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**Using Inclusive Research with Participants with Learning (Intellectual) Disability to
Better Inform Adult Literacy Policies in Aotearoa New Zealand**

A thesis

submitted in fulfilment

of the requirements for the degree

of

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at

The University of Waikato

by

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THE UNIVERSITY OF
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Te Whare Wānanga o Waikato

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A call to action:

Continue exploring the literate lives of people with intellectual disability so that conceptualisations of what constitutes literacy for this group are broadened, local everyday literacies are recognised as legitimate, and people with intellectual disability are valued as literate members of society.

Morgan et al., 2013, p. 432

Why do you think it is important to get people with learning disability involved in research about them?

Because of their knowledge about who they are and what they believe in. It's more like that they are able to do different things and things that they can actually learn from. And actually doing research is important for people with learning disability. It actually is, learning on how to do it, and how they can get support for doing it.

Glen Terry, Advisor with Learning Disability, 26 February, 2024

Abstract

Western ideas about disability and literacy were developed in tandem during the Industrial Revolution and subsequently brought to Aotearoa New Zealand via colonisation. These ideas inform and reinforce educator attitudes, which are the leading factor impeding adults with learning [intellectual] disability from their educational pathways of choice. People without learning disability need to hear the voices of people with learning disability to counteract these attitudes and move towards transformational equality.

There is a paucity of information about the access to and accessibility of adult literacy education for people with learning disability in Aotearoa New Zealand. However, anecdotal evidence reports their exclusion, even from foundational adult learning. There was a gap in knowledge where collaborative research that conveys the experiences of adults with learning disability was needed to gain greater insight to these issues in our bicultural context. My original contribution to knowledge is to present the voices of adults with learning disability as they discuss and demonstrate their literacy practices, and to use their perspectives to make recommendations for adult literacy policies in Aotearoa New Zealand.

I undertook a thematic analysis of current adult literacy policies in Aotearoa New Zealand and found that they target “most” adult learners, while positioning disabled people as needing specialised, and by inference optional to provide, education and resources. These policies also prescribe a linear and progressive andragogy that may not meet the needs of all adults with learning disability, while measuring literacy skills in a way that does not foreground their strengths or value their purposes for engagement.

Then, I conducted Inclusive Participatory Action Research with five adults with learning disability to gather information about their literacy practices and perspectives. Participants in this research decided to call themselves the *Passioners*. We met for 10 research meetings, preceded by at least two home visits, and interspersed by reflective meetings with individual participants. All research information was presented in easy read and key information was distributed audiovisually.

The Passioners added value to this research by providing unique opportunities that are only available through doing inclusive research with them, prompting research improvements, innovation, and my efforts towards acculturation in their worlds. I evaluated my inclusive approach in this research to learn more about how people with learning disability do research *as* people with learning disability, and what dispositions, resources, and skills people without learning disability need to do research with them.

Using reflexive thematic analysis, I constructed six themes from our research meetings data: learning disability cultural literacies, *Māori* (Indigenous peoples of Aotearoa New Zealand) cultural literacies, *Pākehā* (New Zealanders of European descent) cultural literacies, encoding, decoding, and social media, which extends the narrow definition of literacy in our adult literacy policies. These findings, and those from my policy analysis, were used to inform policy recommendations. Policy recommendations in this research may support implementation of the *United Nations Convention on the Rights of Persons with Disabilities*, particularly access to lifelong learning on an equal basis with others.

Dedication

Dear **Sage**, there are no unlockable doors, there are no unwinnable wars, there are no unrightable wrongs, or unsingable songs, there is nothing that has happened in the past that cannot be reformed. I had my tattoo of you from when you were a baby covered by a Pīwakawaka as a sign of welcoming. A PhD is pretty cool, but nothing compares to family. We love you always.

People who do a PhD need a team of people who believe in and support them. My success is premised by my **Mum** and **Dad** being my biggest advocates. They have gone above and beyond for me. My sister **Jemima** is always at my metaphorical side. Importantly, **Jamie** is an amazing Dad for Tobias, which enabled me to pursue my special interest in this research.

Tobias, I handed this thesis in the day before you started school as a baton of education that goes from me to you. I promise to make sure you are privileged by the same or more opportunities to expand your mind as I have had.

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Dr Diana Amundsen was the first supervisor who saw my spark. Thank you for getting me to confirmation and co-authoring my first academic article with me.

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Dr Sonja Ellis sped up my progress with her sharp insight and extensive supervisory experience. Thank you for being so dedicated to your work, I wish I had been your student the whole time.

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Dr Ingrid Jones did her PhD on reimagining disability and demonstrated being with people and being academic. Thank you for role modelling inclusion that disrupts the status quo.

Stephanie Christie helped me get my Certificate in Adult Literacy and Numeracy Education, without which I never would have had the interest or confidence to do further research about literacy. Thank you for sharing your insights as an experienced adult literacy educator.

Prof Jonathan Scott I could not have done this without you. Thank you.

To my incredible research advisors, who will be introduced more formally in this thesis.

Thank you for being so approachable, committed, and constant sources of inspiration **Glen Terry** and **Te Atakura Ryan**. Finally¹,

¹ Images in the following page were photographed by the author or downloaded from Photosymbols in accordance with their licence agreement.

To the Passioners



Thank you for taking part in this research.



Your words and actions are helping other people learn more about literacy and people with learning disability.



Doing research with you helped me learn a lot and I had a lot of fun.

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Glossary of te reo Māori

All te reo Māori translations were sourced from *Te Aka Māori Dictionary* (Moorfield, 2024).

Āhuatanga Māori	Māori tradition
Atua	Ancestor with continuing influence, god, demon, supernatural being
Awa	River
Haka	Posture dance
Hapū	Kinship group
Harakeke	Flax, <i>Phormium tenax</i>
Hinengaro	Mind
Hui	Gatherings
Iwi	Extended kinship group
Kai	Food
Kāinga	Settlements
Kaitiakitanga	Guardianship
Kanohi ki te kanohi	Face to face
Kāpo	Blind
Karakia	Prayer
Karanga	Welcome call
Kaupapa Māori	A philosophical doctrine, incorporating the knowledge, skills, attitudes, and values of Māori society
Kīngitanga	Māori King movement
Kiwi	Flightless, nocturnal, endemic birds, <i>Apteryx mantelli</i> and <i>tokoeka</i> or <i>Apteryx australis</i>
Kōrero	Speech, narrative
Kōrero tuku iho	Oral tradition

Korowai	Cloak
Kupu	Word, vocabulary
Māori	Indigenous peoples of Aotearoa New Zealand
Marae	Courtyard
Mātauranga Māori	Māori knowledge
Māuiui	Sickness, disorder
Moko	Māori tattooing
Pākehā	New Zealanders of European descent
Papatūānuku	Earth mother and wife of Rangi-nui
Pīwakawaka	Fantail, <i>Rhipidura fuliginosa</i>
Poukai	Māori King movement gathering
Poupou	Carved figure
Pouwhenua	Post marker of ownership
Pōwhiri	Welcome ceremony
Pūrākau	Mythology, legends
Rangatira	Chief, noble person
Taha	Side
Taituarā	Support
Tamariki	Children
Tāngata Turi	Māori Deaf
Tangi	Funeral
Taonga	Treasure
Tapu	Prohibitions
Tāwhiri-mātea	Atua (god) of the winds, clouds, rain, hail, snow and storms
Te ao Māori	the Māori world
Te reo Māori	Māori language
Tikanga	Correct procedure, custom
Tinana	Body
Tino rangatiratanga	Self-determination

Tiritiria	Apportionment
Tohunga	Experts, healers
Waiata	Song
Wairua	Spirit
Waka	Canoe
Wānanga	Instruction or tertiary institution that caters for Māori Learning needs
Whakairo rākau	Carving
Whakapapa	Genealogy
Whakataukī	Proverb
Whakawhanaungatanga	Process of establishing relationships
Whānau	Extended family
Whare	House
Whenua	Land

Glossary of Acronyms

AAC	Augmented and Alternative Communication
ACE	Adult Community Education
ADHD	Attention Deficit Hyperactivity Disorder
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DPO	Disabled People's Organisation
DQ	Delivery + Qualification
HREC	Human Research Ethics Committee
IALS	International Adult Literacy Survey
ILN	Inclusive Literacy and Numeracy
IPAR	Inclusive Participatory Action Research
IQ	Intelligence Quotient
LNAAT	Literacy and Numeracy Adult Assessment Test
NZQCF	New Zealand Qualifications and Credentials Framework
NZSL	New Zealand Sign Language
OECD	Organisation for Economic Co-operation and Development
PAR	Participatory Action Research
SPAT	Starting Points Assessment Test
SRV	Social Role Valorisation
SSG	Special Supplementary Grant
TA	Thematic Analysis
TEC	Tertiary Education Commission
UNESCO	United Nations Educational, Scientific and Cultural Organization
UPIAS	Union of the Physically Impaired Against Segregation

1 Chapter One: Context

This chapter first describes the story that prefaces and inspired this research. It then discusses terminology used to describe the people whom this research is about. The next part is an introduction to United Nations agreements and the right to adult education, followed by an overview of wider contextual issues that frame this research. Finally, the structure of this thesis is outlined, and the purpose and benefits of this research are given.

1.1 Background to this research

Some years ago, I accompanied a man with learning disability to our local polytechnic² so that he could enrol in an open entry course. I expected he would be successful in his application, as there are no academic requirements for domestic students taking part in these courses. However, the question, “what is your reading and writing like?” was asked. He was then directed to an adult literacy education provider, instead of being admitted to the institute of technology alongside peers. I was perturbed by this interaction, in which an assumption about the literacy of a person with learning disability appeared to form a barrier to his pathway of choice. There were funded courses available at that polytechnic for which he met the entry criteria, yet his enrolment did not occur.

Then, while becoming qualified as an adult literacy and numeracy educator, I identified that adults with learning disability, whom I expected to be at a higher risk of having low literacy skills, were absent from the adult literacy policies. I questioned why a group I assumed to be among those with the greatest need for literacy education seemed to receive the least attention from the Tertiary Education Commission (TEC). Having worked with adults with learning disability who had unmet goals to engage in literacy or other education, I began to

² A tertiary education institution that offers vocational and technical education and training. These institutions provide a wide range of programs and courses focused on practical skills and applied knowledge.

wonder if they were able to access lifelong learning “on an equal basis with others” (United Nations, 2007, Article 24.5), with literacy being the foundation of the right to education (UNESCO, 2019).

I later authored a book with consultants with learning disability. Their valuable offerings transformed my understanding of who is literate and enabled me to recognise discrepancies between prevailing assumptions about the literacy of adults with learning disability and their actual position as literate members of society. I decided to find out more about what literacy is and who is literate from the perspective of adults with learning disability, with a view to advocating for their rights under the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD).

My original contribution to knowledge is to present the voices of adults with learning disability as they discuss and demonstrate their literacy practices, and to use their perspectives to make recommendations for adult literacy policies in Aotearoa New Zealand. This contribution addresses a significant gap in the literature as there appears to be no existing research about literacy from the perspective of adults with learning disability in the bicultural context of Aotearoa New Zealand. They have also not been consulted or actively involved in the development of any of our adult literacy policies (see *Appendix A*) and are not the subject of any research informing the adult literacy policies in Aotearoa New Zealand. In neglecting to carry out this consultation or active involvement, the TEC may not be working in alignment with Article 4.3 of the CRPD, which reifies the disability movement dictum “nothing about us without us.” It has been noted internationally that the voices of people with learning disability are largely absent from social policies, resulting in a lack of awareness about their specific contexts and preferences (Gómez-Carrillo de Castro, 2023). Yet those who have lived experience, in this case people with learning disability, are the only people who can truly understand and represent their knowledge (Smith, 2021). Their voices lend experiential insights that can be used in future policy development.

As there is no existing research to draw from, there is no way to measure the implications of the adult literacy policies for people with learning disability outside of anecdotal evidence.

Most adults with learning disability are likely to meet the eligibility criteria for adult literacy education funded by the Intensive Literacy and Numeracy (ILN) fund, which are to be a domestic student and have low skills in either or both of literacy and numeracy (TEC, 2024a). However, that most adults with learning disability would meet the eligibility criteria for these courses does not necessarily guarantee their admission. One example of anecdotal evidence I am aware of is that a local family approached an ILN funded adult literacy education provider in their area during this research, but that provider was not ready to accept all learners, “they were clear that their courses might not suit learning disabled adults” (personal communication, 13 February, 2024). Unfortunately, courses containing embedded literacy learning that are designed specifically for adults with learning disability have also proven difficult for some adults with learning disability to enrol in. As the local family found, “I understand you need to employ a support person to accompany you on this [New Zealand Certificate in Skills for Living for Supported Learners] course. That’s making it difficult for people we know” (personal communication, 14 February, 2024). These anecdotes reinforce what was said by Furness et al. (2021), that adults with the lowest literacy skills have the fewest opportunities to engage in adult literacy education.

This research is now timely due to ongoing shifts in the conceptualisation of literacy within the international community, and recent trends in adult literacy and related policies in Aotearoa New Zealand. The TEC understands literacy as reading, writing, speaking, and listening. However, the international community has been progressing to a more expansive view of literacy that includes reading and writing but is also characterised by contribution, sustainability, increased awareness, critical reflection, and citizenship (UNESCO, 2011, 2019). For example, the extension of literacy to include *Māori*³ (Indigenous peoples of Aotearoa New Zealand) cultural literacy, being the maintenance and promotion of culture and the ability to live well as Māori (Leach et al., 2010; Zepke, 2011), was acknowledged and celebrated by UNESCO (2016). Some changes in Aotearoa New Zealand adult literacy

³ The Indigenous peoples of Aotearoa New Zealand are collectives of *whānau* (extended family), *hapū* (kinship group) and *iwi* (extended kinship group) with regional histories, practices, and dialects (Leoni et al., 2018). The term Māori is plural and used to encompass these groupings.

policies conducive to the aims of this research have already occurred during my candidature and are described in *Section 9.2*. These changes align with the current *Tertiary Education Strategy* objective for barrier free access, in which, “great education opportunities and outcomes are within reach for every learner” (Ministry of Education, 2020b, p. 1). It is amidst these evolving possibilities that this research set out to validate the literacy practices of adults with learning disability in Aotearoa New Zealand.

1.2 Defining Learning Disability

This research uses the term “learning disability” as a positive renaming of what legislation in Aotearoa New Zealand terms “intellectual disability.” The person first term “people with learning disability” is preferred by people whom the term refers to. We know this because People First New Zealand (n.d-b), which is led by and for people with learning disability, has endorsed the use of that term.

According to the Ministry of Health (2003), *intellectual disability* is a permanent impairment resulting from an intelligence quotient expressed as 70 points or less and identified before a person reaches the age of 18 years. In Aotearoa New Zealand, clinicians use an *Intellectual Disability Diagnostic Assessment*, which includes observational, historical, and psychometric assessments, to identify people with learning disability (Explore Hāpainga Ora, n.d, accessed 01 November, 2023). However, the alignment of the term intellectual disability with the medical model of disability may detract from its use by people with learning disability. For example, the *Diagnostic and Statistical Manual of Mental Disorders: DSM-5* categorises Intellectual Development Disorder as mental *disorder*, which requires a “clinically significant disturbance” (American Psychiatric Association, 2013, p. 20) and lists three criteria for Intellectual Development Disorder, each beginning with the word “deficits” (American Psychiatric Association, 2013, p. 33). Furthermore, the term intellectual disability conjures up collective memories of the medical era of learning disability (1904-1990), when

sterilisation, eugenics, and institutionalisation were more common, and many people with learning disability experienced extreme powerlessness in their lives (Jarrett & Tilley, 2022; Wehmeyer et al., 2000). For these reasons, many people choose to avoid the term intellectual disability.

1.2.1 Disambiguation from Specific Learning Disabilities

The term “learning disability” is commonly used in North America (Clouser, n.d) to describe people who would be categorised as having *specific learning disabilities*, such as dyslexia, dyspraxia, dysgraphia, and dyscalculia, in Aotearoa New Zealand (Speld NZ, n.d). Specific learning disabilities pertain to a different set of conditions than those that could be categorised as an intellectual disability using the medical model of disability (Dyslexia Foundation of New Zealand, 2014). As the Dyslexia Foundation of New Zealand (2014) explain, specific learning disabilities are forms of learning preference. Other key differences are that people with learning disability and people with specific learning disabilities are served by different organisations and have different assessment and support pathways (see *Figure 1*). Notwithstanding the similarity of the terms “learning disabilities” and “specific learning disabilities,” people with learning disability is currently the most respectful terminology to use in Aotearoa New Zealand for the group this research is about (People First New Zealand, n.d-b).


Specific Learning Disabilities (dyslexia, dyscalculia etc).	Learning disability (intellectual disability)
One of six priority areas in the last Literacy and Numeracy Implementation Strategy	Not mentioned in the adult literacy policies
	
Woodcock Johnson IV assessment	Intellectual Disability Diagnostic Assessment
An SLD does not make someone eligible for Disability Support Services in Aotearoa New Zealand	Eligible for Disability Support Services in Aotearoa New Zealand

Figure 1 Differences between specific learning disabilities and learning (intellectual) disability

1.2.2 Person First and Identity First Language

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 (American Psychological Association, 2020). Conversely, identity first language uses a disability adjective before the noun, for example, autistic people or Deaf people (American Psychological Association, 2020). There are valid reasons supporting the use of either person first or identity first language.

Person first language intends “to empower individuals with disability by placing emphasis on their humanity rather than their impairments” (Best et al., 2022, p. 127). A consensus was reached by people with learning disability about their preference for person first language at the first People First⁴ conference in Oregon 1974 (Wehmeyer et al., 2000). The literary

⁴ A self-advocacy movement run by and for people with learning disability.

convention can promote respect (Best et al., 2022), and reduce stigma (Botha et al., 2023) and bias (Dunn & Andrews, 2015). Yet the effectiveness of person first language in achieving those aims is contested.

Person first language conventions state that all people should be referred to as a person first, not only people with disabilities (Gernsbacher, 2017). For example, children who are neurotypical or individuals who are gifted. However, Gernsbacher (2017) found that person first language is not used consistently for both people with and without disabilities. For example, in *Web of Science* titles, person first language is 700 times more likely to be used for children with disabilities than for children without disabilities. Therefore, Gernsbacher (2017) argues that person first language enhances linguistic bias rather than avoids it.

Identity first language intends to reclaim disability as diversity and locate disabled people alongside other minoritised groups, such as Black people and gay people (Best et al., 2022; Dunn & Andrews, 2015). Oliver (1990) asserted that identity first language aligns with the social model of disability, wherein 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).

The Office for Disability Issues (2020) promotes the use of identity first language in Aotearoa New Zealand⁵, although there is a caveat for Māori because most Māori identify as Māori first. I have chosen to use the term people with learning disability in this research, in line with the preference of those whom it describes (Garbutt et al., 2010; People First New Zealand, n.d-b; Wehmeyer et al., 2000; White & Morgan, 2012). General references to disabled people will use identity first language.

⁵ As recommended by the New Zealand Disability Strategy Revision Reference Group.

1.2.3 Māori Kupu

There is no universally agreed terminology for describing disability within *te ao Māori* (the Māori world) (Jones et al., 2023). However, it is known that Pākehā words for disabilities, such as “intellectual” and “disability,” may not be culturally appropriate for Māori (Bevan-Brown, 2015a; Hickey & Wilson, 2017; Jones et al., 2023). 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* (extended kinship group).

Māori disability researchers Jones et al. (2023) used the phrase *Māori with lived experience of disability* to encompass multiple terms used by their participants. Kupu included *tāngata whaikaha*, *whānau hauā* (see Section 2.3.2), *māuiui* (sickness, disorder), and references to identities such as *tāngata Turi* (Māori Deaf). Some participants used diagnostic names for medical conditions and impairments, which was largely accepted to meet their needs for rehabilitation, funding, or support (Jones et al., 2023).

Tāngata whaikaha is one contemporary Māori kupu for disability. It means “people who are determined to do well,” and demonstrates person first language in accordance with a Māori first perspective, as Māori emphasise being Māori as their central identity (Ministry of Health, 2018, p. 4). The kupu *tāngata whaikaha* is prevalent in public policy as exemplified by Whaikaha Ministry of Disabled People (n.d), the Ministry of Health (2018), and in New Zealand legislation to describe Māori with disabilities (Parliamentary Counsel Office, 2022). I will use the kupu *tāngata whaikaha* to describe Māori with disabilities in this research, in line with its common usage in Aotearoa New Zealand.

1.3 United Nations Agreements and the Right to Adult Education

The right to adult education is enshrined in the CRPD, which says, “States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others.” (United Nations, 2007, Article 24.5). The CRPD does not specify literacy as an educational right, although United Nations human rights conventions are strategically aspirational rather than binding and ambiguous rather than detailed to encourage their adoption by disparate States Parties (Mazzeschi, 2022). UNESCO (2013, 2019) clarified this detail, finding literacy foundational to the right to education⁶. In 2015, the Education World Forum committed United Nations Member States (including Aotearoa New Zealand) to improve adult literacy among their citizens by 50 percent (Tang, 2015). That forum resulted in the *United Nations Sustainable Development Goal 4 (SDG4)*, which is to, “ensure inclusive and equitable quality education and promote lifelong learning opportunities for all” (United Nations, 2015). The *UNESCO Strategy for Youth and Adult Literacy (2020-2025)* (UNESCO, 2019) was developed to give effect to SGD4. The strategy promotes lifelong and life wide literacy learning, and plans to achieve this through advocacy, capacity building, monitoring, and evaluation. UNESCO (2011, 2019) also recommended enriching literacy environments, such as by providing audio, visual and written information in public places, as a key factor in the promotion of literacy learning and subsequent achievement of SDG4. These goals and agreements underscore the importance of inclusive and equitable education, with literacy being an intrinsic element in the pursuit of lifelong learning opportunities for all.

⁶ In Aotearoa New Zealand, all foundation level education includes a literacy component.

1.4 Wider Contextual Issues

This section presents information relevant to the broader context of this research and compares practices in Aotearoa New Zealand with those internationally. The first is about lifelong learning for adults with learning disability in Aotearoa New Zealand. The second details comparable opportunities available in other countries. The third is about barriers to adult literacy education for people with learning disability in both Aotearoa New Zealand and other countries. Understanding these barriers could serve as a background to adult literacy policy recommendations that seek to promote their equal access. The fourth is about literacy assessments that have been used with adults with learning disability internationally. The fifth focuses on assumptions about the literacy of adults with learning disability, noting how they have been applied in Aotearoa New Zealand. These assumptions influence the attitudes of educator, thereby affecting their opportunities for literacy learning and their status as literate members of the community.

1.4.1 *Lifelong Learning for Adults with Learning Disability in Aotearoa New Zealand*

There are two main tertiary qualifications intended for adults with learning disability in Aotearoa New Zealand: the *New Zealand Certificate in Skills for Living for Supported Learners (Level 1)* (New Zealand Qualifications Authority, 2023), and the *New Zealand Certificate in Skills for Learning and Working, for Supported Learners (Level 1)* (Te Pūkenga, 2023). Both qualifications contain embedded literacy and numeracy education and are available at many but not all divisions of *Te Pūkenga* (The New Zealand Institute of Skills and Technology). They do not extend to the arguably more prestigious university environment.

1.4.2 International Inclusive Post School Education Programmes

Isolated university based Inclusive Post School Education programmes are offered in Australia (Ticket to Work, 2021), North America (Think College Institute for Community Inclusion, 2023), and Europe (Join In, n.d). According to Johnson (2023), university students with learning disability in the United Kingdom used their enrolment as an alternative to disability support services and reported improvements in their confidence and motivation that were related to both the experience of being a student and the course work itself. Gaining a student ID card and graduating alongside their peers were of key importance to these students. However, IPSE programs have been limited by tuition costs, campus accessibility, lack of transport, and the attitudes of educators, such as perceived limitations on the learning ability of adults with learning disabilities and a belief that enrolment in tertiary education is setting them up to fail (Johnson, 2023; Moni et al., 2018).

1.4.3 Barriers to Literacy Education for Adults with Learning Disability

It is challenging to ascertain the barriers to adult literacy education in Aotearoa New Zealand because as noted, there is no data and no research available about their participation in this arena. Furthermore, there is limited data about their participation in tertiary education (see *Section 9.4.2*). However, it can be inferred that many adults with learning disability may experience the same barriers to general education as those reported in international and Aotearoa New Zealand literature, and the same barriers to adult literacy education discussed in international literature. The adult literacy policies and other legislation in Aotearoa New Zealand may also form barriers to their learning opportunities.

In terms of barriers to general education for adults with learning disability, this group can experience increased health needs, increased parental anxiety, and decreased involvement in transition planning (Foley et al., 2013). Khanlou et al. (2021) also found that reduced

access to digital technology was a barrier to lifelong learning for adults with learning disability. Other barriers can include costs, accessibility of the built environment, lack of transport, and the limiting attitudes of educators (Johnson, 2023). Mirfin-Veitch (2003) reported that attitudes about the academic abilities of adults with learning disability was the most significant barrier to them accessing educational opportunities in Aotearoa New Zealand.

In terms of barriers specific to adult literacy education, Moni et al. (2007) expressed concern about the lack of literacy education opportunities that were suitable for adults with learning disability in Australia. A lack of information about literacy programs and insufficient interest in literacy learning were barriers for some adults with learning disability in Canada (Trenholm & Mirenda, 2006). Further barriers included inadequate prioritisation of literacy education for adults with learning disability, in favour of social, vocational, and independence skills, even though improved literacy skills can enhance development in each of these three areas (Moni et al., 2007; Trenholm & Mirenda, 2006). Relevant education providers were also found to communicate expectations perceived as being too high or too low for adults with learning disability (Trenholm & Mirenda, 2006). Another salient issue pertains to the lack of age-appropriate resources for use in literacy education for adults with learning disability in Australia (Morgan & Moni, 2008). The Roeher Institute (1994) discussed a lack of strategies to facilitate the inclusion of adults with learning disability in Canada, which was said to be caused by policy development that fails to consider their needs, as a major barrier to literacy education for this group. It is noted that all research reviewed in this paragraph is Australian or Canadian and more than 15 years old, which highlights the need for both domestic and current research on this topic.

Aotearoa New Zealand engages a social model of disability (see *Section 2.5.2*) via the *New Zealand Disability Strategy 2016-2026* (Office for Disability Issues, 2016), which lists education, including life-long learning, as the first outcome for a non-disabling society. However, potential barriers to adult literacy education for people with learning disability in Aotearoa New Zealand may still result from our adult literacy policy settings and other

legislation. The *Education and Training Act* permits tertiary education to exclude any learner they perceive as not being capable of completing a tertiary level course with reasonable accommodations (Ministry of Education, 2020a). This caveat is subjective and may not promote the inclusion of adults with learning disability. Another barrier is the lack of information about the participation of adults with learning disability in education and the supports they need. Tertiary education organisations are required to report on how many learners disclosed a disability and whether or not they accessed disability services (Ministry of Education & TEC, 2024). However, these data are based on learner self-identification and many people with learning disability do not assert their status as disabled people (Jones, 2019; Morgan et al., 2014). Divisions of Te Pūkenga are required to report on the range of Special Supplementary Grant (SSG) funded actions they undertook to provide reasonable accommodations for their students with learning disability (TEC, 2023h). This information only describes met needs that required financial investment and does not capture unmet needs or those that occurred as part of unfunded initiatives or universal design. The present research conducts an analysis of adult literacy policies with a view to understanding how they are likely to impact adults with learning disability, and to identify potential changes that could improve their inclusivity.

1.4.4 Literacy Assessment for Adults with Learning Disability

This section explores the results of quantitative literacy assessment for adults with learning disability and alternative methods that could better represent their literacy practices. Quantitative literacy assessments do not foreground the literacy strengths of adults with learning disability (Morgan et al., 2011).

Assessment methods that represented adults with learning disability as having reading ages that were lower than their chronological age were:

- The Peabody Picture Vocabulary Test–Revised, Form A (PPVT-R) and the Waddington Diagnostic Reading Test (WDRT) used by Bochner et al. (2001).
- The Peabody Picture Vocabulary Test (PPVT) (Dunn & Dunn, 1997) and the Neale Analysis of Reading Ability (Neale, 1989) used by Morgan and Moni (2008).
- Survey and estimates used by Trenholm and Mirenda (2006).
- The Neale Analysis of Reading Ability (Neale, 1989), Burt Word Test (Gilmore et al., 1981), and PPVT used by Moni et al. (2018).

These assessments all focused on reading or vocabulary, including the survey in Trenholm and Mirenda (2006), which asked questions about reading and writing, and their estimates, which were estimates of reading and writing ability. Some literacy gains were identified using these methods. Moni et al. (2018) tracked the literacy development of 191 adults with learning disability over their two-year participation in the post school *Latch-On (Literacy and Technology-Hands On)* program in Australia and found that participants increased their average reading age by four months when participating in education for two years. Australian research reported that adults with learning disability delivered lower average results on literacy assessments than adults without learning disability (Bochner et al., 2001; Moni et al., 2018; Morgan & Moni, 2008; Trenholm & Mirenda, 2006).

Assessing the literacy of adults with learning disability presents additional challenges. Moni et al. (2018) found that participant test results varied so considerably that aggregation of their outcomes could be misleading. The insights of Moni et al. (2018) echoed those of the The Roeher Institute (1990), who used grade level attainment and existing Canadian literacy studies⁷ to determine the literacy levels of 2,948 adults with learning disability. However, they concluded, “it is not possible with existing data sources to measure the prevalence of literacy among adults with a mental handicap [sic] as accurately as is possible with other

⁷ The Southam Literacy Study and the Canada Survey of Literacy Skills Used in Daily Activities.

populations” (The Roeher Institute, 1990, p. 18). Although they later claimed to have found a “very low level of literacy” among adults with learning disability (The Roeher Institute, 1994, p. 1). Fabio et al. (2023, p. 3) agreed that “assessing the literacy abilities of individuals with severe cognitive disabilities is challenging.” For example, one study in their systematic review involved measuring the prerequisite skills required to complete existing literacy assessments in people with Rett syndrome, including the ability to maintain gaze and posture for the assessment period. Demonstrating how completing a test can present challenges for some people. Benson-Goldberg and Erickson (2021) also found that co-existing physical and sensory challenges, such as being able to view a test and provide a spoken response, have complicated literacy assessments for some people with learning disability. Therefore, alternative methods of literacy assessment may prove more effective for adults with learning disability who seek a clearer understanding of their literacy strengths, or for whom such information would benefit their learning.

Literacy or literacy encompassing assessments that have proven more successful at valuing the literacy practices of people with learning disability will now be described. Fajardo et al. (2014) assessed the reading comprehension of adults with learning disability using easy read materials. Sixteen adults with learning disability aged 16 to 22 years old from the Camí Obert Vocational Training Centre in Spain accessed news articles that met the International Federation of Library Association and Institutions (2010) *Guidelines for Easy-to-Read Materials* (Fajardo et al., 2014). Respondents gave correct answers to 87 percent of questions in a multiple-choice reading comprehension test. Their success demonstrated the usefulness of modifying assessment questions to be more accessible for adults with learning disability. Two literacy assessments used with children with learning disability that could be used with adults with learning disability are detailed in *Appendix B*.

1.4.5 Assumptions about the Literacy of People with Learning Disability

Ideas about literacy and learning disability have been intertwined since the Industrial Revolution. Of note, the role of literacy in the construction of learning disability is apparent in now outdated diagnostic manuals that include conditions known within the medical model as “Intellectual Development Disorder” and similar terms. The *International Classification of Impairments, Disabilities, and Handicap* (World Health Organization, 1980) and the *Diagnostic and Statistical Manual of Mental Disorders IV* (American Psychiatric Association & Task Force on Dsm-iv, 2000) both use low literacy skills as a criterion to diagnose people with the aforementioned condition. For example, the World Health Organization (1980, p. 53) uses the ability to acquire functional reading as a differentiator between “mild” and “moderate mental retardation [sic].” While current versions of these manuals no longer include references to literacy, their prominence within established ways of thinking about learning disability is evident, ultimately informing prevailing assumptions about the literacy of people with learning disability (Kliewer et al., 2016).

Three assumptions about the literacy of people with learning disability are that they,

- are unable to demonstrate literacy competencies, or
- are competent unless proven otherwise, or
- that they are literate citizens regardless of what competencies they demonstrate.

These assumptions influence the curriculum provided to people with learning disability, the expectations other people hold regarding them, and the respect given to the role of literacy in their lives (McIlroy, 2017).

The “*myth of inability*” occurs when people with learning disability are assumed to have a generalised lack of educational competence (Wansart, 1995, p. 175). Such views have resulted in negative assumptions about the literacy skills of people with learning disability. In Aotearoa New Zealand, McIlroy (2017) found some teachers and professionals in her primary school were unable to perceive her participants with learning disability as capable

learners, and that perceptions of deficit led to a restricted curriculum for these children⁸. Copeland et al. (2016) similarly discussed the negative impacts of teacher's low expectations of children with learning disability on their literacy education at school. While research undertaken by McIlroy (2017) relates to children, observations made by Keefe and Copeland (2011), Kliewer et al. (2016), and Moni et al. (2018) indicated that assumptions about adults with learning disability are likely to be similar. The opposite assumption of the myth of inability is to presume competence.

The concept of *presuming competence* asserts that all people are competent unless they present evidence to the contrary (Biklen & Burke, 2006). Biklen and Burke (2006) contended that observers cannot maintain a state of ambivalence regarding competence, and always determine a person to be cognitively competent or incompetent. Such a distinction has ramifications in relation to assumptions about their literacy (Biklen & Burke, 2006). Drawing on the principle of the *least dangerous assumption*, which will do the minimum harm to the likelihood of a disabled person functioning independently (Donnellan, 1984), Biklen and Burke (2006) said that presuming competence is the safer choice in the pursuit of literate expression that other people can understand. In a critique of Biklen and Burke (2006), Travers and Ayres (2015) recommended an *agnosticism of ability* approach, which is to suspend judgement about the competency of a person until evidence arises, rather than to engage in what they claim to be a false dichotomy. Their reasoning was that any assertion of competence in the absence of evidence relies on externally generated ideological justifications and obfuscates the credibility of assessment and observation. On the contrary, Kliewer et al. (2016) argued that presuming competence, not positive test results, was the first step towards achieving literate citizenship for adults with learning disability.

North American Professor of Special Education Christopher Kliewer and his colleagues have used the term literate citizenship in conjunction with people with learning disability across several publications (Kliewer, 1998, 2008; Kliewer & Biklen, 2007; Kliewer et al., 2016;

⁸ Further discussion about schooling for children with learning disability in Aotearoa New Zealand is provided in *Appendix C*.

Kliewer et al., 2004). *Literate citizenship* is described as “value, intelligence, and imagination,” and inclusion within literate communities, such as classrooms (Kliewer & Biklen, 2007, p. 2580). Kliewer et al. (2004) used his observations of children with learning disability participating in literacy such as displaying signs, chanting, marching, voting, facial expressions, and other bodily movements, and engaging with communication devices to challenge established definitions of literacy. Adopting their concept of literate citizenship, Collins (2011) considered how expanding literacy to include creative arts could support the literate citizenship of a student who used drawing to express their preferred identity. This chapter will now turn from the broader context of this research to the thesis structure.

1.5 Thesis Structure

The overall format of this thesis is as follows. Chapters two to four explore foundational elements that contextualise this research. *Chapter Two* discusses models of disability, beginning with a rationale for the disability terms used in this research, it then examines the principles of able and normal with their corollaries of ablism and normalisation and how they have shaped ideas about disability. Within this context, Māori, Pasifika⁹, and Western models of disability are then surveyed. *Chapter Three* is about literacy and includes key theories of literacy, followed by descriptions of literacy practices, including those used by Māori, Deaf, and disabled people. A definition of literacy for this research is then posited, and the research questions are listed. *Chapter Four* considers the past and current adult literacy policies in Aotearoa New Zealand, their antecedent factors, and the assessment practices these policies mandate. *Chapter Five* describes the research design, philosophical and theoretical underpinnings of this research, data collection methods and methods of

⁹ The term Pasifika was coined by government agencies in Aotearoa New Zealand to describe migrants from countries located in the Pacific and people with heritage linking them to those nations Ministry of Education. (n.d-b). *Pacific and Pasifika terminology*. <https://tapasa.tki.org.nz/about/tapasa/pacific-and-pasifika-terminology/#:~:text=The%20terms%20%E2%80%9CPasifika%E2%80%9D%20and%20%E2%80%9C,Pacific%20regions%20and%20their%20descendants..>

analysis, and the ethical considerations undertaken. *Chapter Six* is about the findings from my policy analysis that forms a background to inclusive research that intends to inform future adult literacy policies. *Chapter Seven* is about the findings from the research I undertook with people with learning disability. *Chapter Eight* is the findings from an evaluation of my inclusive approach in this research. *Chapter Nine* concludes this thesis with a discussion of the main findings of this research, adult literacy policy recommendations, the limitations and implications of this research, and prospects for research in the future.

The research questions are answered in the following chapters. *Chapter Six* answered the first sub question by identifying the current adult literacy policies in Aotearoa New Zealand and discussing their impact on adults with learning disability with reference to the existing literature. *Chapter Seven* answered the second sub question by telling us about the literacy practices and perspectives of adults with learning disability. *Chapter Eight* does not intend to answer a research question; rather it evaluates the research itself. This aspect of my research is particularly unique, and I will argue for the adoption of this method in future inclusive research. My main research question was answered in *Chapter Nine*, which made policy recommendations based on findings from my policy analysis and IPAR (see *Figure 2*).

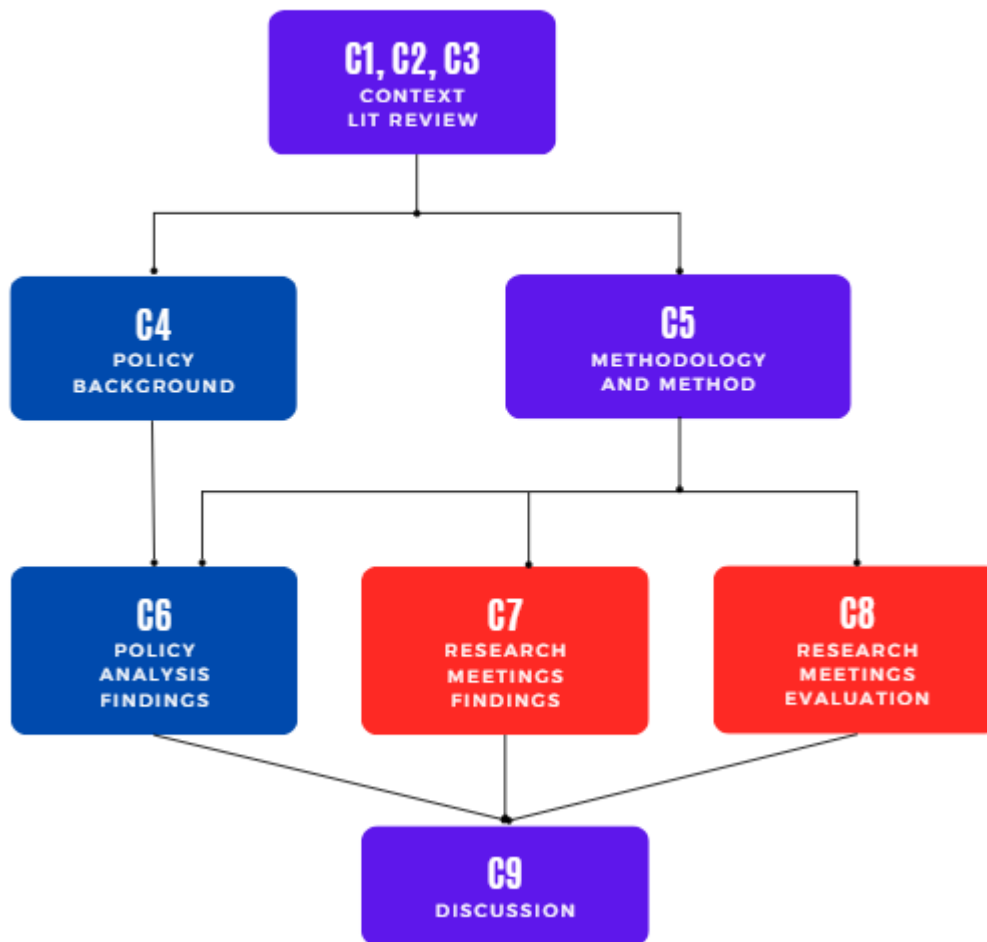


Figure 2 Thesis structure flow chart. C = Chapter

1.6 Purpose and Benefits of this Research

The purpose of this research was to challenge assumptions about the literate capability of adults with learning disability and to make policy recommendations that promote the realisation of the CRPD. In particular, Article 24.5, which aims to “ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education

and lifelong learning without discrimination and on an equal basis with others” (United Nations, 2007).

This research sought to benefit people with learning disability by raising awareness about their literacy practices and making policy recommendations that are more inclusive for them. This research sought to benefit participants by engaging them in research and literacy. The benefits of literacy for adults with learning disability include experiencing enjoyment, expanding social connections, becoming more informed and consequently more effective decision makers, and increased personal satisfaction and confidence (Moni et al., 2007; van Kraayenoord, 1994). A further benefit of promoting the realisation of the CRPD is that it fosters a more equal and just society that is better for everyone.

1.7 Conclusion

This research focused on the literacy practices and perspectives of adults with learning disabilities, the current adult literacy policies, their impact on adults with learning disabilities, and the changes to those policies that would improve their equal access to adult literacy education. These foci constitute the basis for the research questions that will be introduced in *Section 3.5*. The injustice this research addresses is that a narrow conception of literacy appears to structurally exclude many adults with learning disability from their pathways of choice, particularly in tertiary education. This research endeavoured to understand how such exclusion could be addressed.

2 Chapter Two: Models of Disability

Disability can be viewed through different models, which offer varying patterns of thought about what disability is and what it means (Olkin, 2002). Models of disability construct frameworks for understanding disability, which ultimately affect the ways we as disabled people understand ourselves and are responded to in society.

This chapter first discusses the concepts of ableism and normalisation, because ableism underpins the medical model of disability and normalisation underpins the policy governing Disability Support Services in Aotearoa New Zealand. Then, Indigenous models of disability used in Aotearoa New Zealand and the Western medical and social models of disability will be examined. Finally, a critique of the social model of disability leads to the selection of the affirmation model of disability for use in this research.

2.1 Ableism

Ableism is the worldview, and ways of promoting the worldview, that it is preferable to be non-disabled rather than disabled (Campbell, 2009). It can also be said to construct disability via the creation of a binary in which the concepts of disability and non-disability support and reinforce each other (Campbell, 2009). De Schauwer et al. (2017) spoke of this phenomenon in terms of disability and non-disability having a subordinate to dominant relationship, wherein members of one group are normed in relation to the other group.

