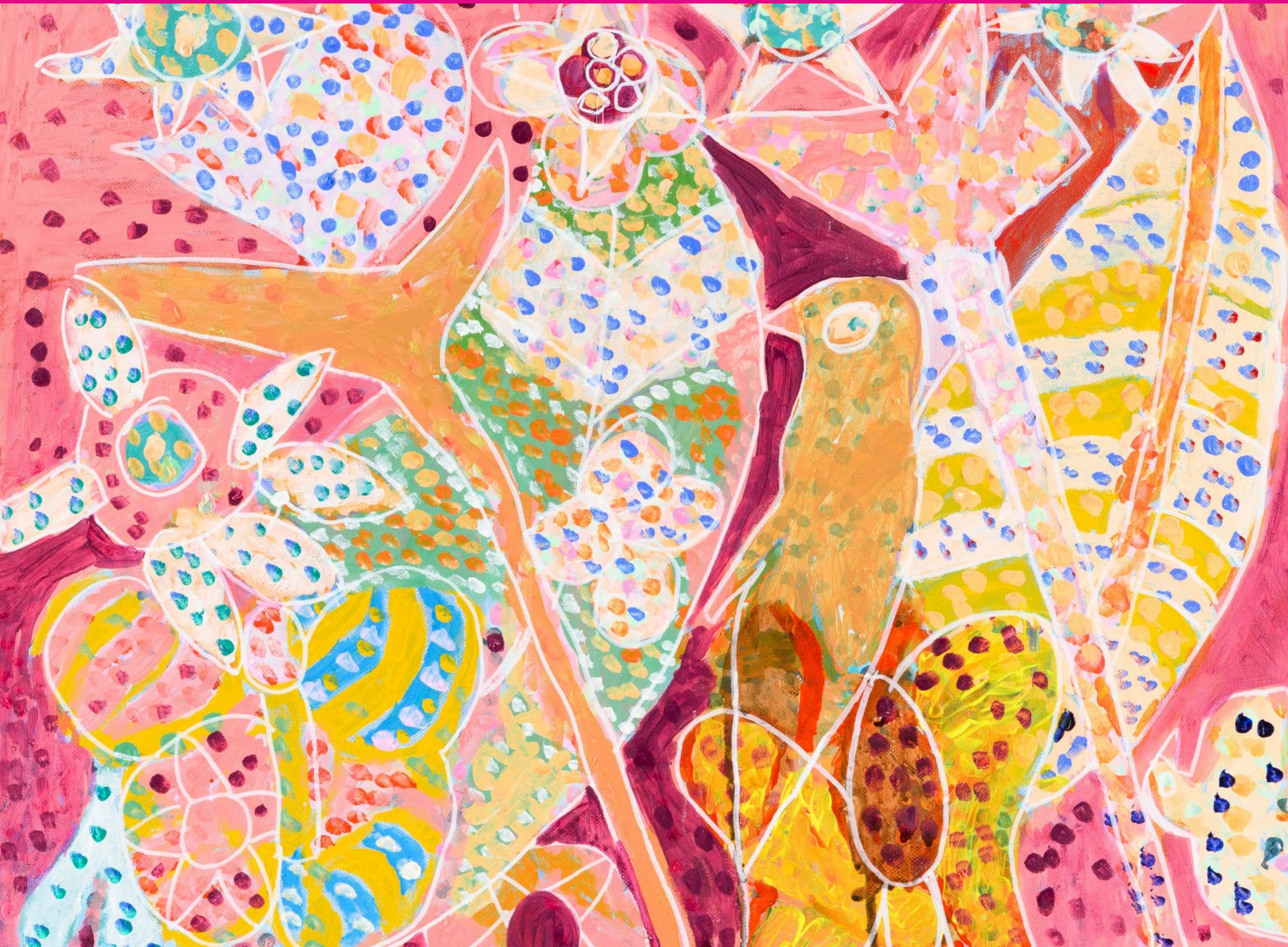
# Models of disability in Aotearoa New Zealand

Dr Nicolina Newcombe

2025



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**Suggested citation:**
Newcombe, N. (2025). *Models of disability in Aotearoa New Zealand*. IHC.

# Contents

# Introduction

Models of disability are theories. A theory is an idea that explains how something works. Models of disability create ways of understanding what disability is and what it means, which ultimately affects how we as disabled people understand ourselves and how society responds to us.

In this document, I show that different models of disability are appropriate for different people in different situations. Readers are reminded that both the medical and social models of disability (two of the most common ways of thinking about disability in Aotearoa New Zealand) originate in England, while Māori and Pasifika models may be more aligned with the context and values of Aotearoa New Zealand.

I know that Māori models of disability vary from *whānau* (extended family, family group) to whānau, and that the term 'Pasifika' encompasses hundreds of distinct cultures and languages. Much of the knowledge about both Māori and Pasifika models of disability remains unwritten. The information presented in this document is drawn solely from publicly available sources.

Understanding disability in Aotearoa New Zealand requires knowledge of the settler colonial context in which our systems, services, and dominant worldviews were formed. Colonisation is when non-Indigenous peoples take land and resources from Indigenous peoples and implement our own values and culture in that place, including ideas about ability, race, class, and gender (Pihama, 2019).

This document was a chapter in my doctoral thesis, *Using Inclusive Research with Participants with Learning (Intellectual) Disability to Better Inform Adult Literacy Policies in Aotearoa New Zealand*. I did not find a publication that discussed disability models in Aotearoa New Zealand, including Māori, Pasifika, and Western models, and sought to create a such resource, written from the perspective of a disabled person.

I acknowledge my PhD supervisors Dr Sonja Ellis, Dr Gretchen Good, and Dr Diana Amundsen. Further thanks must be extended to Tania Thomas, Director of Advocacy at IHC, for encouraging me to adapt my chapter into a booklet, and Shara Turner, Senior Advocate at IHC, for her contribution to the editing.

## Positioning statement

I am a late-diagnosed Autistic Pākehā woman with OCD. Most people in my family have some form of neurodivergence collectively representing most letters of the alphabet. I fully embrace my disabled identity and consider the advancement of disability rights to be my key purpose and way of self-actualising. I have participated in the disability sector for 15 years, mainly working with people with intellectual disability, and am currently employed by the largest disability organisation in Aotearoa New Zealand, namely IHC Group.

My paternal ancestors came from England in the 1960s to build schools in Aotearoa New Zealand. My Mother immigrated from the Netherlands.

