special relationship with Māori under Te Tiriti o Waitangi. The principles of Te Tiriti o Waitangi as articulated in the Pae Ora (Healthy Futures) Act 2022 provide the framework for how the Agency will meet our obligations to Māori under Te Tiriti in our day-to-day work. The Agency is committed to upholding these principles. Our intent is to work in a manner that improves cancer outcomes for Māori.

Principle	Application to disability and cancer literature review
Tino rangatiratanga	Tāngata whaikaha Māori with lived experience and Māori cancer specialists involved in the scope/design of the literature review, Kaitiaki Research and Evaluation undertook an initial review of literature providing a summary of available evidence. Findings from the review generates evidence for Māori cancer specialists and Māori leaders in health across the system to advocate for and/or use in the design and delivery of cancer services that meet the needs of tāngata whaikaha Māori.
Equity	Establishing what the current state looks like for tāngata whaikaha Māori with cancer. We need to understand the nature and scope of inequities to inform our commitment, plans and actions to improve cancer outcomes.

Active protection	Evidence generated from this review provides the Crown with evidence to act and tāngata whaikaha Māori, iwi, hapū and Māori leadership with evidence to hold the Crown accountable in their efforts to improve health outcomes.
Options	Evidence generated from this review could be used to inform the design of kaupapa Māori cancer services or related health services that will ensure the right options for the system of cancer care in Aotearoa New Zealand to serve the needs of tāngata whaikaha Māori.
Partnership	This work highlights the case for tāngata whaikaha Māori to be co-designers with the Crown in the delivery of cancer services specifically, and health services generally, that better support the needs of tāngata whaikaha Māori and their whānau.

Appendix C: Disabled population insights

Āpitihanga tuatoru

Although not intending to be exhaustive, this section gives an overview of the health status and known inequities for eight parts of the disabled community:

tāngata whaikaha Māori
disabled Pacific peoples
disabled Asian people
disabled women
disabled people who live rurally
disabled members of Rainbow communities
disabled older people
disabled migrants and refugees.

This section has a focus on Aotearoa New Zealand data.

Tāngata whaikaha Māori

The prevalence of disability among Māori is likely underestimated due to under-reporting of both ethnicity and disability data (Jones et al

2023). Nevertheless, Māori have the highest prevalence of disability (age adjusted at 24%) compared with Pacific peoples (21%), European New Zealanders (18%) and Asian New Zealanders (13%) (Stats NZ 2023).

Tāngata whaikaha Māori have been observed to experience extremely poor and inequitable health outcomes compared with disabled non-Māori (Ingham et al 2022; Waitangi Tribunal 2023), including conditions such as diabetes, gout and stroke (Ministry of Health 2019b). Te Kupenga, a Stats NZ survey of Māori wellbeing (Stats NZ 2018b), found tāngata whaikaha Māori have poor health and wellbeing related outcomes. This included:

55% reporting their self-rated health status as high, compared with 84% of non-disabled Māori

51% reporting feeling cheerful or in good spirits all or most of the time, compared with 67% of non-disabled Māori

67% reporting having a high sense of control over their life, compared with 82% of non-disabled Māori.

King (2019, p35) links these inequities in outcomes to ‘exposure to the determinants of health and wellbeing, access to health and disability services, and the quality of health and disability care received'. This is in turn caused by the impacts of colonisation and racism, disability legislation, ableism and disablism (Hickey and Wilson 2017; Ingham et al 2022; Smylie et al 2018).

Tāngata whaikaha Māori have inequitable experiences of the determinants of health and wellbeing (Hickey and Wilson 2017; Ingham et al 2022). This can be outlined in a variety of ways:

The labour force participation rate for tāngata whaikaha Māori aged 15–64 was 34.4%, compared with 78.1% for non-disabled Māori (Stats NZ 2024).

The employment rate for tāngata whaikaha Māori aged 15–64 was 27.2%, compared with 71.2% for non-disabled Māori (Stats NZ 2024).

In 2013, 68% of disabled Māori adults had incomes of $30,000 or less and were less likely to be in the middle- or higher-income brackets than non-disabled Māori (Stats NZ 2015).