Ableism has profoundly impacted people with learning disability. One way is by introducing a hierarchy of preference for non-disabled people over disabled people, as well as for people with physical rather than mental disabilities (see *Section 3.3.3*). The concept also contributes to a preoccupation with independence (Gappmayer, 2021), supports the tragedy view of disability (Campbell, 2009; Loseke & Green, 2019) and has a reciprocal relationship with neoliberal values (Aho, 2017; Campbell, 2015; Goodley, 2014; Loseke &

Green, 2019; Wolbring et al., 2019). Jones (2019, p. 280) found that, outside of Māori models¹⁰, all models of disability used in Aotearoa New Zealand are ableist in their “other” and “inferior” positioning of people with learning disability. Therefore, any exploration of learning disability and its representation in models of disability must engage with an understanding of ableism.

Coined by Seamoon House (1981, p. 34) in her article *A Radical Feminist Model of Psychological Disability*, ableism was first defined as “the oppression of disabled people.” However, the term *disablism* now captures assumptions and practices that disadvantage disabled people (Campbell, 2009). As Campbell (2009) described, ableism has two main tenets, that which identifies non-disabled people as species-typical and therefore ideal, and that which perpetuates the dominance of non-disability. Gappmayer (2021) called ableism the social norming of non-disability. Wolbring et al. (2019) described ableism as a form of governance that uses privileges to promote non-disability, such as by restricting education and employment to people who have certain abilities. For Campbell (2009), ableism generates an appeal to practice, emulate or mask as non-disabled. 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.

Bogart and Dunn (2019) explained that ableism emerges when non-normative actions become attributed to disability, rather than to a situation or environment. This attribution occurs because disabling situations and environments are perceived as normal by non-disabled observers. Ross (2018) theorised that each person understands their own experience as normal, resulting in what he calls the *fundamental attribution error*. Furthermore, a *truly fundamental attribution error* occurs when each person finds their own perception to be reasonable and assumes that dissent from their perception is flawed and in

¹⁰ Pasifika models of disability were not surveyed in her thesis.

need of correction (Ross, 2018). The work of Bogart and Dunn (2019) and Ross (2018) highlights the subjectivity of ableism.

2.1.1 *Ableism and Learning Disability*

This research centred the experiences of people with learning disability, so the way that ableism is understood in this research should avoid further marginalising that group. House (1981, p. 34) found that many people engaged in what she called *ablebodiedism*, the tendency to recognise bodily impairments as legitimate while minimising those experienced by people with other disabilities. Some authors discuss ableism in the context of abled and disabled bodies. For example, seminal writer Campbell (2009, book description) described her book as “challenging notions of what constitutes ‘normal’ and ‘pathological’ *bodies* [emphasis added]... focusing on the practices and formations of *able-bodiedness* [emphasis added] to uncover what it means to be ‘able’ rather than ‘disabled.’” The use of words associated with bodies and bodiedness within literature about ableism evidences a further hierarchy of preference for ability that privileges physically disabled people over people with learning disability (see *Section 3.3.3*).

Gappmayer (2021) and Jones (2019) presented research on ableism specific to people with learning disability. Drawing on his experience as an occupational therapist, Gappmayer (2021) understood the public as having a heightened perception of people with learning disability as being non-productive when compared to other forms of disability. In addition, he identified independence skill development as being mainly aimed at people with learning disability, which reinforces the perceived gap between the skill level of people with learning disability and the normed skill level. For Gappmayer (2021), the ablest construction of people with learning disability as dependant on care has obscured their true nature, which can be uncovered through authentic interactions with the people themselves. Jones (2019) also commented on the intertwining of independence and ableism. Some participants with

learning disability in her research had internalised discourses of independence that linked to their desire to be seen as able. The desire to be seen as able and the acceptance of that desire is quintessentially encapsulated in an anecdote from Jones (2019, p. 224), in which she remembers working in a support service for people with learning disability.

I would often receive referrals for new clients which would state that the person does not like to be described as disabled, and that it is important we do not use the 'disability' word when meeting the person. These statements were never questioned by those of us who worked with the people – we simply seemed to accept the 'natural' desire not to be recognised as disabled.

Both Jones (2019) and Gappmayer (2021) highlighted the pervasive impact of ableism on people with learning disability, underscoring the need for a critical re-evaluation of the models of disability that contribute to the continuance of ableism.

One example of the impact of ableism on people with learning disabilities is the constant flux of terms used to describe them, as successive labels become associated with the perceived gap between people with and without learning disability (Jarrett & Tilley, 2022; Sinason, 2010). What Jarrett and Tilley (2022, p. 139) called “a bewildering process of rapidly changing terminology” has always presented complexities for researchers. Sinason (2010) argued that all terms associated with learning disabilities, including learning disability and intellectual disability, are euphemisms intended to distract people without learning disability from our existential anxiety about the temporary nature of ability. Jarrett and Tilley (2022) added that people with learning disability do not change, rather, that naming conventions change in accordance with the perspectives of people without learning disability. For Sinason (2010), the selection of terms is insignificant compared to the nature of relationships between people with and without learning disabilities, although Jarrett and Tilley (2022) argued that public perceptions do shift to align with terminological changes.

2.1.2 *The Tragedy View of Disability*

The ableist construction of non-disability as preferable relies on the premise that disability is “inherently negative,” which is called the tragedy view of disability (Campbell, 2009, p. 17). This view of disability is a narrative that makes sense when framed by the medical model of disability (Loseke & Green, 2019). The medical model of disability (see *Section 2.5.1*) positions disability as an individual tragedy that warrants external interventions (Loseke & Green, 2019). Colin Cameron said the tragedy view of disability is the “cultural materialisation” of the medical model of disability (as cited in Hambrook, 2009, p. 2). As in, it is how the medical model becomes reified in society.

The media, charities, and even some religious texts often similarly promote negative perceptions of disability (Swain & French, 2000). These negative perceptions of disability encompass “inferiority, inadequacy, pity, sadness, evil and disgust” (French & Swain, 2008, p. 8). Hevey (1993) explained that disability is used as a metaphor for an unacceptable person in these instances, reinforcing the idea that there is something wrong with being disabled.

The tragedy view of disability is far more prevalent among non-disabled than disabled people, as in, disabled people are less likely to consider their own disability as tragic, although it may be viewed that way by others (Heyman, 2018). Importantly, the tragedy view of disability is one device that works to maintain ableism, because the construction of disability as unfavourable contributes to the construction of non-disability as favourable (Campbell, 2009). Therefore, the tragedy view of disability must be countered if the ableist binary of disability and non-disability, which harms people with learning disability (and all disabled people), is to be dismantled (de Schauwer et al., 2017).

2.1.3 *Ableism in the Neoliberal Era*

Neoliberalism describes the resurgence of free-market capitalist ideals, such as freedom, individualism, and productivity, which have dominated the Western world since the 1980s (Vincent, 2010), and underpinned much of Aotearoa New Zealand public policy since 1984 (Kelsey, 1995; O'Brien, 2020). Neoliberal ideals are founded on ablest notions of non-disability and have led to the norming of independence, democratic participation, and marketability (Aho, 2017; Campbell, 2015; Goodley, 2014; Loseke & Green, 2019; Wolbring et al., 2019).

Goodley (2014) coined the term *neoliberal-ableism* to describe ableism within a neoliberal context. He argued that neoliberalism is intrinsically linked with ableism, as ability becomes increasingly demanded to survive the continuous assessment and requirements for development inherent to the neoliberal agenda. The precarity of neoliberalism also means that many people experience heightened anxiety concerning their adaptability to the market (Goodley, 2014). They seek to be resilient to public sector cutbacks and avoid stigma that is attached to receiving welfare, both of which favour non-disability (Goodley, 2014). Gappmayer (2019, p. 259) agreed that full personhood is increasingly confined to those who demonstrate neoliberal values, chiefly “individualism and consumerism.” For Taylor (2020, p. 56), neoliberalism promotes “a view of the citizen as a white, property-owning male,” which is an idea that works to exclude disabled people from equal access to education, decision-making, and reciprocal deliberation within democratic processes. Aho (2017) used the term *labour-normativity* to describe the measurement of human worth in terms of remunerated or reproductive work within a neoliberal worldview. This situation is discriminatory because employment is not accessible for all disabled people (Kittay, 2015). A preference for non-disabled attributes have 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.

2.2 Normal and Normalisation

The term *normal* acts as a classification for people who are privileged by the nature of their characteristics. The question of who is normal influences the outcome of who may be subject to *normalisation*, a process of becoming or appearing normal, as recommended by sociologists Wolfensberger and Tullman (1982) for people with learning disability. While normalisation is a separate theory to definitions of normal, the former was built on the principles of the latter. One example of the influence of normalisation on expectations for people with learning disability is the emphasis on their mastery of normed forms of literacy, namely reading and writing.

2.2.1 Normal

The circumscription of normality in relation to non-disabled ways of learning has evolved alongside the development of intelligence quotient (IQ) assessments over the past 200 years in Western contexts. The following exploration of the historical shaping of the medicalised perspective of learning disability as a binary contrast with normal aims to destabilise this narrative.

Prior to the early 1800s, the concept of *ideal* was used to mean godlike and unattainable, while *grotesque* was used to describe ordinary people, which included both those who were disabled and non-disabled (Davis, 1997). The first method of human classification by intelligence involved identification based on skull measurements known as craniology (Gould, 1997). Alfred Binet progressed medical statistics from that anthropological observation to the Binet scale of IQ in 1905-1911 (Gould, 1997). The Binet scale involved a series of tests, such as counting coins, to ascertain the mental age of a respondent (Gould, 1997). Children with a significant discrepancy between their chronological age and their mental age would receive interventions (Gould, 1997). Then, drawing on Gregor Mendel's

laws of heritability, Henry Goddard sought to identify “morons” with a view to reducing their population via restrictions on their movement and reproduction (Gould, 1997).

In 1916, Lewis Terman revised the Binet scale so that the average IQ score would be 100, this became known as the Stanford-Binet test (Gould, 1997). Terman’s work on IQ variance reinforced the idea that intelligence is innate and that people with different IQ scores would be predestined for different vocations and social statuses (Gould, 1997). World War I marked the start of IQ testing among adults (Gould, 1997). Nearly two million North American Army recruits underwent IQ testing, including written and pictorial tests (Gould, 1997). Robert Yerkes used the resulting data to encourage mass IQ testing from the 1920s onwards (Gould, 1997). Charles Spearman went on to reify intelligence to a single number known as *g* for general intelligence in 1923 (Gould, 1997).

Using the *g* principle of intelligence, Herrnstein and Murray (1994) argued that intelligence conforms to a normal pattern of distribution across a bell curve. The IQ score of most people could be graphed at the peak of the curve, having average intelligence, with fewer people occupying positions at either tail, having lesser or greater intelligence. The central premises of Herrnstein and Murray (1994) were that intelligence is inherited and immutable. The authors used their theory to justify the existing class structure in North America, including the statuses of different ethnic groups. Haynes (1995) critiqued Herrnstein and Murray (1994), saying they were politically motivated rather than scientifically accurate. Furthermore, that mathematical scales of measurement are inadequate for describing the fluidity of human characteristics. Ultimately, the bell curve divided people into standard (i.e. normal) and nonstandard populations (Davis, 1997).

For people with learning disability, the aforementioned processes have resulted in a diagnostic approach that focuses on perceived deficits and impairments in their mental abilities. The most recent *Diagnostic and Statistical Manual of Mental Disorders: DSM-5* (American Psychiatric Association, 2013) ascertains a diagnosis for Intellectual Development Disorder by comparing people with learning disability to their non-disabled peers. The same diagnosis in the *International Classification of Diseases 11th Revision* aims to, “distinguish

disorder from normality” (World Health Organization, 2023, Boundary with Normality). These assertions are negative and essentialist in nature.

Moving from the medical into the cultural realm, Ervive Goffman (1963) was a seminal writer who understood *normals* as people who fulfilled the expectations that society places upon them. These expectations are to be “a young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports” (Goffman, 1963, p. 128). Whereas *deviants* were those whose *actual social identity*, the qualities possessed by a person, and *virtual social identity*, the expectations placed upon a person by society, are mismatched and consequently subject to stigmatisation. Therefore, just as the concept of non-disability produces disability as a comparison (Campbell, 2009), the concept of normal produces deviants by stigmatising people who do not hide their failure to conform (Goffman, 1963). He identified three ways to ameliorate the experience of stigma, which are to categorise oneself as different from the norm, to devalue the norm or avoid those who value the norm, or to employ “a special application of the arts of impression management,” that is, to mask as normal (Goffman, 1963, p. 130).

2.2.2 Normalisation

Wolfensberger and Tullman (1982) operationalised the Goffmanian art of impression management by encouraging changes to the appearance, behaviour, and free association of deviants, calling their theory *normalisation*. They argued, “a person can be considered ‘deviant’ or devalued when a significant characteristic (a ‘difference’) is negatively valued by that segment of society that constitutes the majority or holds norm-defining power” (Wolfensberger & Tullman, 1982, p. 132). In 1983, Wolf Wolfensberger revised normalisation into a theory called social role valorisation (SRV) directed specifically at people with learning disability via their services and supports.

SRV encourages people with learning disability to mirror the activities and appearances performed by their non-disabled peers, to the extent that people with learning disability are perceived as normal in society (Wolfensberger, 2011). The intention of normalisation is to support people with learning disability to conform to an ordinary life and to avoid attracting discrimination. New ways of living under normalisation offered some arguably positive changes, such as a move away from institutions, although the resulting lifestyles have been externally prescribed and therefore undermine individual choice and control (Culham & Nind, 2003). The widespread use of SRV has resulted in educational, occupational, and disability support settings becoming sites of normalisation for people with learning disability (Gapmayer, 2021).

SRV has been hugely influential in disability support services in Aotearoa New Zealand. As Jones (2019, p. 50) said, “it is difficult to understate the influence of normalisation in Aotearoa New Zealand’s disability policies, strategies and support practices.” For example, current service specifications governing Disability Support Services require that, “services contribute to ensuring that the conditions of the everyday life of [disabled] people are the same as, or as close as possible to norms and patterns, which are valued in the general community (normalisation)” (Ministry of Health, 2015, p. 2). I personally recall working in a disability support service in 2012 and being restricted from going out in public with too large a group of people with learning disability because such action would contravene the principles of normalisation.

In their critique of normalisation, Culham and Nind (2003) described how it denies people with learning disability the opportunity to organise together and celebrate their unique ways of being, as has been the community building approach taken by many other marginalised groups. Rather, people with learning disability have been subject to dispersal tactics and coerced into imitating people without learning disability (Culham & Nind, 2003). Dispersal tactics involve limiting the congregation of people with learning disability, or as Wolfensberger (1983, p. 438) termed it, achieving a “grouping size that facilitates social integration.” Commenting on normalisation and the oppression of disabled people, Oliver

(1999, p. 163) said that normalisation is “at best, a bystander in these struggles and, at worst, part of the process of oppression itself.” Far from challenging power relations, normalisation recommended that people without learning disability impart lessons about being normal to people with learning disability, and that people with learning disability should be compelled to follow them (Chappell, 1992).

Ultimately, normalisation serves to disempower people with learning disability. Chappell (1992, p. 39) called normalisation “a theory for professionals,” as normalisation does not represent the views and experiences of disabled people. Rather, it asks people with learning disability to become normal in ways that are decided on by people taking the role of experts in their lives (Culham & Nind, 2003). The professionalisation of the lives of people with learning disability fits within the medical model of disability. The relevance of normalisation to this research is that normed elements of literacy are promoted to people with learning disability, who are expected to take steps to enhance their perceived normalcy to others. In this way, normative literacy practices -reading and writing- are socially valued while other literacy practices are devalued.

2.3 Māori Models of Disability

Māori understandings of disability span disparate philosophies because there is no concept in *mātauranga Māori* (Māori knowledge) that is directly related to disability. Rather, disability is a Western concept that arrived in Aotearoa New Zealand as part of colonisation (Bevan-Brown, 2015a; Graham et al., 2023; Hickey & Wilson, 2017; Ingham et al., 2022; Jones et al., 2023; King, 2019; Kingi & Bray, 2000; Tikao et al., 2009). As discussed in *Section 1.2.3*, a te reo Māori kupu that better approximates to Māori understandings of disability is *tāngata whaikaha*.

Knowledge of *tāngata whaikaha* sit within the ontological paradigm of *kaupapa Māori* (“a philosophical doctrine, incorporating the knowledge, skills, attitudes, and values of Māori

society” [Moorfield, 2024, Kaupapa]) (Bevan-Brown, 2013; Jones et al., 2023; King, 2019). In contrast to Western knowledge traditions, kaupapa Māori builds on a foundation of mātauranga Māori seminally gathered from *Papatūānuku* (Earth mother and wife of Ranginui) through oral traditions and experiential insight (Smith, 2021). Within kaupapa Māori, knowledge of disablement is uncovered through *kōrero* (speech, narrative) with *whānau* (extended family), *hapū* (kinship group), *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 during that era, even though the status could also be understood as punishment for breaking *tapu* (prohibitions) (Bevan-Brown, 2013; Hickey, 2014; Tikao et al., 2009). However, disability has also been rejected in some areas of Māoridom, reflecting the close connection between disability and colonisation in *te ao Māori* (Hickey & Collins, 2006; Hickey & Wilson, 2017; Ingham et al., 2022; Jones et al., 2023).

2.3.1 Disability as Ordinary

Tāngata whaikaha are seen by many Māori as being the same as other Māori (Jones et al., 2023; Kingi & Bray, 2000). As my Māori cultural advisor expressed, “everyone is a *rangatira* (chief, noble person), doesn’t matter if you have a disability, we have that *korowai* (cloak)¹¹ [of being a *rangatira*] around them” (T. Ryan, personal communication, 30 August 2023). Thus, many Māori hold *tāngata whaikaha* and non-disabled people in an equal regard.

Jones et al. (2023) identified a theme of invisibility around being *tāngata whaikaha*. Invisibility could be positive, in that several participants viewed themselves as *tāngata whaikaha* in terms of their *wairua* (spirit), rather than their encounter with physical

¹¹ A *korowai* is a cloak traditionally made of woven feathers, using rare materials and being laborious to construct, *korowai* denote significant celebrations and people of high esteem.

limitations, and one participant described being *kāpo* (blind) as an element of their *whakapapa* (genealogy). However, the same invisibility could also result in some *tāngata whaikaha* not being recognised as such and therefore being unable to access adequate resources and supports to meet their needs. This motif communicates the ordinariness and even undetectable nature of *tāngata whaikaha* among many Māori.

2.3.2 Disability as Whānau Hauā

Whānau hauā is a well-known Māori model of disability (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* (Hickey, 2006, 2015). *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 presents a holistic view of a person, and purposely circumvents medicalised views of

disability (Hickey, 2015). Whānau hauā has been used as a Māori model of disability by the Waitangi Tribunal (Kaiwaik & Allport, 2019) and Waikato District Health Board (2021).

2.3.3 Disability as Being Like Characters in Pūrākau

Pūrākau and metaphor are prevalent in many Māori understandings of tāngata whaikaha (Graham et al., 2023; Jones et al., 2023; Tikao et al., 2009). For example, Tikao et al. (2009) found that prior to colonisation, kāpo 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 kāpo¹². 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 conceptualisation of what the medical model would term Attention Deficit Hyperactivity Disorder (ADHD) is to be like a *Pīwakawaka* (fantail) that flick their wings and quickly change direction (Rangiwai, 2023a). Rangiwai (2023b) was influenced by Rangihuna et al. (2018), who use a *mahi a Atua* (tracing ancestral footsteps) approach 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 and metaphor mean that Māori understandings of tāngata whaikaha can be diverse and adaptive.

¹² Such as Hina, wife of Maui, Murirangawhenua, Grandparent of Maui, Tāwhaki, relative of Maui, and Mahuika, goddess of fire.

2.3.4 Disability as Part of Colonisation

As noted, Western concepts of disability in Aotearoa New Zealand are intrinsically tied to colonisation for Māori. (Bevan-Brown, 2010, 2013, 2015a; Graham et al., 2023; Ingham et al., 2022; Jones et al., 2023; King, 2019; Kingi & Bray, 2000). Furthermore, the experience of colonisation is itself disabling. Examples of the disabling effects of colonisation include dislocation from or within whānau, *whenua* (land), mātauranga Māori, *tikanga* (correct procedure, custom), or *te reo Māori* (Māori language) (Bevan-Brown, 2013, 2015b). 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 disproportionately impaired (Kingi & Bray, 2000).

2.4 Pasifika Models of Disability

Aotearoa New Zealand is in the Pacific Ocean. Our nation shares rich cultural ties with other Pacific nations, and more than eight percent of Aotearoa New Zealanders have a Pasifika identity, such as Samoan, Cook Islander, or Tongan (Stats NZ, 2018). There are few publications about Pasifika models of disability as this knowledge is often restricted or sacred (N. Muliaumasealii, personal communication, 30 October 2023). The *popao* model of disability and Tagata Sa'ilimalo movement have been made available to the public.

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 expatriate Tongans to reconnect with their culture and traditional activities, identify *kāinga* (family) and community roles, and to 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 Pasifika with disabilities (Vaka Tautua, 2022). The name was coined by the Tōfā Mamao Collective, a group of *tagata sa'ilimalo*, *nofo-a-kāinga* (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 analogous names in their own languages. Ultimately, Tōfā Mamao (2023) hope *tagata sa'ilimalo* and other names will replace the umbrella term "Pasifika with disabilities."

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 for those *kāinga* as they navigate new experiences.

2.5 Western Models of Disability

The Western models of disability reviewed in this thesis will be the medical model, the social model¹³, and the affirmation model. The medical and social models of disability are prevalent in Aotearoa New Zealand. The medical model of disability is used in Aotearoa New Zealand law (Mander, 2022), diagnosis (Explore Hāpainga Ora, n.d), and eligibility criteria for Disability Support Services (Ministry of Health, 2003, 2019). 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 government response to advice from CRPD monitoring mechanisms (Farrar, 2022). The affirmation model of disability will also be discussed as it is the model of disability used in this research.

2.5.1 The Medical Model of Disability

The medical model situates disability as an individual pathology caused by defects, disease, or injury (Berger, 2013; Goodley, 2017; Haegele & Hodge, 2016). The identification and isolation of impairments thought to exist within a person is key to the medical model of disability (Goodley, 2017). After naming impairments, efforts are made to treat, rehabilitate, or cure disabled people (Goodley, 2017). Within the medical model, knowledge of disablement is ascertained through systematic and objective modes of enquiry, for example by using scientific testing and observation (Berger, 2013). Loseke and Green (2019) asserted that the medical model of disability, with its underpinning tragic perspective (see *Section 2.1.2*), continues to maintain the dominant narrative regarding disability in both society and public policy.

¹³ There are numerous social models of disability. This research uses the term social model of disability in reference to the UK strong model.

The medical model of disability works to maintain a hierarchy, within which disabled people are expected to acquiesce to the authoritative terminology and interventions of medical professionals (Goodley, 2017). However, Berger (2013) also recognised the impact of patient's rights advocacy and the increasing availability of medical information in moderating inequalities brought about by the differential statuses of the helper and the helped in that system. Furthermore, the medical model has benefited some disabled people, for example, those who seek rehabilitation or treatment for unwanted symptoms (Berger, 2013). While medicine may alleviate some experiences, the medical model of disability confers a power dynamic that relegates 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.

2.5.2 The Social Model of Disability

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

The UK 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 that limitations on the full participation of disabled people in society

is a form of oppression that results in disabled people being an oppressed group. In living without obvious intersectional oppression, members of UPIAS theorised a model distinctive in its simplicity but critiqued for lacking relatability for other groups of disabled people, including people with learning disability (Shakespeare, 2013).

Policy scholar Deborah Stone (1984) argued that disability is a socially constructed administrative category used to justify modes of distribution in capitalist societies, which became a foundational theory in the development of the social model of disability. In her analysis, 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. This two-fold system creates a dilemma, namely, how to decide which people will be allocated the privileges and oppressions of meeting their needs through the work-based system and which people will be allocated the privileges and oppressions of meeting their needs through the needs-based system, as in, “[disability] is an instrument of the state in controlling labour supply” (Stone, 1984, p. 179). For Stone (1984), disability is a device that is used to resolve the tension between work-based and needs-based systems, while maintaining the dominance of labour.

Incorporating work by Stone (1984) on modes of distribution, Michael Oliver (1990) gave his seminal historical materialist account of disability. Oliver (1990) explained how, prior to the Industrial Revolution, families, and communities incorporated people with different abilities into their locally based agrarian and small-scale economies. The urbanisation and technological advancements that occurred during the Industrial Revolution pushed families away of their self-determined rhythms of production and into less accessible waged labour (Oliver, 1990). At the same time, medical institutions formed to house disabled people so that non-disabled people could continue working outside the home, unencumbered by care responsibilities (Oliver, 1990). Therefore, according to Oliver (1990), disability was first constructed by the material conditions of the Industrial Revolution.

While the social model of disability has some useful insights, it also has numerous limitations. Chapman (2020) found two conflicting problems with the social model of

disability, in that, it either maintains a dichotomy between people with and without impairments, or denies the corporeal realities potentially involved with being disabled. His first critique is of the premise that impaired bodies and minds are the ones that are susceptible to disablement, which perpetuates the notion of species-typical functioning. As Chapman (2020, p. 63) explained, “to be considered impaired, you must be impaired in relation to something that is considered unimpaired.” Affirmation model proponent Colin Cameron (2010) critiqued the social model for the same reason. He added that the social model 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. The second critique put forward by Chapman (2020) was that the social model disregards the lived experience of disabled people. Owens (2015) agreed, saying it ignores the plurality of disability experiences that may persist, irrespective of social, political, or physical environments. Pain and confusion are two examples of potentially persistent experiences that may not be ameliorated by a change in context (Owens, 2015). As such, the social model of disability may not meet the needs of people with learning disability because their lives may not necessarily be significantly different in an alternative environment.

Barnes and Mercer (2010) posited two theories about why the social model may disregard the somatic and biological experiences of disability. It could be that founders of the social model, the UPIAS, were being cautious about disabled experiences having the potential to conjure up empathy, which they viewed as counterproductive to radical disability politics. The other explanation is that highlighting any physical, sensory or cognitive constraints could lend weight to the medicalised 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 realities of disabled people may reflect the male

dominance of the UPIAS in their early theorisation of the social model of disability (Barnes & Mercer, 2010).

Hickey (2006), Hickey and Collins (2006), and Hickey (2014) criticised the social model from a Māori perspective. First, the social model traces the concept of disability to the Industrial Revolution, but Māori history is different than that which occurred in England, where the Industrial Revolution began (Hickey, 2006). For example, kāpo Māori were valued as *tohunga* (experts, healers) if they were not suited to other types of work. This stands in contrast to the history of disability in the Western world, in which disability was overtly and is now covertly used to categorise people into differing relationships with capitalist modes of distribution (Oliver, 1990; Stone, 1984). Second, the social model shifts the genesis of disability from the person onto society, but the society imagined in the social model is Western and fails to take Māori culture into account (Hickey, 2006). As Hickey (2006) described, 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 contractually obliged to promote independence, in contrast with Māori practices of collectively and interdependence (Hickey, 2014). For Hickey and Collins (2006), the continued dislocation of tāngata whaikaha from whānau that is characteristic of disability support services may further oppress Māori. For these reasons, Hickey (2006), Hickey and Collins (2006), and Hickey (2014) argued that the social model of disability is inadequate for Māori.

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 redefined the problem of disability, locating it within society rather than within the person, instead of disavowing disability as being a problem at all. Furthermore, Cameron (2011) understood the social model as identifying disability as a form of oppression that is “imposed” (UPIAS, 1975, p. 20) on people with impairments, which positioned disabled people as passive recipients of their

circumstances. In summary, these authors assert that the social model continues to hold disability in a negative regard.

The social model captures the disadvantages of labour-normativity and presents an opportunity to frame adult literacy policy as a barrier that constructs disability. However, rather than affirming disabled people, it carries over a negative view of disability from the medical model and has been identified as culturally inappropriate for Māori. Emerging from a critique of the social model, a more positive approach can be found in the affirmation model of disability.

2.5.3 *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 (Cameron, 2007, 2010; Swain & French, 2000). Furthermore, the degree of impairment at which a person can claim to be disabled is arbitrary and therefore constructed. The affirmation model positions disabled people as having a disabled culture and identity, rather than as having an impairment or being affected by a disabling environment (Cameron, 2010, 2011; Cameron & Lingwood, 2020; 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 et al. (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” (as cited in Swain & French, 2000, p. 575). Another example is that learning disability can be a contributor to wellbeing. As Skotko et al. (2011, p. 2363) confirmed, “the overwhelming majority of people with [Down syndrome] are happy with their lives, like how they look, and like who they are.” In touting the advantages of disability, the affirmation model represents a radical departure from a preference for ability.

Swain and French (2008) recognised that the affirmation model may dismiss the experiences of disabled people who do not share a positive view of disability and could infringe on the territory of toxic positivity. *Toxic positivity* only acknowledges positive emotions and experiences and invalidates negative emotions and experiences (Cross, 2022; Pangestu et al., 2022). Cameron and Lingwood (2020) addressed the impact of both negative and positive experiences on disabled people, drawing on *The Importance of Suffering: The Value and Meaning of Emotional Discontent* by Davies (2012). In doing so, they acknowledged that disabled people could have difficulties, but that these should not be interpreted as necessarily being negative. For example, suffering can give rise to enhanced internal and external relationships, identification of what is not working well, and personal transformation (Davies, 2012). In discussing these issues, the affirmation model takes a holistic view of disability.

Brandon and Pritchard (2011) helpfully 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 (Brandon & Pritchard, 2011). 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 be,

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 central problem of this thesis is that adults with learning disability are restricted from equal opportunities to participate in lifelong learning because of disabling assumptions about their status as literate people. Following Hickey (2006), who drew on the affirmation model of disability in her early work to create a communities-based model of disability in Aotearoa New Zealand¹⁴, I will apply the affirmation model of disability in this research.

¹⁴ A forerunner to the whānau hauā model.

2.6 Conclusion

In maintaining a bicultural approach in this research, it was important to begin with Māori models of disability so that Western perspectives were not centred as mainstream. I examined Māori, Pasifika, and three Western models of disability to help me choose which model to use. I ultimately chose the affirmation model of disability for this research because it represents disability as a culture and identity so will be useful as a lens for understanding the cultural phenomena of literacy as it pertains to adults with learning disability. The affirmation model invites disabled people to use our differences as a catalyst for challenging what is not working in society. As such, the affirmation model could be transformational in changing assumptions and attitudes about the literacy of adults with learning disability and consequently disrupting the status quo of people with learning disability lacking access to adult education.

3 Chapter Three: Literacy

This chapter first summarises key theories of literacy, which are the technological model of literacy, the sociocultural model of literacy, multimodal literacies, uses of language, and functional literacy. Then, an overview of Māori literacy practices and those used by Deaf and disabled people also be described. These practices problematise the status quo of literacy being understood as limited to reading, writing, speaking, and listening skills, as it is in adult literacy policies in Aotearoa New Zealand. Culture and cultural literacy are discussed. Next, a definition of literacy that values adults with learning disability as literate will be formulated. This definition seeks to transform attitudes about adults with learning disability as literate members of the community, particularly those of educators, as their outlook has the most significant impact on learner opportunities. Finally, this chapter identifies research questions that stem from a gap in the existing research and aim to generate knowledge from which to make adult literacy policy recommendations. Such recommendations seek to facilitate equal access to adult literacy education for people with learning disability and mitigate the literacy barriers they face in pursuing their pathways of choice.

3.1 Theories of Literacy

This section introduces relevant theories of literacy that underpin different ways to understand literacy. These theories will also be used to make sense of literacy practices that arise in the data from this research (see *Section 9.1.2*) and to inform a definition of literacy in this research (see *Section 3.4*).

3.1.1 The Technological Model of Literacy

The technological model of literacy is included in this review because it has assumed a pivotal function in the development of understandings of literacy as reading and writing (Lee, 2014) and in the Aotearoa New Zealand approach to adult literacy (Furness & Hunter, 2018; Hayward, 2010). The technological model promotes a narrow view of literacy and is a perspective that Furness and Hunter (2018) identified as being persistent in the adult literacy policies and assessment practices in Aotearoa New Zealand.

In the *technological model*, literacy is independent from its context, with changes to literacy being linear, and progressing from oral to written literacy (Altmann, 1998; Collin, 2013; Goody, 1968, 2000; Goody & Watt, 1963; Joyce & Borgwaldt, 2013). This model only promotes the validity of one literacy practice, being reading and writing (Goody, 1968, 2000; Goody & Watt, 1963). While the technological model seeks to understand the development of writing, applying it to literacy practices in general is Eurocentric and imposes of Western values onto other cultures (Street, 1993).

The superiority of reading and writing described in the technological model stems from a perspective on human evolution held by Altmann (1998), Goody (1968, 2000), and Goody and Watt (1963). Goody and Watt (1963) argued that writing is a delineator between prehistory and history, with writing cultures occupying the latter position. Furthermore, that people from some writing cultures were able to colonise people from some oral cultures because of their evolutionary advantages exemplified by mastery of reading and writing (Goody, 2000). Proponents of the technological model went so far as to say print literacy is unique in its ability to promote brain development (Altmann, 1998), with Goody (2000, p. 133) calling writing, “the technology of the intellect.” Many of these assertions are blatantly racist and have attracted significant critique.

Street (1984) coined the term *autonomous model of literacy* to describe the technological model as it renders literacy abstract and independent from its social context. Graff and

Duffy (2011, p. 35) called the technological model “the literacy myth” and claimed there was no evidence to support the view that reading and writing is required for individual or cultural development. In the view of Lee (2014, p. 89), the technological model erroneously capitalises on scientific ideas to “reify and normalize its legitimacy.” Whereas Street (1993) was straightforward in claiming the technological model was constructed to justify Eurocentric views about literacy, which include assertions that print cultures are more advanced than cultures with other literacy practices. Street (1984) was the first to introduce the sociocultural model of literacy as a challenge to the technological model.

3.1.2 *The Sociocultural Model of Literacy*

The *sociocultural model of literacy* says that literacy practices evolve and respond to changes in culture and society, rather than culture and society responding to changes in literacy as was described in the technological model (Barton & Hamilton, 2005; Burnett & Merchant, 2020; Cope & Kalantzis, 2000; Lytle, 1991; New London Group, 2000). This model recognises literacy as diverse and multimodal (Lankshear & Knobel, 1997), creating space for valuing the literacy practices of adults with learning disability.

The sociocultural model conceptualises literacy practices as plural and situated social practices (Barton & Hamilton, 2005; Gee, 2015; Hamilton, 2005; Street, 1984, 1993). Meaning that literacy is social construct that embraces a range of localised dialects, variations, discourses, codes, meanings, and relationships (Luke, 2018; New London Group, 2000). In this regard, Street (1993, p. 430) asked people to “recognise the central role of power relations in literacy practices,” rather than comparing the relative value of different literacies. Additionally, it serves as a counteractive force against the technological model (Street, 1984), which is dominant in existing adult literacy policies and practices in Aotearoa New Zealand (Furness & Hunter, 2018).

Collin (2013) critiqued the sociocultural model, finding it to be ambiguous and culturally determined in a way that underemphasises the material technology of literacy. Similarly, Brandt and Clinton (2002) considered the sociocultural model to overemphasise cultural aspects of literacy. Pardoe (2005, p. 152) even claimed that adherents of the sociocultural model romanticise illiteracy with their “anything goes” approach. In his opinion, those using the technological model seek to improve literacy, while those using the sociocultural model only aim to conceptualise it. A key theory coming from the sociocultural model of literacy is the idea of multimodal literacies (New London Group, 2000).

3.1.3 *Multimodal Literacies*

Multimodal literacy theory is relevant to this research because it broadens the scope of literacy, embracing new and theoretically infinite possibilities for literate expression. Instead of viewing literacy as having a specific meaning that can be received correctly or incorrectly, multimodal literacy positions users as self-determining agents who continuously remake available resources within their cultural contexts (Kress & Jewitt, 2003). This fundamental shift away from literacy as a measurable skill will be useful in redefining what it means to be literate in ways that meet the needs of adults with learning disability.

Multimodal literacies are made up of semiotic systems that are assembled using modes, such as words, lines, contrast, proximity, colour, images, weight, and texture (Danielsson & Selander, 2021; Kress, 2010). Literacy becomes multimodal as modes are combined to create meaning (Danielsson & Selander, 2021). As such, multimodal literacies cross boundaries with art, music, drama, and dance (Bull & Anstey, 2018). Semiotic systems were originally described by Kress (2010) as being the design elements of linguistic, visual, gestural, spatial, and audio literacies. However, debate has arisen over whether semiotic systems would be better expressed in terms of the five senses, being sight, taste, smell, hearing, and touch (Bull & Anstey, 2018). For example, touch is used in the reading of

braille, which is not addressed by the former five elements (Bull & Anstey, 2018). Increasing digitisation is also bringing new possibilities for semiotic systems to the fore (Danielsson & Selander, 2021). In terms of digitised literacy practices, features such as links, colour, animation, and sound can now be layered together and consumed in different ways such as searching and sharing, adding further semiotic resource combinations and options for meaning creation (Danielsson & Selander, 2021).

Multimodal literacies are discussed using terms that break from technological model ideas about reading and writing. Kress (2010) used the term *design* to encompass creating meaning through multimodal literacies, rather than terms such as *competence*, which focuses on literacy as a skill. The term *grammar* is not used because that word communicates ideas about writing as having one singular way of being correct, while the term *semiotic resource* includes all possible modes that could be used in design (Kress, 2010). Bull and Anstey (2018) used the terms *consumers* and *producers* as they bring focus to the multimodality of literacy, rather than the terms *readers* and *writers*, which are traditionally associated with print literacy. This research does use the terms reading and writing, but does so to decentre those literacy practices, rather than allow reading and writing to be assumed as synonymous with literacy.

3.1.4 Uses of Language

Several models have been devised to categorise the uses or functions of language. Different authors have focused on uses of language from different perspectives, each bringing distinct contributions to use of language theory, with numerous convergences. These models can be used to explore literacy practices in ways that might be more meaningful and useful for people with learning disability.

Halliday (1973) was the first to write about uses of language. Smith (1983) and Hurst (1990) productively extended ideas about literacy to include non-language and noncommunicative

literacy practices, and Avinera and Harasta (2021) discussed uses of language that prioritise social justice, human rights, and cultural expression, rather than the conveyance of meaning. Examples of uses of language include instrumental, which is to communicate personal needs (Halliday, 1973; Heath, 1986; Hurst, 1990; Smith, 1983), interactional, which is to determine relative status and navigate interpersonal relationships (Halliday, 1973; Hurst, 1990; Smith, 1983), and poetic, which is to create sonic or rhythmic structures from language (Hurst, 1990; Stubbs, 1983). Smith (1983) gave non-language alternatives for each of his 10 uses of language and added that language is not even necessarily the best way of realising the uses of language. For example, language is not better at conveying imaginativeness than art is at achieving that function (Smith, 1983). The non-language alternatives identified by Smith (1983) include facial expressions, pointing, ornamentation, mime, rituals, architecture, and photographs, with the noticeable omission of literacies often used by disabled people, such as sign language or braille.

Hurst (1990) focused on the language of children and draws on the work of Thelma Weeks to compile a list of uses of language with communicative or noncommunicative functions. According to Hurst (1990), noncommunicative language is when people talk to themselves either silently or aloud. Examples of uses of noncommunicative language include language play, self-image formation, and avoidance (Hurst, 1990). Smith (1983) also asked whether forms of communication had to be expressed to be considered literacy. He conceptualised that all literacy practices can be imagined or rehearsed within the mind of the author so as not to require a viewer, listener, or reader to be literacy.

Avinera and Harasta (2021) discussed uses of language that are unique to minoritised language communities. In their analysis, language is often used by minoritised language communities irrespective of an intention to communicate meaning. For these communities, language used symbolically in ways that may not be accurate in term of grammar or pronunciation, or understandable to the speaker or the audience. Outside of communication, minoritised languages can be used to counter colonisation, demonstrate authenticity, and establish political recognition. The uses of language in minoritised

language communities described by Avinera and Harasta (2021) have significant overlap with Māori cultural literacy (Leach et al., 2010; UNESCO, 2016; Zepke, 2011) (see *Section 7.3.1*). None of the authors who theorised about uses of language have included uses of language by disabled people, this could be a topic for further study.

3.1.5 Functional Literacy

Functional literacy describes the literacy skills a person requires to meet the demands of everyday life in their context (Kirsch & Guthrie, 1977; OECD, 2016). This means possessing both the ability to decode and the ability to comprehend literacy so that information can be read and utilised in a manner commensurate with relevant societal expectations (Boudard & Jones, 2003). Rather than testing for literacy as an abstract or binary condition, wherein adults are either literate or not, UNESCO (1970) and the OECD (2000, 2016) adopted a functional literacy approach. Functional literacy was defined as, “the ability to understand and employ printed information in daily activities, at home, at work and in the community—to achieve one's goals, and to develop one's knowledge and potential” (OECD, 2000, p. x).

There are also criticisms of functional literacy. For example, sociologist Geoff Payne (2006) says the concept of functional literacy creates arbitrary literacy standards and encourages the discriminatory conclusion that only people who are print literate can function in society.

An understanding of functional literacy is important to this research because functional literacy served as the foundation for the Organisation for Economic Co-operation and Development (OECD) International Adult Literacy Survey (IALS), the results of which catalysed the development of adult literacy policies in Aotearoa New Zealand (see *Section 4.2*). Current adult literacy policies continue to hold functional literacy as, “central to meeting the needs of adult learners” (TEC, 2008d, p. 11). The concept is also relevant to policy recommendations where functional literacy could be understood as the literacy

required in culturally specific contexts, such as those encountered by adults with learning disability.

3.2 Literacy Practices

This chapter will now discuss examples of literacy practices that arise in different cultural contexts in Aotearoa New Zealand. These comprise a partial list and demonstrate the breadth of literacy practices.

3.2.1 Māori Literacy Practices

Māori have diverse literacy practices that originate from Papātūānuku, are holistic, and include all aspects of their cultures (Edwards, 2010; Hindle & Matthewman, 2017; Māori Adult Literacy Working Party, 2001). Upon its arrival to Aotearoa New Zealand, print literacy was also adopted by Māori, and used to convey te reo (Derby, 2021; McRae, 2017; Paterson, 2020). The Māori Adult Literacy Working Party (2001) define Māori literacy as reading and writing in te reo Māori and English, as well as reading the land, knowledge of history including colonisation, body language, and Māori symbols. Similarly, Zepke (2011) described Māori literacy practices as having three parts: written and oral language, the criticality to progress change, and the ability to live as Māori in the Māori world.