I have a Master's in Māori and Pacific Development and completed my thesis under the supervision of *Decolonizing Methodologies* author Professor Linda Tuhiwai Smith. I later completed a PhD in Education.

**Ella Davenport**
*String Light Festival*
2025 IHC Art Awards Entrant

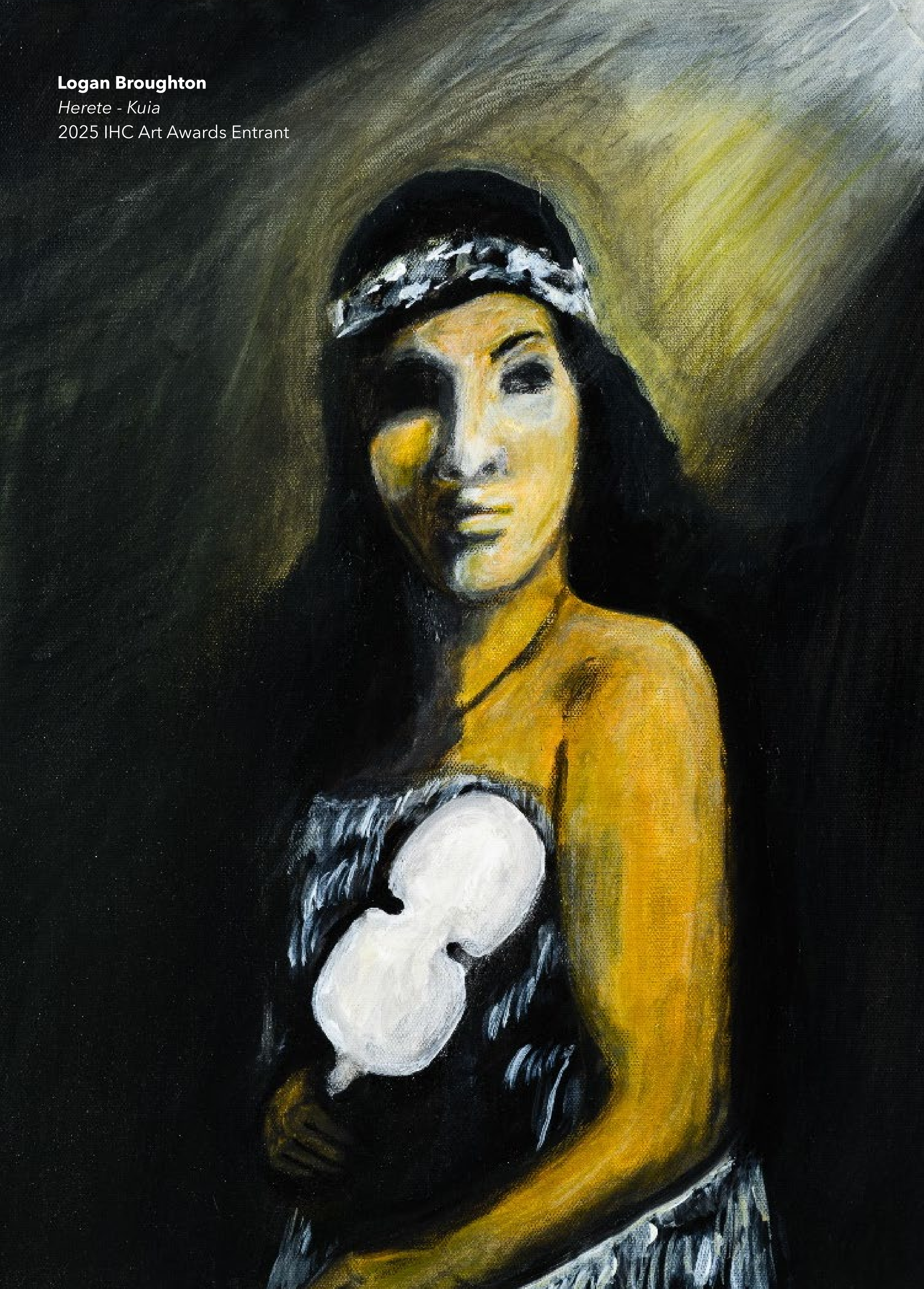
## Enabling Good Lives

Enabling Good Lives is a social movement that advocates for disabled people, *tāngata whaikaha* (people with disabilities), families, and whānau to have control over our lives and supports. It is grounded in the rights outlined in the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD), particularly Article 19, which affirms our right to live independently and be included in the community.

As a signatory to the UNCRPD, Aotearoa New Zealand has immediate obligations to implement the civil and political rights set out in the Convention, and to work towards realising our economic, social, and cultural rights. The Committee on the Rights of Persons with Disabilities makes observations about how Aotearoa New Zealand is progressing. The Committee identified that some disabled people have limited choice regarding where we live, who we live with, and what we do during the day (Committee on the Rights of Persons with Disabilities, 2013). These observations reflect a disability support system built on the medical model of disability, in which disabled people are viewed as individually disordered and offered specialised or segregated care. Enabling Good Lives represents a different approach, aiming to create a non-disabling society, in which we live, learn, and work alongside everyone else.

Enabling Good Lives has sought to achieve universally available supports through the social model of disability (Farrar, 2022). This model asserts that disability is caused by social and environmental barriers, rather than by individual impairments. However, while the social model addresses ability-based oppression, it does not fully capture the ongoing harms caused by racial and other forms of discrimination in our settler-colonial context. Whaikaha Ministry of Disabled People (2023, p. 10) notes that “tāngata whaikaha Māori, Pacific disabled people and other intersectional disabled populations experience greater disadvantage than other disabled people across most domains.” In practice, the social model of disability has failed to provide Māori with the same rights as other New Zealanders.

I argue that additional models of disability are now needed to realise the Enabling Good Lives vision: choice and control for disabled people, tāngata whaikaha, families, and whānau. As the Māori *whakataukī* (proverb) says, “*ka mua, ka muri*,” which translates to “walking backwards into the future,” we are invited to step outside the norm and ask new questions about what needs to be in our collective *kete* (basket, kit) as we advance towards an equitable future (Gray, 2024).