Tāngata whaikaha Māori adults are three times as likely as non-disabled Māori adults to indicate they do not have enough money to meet everyday needs (Ombudsman 2022).

Around four in ten disabled Māori lived in quintile five – the most deprived 20% of areas in Aotearoa New Zealand (Stats NZ 2015).

In 2013, 41% of tāngata whaikaha Māori had no formal qualifications, compared with 15% of non-disabled Māori (Stats NZ 2015).

Tāngata whaikaha Māori are more likely to experience cold and damp housing and unemployment, and less likely to participate in culturally popular recreational activities compared with non-disabled Māori (Ministry of Health 2018a; Stats NZ 2015).

Poor access to culturally safe health and disability care is also reported (Hickey and Wilson 2017; Ingham et al 2022). Ingham et al (2022) found that tāngata whaikaha Māori and their whānau often experience culturally unsafe disability services in Aotearoa New Zealand. The quality-of-service provision for tāngata whaikaha Māori and their whānau is negatively impacted by the dominant Western model of health, which focuses predominantly on the individual and ignores the collective and cultural values that underpin Māori world views (Ingham et al 2022).

There is differential quality of health and disability care for tāngata whaikaha Māori (Hickey and Wilson 2017; Ingham et al 2022; King 2019) – namely, issues with insufficient assessments, treatment, and access to culturally acceptable support, equipment and care funding (Bromhead et al 2021; Hale et al 2018; Ingham et al 2022; Ratima and Ratima 2007; Roy et al 2021; Stats NZ 2015).

Indigenous perspectives on disability are grounded in holistic views of health and wellbeing, and people are not defined or categorised by a single characteristic (Jones et al 2023). Western concepts of disability, particularly those that are deficit based such as the charity or medical models, are increasingly perceived by Indigenous populations to reflect 'a colonial tool of oppression' (Hickey and Wilson 2017; Jones et al 2023). Tāngata whaikaha Māori may experience barriers to connecting to te ao Māori, which is considered a negative impact that can sometimes be 'amplified' by their lived experience of disability – for example, barriers to accessing and engaging on their marae or whenua/land (Hickey and Wilson 2017; Jones et al 2023).

Pacific peoples

After adjusting for differences in ethnic population age profiles, the rate of disability amongst Pacific peoples in Aotearoa New Zealand is 21% (Stats NZ 2023). It is likely the prevalence of disability among Pacific peoples is underreported. This could be linked to differences in cultural beliefs about disability, which may cause individuals to be less likely to self-identify (Ministry of Social Development 2020).

There is limited information available about Pacific peoples' experiences of disability in Aotearoa New Zealand. A Ministry of Health (2008) report identified that Pacific peoples:

are less likely to receive a needs assessment than non-Pacific people with a disability

experience barriers to accessing recommended support services. Reported reasons for this include lack of coordination between disability providers and health services, and the difficulties experienced navigating a complex disability support system.

In a Youth2000 survey looking at intersectionality of multiple identities, Roy et al (2021) found that:

Pacific young people with a disability or chronic condition reported lower family acceptance, poorer safety at school, poorer mental health and wellbeing, and more forgone health care than Pacific young people without a disability or chronic condition (Roy et al 2021).

Pacific young people with a disability or chronic condition also reported greater housing and food insecurity, poorer access to health care, more forgone health care, and higher ethnic discrimination from health care providers, but were more likely to have good wellbeing than Pākehā young people with a disability or chronic condition (Roy et al 2021).

In two separate reports focused on Pacific People's, the Ministry of Health found:

A higher proportion of Pacific peoples (72%) live in the most socioeconomically deprived areas, compared with disabled non-Pacific people (42%) (Ministry of Health 2008).

Other key population groups

There are many other population groups who experience disadvantage in terms of health status and outcomes. Disabled people who identify as members of other population groups can experience cumulative layers of disadvantage (Edwards et al 2020; Hughes et al 2022). This includes Asian people, women, people who live rurally, Rainbow communities, older people, migrants, and refugees. This is not intended to be an exhaustive list, but rather to highlight the interplay of disadvantage that is cumulative when combined with disability.