Māori literacy practices are expressions of Māori worldviews (Hindle & Matthewman, 2017). As such, an understanding of te ao Māori is fundamental to an understanding of Māori literacies (Hindle & Matthewman, 2017). Te ao Māori consists of interpenetrating temporal and transcendent worlds (Hindle & Matthewman, 2017; Marsden, 1992). For Hetaraka et al. (2023), Māori literacy is learned via *tiritiria* (apportionment), as knowledge passes from the spiritual realm into the physical. Accordingly, Māori literacy practices have interconnected

physical and spiritual aspects (Hindle & Matthewman, 2017). Such values are demonstrated in the following examples of Māori literacy practices: *kōrero tuku iho* (oral tradition), *moko* (Māori tattooing) and *whakairo rākau* (carving). It is important to know what Māori literacy practices are to recognise them when they appear in the literacy practices of people with learning disability.

3.2.1.1 Kōrero Tuku Iho.

Kōrero tuku iho is an oral literacy that encompasses four main genres: whakapapa, *whakataukī* (proverb), *kōrero*, and *waiata* (song) (McRae, 2017). Whakapapa is the patterned recitation of names, words or phrases that describe relationships. Whakataukī are short memorable sayings that communicate Māori guidelines, concepts, and history (McRae, 2017) with coded meanings that can depend on their origin and context (Whaanga et al., 2018). *Kōrero* are descriptive stories that transmit norms and customs through the telling of *pūrākau*, personification of the natural world, and sagas about important people (McRae, 2017). Finally, *waiata* are songs or chants, often poetic, that communicate emotions and include well known forms such as *karakia* (prayer) and *haka* (posture dance) (McRae, 2017).

3.2.1.2 Moko.

Moko is a visual literacy that represents information through permanent inking carved into the face, chin, or body using traditional protocols (Ellis, 2014; Gallagher, 2002; Jones & Hoskins, 2016). Each *moko* is unique invites the reader to make connections, remember ancestors, and respect the authority of the wearer (Jones & Hoskins, 2016). Gallagher (2002, p. 39) argued that this way of communicating was “a pre-European textual culture,” the

legitimacy of which was respected by colonial era Pākehā. Painted representations of moko were acknowledged as legal signatures in Aotearoa New Zealand until the mid-1840s (Ellis, 2014).

3.2.1.3 Whakairo Rākau.

Whakairo rākau is a tactile literacy that uses carving to tell a story about a person, whakapapa, or event (Kiddle, 2012; Mulholland & Bargh, 2015) (see *Figure 3*). For example, the head, shoulders, arms, hands, genitalia, and surface patterns of a *poupou* (carved figure) are unique and symbolic (Mulholland & Bargh, 2015).



Figure 3 The positioning of the figures in this pouwhenua (post marker of ownership) acknowledges the whakapapa of three iwi local to Matamata (Photo: N. Newcombe).

3.2.2 Deaf and Disabled Literacy Practices

This section will discuss the multimodal literacy practices of New Zealand Sign Language (NZSL), Makaton, braille, and other literacy practices used by adults with learning disability to bring awareness and understanding to these literacy practices.

3.2.2.1 New Zealand Sign Language

NZSL is a unique language that incorporates English and te reo Māori words and concepts and is of cultural importance to Deaf people and tāngata Turi (Human Rights Commission, 2013; Williams, 2022). There is no specific te reo Māori sign language, rather NZSL can be translated into either te reo Māori or English (Deaf Aotearoa, 2023). It became an official language in Aotearoa New Zealand via the NZSL Act 2006 and is also used by non-Deaf people (Human Rights Commission, 2013; Williams, 2022).

The NZSL Act legislates that NZSL be brought into everyday usage (Williams, 2022). However, the Act is often interpreted in a symbolic manner, as implementation has been stymied by the cost and availability of NZSL translation services, and lack of political will (McKee, 2011). One of the benefits of the NZSL Act has been to recognise NZSL users as a minority language community (McKee, 2011), although that recognition has not brought an end to the additional barriers NZSL users experience in relation to their visual literacy (Human Rights Commission, 2013; Williams, 2022).

In Aotearoa New Zealand, Voice Thru Your Hands supported everyone to use NZSL, including people who are not Deaf (Newcombe, 2015). The organisation was founded by Alison Attwell, whose daughter has Down syndrome and uses NZSL as an alternative to speech (Newcombe, 2015). *Key word signing*, the use of a restricted sign language vocabulary in conjunction with spoken words, is also commonly used in Aotearoa New Zealand with children who are not Deaf but have difficulties with spoken language (Hand, 2021).

3.2.2.2 Makaton

Makaton is a form of communication that draws vocabulary from British Sign Language, spoken words, and drawn symbols (Law, 2021). It is often used with people with learning disability (Law, 2021). The Makaton vocabulary was developed by the The Makaton Charity and follows the structure of English, making it easier for some people to learn than other sign languages that have their own grammar (The Makaton Charity, 2023). Makaton can also be used as an intermediary step towards learning to speak or write in English (The Makaton Charity, 2023).

3.2.2.3 Braille

Braille is a tactile literacy that uses embossed paper to represent letters or words (Blind Low Vision NZ, 2023). It can be written manually using a braille writer or a slate and stylus, or using electronic methods (Blind Low Vision NZ, 2023). There are many forms of braille, for example uncontracted braille, which is equivalent to written letters, contracted braille, which is made up of short form words, braille musical notation, and Nemeth braille code for mathematic and scientific notation (Blind Low Vision NZ, 2023). Braille can be accompanied by tactile diagrams or pictures in the same way as written words can be accompanied by visual diagrams or pictures (Blind Low Vision NZ, 2023). Aotearoa New Zealand adopted the Unified English Braille Code in 2005, which is a braille code commonly used across English-speaking countries (American Foundation for the Blind, 2006).

3.2.3 *Literacy Practices Used by Adults with Learning Disability*

In this section, literacy practices used by adults with learning disability, including reading and writing, easy read, individualised communication systems, and Augmented and

Alternative Communication (AAC) are outlined. The role of facilitated communication is also discussed.

3.2.3.1 Reading and Writing

Many adults with learning disability use reading and writing as a literacy practice. Participants in Bochner et al. (2001) used reading strategies such as recognising single words, approximating the sound of reading, and recalling texts from memory. They were most competent at reading texts that were salient in their daily lives, such as menus, recipes, shopping lists and comics. Morgan et al. (2013) observed adults with learning disability concentrating most often on main headings and pictures or a random selection of words when pictures were not available. In terms of writing, participants reported completing workbooks, typing lists, and copying pages from books and magazines, alongside writing stories and plays (Morgan, 2013). The writing activities undertaken most frequently by adults in the study by Trenholm and Mirenda (2006) were writing or copying their name or familiar words, writing messages, and writing lists. Forts and Luckasson (2011) described how they, an adult with and an adult without learning disability (respectively), used reading and writing to send cards and letters to each other, and wrote an academic journal article together. Ann Forts used literacy practices including keeping an address list and a calendar of birthdays and anniversaries, as well as reading to children in her voluntary role as a teacher aide (Forts & Luckasson, 2011). Forts and Luckasson (2011) importantly described these literacy practices without appraisal or judgement. These authors demonstrate the range of reading and writing practices undertaken by adults with learning disability.

Adults with learning disability have been shown to have positive (Bochner et al., 2001; Morgan et al., 2013) and mixed (Morgan & Moni, 2008) attitudes towards reading and writing. Almost half of the participants in Bochner et al. (2001) described language and reading activities as their favourite form of recreation. However, research by Morgan and

Moni (2008) showed that adults with learning disability were reluctant to read texts they perceived to be above their reading capacity, or that which was visually similar to school reading materials. Easy read is one response to the inaccessibility of print literacy experienced by some adults with learning disability.

3.2.3.2 Easy Read

“Easy read is a communicative format intended to be more accessible for adults with learning disabilities and align more effectively with their preferences” (Newcombe, 2022, p. 30). The text element is arranged in short active sentences using limited punctuation with content being restricted to one idea per page; white space is maximised, and there is an image paired with every sentence (Buell et al., 2020; Chinn, 2019; Fajardo et al., 2014; People First New Zealand, 2017; Turnpenny et al., 2018). Many adults with learning disability and other people choose to use easy read information. In Aotearoa New Zealand, People First New Zealand has an online library of easy read documents with information about disability rights, support, voting and the government, employment, health, and other topics (People First New Zealand, n.d-a). Easy read information is often developed with a view to realising CRPD Article 9.2 (h), “to promote the design, development, production and distribution of accessible information” (United Nations, 2007). Although Walmsley (2013, p. 17) finds that that easy read can be a “cosmetic device” used to satisfy the sensibilities of people without learning disability, rather than being most accessible for adults with learning disability.

The main objective of easy read is to reduce cognitive demand on the reader as compared with other documents (Buell et al., 2020). Cognitive demand while accessing documents is mediated by intrinsic factors, such as prior knowledge, executive functioning skills, interest, and motivation; and extrinsic factors, such as the presence of someone reading aloud, the vocabulary range presented, and the prominence of punctuation used in the document

(Buell et al., 2020). Turnpenny et al. (2018) also suggested a list of writing features that may be more difficult for some adults with learning disability and are best avoided. These relate to,

- sentence structure, for example, passive voice and double negatives;
- vocabulary, for example, difficult, ambiguous, or unusual words;
- concepts that use prior knowledge, for example, ideas about time, frequency, distance, or quantity; and
- devices such as abstractions, generalisations, and rhetorical questions.

Good visual design is also an important enabler in easy read documents (Turnpenny et al., 2018).

Easy read guidelines vary and different ways of presenting easy read information have different impacts on audiences of adults with learning disability (Buell et al., 2020; Hurtado et al., 2014; Turnpenny et al., 2018). Hurtado et al. (2014) conducted an experiment on the accessibility of easy read documents. In their study, 44 adults with learning disability undertook a questionnaire to demonstrate their knowledge of a topic before and after accessing an easy read leaflet about it. The words were read aloud to avoid disadvantaging participants who had limited reading skills. One leaflet had words and pictures and the other leaflet had pictures only, however the words (while not present on the only pictures leaflet) were read aloud to participants in both instances. The conclusions of this study were that the pictures only format may reduce cognitive demand, allowing for greater focus, and that the presence of a person reading documents aloud is more important in terms of knowledge acquisition than document design (Hurtado et al., 2014). In contrast, Walmsley (2013) found that many pictures used in easy read are only loosely associated with the words, and can be confusing, distracting, and fail to contribute to an understanding of the text. Turnpenny et al. (2018) also contradicted Hurtado et al. (2014) by cautioning against having another person reading easy read aloud because readers have been known to transmit their biases, particularly when accessing sensitive content. Buell et al. (2020) did their easy read research using a randomised trial with 60 adults with learning disability who

accessed linguistically simple and complex easy read documents, with and without a reader. They reported no significant differences between participant understanding of the four variations of easy read being more or less complex and being with or without someone reading aloud (Buell et al., 2020). These conflicting studies revealed that care needs to be taken to make information easier to understand for an individual person, rather than responding to the generalised needs of adults with learning disability.

There are numerous critiques of easy read, which is often deemed accessible and appropriate by people without learning disability (Chinn, 2019). However, accessibility is subjective, and what qualifies as a difficult word or a long sentence may be different for different people (Fajardo et al., 2014). As Walmsley (2013) contended, the easy read format erroneously conflates learning disability with low literacy skills and fails to respond to other difficulties adults with learning disability may have in accessing information, such as memory difficulties or a lack of prior knowledge from which to construct meaning. Chinn (2019) also shared concerns about the age appropriateness of some easy read documents, questioning whether they have the unintended effect of infantilising adults with learning disability through their similarity to picture books. Producers of easy read can mitigate these issues by testing their easy read documents with people from their target audience before publishing them (Turnpenny et al., 2018). In summary, easy read intends to reduce barriers to reading and writing for people with learning disability and does so with mixed results.

3.2.3.3 Individualised Communication Systems

Some people with learning disability use individualised communication systems, which Dennis (2002) called “nonverbal nonsymbolic” literacy practices. *Individualised communication systems* are often self-developed and can include, but are not limited to, behaviours, sounds, gestures, directionality, such as moving or looking towards or away from, and facial expressions (Dennis, 2002).

There are barriers and enablers to individualised communication systems. Two barriers to are that communication partners are required to engage in active interpretation, and that such literacy practices are often restricted to communication partners who enjoy high levels of trust with, and knowledge of, the teller (Dennis, 2002). Two enablers are communication partners developing their own literacy in relationship to the preferences of the teller, and an attitude of expectation that the teller can and will communicate (Danker et al., 2023).

3.2.3.4 Augmentative and Alternative Communication and Other Communication Assistive Technology

Augmentative and Alternative Communication (AAC) is a process of using non-electronic (such as a communication board, talking mat [see *Figure 4* above], or Pragmatic Organisation Dynamic Display¹⁵) or electronic technology (such as the TouchChat app¹⁶ [see *Figure 4* below]) to assist communication (Fabio et al., 2023; Hetzroni, 2004)¹⁷.

¹⁵ <https://novitatech.com.au/podd-communication-books/>

¹⁶ <https://touchchatapp.com/>

¹⁷ AAC tools and strategies are publicly funded in Aotearoa New Zealand for qualifying disabled people, including people with learning disability, from TalkLink Trust.



Figure 4 Talking mat (Photo: N. Newcombe) (above) and TouchChat app on iPad (Photo: G. Good) used with permission (below).

People who use AAC often communicate through “objects, pictures, and graphic symbols such as line drawings,” rather than reading, writing, speaking, or listening (Hetzroni, 2004, p. 1307). In these systems, graphic symbols are assigned a specific meaning. For example, the selection of a particular image is interpreted in a predictable way. One common system used in AAC is *Bliss Symbols* (see *Figure 5*), an ideographic code made up of 100 symbols that can be arranged in various ways (Nicholas, 1978). Bliss symbols can be used with speech generating devices (Olaszi et al., 2002). Speech generating devices are often used when spoken language is absent or difficult for other people to understand (Hetzroni, 2004). Benson-Goldberg and Erickson (2021) said the quality and availability of AAC has dramatically increased in recent years. For example, artificial intelligence is now beginning to generate speech from images and gestures and improve the intelligibility of disabled speech patterns for audiences without learning disability (Zdravkova et al., 2022).

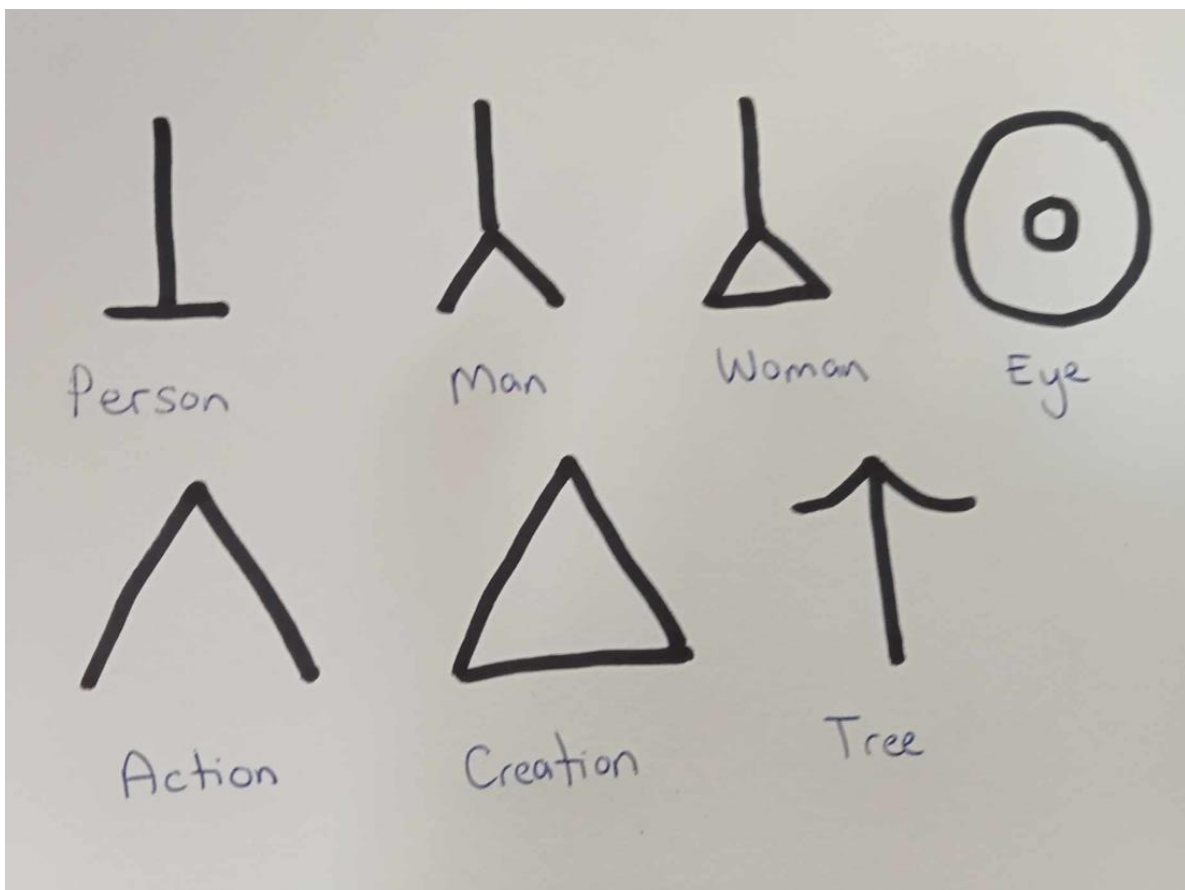


Figure 5 Bliss symbols (Drawing: N. Newcombe).

Jerome and Ainsworth (2020) discussed the use of assistive technology to supplement reading and writing experiences for people with learning disability, for example, by highlighting or shortening text, or adding pictures. The following examples of assistive technology can individualise text for a learner. *Helperbird*¹⁸ is a browser extension that has a range of reading and writing accessibility features including speech to text generation with predictive text and the ability to display text one word at the time. *Glean*¹⁹ is a digital notetaker that transcribes audio to text and can toggle between audio and text. There are also digital pens that read printed text aloud such as the *ReaderPen*²⁰. Such assistive technology is now widely adopted in learning environments (Spooner et al., 2015).

3.2.3.5 Other Forms of Literacy

In addition to the literacy practices discussed above, adults with learning disability have also been reported to engage in other forms of literacy including drama, drawing, speech, and board games. Atkinson and Williams (1989) published the stories of adults with learning disability in an anthology called *Know me as I am*. In this project, storytellers used role play, drawing, speech, Makaton, or writing to convey their life stories. Examples of other literacy practices include a dramatisation of information about bowel screening played by actors with learning disability to communicate that information to other adults with learning disability (Donaghy & Anderson, 2015). Montenegro and Greenhill (2015) reported on a board game co-produced by adults with learning disability to aid in learning about their rights. The literacy practices discussed here are likely to represent a small percentage of all literacy practices used by adults with learning disability.

¹⁸ <https://www.helperbird.com/>

¹⁹ <https://glean.co/>

²⁰ <https://www.scanningpens.com/nz/ReaderPen-Products-SPNZ.html>

3.2.3.6 Facilitated Communication

Facilitated communication is an assisted typing technique in which physical assistance, such as stabilisation or touch applied to the wrist or elbow, is provided to a disabled person with significant needs for support to the effect that they type understandable words (Biklen, 1990). The technique attracts ongoing debate, with polarising opinions about the authenticity of authorship, particularly concerning the use of facilitated communication in abuse allegations and legal defences (Erevelles, 2015; Simmons et al., 2021). Critics claim that facilitators unconsciously interfere in the writing process by moving the disabled person to indicate keystrokes aligned with the preferences of the facilitator (Simmons et al., 2021; Travers & Ayres, 2015). Whereas advocates Biklen (1990), Kasa-Hendrickson (2005), Morton (2012), and Kliewer et al. (2016) defend facilitated communication.

Simmons et al. (2021) outlined data from over 40 experiments that all disprove the authenticity of facilitated communication. However, Biklen (1990) was an apologist for the negative outcomes that occurred during facilitated communication experiments, saying some people may choose not to express themselves in test conditions because they are only willing to engage with specific people in specific circumstances. Kasa-Hendrickson (2005) claimed it was too stressful for facilitated communication to occur within the artificial environment produced by undertaking an experiment. Morton (2012) discussed legal decisions regarding facilitated communication and called for uniformity in ascertaining the competence of witnesses who use spoken language and those who communicate through other means. She concluded by requesting that positional privilege not be used to silence different literacy practices.

Taking another approach, Kliewer et al. (2016) had philosophical grounds for rejecting attempts to test the authenticity of facilitated communication. They used the social model of disability to place the burden of learning to understand communication on the observer, rather than the burden of learning to communicate in culturally normative ways on the disabled person. The authors illustrated their argument by drawing parallels between the

experiences of disabled people using facilitated communication and those of Phillis Wheatley, a formerly enslaved poet, and Helen Keller, a Deaf and blind author, who were both subjected to tribunal hearings on the validity of their literacy practices (Kliewer et al., 2016).

While popular in the early 1990s, facilitated communication has been discredited as pseudoscience, and was denounced by the American Psychological Association and the American Association on Intellectual and Developmental Disabilities (Simmons et al., 2021). Simmons et al. (2021) argued that facilitated communication also threatens the human rights of disabled people with significant needs for support by diverting attention away from their authentic expression and increasing their vulnerability to miscommunication occurring in their name. For these reasons, facilitated communication will not be included as a literacy practice in this research.

3.3 Culture and Cultural Literacy

This section serves as background information for the theme of learning disability cultural literacy that I construct in my reflexive TA.

3.3.1 Culture

In this research, the term *culture* is used according to its anthropological definition, which is about 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) 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. Culture can also be understood as having objective and subjective aspects (see *Section 3.3.1*) (Berry & Triandis, 2014).

3.3.2 *Disability Culture*

Many disabled people have said 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 non-disabled people and therefore 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." Autistic pioneer Judy Singer (2017) coined the term *neurodiversity*, now commonly used by autistics, ADHDers and others, as a counter-hegemonic social movement and culture for autistic people. The affirmation model of disability also constructs disability in similar terms to those used by cultural studies authors Highmore (2016) and Berry and Triandis (2014) to describe culture, for example, "disability is created through interactions, expectations, assumptions, remarks and ways of doing things" (Cameron, 2007, p. 508). Disability is similarly regarded as a culture in this research.

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).

3.3.3 *Learning Disability Culture*

As with any population, there are numerous views about learning disability among people with learning disability. Morgan et al. (2014, p. 1309) understand that “some individuals who are labelled with intellectual disability are not aware that the label is applied to them and some reject the label outright.” Likewise, in Jones (2019), only two of eight participants with learning disability identified as being disabled. Other participants identified as a “normal person” (p. 213), someone who lives “around disability stuff” (p. 216), someone who is “not known as a disability person” (p. 216) and someone who has an “able-ability” (p. 217). However, while a disabled identity may be problematic for some people with learning disability, it is clearly positive for others. Other participants in Jones (2019, p. 179) were positive about their disability, “Glen: I know I am. Natalie: Yeah I'm proud. Luke: So am I, I'm proud. Jonathan: Of course I am cuz I do, I (think of that) in my heart. Natalie: I wouldn't want to be any other way.” While other groups, such as Deaf (Deaf Aotearoa, 2023) and autistic people (Singer, 2017) have adopted a cultural outlook, I was unable to find literature on the application of culture to learning disability or any literature on this topic authored by a person with learning disability. The next step was to develop an understanding of why people with learning disability do not appear to have claimed their disability as a cultural identity.

This section will now explore possible reasons why people with learning disability may not have expressed themselves as having their own culture. One possible reason is that learning disability carries a greater degree of stigma than other disabilities (Jansen-van Vuuren & Aldersey, 2020; Thomas, 2000; Tringo, 1970). For example, on using a social distance scale to measure respondent sympathy towards different disabilities, Tringo (1970) found that people with learning disability²¹ 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 different disabilities.

²¹ “Mental retardation” in the original text.

Thomas (2000) replicated the hierarchy of preference study by Tringo (1970) to measure changes in attitudes over the intervening 30 years between the studies. The new study replaced some disability categories (such as old age and ulcers) with other disability categories (such as AIDS and learning disability). However, 15 of the 16 disabilities included in both studies maintained their rank order, with cancer being the only category to change positions (by moving four places more acceptable). Thomas (2000, p. 1156) concluded the original hierarchy of preference further marginalises people with learning disability and remained “firmly entrenched.” While these studies produced similar outcomes, there were methodological differences. Tringo (1970) surveyed respondents on their educational attainment, employment status, and gender, but respondents were not asked if they were disabled. Thomas (2000, p. 1156) did not report asking for the same demographic information yet proposed that “disabilities are not perceived equally by nondisabled persons.” It is unclear as to how he ascertained or assumed that respondents were disabled or non-disabled. Nevertheless, people with learning disability were said to be the subject of discriminatory ideation in both studies.

Ouellette-Kuntz et al. (2010) conducted another study concerning attitudes towards people with learning disability. Their study modernised the aforementioned social distance scale, such as by replacing “would put to death” (Tringo, 1970, p. 298) with “I would rather not have people who have intellectual disabilities live in the same apartment building I live in” (Ouellette-Kuntz et al., 2010, p. 135). The 2010 study only investigated attitudes towards people with learning disability, rather than making comparisons between different disabilities. In contrast with Tringo (1970) and Thomas (2000), Ouellette-Kuntz et al. (2010, p. 139) concluded that public attitudes towards people with learning disability were now “surprisingly positive.” The authors noted that community integration policies have worked to increase the frequency of contact between people with and without learning disability, with the outcome being improved attitudes of the latter towards the former. Inclusive education could be one example of such integration between people with and without learning disability.

Jansen-van Vuuren and Aldersey (2020) conducted a literature review titled *Stigma, Acceptance and Belonging for People with IDD Across Cultures*. Searching literature published from 2017 onwards, they found that the adoption of strength-based approaches had fostered positive trends for the status of people with learning disability. Yet in every ethnic culture reviewed, with particular emphasis on Western capitalistic cultures, there was ongoing stigma towards that group. In contrast, Chapko et al. (2020) found that people with learning disability expected public attitudes towards them to be negative, but that results of their co-designed survey were surprisingly positive. Taken together, research by the preceding authors demonstrates a stigmatisation of learning disability that could discourage the group from building a social movement based on their unique ways of being.

Another reason why people with learning disability may not have expressed themselves as having their own culture is because of the effects of normalisation (see *Section 2.2.2*). Normalisation practices targeted at people with learning disability have created a barrier to group identity formation (Culham & Nind, 2003). The principles of normalisation, promoted by public policy in Aotearoa New Zealand (Jones, 2019), work to present people with learning disability as being the same as people without learning disability to the greatest extent possible (Wolfensberger, 2011). This is incongruent with the formation of other cultures and movements (Parsons, 1999). Culham and Nind (2003) expressed how normalisation undermines group empowerment by restricting the congregation of people with learning disability and allowing people without learning disability to make decisions for them. Even the People First exhortation to “label jars not people” (Together 4 Change, 2023, subheading) could suggest the rejection of a learning disabled identity.

3.3.4 *Cultural Literacy*

Hirsch (1984) coined the term *cultural literacy* to encompass the background information people use to make sense of what they read. Expressed differently, it is the bank of concepts that allow readers and listeners to know what words mean. His concept is like that

of reading comprehension. *Reading comprehension* involves using knowledge of how printed letters group together to form sounds, how to map these sounds onto a remembered vocabulary, and using strategies such as prior knowledge and creating mental images to comprehend what is being read (TEC, 2008a).

For Hirsch (1984), cultural literacy requires active involvement in and familiarity with a collective reservoir of information. He suggested the concept of a “common reader,” being a person who holds a set of background knowledge particular to their country (Hirsch, 1984, p. 7). (Hirsch, 1984, 1988) wrote for a North American audience and sought a national consensus on a cultural canon of people, places, events, and ideas that North Americans could learn as part of becoming a literate common reader. A major flaw in the cultural literacy work of Hirsch (1984, 1988) was his assumption of cultural uniformity, specifically that each country would be monocultural.

Numerous authors have critiqued Hirsch (García Ochoa & McDonald, 2020; Hodgson & Harris, 2022; Kaufer, 1989). Kaufer (1989) thought learners should focus on a smaller number of relevant cultural artefacts, rather than a nationwide cultural canon. García Ochoa and McDonald (2020, p. 8) gave their own definition of cultural literacy, being “the skills and knowledge that help our students understand cultural differences and draw meaning from them.” Hodgson and Harris (2022, p. 384) found that cultural reference points are not uniform across a country, but rather unique to “region, class, gender, ethnicity, education, and other factors.” Each of these authors point to the multiculturalism of knowledge.

3.4 A Definition of Literacy in this Research

There are many and varied definitions of literacy. It is currently defined by the TEC (n.d-a, Literacy) as, “the written and oral language people use in their everyday life and work. It includes reading, writing, speaking and listening.” This definition is narrow and positions people who demonstrate skills in English as being literate and people who use other literacy

practices as having low literacy skills. Furthermore, literacy as reading, writing, listening, and speaking is subjective and may not be appropriate for all cultures and groups (Edwards, 2010).

There is an opportunity to consider how the privileging of reading and writing skills evolved in tandem with the privileging of non-disability (ableism) from the Industrial Revolution onwards, with both phenomena serving the status quo of labour-normativity. This understanding of literacy has structurally marginalised people with learning disability, for whom reading and writing is often not as accessible. Rather than using quantitative assessments to construct adults with learning disability as having lower literacy outcomes than others (Bochner et al., 2001; Moni et al., 2018; Morgan & Moni, 2008; The Roeher Institute, 1990, 1994; Trenholm & Mirenda, 2006), this research affirms that all people are literate. A process that begins with the first literacy, reading the vibration of conception (Hetaraka et al., 2023).

Rather than being restricted to reading and writing or reading, writing, speaking, and listening, there is an interminable range of semiotic systems that can be used in literacy practices. For example, Kress (2010) categorised semiotic systems as pertaining to linguistic, visual, gestural, spatial, and audio literacies, and Bull and Anstey (2018) discussed the addition of sight, taste, smell, hearing, and touch to those categories. An increasingly digital world is likely to bring us new semiotic resources and combinations that are not yet known (Danielsson & Selander, 2021). In the future, thought information could even be externalised via brain-machine interface technologies that could revolutionise the ways some disabled people communicate (Neuralink, 2023). Literacy needs to be understood as much wider than “squiggles on a page” (Turia, 2003, para 4) in our context of rapidly changing technology and constant reimagining of literacy (Danielsson & Selander, 2021).

In this research, *literacy* is a practice that has the potential to effect communication. This definition acknowledges Morgan et al. (2011), who advocated for broadening conceptualisations of literacy to encompass the diverse literacy practices of people with learning disability.

3.5 Research Questions

There is no identified research about the literacy practices of adults with learning disability in the bicultural context of Aotearoa New Zealand. Bochner et al. (2001), Morgan and Moni (2008), Forts and Luckasson (2011), Moni et al. (2018), Morgan et al. (2013), and Trenholm and Mirinda (2006) have engaged in research aiming to understand the reading and writing skills of adults with learning disability in Australia, Canada, and North America. However, these studies adhere to a narrow definition of literacy as reading and writing and do not encompass other literacy practices that may be areas of strength for people with learning disabilities. Mirfin-Veitch (2003, p. 41) is an older literature review published in Aotearoa New Zealand titled *Education for Adults with an Intellectual Disability* and has a section on “literacy and adults with an intellectual disability,” although this section only reports international research. McIlroy (2017) is the only Aotearoa New Zealand based study that aligns more closely with my research focus, but her research is with children and not specific to literacy. As described, existing research on literacy and adults with learning disability has primarily focused on reading and writing. There is a gap in research where the literacy practices of adults with learning disability have not been adequately explored in a way that is open to diverse forms of literacy, not just limited to reading and writing. In response, this research proposes one overarching research question, which is supported by two sub questions:

What changes to adult literacy policies would value adults with learning disability as literate members of the community and promote their access to adult literacy education on an equal basis with others?

Sub questions:

1. What are the current adult literacy policies in Aotearoa New Zealand and what is their impact on adults with learning disability?

2. What are the literacy practices and perspectives of adults with learning disability in Aotearoa New Zealand?

3.6 Conclusion

Reading and writing constitute one literacy practice among many literacy practices, which all have origins and trajectories. Other than reading and writing in English and te reo Māori, this chapter also outlined Māori oral, visual, tactile, geographic, and relational literacies through which Māori understand and act upon their contexts. Familiarity with the kaupapa of Māori literacy and Māori cultural literacy is essential in the bicultural context of Aotearoa New Zealand. Furthermore, such an understanding can support an appreciation of how other cultures, including disability cultures, may also have different approaches to literacy and cultural literacy practices.

Literacy practices used by Deaf and disabled people are also described. These include linguistic literacy (reading, writing, NZSL, Makaton), visual literacy (AAC, facial expressions, Bliss symbols), gestural and spatial literacy (behaviour, movement), audio literacy (sounds, speech), touch literacy (AAC, Braille), and highly multimodal literacies such as drama and board games. The integration of AAC and artificial intelligence further expand the concept of literacy. For some disabled people, these technologies add selection and prediction as semiotic systems to their literacies. Culture and cultural literacy are explored in this chapter because cultural literacy practices are a key element of literacy. The range of literacy practices in this chapter illustrate and emphasise that literacy extends beyond reading and writing, a perspective that foregrounds the definition of literacy in this research.

4 Chapter Four: The Adult Literacy Context in Aotearoa New Zealand

Adult literacy in Aotearoa New Zealand exists within the historical context of print literacy arriving in Aotearoa New Zealand as part of colonisation. This chapter presents a history of English literacy practices from their origins to their convergence in Aotearoa New Zealand, and into the present day, forming a background to the real-world problems this research addresses.

In modern times, international agreements contribute to the expectations and standardisation of adult literacy in Aotearoa New Zealand. In terms of human rights agreements, only the CRPD is discussed as it is most relevant to this research. UNESCO and the World Education Forum also play crucial roles in promoting adult education, including literacy. Notably, the OECD has significantly influenced the trajectory of adult literacy in Aotearoa New Zealand, as we have drawn from and responded to their adult literacy measures and attitudes.

Turning to our adult literacy policies, a pivotal juncture emerged following the International Adult Literacy Survey (IALS), after which Aotearoa New Zealand embarked on a period of intense adult literacy infrastructure development that included increased funding and regulation of adult literacy education (Furness & Hunter, 2018; Walker et al., 1996). To this effect, the Ministry of Education (2001) published their strategy *More than Words*, and Māori responded with their influential report *Te Kāwai Ora: Reading the World, Reading the Word, Being the World* (Māori Adult Literacy Working Party, 2001).

Responsibility for adult literacy was transferred to the TEC in 2007. The TEC continues to promote adult literacy as skills in reading, writing, speaking, and listening in English, and the ability to apply those skills to meet the demands at home, the community, and the knowledge economy (TEC, 2008b). This chapter describes previous adult literacy policies to support an understanding of the current adult literacy policy landscape.

The Ministry of Education continue to oversee some aspects of adult literacy education via their *Tertiary Education Strategy* (Ministry of Education, 2020b). Another relevant function of the Ministry of Education is to require tertiary education organisations to provide learning support for disabled learners who are enrolled in courses on the New Zealand Qualifications and Credentials Framework (NZQCF) and to require some organisations to submit a Disability Action Plan (Achieve, 2023). Ministry of Education policies described in this chapter scaffold the adult literacy policies analysed in *Chapter Five*. They also structure and fund reasonable accommodations that may be needed to enable people with learning disability to access adult literacy education “on an equal basis with others” (United Nations, 2007, Article 24.5). Consultation with disabled people and adults with learning disability occurred for the *Tertiary Education Strategy* (see *Appendix C and D*) and will be discussed in this chapter in terms of the strengths, weaknesses, and applicability of that consultation.

Adult literacy testing is then introduced. The Literacy and Numeracy Adult Assessment Test (LNAAT) or Starting Points Assessment Test (SPAT) are part of the eligibility criteria for adult literacy education funded by TEC Foundation funds (except Adult Community Education [ACE]²²) (TEC, 2024). The TEC also uses the LNAAT to measure learners against a literacy threshold, which represents competencies thought to be required to meet the reading, writing, speaking, and listening demands of living and learning in Aotearoa New Zealand (TEC, 2024). Those who meet the literacy threshold do not require reassessment (TEC, 2024). These adult literacy assessments are quantitative and only test a predetermined range of literacy skills that are related to reading, writing and vocabulary.

International research has shown that quantitative testing is not adequate for understanding the literacy practices of adults with learning disability (Bochner et al., 2001; Moni et al., 2018; Morgan & Moni, 2008; The Roeher Institute, 1990, 1994; Trenholm & Mirenda, 2006). This may be because their literacy practices are more likely to be different

²² Community-based education, foundation skills, and pathways into other learning opportunities that meet community learning needs. These courses have no minimum hours of delivery and are not formal qualifications. They are typically introductory courses of short duration.

to those used in most literacy assessments. Literacy assessment methods that may be more meaningful to this group are discussed in this chapter, including one example used in Aotearoa New Zealand research with children with learning disability. Literacy assessment is a key feature of the adult literacy policies that will be analysed in the next chapter.

By highlighting the adult literacy context in Aotearoa New Zealand and the impact of that context on people with learning disability, issues that policymakers need to consider when developing adult literacy policies are brought to the fore. In understanding these issues, policy recommendations can be made that better value the literacy practices of adults with learning disability and improve their access to adult literacy education.

4.1 A History of Reading and Writing in English from the Beginning Until the Colonisation of Aotearoa New Zealand

A history of reading and writing supports an appreciation for the cultural, social, and technological factors that have shaped print literacy over time. It also provides a context for understanding the literacy practices and perspectives that were ultimately exported to Aotearoa New Zealand.

Printed communication began around 5000-7000 years ago (Altmann, 1998; Goody, 2000). Two key contributors to the history of writing, Isaac Taylor in 1883 and Ignace Gleb in 1952, both put forward evolutionary models of writing development²³ (Joyce & Borgwaldt, 2013). English writing began as Anglo-Saxon runes that were later replaced with a mix of Latin and Roman script, then a phonetic literacy began to develop informally within communities according to their contexts and needs (Altmann, 1998; Cook-Gumperz, 1986; Gaur, 1984; Goody, 2000). The first iteration of the modern English alphabet was recorded in 1011, with

²³ Taylor's model moves from ideograms; pictures, pictorial symbols and verbal signs, to phonograms; syllabic signs and finally alphabetic signs. Gleb's model charts writing from pictorial representation to mnemonic devices and then full writing.

the modern grouping of 26 letters being standardised in the early 1800s, and then remaining constant and widespread from the Industrial Revolution onwards (Gaur, 1984).

Reading and writing only assumed the form known today during the Industrial Revolution (Gaur, 1984), which was a time of great structural change in Western Europe and North America (More, 2000). Urbanised and larger-scale commercial operations characteristic of that period demanded increasingly print-literate populations (Gaur, 1984). Two key changes facilitated the spread of reading and writing: the invention of the steam-powered printing press in 1811, and the introduction of widespread schooling in England in 1870 (Cook-Gumperz, 1986). Urbanisation brought large groups of people together who had previously used local dialects, and standardised conventions of spelling and grammar were required to facilitate communication between them (Cook-Gumperz, 1986). School curriculums were concomitantly regulated to achieve uniformity in literacy (Cook-Gumperz, 1986). The printing press democratised information, but also led to cultural homogenisation as different communities became recipients of the same information, rather than experiencing the variability that existed when local and oral literacy practices were primarily used (Heath, 1986).

The Industrial Revolution marked a change in power dynamics affected by reading and writing (Cook-Gumperz, 1986; Gaur, 1984; Graff & Duffy, 2011). Prior to the Industrial Revolution, the ability to read and write was positioned as a threat to the established order and thus reserved for religious purposes and the upper class (Cook-Gumperz, 1986). For example, in 1807, the President of the Royal Society opposed moves to extend reading and writing education to the working classes, saying in the English Parliament, “it would render them [working people] factious and refractory” (Cipolla, 1969, p. 66 as cited in Cook-Gumperz, 1986, p. 25). However, reading and writing became imbued with English values during the Industrial Revolution and were subsequently elevated to a criterion for civility and soundness of mind (Cook-Gumperz, 1986; Gaur, 1984; Goody, 2000; Graff & Duffy, 2011). Being, “the key to better health, a better character, greater sensibility and, as far the colonies were concerned, political freedom” (Gaur, 1984, p. 207). Ideas about the need for

and values associated with reading and writing migrated with English colonisers on their mission to Aotearoa New Zealand soon after.

4.1.1 The Arrival of Reading and Writing in Aotearoa New Zealand

British missionaries reached Aotearoa New Zealand in 1814, bringing their reading and writing skills and values with them (McKenzie, 1987; Parr, 1961). Missionaries worked with Māori to develop an orthography for te reo, largely basing this work on a dictionary of Tahitian words (Moon, 2018). Moon (2019, p. 497) further outlines the “extraordinary efforts” of early missionaries to preserve te reo Māori using print. Additional missionaries were invited to Aotearoa New Zealand by Māori who sought to learn to read and write (Carson, 1992).

Māori were quick to embrace print literacy and had higher rates of proficiency in reading and writing te reo Māori than Pākehā did by the 1840s (Derby, 2021; Hutchings & Ikin, 2016; Paterson, 2020). Settlers arriving in Aotearoa New Zealand were unable to read the messages conveyed through Māori literacy practices and consequently grouped those literacy practices into the category of art (Edwards, 2010). Māori may have learned to read and write quickly because of transferable skills gained from their indigenous literacy practices (Newman, 2010). The first te reo Māori book, *A Korao no New Zealand*, was published in 1815 by the missionary Thomas Kendall (Parr, 1961). The Church Missionary Society sent a small printing press to Aotearoa New Zealand in 1824 (Parr, 1961). Letters were sent between *kāinga* (settlements), sometimes scratched on *harakeke* (flax) leaves, and a bilingual newspaper called *Te Karere Maori* (the Māori messenger) started in 1855 (Paterson, 2020).

It is significant that Māori chose to adopt reading and writing, as some cultures, such as several Indigenous American peoples, rejected the new technology (Heath, 1986). Jenkins (1993) explained that two Māori named Tuai and Titere travelled to England where they

were impressed by iron smelting and glass making because these processes resembled the powers of *Māui* (cultural hero). Their experiences in England inspired Tuai and Titere to commend British technologies, including print literacy, to other Māori (Jenkins, 1993). However, substantial immigration from England changed the demographic of Aotearoa New Zealand, and English replaced te reo Māori as the dominant language, to the detriment of indigenous literacy practices (Hutchings & Ikin, 2016; Jenkins, 1993; Pool & Kukutai, 2018).

4.1.2 The Impact of Reading and Writing Arriving in Aotearoa New Zealand

Derby (2021) outlined two theories about the impact of print literacy arriving in Aotearoa New Zealand. One being that reading and writing comprised “cultural continuity” for Māori, and the other being that it was a “fatal impact” (Derby, 2021, p. 5). Another author found any link between reading and writing and colonisation unclear (Ballantyne, 2010). The purpose of this section is to uphold a bicultural approach (see *Section 5.1*) and to provide background information for my critique of the conceptualisation of literacy used in the adult literacy policies, which is about reading, writing, speaking, and listening in English.