**Logan Broughton**
*Herete - Kuia*
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## Settler Colonial Context in Aotearoa New Zealand

Māori are the Indigenous peoples of Aotearoa New Zealand. The word Māori encompasses many whānau, *hapū* (kinship group, clan, tribe, subtribe), and *iwi* (extended kinship group, tribe, nation), who are distinct peoples. Aotearoa New Zealand is a colonised nation. Two treaties were signed in 1840-41 between Māori *Rangatira* (high ranking, chiefly, noble, esteemed), and the British Crown: 1) Te Tiriti o Waitangi (te Tiriti) written in te reo Māori and, 2) The Treaty of Waitangi (the Treaty) in English. There have been ongoing disagreements about the meaning, intent, and pre-eminence of the two treaties ever since (O'Sullivan et al., 2021). More Māori signed te Tiriti, an agreement outlining a partnership in which they continued to govern and maintain *mana* (prestige, authority, control, power, influence, status, spiritual power, charisma) over their lands and people, than those who signed the Treaty, a different version that cedes Māori sovereignty to the Crown (Orange, 2015).

Pākehā have not upheld our end of the authentic agreement signed by Crown representative Captain William Hobson and the majority of Rangatira (Orange, 2015). We have instead engaged in the colonisation of Aotearoa New Zealand for generations, bringing about disastrous consequences (Human Rights Commission, 2012; Newcombe & Amundsen, 2022; Pihama, 2019; Smith, 2021). Alongside setting up a government in Aotearoa New Zealand based on the one in England and making more than 50 laws that made life harder for Māori (see Network Waitangi, 2018, pp. 56-63), we also brought in our own ideas about disability. This included the medical model of disability, and the more general belief that disabled people are different from non-disabled people.

As Pākehā, part of becoming better te Tiriti partners is to decentre our own culture (Awatere, 1984). We seek to understand our norms as British ideologies with histories and origins, alongside our learned appreciation of the *mātauranga* (knowledge, wisdom, understanding) and *kaupapa* (a philosophical doctrine, incorporating the knowledge, skills, attitudes, and values of Māori society) that defined Aotearoa before we arrived (King, 2019; Kingi & Bray, 2000).

## Person First and Identity First Language

There are two main ways to describe a disabled person:

1. Person first language 'person with disability'
2. Identity first language 'disabled person.'

Person first language uses a noun associated with personhood before introducing disability as an adjective, for example, children with Down syndrome or women with vision impairment. Conversely, identity first language uses a disability adjective before the noun, for example, autistic teens or Deaf fathers. There are valid reasons supporting the use of either person first or identity first language, and different groups tend to have different preferences.

Person first language aims to empower by focusing on our common humanity rather than on perceived differences brought about through disability (Best et al., 2022). Using person first language can promote respect (Best et al., 2022), and reduce stigma (Botha et al., 2023) and bias (Dunn & Andrews, 2015). It is worth noting that the *United Nations Convention on the Rights of Persons with Disabilities* uses person first language.

Everyone should be referred to as people first in person first language, not only people with disabilities (Gernsbacher, 2017). For example, 'people without intellectual disability' or 'individuals who are gifted'. However, Gernsbacher (2017) found that person first language is used up to 700 times more frequently to describe children with disabilities than children without disabilities. Based on how person first language is applied in practice, she argues that it increases bias rather than reducing it.

Identity first language intends to reclaim disability as a form of diversity. It is similar to how other minoritised groups, such as Black people and gay people, use language to show pride in their identity (imagine saying 'a person who is gay', 'or a person who is Black') (Parsons, 1999). Oliver (1990) advocated identity first language for a different reason: identity first language aligns with the social model of disability, where a person is disabled by their environment, rendering them a disabled person. Furthermore, that identity first language reflects the essential role of disability in the lives of disabled people (Oliver, 1990).

Most people with intellectual disability use person first language. This approach has been socialised by People First, a self-advocacy movement run by and for people with intellectual disability, following a consensus about their preference for person first language reached at the first People First conference in Oregon 1974 (Wehmeyer et al., 2000).

Whaikaha Ministry of Disabled People (2025) promotes the use of identity first language in Aotearoa New Zealand, as recommended by the New Zealand Disability Strategy Revision Reference Group. Even though most Māori emphasise being Māori as their central identity (Ministry of Health, 2018). With this information in mind, claiming that disabled people in Aotearoa New Zealand use identity first language further marginalises two group, people with intellectual disability and tāngata whaikaha.

### Māori Kupu

Disability is a colonial construct so English words such as 'intellectual' and 'disability,' may not be culturally appropriate for Māori (Bevan-Brown, 2015a; Hickey & Wilson, 2017; Jones et al., 2023). Huhana Hickey (2006, p. 37) called the word disability "inherently negative," and Jones et al. (2023, p. 3) said, "the term 'disability' has been designated a symbol of colonialism." Carrucan (2021) agreed, saying the words "disability" and "disabled" are not acceptable in his iwi.

*Tāngata whaikaha* is one contemporary Māori kupu (*word*) for disability. It means "people who are determined to do well," and demonstrates person first language in accordance with a Māori first perspective (Ministry of Health, 2018, p. 4). It is the term used in this document.

Other kupu include *whānau hauā* (explained in the next section), *māuiui* (sickness, disorder), and words for specific identities such as *tāngata Turi* (Māori Deaf) (Jones et al., 2023). Some Māori use diagnostic names for medical conditions and impairments, largely to meet their needs for rehabilitation, funding, or support while navigating Pākehā led systems (Jones et al., 2023).

## Māori Models of Tāngata Whaikaha

Within kaupapa Māori, knowledge of disablement is uncovered through *kōrero* (speech, narrative) with whānau, hapū, iwi, and communities as they struggle for *tino rangatiratanga* (self-determination) (King, 2019). Most of what is known about precolonial Aotearoa New Zealand indicates a reverence for tāngata whaikaha and suggests their full inclusion, even though the status could in some cases be understood as punishment for breaking *tapu* (prohibitions) (Bevan-Brown, 2013; Hickey, 2014; Tikao et al., 2009). The following four models describe some of the ways tāngata whaikaha are understood.

## Ordinary

Tāngata whaikaha are seen by many Māori as being the same as other Māori (Jones et al., 2023; Kingi & Bray, 2000). As Te Atakura Ryan expressed, "everyone is a *rangatira* (chief, noble person), doesn't matter if you have a disability, we have that *korowai* (cloak to denote significant celebrations and people of high esteem) [of being a rangatira] around them". Thus, many Māori hold tāngata whaikaha and non-disabled people in an equal regard. For some, being tāngata whaikaha is an ordinary element of their *whakapapa* (genealogy) (Jones et al., 2023).