Asian people

The Asian population makes up 17.3% of the population in Aotearoa New Zealand (Stats NZ 2023). After adjusting for differences in ethnic population age profiles, the rate of disability amongst the Asian population living in Aotearoa New Zealand is 13%. This is the lowest prevalence rate by ethnicity when compared with European New Zealanders, Māori and Pacific peoples (Stats NZ 2023). However, due to the considerable stigmatisation associated with disability, this is likely to be an undercount (Mehta 2012). There is very little information on disability amongst Asian people living in Aotearoa New Zealand.

Women

Women make up 50% of the total adult population of Aotearoa New Zealand. Within this population 18% identified as disabled women, 3% more than the proportion of males who identified as disabled (15%; Stats NZ 2023). Females were more likely to be disabled at all stages of life, except for childhood (Stats NZ 2023).

Women are a diverse population consisting of many different population groups, identities and cultures. A health system responsive to women is a health system that responds to the diverse population of women, inclusive of disabled women.

Gender bias in the health system means it often does not respond well to women's health and wellbeing. Women report experiencing challenges being heard and understood when accessing health care, a lack of understanding and support, racism, ableism, transphobia and homophobia. These issues raised by women affect their access to, and the quality of, health care they receive (Minister of Health 2023b).

Gender is also very relevant to broader determinants of health. For example:

The gender pay gap for disabled women compared with all men is 14.2% (Ministry for Women – Manatū Wāhine 2023).

According to the 2023/24 New Zealand Health Survey, 26% of disabled women had unmet need for a GP due to cost, compared with 16% of disabled men and 18% of non-disabled women (Ministry of Health 2024).

Lack of transport creating a barrier for health care is higher for women compared with men, particularly for disabled women (Ministry of Health 2024).

A New Zealand study of women with a learning disability found that in relation to breast and cervical screening programmes, women with a learning (and/or intellectual) disability are consistently less likely to participate in screening programmes compared with their non-disabled peers (Mirfin-Veitch et al 2016). Women with a learning disability were interviewed to better understand the drivers of this inequity. Themes collated from literature and the experiences of women reinforced common barriers:

attitudes and perceptions of third parties

a lack of responsiveness from health professionals who do give adequate focus to a woman’s needs (ie, communicative needs) or do not necessarily know how to respond to those needs

sense of fear, pain and anxiety for women associated with screening procedures and outcomes issues with receiving important health information in accessible formats

gaps in the knowledge and understanding of women with a learning disability or their close supporters (Mirfin-Veitch et al 2016).

Women are more likely than men to be disabled at all stages of life except for childhood (Stats NZ 2023).

Of note, people who do not identify as women may still require health services that are specific to female anatomy, such as cervical screening (Waring 2022).

People living in rural communities

People in rural communities face greater challenges accessing health services and specialist treatment. The challenges include the cost of accessing services and their geographical distance from specialist services, predominantly located in main centres. Nikora et al (2004, p14) note that:

> ‘the majority of disability support services, particularly specialist services are concentrated in major urban centres like Hamilton, Tauranga, and Rotorua. People in major urban centres are also more likely than

> those in minor urban centres like Gisborne, Whakatane, and Opotiki and rural communities like Murupara, Tirau, Ruatoki, Whatawhata, and Waimana to have a diversity of disability support services available to them, particularly community-based services focused on specific disabilities like stroke, blindness, deafness, epilepsy, and on specific types of service delivery (eg, Kaupapa Maori). However, in rural areas, tasks like visiting a medical practitioner, having blood tests completed, or accessing day care facilities, or specialists are complicated by the need for and expense of transport.'

Disabled people use health services at a rate at least double that of the non-disabled population, regardless of age or impairment (Health and Disability System Review 2020). They are also a population disproportionately impacted by poverty (New Zealand Productivity Commission 2023). Having the financial resources to mitigate the challenge of living rurally and accessing health care services as a disabled person means geographical location is an important consideration in the intersection of disadvantage.