In the cultural continuity theory, reading and writing is said to have presented valuable opportunities for Māori while having little effect on their culture (Derby, 2021). Derby (2021) described reading and writing as benefitting colonial era Māori as they used the new technology to express their culture and counter British authority. McRae (2017) also asserted Māori that used print literacy for their own purposes, such as to record oral traditions, keep minutes, and preserve knowledge. McKenzie (1987) described how, like in many cultures when print is first introduced, Māori treated books as ritual objects, carried them around, and wore pages from books as jewellery.

In the fatal impact theory, print literacy was said to have been a catalyst for colonisation and to have undermined Māori culture (Derby, 2021). Authors whose views align with the fatal impact theory consider that British missionaries disrupted Māori literacy practices by

representing te reo Māori in an alphabetic form (Awatere, 1984; Gibbons, 2002; Jenkins, 1993; Middleton, 2019). For example, Middleton (2019) claimed reading and writing was introduced in Aotearoa New Zealand with the explicit purpose of preparing Māori for written forms of governance and Christianity.

Several cultural shifts may have occurred for Māori in response to the introduction of reading and writing. These include the loss of oral records and the acceptance of written words as permanent and true (McKenzie, 1987). Another change is that, while Māori literacy practices are sacred and alive (Ellis, 2014; Gallagher, 2002; Hindle & Matthewman, 2017; Jones & Hoskins, 2016; McRae, 2017; Te Awekotuku, 2009), print literacy could have been perceived as devoid of spirituality and “mere extracts of the true knowledge” (Smith, 1913, p. 13, as cited in Royal, 1998, p. 81). These shifts are thought by Awatere (1984) and Royal (1998) to have been colonising and deleterious to Māori cultures.

4.2 The Impact of the OECD and the International Adult Literacy Survey on Adult Literacy Policies in Aotearoa New Zealand

Various international frameworks have an influence on adult literacy policies in Aotearoa New Zealand, with the OECD having particular reach in this area. The OECD is a cross-governmental organisation that works to set international policy standards for member countries. Aotearoa New Zealand became a member of the OECD in 1973 (New Zealand Foreign Affairs & Trade Manatū Aorere, n.d). As such, we actively participate in OECD adult literacy benchmarking and take direction from their policy advice (Furness & Hunter, 2018; Ministry of Education, 2001, 2019; Walker et al., 1996). One example of this participation was taking part in the IALS.

The IALS was a psychometric test developed by Statistics Canada and the United States Education Testing Service, and distributed to 24 OECD member countries in 1996 (Walker et al., 1996). The test involved interviewers visiting households and asking respondents to

answer predetermined questions to assess their functional literacy (Boudard & Jones, 2003). There is no reason to assume the results of this survey represent the literacy practices of Aotearoa New Zealand communities in our bicultural context.

Critics of the IALS found the test to be arbitrary (Payne, 2006), monocultural (Blum et al., 2001; Hamilton & Barton, 2000), and demonstrative of a deficit-based approach (Furness & Hunter, 2018). Payne (2006, p. 226) argued that the IALS has constructed higher rates of illiteracy by using inflated standards for what skills were required for respondents to be considered literate. Of relevance to Aotearoa New Zealand, Hamilton and Barton (2000) and Blum et al. (2001) identified the IALS as representing North American norms, and failing to recognise the cultural specificity of literacy, making comparisons across different countries problematic.

Approximately one in five respondents in Aotearoa New Zealand, Australia, North America, and the United Kingdom scored in the lowest group of respondents in the IALS. Only half of Aotearoa New Zealand adults achieved at or above Level three out of six levels, meaning the other half were thought to be not functionally literate (Walker et al., 1996). Johnson (2004) and Benseman (2008) celebrated that many countries, including Aotearoa New Zealand, went on to cultivate an increased focus on adult literacy following results from the IALS. Prior to this survey, there was limited research substantiating the calls of advocates as they petitioned successive governments to extend the target of literacy education investment from children to adults (Benseman, 2008).

Results from the IALS brought an awareness of adult literacy needs in Aotearoa New Zealand and how remediation efforts could benefit the economy and society (Johnson, 2004). The Fifth Labour Government responded to these results with an inaugural adult literacy policy, *More Than Words* (Ministry of Education, 2001), which aimed to overhaul our fragmented and volunteer based adult literacy education system to one that conformed to benchmarked standards. Of note, the IALS introduced the assessment of literacy on a continuum rather than a binary, which became an important feature of adult literacy policies in Aotearoa New Zealand (Benseman, 2008).

4.3 More Than Words: The New Zealand Adult Literacy Strategy: Kei Tua Atu I Te Kupu: Te Mahere Rautaki Whiringa Ako o Aotearoa

Following results from the IALS, *More than Words* cast adult literacy as “an urgent priority” in Aotearoa New Zealand, and set a work plan for implementing a national infrastructure to deliver adult literacy education in a manner comparable to other OECD countries (Ministry of Education, 2001, p. 4). For example, Aotearoa New Zealand needed to expand the scope and enhance the calibre of adult literacy education in ways that recognised the growing literacy demands of the information age we are now living in (Benseman, 2008; Hunter, 2016). Importantly, *More than Words* began the work of transitioning adult literacy education in Aotearoa New Zealand from being mainly ad hoc community-based education that was largely delivered by volunteers, to a centrally funded and organised system that has clear objectives (Furness & Hunter, 2018; Hunter, 2016).

More than Words readied Aotearoa New Zealand to increase the number of adult literacy education opportunities, invest in the capability of educators, and develop ways to ensure quality in this arena (Ministry of Education, 2001). Crucially, *More than Words* signalled an era of government control and strategic partnerships in delivering nationwide standardised adult literacy programmes, which could be effectively monitored and evaluated to ensure a return on investment (Furness & Hunter, 2018). It also introduced adult literacy education that occurred within the framework of tertiary-level qualifications, as well as raising the level of educational attainment required to work as an adult literacy educator (Hunter, 2016). Overall, *More than Words* identified the inadequacy of schools to meet the literacy needs of all Aotearoa New Zealanders, and endorsed post school literacy education (Ministry of Education, 2001). Results from the IALS demonstrated that low literacy skills affect adults from every sector of society, albeit at different rates (Benseman, 2008). *More than Words* is meant to meet the needs of diverse learners but makes a particular effort to reach learners who are unable or unwilling to access tertiary education organisations, are not in work, or are incarcerated (Ministry of Education, 2001).

In 2001, the Māori Adult Literacy Working Party published *Te Kāwai Ora: Reading the World, Reading the Word, Being the World* to promote debate and contributions that give effect to *More than Words*. Unlike *More than Words*, which forms part of the canon of Aotearoa New Zealand adult literacy policies, *Te Kāwai Ora* only constitutes recommendations, with the working party musing that it could be “another exercise of meaningless consultation” (Māori Adult Literacy Working Party, 2001, p. 23). The working party found a lack of Aotearoa New Zealand based research available to inform adult literacy policy in Aotearoa New Zealand. As such, *Te Kāwai Ora* has become an important reference document and challenge to future researchers.

Te Kāwai Ora performs three functions. First, it defined Māori literacy practices. Second, it critiqued *More than Words* for lacking a bilingual approach based in *Te Tiriti o Waitangi* (Treaty between the British Crown and Māori Rangatira [Chiefs]), and for not providing multiple flexible pathways to literacy learning that include life long and intergenerational learning through whānau, hapū, and iwi. Third, it commended *More than Words* for increasing the resources available for adult literacy learning, and for encouraging a critical awareness of the world.

4.4 A History of Tertiary Education Commission Adult Literacy Policies 2007 up to the Present

This section describes the adult literacy policies from 2007, when the TEC assumed responsibility for the adult literacy portfolio, until the present (the current policies are described in *Section 6.1*). Two key governmental work plans influenced the context of adult literacy education in the period these policies were written. These were *Better Public Services* and the social investment approach of the Fifth National Government (2008 to 2017). This historical overview provides an understanding of the trends and patterns that have informed the current adult literacy policies.

Better Public Services was a 2012 initiative that aimed to prioritise ten key targets through cost-effective government services and cross-agency collaboration (Te Tai Ōhanga The Treasury, 2015). Adult literacy education was set up to reduce welfare dependence, although this target ultimately served cost saving measures within a contracting fiscal environment (Jackson & Jones, 2012). The endeavour was cancelled in 2018 after National lost its bid for a fourth term of governance.

The social investment approach was a neoliberal method of using data to direct government programs and spending in accordance with measurable outcomes and value for money (O'Brien, 2020). While the purpose of this approach in Aotearoa New Zealand was to reduce overall costs to the taxpayer (Te Tai Ōhanga The Treasury, 2017), the outcomes could still yield positive results depending on the circumstance. For example, data was used to reallocate costs potentially associated with people who present the greatest risk of not meeting educational objectives, this was achieved by investing upstream in adult literacy education to avoid the downstream costs of welfare and corrections for those people (Social Sector Board, 2016). Social changes resulting from these government priorities impacted adult literacy policies during this period.

4.4.1 *Literacy, Language and Numeracy Action Plan 2008–2012.*

The first adult literacy policy published by the TEC was the *Literacy, Language and Numeracy Action Plan 2008–2012: Raising the Literacy, Language and Numeracy Skills of the Workforce* (2008 Plan) (TEC, 2008c). The 2008 Plan was formed alongside business and union peak bodies to identify and respond to the challenges of low literacy skills in the workplace, while tertiary education organisations were notably absent as stakeholders. Significant changes deployed by the 2008 Plan include that all Level 1-2 National Qualifications Framework²⁴ qualifications became required to embed literacy in their

²⁴Now called the New Zealand Qualifications and Credentials Framework

curriculum. Embedding literacy involves integrating literacy education into the instruction of other skills, such as trades, to render literacy more meaningful and applicable for learners (Alkema & Rean, 2013). Study grants became available for adult literacy educators to gain a formal qualification to do this work²⁵. The 2008 Plan also prescribed engagement in research, evaluation, and monitoring to build an evidence base for improving adult literacy outcomes in Aotearoa New Zealand and to inform future policies.

4.4.2 *Getting Results in Literacy and Numeracy*

Data driven social investment is evident in adult literacy policies beginning with *Getting Results in Literacy and Numeracy* (TEC, 2010a), which effected a shift from calculating inputs, i.e. participation, to outputs, i.e. performance. As such, the LNAAT was made compulsory for all TEC funded adult literacy education (excluding ACE) from 2011 onwards (TEC, 2010a). This way of “charting and ranking” learners (Hunter, 2016, p. 223) has been used for cost analysis and funding purposes (TEC, 2010a, 2012, 2015, 2017a), with a view to ensuring that adult literacy education is “affordable and effective” (TEC, 2010a, p. 18). *Getting Results in Literacy and Numeracy* heralded a sharpened focus on measurable outcomes and explicitly recognised that broader social goals of adult literacy education, such as increased confidence and improved relationships, did not meet the aims of this policy.

4.4.3 *Adult Literacy and Numeracy Implementation Strategy*

In line with expectations set by the *Better Public Services* plan and the skilled and safe workplaces area of the *Business Growth Agenda*, the *Adult Literacy and Numeracy*

²⁵ One of which I received.

Implementation Strategy (2012 Strategy) aimed to lift course completion rates while reducing costs (TEC, 2012). It emphasised the LNAAT for assessing adult literacy saying, “this requirement [to use the LNAAT] will be better enforced through TEC funding levers and monitoring of progress” (TEC, 2012, p. 15). Positively, the 2012 Strategy made *Pathways Awarua*, an online adult literacy and numeracy teaching resource (released in 2011 to contracted providers) freely available to everyone. Two sub funds (Targeted English for Speakers of other Languages and Refugee English) were also added, catering to migrants and refugees, intending that Intensive Literacy and Numeracy (ILN) class space could be made more readily available for domestic learners.

Two new workstreams were introduced in the *2012 Strategy*, which sought to address Māori and Pasifika needs and cross-government engagement. The first workstream promised to engage targeted and culturally responsive adult literacy and numeracy interventions for Māori and Pasifika, to revise the cultural relevance of existing learning materials, and to attract more Māori and Pasifika educators. However, the policy only proposed to use existing programmes such as Learning Representatives and Pathways Awarua to meet the needs of Māori and Pasifika, rather than resourcing them to develop their own initiatives. The second workstream aimed to collaborate with other government agencies in sharing a whole-of-government approach to improving adult literacy and numeracy skills in Aotearoa New Zealand.

4.4.4 Literacy and Numeracy Implementation Strategy

The *Literacy and Numeracy Implementation Strategy* (2015 Strategy) (TEC, 2015) was informed by the OECD *Adult Literacy and Lifeskills Survey* (OECD, 2013) and TEC commissioned research that linked literacy skills with participation in information societies (Thomas et al., 2014). An awareness of the overlaps between literacy, social positioning, and

family and whānau wellbeing demonstrated in the *2015 Strategy* signifies an important shift in the trajectory of adult literacy policies in Aotearoa New Zealand.

While an overarching theme in the *2015 Strategy* is to get more value for money in tertiary education, it also makes several more inclusive commitments. For example, to produce the *Te Ata Hāpara* reading option (see *Section 6.1.4*) within the LNAAT and to consider the findings of *Haea Te Pū Ata: A National Strategy for Māori Adult Literacy and Numeracy: 2016–2020 (and beyond)* (Hutchings & Ikin, 2016). Furthermore, the 2015 Strategy sets an intention to work towards supporting learners with learning difficulties, such as dyslexia and dyscalculia.

Haea Te Pū Ata (Hutchings & Ikin, 2016) was commissioned by the TEC to review adult literacy policies from community and whānau, hapū, and iwi perspectives. The strategy presents a kaupapa Māori approach to increasing the capability of providers to deliver adult literacy education to Māori learners, building awareness of the connection between adult literacy and whānau wellbeing, encouraging collaboration across government and with communities and stakeholders, and ultimately improving whānau literacy. *Haea Te Pū Ata* defines adult literacy as, “biliteracy in te reo Māori and English and literacy practices that express and value a Māori worldview where learning contributes to whānau wellbeing,” and is supported by a strategic plan based on Māori values (Hutchings & Ikin, 2016, p. 14).

Thus concludes the TEC adult literacy policies and their political context that predate the current adult literacy policies in Aotearoa New Zealand. The current TEC policies are described and analysed in *Chapter Five* of this thesis.

4.5 Adult Literacy Assessment in Aotearoa New Zealand

The LNAAT (see *Section 6.1.4*) and SPAT (see *Section 6.1.3*) are quantitative literacy assessments. They can be completed on paper (non-adaptive) or online (adaptive), with the

online test being favoured as a more accurate measurement of achievement, according to a method called the Rasch Measurement Scales (New Zealand Council for Educational Research, 2018a). The online adaptive method presents a slightly harder or slightly easier question from a bank of over 2000 questions in response to the accuracy of the preceding answer (New Zealand Council for Educational Research, 2018a). An individual learner report is then produced for educators that represents correct and incorrect answers, the difficulty of those questions, and locates the learner on a scale aligned with the learning progressions (New Zealand Council for Educational Research, 2018b).

The LNAAT or SPAT are compulsory as formative adult literacy assessments for learners accessing TEC funded education at foundational levels (excluding ACE) as part of their eligibility criteria (TEC, 2023d). YMCA New Zealand (2023)²⁶ provided an example of how these assessments are used, saying they implement the LNAAT or SPAT to “measure need, inform tailor-made programmes and measure progress.” The LNAAT and SPAT were adapted from the OECD standardised testing scheme and as such may not meet bicultural needs effectively in Aotearoa New Zealand (Furness & Hunter, 2018). Māori (Hutchings et al., 2013) and bicultural (Furness & Hunter, 2019) literacy assessments could previously be used alongside the LNAAT or SPAT, and, as of 2023, can now be used for assessing learner progress (TEC, 2023b).

The LNAAT and SPAT only capture reading and vocabulary or reading and writing skills and exclude other outcomes of importance to Māori (Hutchings et al., 2013). For Hutchings et al. (2013), examples of these outcomes included impacts on whānau, such as by obtaining a driver’s licence, hinengaro, such as increased confidence, wairua, such as through improved lifestyle approaches, and tinana, such as those facilitated by a better understanding of food prices and labelling (Hutchings et al., 2013). Hutchings et al. (2013) and Furness and Hunter (2019) have developed assessment alternatives that are more relevant and meaningful for

²⁶ A community development organisation

Māori and other learners. These are the wellbeing model and the wellbeing framework respectively.

Drawing on *Te Kāwai Ora* (Māori Adult Literacy Working Party, 2001) and the concept of Te Whare Tapa Whā (Durie, 1998), Hutchings et al. (2013) proposed a kaupapa Māori approach to adult literacy assessment. *Hei Ara Ako ki te Oranga* uses conversational interviews that educators record on a table with accompanying whakataukī to recognise the positive outcomes of Māori adult literacy learning, rather than measuring skill acquisition. Their work establishes a relationship with the LNAAT, but overlooks the SPAT, which is used more commonly with adults with learning disability. Hutchings et al. (2013) invited others to use and adapt *Hei Ara Ako Ki Te Oranga* for their purposes.

Furness and Hunter (2019) extended the work of Hutchings et al. (2013) to develop a wellbeing framework. The wellbeing framework includes guiding questions for creating learner mind maps, informal and formal conversations, and written interactions via Facebook posts and journal entries. This framework avoids the assessment of any specific skill and aims to provide a more sustainable way to record the positive outcomes of adult literacy education for Māori and non-Māori learners.

4.6 Ministry of Education Policies with Relevance to Adult Literacy

The Ministry of Education continues to publish policies with relevance to adult literacy. The current policies with relevance to adult literacy were written during the Sixth Labour Government (2017-2023), which returned a focus on broader social goals, including partnership with Māori. The administration intended to measure growth in terms of social and environmental wellbeing, rather than economic output alone (Elliott, 2020). In 2020, a Social Wellbeing Agency replaced the Social Investment Agency of the Fifth National Government (Sepeloni, 2020). The new approach aimed to foster collaboration with and offer support to communities rather than viewing people as liabilities (Sepeloni, 2020). One

action that sought to achieve this aim was to divest some control to educators and providers. It is in this context that the *Plan Guidance for Providers Submitting Plans for Funding From 1 January 2024* (Plan Guidance 2024), *Disability Action Plans: A Guide for the Tertiary Education Sector*, *Kia Ōrite Toolkit for Achieving an Inclusive and Equitable Tertiary Education Environment for Disabled Learners*, and the *Tertiary Education Strategy 2020* were released.

4.6.1 *Plan Guidance for Providers Submitting Plans for Funding From 1 January 2024*

The *Plan Guidance 2024* (TEC, 2023f) supports tertiary education organisations to apply for funding from the TEC. It has a focus on underserved learners, including disabled learners (TEC, 2023f). To realise this focus, the TEC encourages all tertiary education organisations to develop a Disability Action Plan and a Learner Success Plan (TEC, 2023f). The *Plan Guidance 2024* encourages tertiary education organisations to work towards learner equity by prioritising those who are not yet competent in foundational literacy skills (TEC, 2023f).

4.6.2 *Disability Action Plans: A Guide for the Tertiary Education Sector*

Organisations receiving more than five million dollars in TEC funding needed to submit a Disability Action Plan from 2023 onwards (TEC, 2023f). A Disability Action Plan intends to give effect to the CRPD Article 24 mandate for an inclusive education system and enables organisations to evidence their use of the *Kia Ōrite Toolkit* (TEC, 2021b).

The TEC aimed for tertiary education organisations to become more “inclusive and equitable” for disabled learners and commissioned the *Kia Ōrite Toolkit* to guide them in

this endeavour (Achieve, 2023, executive summary)²⁷. The *Kia Ōrite Toolkit* describes learning supports as reasonable accommodations, which “allow disabled learners to access the curriculum, pedagogy, lab work, field work, assessment and examination in ways that meet their needs” (Achieve, 2023, practicing equity). These supports are generalised to all disabled students and not specific to adults with learning disability.

A Disability Action Plan is intended to direct organisations to set and communicate goals, targets, and strategies through such fora as policies and public statements (TEC, 2021b)²⁸. The plans do not ensure funds are committed to disabled learners, are not enforceable, and are not universal design initiatives²⁹. Disability Action Plans impact adults with learning disability by requiring larger organisations to describe how they will work towards equity in participation and outcomes for disabled learners (TEC, 2021b).

4.6.3 *The Tertiary Education Strategy*

The *Tertiary Education Strategy* (Ministry of Education, 2020b) forms an overarching direction for tertiary education in Aotearoa New Zealand and seeks to ensure that every learner has barrier-free access to education, including adult literacy education. The policy responds to the strengths and weaknesses of the tertiary sector in Aotearoa New Zealand (Ministry of Education, 2019) and draws on results from the *Survey of Adult Skills 2014*

²⁷ Disabled people were heavily involved in the development of the *Kia Ōrite Toolkit* (Achieve Administrator, personal communication, 10 August, 2023). Grant Cleland, who uses a wheelchair, was Project Lead in developing *Kia Ōrite Toolkit*, and other disabled people were involved in interviews and focus groups, as well as having representation at a governance level for the project. There were also high levels of engagement with other disabled stakeholders.

²⁸ Disability Action Plans were initially assessed by a panel of five disability subject matter experts, two of whom were disabled people, but are now assessed internally by the TEC (Enquiries National Team Ministry of Education, personal communication, 6 August, 2022).

²⁹ Aotearoa New Zealand should seek to emulate the Republic of Ireland in their *Programme for Access to Higher Education*, which allocates funding to enhance the accessibility of physical and digital spaces in higher education, along with the incorporation of sensory spaces, and universal design for learning training and curriculum development (Department of Further and Higher Education Research Innovation and Science, 2023).

(OECD, 2016) and the *Programme for International Student Assessment 2018* (May et al., 2019). Key areas of concern included lower than expected personal income by qualification, lower than expected worker productivity, mismatches between vocational education and industry needs, and the identification of underserved populations, namely Māori, Pacifica, disabled people, and those with learning support needs (Ministry of Education, 2019). In summary, the *Tertiary Education Strategy* intends to “remove barriers to participation and improve achievement,” to create a more responsive and accessible tertiary environment (Ministry of Education, 2019, p. 2). The *Tertiary Education Strategy* influences adult literacy most significantly through its second objective, which aims to ensure every tertiary learner will have “access to quality literacy and numeracy provision” (Ministry of Education, 2020b, p. 3) and “gains sound foundation skills, including language, literacy and numeracy” (Ministry of Education, 2020b, p. 1).

The Ministry of Education did undertake consultation with disabled people and adults with learning disability in the development of the *Tertiary Education Strategy*. This occurred via consultation with the DPO Coalition³⁰ (see *Appendix D*)³¹ and an online survey for people with disabilities or learning support needs, which asked how the education system could become better for everyone (Ministry of Education, n.d-a). The online survey yielded two responses from adults with learning disability (see *Appendix C*). Both respondents advised the Ministry of Education to expand literacy options (although it is unclear if this was intended for school aged or adult learning) as well as to make more literacy assistants and educators available. Respondents described literacy options including Tar Heel Reader, an online library of easy to read books that can be accessed using a mouse, keyboard, or switches (Tar Heel Reader, n.d); the TouchChat app, a digital communication board that allows users to electronically vocalise words from a vocabulary set (Saltillo, n.d), and New Zealand Sign Language (see *Section 3.2.2.1*). The consultation with the DPO Coalition

³⁰ The Disabled Persons Organisation status recognises organisations that promote active involvement and decision-making by disabled people on matters that affect them and necessitates governance by its members.

³¹ The Ministry of Education met with the DPO Coalition representatives, including from the pan disability organisation Disabled Persons Assembly NZ, to ask for feedback on how equity for all learners could be created in the tertiary sector, and how the ministry could better invest to achieve that aim.

occurred at a meeting with the Ministry of Education and the Office for Disability Issues. While the DPO Coalition includes People First, People First did not have a representative at that meeting, and no one with a learning disability was present. I also surveyed submissions for the Education and Training Act 2020 and read any submissions that appeared as if they might potentially contain the voices of adults with learning disability, yet none were found.

4.7 Conclusion

The adult literacy policies discussed thus far represent the problem they aim to address as being that respondents in Aotearoa New Zealand performed less well in OECD literacy tests than those in comparable countries. The OECD (2000) claimed these outcomes have relevance to employment statistics and Gross Domestic Product. Such indicators are therefore promoted in the adult literacy and relevant policies, although they may not be as meaningful for adults with learning disability. These policies attribute the problem of low literacy skills, as defined by current assessment practices, to a lack of education, caused by under-skilled educators, and tertiary educational organisations being too inflexible, expensive, and inaccessible. In doing so, they divert attention from other potential causes of low literacy skills that may be more relevant to adults with learning disability, such as narrow understandings of literacy, inappropriate assessments, and a lack of consultation, leading to adult literacy policies that do not meet their needs.

This chapter provided an overview of the adult literacy context in Aotearoa New Zealand and underscored that reading and writing constitute relatively recent and mutable inventions. Such literacy practices have become the epitome of the adult literacy policies. Furthermore, these policies have promoted neoliberal and labour-normative values through the acts of counting learners as investments, prioritising the needs of industry, focusing on measurable performance, and conducting testing that reinforces a narrow understanding of what literacy is. This is problematic because it perpetuates the attitudes of educators and

others who assume that people with learning disability typically have low literacy skills, a stance that can impact their ability to pursue pathways of choice.

5 Chapter Five: Methodology

This chapter discusses my use of qualitative research methodologies supported by social constructionism as a meta theory in this research, and a rights-based approach to transformative equality as a conceptual framework. The methodologies employed in this research occur in two parts. The first part is a policy analysis, and the second part uses inclusive participatory action research (IPAR) to respond to that policy analysis. In this research, data was collected using thematic analysis of adult literacy policies, research meetings conducted online and in person, a reflexive thematic analysis of data collected during the research meetings, and by evaluating the inclusive approach taken in this research. The ethical considerations pertinent to this research are then explained, before the benefits of this research for participants are listed.

5.1 About this Research

As mentioned in *Section 1.1*, after supporting a man with learning disability who was denied access to an open-entry course at our local Polytech, I proposed to find out what changes to adult literacy policies would value adults with learning disability as literate members of the community and promote their access to adult literacy education on an equal basis with others. The wording “on an equal basis with others” mirrors the CRPD (United Nations, 2007, article 24.5).

I carried out a preliminary analysis of the current adult literacy policies in Aotearoa New Zealand³² (TEC, 2008a, 2008d, 2010b, 2023a, 2023d). It was important to do this analysis to better understand the current adult literacy policies because these policies establish norms, represent problems, and structure commitments to action (Bacchi, 2009; Colebatch, 1998;

³² As of June 2023.

Parsons, 1995; Shafritz, 2004; Shaw & Eichbaum, 2011; Simon, 2007) that have direct consequences on the lives of adults with learning disability. Of note, their framing of literacy informs perceptions of what literacy is and who is literate in ways that marginalise many adults with learning disability. These policies direct resources and regulation towards the problem of low skills in reading and writing. In doing so, they confer legitimacy upon the preferred solution of the TEC, which involves teaching and testing reading and writing in English along a predefined progression of skills to the exclusion of other literacy practices. In contrast, this research aims to recognise and value the literacy practices of adults with learning disabilities, asserting their literacy, and promoting their access to adult literacy education on an equal basis with others.

The next part of this research was collaborative and conveyed the experiences of adults with learning disability to understand their literacy practices and perspectives in our bicultural context. Following adults with learning disability literacy researchers Forts and Luckasson (2011) and Morgan (2013), this research included people with learning disability. It was the first inclusive research on this topic undertaken in Aotearoa New Zealand.

I conducted Inclusive Participatory Action Research (IPAR) with five adults with learning disability, who decided to call themselves the Passioners. We met for 10 research meetings, preceded by at least two home visits, and interspersed by reflective meetings with individual participants. All research information was presented in easy read and key information was distributed audiovisually via YouTube.

It was important to include people with learning disability in this research because they possess the most knowledge about their experiences and are in the best position to initiate change at a foundational level. Data created by participants in this research formed the basis of adult literacy policy recommendations that intend to move Aotearoa New Zealand towards transformational equality and implementation of the CRPD. In doing so, this research emphasises the importance of utilising the perspectives of people with learning disability in the development of policies that affect them.

The affirmation model of disability (see *Section 2.5.3*) and the voices of adults with learning disability were used to encourage an appreciation for the literacy practices of participants in this research. The affirmation model constructs disability as a culture and identity and can embrace different ways of thinking about literacy. As such, I explored what it means for adults with learning disability to use the same or different literacy practices as those described in the adult literacy policies while maintaining their status as literate people.

I was diagnosed with Autism Spectrum Disorder part way through my PhD candidature, which shifted my positioning from an ally to a fellow disabled person. The revelation of my disabled status gave context to my lifelong enthusiasm for disability issues. I now understand my interest in this research as seeking to address an injustice I identified as affecting my disabled peers. As an autistic woman and *Pākehā* (New Zealander of European descent), I experience different privileges compared to the participants in this research, who are adults with learning disability. Embodying aspects of both an insider and outsider, I am impassioned about working in partnership with people who are directly affected by this research.

The measures undertaken to enhance the accessibility of this research are as follows. I used Photosymbols templates and images to develop easy read research information and consent forms (see *Appendix E*), which were delivered *kanohi ki te kanohi* (face-to-face) using an individually responsive communication style. *Easy read* is a printed format featuring larger font and simpler text with accompanying descriptive images (Buell et al., 2020; Chinn, 2019; Fajardo et al., 2014; People First New Zealand, 2017; Turnpenny et al., 2018). An IPAR methodology shaped the data collection phase of this research. Participants with learning disability engaged in action and reflection throughout our research meetings, with reflective opportunities also taking place between these sessions in the form of *kanohi ki te kanohi* visits with participants where possible. I also committed to supporting participants to conduct their own research in the future if they wished. Participants and my advisor with learning disability disseminated information about this research to their community via the Hamilton and Midland Region groups of People First New Zealand, a Disabled People's

Organisation (DPO) for people with learning disability. Findings were reported to participants in easy read and kanohi ki te kanohi.

As this research occurred in Aotearoa New Zealand, it was essential to have a bicultural approach that intends to avoid or mitigate perpetuating research practices that are harmful to Māori (Furness et al., 2015). Such an approach seeks restoration from the impacts of colonisation by using viewpoints, beliefs, and understandings from both Māori and Pākehā sources to inform a new way of working that is right for both worldviews (Community Sector Taskforce, 2006; Dionisio & Macfarlane, 2021; Spelman, 2013).

A bicultural approach was implemented in this research in four main ways. First, my Māori cultural advisor provided guidance to support the cultural appropriateness of my data collection and evaluation methods. Second, I incorporated Māori research on disability and literacy, which increased my awareness of knowledge that could be salient to Māori when it arose in data from our research meetings. Third, I acknowledged the context of colonisation in Aotearoa New Zealand, with specific foci on the colonisation of ways of thinking about disability (see *Section 2.3.4*) and literacy (see *Section 4.1*). Fourth, this research had two Māori participants and Māori issues were incorporated into my research ethics application. A bicultural approach is particularly important in disability research that occurs in this country, as Māori are more likely to be disabled than any other ethnic group in Aotearoa New Zealand (Stats NZ, 2014).

5.2 Qualitative Research

Qualitative research uses detailed and descriptive non-numerical data to generate subjective meanings and interpretations of phenomena within the context in which they occur (Denzin & Lincoln, 2013). Patterns and themes are identified to construct new insights and theories about the world (Denzin & Lincoln, 2013). Paulus et al. (2008) add that

qualitative research should be transparent, in that researchers and their processes are clearly articulated to demonstrate rigour in qualitative research on its own terms.

This research seeks to elicit and privilege the views of adults with learning disability. Qualitative research is appropriate for this research because it lends itself to positioning disabled people as experts rather than subjects (Hart et al., 2017). Qualitative research is also better suited to smaller-scale more egalitarian studies and engagement with marginalised groups, which this research undertakes, compared to quantitative research (Jordan & Kapoor, 2016). For these reasons, this research adopted a qualitative approach.

In contrast to the quantitative tradition of objective and independent research, qualitative research finds meaning in the relationship between the researcher and their research via a process of reflexivity (Berger, 2015). *Reflexivity* involves critical reflection of the roles and perspectives of the researcher in their research process (Berger, 2015). This means engaging with the ethics and process of power relations in our endeavour to represent the people we research (The Critical Methodologies Collective, 2022). Preissle and deMarrais (2015) explained that reflexivity is central to qualitative research, as researchers seek to recognise the influence of our own subjectivities on how we make sense of data. Goethals et al. (2015) discussed the importance of reflexivity in disability research and argued that reflexivity is a necessary tool for researchers to reprocess our own assumptions about disability so that we can highlight the authentic voice of disabled participants.

Personal characteristics that arise from statuses, identities, and experiences all influence researcher understandings of the knowledge we take part in creating (Berger, 2015; Lumsden, 2019). In qualitative research, these personal characteristics are called our *positioning*. Researchers can be categorised as having an insider or outsider positioning. An *insider* is someone who has experience of their subject matter, for example, having the same minority group standpoint as their research participants (Berger, 2015). An *outsider* is other to the research group, for example, they are from a different geographic or social class (Berger, 2015). There are advantages and disadvantages associated with both outsider and insider research (Berger, 2015). For Gair (2012), understanding our positioning is a

process of becoming more conscious of the relative locations of ourselves as researchers, the subjects of our research, and how those dynamics change over the research period.

In terms of my positioning, I am a well-educated 37-year-old late diagnosed autistic Pākehā mother with disabled friends and family and disability sector experience as a service user, support worker, coordinator, and governance group member. Being an autistic woman formerly misdiagnosed with psychiatric disorders places me in a minority among a minority (Hefferon, 2020). Like Hefferon (2020, p. 15), I bring a lifetime of minority experience, within which we have been “unable to pinpoint the cause of [our] sense of difference.” As I am autistic, my autism has neurospecific impacts on this research.

Grant and Kara (2021) used the concept of *autistic advantage* to describe how autism can affect qualitative research. For example, some autistic people have a tendency towards creative thinking (Grant & Kara, 2021). As an outside the box thinker, I have opted to widen the scope of the traditional focus group method to become research meetings that include activities with digital technology, as well as to employ a wider conceptualisation of literacy than expressed in existing literature. Another autistic advantage is the disposition that some autistic people have towards meticulous planning (Grant & Kara, 2021). As such, I was able to leverage my attention to detail to enjoy tailoring information individually, meeting with each prospective participant at least twice before commencing research, organising consent and logistics with or for all participants, and having weekly follow ups during the data collection period, all of which required considerable planning. The disadvantage of a love for planning is that some autistic people can have challenges with adaptability (Grant & Kara, 2021). Therefore, when COVID-19 interrupted my plan to facilitate research meetings in person, it took me three months to reorient myself to a new plan to go online. Russell et al. (2019) similarly found that their participants were also creative and had strengths in organisation and attention to detail, both of which contribute to planning abilities. Participants in Russell et al. (2019) discussed other attributes that could contribute to the completion of research projects, such as enhanced concentration, enthusiasm,

perseverance, and determination. These factors have also supported me in undertaking this research.

My autistic identity makes me both an insider and an outsider in this research. I am an insider in this research as a disabled person, and an outsider in this research as a person without learning disability. On the one hand, I share several experiences with adults with learning disability, such as receiving disability support services and having overlapping peer groups. On the other hand, I can pass as being non-disabled where many adults with learning disability do not have that same privilege. I am also included in mainstream roles and spaces that are largely inaccessible to most adults with learning disability, such as being a student at university. Furthermore, my characteristics have enabled me to live a significantly more independent and self-determining life than most adults with learning disability are supported to have. In saying that, the affirmation model of disability avoids differentiating between impairment types derived from the medical model of disability (Cameron, 2010). As Cameron (2010, p. 23) said, disability is regarded as “different but equal,” both between disabled and non-disabled people and among people with what could be described as different disabilities.

In practice, I have a different set of experiences than are afforded most adults with learning disability. Pillow (2003) cautioned researchers with privilege against positioning ourselves alongside marginalised participant groups. In seeking to find similarities between our participants and ourselves, we risk carrying our privileged assumptions with us and misrepresenting them as being from a marginalised group (Pillow, 2003). Duckworth (2020) used her *Wheel of Power/Privilege* to illustrate *intersectionality*, how multiple social categories intersect and interact within an individual experience. Identities in her wheel related to gender, citizenship, race, education, sexuality, bodily ability, neurodiversity, mental health, body size, housing, wealth, and fluency in English. I acknowledge that I belong to the most privileged group in most sections of the *Wheel of Power/Privilege*.

According to Berger (2015), researcher positioning impacts on research in three main ways. First, different sets of prospective participants will be accessible for recruitment. Second,

the quality of research relationships will be different. Third, assumptions underpinning research will be shaped in different ways. For example, a researcher with personal experience in a particular domain may have more empathy for others in the same domain. Considering a point raised by Rinaldi (2013, p. 10), in which she recognises that reflexivity can perpetuate the silencing of disabled people, when “in being self-reflexive, we turn the lens back on ourselves,” I will now provide examples of how my positioning has impacted this research in the three ways Berger (2015) describes.

First, my preexisting relationships and work history, multiple identities, and disability positive experiences have impacted this research. I was able to draw on my social networks with adults with learning disability to start the process of recruiting participants immediately, whereas someone lacking those connections may have had to spend time developing trust before recruiting participants. Furthermore, my prior employment status of having worked for several disability organisations may have encouraged prospective participants and their supporters to feel more comfortable taking part in research with me.

Second, participants in this research may have shared different information with me as a disabled rather than non-disabled researcher. However, participants with learning disability could also view me as having significantly different life experiences to them and some may not perceive me as being disabled because my disability is invisible. Other identities, such as my being Pākehā, may have formed a barrier to mutual understandings with Māori. This is because, to abridge the words of Ellsworth (1989), my understanding will always be constrained by my privilege.

Third, my disability positive prior experiences led me to gravitate towards the affirmation model of disability when I found out about the model through doing this research. As discussed in *Section 2.5.3*, the affirmation model embraces disability as diversity, rejects the link between disability and impairment, and recognises the unique cultures and identities of disabled people, highlighting how we challenge societal norms (Cameron, 2010, 2019; Cameron & Lingwood, 2020; Swain & French, 2000). My perspectives are informed by my experiences of being surrounded by and attracted to disability my whole life before finding

out I have Autism Spectrum Disorder. Acquiring a disabled identity has positively and profoundly influenced all aspects of my life.

5.3 Social Constructionism

Social constructionism is an epistemological position that understands knowledge as being relational, multiple, subjective, subject to change, and produced through the same processes by which we came to understand them (Berger & Luckmann, 1966). As Lock and Strong (2010) asserted, we cannot identify that which we are immersed within, so social constructionism continuously revises, and co-creates what can be known. In understanding knowledge as being socially relative, knowledge is subjectively constructed through interactions, particularly language and practices, and an interrogation of the relationship between knowledge and power (Berger & Luckmann, 1966; Burr, 2015). Social constructionists understand the construction of knowledge to promote and sustain social power relations (Burr, 2015).

Social constructionism also challenges existing hierarchies of knowledge by valuing different systems of knowledge as equal perspectives, which poses a particular threat to the epistemological privilege of science (Berger & Luckmann, 1966). As Weinberg (2014) explained, there is no way to distinguish between what is real and unreal without legitimating a hierarchy of knowledge. Therefore, social constructionism places equal weight on both subjective and empirically based knowledge (Berger & Luckmann, 1966; Weinberg, 2014).

Using a social constructionist lens, this research challenges the hierarchy of knowledge that has traditionally privileged reading and writing skills and devalued other literacy practices. In contrast to adult literacy policies in Aotearoa New Zealand, this research values multiple understandings about what literacy is and who is literate. This research also eschews

empirical medical understandings of learning disability in favour of using the affirmation model of disability, which asserts disability as a chosen identity.

The methodologies used in this research fit within the framework of social constructionism. First, a policy analysis is undertaken to clarify the ways in which literacy is constructed in the relevant policies and explore the power relationships within these constructions. Second, inclusive research rejects the traditional role of the researcher as an expert by giving voice to the perspectives of people with learning disability and works to reduce power imbalances in research by recognising these perspectives as equally as valid (Walmsley & Johnson, 2003). Third, participatory action research (PAR) contributes to the development of shared understandings and co-created knowledge by continuously adapting research methods in line with participant feedback and checking in with participants to find out what they understand their data to mean (Nind & Vinha, 2014). Fourth, reflexive thematic analysis (TA) was used to create meanings by constructing themes from salient data points that are then filtered through my positionality as a researcher (Braun & Clarke, 2022).

5.4 Conceptual Framework: A Rights-Based Approach to Transformative Equality

The conceptual framework in this research is a rights-based approach to transformative equality. The role of this conceptual framework was to effect positive change by using the CRPD as a justification for making recommendations about inequalities that impact adults with learning disability within the adult literacy context in Aotearoa New Zealand.

A rights-based approach draws on the principles of human rights (Gatenio Gabel, 2016). Human rights are the freedoms, entitlements, and protections that all people can reasonably demand in any society (Mazzeschi, 2021). They are constant, fundamental to human life, and unable to be removed or relinquished, in summary they form a minimum standard of dignity for all people (Mazzeschi, 2021). While human rights are inalienable and not limited to United Nations conventions, these conventions summarise an international consensus on human rights (Mazzeschi, 2022). The CRPD is one such agreement that

promotes equality for disabled people. The CRPD Article 4 General Obligations, and Article 24 Education, are of most relevance to the topic of this research. Article 5, Equality and Non-discrimination, Article 12, Equal Recognition Before the Law, and Article 16, Freedom from Exploitation, Violence, and Abuse are also discussed in this thesis in relation to research ethics (Mirfin-Veitch, 2016; Nilsson & Broström, 2019; Nilsson & Series, 2018). A key difference between a needs-based approach and a rights-based approach lies in the scope and depth of the intervention they respectively warrant. A needs-based approach is normally quantified via assessment and on an individual basis, seeking to immediately relieve experienced deficit (Gatenio Gabel, 2016). On the other hand, a rights-based approach is focused on the elimination of patterns that culminate in marginalisation and works towards rights ascertained from agreements such as the CRPD (Gatenio Gabel, 2016).

Minkowitz (2017) identified three forms of equality. The first is *formal equality*, which relates to distributional sameness, and can be measured using objective methods. The second is *substantive equality*, which relates to distributional goodness and is matter of equity, fairness, and justice. The third is *transformative equality*, which seeks to address the factors that precede inequality. It does this by identifying, challenging, and changing the attitudes and systems that cause inequalities to occur (Atrey et al., 2017; Holtmatt, 2013; Minkowitz, 2017). Minkowitz (2017, p. 85) described transformative equality as, “a real transformation of opportunities, institutions and systems so that they are no longer grounded in historically determined (dominant-actor) paradigms of power and life patterns.” To illustrate these three approaches, a tertiary education organisation could establish a formally equal enrolment process by removing identifying information from their application forms, or a substantively equal enrolment process by allowing some groups to enrol using different criteria. Alternatively, it could advocate for transformative equality by enabling marginalised groups to experience the kinds of prior opportunities that would improve their selection prospects and ultimate likelihood of success in tertiary education.