## Whānau Hauā

*Whānau hauā* is a well-known Māori model (Hickey & Wilson, 2017). Hickey (2014, p. 161) introduced whānau hauā as, "Māori who are part of the family and who are uniquely different." Later, Hickey and Wilson (2017, p. 86) translated the kupu as "the wind that propels whānau with member(s) who have a disability." Both translations locate tāngata whaikaha within their whānau, which can be *whakapapa whānau* (genealogy) or *kāupapa whānau* (people with similar experiences) (Hickey & Wilson, 2017). The wind metaphor uses *pūrākau* (mythology, legends) to describe the experiences of whānau hauā within their environment as, "depending upon the mood of Tāwhiri-mātea [atua of the winds, clouds, rain, hail, snow and storms], the wind can quickly change the environment, making it unstable" (Hickey & Wilson, 2017, p. 86). As such, tāngata whaikaha navigate their environments with the help of whānau to attain stability in their lives (Hickey & Wilson, 2017).

Whānau hauā is informed by te whare tapa whā. *Te whare tapa whā* is a Māori health and wellbeing framework, in which a metaphorical *whare* (house) is upheld by four equal and interdependent walls (Durie, 1998). The walls are known as *taha wairua* (spirit side), *taha hinengaro* (mind side), *taha tinana* (body side), and *taha whānau* (extended family side) (Durie, 1998) Te whare tapa whā is used in whānau hauā because the model is holistic and non-pathologising (Hickey, 2014).

## Being Like Characters in Pūrākau

Pūrākau and metaphor are prevalent in many Māori understandings of tāngata whaikaha (Graham et al., 2023; Tikao et al., 2009). For example, Tikao et al. (2009) found that prior to colonisation, *kāpo* (blind person, blindness) was not regarded a disability, but as a gifting of greatness, with numerous pūrākau describing *atua* (ancestor with continuing influence, god, demon, supernatural being) as being kāpo. Such as Hina, wife of Maui, Murirangawhenua, Grandparent of Maui, Tāwhaki, relative of Maui, and Mahuika, goddess of fire. Jones et al. (2023, p. 8) similarly found that tāngata whaikaha were thought to have an "elevated status." Tāngata whaikaha may have also been recognised as guardians of *taonga* (treasure) (Bevan-Brown, 1996).

Comparisons have been made between tāngata whaikaha and characters in pūrākau. One Māori way of thinking about of what the *Diagnostic and Statistical Manual* would term Attention Deficit Hyperactivity Disorder (ADHD) is to be like the *Pīwakawaka* (fantail) who flick their wings and quickly change direction (Rangiwai, 2024). Another Māori approach is *mahi a Atua* (tracing ancestral footsteps) to reframe disability and psychiatric experiences as pūrākau. For example, a child with ADHD became ready to understand himself as being like a "curious and impish Māori Atua (deity) called Uepoto" (Rangihuna et al., 2018, p. 16). The interpretive nature of pūrākau mean that Māori understandings of tāngata whaikaha can be diverse and adaptive.

## Disability as Part of Colonisation

As noted, Western concepts of disability in Aotearoa New Zealand are intrinsically tied to colonialisation. Furthermore, the experience of colonisation is itself disabling. Examples of the disabling effects of colonisation include dislocation from or within whānau, *whenua* (land), *tikanga* (correct procedure, custom), or *te reo Māori* (Māori language) (Bevan-Brown, 2010, 2013, 2015a, 2015b; Graham et al., 2023; Ingham et al., 2022; Jones, 2023; King, 2019). Bevan-Brown (2010, 2015b) made a special note of Māori who consider the inability to speak te reo Māori to be a disability, and Graham et al. (2023) identified the link between land alienation and blindness. Furthermore, the direct consequences of colonisation on Māori health, such as being subject to higher rates of poverty, addiction, incarceration, and the removal of *tamariki* (children), have caused Māori to become disproportionally impaired (Kingi & Bray, 2000).

**Falefatu Carreras Enari**
*Shells*
2025 IHC Art Awards Entrant

## Pasifika Models of Disability

There are few publications about Pasifika models of disability as this knowledge is often restricted or sacred. However, the popao model of disability and Tagata Sa’ilimalo movement have been made available.

The popao model of disability is predominantly used by Tongan people in Aotearoa New Zealand (Tafa et al., 2009). The *popao* is an outrigger canoe used to navigate lagoons in Tonga. Lagoons are rich in sea life, but harvesting food in the lagoon requires an intimate knowledge of the environment as well as of the strengths and weaknesses of the vessel (Tafa et al., 2009). This metaphor for disability supports Tongans to reconnect with their culture and traditional activities, identify *kāinga* (family) and community roles, and recover skills and knowledge that may have been lost through their impairment (Tafa et al., 2009).

*Tagata Sa’ilimalo* is a movement and *tagata sa’ilimalo* (lower case) is an identity for Pacific disabled people (Vaka Tautua, 2022). The name was coined by the Tōfā Mamao Collective, a group of *tagata sa’ilimalo*, *nofo-a-kainga* (families), and *tautua soifua* (carers/supporters) in Aotearoa New Zealand (Tōfā Mamao, 2023). *Tagata sa’ilimalo* is *Gagana fa‘a Sāmoa* (Samoan language) and translates into English as *tagata* (person or people) *sa’ilimalo* (pursuit of success). It originates from the saying, *“malo le sa’ili malo, malo le finau, malo le tauivi,”* which means in English, “well done for pursuing success, well done for raising and arguing the point, well done for persevering with the struggle” (Tōfā Mamao, 2023, our vision). Pasifika peoples from other nations are encouraged to develop names in their own languages.

PhD researcher Nafatali (2023) used Tagata Sa’ilimalo to build a model called *Tapasā a Tagata Sa’ilimalo*, which aimed to guide professionals as they work with Pasifika kāinga of autistic children in Aotearoa New Zealand. The Tapasā a Tagata Sa’ilimalo model maps the experiences of those kāinga onto a compass with a central point being “Diasporic Adaptation to Neurodiversity” (Nafatali, 2023, p. ii). The practical implications of the Tapasā a Tagata Sa’ilimalo model are to recognise the ways in which many kāinga bridge traditional Pasifika beliefs and contemporary disability support services in Aotearoa New Zealand, as well as to highlight the essential role of language and culture as they navigate new experiences.