Rainbow people (inclusive of LGBTTQIA+, SOGIESC, MVPFAFF+)

Rainbow people are represented across all demographics such as age, ethnicity and disability. A higher proportion of disabled people identify as part of Rainbow communities compared with non-disabled people (National Public Health Service 2023). The 2023 Stats NZ Household Disability Survey 2023 Summary showed the LGBTIQ+ population had a higher proportion of disabled people (29.9%) compared with the non-LGBTIQ+ population (17%), after adjusting for age the LGBTIQ+ rate was 31% (Stats NZ 2023).

Rainbow communities are marginalised groups. Rainbow disabled young people report feeling less safe at school, having higher levels of forgone health care and food insecurity, and having poorer health care access than non-rainbow, non-disabled young people (Roy et al 2021).

Members of Rainbow communities who identify with other marginalised identities, such as Māori, experience even greater harm due to cumulative layers of disadvantage or intersectionality (National Public Health Service 2023).

Older people

As we age, the likelihood of experiencing a disability increases. People aged 65 and older have much higher rates of long-term chronic health conditions and other impairments that require support on a daily or regular basis compared with young people (Associate Minister of Health 2016). In addition, inequities between ethnicities in this age group are notable and likely driven by inequities in income and employment rates, and barriers to health care access, including cost, transportation issues, and limited culturally appropriate services. In 2023, 35% of those aged 65 and over identified as disabled (Stats NZ 2023). Despite having a younger population age profile, within the 65 and over age group Māori and Pacific peoples experience higher rates of disability compared with European New Zealanders (Stats NZ 2023).

Migrants and refugees

Migrants and refugees experience attitudinal barriers (ie, inadequate cultural competency, stigma, racism) and structural barriers (ie, high user fees, limited entitlements) that impact their access to health care in Aotearoa New Zealand (Kanengoni-Nyatara 2024; Livingston 2023a).

Reports from refugee and migrant disabled people with lived experience of cancer in Aotearoa New Zealand speak to the intersection of disadvantage (Livingston 2023a). For example, Amr [not their real name] is a migrant with lived experience of cancer who was often made to feel unwelcome and a burden to the country. At their lowest point, they did not seek medical attention when they needed to and thought about ending their own life. Amr explains:

> ‘Many times I was told by people, sometimes by other patients, service providers and even some medical professionals that “New Zealanders” are dying because migrants like me were “cheating” and “stealing” their medical resources. Some even told me that I should go home and die there instead.
>
> For many years and even now still, I suffer from this mixture of internalised ableism, xenophobia, and racism. I often worry that I took too much space and feel guilty that I do not deserve to be here or be alive.’
>
> (Amr, as quoted in Livingston 2023a)

Appendix D: Search strategy

Āpitihanga tuawhā

A keyword search was performed in the Medline, Scopus, Embase, PubMed, Google Scholar and Europe PMC databases, as well as in the Analysis & Policy Observatory (APO) and King's Fund grey literature databases. An example of the search protocol used in Medline can be seen below.

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review and Other Non-Indexed Citations, Daily and Versions <1946 to June 21, 2023>

1 (disabilit* or impair* or "serious injury").mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

2 (cancer or oncolo* or haematology).mp. [mp=title, book title, abstract, original title,

name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

3 (cancer adj8 (treatment or "treatment option*" or "treatment outcome*" or barrier* or Delay* or screen* or detect* or Diagnos* or stage or equity or disparity or ableism or stigma or "unwarranted variation" or survivorship or mortality or morbidity or "life expectancy" or palliative or "mental health" or "disability support" or "social rehab*")).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

4 New Zealand.mp. or New Zealand/

5 disability.mp. or Intellectual Disability/ or "physical disability".mp. or "physical impairment".mp. or "long term disability".mp. or "congenital disability".mp. or "cognitive disability".mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

6 (outcom* or experienc*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

7 Indigenous Canadians/ or Indigenous Peoples/ or "Australian Aboriginal and Torres

Strait Islander Peoples"/ or "Native Hawaiian or Other Pacific Islander"/ or Maori People/ or pasifika.mp. or maori.mp. or "pasific people".mp. or "indigenous communit*".mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

8 1 and 2 and 3 and 5 and 6 and 7

9 1 or 5

10 2 or 3

11 6 and 7 and 9 and 10

12 2 and 5 and 7

13 1 and 3 and 7.

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