Transformative equality is the most preferable form of equality to use in this research for three compelling reasons. First, it is most suited to instigating enduring and widespread

change (Minkowitz, 2017). Second, it aligns with the CRPD. Atrey et al. (2017) understood the form of equality described in the CRPD as being transformative equality, and Minkowitz (2017) also argued for the application of transformative equality in interpreting the CRPD. Third, transformative equality aligns with the recommendations of DPO Coalition et al. (2023), which encourage proactive action for universal design to reduce the need for reasonable accommodations on an individual basis.

Reasonable accommodations are adaptations and customisations that are both reasonable and necessary for the enablement of equal participation (Fluyt et al., 2023; United Nations, 2007). In Aotearoa New Zealand, legal requirements underscore the provision of reasonable accommodations to remediate environmental barriers for disabled people (DPO Coalition et al., 2023). The extent of reasonable accommodations required is contested, with DPO Coalition et al. (2023, p. 3) saying reasonable accommodations must “ensure *full participation* for disabled people [emphasis added],” and Employment New Zealand (2024, p. 1) saying they only need to effect participation “on a *more equal* basis [emphasis added].” Both Employment New Zealand (2024) and DPO Coalition et al. (2023) recognise the importance of accommodations not being too onerous on others. This caveat is also recorded in the CRPD (United Nations, 2007, Article 2). There are multiple approaches to determining which accommodations are both necessary and reasonable, such as considering multiple factors (DPO Coalition et al., 2023), engaging a structured decision-making process (Fluyt et al., 2023), and assessing undue burden from the standpoint of the disabled person (Atrey et al., 2017). While reasonable accommodations are often justified because of need, transformative equality is promoted because of rights.

The United Nations (2007) use both rights-based and needs-based approaches to education. The rights-based aspects of Article 24 Education are to mandate enhanced educational inclusivity at all levels, while recommending the use of disabled teachers, and the implementation of disability awareness training. The needs-based aspect of the same article is an exhortation to meet individual requirements with appropriate reasonable accommodations and support. At present, the TEC (2023a) takes a needs-based approach to

adult literacy education in Aotearoa New Zealand by using adult literacy assessments to establish learner need. This research seeks to produce outcomes that progress rights for people with learning disability and recommends they be reflected in the adult literacy policies.

5.5 Methodology of Policy Analysis

This section describes the policy selection process I undertook to identify the current adult literacy policies and the method of thematic analysis I used to analyse them.

5.5.1 Policy Selection

I aimed to understand the impact of the adult literacy policies by selecting policies that adult literacy educators and managers currently use to fund and direct their practice. To do this, I started with the *2023 Funding Conditions Catalogue* (2023 Catalogue), which allocates who gets what resources to provide adult literacy education (TEC, 2023a)³³. I then continued selecting the policies that need to be used to access the relevant funds until I achieved a comprehensive list. According to the *2023 Catalogue*, providers accessing foundation Funds³⁴ (except Adult Community Education [ACE]) must use the assessment outlined in the *Guidelines for Using the Literacy and Numeracy for Adults Assessment Tool* (Guidelines) (TEC, 2023d). These guidelines indicate that the Literacy and Numeracy for Adults Assessment Tool (LNAAT) is based on the *Learning Progressions for Adult Literacy* (Learning Progressions) (TEC, 2008a) and that *Learning Progressions* should guide providers in addressing learner literacy needs. The analogous policy that aims to meet the needs of foundation literacy learners is *Starting Points: Supporting the Learning Progressions for*

³³ Most recent catalogue at time of writing

³⁴ Intensive Literacy and Numeracy education, Workplace Literacy funds, and delivery of the New Zealand Qualifications and Credentials Framework at Levels 1 and 2.

Adult Literacy (Starting Points) (TEC, 2008d). Adult literacy policies specific to groups that are not people with learning disability, such as the Māori and Pasifika Trades Training Fund or Intensive Literacy and Numeracy funds for refugees or speakers of other languages were excluded as these are not the focus of this research. I consulted with the Principal Advisor at Ako Aotearoa, Victoria Beckwith, to ensure the accuracy of my sample. The dataset for my thematic analysis (TA) will now be outlined in chronological order.

5.5.2 *Thematic Analysis Method*

A TA method was chosen for this policy analysis because there is no existing research addressing the impact of Aotearoa New Zealand adult literacy policies on people with learning disabilities. This approach provides a broad overview of the dataset, identifying areas that may be problematic and warrant further investigation.

There are many forms of TA. TA comprises a systematic approach to exploring patterns in the data using layers of analysis that lead to the construction of *themes*, which capture conceptual patterns or ideas (Fugard & Potts, 2019; Nowell et al., 2017; Saunders et al., 2023; Vaismoradi et al., 2013). These themes facilitate a better understanding of the data. Analytical findings can be more descriptive or more interpretive depending on the form of TA undertaken (Vaismoradi et al., 2013). The form of TA described here offers a more transparent analysis of the data and therefore is different from reflexive TA, which highlights the impact of the researcher on their research (Braun & Clarke, 2022). The reflexive TA method pioneered by Braun and Clarke (2022) takes a six-phase approach to analysis, which are familiarisation with the data; coding the data; generating initial themes; developing and reviewing those themes; refining, defining, and naming the themes; and writing up the analysis. These six phases will be used in my reflexive TA of data from research meetings with participants in *Chapter Seven*. A shorter policy analysis undertaken in this chapter will use the approach outlined by Saunders et al. (2023), who borrowed and

simplified the method in Braun and Clarke (2006) to become a process of reading, coding, and theming. These phases occur in iterative cycles but are described in a linear manner (Saunders et al., 2023). This method is appropriate for analysing the adult literacy policies because it will integrate cohesively with the IPAR part of this research and can be used to answer my research questions.

5.5.2.1 Reading

I have kept abreast of adult literacy policies in Aotearoa New Zealand throughout my candidature and came to this TA with a working knowledge of these policies. I subsequently revisited the current policies and carefully read them in their entirety to refresh my knowledge of them.

5.5.2.2 Coding

Coding is an early analytical step in TA that occurs through the process of making the dataset more manageable by selecting parts of the data that are relevant to the research questions and assigning labels to those parts (Saunders et al., 2023). I carried out multiple phases of coding using both computer and paper-based approaches. The steps I took were as follows. First, I printed the policies out and used a highlighter pen to mark up any sections that could contribute to answering the research questions. Then, I located the highlighted sections of the policies and copied those sections into Microsoft Word tables. I added background colours to the excerpts corresponding with their respective policies, allowing me to easily identify where excerpts were coded from. Next, I printed out the tables and cut them up into individual squares using scissors. This allowed me to view the complete set as I arranged them into codes. I alternated between coding on paper and on the computer

because switching between formats led me to gain new insights into how to group excerpts and what codes to name them.

On reviewing the coded excerpts, I removed as much repetition as possible from each code. I also continued to make changes to the codes where appropriate to my research questions. One example was splitting the “all about adult learners” code into two codes, “all about adult learners” and “what happens before people get to us.” Another example was redistributing excerpts from two codes, “literate if you are like us” and “English communication skills knowledge and strategies” into two new codes, which were “in English” and “communication skills knowledge and strategies.” To mitigate my biases, I used ChatGPT to brainstorm neutral alternatives for some of my preliminary codes, specifically for the codes “remedial,” “judgement,” and “aberrations,” which I had initially replaced with the codes “responding to learner strengths and weaknesses,” “report progress,” and “non-conformists.” I did this with a view to fostering my openness towards unexpected findings throughout my TA. I filed the excerpts grouped by code into a display folder.

The next step was to create an easier way to retrieve excerpts. I created headings in Microsoft Word for each code and dragged excerpts from the tables arranged by policy into new tables arranged by code, retaining their background colours so I could identify which policy they came from. I revised the length of excerpts throughout this process. These phases of revision resulted in the reduction of around 250 excerpts to around 100 excerpts, which made the size of the data set manageable for analysis while ensuring the breadth of content was maintained.

5.5.2.3 Theming

I arranged my codes into themes related to “who,” “what,” “how,” and “why” as a way to organise them. The challenge was in clearly explaining what the “who,” “what,” “why,” and “how” pertained to. I decided that “who” was “who is literate,” “what” was “what literacy

is,” “how” was “how to teach literacy,” and “why” was “why literacy is important.” As the work of revising codes and themes continues into the TA report writing phase in Saunders et al. (2023), I remained flexible to further shifts in the codes and themes as I constructed stories about the current adult literacy policies in Aotearoa New Zealand.

As alluded to, I made additional changes to my codes and themes as I learned more about the excerpts through doing research involved in writing my TA report, which in turn helped me to learn more about the excerpts. I thought of other words to better convey my understanding of the excerpts, or merged, condensed, or deleted codes during that time. Here are two examples of such changes. I changed the code “non-conformists” to “outliers” because I thought the new code made an interesting parallel to the mathematical bell curve that is part of the medical model for determining who has standard and non-standard intelligence (see *Section 2.2.1*). I was then able to make a comment about people who use literacy strategies described in the *Learning Progressions* being represented as normal and those who use different strategies as outliers. I also expanded the code “the missing link” into a theme called “why people learn literacy.” I realised that “the missing link” articulated why the TEC says adult learners with low literacy skills should increase those skills. However, discussing the wider topic of “why people learn literacy” allowed me to present alternatives to the theory that specific literacy skills are always required to connect people with participation in society and the economy. In my final revision, I changed some codes and themes to fit with a logical flow in the thematic analysis report, such as making the code “about adult literacy learners” into a theme. Being able to revise codes and themes during the writing phase is a key advantage of TA, in that fresh understandings garnered through the act of writing can become part of the analysis.

5.6 Methodology of Inclusive Research

This research used an inclusive approach to the recruitment of participants and data collected with them, as well as to the evaluation of the methods used.

5.6.1 *Inclusive Research*

Inclusive research grew out of the emancipatory paradigm of politicised and change-oriented research, which although embraced by the disability movement, still excluded people with learning disability (Ramcharan et al., 2004). Seeking to remedy this exclusion, Walmsley and Johnson (2003) borrowed the term inclusive research from other research that centres groups of people who experience barriers to research and were previously treated as research subjects. Examples of inclusive research include research with children (Johnson et al., 2003), people with other disabilities (Gundy et al., 2003), and with any oppressed group (Jones, 2020). In this research, *inclusive research* is an umbrella term that describes research that has four guiding principles: that it originates from, collaborates with, benefits, and creates outputs that are accessible for people with learning disability (Walmsley and Johnson, 2003).

Nind and Vinha (2014) have now called for a second generation of inclusive research that prioritises quality and outcomes over process to maintain recognition of its validity within the wider research community. Fyson and Fox (2014) similarly identified tensions between good processes and good outcomes and raised questions about the utility of groups that work to hear the voices of people with learning disability compared with their value to those who attend these groups. Walmsley et al. (2018) disagreed with Nind and Vinha (2014) and Fyson and Fox (2014), finding it premature to move past a focus on improving the process of inclusive research when people with learning disability and researchers without learning disability are still grappling with the task of power sharing, and inclusive research is not yet fully accessible to all people with learning disability.

In consideration of appeals for a greater focus on rigour from Nind and Vinha (2014), Walmsley et al. (2018) updated and expanded their definition of inclusive research with a view to maximising the potential for high-quality research. Rather than originating from people with learning disability (Walmsley & Johnson, 2003), Walmsley et al. (2018) now say inclusive research should be on a topic of significance to people with learning disability, and

use their experience when setting the research agenda, design, and anticipated outcomes. Instead of collaborating with people with learning disability (Walmsley & Johnson, 2003), Walmsley et al. (2018) call on inclusive researchers to highlight and value the skills and strengths of people with learning disability, while listening to and supporting those who have lived experience of the research topic. In place of benefiting people with learning disability (Walmsley & Johnson, 2003), Walmsley et al. (2018) have widened the aims of inclusive research by saying it should bring about social change that works to better the lives of any marginalised group, not specifically people with learning disability. Alternatively to creating that are outputs accessible for people with learning disability (Walmsley & Johnson, 2003), Walmsley et al. (2018) now ask that the outputs of inclusive research are useful for people with learning disability in their pursuit equity and justice.

In updating their definition of inclusive research, Walmsley et al. (2018, p. 753) articulated that, “the main added value of inclusive research is that people with intellectual disabilities bring something unique to the research process and to the quality of the research.” Koenig (2012) also talked about the added value of including people with learning disability in research because of their originality, experiential insight, and ability to rethink and revise research methods.

There is no standard way to engage in inclusive research and multiple approaches have been used (Ollerton, 2012). Bigby et al. (2014) developed three categories for approaches to inclusive research they found in their literature review on the topic. The first approach was advisory, such as people with learning disability being involved in a steering group or making recommendations. The second approach was leading and controlling, being that people with learning disability were involved in the whole project, and the role of people without learning disability was limited to that of support. The third approach was collaborative, involving people with learning disability throughout the entire project, with key roles shared among people with and without learning disability.

Nind (2014) categorised approaches to inclusive research using the concept of spatial practices as closed/invited and claimed/created spaces, which she borrowed from Thomson

(2007). As a children's researcher, Thomson (2007) described closed/invited research spaces as existing when researchers define the research problems and methods before involving participants. Participants have limited decision-making capacity in closed/invited spaces, for example to fill in a worksheet or to abstain from filling it in. Whereas claimed/created spaces are organic opportunities for participants to claim and create research for themselves, for example by designing their own worksheet. Nind (2014) drew on Cornwall and Jewkes (1995) to further describe how research can be made flexible and iterative, akin to claimed/created spaces, or rigid and linear, akin to closed/invited spaces.

Some researchers with learning disability and mixed ability research groups have criticised inclusive researchers without learning disability for not including people with learning disability in all aspects of research. Townson et al. (2004, p. 73) called inclusive research that does not include people with learning disability from the beginning, use their preferred words and methods, and have outputs they can understand "rejected research," countering the idea that research can fail to meet inclusive ideals and still be described using that term. Aspis (2000, p. 2) also used her perspective as a person with learning disability to caution that some mixed ability research groups engage in tokenism by working with "the 'tame' ones" and those who lack research skills.

Inclusive researchers have presented arguments for and against doing research skills training with people with learning disability (Bigby & Frawley, 2010; Koenig, 2012; Nind et al., 2016). Inclusive researchers Bigby and Frawley (2010) and Koenig (2012) championed teaching research skills to people with learning disability. However, Nind et al. (2016) took a more critical view, concluding that it might impart a normalising effect on people with learning disability who would otherwise respond more authentically. While training and capacity building in inclusive research should not create or reinforce a hierarchy or undermine relationships (Nind et al., 2016), Ollerton (2012) pointed out that members of a research team with and without learning disability learn research skills from each other.

Inclusive research can be undertaken using with a range of methods. Researchers with learning disability and mixed ability research groups have asked for methods used in

inclusive research to be designed to make the best use of their strengths and abilities (Townson et al., 2004), and advocated for the freedom to adapt existing methods (Garbutt et al., 2010). For example, White and Morgan (2012) used scaffolds, such as headings, tables, prompt cards, *How To* guides, and planning and practice sessions, to make research methods more inclusive for researchers with learning disability. Inclusive researchers without learning disability have generated data via autobiographical accounts (Atkinson & Williams, 1989), focus groups (Bigby & Frawley, 2015; Nind & Vinha, 2016), workshops (Cook & Inglis, 2012), tea parties and surveys (Chapko et al., 2020), photo-voice (Ollerton, 2012), and, in Aotearoa New Zealand, *hui* (gatherings) (Jones, 2019), and storytelling (Milner et al., 2019), using modified techniques.

Doing inclusive research is not only about making the right modifications to research methods, but also about *being inclusive*. Researchers need to embody attitudes and values appropriate for the participant group (Nind et al., 2016). As Walmsley and Johnson (2003) found, inclusive research is characterised by the quality and effectiveness of relationships with people with learning disability. In general, researchers need to be sensitive, non-judgemental, respectful, open-minded, knowledgeable, patient, and flexible, as well as in possession of good listening, leadership, and observation skills (Liamputtong & Ezzy, 2013). Yet inclusive researchers also need to be socially present for participants in a way that actively works to make research safe for people with learning disability (Atkinson, 1993). Hollomotz (2018) suggested that inclusive researchers work on developing practices such as authenticating feedback, being attentive to non-verbal cues, and reflecting participant word choices. Researchers with learning disability and mixed ability research groups reinforce the importance of using accessible language in inclusive research (Garbutt et al., 2010; Townson et al., 2004; White & Morgan, 2012). Garbutt et al. (2010) were strong on not using jargon, while a researcher with learning disability in White and Morgan (2012) learned to use some research jargon, such as data, reflection, and analysis. In summary, being a good inclusive researcher requires relational skills and a consideration for participants that is responsive to their needs.

Inclusive research often involves unique challenges. Hollomotz (2018) described three common complexities involved with doing inclusive research. First, participants may have a tendency for *recency*, choosing or repeating the last option or thing that was said, which could be caused by memory load and recall difficulties. Second, after a lifetime of expectations to comply with instructions, participants may struggle with *acquiescence*, saying yes to everything, or *anti-acquiescence*, saying no to everything. Third, participants can be silent until prompted to say something, *unresponsiveness* can be part of a reactive communication style, or represent an intention not to contribute. Aspis (2000) and Bigby et al. (2014) also raised concerns that participants and researchers with learning disability may not understand what is involved in research, be used as tokens to advance other agendas, or not be supported well enough in their roles. The interest and attendance of participants and researchers with learning disability can also fluctuate in some studies (Bigby & Frawley, 2010; Hart et al., 2017; Johnson, 2009). For Hollomotz (2018), no research method can be fully accessible for all people, and elements of complexity cannot be eliminated, yet being aware of common difficulties can lead to a more equitable research process.

Walmsley and Johnson (2003) asked that research outputs be accessible for people with learning disability but did not speak about who would create those outputs. Mixed abilities research group Townson et al. (2004) said researchers with learning disability should be involved in creating inclusive research outputs, not just consuming them. Garbutt et al. (2010) went further by making sure most of their dissemination audience also comprised people with learning disability, which they achieved by presenting to groups.

Inclusive research is vital to this research for two reasons. First, the disability movement dictum “nothing about us without us” encourages the active participation of disabled people in matters relating to them (Charlton, 1998). People with learning disability know the most about their own experiences and have the most to contribute to research about them (Townson et al., 2004). Furthermore, as McFarlane and Hasen (2007) said, research must be conducted with the people it seeks to represent in order to challenge oppression and effect change. Second, this research seeks to influence adult literacy policies in Aotearoa New

Zealand by presenting inclusive research informed recommendations in a context where the perspectives of adults with learning disability are not yet reflected. The ways in which this research originates from, collaborates with, benefits, and creates that are outputs accessible for people with learning disability will now be described.

This research originates from a problem experienced by some adults with learning disability that occurs when their literacy practices result in exclusion from their pathways of choice. Having witnessed this problem in action as a support worker, I decided to consult with disabled people to come up with a research topic to benefit adults with learning disability in this area of their lives.

I was able to collaborate with an advisor with learning disability from the beginning of this research, namely Glen Terry, who will be introduced more fully in *Section 5.10.1*. Glen set the standard of accessibility in this research and ensured that data collection methods were appropriate. For example, he provided guidance on how to make the research meetings fun. Glen also reviewed all easy read materials going out to participants to ensure my language was clear and understandable. Participants also took an active role in this research, making choices through snowball sampling (see *Section 5.7.1*), and giving feedback after each research meetings (see *Section 7.1.3*), much of which was implemented in future research meetings.

Benefits for participants included the opportunity to meet as a group, share their experiences, upskill in using digital technology, including zoom, and learn more about research. Participants who did not already have what they needed to participate on Zoom were gifted devices paid for out of my research fund. Certificates were distributed at the conclusion of our research meetings (see *Appendix H*).

Importantly, this research used accessible formats for all communication with participants, including but not limited to paper-based easy read and YouTube videos. Reporting back to the participants also occurred in the context of home visits, in which I gave participants an

easy read book containing my findings (see *Appendix I*) and spent time explaining it to them and their supporter according to their preferences.

I personally committed to spending more time with people with learning disability to acculturate myself in their worlds and better facilitate accessibility and inclusion in this research as exemplified by Atkinson (1993). To do this, I took on employment at People First New Zealand for three months during my candidature so that I could be in more spaces that are led by people with learning disability, and went to *Launched*, a festival showcasing the talents of people with learning disability. Being autistic also helped make regular opportunities to spend time with autistic people with learning disability more accessible to me. This included co-authoring an article with an autistic person with learning disability (Crawford & Newcombe, 2023). I also undertook disability leadership development programs with Te Pou and Be. Leadership during my candidature.

5.6.2 Participatory Action Research

Participatory action research (PAR) is a methodology that encourages collaboration between a researcher and a community to undertake iterative cycles of theory, action, and reflection (Jordan & Kapoor, 2016; Liamputtong & Ezzy, 2013). It brings together influences from Freire, liberation theology, neo-Marxism, feminism, community development and human rights activism with the goal of challenging oppressive power structures (Jordan & Kapoor, 2016). While PAR can be undertaken using a range of approaches, their commonalities are reciprocal relationships, standpoint theory, and action and reflection.

PAR is anti-hierarchical and understands that the terms “researcher” and “community” do not necessarily refer to different people (McGuirk, 2012). Therefore, the researcher and the community involved in the research must have a reciprocal commitment to each other that works to foreground the voice of participants (Liamputtong & Ezzy, 2013). In her analysis of PAR in Aotearoa New Zealand, McGuirk (2012) highlighted the importance of investing in

relationships, particularly given the small and closely connected population in this country of five million people.

PAR makes use of standpoint theory (Fine, 2008; Kindon, 2012). Coined by feminist Sandra Harding, *standpoint theory* claims that oppressed peoples have unique knowledge and perspectives by virtue of their experience, which cannot be found in any other way (Borland, 2020). A key attribute of PAR is the recognition that expertise and knowledge are everywhere (Fine, 2008). Thus, it looks outside of expertise and knowledge that may be concentrated around the researcher to learn from people whom the research is about (Fine, 2008).

Researchers and communities work together in PAR through cycles of theory, action, and reflection. Action and reflection are processes of continuous struggle for resistance, punctuated by times of looking back through engagement with theory to evaluate the effectiveness of what has been done so far, and looking forwards by planning future action (Smith, 1999). For Walmsley and Johnson (2003), action can include people affected by the research taking an active part in the research. The ways in which this research uses PAR will now be described.

I used PAR in this research by implementing cycles of action and reflection, supporting research capacity development and collaboration, and engaging with standpoint theory. To realise action and reflection, I contacted each participant after every research meeting that they took part in to reflect on what worked well and what did not work for them in our research meetings. Contact occurred via email, Facebook messenger, phone, or in person as requested by participants. This reflection process led to changes in subsequent research meetings. Sometimes changes were minor, for example, to shorten the length of research meetings occurring on Zoom. Sometimes changes were major, for example, when two participants suggested I abandon my frame analysis template and use a limited number of picture cards to aid discussion instead (see *Section 5.7.3.2.4*). I also created a table on Microsoft Word for my own reflection. I selected sections of the research meeting transcripts I thought “went well” or “could be improved” each week, adding them to the left

side of the table. On the right side of the table, I wrote comments to help me reflect on and improve my research skills in subsequent sessions. For example, “I use the word ‘perspective’ a lot. Could be good to have an easy read explanation for perspective.” Another example is that it helped me become conscious of, and seek to remedy, my tendency to summarise what the Passioners were saying, thereby highlighting what was most important to me as a researcher. Alongside reflections from the Passioners, this additional reflective practice supported me to improve our research meetings in an iterative manner.

The success of PAR is measured not only by the outcomes of research, but also by the process in which research capacity is developed through participation (Kendon, 2012). In this research, research capacity development occurred by talking about research (see *Section 7.1.1*) and analysis (see *Section 7.1.3*). Participants were given additional copies of research templates to use for their own purposes, with an open offer of my support to aid them in any future research projects they may choose to embark on (see *Section 5.11*).

This research was a collaboration between participants who identified as being interested in this literacy (see *Section 5.7.1.2*) and myself as a person committed to their community. As evidence of my commitment, I have been involved in disability spaces my whole life. In 2015, I undertook a *National Certificate in Adult Literacy and Numeracy* because I wanted to support adults with learning disability more effectively. Later, I wrote a book alongside adults with learning disability (Newcombe, 2019). One of my collaborators talked about her experience of being involved with writing that book saying, “I felt very privileged. This will stay a big part of my life for the rest of my life... I feel from the bottom of my heart that all disab[led people]... should have a go at it as well” (K. McMurray, personal communication, February 19, 2020). These experiences were part of what inspired me to want to do this research.

One of the strategies I used to engage standpoint theory was to try to remain in agreement with everything participants said and to reaffirm them as experts as much as I could. The purposes of such affirmations were to presume that participants were in an ideal position to

decide what knowledge is valid, to demonstrate my willingness to understand their perspectives, and to encourage participant confidence as valuable contributors in this research. However, I was also limited by the parameters of my research questions and the scope of my ethics approval. For example, I would have redirected participants if they decided to do a project on something other than literacy or went ahead with recruiting further participants without my involvement. I also placed limitations on participants in line with COVID-19 restrictions. The next section will discuss how inclusive research and PAR work together in inclusive participatory action research (IPAR).

5.6.3 Inclusive Participatory Action Research

Inclusive research is an approach that can be used within many methodologies but has a particularly close association with PAR (Miller & van Heumen, 2021; Nind, 2014; Ollerton, 2012; Walmsley & Johnson, 2003). One reason for this association is that PAR and related methodologies (e.g., emancipatory, participatory, and decolonising research) informed the development of inclusive research, to the extent that inclusive research is said to have borrowed from participatory and emancipatory approaches (Nind, 2014; Walmsley & Johnson, 2003). As Nind (2014, p. 5) confirmed, “the term inclusive research also allows for the overlap and reciprocity between participatory and emancipatory research.” She described this connection using a Venn diagram with participatory research, emancipatory research, and PAR intersecting and surrounded by a bigger circle called inclusive research.

Links between PAR and inclusive research have been established by multiple authors. Titchen (2015) assumed the role of PAR in inclusive research. Laes (2017) described inclusive research as being the use of participatory methodologies in a way that involves and underscores the engagement of people with learning disability in research about issues of importance to them. McFarlane and Hasen (2007) drew on their experiences as disabled women and as disability researchers to assert that PAR is an appropriate methodology for

inclusive research. Of most relevance to this research, Ollerton (2012) formally amalgamated inclusive research and PAR into a methodology called IPAR.

While inclusive research and PAR both pose serious questions to Western cultural traditions about who can do research, and both transfer research processes to the subjects of the research, there are also key differences between them (Ollerton, 2012). Inclusive research is specific to research with people with learning disability (Bigby & Frawley, 2010, 2015; Bigby et al., 2014; Johnson, 2009; Milner & Frawley, 2019; Nind, 2017; Ollerton, 2012; Walmsley & Johnson, 2003), whereas PAR can be undertaken with any group of marginalised people (Higginbottom & Liamputtong, 2015; Jordan & Kapoor, 2016; Kesby et al., 2007; Ollerton, 2012; Vallianatos, 2015). PAR adheres to a formula involving iterative cycles of research (Jordan & Kapoor, 2016; Liamputtong & Ezzy, 2013), but inclusive research is not organised in any predetermined way (Ollerton, 2012). Inclusive research does not have to be oriented towards social change outside of benefiting people with learning disability (Walmsley & Johnson, 2003), whereas PAR always intends to challenge the status quo (Fine, 2008; Ollerton, 2012; Smith, 1999). Borrowing the term IPAR from Ollerton (2012), the ways this research used an inclusive research approach within a PAR methodology will now be described.

I used IPAR in this research by doing research that was specific to people with learning disability, using a formulaic process of action and reflection, ensuring reciprocity, and intending this research to be used to influence policy in a way that effects real change. One example of using IPAR in this research is that in our reflection time, AJ shared that he intended to be someone who would “help out with the management sort of side.” My impression was that he wanted to spend more time with me and to have a special role within the research. IPAR is an anti-hierarchical methodology, so I talked with AJ about how he could share his ideas with the group. One of his suggestions for helping in a way that supported the whole group was to take action by creating a poster, so I brought a large sheet of paper to his house for him to do that project. Poster making will be described as a learning disabled research method later in this thesis (see *Section 8.5.2*).

Following an IPAR methodology, I invited participants to join in a presentation about this research at a People First meeting (see *Figure 6*). Although the presentation was external to data collection, I reminded participants to maintain confidentiality by not identifying themselves or other participants as being involved in this research. Three participants were excited about attending the presentation and two participants decided to contribute by reading out one PowerPoint slide each. Through People First, participants had another opportunity to take action by sharing this research with their community, being those who are most affected by this research.

Figure 6 Example of slide read by Glen at a People First meeting (Screenshot: N. Newcombe).



5.7 Inclusive Participatory Action Research Method

This section describes the methods I used in the IPAR part of this research.

5.7.1 Eligibility Criteria

The eligibility criteria for participation in this research were fivefold. Participants were required to:

- Identify as having a learning disability,
- Be interested in literacy,
- Live in Hamilton,
- Be 21 years old or older, and
- Have a supporter who can stay in contact with me and help them with making decisions if they need it.

I did not require that participants use verbal communication. These criteria will now be explained in more detail.

5.7.1.1 Identify as Having a Learning Disability

Everyone who participated in this research had to be learning disabled because this research seeks to remedy a research and consultation gap where people with learning disability have not yet been asked about their literacy practices and perspectives. This research used self-identification as a method for determining learning disability in line with accepted practice by Disabled People's Organisations in Aotearoa New Zealand and recommended by my advisor with learning disability. This criterion does not distinguish between adults with learning disability who have different needs for support in their lives, i.e. what the DSM-V classifies using severity specifications as being mild, moderate, severe, and profound³⁵. Milner et al. (2019) explained that severity specifications are aligned with

³⁵ Presently, there is a shift towards describing people with learning disability in terms of the extent of support they may require. For example, a person who may have previously been described as having a mild learning disability is now described as a person with learning disability who has minimal needs for support.

the medical model of disability and form a triage system reminiscent of those used by Nazi doctors. These specifications are therefore inappropriate for this research.

Inclusive research has disproportionately focused on people with learning disability who have minimal needs for support (Bigby et al., 2014; de Haas et al., 2022; Doody, 2018; Hart et al., 2017). De Haas et al. (2022) identified the comparative exclusion of people with higher support needs in inclusive research as being ableist and reflective of wider societal dynamics. In response to these issues and with the aim of including as wide a range of literacy practices and perspectives as possible, I hoped to attract participants with different needs for support in their lives. However, my approach to snowball sampling resulted in all participants being people with learning disability who have minimal needs for support (see *Section 5.7.2*).

Many inclusive researchers have relied on learning disability support service use as a way of determining who has a learning disability for the purpose of taking part in their research (Gappmayer, 2019; Gillovic, 2019; Jones, 2019; Milner et al., 2019; Morgan et al., 2014; Ollerton, 2012). I chose not to use this approach for two key reasons. First, disability support services are allocated to people based on needs rather than rights (Ministry of Health, 2020; Waikato District Health Board & Disability Support Link, n.d). Meaning that service use as a proxy for research eligibility upholds the medical model of disability, which is contrary to the affirmation model of disability that underpins this research. Second, Aotearoa New Zealand is moving towards an Enabling Good Lives approach that prioritises mainstream and individualised disability supports (Enabling Good Lives, 2023). Therefore, restricting participation to those who use disability support services intended for people with learning disability may now exclude people with learning disability who manage their own supports with their families and whānau.

5.7.1.2 Be Interested in Literacy

An interest in literacy was an eligibility criterion for this research because PAR necessitates that participants are interested in the research that they are participating in (Liamputtong & Ezzy, 2013).

5.7.1.3 Live in Hamilton

Prospective participants were required to be living in Hamilton because I intended for participation in this research to comprise weekly in person research meetings. Participation in person was important because of the cultural value of kanohi ki te kanohi interactions for Māori (Education Gazette Editors, 2020; Rangiwai, 2020), and the preference of many people with learning disability for meeting in person (Miller & van Heumen, 2021). In my understanding, prior to COVID-19, inclusive researchers and their participants typically met in person. However, the mode of these encounters was only briefly described, as it was assumed that inclusive research would primarily be conducted in person rather than online (Bigby & Frawley, 2010; Jones, 2019; Milner et al., 2019; Ollerton, 2012; Ollerton & Horsfall, 2013). I chose Hamilton as the location for this research because it is where both my advisors and I live and we have established networks located here.

5.7.1.4 Be 21 Years old or Older

Being 21 years old or older was an eligibility criterion because students in Aotearoa New Zealand who access inclusive education³⁶ are entitled to remain at school until they are 21 years of age (Ministry of Education, 2020a, section 37). While many young adults with learning disability leave school at a comparable age to their peers, they are entitled to remain at school until they are 21 years old. Therefore, they may not be affected by adult

³⁶ Formerly called “special education” (see *Section 9.2*).

literacy policies that form the background to this research until this time. It is noted that people aged 16 years old or older can enrol in tertiary education, beginning from when they exit school, and that statistics arising from the *New Zealand Census of Population and Dwellings* (Census) and associated surveys define an adult as being 18 years old or older.

5.7.1.5 Have a Supporter

Participants were required to have a family or whānau member, friend, or another support person (supporter) who agreed to support them to participate in this research. This was because inclusive researchers have reported obtaining support and guidance from someone who is familiar with the participant as being instrumental for organising schedules and transportation, as well as addressing any communication, safety, and wellbeing requirements that a participant may have (Inglis & Cook, 2011; Jones, 2019; Walmsley, 2004). The supporter role was also instrumental in my two-option participant consent process (see *Section 5.10.3*). While no objections to the criterion of having a supporter arose, it could have potentially contravened participant preferences or been perceived as disempowering to their autonomy.

For Walmsley (2004), the naming of people involved in inclusive research has important ramifications for their role, influence, and positioning within the research. This research used the term *supporter*, as it is role descriptive, and inclusive of, but differentiated from, *support worker*, which is a job title for people who are employed to provide support. Walmsley (2004) used the term supporter to describe non-disabled researchers such as herself. Where Walmsley (2004) failed in her definition is the assumption that people who are not participants in inclusive research are non-disabled. In this research, at least one supporter and I were also disabled, but not learning disabled. Furthermore, there is nothing to preclude a person with learning disability from taking on the role of supporter. The term supporter worked well in this research, but a more bicultural term could have included te reo Māori *taituarā* (support).

Supporters were given a copy of the *Information for Supporters* (see Appendix J), and *Research about Literacy and Adults with Learning Disability* (research booklet) (see Appendix E). They also had at least one in person meeting with me, as well as phone or email contact.

The contents of *Information for Supporters* are as follows.

Information for Supporters	
Heading	Description
<i>Information for Supporters</i>	<p>The times, dates, and location of our research meetings.</p> <p>A description of the supporter role.</p> <p>Information about my ethics approval.</p> <p>Contact details for myself, my chief supervisor, and the Human Research Ethics Committee (HREC).</p> <p>A map of the university and bus route information.</p>
<i>Declaration by Supporter</i>	<p>An agreement to support the participant in this research or give consent for them to participate as required.</p> <p>A request for information on dietary or other wellbeing requirements.</p>
<i>Agreement for Supporters Attending Research Meetings</i>	An outline of what support means in this research.

	<p>A list of limitations on how supporters can contribute to our research meetings.</p> <p>Information about confidentiality.</p>
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The supporter role existed to help organise transport for participants, to support participants to make decisions as required, and to discuss any issues that may arise. Supporters could attend research meetings if participants needed assistance with personal care, eating and drinking, interpretation, or any other agreed support. Any supporters attending research meetings were required to complete an *Agreement for Supporters Attending Research Meetings* (see *Appendix J*), which explained the limits of their role and reminded them about confidentiality in this research. No participant asked for their supporter to be present with them during research meetings, although presentation of the agreement document dissuaded one supporter from wanting to attend research meetings of their own accord.

5.7.2 Snowball Sampling

This research used an accumulative non-probability sampling method known as snowball sampling (Bindah, 2019; Noy, 2008). *Snowball sampling* involves recruiting a smaller number of prospective participants, called *informants*, and asking them if they want to recruit further prospective participants (Bindah, 2019; Noy, 2008). Snowball sampling was appropriate for this research because it enabled prospective participants to take an active role in recruitment, which fits within an IPAR approach.

To begin snowball sampling, I separately contacted and met two prospective participants, Hōri and John, with whom I had pre-existing relationships. My intent in approaching prospective participants with whom I had pre-existing relationships was to expedite

familiarity and rapport building (Roiha & Ikkänen, 2022). While noting that Gómez-Carrillo de Castro (2023) identified many inclusive researchers as gravitating towards working with the same group of participants with learning disability who have become privileged by their roles as self-advocates. One of the first prospective participants had a history with two self-advocacy organisations and decided to recruit further prospective participants with support by calling some of his friends and asking them if they were also interested in taking part in this research. He then asked those prospective participants if they would like him to give me their contact details. Upon their verbal consent, I took down the sets of contact details and subsequently arranged to meet those new prospective participants. The other of the first prospective participants did not have a history within self-advocacy organisations and decided not to recruit further prospective participants.

While snowball sampling included participants in the recruitment process, it also had the unintended consequence of selecting a group of people with learning disability who all have minimal needs for support. The person who chose to perform the informant role selected other prospective participants who were similarly independent and conversant decision makers like himself. The informant was also male and mainly selected other males.

5.7.2.1 Prospective Participants

I contacted seven prospective participants, five of whom participated in this research.

Prospective participants and participants are represented in the table below using pseudonyms.

Prospective participants			
Pseudonym	Age	Ethnicity	Gender
AJ	29	Māori	Male
David	63	Pākehā	Male
Hōri	59	Māori	Male
John	39	Pākehā	Male
Mark (did not participate)	61	Pākehā	Male
Melissa	26	Pākehā	Female
Sarah (did not participate)	36	Pākehā	Female

5.7.2.2 Participant Recruitment Challenges

The recruitment phase of this research presented two challenges that may be unique to inclusive research. Namely, navigating friendship with a participant who is affected by loneliness, and ensuring participants were able to withhold consent independently of their supporters.

One of the prospective participants with whom I had a pre-existing relationship was John, a friend from school whom I had continued to meet up with every few years since school ended. However, it became clear that the lines between participant and friend were particularly blurry for John. John told his supporter and me that I am his best friend. I replied that we are friends, but not best friends. John appeared very hurt and said, “well, you are my best friend.” I received a call from John’s mother outlining her concerns that John was quite lonely, and I should clearly communicate my role as a researcher, stipulating that I am not his friend. I found this advice challenging, as I did consider John to be someone

whom I had been friends with, although our relationship had lapsed into acquaintanceship. I tried to say “yes” to all participant requests and was subsequently invited to and attended his mother’s home, his 40th birthday party, and several walks and other social engagements. I also provided disability service information to his mother at her request. These interactions demonstrated the asymmetrical relationship experienced by John and I (for example I was likely to actually be his best friend given that I was the only non-family member who attended his 40th birthday party), and stretched my commitment to “reciprocity in the research process” to the limits of my capacity (McFarlane & Hasen, 2007, p. 93). I became unsure about continuing to meet with John so frequently after my data collection was complete as I had multiple demands on my time. This experience prompted me to consider how to manage post-project relationships with inclusive research participants. This issue is not adequately addressed in the existing literature, such as Chalachanová et al. (2020), who describe friendships and friendly research relationships developing organically between researchers and participants during inclusive research projects.

Another challenge occurred with the supporter of David. I had emailed the research booklet to David and his supporter ahead of my visit to his house. David’s supporter called me to say she had filled out all the forms and that David “is a definite” to do the research. I explained that consenting to research involves more than filling out forms and I needed to start building a research relationship with David. I discussed my concerns about this interaction with my supervisors. My apprehensions centred on the possibility that David's supporter might have influenced his consent process by expressing her agreement on David's behalf, and that David might consequently feel pressured to participate in this research. My supervisors encouraged me to meet with David and his supporter as agreed. In doing so, I was able to explain the method of recruitment in this research and move forward with our relationship as planned. My experiences demonstrated that recruiting inclusive research participants and engaging with their supporters is not always a smooth process and there are unique challenges that need to be responded to and learned from.

5.7.2.3 People who did not Participate

Two prospective participants did not participate in this research. The first was Mark, who indicated he would prefer for a supporter to consent to this research, yet I was unable to obtain proxy consent on his behalf. Following a meeting with Mark and his support worker, I received an email from his support worker saying, “Yeah, he is ready participate, I discussed him when I received your first email. Even he is excited” (personal communication, 26 October, 2021). However, there was ongoing confusion and deflection of responsibility between Mark’s support worker and her service manager regarding who would provide proxy consent. Mark’s support worker went on to insist on my obtaining proxy consent for Mark from her service manager and Mark acquiesced to this proposal. Following up with her service manager over email, the service manager indicated that he was new to the job and needed time to ask a colleague what to do in this situation. The service manager later directed me to go back to Mark’s support worker and ask her again to provide proxy consent. This support worker was subsequently uncontactable, and her service manager did not supply any contact details for another support worker who could continue the proxy consent process. Unfortunately, I had to let Mark know he would not be able to participate in this research. My experience was similar to that of Migliore et al. (2007), who found third parties not completing consent forms to be the most frequent reason for non-participation among 154 adults with learning disability prospectively involved in their research.

Being unable to obtain informed consent or proxy consent from Mark highlighted a discrepancy between the supporter concept introduced in the research booklet and the person who can give proxy consent as per the *Regulations* (University of Waikato, 2008). The research booklet describes the supporter role as someone who is contactable, willing to help with making decisions, and knows the prospective participant well. In this instance, neither Mark’s support worker, who was uncontactable and unwilling to help with making decisions, or her service manager, who did not know Mark well, were able to fulfil the supporter role. In contrast, the *Regulations* describe the person who can give proxy consent

as being “the person who has responsibility for the prospective participant's welfare” (University of Waikato, 2008, 9.4.e). In which case, both his support worker and her service manager may have met criteria for giving proxy consent. The learning I have taken from this experience is to mirror regulations more closely when adapting information for easy read.

The second prospective participant who did not participate in this research was Sarah. Sarah’s support worker communicated her own willingness to consent on Sarah’s behalf. After receiving the research booklet, her support worker said, “[Sarah] doesn’t understand it, but she is agreeable to doing anything, if you want her to do it, I can get her to do it” (personal communication, 5 August, 2021). I discontinued selecting Sarah for this research because I was concerned about a consent dynamic that did not seem to be driven by Sarah. In saying that, I may have discounted a person with learning disability who has more than minimal needs for support from taking part in this research. These instances demonstrate the limitations to inclusivity within doctoral research, in which gaining active consent from Sarah would have taken greater time and relational resources than were available.