**Rhys Thomason**
*Marlborough Sounds*
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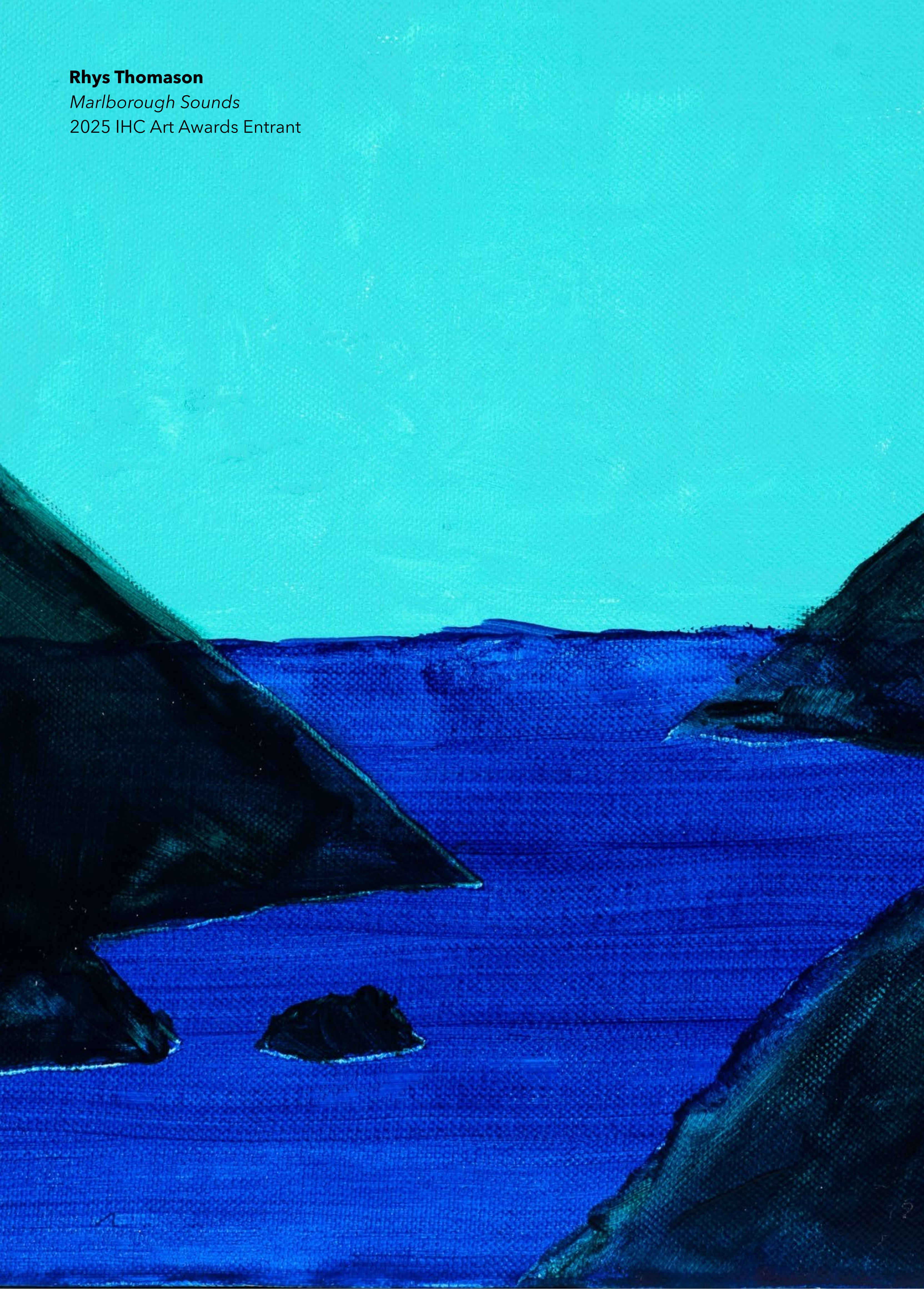


## Western Models of Disability

The Western models of disability most prevalent in Aotearoa New Zealand are the medical and social models. The medical model of disability is used in Aotearoa New Zealand law (Mander, 2022), diagnosis, and eligibility criteria for Disability Support Services (Ministry of Health, 2019, 2020). It is underpinned by the concepts of normal and ableism.

The social model of disability is used in the *New Zealand Disability Strategy 2016–2026* (Office for Disability Issues, 2016) and by Enabling Good Lives, a social movement promoting leadership by disabled people, families and whānau (Farrar, 2022).

### Normal

The term *normal* is a way to describe people who are privileged by the nature of their characteristics. For example, Herrnstein & Murray (1994) argued that intelligence follows a normal pattern of distribution across a bell curve, a graph shaped like a bell that shows how traits are spread across a population. The Intelligence Quotient (IQ) scores of most people cluster at the peak of the curve, reflecting average intelligence, while fewer people are positioned at either end, representing lesser or greater intelligence. Such a process of dividing people into standard (i.e. normal) and nonstandard populations underpins the medical model of disability (Davis, 1997). For people with intellectual disability, this means diagnosis tends to focus on perceived deficits and impairments in their cognitive abilities, marking them different from people with average or greater intelligence.

### Ableism

Ableism is the worldview that it is preferable to be non-disabled rather than disabled (Campbell, 2009). This way of thinking creates disability by dividing people into two groups: disabled and non-disabled as species-typical and therefore ideal. The two concepts depend on each other and help to keep the divide in place (Campbell, 2009).

The ableist idea that non-disability is a preferable state of being relies on the premise that disability is tragic (Campbell, 2009). The media, charities, and even some religious texts have often promoted this negative perception of disability (Swain & French, 2000). However, the tragedy view of disability is far more prevalent among non-disabled than disabled people; disabled people are less likely to consider their own disability as tragic (Heyman, 2018).

Gappmayer (2021) called ableism the social norming of non-disability. Wolbring et al. (2019) identified ableism as a form of governance that uses privilege to promote non-disability, such as by restricting education and employment to people who have certain abilities. Campbell (2009) pointed out that ableism makes it so many disabled people try to be seen as if they are non-disabled by practicing non-disabled ways of looking and behaving. Ableism may also produce impairment in real terms because people who experience ableism are more likely to develop mental and physical health problems (Nario-Redmond, 2019). In this way, ableism is itself disabling.

## *Hierarchy of Disability*

Ableism separates disabled people based on the types of impairment we have. It creates a ranking where non-disabled people are seen as better than disabled people, and people with physical disabilities are often treated as more acceptable than those with cognitive or mental disabilities.

House (1981) claimed that many people engage in what she called *ablebodiedism*, the tendency to recognise bodily impairments as legitimate while minimising the experiences of people with other disabilities. An example of how this phenomenon can manifest is in the heightened perception of people with intellectual disability as being non-productive (Gappmayer, 2021). He identified independence or life-skill development as being mainly aimed at people with intellectual disability, which reinforces the perceived gap between the skill level of people with intellectual disability and the normed skill level.

Using a social distance scale to measure sympathy towards people with different types of impairments, Tringo (1970) found that people with intellectual disability were ranked twentieth out of twenty-two disabilities, with the highest rank attracting the most social prejudice. That study established an understanding of a hierarchy of preference towards people with different types of impairments. Thomas (2000) replicated the hierarchy of preference study to measure attitude changes in the intervening 30 years between the studies. Surprisingly, 15 of the 16 disabilities included in both studies maintained their rank order.) The original hierarchy of preference that further marginalises people with intellectual disability has remained “firmly entrenched” (Thomas, 2000, p. 1156).

### *Ableism in the Neoliberal Era*

Ableism has a close relationship with neoliberal values (Aho, 2017; Campbell, 2015; Gappmayer, 2021; Goodley, 2014; Loseke & Green, 2019; Wolbring et al., 2019). Neoliberalism describes the increase of free-market capitalist ideals, for example individualism, and productivity, which have dominated the Western world since the 1980s, and underpinned much of Aotearoa New Zealand public policy since 1984 (O'Brien, 2020). Such ideals are founded on ableist notions of non-disability and have led to the norming of independence and employability (Aho, 2017; Goodley, 2014).

Scholars have increasingly drawn attention to the ways neoliberalism reinforces and reshapes ableism, creating social and economic conditions that marginalise disabled people. Goodley (2014) coined the term *neoliberal-ableism* to describe ableism within a neoliberal context. He argued that neoliberalism is intrinsically linked with ableism, as it causes ability to become increasingly essential to survive in the modern world. The precarity of neoliberalism also means that many people experience heightened anxiety about their ability to adapt to the market (Goodley, 2014). They seek to be resilient to government funding cuts and to avoid the stigma attached to receiving welfare, both of which favour non-disability (Goodley, 2014).

Aho (2017) used the term *labour-normativity* to describe the measurement of human worth in terms of remunerated or reproductive work. This situation is discriminatory because employment is not accessible for all disabled people (Kittay, 2015). A preference for nondisabled attributes has led some people to desire becoming, or to support others to become, normalised in specific and unique ways that are idealised in neoliberal societies, including Aotearoa New Zealand (Jones, 2019).

## The Medical Model of Disability

The medical model says that disability as an individual problem caused by disease, or injury (Berger, 2013; Goodley, 2017; Haegele & Hodge, 2016). The identification and isolation of impairments is key to the medical model of disability (Goodley, 2017). After categorisation, efforts are made to treat, rehabilitate, or cure disabled people (Goodley, 2017). Within the medical model, knowledge of disablement is found through systematic and objective modes of enquiry, for example by using scientific testing and observation (Berger, 2013).

Zaks (2024, p. 3234) argued, "the fundamental assumption of the medical model is that the bodies and brains of disabled people are tragically abnormal and that disabled individuals are responsible for any consequences of their presumed or actual incapacity." This way of thinking positions disability as a defect to be corrected through medical intervention. As the social model of disability gained prominence, shifting attention from individual impairments to societal and environmental barriers, many disabled people began to reject the medical model and the normalising treatments it promotes (Zaks, 2024). However, the relationship between disability and medicine is not straightforward. Some disabled people find value in medical care and actively seek treatment, the denial of medical support can itself be oppressive. To better reflect these tensions, Zaks (2024) proposed renaming the medical model as the *normalisation model* of disability, shifting the critique from medicine itself to the broader project of enforcing normative embodiment.

An important issue with the medical model of disability is how it works to maintain a hierarchy between disabled people and medical professionals (Goodley, 2017). As such, we are expected to agree with the decisions of medical professions about our disabilities (Goodley, 2017). However, Berger (2013) also recognised the impact of patient's rights advocacy and the increasing availability of medical information in moderating inequalities between the helper and the helped in that system. This means medical information is now more accessible to the public and can be more useful to disabled people when we are able to access and use it ourselves.

While the medical system has some benefits, the medical model of disability creates a power dynamic that assigns atypical bodies and minds to the realm of deviants (Chapman, 2020; Snyder & Mitchell, 2006). In contrast, the social model of disability emerged as a response to the medical model of disability, shifting the focus from individual impairments to the societal and environmental barriers that oppress disabled people.

Pros of the medical model of disability

- Treatment and rehabilitation options
- Knowledgeable and specialised experts
- Some medical information is now widely available, especially to those with access to the internet
- Creates a shared understanding of who is disabled
- Provides a way to ration services and supports.

Cons of the medical model of disability

- The medical model is based on norms
- Creates a hierarchy that privileges predominantly non-disabled 'professionals'
- Ignores people with disabled experiences who present slightly outside of a diagnostic threshold
- Does nothing to change social and environmental relations
- Has been used to justify the exclusion of disabled people
- At the logical extreme, it seeks to erase disability
- Not holistic.

## The Social Model of Disability

The social model of disability separates impairment from disability (Oliver, 1990). In this model, disability is a social phenomenon that arises from a mismatch between a person who has an impairment and their environment, leading to barriers to full participation (Oliver, 1990). Supporters of the social model find knowledge of disablement by investigating power relationships, such as identifying the impacts of inaccessible buildings or the way we create ability and disability through cultural artefacts (Barnes & Mercer, 2010; Berger, 2013; Goodley, 2017).

Prior to the early 1800s, people were not divided into disabled and non-disabled categories, even in Western contexts (Oliver, 1990). Stone (1984) argued that disability was made up to justify modes of distribution in capitalist societies. In *The*

*Disabled State*, Stone (1984) explains how some people cannot meet their needs through earning money from work, which is the primary mode of distribution in market economies, therefore, they require access to needs-based assistance, i.e. welfare. This system creates a forked pathway as some people are allocated the privileges and oppressions of meeting their needs through work and some people are allocated the privileges and oppressions of meeting their needs through welfare. In this way, "[disability] is an instrument of the state in controlling labour supply" (Stone, 1984, p. 179). Essentially, it is a way to maintain the dominance of labour.

Incorporating work by Stone (1984) on modes of distribution, Oliver (1990) explained how, prior to the Industrial Revolution, families, and communities included people with different abilities in their locally based farming and small-scale economies. However, urbanisation and technological advancements that occurred during the Industrial Revolution pushed families from their self-determined rhythms of production into less accessible waged labour (Oliver, 1990). At the same time, medical institutions were formed so that non-disabled people could work outside the home, without the responsibility of caring for disabled loved ones (Oliver, 1990). Therefore, according to Oliver (1990), disability was made up by the material conditions of the Industrial Revolution.