5.7.3 *Research Meetings Method*

I coined the term *research meetings* to highlight the integration of activities into a method that might have otherwise been called focus groups. Like focus groups, research meetings facilitate discussion between participants who have a shared interest or experience within a defined time and place, with the most significant dynamic being participant-to-participant group interaction (Carey & Asbury, 2012; Krueger, 1994). One purpose of group interaction is to dilute researcher cues, structures, oversights, and omissions, and to assist participants to clarify and contribute their own ideas (Carey & Asbury, 2012; Krueger, 1994). Cook and Inglis (2012) identified the benefits of group interaction for inclusive research. Group interaction supports participants to engage with information from different perspectives and enables participants to work together as peers.

I supplied digital technology comprised a Canon EOS-90D DSLR camera and tripod, along with a reMarkable tablet (digital notepad and high-precision stylus that allows for accurate handwriting and drawing), and an additional dictaphone for the Passioners to use when our research meetings occurred in person. The inclusion of activities aimed to make data collection more fun (Inglis & Cook, 2011; Jones, 2019), beneficial for participants (Walmsley & Johnson, 2003), and to bring about different forms of data, particularly those relating to multimodal literacies (see Section 3.1.3). Whereas, limiting the mode of communication to discussion, as occurs in focus groups, would have been too restrictive for IPAR research with adults with learning disability, and fail to capture important visual, gestural, and spatial examples of literacy (Bull & Anstey, 2018). I included digital technology in our research meetings so that participants could express and record themselves and each other beyond the realms of linguistic and auditory literacy practices. In addition to data collection outcomes, I also anticipated that using digital technology could also be fun, social, and generate new opportunities for teaching and learning among participants.

Each research meeting started with a *karakia*, *whakawhanaungatanga* (process of establishing relationships), confirmation of consent, and was closed with another *karakia*. In person meetings included social time with hot drinks and kai. In line with an IPAR methodology, I contacted all participants who participated in the preceding research meeting to reflect with them and gather their feedback prior to the next research meeting.

There were ten research meetings, which occurred in two sets. The number of meetings was in the upper range compared to other inclusive research projects. Cook and Inglis (2012) met for eight workshops, Jones (2019) met for nine hui, Chapko et al. (2020) held 10 tea parties, and Townson et al. (2004) visited five People First groups and then held a two day workshop. In saying that, quantifying the participation of people with learning disability in research is somewhat ambiguous because a lot of time is spent building relationships and making sure research is accessible by talking about it one on one and face to face. While there were 10 research meetings, there were also numerous other meetings before, between, and after the research meetings.

The first three research meetings formed an opportunity to discuss key concepts related to this research, such as consent, research, and literacy, and to show and discuss examples of our literacy on Zoom. The next three research meetings were held in person and provided a forum for participants to review earlier data, show and discuss examples of their literacy, and use other digital technology. The final four research meetings comprised an inclusive analysis I developed in line with elements of frame analysis, and subsequently modified in response to participant feedback.

5.7.3.1 The Impact of COVID-19 on this Research

This section will describe the process of moving from in person to online data collection using Zoom. Online research methods bring unique challenges to inclusive research, especially with regards to maintaining accessibility, connectivity, and dynamic (Miller & van Heumen, 2021). Therefore, I looked at accessibility information and consulted with disabled people to mitigate these issues. Finally, I applied for and was granted an amendment to the ethical approval for this research to allow me to move data collection online (HREC(Health)2021#41, 7 December 2021). Participants and supporters were informed of and agreed to this change of plan, in line with advice from HREC (Health).

I found a paucity of information specific to accessible online meetings for people with learning disability. However, I was able to apply learnings from generic information in *Running Accessible Meetings* (Office for Disability Issues, 2022) to the digital environment, such as guidance about taking frequent breaks. Then, I undertook consultation about making online meetings more accessible with three disabled people: Kia Roha trustee and Hamilton City Council Access Advisory Group member Vaughan Mikkelson, Te Whatu Ora Waitematā Consumer Council member Kaeti Rigarlsford, and People First North Island Team Leader Yi Small.

Consultation with disabled people revealed that Zoom is more accessible than Microsoft Teams. Although Yi said the word “Zoom” can be scary for some people with learning disability. She explained that some people with learning disability enjoy the online forum, and others feel left out initially, but most are “brilliant on Zoom” once they learn how to use it (Y. Small, personal communication, 26 November, 2021). It was also shared that people with learning disability can have shorter attention spans during online meetings, and that the cost of using the internet was a concern for some. I responded to advice about making online meetings more accessible by selecting to use Zoom rather than Teams, changing the meeting duration from three hours to one hour, and sending the easy read document *How to use Zoom* (Learning Disability Wales, 2020) to prospective participants and their supporters, along with offering devices and technical support.

There were positive and negative aspects about moving to online data collection. As mentioned, I delayed changing to Zoom research meetings for three months. I was predominantly worried that the meetings would be too boring for participants without the social aspects of sharing kai and using digital technology as I had initially planned. Furthermore, towards the beginning of the COVID-19 pandemic, I was like many people in being inexperienced with Zoom myself, and unsure if I had the skills to facilitate sessions on that platform. The benefits of moving to online research meetings included that participants could more easily retrieve examples of their literacy from their houses and moving to online data collection supported participants to access and learn to use Zoom. Furthermore, online research meetings provided an opportunity for connection with and among participants during the COVID-19 pandemic, and the schedule of this research called for data collection to occur.

5.7.3.2 Inclusive Analysis

I attempted use an inclusive analysis method based on frame analysis during the final four research meetings. Research participants with learning disability sometimes take a role in

inclusive analysis, but I could not find an example of them doing analysis themselves. Examples of inclusive analysis roles undertaken by participants included counting and choosing (Ollerton, 2012; Williams, 2011); identifying themes (Rolph, 1999; Walmsley & Johnson, 2003), main points (Dowse, 2009), or “best bits” in the research (Nind, 2011, p. 358); analysing one small section of the overall study (Kramer et al., 2011); and approving an analysis undertaken by other researchers (Nind & Vinha, 2014; Riches et al., 2020). I sought to provide an opportunity for participants to analyse their data, although I ultimately ended up completing my own analysis later.

I drew on frame analysis to develop an inclusive analysis method, wherein we shared the tasks necessary for conducting this analysis. I initially designed 22 picture cards that represented the concept of *keys*, metaphorical devices that help people make sense of social interactions, drawn from Goffman (1974). The Passioners were invited to select cards as stimuli for thinking about their data in different ways. The cards were intended to be used with a research template I designed called *Thinking about what our Research Means* (see *Appendix K*) to include the Passioners in doing analysis. In line with an IPAR methodology, the inclusive analysis process was iteratively modified in response to various challenges we encountered. I ultimately called this process *picture card analysis*.

5.7.3.2.1 Frame Analysis

Frame analysis uses the concepts of strips, frames, and keys to understand and interrogate the status quo as rather being nameable perspectives (Goffman, 1974). In frame analysis, the information being analysed is called a *strip*, a strip is bracketed in that it has a beginning and an end. Only a strip in its exact presentation of itself is real, as in, any description of the strip is in fact a *frame*. Essentially, frames are ideas about what might be going on in a strip and thus construct reality. A *key* is an organising principle that maintains a frame, it is a categorisation of what might be going on. Each key is a layer of interpretation, changing the key can change the frame. The processes of frame analysis devised by Goffman supports an

understanding of social interaction in data. Frame analysis appealed to me as a useful approach for introducing new insights into this research due to its emphasis on examining the assumptions and principles that shape our interpretation of events and interactions. I thought I could make the process of frame analysis amenable to inclusive research because of how other authors have demonstrated framing analysis in a flexible way, with approaches varying considerably (Durham & Carpenter, 2015; Graber, 2018; Mellifont & Smith-Merry, 2016; Spehar, 2015).

5.7.3.2.2 About the Template

I created an easy read frame analysis template called *Thinking About What Our Research Means* (see *Appendix K*). The purpose of the template was to assist the Passioners to choose parts of their data and think about what those parts mean. The template described what analysis is before setting out aspects of frame analysis, namely strips, frames, and keys. It then instructed the Passioners to look at their data on the PowerPoint presentation and select a picture card to help them answer the question “what is going on right now” and further questions of “what else could be going on.” This was intended to help the Passioners think about how their data could be seen through different lenses. There were spaces for the Passioners to write or draw their answers, but I also told the Passioners they could write, draw, or verbalise what they wanted to say as I was also recording the meeting.

I drew the idea for a template from *My Health Passport* (Health and Disability Commissioner, n.d). *My Health Passport* is an easy read booklet that incorporates lined spaces indicating where users can add their own information. Of importance to inclusive research, research templates can simplify research processes, enabling researchers with less experience to undertake research projects (Köhler et al., 2022). However, while templates present a structure for organising ideas and information, they also restrict methodological creativity by predetermining some research decisions (Köhler et al., 2022). There are

numerous research templates available (for example, Isl collective, n.d; Twinkl, n.d), however, I have not found another research template that specifically supports research by people with learning disability.

5.7.3.2.3 About the PowerPoint Slides

I developed 28 PowerPoint slides (see *Figure 7*) of examples of literacy from the preceding six research meetings. These were projected onto a screen during the final four research meetings as part of my inclusive analysis method. To create the PowerPoint slides, I started with 80 excerpts from the transcripts that best represented what I thought to be the breadth of examples of literacy practices from the Passioners. I organised those excerpts into 31 types of literacy, eight categories, and two questions. Then, I selected 28 excerpts from my previous subset, seeking to equalise the contribution made by each of the Passioners as much as possible. This was intended to be a manageable number of excerpts. Excerpts had an average of 20 words per slide. I added images created by the Passioners to the slides where possible. Photosymbols were added to other slides to make them more visually appealing. *Photosymbols* (2023, We are Photosymbols) are “a photo library for easy read information featuring actors with learning disabilities.” I scheduled up to seven slides to be analysed per research meeting but not all the slides were used.

I send text messages,
means that you can text
anybody and get a text.

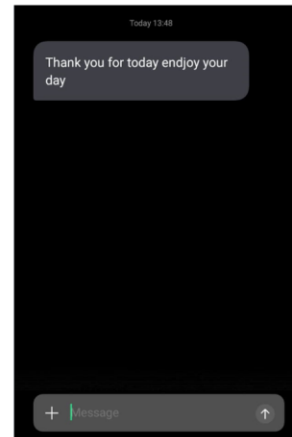


Figure 7 Example of PowerPoint slide for inclusive analysis (Screenshot: N. Newcombe).

5.7.3.2.4 About the Picture Cards

I made a set of picture cards representing 22 keys. These were made by printing pictures from Photosymbols and Aotearoa New Zealand specific images I sourced from Google, some of which were assemblages of images I compiled to communicate a key, and then laminating the pictures onto cards (see *Figure 8*). I derived the keys from four sources. The first source was *Frame Analysis*, in which the five major keys are “make believe, contests, ceremonials, technical redings, and regroundings” (Goffman, 1974, p. 48). The second source was *Te Kāwai Ora* (Māori Adult Literacy Working Party, 2001), from which I used their six examples of literacy, being reading (in te reo Māori or English), writing (in te reo Māori or English), geography, symbols, the politics of everyday life, and mediums that link us to the e-world. The third source was the *Learning Progressions* (TEC, 2008a), from which I used four concepts not already covered by previous sources, being speaking, listening, progression, and assessment. The final source was the transcripts from our research meetings, from which I used seven more salient ideas about literacy, being draw, careful, create, look, plant,

show, and come together. I did not disclose my understandings of the picture cards to the Passioners, as I wanted them to draw on their own understandings. I intended the Passioners to select picture cards and use them with the template to stimulate discussion.



Figure 8 Picture cards (Photo: N. Newcombe).

5.8 Reflexive Thematic Analysis Method

I used reflexive TA to analyse the transcripts of research meetings with the Passioners. The analysis presented here followed the six-phase approach suggested by Braun and Clarke (2022) (see *Section 5.8*). In addition, the emotional aspect of doing reflexive TA contributes meaningfully to subjectivity, which is a key point of difference between reflexive TA and other forms of TA (Braun & Clarke, 2022), such as the more transparent TA approach taken

in my policy analysis. As the Passioners and I are all disabled, the reflexive aspect of reflexive TA helped me understand our similarities and differences, and how our interactions affected this research.

5.8.1 Familiarisation with the Dataset

Research meeting data was collected data in two sets. The first set comprised six research meetings with up to five participants, and ended four months before the second set began. The second set comprised four research meetings with three participants.

I familiarised myself with data from the first set of research meetings by listening to all recordings and manually transcribing them. I then re-ordered the transcripts into topics so I could find excerpts more easily. Once I had a full set of six transcripts, I developed PowerPoint slides from that data to use in the second set of research meetings (see *Section 5.7.3.2.3*). Each of these processes aided my familiarisation with the first set of data.

I familiarised myself with the data from the second set of research meetings by listening to all recordings and transcribing them with assistance from Otter.ai, a speech to text transcription application. Most words spoken by the Passioners still required manual transcribing because Otter.ai did not capture their words well. I created a table on Microsoft Word for my weekly reflections of the transcripts so that I could become more conscious of disabling practices, such as my tendency to start reading slides out for the Passioners. Each of these processes aided my familiarisation with the second set of data.

5.8.2 Coding

In reflexive TA, coding means to, “identify segments of data that appear potentially interesting, relevant or meaningful” (Braun & Clarke, 2022, p. 35). I undertook multiple

phases of coding using both computer and paper-based approaches, as well as reading printed transcripts from different starting points and in different directions.

First, I printed and read the entire transcript of our research meetings from page one to page 207, using a highlighter to mark up any sections that could be relevant to my research questions. New reasons to highlight data came to mind after I started, for example, the Passioners talking about their difficulties with literacy. Then, I reread the entire transcript from page 100 to page 99, highlighting more sentences and reconsidering the relevance of others to promote evenness between ideas that had occurred to me earlier and later in the coding process. These processes comprised the first iteration of coding in this research.

I initially came up with so many ideas about how to answer the research question that I paused to reflect on what it was about literacy that I was actually highlighting. The idea of literacy had become increasingly porous to me. I was finding elements of literacy in almost everything the Passioners said because I was coding for forms of communication, subject knowledge, and application. For example, I had coded “*awa* [river] is our river, where we get our water” (Hōri) as “water literacy”. I decided to remedy this plethora of codes by adopting a frame around what counts as literacy. As suggested by Furness and Hunter (2018), I referred to *Te Kāwai Ora: Reading the world, Reading the word, Being the world* (Māori Adult Literacy Working Party, 2001) for guidance on what literacy is and to create folder headings for the next stage of coding.

In the next stage of coding, I copied and pasted coded sections into an analysis table on Microsoft Word. I printed these excerpts out, cut them up, and sorted them into piles (see *Figure 9*). Then, I grouped the excerpts into folders (see *Figure 10*), reconsidering the relevance of each selection to my research questions. I removed several excerpts that were very similar and made another folder for hard-to-group excerpts. Next, I taped my excerpts onto a large sheet of brown paper, arranged by folder (see *Figure 11*), moving some of the excerpts around and creating subgroups. For example, I developed the “marae protocol” and “Kīngitanga” subgroups from the cultural group. Then, I applied sticky notes to almost

all the excerpts and added codes to describe what I thought might be going on in those excerpts.

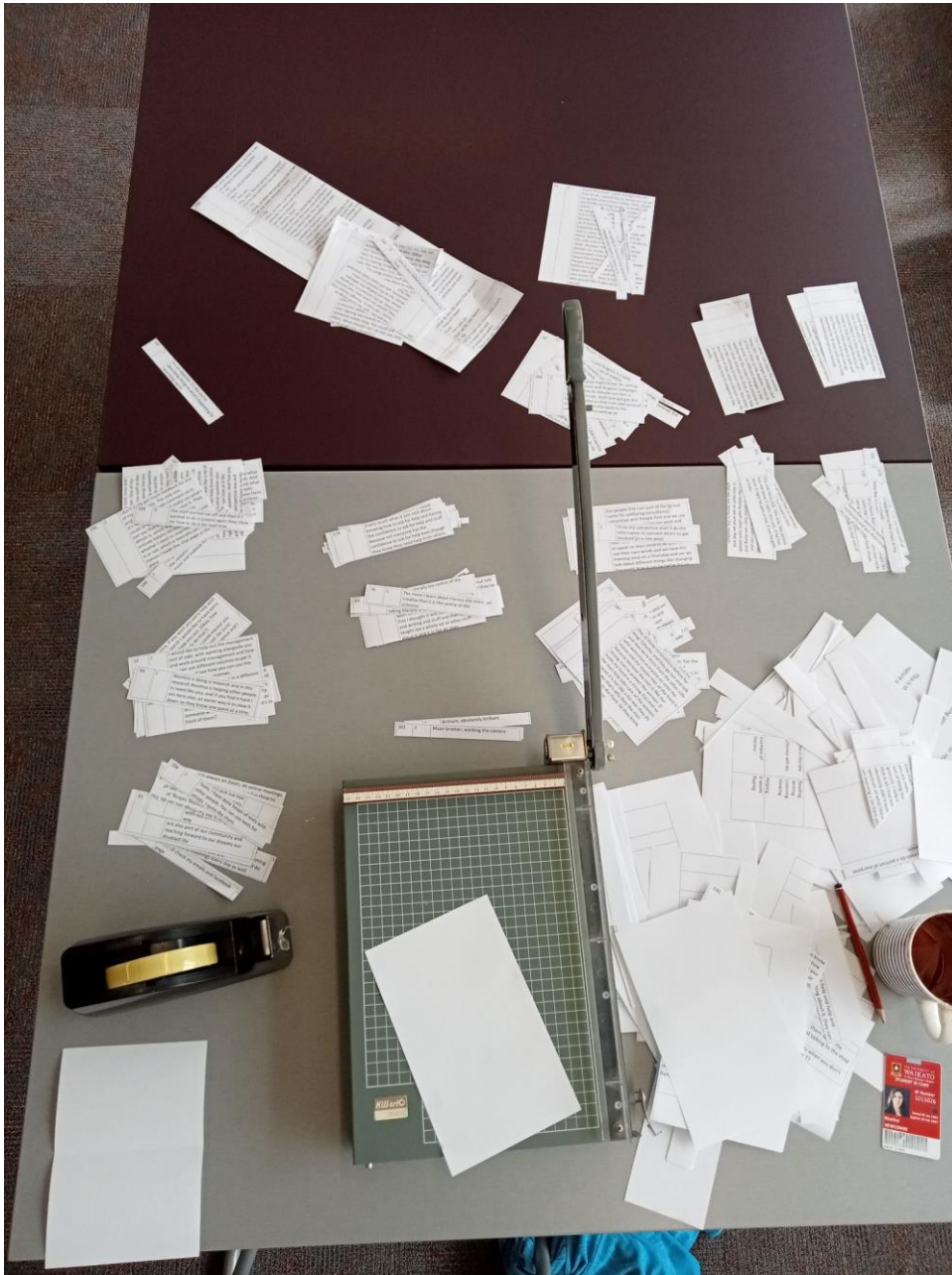


Figure 9 Cutting up printed excerpts (Photo: N. Newcombe).

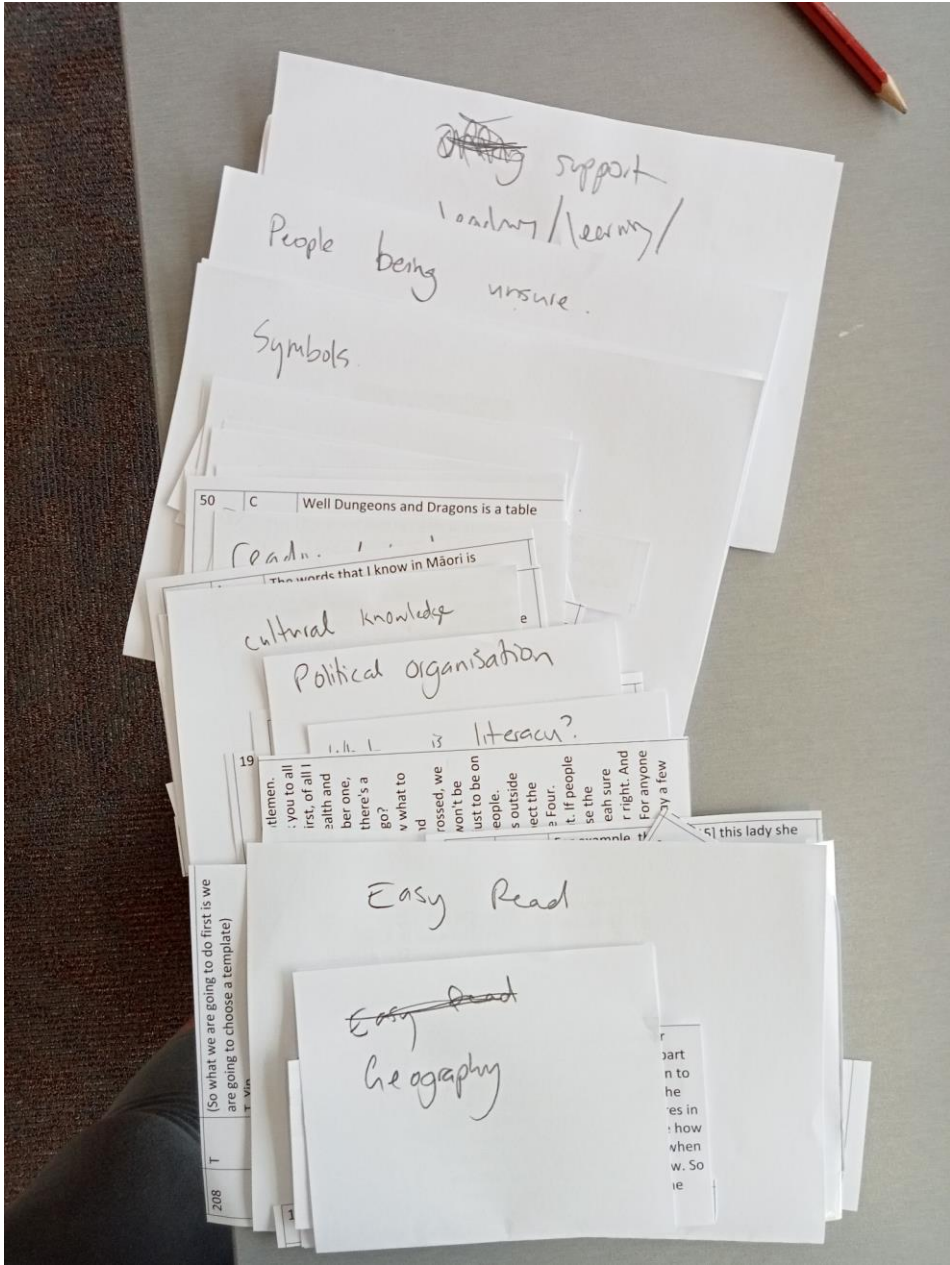


Figure 10 Filing printed excerpt (Photo: N. Newcombe).

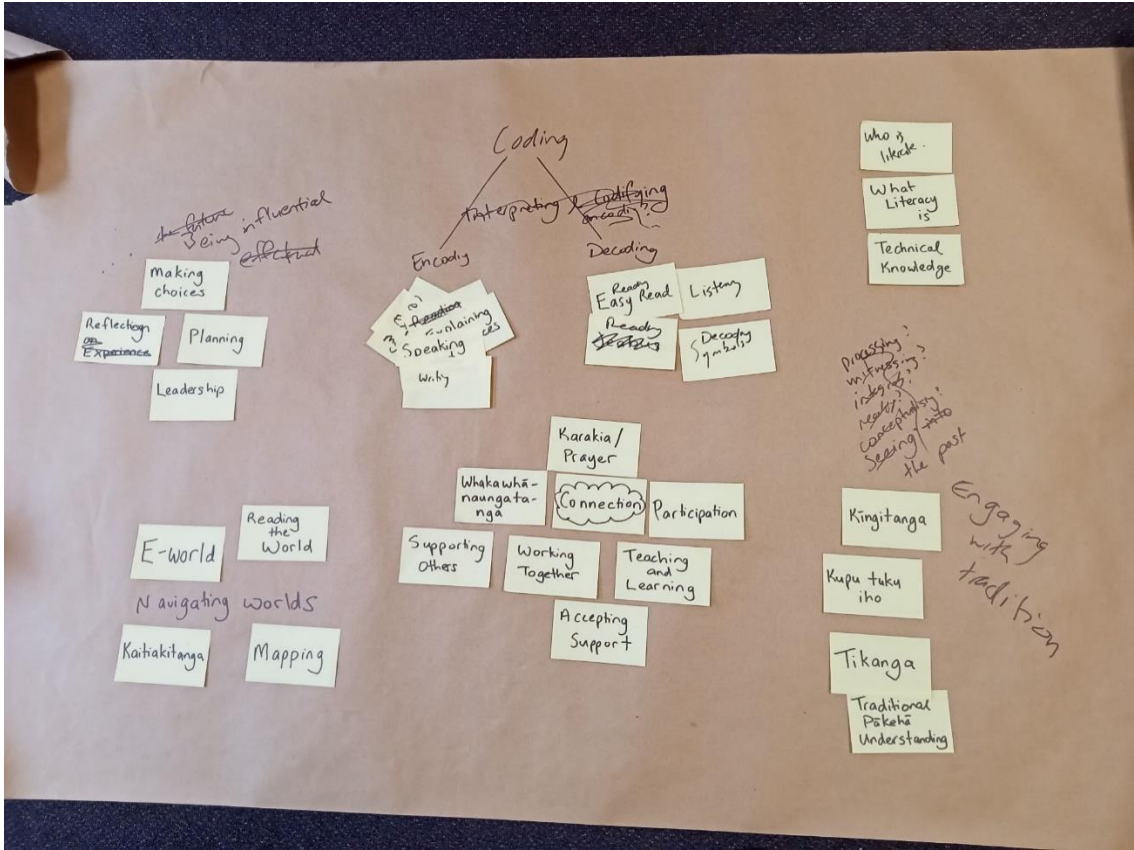


Figure 11 Coding on brown paper, step one (Photo: N. Newcombe).

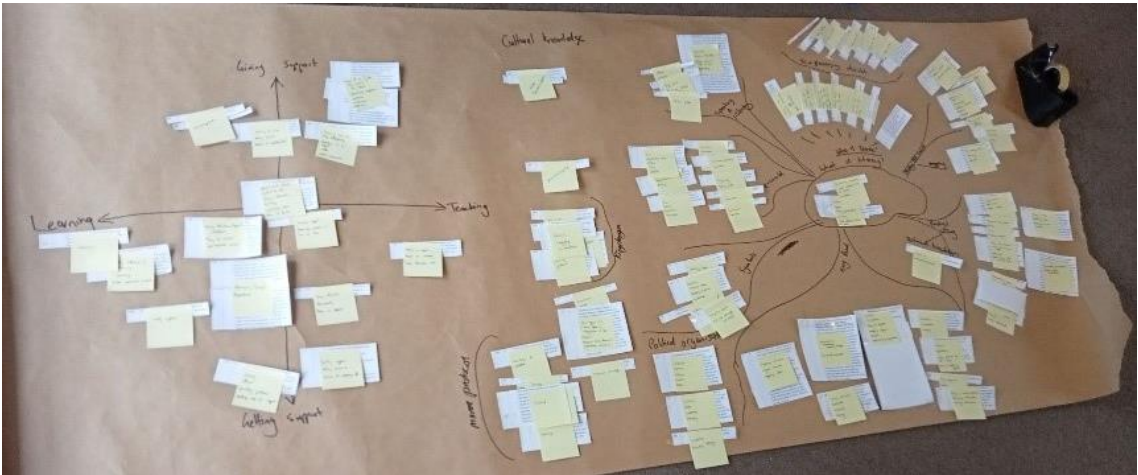


Figure 12 Coding on brown paper, step two (Photo: N. Newcombe).

The next step occurred as I recorded my paperwork onto the computer. First, I removed excerpts I had culled on paper from my analysis table on Microsoft Word. Then, I worked back and forth with my entire transcript to resize excerpts that contained too many ideas or where the context had been lost. I added the folder labels to a column on my analysis table and the sticky note codes to a second coding column, aggregating and disaggregating codes until my lists appeared concise and complete. Formulating and inputting codes helped me reflect on several issues. I made a code called “I don’t understand,” recognising that *my* lack of understanding of an excerpt does not indicate that it was not meaningful. One of the excerpts thus coded was, “the more I learn about literacy the more I realise that it is the centre of the universe” (John). Most excerpts attracted one or two primary codes and one to four secondary codes.

It struck me that I had coded excerpts relating to Māori culture as “cultural,” but references to Pākehā culture went uncoded. Pākehā culture is less visible to me because I am Pākehā and Māori culture stands out as other by comparison (Awatere, 1984). On making this realisation, I broke the “cultural” code into codes with more specificity, such as “*Kīngitanga*” (Māori King Movement) or “kupu tuku iho.” I also made the code “traditional understanding” more precise by adding the word Pākehā, as in “traditional Pākehā understanding.” An example of an excerpt with this code was “I thought literacy is more about reading and writing” (John), in that it was a traditional Pākehā understanding of literacy.

On reading through my analysis table on screen and checking all the codes again, I realised I had only used the code “interest-specific” for one interest, which was *Dungeons and Dragons*. I noticed that, similarly to learners in the Glory and Dismay Football Literacy Programme (Player, 2012), John displayed a significant uptick in confidence about the literacy practices he uses while engaging in his key interest. However, I realised I was singling out *Dungeons and Dragons*, even though it was no more interest-specific than when Hōri described planting by the seasons, or Melissa reflected on her love of healthy food. I

removed the “interest-specific” code and recoded those excerpts with the literacy practices they described.

5.8.3 *Generating Initial Themes*

The third step in reflexive TA is generating initial themes (Braun & Clarke, 2022). To begin this step, I copied each code from my analysis table onto more sticky notes that I clustered on another large sheet of brown paper and wrote words to encapsulate the groups of codes (see *Figure 12*).

Codes and themes can be revised at any stage of reflexive TA. I removed the codes “demonstrating competence” and “describing competence” because I realised that I had decided what competence is far too early in the analysis to understand competence from the perspective of the Passioners. I also removed “teaching and learning” and “participation” codes because the entire data collection was teaching and learning and participation. Another reason to delete the code “participation” was its implication that the Passioners would also have instances of non-participation. Some excerpts were recoded because of these code deletions.

The first themes I generated were “reading the future,” “reading the past,” “interpreting and codifying,” “connection” and “navigating words.” I copied these initial themes with their codes onto PowerPoint slides with a theme in the centre of each slide and the codes surrounding the themes (see *Figure 13*). PowerPoint made it easier for me to move around and keep track of my themes and codes. I continued to change, divide, and amalgamate my initial themes.

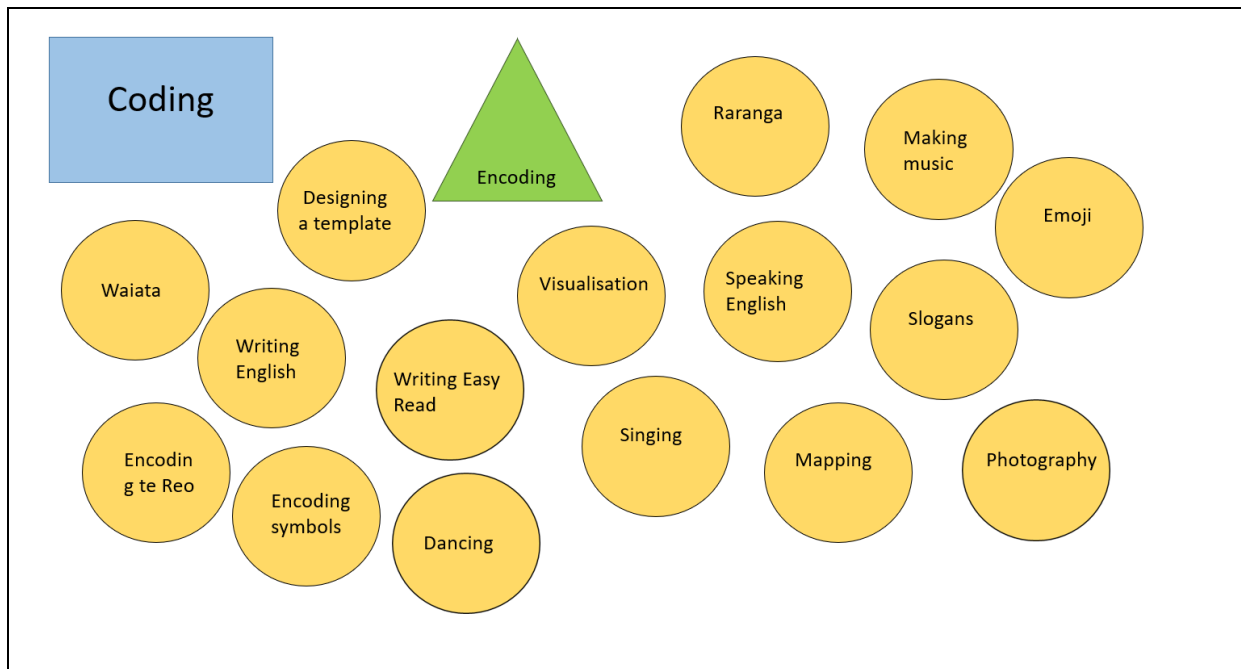


Figure 13 Example of PowerPoint slide with a theme, subtheme, and codes (Screenshot N. Newcombe).

The themes “reading the future” and “reading the past” seemed to suggest an element of sequence. Linear time is a Western concept, and this research aims to be bicultural. In te ao Māori, the past, present and future are all now, as time is “tied to the cyclic rhythm of nature and to the ancestors’ rhythm of life and death” (Awatere, 1984, p. 60). Furthermore, codes such as “Kīngitanga” and “tikanga” would have needed duplication under both past and future themes. I devised new, more representative themes, which were “being influential” and “engaging with Māori tradition.”

I then broke “interpreting and codifying” into a theme called “coding” and subthemes called “encoding” and “decoding.” True to the recursive nature of thematic analysis, I needed to recode “reading and writing,” “speaking and listening,” “symbols,” and “easy read” into their respective encoding and decoding forms. I further specified whether reading, writing, speaking, and listening were in te reo Māori or English language. Then, I rechecked the new codes with the data excerpts to make sure they were still consistent. I realised there were no examples of listening to te reo Māori so I removed that code. I retained “speaking English” because AJ said, “sometimes I sing, sometimes I do talking, and sometimes I do

dancing.” I presumed this to be in English because he was communicating that information in English.

Reconsidering the “navigating worlds” theme, I separated the “e-world” code into the specific applications the Passioners were engaging with. Most were social media, so I created a “social media” subtheme within the theme of “connection.” I also recoded data labelled “reading the world” because it was not clearly defined in meaning for me. I formed three new codes, “cultivating or obtaining food,” “visualisation,” and “reading a tide chart.” This meant I no longer had enough codes to support the “navigating worlds” theme and deleted it.

After some reflection time, I created two new codes. The first was “aspiration” to replace “planning,” where an intention was stated but no interventions or steps to completion were explored, I then revived this code as “aspiration and planning” because of the ambiguity between these concepts in the data. The second was “vaccine passport,” which was initially coded under “e-world” but is not part of social media or decoding, as that theme became. It was challenging to understanding how I differentiated Passioners demonstrating literacy at our research meetings, talking about literacy they have previously demonstrated, or saying what they know about a form of literacy. I came to realise this was a subjective delineation. Finally, I created a visual summary of the coding and thematic changes made during this generation of initial themes by drawing a table of initial themes and those used now and drawing lines to track where codes had moved, and which had been deleted or created (see *Figure 14*).

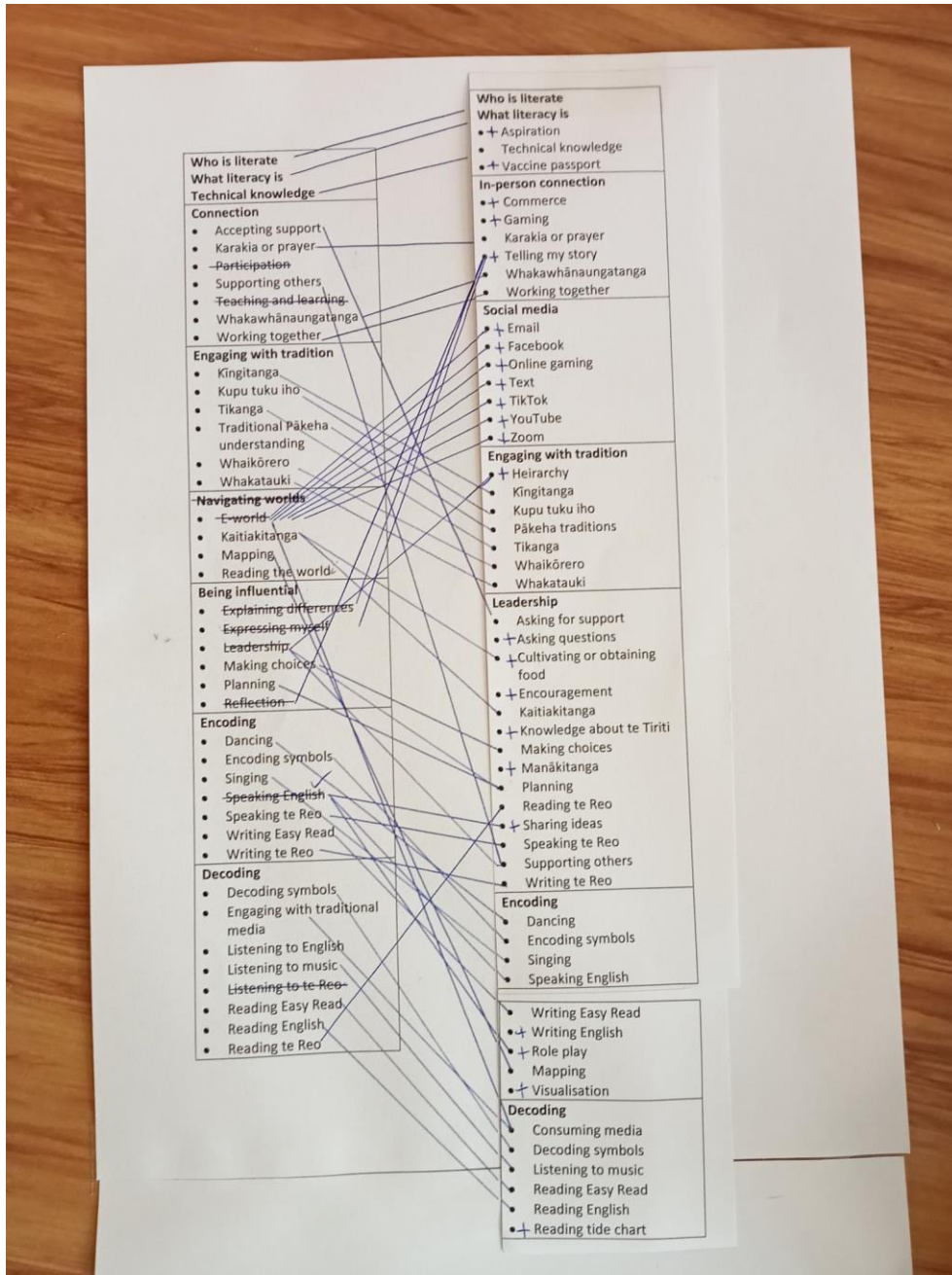


Figure 14 Mapping codes (Photo: N. Newcombe).

5.8.4 *Developing and Reviewing Themes*

In the fourth step in reflexive TA, Braun and Clarke (2022) recommend reflecting on the boundaries, size, and importance of initial themes. As part of this step, I also sought input from my Māori cultural advisor and advisor with learning disability in developing and reviewing themes. I also conducted another full reading and coding of the data, as will be described.

On reviewing my initial themes, I noticed elements of my cultural bias. For example, excerpts coded with “leadership” related to Pākehā forms of hierarchy such as committees, management, and mentoring. I then sought to appreciate Māori perspectives on leadership, with a view to coding these in the data. Mead (1997, p. 203) lists abilities in obtaining or cultivating food, building houses or *waka* (canoe), holding meetings, or mediating between parties, geographical knowledge, and being inviting and welcoming to visitors as “chiefly qualities” in traditional Māori leadership. For Mika and O’Sullivan (2014), contemporary Māori leadership builds on traditions that serve the continuance of whānau, hapū and iwi. Henry and Wolfgramm (2018) emphasise the relational aspect of Māori leadership, including relationships with people, animals, nature, and spirits. Finally, I consulted with my Māori cultural advisor, TeAtakura Ryan, in seeking to made changes to my codes and themes after reading these texts.

In discussing my codes and themes in respect to Māori leadership, TeAtakura agreed it was “important” to have use of te reo Māori within the “leadership” theme, as well as saying that a leader is a “repository of knowledge” (personal communication, September 27, 2022). Reflecting on Kīngi Tūheitia³⁷ and his advisors, she thought the code “asking for support” should be recoded as a form of leadership, saying, “a leader normally has a few people around that they get support from.” I responded by replacing what I had generalised as leadership with the more specific codes, “hierarchy,” “planning,” and “supporting others” as appropriate. Then, I made “leadership” a theme to replace “being influential” and

³⁷ Tūheitia Pōtatau Te Wherowhero VII is the current reigning Māori King.

encompass the overlapping concepts of interpersonal and intrapersonal leadership. I recoded a reference to gardening food from “*kaitiakitanga*” (guardianship) to “cultivating or obtaining food” and moved reading, writing, and speaking te reo Māori from the “coding” to the “leadership” theme. I also repositioned the code “asking for support” into the “leadership” theme. Importantly, leadership relationships are fluid, as exemplified by AJ, who said, “I want to mentor you,” which meant for one of the Passioners to take a leadership role in this research.

TeAtakura and I also discussed my “engaging with traditions” theme, as I had more codes representing Māori culture than Pākehā culture, even though I facilitated my data collection as a Pākehā. She pointed out that disability support services should be regarded as a Pākehā tradition. Our *kōrero* about dominant culture and cultural blindness led to six new codes within a new subtheme “engaging with Pākehā traditions.” These were, “Pākehā death rituals,” “independent learning,” “Pākehā understanding of literacy,” “quantifiable binary,” “using disability support services,” and “progression.” These codes are not a full list of engagement with Pākehā culture. However, excessive repetition of one theme does not contribute meaningfully to reflexive TA.

I also met with my advisor with learning disability, Glen Terry, to talk about my codes and themes (see *Figure 15*). Glen recommended I change the theme “initiating in-person connection” to “getting to know people.” He also asked me to move “role play” from the “encoding” to the “getting to know people” theme, and “telling my story” from “encoding” to the “leadership” theme because, “when you are telling your own story you are stepping up as a leader, you are actually standing up for yourself and other people” (personal communication, October 9, 2022). I cut and repositioned codes from the printed PowerPoint slides we looked at according to his instructions and noted his comments separately.



Figure 15 Consultation with Glen (Photo: N. Newcombe, used with consent).

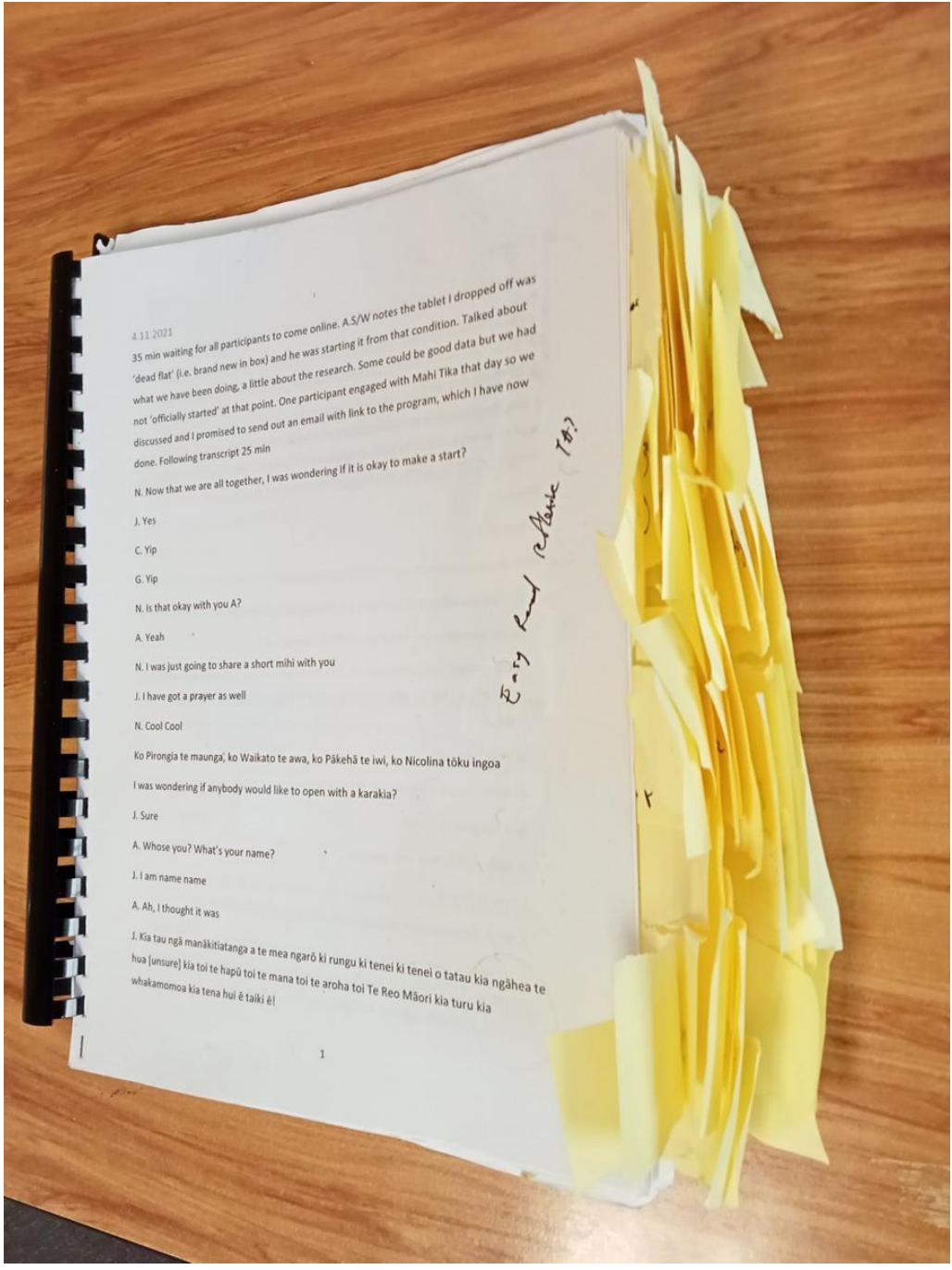


Figure 16 Transcript of research meetings with yellow sticky notes (Photo: N. Newcombe).

Multiple changes to my codes and themes compelled a fresh look at the entire data set. I reread my full transcript and put sticky notes with codes next to excerpts of interest (see *figure 16*). Many of the sticky notes prompted a rechecking of excerpts in my analysis table and I revived several previously deleted excerpts. New excerpts were also identified, but these were mostly thin, with only one or two codes attached to them.

5.8.5 Refining, Defining and Naming Themes

The fifth step in reflexive TA involves refining, defining, and naming themes. I took the suggestion of Braun and Clarke (2022) to pair a brief excerpt from the data with an explanatory subheading. Looking for excerpts gave me another opportunity to review the current stage of categorisation among codes and themes. I realised that the “getting to know people” theme was not cohesive and changed the theme to “making community.” I also broke up the most populated theme, “leadership,” into “being a leader in my own life” and “being a leader with *tāngata* and *whenua*.” The last change I made to my codes and themes before beginning to write up my reflexive TA report was to combine the “community” and “leadership” themes into one theme of “learning disabled cultural literacies.”

While cultural literacy has been discussed in other places (García Ochoa & McDonald, 2020; Hirsch, 1984, 1988; Hirsch et al., 2002; Hodgson & Harris, 2022; Kaufer, 1989; Leach et al., 2010; UNESCO, 2016; Zepke, 2011), my theme of learning disabled cultural literacies is new. Cultural literacies may also form a use of language that has not been listed by Halliday (1973), Smith (1983), or Heath (1986) (see *Section 3.1.4*).

Themes in my reflexive TA:

- “What’s your whakapapa and what iwi you come from”: The Passioners have Māori cultural literacies.
- “Go home and do their homework”: The Passioners have Pākehā cultural literacies.

- “An easier way is to slow it down”: The Passioners have learning disabled cultural literacies.
- “You can say some words and I can put them in the poster”: The Passioners have literacy practices that change ideas and information into lines, patterns, pictures, sounds and movements (encoding).
- “I just watch Shark Week and just listen to what those guys tell me”: The Passioners have literacy practices that change lines, patterns, pictures, sounds and movements into ideas and information (decoding).
- “I make TikToks and watch them”: The Passioners have social media literacy practices.

My reflexive TA report can be found in *Chapter Seven*

5.9 Evaluation Method (An Adapted Wehipeihana Model)

I undertook an evaluation to investigate how inclusive researchers can use a more empowered approach when doing research with people with learning disability and to add rigour to the overall project. I have borrowed from Wehipeihana (2019), who used a developmental evaluation model to empower Indigenous-led evaluation (see *Figure 17*). At one end of the spectrum in her model, non-Indigenous people are in control, which results in negative outcomes. At the other end, Indigenous peoples are in control, which results in positive outcomes. The model uses the plot points “to,” “for,” “with,” “by,” and “as” to illustrate different levels of Indigenous control and their corresponding outcomes, offering a nuanced understanding of the relationship between control and outcomes in the evaluation process.

Inclusive researchers have used similar terms to describe levels of participant and researcher involvement (Milner & Frawley, 2019; Nind, 2014). For Nind (2014), research is inclusive if it is “with,” “by,” or “for” people with learning disability, as long as it is not “on”

them, which was the norm under a medical model of disability. Whereas Milner and Frawley (2019, p. 382) described a trajectory of inclusive research, saying it has been moving “from ‘on’ to ‘with’ to ‘by’” people with learning disability over time. This research acknowledges various compositions of whether inclusive research could be “on,” “for,” “with,” or “by” people with learning disability (Milner & Frawley, 2019; Nind, 2014), as well as other models that have already been used to evaluate inclusive research (French & Swain, 1997; Nind & Vinha, 2012).

I decided to adapt the Wehipeihana (2019) model for this evaluation. First, because Wehipeihana (2019) highlighted the relevance of values in evaluation and Walmsley et al. (2018) also commented that inclusive research is a values-based practice. Second, because I was aware that my advisor with learning disability had used the Wehipeihana (2019) model in one of his roles, to which I anticipated his experience would assist his meaningful contribution. Third, because the work of Wehipeihana (2019) fits within the field of developmental evaluation, which intends “to support innovation *development*” (Patton, 2016, p. 291). Developmental evaluators record and help understand changes and improvements as they occur, with a view to informing further progress (Patton et al., 2016). Developmental evaluation positions this research as a contribution to the unfolding field of inclusive research approaches.

As a non-Indigenous person, I was eager to ensure my use of the Wehipeihana (2019) model was appropriate and culturally sensitive. I approached my Māori cultural advisor to discuss applying this Indigenous method to research with people with learning disability. She expressed approval for my adapted Wehipeihana (2019) model (see *Figure 18*) and said it was, “simple and easy to follow, the simpler we make it, the easier it is to understand” (T. Ryan, personal communication, August 30, 2023). I additionally consulted with Louise Were, Executive Member of Mā te Rae Māori Evaluation Association, who called my approach “a great idea” (personal communication, September 1, 2023). Their responses encouraged me to proceed with using the proposed model.

As previously mentioned, Wehipeihana (2019) defined the plot points in her evaluation model as being “to,” “for,” “with,” “by,” and “as.” For Wehipeihana (2019), evaluation is done “to” Indigenous peoples when it rests on Western worldviews and conducts an evaluation within which Indigenous peoples have no control. Evaluation is done “for” Indigenous peoples when Western worldviews are used and evaluators use paternalistic forms of engagement, such as consultation. Consultation is paternalistic when it assumes a perfunctory or tokenistic role but does not impart any real power to consultants (Wyeth et al., 2010). The “with” category occurs when Indigenous and non-Indigenous peoples collaborate, using both Western and Indigenous worldviews. Evaluation becomes “by” Indigenous peoples when Indigenous peoples are in control of the project and have most of the power. It is only “as” Indigenous peoples when Indigenous worldviews are normed and Indigenous peoples make up most of the group, with non-Indigenous people taking part by invitation only. Baaijens (2011) similarly noted that disabled people need to make up at least half of any total group to avoid conforming to norms presented by non-disabled people.

Wehipeihana (2019) drew the concept of “as” from Durie (2003), who recommended that some actions were unsuitable for outsider involvement and should be dealt with by Māori independently. Wehipeihana et al. (2016) gave an example of “as” Māori, being a Māori project organised and delivered by Māori using total immersion te reo Māori and tikanga in a location of cultural relevance to Māori. While there was no definition of what would be needed for “as” to take effect prior to Wehipeihana et al. (2016), the direction set out by Durie (2003) signalled a turning point towards an “as” Māori approach. In the same way, work that happens now could establish a course for people with learning disability to be doing research “as” people with learning disability in the future.

The concept of “as” (Durie, 2003; Wehipeihana, 2019; Wehipeihana et al., 2016) resonates with the popular disability rights dictum “nothing about us without us” (Charlton, 1998). Pfeifer (2023, title) reported on a change in usage from “nothing about us without us” to “nothing without us,” and Riches et al. (2020, p. 279) concluded there should be, “no

research about us without us.” The dictum remains a demand for self-determination, in which disabled people take responsibility for their own lives and work with people who make decisions that affect them (Pfeifer, 2023). Wehipeihana (2019) made a similar call for *tino rangatiratanga* (self-determination), as was promised in *Te Tiriti o Waitangi*. Conversely, Milner and Frawley (2019) argued that inclusive research can extend an invitation to people with learning disability conducive to their demand for “nothing about us without us,” while maintaining the prerogative of researchers and their institutions to decide which forms of knowledge production will ultimately be used. While Milner and Frawley (2019) observed the status of research conducted within academia, research that occurs “as” people with learning disability would be self-determining and norm their own epistemological values.

I adapted the Wehipeihana (2019) (see *Figure 17*) model to fit this evaluation of my inclusive approach undertaken in this research (see *Figure 18*).

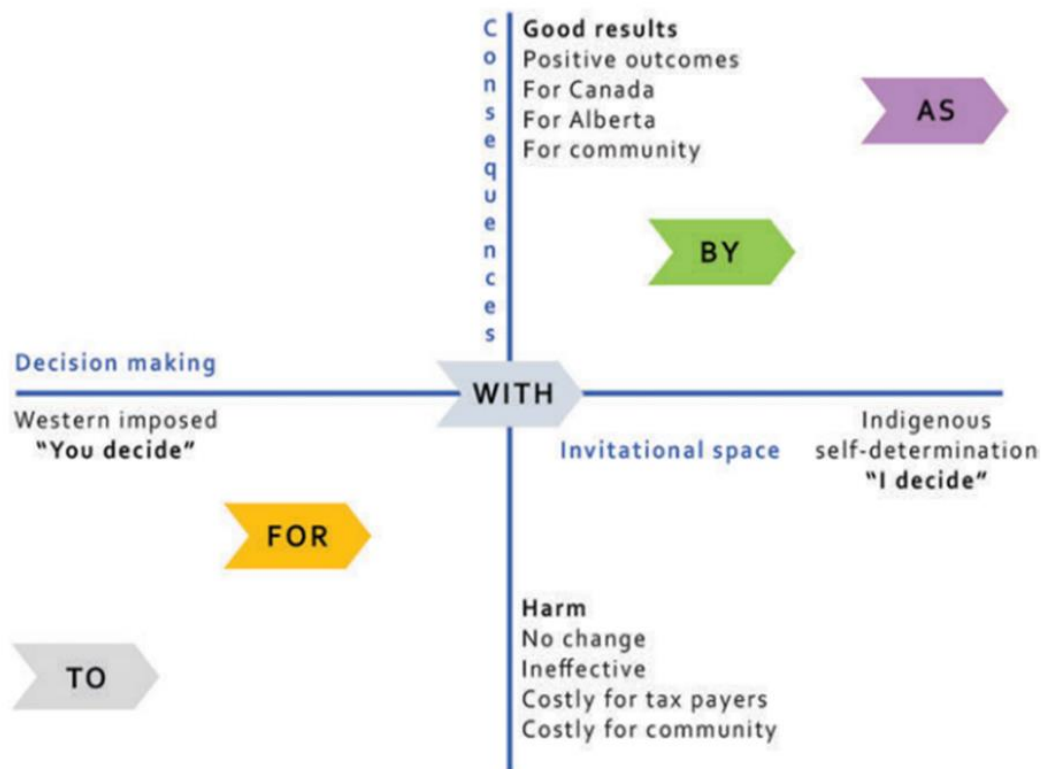
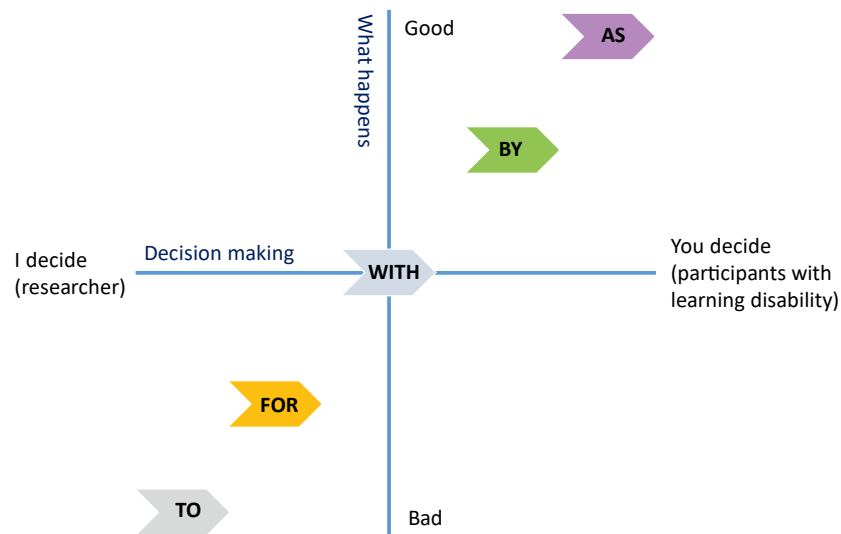


Figure 17 Wehipeihana Model (Wehipeihana, 2019, p. 379).



Adapted from Wehipeihana, 2019, p. 379

Figure 18 Adapted Wehipeihana model

My advisor with learning disability defined the concepts of “to,” “for,” “with,” “by,” and “as” for me as they pertain to inclusive research from his perspective (G. Terry, personal communication, 30 August, 2023). Below is a table of transcripts from our meeting. My own interpretation is situated below each row. I have colour coded the table to correspond with the models in figures 17 and 18 for ease of reference.

Definitions for to, for, with, by, and as	
To people with learning disability	You are presenting your research to the group (Glen).
A researcher without learning disability does research and shows it to people with learning disability (Nicolina).	

For people with learning disability	If you are going to do things for [people with learning disability] that means that you decide because it is your research. It is you decide on how that goes, but they decide what they actually want to learn from you, what they want to tell you (Glen).
A researcher without learning disability does research and people with learning disability decide how they will engage with that research (Nicolina).	
With people with learning disability	Working with [people with learning disability] means you decide for you, and they decide for them, and you are working with them making it easier for everyone. When you are working with each other. I have a learning disability, and I am working with you (Glen).
People with and without learning disability doing research together (Nicolina).	
By people with learning disability	She [Ingrid Jones] came to me with support, with help. The way that she was running her research was running things by me and working with me on deciding what she wants to put in. (Nicolina, how so?) By actually being there, like being beside you. Like deciding, she had her input on deciding what she wants to put in because it is her research. I put my input so it's like that, I am actually involved in the research and actually me actually running the hui (Glen).
People without learning disability get input from people with learning disability before they make decisions about research (Nicolina).	
As people with learning disability	I would definitely get support from those who has done it before me. Like say I would come to you. Just because of the relationship that you and I have. It is on how you know people. If one was doing that research, they would have to go to the people who has done it before them so they can have a little bit of guidance on what to do and how to do it and what to put in and what not to put in. You

	<p>have a disability right? [Nicolina, yeah, but I don't have a learning disability]. That wouldn't matter, I would still come to you. It wouldn't matter whatever disability you have; you are still that one person who has done it before. I would come to you because you have done it, and you are doing it. Even though you don't have a learning disability, I would come to you. Doing things like research is more like you need people to support you in the way you want them to support you. You wouldn't go to people if they didn't know what research is like, and actual real important research is like (Glen).</p>
<p>People with learning disability need support to do research. That support needs to be from people who are experienced in research and are ideally disabled, although they do not need to have learning disability (Nicolina).</p>	

I reviewed the methods used in the present research. Then, I reflected on the ways in which elements of this research might have been “to,” “for,” “with,” “by,” or “as” the Passioners according to the definitions given by my advisor with learning disability. This section will now discuss the ethical considerations in this research.

5.10 Ethics

Inclusive Participatory Action Research with participants with learning disability is complex and mostly uncharted, particularly in the bicultural context of Aotearoa New Zealand. Therefore, it was imperative I seek guidance from advisors with lived experience. Researching with people with learning disability raised the spectre of their potential vulnerability in this research, while I argued that restricting the agency of participants in research is itself disabling and therefore causes participants to become vulnerable. I also

had to navigate potential incongruences between two documents I had committed to follow, the *Ethical Conduct in Human Research and Related Activities Regulations* (Regulations) and the CRPD. These issues are briefly described below and more thoroughly discussed in my article *Reflecting on an Unexpected Challenge in Obtaining Ethical Approval for Research with Adults with Learning Disabilities* (Newcombe, 2022) (see *Appendix L*). This research was approved by HREC (Health) (14 July 2021 HREC(Health)2021#41) (see *Appendix M*).

5.10.1 Advisors

I recruited advisors and began consulting with disabled people early in my candidature to ensure that people directly affected by this research informed the entire project. Consultation began in the second week of my candidature. Initially as a consultant, Glen Terry, a person with learning disability, talked about how his literacy enabled him to work at Gilmores Wholesale Food using a checklist, but restricted him from starting a course in personal training. This confirmed my observation that literacy was a cause of exclusion for adults with learning disability. Consultants with other disabilities were aware of the same phenomenon, such as when Hamilton City Council Access Advisory Group member and Your Way Kia Rohe trustee Vaughan Mikkelson said, “I see people with learning disability get excluded because of literacy all the time” (personal communication, 7 September, 2020). I subsequently began working with Glen as my advisor with learning disability and Te Atakura Ryan as my Māori cultural advisor from the second month of my candidature. I continued working with them until the completion of my PhD. Both advisors contributed valuable insights and supported me in making this research as accessible, trustworthy, and balanced as possible.

This research includes people with learning disability and has a bicultural approach. Therefore, I recruited an advisor with learning disability and a (non-disabled) Māori cultural advisor to undertake this research in a socially and culturally sensitive manner with appropriate consultation.

My advisor with learning disability was Glen Terry. Alongside being the President of the Midland Region People First group, Glen also serves on the Enabling Good Lives Waikato Leadership Group and the Health and Disability Commissioner's Consumer Advisory Group. He has received a Hamilton City Council award for outstanding achievement made by a young Hamiltonian³⁸, a Life Unlimited Award for his significant contribution to the disability sector in the Waikato³⁹, and was an Attitude Leadership Award finalist in 2017⁴⁰. Media attention has also been given to Glen for his pathway to mainstream employment⁴¹.

My Māori cultural advisor was Te Atakura Ryan of Ngāti Porou Te Whānau a Tuwhakairiora. She has extensive experience supporting people with learning disability and is the Kaitakawaenga (cultural advisor) for the largest learning disability service provider in Aotearoa New Zealand, namely IDEA Services. Both advisors are highly experienced and well regarded in their communities.

I met with my advisor with learning disability 11 times and my Māori cultural advisor seven times over the course of my candidature, including before submitting my research proposal, human research ethics application, and before commencing data collection. I showed appreciation to my advisors by bringing them *kai* (food) at every meeting and giving them vouchers in recognition of their overall service. My advisors contributed practical and conceptual advice that led to improvements in this research.

³⁸ <https://www.enablinggoodlives.co.nz/good-life-stories/future-leader-found-within-enabling-good-lives-leadership-group/>

³⁹ <https://www.facebook.com/peoplefirstnz/photos/congratulations-to-people-first-hamilton/231869230335043/>

⁴⁰ <https://www.stuff.co.nz/business/97993308/attitude-awards-finalist-glen-terry-stands-up-for-disabled-community>

⁴¹ <https://www.stuff.co.nz/business/better-business/124001962/a-helping-hand-and-a-shoutout-online-nets-glen-his-first-job>

5.10.2 Participant Vulnerability

The Human Research Ethics Committee (HREC) *Research Ethics Application* asks researchers if their participants are vulnerable. On stating that people with learning disability are not inherently vulnerable (Doody, 2018), further clarity was requested on why participants in this research “may not be viewed as vulnerable” (L. Vuursteen, personal communication, 22 June, 2021), indicating that participant vulnerability was of concern to the committee.

People with learning disability are vulnerable according to the table of vulnerable groups in Bracken-Roche et al. (2017). Furthermore, individual participants could also be identified as economically or educationally vulnerable, vulnerable because they are a woman, or because they have a compromised health status. In contrast, Schroeder and Gefenas (2009) argued that so many groups are considered vulnerable that the concept has become too vague to have meaning. Another perspective is that groups of people are never homogenous, and people ought not to be stereotyped as being vulnerable because of the group they belong to (Banas et al., 2019; Hollomotz, 2013). Hollomotz (2013) added that concentrating on vulnerability in research distracts from the conditions that produce vulnerability, as in, the people and systems that commit wrongs. As I described in Newcombe (2022), the *Regulations* (University of Waikato, 2008, section 9.4.e) have different wording to the CRPD regarding equal recognition before the law and could itself produce participant vulnerability by validating a judgement of incapability to give informed consent thought to be reasonable.

5.10.3 Information Sheet and Consent Form

Prospective participants were given an information sheet and consent form, which I am calling the research booklet (see *Appendix E*). I also uploaded video clips of me reading the document aloud on YouTube in sections, so that participants would have multiple ways to

access it⁴². I also met with prospective participants at least twice and their supporters at least once to explain this research and the consent process in person. Easy read research documents “can contribute to an enhanced understanding of research processes for some people with learning disability” (Newcombe, 2022, p. 30), and using them is one strategy that supports the recruitment and retention of this population (Banas et al., 2019).

The contents of the research booklet are as follows.

Research about Literacy and Adults with Learning Disability	
Heading	Description
Title page	Title and YouTube links to listen to <i>Research about Literacy and Adults with learning disability</i> being read aloud.
Preface page	My name and a description of what research is and why I am doing this research.
<i>If you want to know more about this research</i>	My contact details.
<i>You could take part in this research if you</i>	Eligibility criteria.
<i>In this research we can</i>	Method.
<i>At this research</i>	Information about food, transport, and accessibility.
<i>People who take part in this research might</i>	Research benefits.

⁴² <https://www.youtube.com/watch?v=kh5ZPo9lwvY>; <https://youtu.be/hpY28Vh1nBk>; https://youtu.be/h8DSXG_G02k; https://youtu.be/SklOV_Xpf2I; <https://youtu.be/kZFNy3ly4pE>

<i>Some people know me</i>	A list of disability adjacent places I have worked and a plan for managing pre-existing professional relationships.
<i>Consenting to take part in this research</i>	Information about the different ways to consent to take part in this research.
<i>Consent form</i>	A tick and cross system with large boxes beside each clause, culminating in a final box for a tick or cross to communicate consent to take part in this research.
<i>I would like to take part in this research</i>	A page for signing.
<i>If you want to talk to someone about this research</i>	Contact details for myself, my chief supervisor, and the HREC.

This section will now describe some innovative parts of the research booklet in more detail. After information that would normally be presented in a research information sheet, the next part of the booklet is called *Some People Know Me*. *Some People Know Me* intends to mitigate real or perceived conflicts of interest, reminding prospective participants of their choice to take part or not take part in this research regardless of whether or not I have worked with them in the past.

The next part of the research booklet is called *Consenting to Take Part in this Research*. *Consenting to Take Part in this Research* outlines a process I used to engage in “edgewalking,” a term I borrowed from Stewart-Withers (2016) to describe the compromises required to negotiate consent processes between multiple stakeholders. In this case, the stakeholders were the University of Waikato HREC and prospective

participants and their supporters, who may be well versed in their right to equal recognition before the law. The *Regulations* (University of Waikato, 2008, section 9.4.e) state, “if a prospective participant is reasonably judged incapable of giving informed consent, the researcher must obtain the proxy consent from the person who has responsibility for the prospective participant's welfare.” This clause invoked multiple ethical conundrums about the nature of reasonable judgement, the meaning of proxy consent, and the identification of who has responsibility for participant welfare post Aotearoa New Zealand ratifying the CRPD (Newcombe, 2022).

As explained in Newcombe (2022), this research resolved tensions between the *Regulations* (described above) and the CRPD (United Nations, 2007, Article 5 and Article 12) by providing two options for participant consent. The section *Consenting to Take Part in this Research* in the research booklet explains that prospective participants whose supporters normally sign forms and contracts representing comparable decisions, such as opening a bank account and becoming a tenant, can sign their own consent form, but also need proxy consent from their supporter. Whereas prospective participants who normally act independently in these regards can sign their own consent form, but still need their supporter to agree to support them to take part in this research. Including supporters in the consent process, whether or not prospective participants needed proxy consent to satisfy the *Regulations*, ensured that supporters were fully aware of and committed to the research. This provided an additional safeguard to mitigate potential vulnerability. It also meant that prospective participants who sign their own forms and those for whom supporters sign their forms would engage in similar processes. This bespoke process enabled me to adhere to both the *Regulations* and the CRPD, as stated in my *Research Ethics Application*.

5.10.4 Consent, Assent, and Withdrawal

Consent, assent, and withdrawal processes in this research considered the potential vulnerability of participants. The concept of vulnerability in research recognises that for some people there is, “an identifiably increased likelihood of incurring additional or greater wrong” (Hurst, 2008, p. 191). While people with learning disability have experienced a stark history of research abuses (Doody, 2018; Dowse, 2009; Walmsley & Johnson, 2003), an excessively cautious approach to their vulnerability can continue to harm people with learning disability by stigmatising them and restricting their agency (Banas et al., 2019; Doody, 2018; Douglass & Ballantyne, 2019; Edwards et al., 2004; Hollomotz, 2013). Furthermore, a focus on vulnerability can exclude people with learning disability from sharing in the benefits of research participation, and the wider benefits of research that includes them as participants (Banas et al., 2019; Hollomotz, 2013). This research aimed to mitigate participant vulnerability by using appropriate consent, assent, and withdrawal processes.

Participation in this research was voluntary and required informed consent or proxy consent as per the *Regulations* (University of Waikato, 2008). Assent and withdrawal from participation were also considerations in this research. Informed consent includes the right to withdraw from participation at any time, to withdraw data as agreed, an understanding of how findings will be distributed, an assurance of data security, and ongoing sovereignty over personal information (University of Waikato, 2008). Assent is an expression of preference to participate in research, typically identified in children and other groups deemed too vulnerable to provide informed consent (Bracken-Roche et al., 2017; Cohn, 2018; Hart et al., 2020). While all participants in this research gave informed consent, I continued to observe assent through maintaining awareness of participant verbal and body language at each group workshop session (Banas et al., 2019; Hart et al., 2020), as per my *Research Ethics Application*.

The consent form I made for this research outlined the right of participants to withdraw from the research without needing to provide a justification, and that there will be no consequences for doing so. Sim and Waterfield (2019) identified the perceived social pressure to remain in a group activity until completion as an additional challenge of withdrawal from group research. Thus, I reminded participants it was okay if they or someone else wanted to leave at any time. One participant left our research meetings early on two occasions so they could meet their support worker. I was grateful for this demonstration of the right to withdraw at any time for any reason, as it was likely to solidify for other participants that they were welcome to do the same.

5.11 Benefits of this Research for the Passioners

The Passioners reported benefits of our research meetings including acquiring new knowledge, becoming more confident about their research skills, and experiencing enjoyment. Hōri said, “I have learned something from it,” and “I enjoyed coming here,” Melissa said, “It gets me out of the house,” and AJ said, “doing this course is helpful in a way to me.” AJ asked if I would do another research project with the Passioners and invite more people to take part. I replied by asking AJ if he would need me to facilitate the research or if he would organise the next project. AJ said, “I’m thinking of doing one research, but I’m gonna run that one.” He also said, “You’re inspiring me to do my own research.” I offered my support for his research in the future.

Supporters confirmed the Passioners found our research meetings enjoyable. For example, when I emailed supporters to let them know our research meetings were on hold due to COVID-19 lockdown restrictions, Hōri’s supporter emailed back, “that’s unfortunate as I know people were looking forward to the workshops” (personal communication, 24 August, 2021). David’s supporter said he, “would love to come [back after breaking his arm⁴³] to

⁴³ Details altered for anonymity.

catch up with [Hōri]" (personal communication, 06 December, 2021). The positive impact of our research meetings for the Passioners was substantiated by endorsements from their supporters.

5.12 Conclusion

Walmsley and Johnson (2003, p. 99) note, "there is no doubt that inclusive research takes more time, energy and resources than comparably sized projects which do not aspire to be inclusive." However, it would also be hard to believe it is not also more exciting, interesting, and enjoyable. Conducting the actions reflected in this chapter allowed me to seize the benefits of being someone who is continually involved in disability spaces to do research that highlights the voices of adults with learning disability on the topic of literacy.

One of the best parts of inclusive research is getting real feedback when something is not working. Much of this research was experimental and some of my data collection methods proved to be ineffective. The Passioners were ready to reject parts of the research I had spent a lot of time developing. Using an IPAR methodology meant I could still make changes and try different approaches until we were able to proceed in a way that was more workable for everyone.

6 Chapter Six: Policy Analysis

This chapter seeks to determine what impact the current adult literacy policies have on adults with learning disability with the purpose of using those findings alongside the voices of participants in this research to make policy recommendations. Such policy recommendations are intended to improve the lives of adults with learning disability by valuing them as literate members of the community and promoting their access to adult literacy education on par with others.

The adult literacy policies define what literacy skills are said to be required to participate in society and be productive in the workplace in Aotearoa New Zealand. As previously discussed, these centre on reading and writing that is primarily in the English language. These policies concentrate on a continuum of competence in reading and writing, which privileges people who have certain reading and writing skills as being literate and marginalise people who mainly use other literacy practices. Such marginalisation refers to possible stigma and discrimination, such as the attitudinal barriers to education discussed by Mirfin-Veitch (2003) and anecdotal evidence detailed in *Section 1.1*. Prior research demonstrates that low literacy skills are more likely to affect adults with learning disability (Bochner et al., 2001; Moni et al., 2018; Morgan & Moni, 2008; The Roeher Institute, 1990, 1994; Trenholm & Mirenda, 2006). Yet the boundaries of who is considered literate are constructed and can therefore be reconstructed.

Another function of the adult literacy policies is that they influence educator perceptions about adult literacy learners, enabling anticipation of their backgrounds, characteristics, and learning needs. Assumptions in the adult literacy policies draw on research about and experience of a normed population and may therefore create barriers for adults with learning disability. Analytical awareness of the conventions and practices communicated in the adult literacy policies thus provide the foundation for critical engagement and policy recommendations based on inclusive research with people with learning disability.

6.1 Critical Description of the Current Adult Literacy Policies

The following sections critically describe the current adult literacy policies, focusing on their impact on adults with learning disabilities, with reference to existing literature.

6.1.1 *Learning Progressions for Adult Literacy*

Learning Progressions (TEC, 2008a) is the foundation for the adult literacy curriculum in Aotearoa New Zealand. It offers a framework for educators to improve adult learner competencies in four strands: listening, speaking, reading, and writing in English. Each strand is composed of progressions, progressions comprise an ordered sequence of steps, and steps represent significant developmental transitions through literacy learning. The sequential nature of the progressions aims to divide the work of education into achievable and advancing units (Hunter, 2016).

Competencies form a key framework for how adult literacy skills are understood in Aotearoa New Zealand. *Learning Progressions for Adult Literacy and Numeracy: Background Information* defines competencies as, “the knowledge, the cognitive and practical skills and the attitudes (including motivation) needed to meet demands or carry out tasks successfully” (TEC, 2008b, p. 6). This concept was adapted from the *Definition and Selection of Key Competencies (DeSeCo) Project*, in which competencies draw on multiple resources, such as knowledge, learning, and experiences (OECD, 2005).

The *Learning Progressions* begin from a base of prerequisite literacy skills that include the ability to identify and form letters of the alphabet and encode and decode basic English words, such as “cat” and “dog.” *Starting Points* is the applicable policy for learners who are working towards prerequisite literacy skills.

6.1.2 *Starting Points: Supporting the Learning Progressions for Adult Literacy*

Starting Points (TEC, 2008d) guides the provision of education for prerequisite literacy skills in reading and writing. Underpinning *Starting Points* is the principle of meeting the needs of adult learners who are impacted by disadvantage. The policy makes use of the transformative ideology of Paulo Freire, the cultural capital theory of Pierre Bourdieu, and the scaffolding framework of Lev Vygotsky to this effect. However, these ideals can be difficult to achieve within the educator-led nature of TEC funded adult literacy education (Benseman, 2008), as Freire (1970) understood traditional education to be a key factor in perpetuating oppression and inequality.

Starting Points contains seven case studies comprising fictional stories about learners from refugee or immigrant backgrounds, or those who experienced low school attendance, presumably in Aotearoa New Zealand. There is no mention of learners with learning disability in the policy. Disabled learners are mentioned more generally where it is said that this group “may require specialist resources or programmes” (TEC, 2008d, p. 9). It is unclear what specialist resources or programmes are available (see *Section 6.1.2*).

Starting Points has several key differences from *Learning Progressions*. The *Learning Progressions* refer to the literacy demands associated with work and education, whereas *Starting Points* draw on the literacy demands people may face in their everyday life, such as making a shopping list. *Starting Points* divides progressions into precursor skills that are “closely interdependent,” rather than sequential as in the *Learning Progressions* (TEC, 2008d, p. 3). Just as the *Learning Progressions* informs the curriculum assessed by the LNAAT, *Starting Points* informs the curriculum assessed by the SPAT, which is outlined in the *Starting Points: Assessment Guide*.

6.1.3 *Starting Points: Assessment Guide*

The *Starting Points: Assessment Guide* (TEC, 2010b) instructs educators on how to deliver the SPAT, a quantitative multi-choice assessment for learners who do not have the prerequisite skills needed to attempt the LNAAT (see *Section 4.5*). It also guides educators on developing learner profiles and individualised progress reports. The policy encourages the use of a literacy attitude survey for learners⁴⁴ (the survey can be found on p. 14 of TEC, 2008e). It also recognises that some learners may not be able to access the survey without support. Some learners may also require reasonable accommodations to complete the SPAT due to the absence of accessible format options beyond the standard online and paper-based tests.

The *Guidelines* say the SPAT is said to be suitable for “ESOL and non-ESOL learners,” but no policy attention has been given to the viability of this test for adults with learning disability (TEC, 2023d, p. 14). Encouragingly, a promotional video demonstrating delivery of the online SPAT features a learner who appears to have Down syndrome (NZ Assessment Tool, 2019), indicating the inclusion of adults with learning disability as part of their intended learner population.

6.1.4 *Guidelines for Using the Literacy and Numeracy for Adults Assessment Tool 2023*

The *Guidelines* instruct educators on how to deliver the LNAAT, a quantitative multi-choice assessment that aligns with competencies outlined in the *Learning Progressions* (see *Section 4.5*) (TEC, 2023d). The LNAAT is intended to identify the literacy and numeracy skills of learners, provide an overall score aggregated from the progressions, and support educators to tailor education to their needs (TEC, 2023d). It also contributes information for funding

⁴⁴ The survey addresses the frequency and nature of reading materials learners’ access, a self-assessment of their proficiency and confidence, and their current strategies and aspirations.

and educational purposes, as well as organisational and national data sets, including to “identify where progress is being made due to the nationally consistent measures of learner skill level and gain” (TEC, 2023d, p. 4). Anonymised LNAAT data can also be used for research purposes (New Zealand Council for Educational Research, 2018d).

The LNAAT is not intended to be used as screening devices to restrict learners and employees from accessing education or work (TEC, 2023d). However, it forms part of the eligibility criteria for all foundation funds (except ACE) (TEC, 2023e), which includes all funds likely to be accessed for adults with learning disability. Use of the LNAAT for progress reporting is now expected and recommended, but no longer mandatory, for TEC funded adult literacy education (TEC, 2023e).

There are several limitations affecting the LNAAT. It only assesses reading and vocabulary or reading and writing, meaning that other literacy practices, including speaking and listening and other forms of literacy are not assessed. The *Guidelines* also recognise the challenge of assessing embedded literacy learning using the LNAAT, as embedded literacy learning tends to be more discipline-specific than the LNAAT accommodates. These limitations may have contributed to the reasons why alternative progress assessments are now recognised in place of the LNAAT where appropriate.

No accessible format options exist in either the non-adaptive or adaptive LNAAT, for example, for people with dexterity or vision impairments. Those learners may require reasonable accommodations to help them complete their test (TEC, 2023d). The *Guidelines* acknowledge that some learners may struggle with the digital skills required to access the LNAAT online. Given the significant digital divide affecting adults with learning disability (Access Advisors, 2021; Digital Government, 2021a; Digital Inclusion Research Group, 2017; Grimes & White, 2019) (see *Section 5.7.3.1*), the paper version of the LNAAT could be easier to access for some people in that group.

The LNAAT has three versions: the *Adult* “default” version (TEC, 2017a, p. 6; 2023d, p. 13), the *Youth* version, which contains more references to everyday life (New Zealand Council for

Educational Research, 2018c), and *Te Ata Hāpara*, which is written and illustrated to be more culturally relevant for Māori (Emery & Kākahi Consulting, 2017). Although, the statement that *Te Ata Hāpara* “can be used with any learners” (TEC, 2017, p. 6) has been removed from the 2023 *Guidelines*. In describing the *Adult* version of the LNAAT as the default version, the TEC imply that the level of English reading and writing skills required to use the *Adult* version of the LNAAT is a normed expectation for adults. Having one version of the LNAAT called *Adult* and another version called *Youth* may be intended to differentiate the versions. However, people with learning disability are often infantilised (Robey et al., 2006). Therefore, this terminology may be perceived as derogatory towards them if they are unable to access the *Adult* version of the LNAAT because it is too difficult and may imply that their literacy practices are considered to be underdeveloped and therefore inferior.

6.1.5 2023 Funding Conditions Catalogue

The 2023 *Catalogue* invites employers and tertiary education organisations to apply for funding to improve adult literacy skills for learners in Aotearoa New Zealand (TEC, 2023a). All foundation funds are intended to benefit learners who have either or both of low literacy and numeracy skills. The 2023 *Catalogue* prioritises learner success in the form of achieving tertiary and career goals that deliver good outcomes, with a focus on Māori, Pacifica, disabled and other underserved learners. Programmes are still expected to be “value for money” (TEC, 2023a, pp. 55, 68, 92) and TEC decision-making authority continues to be reinforced, such as via the phrase “as determined by us” (TEC, 2023a, pp. 52, 55, 65, 68, 88, 92, 97, 136, 177). All funds are subject to base funding conditions, such as an investment plan.

A summary of relevant funds demonstrates the targeting and limitations of TEC-funded adult literacy education. The ACE fund pays for courses that improve learner employability and promote second-chance educational participation, foundational literacy, numeracy and digital literacy skills, and health and wellbeing. The Workplace Literacy and Numeracy fund

has two streams, employer led, and tertiary education organisation led, and seeks to improve literacy and numeracy opportunities for people in low-skilled employment. The Intensive Literacy and Numeracy (ILN) fund provides up to 300 hours of free literacy and numeracy education per year in a tertiary education organisation setting but is restricted compared with people who meet the eligibility criteria for the Workplace Literacy and Numeracy fund (i.e. they are assessed as having low literacy skills and are in work). People who are not employed and seek to develop their literacy skills beyond Step 2 on the learning progressions have the options to use *Pathways Awarua*, a set of free online courses with self-paced modules (TEC, n.d-b), informal learning opportunities such as evening or weekend courses through ACE (ACE Aotearoa, 2023), or enrol in other tertiary education.

In terms of tertiary education, the Delivery + Qualification (DQ) at Levels 1 and 2⁴⁵ fund is meant to “promote progression to higher-level study and skilled employment” (TEC, 2023a, p. 31). All foundation level education, such as DQ 1- 2, includes a literacy component (TEC, 2023a). The DQ 1-2 fund and the ACE fund are the only funds that can be used for courses in te reo Māori. The DQ 1-2 fund also provides access to the Special Supplementary Grant (SSG), which pays for additional support for disabled learners.

SSG (TEC, 2023a) funding is available for learners described as having special needs (TEC, 2017b) or being resource-intensive learners with special needs (TEC, 2023h) accessing the Te Pūkenga network of eight institutes of technology⁴⁶. The TEC (2023a, p. 45) stipulates, “the purpose of the SSG Funding is to provide additional tutorial support for learners with special needs.” While the majority of SSG funding has been spent on specialised and dedicated tutors that were engaged in addition to existing teaching staff, it was also used for support with independent travel by three providers in 2022 (TEC, 2023h), which is an increase of one provider from 2020 and 2021 (TEC, 2022b). This is significant because it sets

⁴⁵ Previously Student Achievement Component 1&2

⁴⁶ I.e. not incorporated societies, charitable trusts, or private training enterprises, Wānanga, or universities, excluding such literacy providers such as Literacy Aotearoa.

a precedent for using SSG funding to meet a wider range of reasonable accommodations than are described in the *2023 Catalogue*.