The strong social model of disability originated in Britain from a meeting of the Union of the Physically Impaired Against Segregation (UPIAS), a group of academically minded white heterosexual men with physical impairments (Goodley, 2017; Shakespeare, 2013). The UPIAS (1975) identified limitations on the full participation of disabled people in society as a form of oppression that results in disabled people being an oppressed group. In living without obvious intersectionality, members of UPIAS theorised a model distinctive in its simplicity but critiqued for lacking relatability for other groups, including people with intellectual disability and those with pain whose lives will not be significantly different in an alternative environment (Shakespeare, 2013).

Barnes and Mercer (2010) had two ideas about why the social model may disregard the bodily experiences of disability. First, it could be that founders of the social model, the UPIAS, were cautious about disabled experiences having the potential to conjure up empathy, which they viewed as counterproductive to radical disability politics. Second, that highlighting any physical, sensory of cognitive constraints could lend weight to the medical idea that disability resides with the individual (Barnes & Mercer, 2010). As Tom Shakespeare said in Barnes and Mercer (2010, p. 31), "to mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is 'really' about the physical limitation after all." These strategies for avoiding discussions about the lived experience of disabled people may reflect the male dominance of the UPIAS in their early work on the social model of disability (Barnes & Mercer, 2010).

Huhana Hickey and colleagues have criticised the social model from a Māori perspective. The social model shifts the genesis of disability from the person onto society, but the society is Western and fails to take Māori culture into account (Hickey, 2006). For example, the adoption of the social model in the *New Zealand Disability Strategy* (Office for Disability Issues, 2016) has not changed the practice of tāngata whaikaha being assessed as individuals and funded for services based on their impairments. These services are contracted to promote independence, in contrast with Māori practices of collectively and interdependence (Hickey, 2014). For these reasons, some have argued that the social model of disability is inadequate for Māori.

For Cameron (2010), the social model of disability hinges on the concept of impairment, yet disability is only one potential response to impairment, and it should not be assumed that impairment will necessarily lead to disability. This weakness in the social model pertains to its similarity with the medical model of disability. For affirmation model of disability authors Swain and French (2000), the social model does not centrally address the tragedy view of disability. The social model redefines the problem of disability, locating it within society rather than within the person, instead of challenging the idea that disability is a problem at all.

The social model of disability offered a radical and necessary alternative to the medical model, however, it is not without significant limitations. Critics have noted the inability of the model to engage with the lived, embodied experiences of disabled people, its neglect of intersectional perspectives, and its cultural specificity to Western, industrialised contexts. Moreover, its continued focus on disability as a site of deficit, although societally imposed, risks continuing the very marginalisation it seeks to challenge. Cultural models, such as those based on Māori or disability cultures may offer positive solutions for the future.

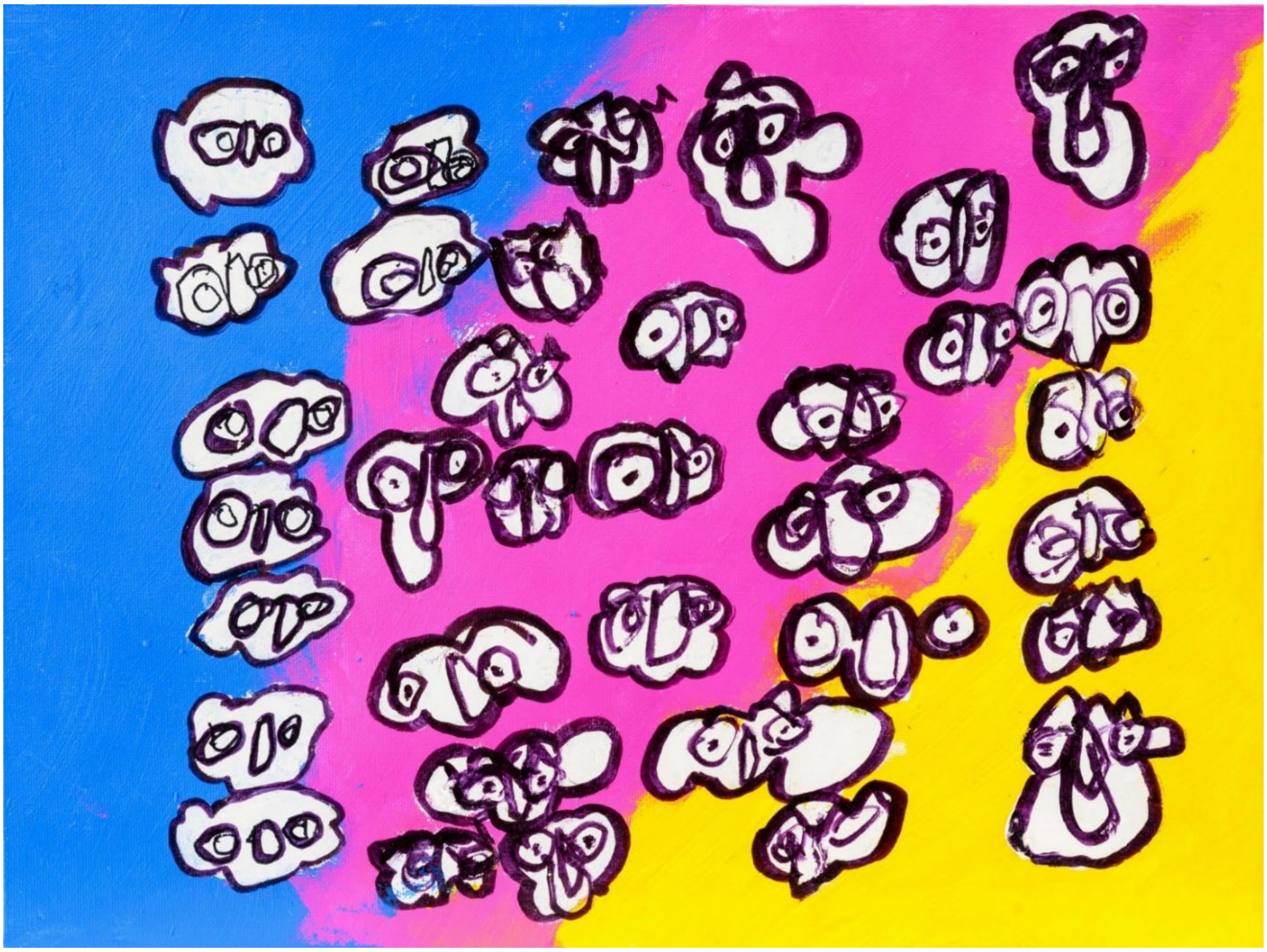
### Pros of the social model of disability

- Shifts the focus of change from the person to society
- Redistributes responsibility from medical professionals to everyone
- Advocates for collectivity among disabled people (avoids siloing by impairment type)
- Encourages full participation
- Promotes accessibility.

Cons of the social model of disability

- Positions disabled people as oppressed
- Denies the lived experiences of some disabled people, for example those who encounter pain, confusion, or distress
- Ignores how disabled experiences may persist, irrespective of social, political, or physical environments.

**Lewis Taito Matamua**
*Manu Samoa*
2025 IHC Art Awards Entrant



## Disability as Culture

In this document, the term *culture* is used to describe shared meanings within a group and diversity of meaning between groups (Highmore, 2016). As Highmore (2016) explained, culture can be thought of as the commonalities that distinguish a particular group as being unique. Berry and Triandis (2014) helpfully characterised culture as having three aspects. First, culture arises from interactions between people and their surroundings as they adapt to each other. Second, culture is expressed as commonalities among a group of people. Third, culture is passed down and preserved over time.

Many disabled people have asserted that disability is a culture (Garland-Thomson, 1997; Singer, 2017; Vasey, 1989). In her essay, *Disability Culture: It's a Way of Life*, disability activist Sian Vasey (1989) argued that disabled people have materially different lifestyles to nondisabled people and therefore we have our own culture. Disabled feminist Rosemarie Garland-Thomson (1997, p. 6) said, "I want to move disability away from the realm of medicine into that of political minorities, to recast it from a form of pathology to a form of ethnicity." The term *neurodivergence*, now commonly used by autistics, ADHDers and others, is a counter-hegemonic social movement and culture (Singer, 2016). Affirmation model of disability proponent Cameron (2007, p. 508) said "disability is created through interactions, expectations, assumptions, remarks and ways of doing things," which aligns with the understanding of culture outlined by cultural studies authors Highmore (2016) and Berry and Triandis (2014).

Disability culture draws on minority and civil rights movements (Snyder & Mitchell, 2006) and presents disability as a resistance to the status quo (Berger, 2013). Seeking self and cultural empowerment, this recounting of dominant cultural narratives presents "a world negotiated *from the vantage points of the atypical*" (Linton, 1998, p. 5). Disability cultures are inclusive of disabled identities. *Identities* are "complex theories about the social and moral world" (Siebers, 2006, p. 18). While each person has numerous identities, a disability identity is salient in the lives of disabled people, and often forms a "master status," which brings people together from different backgrounds (Gappmayer, 2021, p. 107).

## The Affirmation Model of Disability

Swain and French (2000) coined the term *affirmation model of disability* to describe a model that embraces disability as diversity and asserts that we establish identities and shared experiences through our differences as disabled people. The affirmation model rejects the sentiment that disabled people can be identified by the presence or absence of an impairment, as neither impairment nor oppressive encounters are unique to disabled people (Swain & French, 2000). Rather, exclusion, pain, and inability are common features in the lives of both disabled and non-disabled people. Furthermore, the degree of impairment at which a person can claim to be disabled is arbitrary. The affirmation model says that disabled people have a disabled culture and identity, rather than having an impairment or being affected by a disabling environment (French & Swain, 1997, 2008a, 2008b; Swain & French, 2000, 2008).

In the affirmation model, disability can include dysfunction or disorder, but can also include other human experiences, such as disability being "valuable, exciting, interesting, and satisfying" (Cameron, 2010, p. 35). For example, Shakespeare (1996, p. 81) said of the benefits of being disabled, "I am never going to conform to society's requirements and I am thrilled because I am blissfully released from all that crap". Another example is that intellectual disability can be a contributor to wellbeing. Skotko et al. (2011, p. 2363) observed, "the overwhelming majority of people with [Down syndrome] are happy with their lives, like how they look, and like who they are." In talking about the advantages of disability, the affirmation model represents a radical departure from a preference for ability.

Brandon and Pritchard (2011) explained the affirmation model by noting its similarity to the fat acceptance movement. While the medical model presents obesity as disordered, fat bodies are a source of pride and positive admiration for fat activists and others who appreciate size diversity. Like the fat acceptance movement, the affirmation model invites disabled people to "enjoy being who they are" and to take part in disability culture (Cameron, 2010, p. 35).

Cameron (2010) defines the affirmation model as disability being about:

- Being different and thinking differently about being different, both individually and collectively.
- The affirmation of unique ways of being situated in society.
- Disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal,

but also about the assertion, on their own terms, of human embodiment, lifestyles, quality of life and identity.

- Ways of being that embrace difference. (p.36)

Cameron (2023, p. 5) later updated his definition of the affirmation model of disability to,

> You are disabled if on a ‘substantial’ or ‘long term’ basis you have had to deal with other people’s oppressive expectations and assumptions about people with impairments and have on that basis found your life made difficult and your opportunities for equal participation restricted.

The affirmation model of disability could be particularly useful in Aotearoa New Zealand as Hickey (2006) drew on this model in her early work to create a communities-based model of disability in Aotearoa New Zealand, A forerunner to the whānau hauā model.

## Conclusion

I am proud to be disabled and understand my disability, which has a medical diagnosis of Autism Spectrum Disorder, as a culture. As a Pākehā, I am conscious of the role of colonisation in this land. While studying for my PhD in Education, I came to understand the medical and social models of disability as being part of colonisation and questioned why we keep using them in this country. I invite readers to understand all models of disability as having beginnings, purposes, pros and cons.

Disability in Aotearoa New Zealand cannot be fully understood or addressed through Western models alone. The dominance of the medical and social models, while each offering useful insights, reflects a settler colonial legacy that continues to marginalise tāngata whaikaha and other communities. The self-determination of Enabling Good Lives should extend to self-determining the models of disability that best enable our rights and aspirations.

Disability is not a fixed or universal category, but a culturally and politically constructed experience that is shaped by context, history, and power. Māori and Pasifika models of disability, as well as the affirmation model, provide important alternatives that centre collective wellbeing, cultural identity, and pride in difference.

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2025 IHC Art Awards Entrant

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