The Equity Fund for Disabled Learners (TEC, 2023a) contributes to the cost of additional supports required by any disabled learner to improve their tertiary opportunities and outcomes within Tertiary Education Institutions (TEC, 2023c). *Tertiary Education Institutions* are those tertiary education organisations within which the Government has an ownership interest, these are Universities, Te Pūkenga and *Wānanga* (tertiary institution that caters for Māori learning needs)⁴⁷ (TEC, n.d-a). Organisations noted in their 2022 reporting on their use of this Equity Fund that they continued to have an “inability to provide learners identified as having an intellectual disability regular in-class support” (TEC, 2022a, p. 7). However, the most recent disability statistics held by Stats NZ (see *Appendix G*) indicate that adults with learning disability may be less likely to be working towards qualifications that would render them eligible for the SSG and Equity funds.

Stats NZ confirm (see *Appendix G*) that people with learning disability represents 7.94 percent of disabled adults aged 15 years old or older. Within a sample of 59,000 adults with learning disability aged 15 years old or older, 16 percent report themselves as having a post-school qualification (relative sampling error of more than 30 percent and less than 50 percent), although the qualification is not specified as being aligned to the NZQCF. Six percent report themselves as having a bachelor’s degree or higher qualification (relative sampling error of more than 50 percent). Meaning the best information available suggests adults with learning disability may be somewhat excluded from additional support that is available to other disabled adult learners who are, as a total group, almost twice as likely to hold a tertiary qualification (31.5%) (Stats NZ, 2014).

The *2023 Catalogue* also has other funds for groups that are not the focus of this research, or that apportion higher rates of funding to eligible learners in selected qualifications.

⁴⁷ I.e. not incorporated societies, charitable trusts, or private training enterprises.

6.2 Findings

The findings from this TA are described according to five themes, “what literacy is,” “who is literate,” “why literacy is important,” “about adult learners,” and “how to teach literacy to adults.”

6.2.1 *What Literacy is*

The adult literacy policies describe literacy as reading, writing, listening, and speaking skills in English but also includes an understanding of design features and readable print in the environment. While some examples in the *Learning Progressions* include commonly used te reo Māori words, such as *marae* (courtyard), *kiwi* (flightless, nocturnal, endemic birds), and *tangi* (funeral), it is noted that, “the progressions show the development of expertise in listening, speaking, reading and writing in New Zealand English” (TEC, 2008a, p. 4).

Incorporating te reo Māori in the adult literacy policies could benefit adults with learning disability, who are more likely to be Māori (Stats NZ, 2014).

Visual language features are part of the adult literacy policies, albeit in a minor capacity. These are environmental print, for example billboards, signs, and labels (TEC, 2008d); symbols, images that communicate a concept, for example a skull and crossbones; and design, “such as headings, illustrations, diagrams or tables” (TEC, 2008a, p. 37). However, there is no mention of NZSL in the adult literacy policies, even though it became an official language in 2006.

The idea of literacy as a skill is now “ubiquitous” throughout the TEC and in wider public discourse (Hunter, 2016, p. 230). The LNAAT is described as “a way of identifying skills” (TEC, 2023d, p. 6). Reading, writing, speaking, and listening are said to be macro skills that are made up of sub skills. Some sub skills, such as reading from left to right, are regarded as essential, and other sub skills, such as neat handwriting, are regarded as non-essential.

However, as technology advances and digital communication becomes more prevalent, emphasis on certain skills may evolve, for example, the need for neat handwriting has somewhat diminished, making way for a greater concentration on keyboarding skills. As such, assumptions made by the TEC regarding a hierarchy of skills, their interdependencies, and perceived importance as essential or non-essential may not adequately respond to variations across cultures, including disability cultures, and changes that occur over time. Furthermore, some learners with learning disability use AAC or other assistive technology, which may fundamentally change their relationship to the skills discussed in the adult literacy policies (see *Section 3.2.3.4*).

6.2.2 Who is Literate?

The adult literacy policies describe who is literate in terms of their skills in reading and writing. This is called a “continuum of competence” and ranges from beginner to expert (TEC, 2008c, p. 7). The TEC defines low literacy skills for the purposes of accessing ILN as being assessed at, “Step 1 or 2 on the Learning Progressions for reading and/or numeracy” (TEC, 2023a, p. 65). For those accessing Workplace Literacy and Numeracy, having low literacy skills means being assessed at “Step 3 or below on the Learning Progressions for reading” (TEC, 2023a, p. 52). The settings for low literacy skills described above are both below the *literacy threshold*, which is currently set at “Step 4 or above for reading” (TEC, 2023d, p. 12). Again, the definition of who is literate used in the adult literacy policies is contingent on results from the LNAAT, which only assesses reading and vocabulary or reading and writing in English and excludes other literacy practices. These conceptions of literacy and low literacy are likely to influence educator attitudes.

Terms used to describe people with different literacy skills have changed over the 2008 to 2023 period, from the first to the last adult literacy policy analysed in this TA. Prior to the current adult literacy policies, *More than Words* characterised some people as being

“‘below the bar’ of literacy adequacy” (Ministry of Education, 2001, p. 5). In terms of current adult literacy policies, *Starting Points* calls people “non-readers or poor readers,” with the word “poor” also used to describe “poorly developed phonemic awareness,” “poor handwriting,” and “poorer comprehension levels” (TEC, 2008d, pp. 19, 30, 36). Although later policies went on to adopt language that is more neutral and contextualised. For example, “literacy or numeracy skills below the level deemed necessary to understand and use information contained in the texts and tasks that characterise our emerging knowledge society and information economy” (TEC, 2012, p. 6). Subsequent adult literacy policies have used the terms “low” or “very low” literacy skills (TEC, 2023d).

From a social constructionist point of view (see *Section 5.3*), language is important as the words we use create perceptions of the world (Burr, 2015). Terms clustering around low literacy skills have historically been associated with negative social discourses such as poverty and crime (Benseman, 2008; Hunter, 2016). Even the term “low” literacy could preserve a false binary regarding literacy, which is now understood by many to be a continuum (Benseman, 2008).

As Benseman (2008, p. 9) said about foundation learning in Aotearoa New Zealand, “the labels we use matter.” Importantly, the labels used for people with different literacy skills can further marginalise people with learning disability. Terms for low literacy are often experienced as stigmatising, which affects the “self-esteem, motivation for learning, expectations of achieving, and actual achievement” of literacy learners (Solinski, 2010, p. 5). This phenomenon is especially problematic for people with learning disability who already experience stigmatising language because of their disability (Jarrett & Tilley, 2022; Sinason, 2010).

6.2.3 Why Literacy is Important

The adult literacy policies underscore the importance of literacy in various aspects of life, including to participate in the community and contribute to workplace productivity. Literacy is said to be “crucial” (TEC, 2008a, p. 2) and “required” (TEC, 2023d, p. 4) for living and learning. Examples of where the TEC claim reading and writing skills are needed includes, “housing, health, employment, welfare and education services; marae, church, mosque and other community organisations; and the banking and justice systems” (TEC, 2008d, p. 48). In this way, the adult literacy policies maintain the status quo that societal contexts will continue to use literacy that is outside the skill level of many people. Whereas People First New Zealand (2018) countered that notion, saying essential information should be readable for as many people as possible, rather than presented in ways that require increased skills to understand. The Roeher Institute (1994) identified that adults with learning disability may have literacy demands that include reading to children, reading for navigation, such as street signs and bus timetables, reading to identify items, particularly to ascertain the difference between similar products, and writing on forms.

The *Learning Progressions* position literacy as the missing link between a person and participation in society, saying “adults who have not yet developed this expertise [in listening, speaking, reading and writing] will find it difficult to fully participate” (TEC, 2008a, p. 4). This statement assumes the exclusion of many adults with learning disability who may not achieve in the learning progressions set out by the TEC. Put another way, the statement could read as if the only adults who can fully participate in society are those who have listening, speaking, reading, and writing skills above the literacy threshold. Payne (2006, p. 228) discusses the norming of reading and writing skills for adults when he describes how they are positioned as requisite to be “a *concerned* citizen, a *responsible* member of a community, and a *useful* employee.” This assertion mirrors the sentiment expressed in the TEC statement above.

The *2023 Catalogue* specifically connect literacy to workplace productivity by saying adult literacy funds, “contribute to workplace productivity through the provision and evaluation of literacy and numeracy learning” (TEC, 2023a, pp. 51, 87). Unfortunately, adults with learning disability may not share in the same benefits of employment as those without learning disability. In 2013, 36.01 percent of adults with learning disability in Aotearoa New Zealand were employed (van der Westhuizen & Pacheco, 2016), compared with 63.8 percent of all adults in the same year (Stats NZ, 2023). The adult literacy policy focus on employment may have the effect of marginalising many adults with learning disability.

6.2.4 About Adult Literacy Learners

The adult literacy policies tell three stories that construct ideas about adult literacy learners. The first is about what might have happened in the lives of learners that would result in them choosing to or being required to access TEC funded adult literacy education, which I have coded as “what happens before people get to us.” The second is about the characteristics and roles of “most adult literacy learners,” which does not always include adults with learning disability. The third is about adult literacy learners whom the adult literacy policies categorise as being outside of the group of most adult literacy learners, which I have coded as “outliers.”

6.2.4.1 What Happens Before People get to us?

Starting Points uses fictional case studies that intend to give educators insight into the background of adult learners for whom this will be the relevant policy. The case studies categorise adult literacy learners into two groups. The first is people who did not learn to read as a child due to school absence or lack of parental input. For example, “reading was not a regular activity at home” (TEC, 2008d, p. 25). The second is people who are refugees

or migrants. For example, “Mei Ling has recently arrived in New Zealand from China” (TEC, 2008d, p. 37). The case studies in *Starting Points* do not adequately represent the experiences of adults with learning disability.

As discussed in *Appendix F*, issues affecting school-based literacy learning for children with learning disability are more nuanced than whether they regularly attended school. Children with learning disability in Aotearoa New Zealand are more likely to face exclusion at or from school (IHC, 2022; Mhuru, 2020), rather than familial based reasons for low attendance. When attending school, Aotearoa New Zealand children with learning disability could have been dismissed as incapable of accessing literacy education congruent with their strengths and skills (McIlroy, 2017), or placed in a school setting that was either too specialised (McMenamin, 2014) or did not meet their needs for accessibility and inclusion (Nel, n.d). International research reports that children with learning disability often receive restricted literacy education at school compared to their non-disabled peers (Bochner et al., 2001; Copeland et al., 2016; Foley et al., 2013; Moni et al., 2018). Excessive school absences and completing school without qualifications are factors for children with and without learning disabilities. However, the notion that schooling may not have provided adequate or accessible literacy education is missing from the case studies in *Starting Points*.

The case studies presented in *Starting Points* locate the problem of low literacy skills within the experiences of adult learners. In using stories that represent what appear to be non-disabled learners, they obscure experiences that may be unique to adults with learning disability. For example, that neurological differences could have resulted in difficulty assessing the literacy competencies of adults with learning disability (Fabio et al., 2023; Morgan et al., 2011), or that assessed literacy competencies were acquired in isolation instead of following the more typical linear distribution of skills (Moni et al., 2018; Morgan et al., 2006).

6.2.4.2 Most Adult Literacy Learners

The adult literacy policies contain numerous generalisations about most adult literacy learners, which are based on research that does not include adults with learning disability. While there is a recurring sentiment that every learner is different, the policies frequently refer to “most” people, for example, “most people acquire” and “most people begin interacting with print at an early age and on a constant basis” (TEC, 2008d, pp. 19, 27). In making assertions about the literacy development of “most” adults, those who take different steps to literacy competency are discounted from the adult literacy policies.

The adult literacy policies also discuss adults as having certain independence capacities. For example, “adults are self-directed learners and are capable of independent learning” (TEC, 2008d, p. 10), and “adults become aware of their own thinking and learning processes as they become increasingly independent thinkers and learners” (TEC, 2008a, p. 29). As described in *Section 2.2.1*, independence is a key tenet of ableism that has been relentlessly targeted at adults with learning disability. While ideas about adults conveyed in the adult literacy policies may be purposed to instil confidence about adult learner potential, a focus on independence may not be appropriate for some adults with learning disability.

The adult literacy policies do advocate providing a level of support for learners in some circumstances. For example, *Starting Points* suggests that educators, “write them for the learner if they are unable to write independently” (TEC, 2008d, p. 37). Disabled learners and learners with specific learning disabilities such as dyslexia or dyscalculia can access support that includes a reader-writer if they are taking part in a qualification on the New Zealand Qualifications and Credentials Framework (NZQCF) (TEC, 2023d).

Starting Points describes learners as having a range of social roles. These are, “parent; caregiver; employee; beneficiary; inmate; business leader; employer; student; member of community organisation; member of a whānau, hapū and iwi; member of a religious organisation” (TEC, 2008d, p. 48). The list bypasses other social roles that may be occupied

by adults with learning disability. A more inclusive list could add friend, volunteer, and self-advocate to the roles listed above. It is notable that successive adult literacy strategies have focused on priority areas other than adults with learning disability⁴⁸ (TEC, 2012, 2015).

6.2.4.3 Outliers

In contrast to most adult literacy learners, the TEC constructs other adult literacy learners as outliers. The term *outlier* refers to data points that are significantly different from the rest of the data set. I use this term to make a critical observation about how the TEC appears to categorise one group of learners as most adults, and another two groups of learners as exceptional cases. The two groups are Deaf and disabled people and adults who develop non-standard literacy strategies.

The adult literacy policies advocate for the first group of outliers, Deaf and disabled people, to have “specialist resources or programmes” and “specialist assistance” (TEC, 2008d, p. 8). These references are vague and may have the effect of enabling adult literacy education providers to exclude adults with learning disability from their programmes if they do not consider themselves to provide specialist resources, programmes, or assistance. In my research, I found there was confusion around what organisations were responsible for providing those specialised resources, programmes, and assistance.

According to customer service at the TEC, specialist resources, programmes, or assistance should be found on the Ako Aotearoa website⁴⁹, an organisation that supports educators in tertiary education environments (Y. Eden, personal communication, 13 July, 2023). Three examples of specialist programmes were:

⁴⁸ Māori, Pasifika, younger learners, adults who are new to Aotearoa New Zealand, and adults with specific learning disabilities.

⁴⁹ <https://ako.ac.nz/>

- *Work Active: Supporting the “forgotten learners” in Their Journey to Work*⁵⁰ (Grant et al., 2019);
- *The ABC for Inclusive Tertiary art Education* about The Learning Connexion (Baaijens, 2011); and
- *The Supported Training Programme: Supporting Learners with Intellectual Disabilities* about supported learning at the Nelson Marlborough Institute of Technology (Carson, 2008).

However, Manako⁵¹ Programme Manager at Ako Aotearoa, Annette van Lamoen disagreed, saying that specialist resources, programmes, and assistance are “provided by disability and ILN providers” (personal communication, 18 July, 2023). Yet the TEC Chief Executive claimed that ILN is not “specifically designed” for adults with learning disability, rather “specific programmes” are provided by Te Pūkenga (see *Appendix A*, p. 2). Finally, *Section 1.1* of this thesis explained that courses at Te Pūkenga have been found to exert restrictive criteria that exclude many adults with learning disability. Thus, following the constructing of Deaf and disabled people as outliers in the adult literacy policies, organisations that may have been expected to provide specialist resources, programmes, or assistance seemingly redirect that expectation to subsequent entities.

The second group of outliers in the adult literacy policies are adults who develop literacy strategies outside of those described in the learning progressions. The *Learning Progressions* frequently discusses standard literacy strategies, for example, “writers use strategies within a writing process” (TEC, 2008a, p. 26). Yet literacy strategies are also discussed in other terms, for example, “he has developed some sophisticated compensation and avoidance strategies when called on to read,” and “adults develop strategies to survive in a literate world” (TEC, 2008d, pp. 24, 33). The dichotomy of describing strategies in reference to both high and low constructions of reading and writing skills is an inadvertent recognition of the

⁵⁰ Note that this programme is no longer operating (info@skillwise.org.nz, personal communication, 20 June, 2023).

⁵¹ Formerly Adult Literacy, Numeracy and Cultural Capability

unique skills and knowledge possessed by adults whom the TEC deems to have low literacy skills.

6.2.5 How to Teach Literacy to Adults

The adult literacy policies use a limited andragogy that assumes a universal development of literacy skills and has a progressive and systematic structure. They contain frequent assertions that learners must possess prerequisite skills prior to advancing toward subsequent skills. For example, “before they can start to work with print, learners need to be able to hear the sounds in spoken words” (TEC, 2008d, p. 18), and “basic reading skills and strategies, including comprehension strategies, are needed before the reader is in a position to apply a more critical eye to a text” (TEC, 2008a, p. 42). Treating learners as universal, such as by saying, “learners of all ages take the same steps through phonemic awareness towards reading” (TEC, 2008d, p. 19) is problematic for adults with learning disability. For example, neither of the references for the statement about phonemic awareness included adults with learning disability. One was about “smart people [who] can’t read [i.e., they have a specific learning difficulty]” (Shaywitz, 2003, contents), and the other was a Turkish study about reading Turkish script with participants who were specifically identified as not being learning disabled (Durgunoglu & Oney, 2002).

Copeland and Zagona (2022) point out that research about adult literacy learning does not typically include participants with learning disability. However, there was research available on this topic that included participants with learning disability in 2008 when *Starting Points* and *Learning Progressions* were published (Cohen et al., 2006; de la Iglesia et al., 2005; Gallaher et al., 2002; Gordon Pershey & Gilbert, 2002; Jones et al., 2007; Morgan et al., 2004; Stromer et al., 1996; van den Bos et al., 2007). Since 2008, further research about literacy learning for adults with learning disability has been published that could have been used and could now be used in future adult literacy policies (Copeland & Zagona, 2022;

Evans, 2021; Hua, Hendrickson, et al., 2012; Hua, Therrien, et al., 2012; Hua et al., 2013; Lettington & Van Herwegen, 2024; Lynch, 2013; Moni et al., 2018).

As Hunter (2016, p. 224) identified in her analysis of adult literacy policies in Aotearoa New Zealand, the role of adult literacy educators is “narrowly circumscribed.” Furthermore, the adult literacy policies promote norms for teaching literacy in a bid to achieve consistent results. These norms are communicated through words such as accepted, conventions, and correct, for example, “model the accepted way of forming the letter,” and “check for the correct pen position” (TEC, 2008d, p. 31). However, adults with learning disability may not follow a conventional path to reading and writing skills (Morgan et al., 2006). The adult literacy policies fail to recognise that best practice can also be established through practical experience and relationships.

Inclusive literacy researchers Morgan et al. (2006) found that adults with learning disability do not learn in a linear way. Rather than the metaphor of a staircase as in the *Learning Progressions*, they can have a learning style that is like a “jigsaw puzzle,” where each learner has a different number of pieces distributed differently across their board (Morgan et al., 2006, p. 55). Downing et al. (2015) also found that people with learning disability are likely to have receptive literacy skills that are further developed than their expressive literacy skills. Thus, it may benefit learners with learning disability if future adult literacy policies adopted a more learner centred and responsive approach to teaching reading, writing, listening, and speaking.

6.3 Conclusion

Conducting a TA on the current adult literacy policies has given me greater insight into how the TEC constructs literacy competencies within the narrow range of reading and writing, and adult learners in terms of what most people are like. This TA has highlighted assumptions implicit in the adult literacy policies as a distinct perspective, to which inclusive

research with adults with learning disability can provide an alternative perspective to form the basis of recommendations.

7 Chapter Seven: The Literacy Practices and Perspectives of the Passioners

This chapter seeks to understand the literacy practices and perspectives of adults with learning disability in Aotearoa New Zealand using a reflexive thematic analysis (TA) of data collected from the Passioners. The research meetings are first outlined, then findings are discussed. The purpose of the research meetings was to ascertain the literacy practices and perspectives of participants. A key aspect of my findings from this process revolves around my construction of learning disability cultural literacy. Māori and Pākehā cultural literacies are also explored. Next, the themes of encoding and decoding and social media are discussed, with social media presenting new literacy challenges and opportunities for the Passioners and other people with learning disability.

7.1.1 *The First Three Research Meetings (Zoom)*

The research meetings were intended to be friendly, flexible, and informal, with the Passioners determining most of the content and approach. Participants knew this research was about literacy because of the easy read information I gave them during our home visits. Ways to make this research more meaningful for participants, as well as key concepts and examples of literacy, were discussed in the first three research meetings. Our first research meetings were scheduled to begin in person in late 2021 but plans were interrupted by Aotearoa New Zealand going into COVID-19 lockdown.

Only two out of five participants were ready to participate in research on Zoom without additional support. Barriers experienced by the other three participants included lack of a suitable device, lack of internet connection, and Zoom being difficult to use. The stories of participants in this research are indicative of broader digital exclusion trends for disabled people in Aotearoa New Zealand (Access Advisors, 2021; Digital Government, 2021a, 2021b; Digital Inclusion Research Group, 2017; Grimes & White, 2019) (see *Section 5.7.3.1*).

Melissa did not participate in research meetings on Zoom. She did not own a device with which to access the internet and I did not supply her with one because her supporter disclosed that her family are gang affiliated, saying “that device will be gone in a day” (personal communication, 27 August, 2021). An offer was made to Melissa wherein her supporter would look after the device and meet up with her for the duration of our research meetings so she could use it. However, Melissa declined support during COVID-19 lockdown, and was therefore unable to participate online.

Hōri had an internet connection at home, but his older model desktop computer lacked a camera, microphone, and speakers. I purchased these items for him and went to his house to plug in the new hardware, install Zoom, and show him and his supporter how to use them. While I had shown them once, Zoom was new to Hōri and his supporter, so another supporter worked with them to get it going at the start of the first research meeting. Hōri retained his new hardware and has reported continuing to use Zoom to talk to whānau with support.

David did not have independent access to the internet. He lacked an internet connection at home and a device with which to use it. Furthermore, public libraries, being his usual place to access the internet, were closed because of COVID-19. Connectivity proved to be the most difficult aspect of enabling David to take part in research on Zoom. *Skinny Jump*, a prepaid broadband for eligible New Zealanders at risk of digital exclusion, was not available in his area, and all other broadband services required an expensive new modem or commitment to an annual plan. I purchased a tablet for David and his supporter agreed to hotspot data from his cell phone, which resulted in a poor-quality connection. David only participated in one group workshop session on Zoom and returned his tablet to me, as he claimed to have no use for it⁵².

As demonstrated by Melissa, Hōri, and David, people with learning disability frequently experience digital exclusion. Disabled people experience digital exclusion at the second

⁵² The tablet was then donated to People First.

highest rate in Aotearoa New Zealand, after people living in Kāinga Ora (public housing landlord) housing (Grimes & White, 2019). The Digital Inclusion Research Group (2017) identified challenges to digital inclusion that may be of concern to disabled people. For example, it may be difficult to find devices that integrate digital tools used by disabled people, devices may not have accessible design features, or people working in technical support may not be approachable. Disabled people also identified the cost of digital technology, given their disproportionately low incomes, a lack of opportunities for learning digital skills, and frequent housing changes as key barriers to digital inclusion for them (Access Advisors, 2021; Digital Government, 2021a). Digital exclusion is detrimental to equity in research participation for disabled people and needs to be addressed.

A timeline of the impacts of COVID-19 on research meetings at different levels of restrictions are as follows. The first three research meetings occurred during COVID-19 Alert Level Three, which necessitated meeting online. One member reiterated his enthusiasm to meet in person as a group saying,

Why don't all of us and you meet up and have a coffee out somewhere or a cup of tea and go around with our group and go out and have a chat and talk and that way everyone will get to come up with some issues and ideas (Hōri).

As this was not possible under restrictions at the time, I suggested that participants might choose to share their contact details so they could contact each other outside of this research. We discussed different ways to contact each other. Participants agreed to me sending out an email to share email addresses among those attending our research meetings online.

I told participants they were the leaders in this research and listened to what they wanted to do in this research. Their ideas included teaching and learning about literacy, talking about experiences, and gaining information to share with other people. AJ said, "I reckon it would be a good idea to have a leader who knows literacy to teach other people in disabled

communities,” and John replied, “Yeah, amen.” This discussion helped me align our research meetings with the interests of the participants. I asked if they wanted to come up with a group name for themselves. They agreed on the group name *Passioners*. Participants in this research will be referred to as the Passioners henceforth.

I ensured that the Passioners discussed “research” and “consent” in our first research meeting to ascertain a shared understanding of these concepts as per of my ethics application. They confidently articulated *research* as being, “like when you are planning something that you want to research like a topic, and then that topic is different information that you get” (AJ), “looking up through it and going through it” (Hōri) and being about “get[ting] the details right and seeing how it goes from there” (David). I concurred with everything everyone had said, and referred to the research booklet in adding that research is also about “looking for an answer to a question [and] finding out how to do things better” (p. 2). Then, AJ described *consent* as meaning, “to say that you want to do this,” and everyone agreed with his definition. I also talked about being able to withdraw from this research at any time and gave an example of how to go about it, saying “if you want to leave you can just click on *end meeting* and then it will mean you are not in the meeting anymore, and that is totally fine.” Research and consent were discussed in the first research meeting because participants with learning disability often have varying understandings of these concepts and peer discussion can be the most effective method for learning about new information during research (Cook & Inglis, 2012). Chapko et al. (2020) gave another example of how they had the same discussions over tea parties that were held before embarking on their data collection. We also talked about literacy. The Passioners said *literacy* was “reading and writing” (John), “connecting others with different disabilities” (AJ), and “get[ting] involved” (Hōri). The Passioners understandings of the key concepts of research, consent, and literacy, will inform findings in this research.

The Passioners to direct their own topics of conversation as I sought to minimise the influence of my own perspectives about literacy in the research meetings. I occasionally steered them back to literacy with prompts like “we are thinking about ‘what is literacy.’” I

also stimulated discussion by showing screenshots or photos I had taken in the previous meeting and saying things like “what was happening in this picture?” In this way, concepts discussed in the previous research meeting were reviewed in subsequent meetings. I used a transcript of the research meetings to help me remind the Passioners what they had said last time and aimed to extend concepts as we revisited them. Remembering what the Passioners already know from the last meeting, they added new ideas to their definition of research, such as, “how [disabled people] can share their lives with other people” (AJ), “helping those people who can’t help themselves” (Hōri), and “information that you are putting in and you are sharing” (AJ). We also reviewed the concept of literacy. This time the Passioners talked about literacy and people with sensory disabilities. AJ said, “I would also like to add with the literacy sort of things, how are we going to help other people who can’t read or write, or someone who can’t hear or see what’s in front of them?” Our process of reflection aimed to build layers of understanding about concepts in this research.

Our research meetings included an opportunity for the Passioners to share examples of their literacy. I started by sharing two examples of my literacy practices. One being my tattoo of native Aotearoa New Zealand fauna and flora, as it tells a story about my Pākehā identity and love of the outdoors. The other being a gold foil geometric artwork by Josephine Puha title *Āio*, which I used to demonstrate my literacy in making connections between shapes and ideas. AJ disputed my reading of *Āio*, as he found his ideas flowed from other sources, such as “doing TikToks at home, and I feel relaxed and into a zone, like doing posters, hanging out with my flatmate, my cat, and getting on well, and stuff like that.” This critical interaction confirmed an egalitarian group dynamic indicative of an IPAR methodology. AJ was quick to share one of his TikTok videos and the formative stages of his poster as examples of his literacy. John and Hōri had more difficulty identifying examples of their literacy. I prompted John to talk about a *Naruto* poster I saw in the background of his screen. This led to a discussion about the literacy practices involved in games. John showed us a map in his Dungeons and Dragons book. He explained, “you can draw those maps and it tells you where the entrance is and you have to write where the entrance is and where the

exit is and what goes to the next level of the dungeon” (see *Figure 19*). I also assisted Hōri in identifying an example of his literacy by suggesting we talk about the Christmas tree I saw in the background of his screen. Hōri used the Christmas tree as a stimulus to share stories about Christmas traditions. He later invited everyone in the group to his annual Christmas party, of which the invitation comprised another example of his literacy. Unfortunately, we were unable to attend because of COVID-19 restrictions.

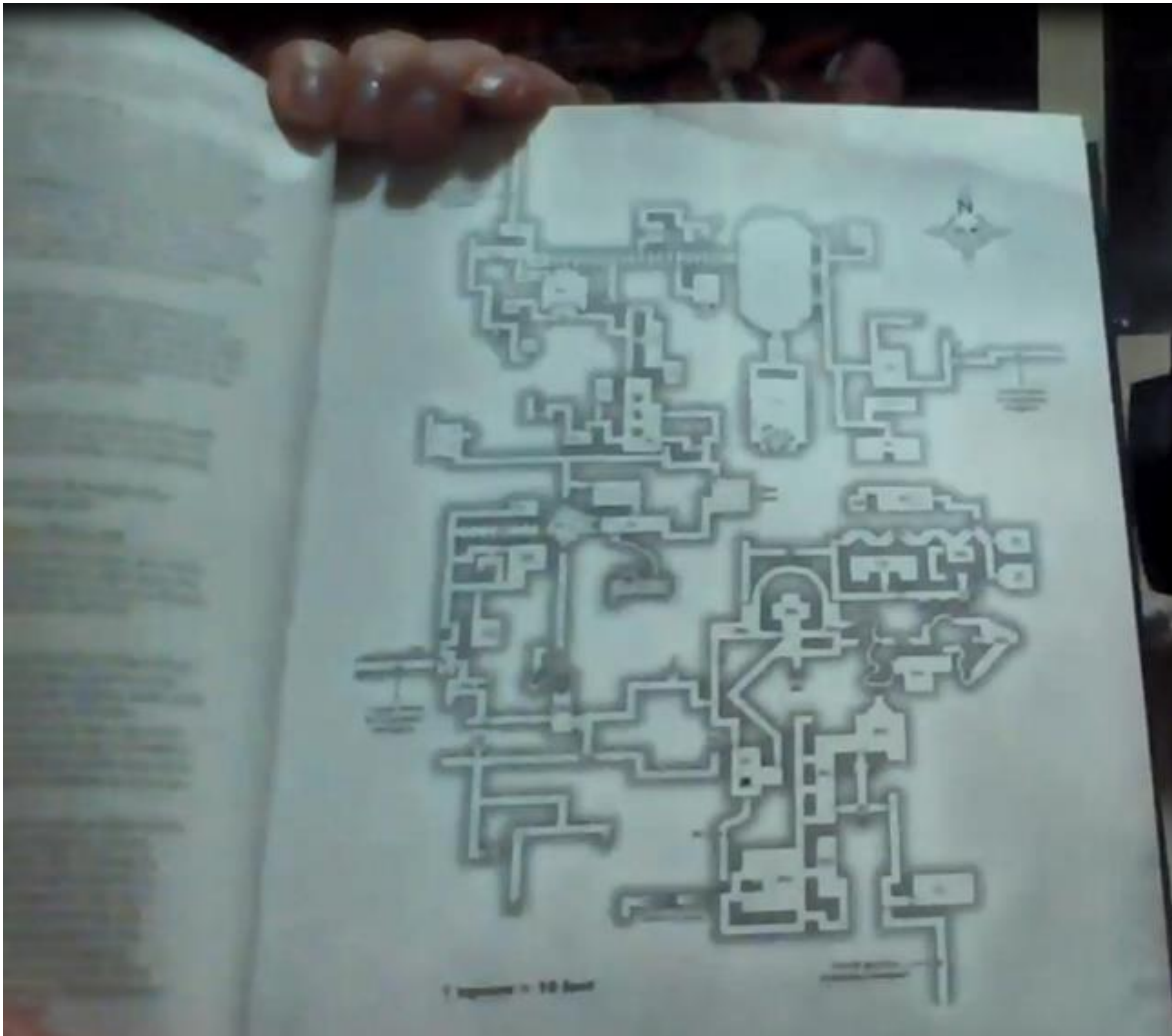


Figure 19 Screenshot of a Dungeons and Dragons map (Screenshot: N. Newcombe).

7.1.2 *The Next Three Research Meetings (in Person)*

The Passioners and I were able to meet in person from research meeting four onwards. I reengaged with supporters to obtain their continuing approval of the safety of my data collection. As part of this process, I sent the Passioners and their supporters Easy Read documents explaining how we would achieve and exceed COVID-19 restrictions (see *Appendix N* and *Appendix O*). In these meetings, the Passioners continuing to share examples of their literacy, reflecting on understandings of literacy gathered in the previous meetings, and using the digital technology I supplied.

Melissa started participating in research meetings once that they were in person. I asked the Passioners how Melissa, who was unable to participate online, should be welcomed to join those of us who had been together for three meetings already. AJ advised me to orient Melissa to what had occurred in our research meetings so far, which I shifted responsibility for back onto the Passioners. When Mellissa arrived, AJ accepted her into the group and introduced the research, saying,

Everyone has a say in what they want to talk about in this research, and also in this research, it is all about individuals or people like you having your own say. You are allowed to say what you want to get through to this group, and we help you in your own lives.

In terms of sharing examples of literacy, Hōri showed the research booklet saying, “you can learn from it as well and get some other ideas about what this is all about.” John brought car magazines and *Dungeons and Dragons* books as examples of his literacy. I further identified that his facemask, which depicted *Star Wars* characters, was also an example of visual literacy, being that he was expressing fandom through his choice of images. John replied that he was a “*Star Wars* fanatic.” He also talked about his intention to enlarge a *Dungeons and Dragons* map. AJ shared about some consultation he had taken part in saying, “we talk about different things like changing the world, how it can be better for us.” He also said that People First had posted him information about COVID-19 in easy read,

People First, they posted me some easy read versions of COVID. At the moment it's still going ahead, they are looking into different levels, but at the moment it's still a pandemic, you still need masks and stuff like that.

Melissa talked about her employment, leading to a group discussion about work and how to get a job. Melissa shared from her experience, "how I got my job, I had a CV, they done a CV up for me, a CV, and then they were thinking on, what is it called, job search, all the jobs and stuff". Other examples of literacy will be discussed in the context of analysis in the next chapter.

I selected and displayed screenshots from the Zoom research meetings, and images from preceding in person research meetings on a projector to assist the Passioners in reflecting on their understandings of literacy. On reviewing the data, Hōri asked me for validation about his understanding of the first two screenshots, saying, "is that right," but gathered more confidence in speaking for himself to describe the following slides. AJ offered a more interpretive lens, beginning each statement with the phrase "I think it is about". The Passioners frequently affirmed each other. Such as when AJ talked about an image of John showing me how to use the camera, he said "mean brother, working the camera".

The Passioners engaged with the digital technology. John facilitated a portrait photography session with the other Passioners. The Canon EOS-90D was a much higher specification camera than John had used before and he was excited about experimenting with this technology during our meetings, saying, "I don't have any of that sort of stuff at home". John explained that he was supplying portraits for free as part of this research, "I am doing this for you and your work, so that's pro bono". AJ entertained the Passioners by modelling poses, imitating body builders and Disney princesses for the photos. Next, the Passioners decided to do a play so Hōri could try out video recording, but Hōri also wanted to be in the play, so John took the role of videographer and Melissa watched. AJ suggested the play could start by someone saying, "hi and welcome to this research". AJ and Hōri performed a play, which demonstrated their positive attitudes towards this research and reasons for taking part, as well as creating an example of their literacy.

AJ: Hi, hi and welcome to Nicolina's research. This is all about her research she is doing for us. This is her thesis and we want to know a bit more. We are here to connect together as one and talk about what is happening.

Hōri: Hi, I just know that I hope that everybody in this group learns a bit more about this research, and learns something from it so they can go home and do their homework and learn from it. By the time we come back, everyone should have some ideas and feedbacks on what they want to bring back to the group, and have a talk in the group with other people as well.

AJ: And also what's research, we have done easy read documents so it can make things easier for people with disabilities to know what this research is all about. There is also photos and information that you know to do an easy read version in easy words to explain more better. And yeah, so you can connect and be helpful with others.

Hōri: That is why I bring that information book [research booklet] that I have with me each time, because it has got all of the different ideas and different things in that book that I bring with me, and the person's picture, Nicolina's photo, and so much other stuff, different issues in there as well.

AJ reflected that the play "was really exciting to do". AJ and John experimented with writing on the reMarkable tablet (see *Figure 22*), but neither of them used any of the features it has, such as grids and layers. No one used the additional dictaphone.

The first six research meetings were primarily for data collection and the next four research meetings were primarily for inclusive analysis of data generated in the first four research meetings.

7.1.3 *The Final Four Research Meetings (in Person)*

The final four research meetings used PowerPoint slides, a template, and picture cards to engage in an inclusive analysis utilising elements of frame analysis (see *Section 5.7.3.2.1*). The Passioners were invited to look closely at information, choose parts of the information, and talk about what those parts mean. The final session concluded with the Passioners being given certificates (see *Appendix H*). We also discussed the benefits of this research for them.

I showed and described the template, PowerPoint slides, and picture cards at the start of the sixth research meeting. AJ explained how to use the template (see *Figure 20*) for the other Passioners, saying,

I think what it says there is what part is interesting to you, and be able to know what you like doing and able to, like, set a goal or something like that. And then you can be able to like tell what's research about that. So, it's about what you think about it and what's important to you.

However, my original plan failed to be sufficiently inclusive for the Passioners and they seemed to lack interest in the template. We continued to try to follow the same process I had envisioned without the aid of a template. Yet John and Hōri both showed signs of finding the inclusive analysis process difficult, for example, by staying quiet in some discussions, or saying things like “it’s a tough one” (John). Then, I asked if I was going about analysis the right way. AJ acknowledged that I was asking for help from the Passioners. John suggested that I “make it look reasonable and make it more sensible and a bit better for people to understand more.” Hōri made a suggestion about how the process could be further simplified, saying, “you might have to tell us 1,1,1, and then you have to have a pen and paper to write down our questions and answers.” I subsequently endeavoured to work with the Passioners to make this method more accessible for them.



Figure 20 Using the picture cards and template (Photo: N. Newcombe).

Processes used by the Passioners to undertake inclusive analysis were different to what I had envisioned. The Passioners most often described a card using descriptive language without connecting it to their data. For example, “she’s bending down on both knees. Must be putting a plant in” (Hōri). I decided to join in with the analysis so I could model using the cards with the data to find alternative framings. Doing this resulted in some responses that considered both the cards and the data. For example, AJ said,

I think I know about the target one [card]. It’s like a goal or looking into something you could learn, that goal and with that one, I think, looking at the screen here, this one [slide], I think you achieve this goal or come to learn this goal about Māori.

I had anticipated the Passioners would bracket their own strips by choosing a few words or a part of an image from the PowerPoint slides. However, the Passioners analysed each slide as a whole, meaning that my construction of the slides was used as a bracketing of the data by default. Furthermore, the Passioners analysed the Photosymbols along with their own data, as in, the Passioners were not differentiating between the data they had created and that which was from an external source and only intended to make the slides more engaging, i.e. was decorative. I responded by removing Photosymbols from the following slides. While the Passioners continued to analyse whole slides, the slides were now limited to data from our research meetings. This meant that I was bracketing strips for the Passioners.

I visited Hōri and John between the eighth and ninth, and ninth and tenth sessions to reflect on the inclusive analysis process. Where the Passioners had previously been selecting from all 22 cards each time, John thought there should only be four or five cards to choose from, and that the cards should be conceptually similar to the slides. For example, “for the Stoney Bay slide, you could have a picture of a beach” (John). Reflecting on input from Hōri and John, I decided to create another 16 picture cards so the remaining 14 slides would each have a set of four conceptually similar cards. Some of the slides used existing picture cards. In making these changes, I actioned advice from the Passioners gathered during their reflections to try and make the research more inclusive.

At the next research meeting, I acknowledged John for his ideas that led to me using different picture cards and only using four preselected cards per slide. I also numbered the cards so I could more readily identify the cards when they were discussed in the transcripts. The Passioners had more robust discussions when there were fewer cards to choose from. They also talked about some of the slides in conjunction with the cards, for example, one slide said, “I am part of the [group name] committee with People First and we use some just little tools for our work and we go to Wellington and we talk about what’s the plan and help with them what their one will be.” AJ identified a card with a group of people on it as being “people talking about [group name] in People First,” and a card with an image of a plan on it as being “plan what we’re gonna do next in People First.” I called this revised method, which involved presenting four thematically similar cards related in concrete ways to each slide, the *picture card analysis*. The picture card analysis engaged the Passioners in reflecting on their data.

7.2 The Passioners are Literate

I came to this research having completed my *National Certificate in Adult Literacy and Numeracy Education* which, coupled with my experience working with adults with learning disability, led me to assume the Passioners would have low literacy skills. However, I did not conduct any literacy testing with the Passioners and did not request the results of any tests they may have taken in the past, so I have no data to identify their competencies using the learning progressions or any other existing measure of literacy. Furthermore, the idea of competencies problematically aligns with normed abilities and may not appreciate broader literacy practices that exist outside of current assessments (McIlroy, 2017). To counteract this phenomenon, McIlroy (2017) used the term *capable* instead of competencies. As McIlroy (2017) challenged the myth of inability (see *Section 1.4.5*), this research similarly affirms universal literacy and agrees with the Passioners in their assertion of themselves as literate.

AJ defined a literate person as “someone who can read and write, someone who can spell, good at math, or be able to help other people out, like connecting others with different disabilities” in our research meetings. When asked if he is literate, he replied, “that I am able to help other people, yip.” Expanding on his aforementioned range of literacy practices, AJ said, “It’s not just me singing or anything like that in literacy, sometimes I sing, sometimes I do talking, and sometimes I do dancing.” For Hōri, people are literate when they are “the ones that get involved.” John also identified himself as literate, particularly regarding *Dungeons and Dragons*, “a tabletop game that has a lot of reading involved, quite a bit of writing involved.” John described himself as “very slow but capable” at reading. Agreeing with the Passioners that they are literate, I embarked on a reflexive TA of data collected during our research meetings.

7.3 My Reflexive TA Report

The final step in the reflexive TA is writing the reflexive TA report. This will be about the six themes I constructed, one being social media, two being encoding and decoding, and three being cultural literacies.

7.3.1 Māori Cultural Literacies

Māori cultural literacy was first documented by *Te Wānanga o Aotearoa* (a Māori tertiary education provider) as a strategy to express the importance of Māori culture in Māori education, and to resist the culturally universal approach to literacy promoted by the TEC (Zepke, 2011). For Leach et al. (2010), Māori cultural literacies exist in parallel with functional and critical literacies but are underpinned by tikanga and *āhuatanga Māori* (Māori tradition). By functional literacies, Leach et al. (2010) meant the TEC (2008c) definition of literacy (i.e. reading, writing, listening, and speaking), with critical literacies

being a reading of the world that supports agency and self-determination. They describe Māori cultural literacies as, “building a strong sense of pride in where you come from and your ancestral or cultural connections” (Leach et al., 2010, p. 10). The cultural literacy adopted by Te Wānanga o Aotearoa is that which “enable[s] its graduates to function appropriately in the Māori world” (Zepke, 2011, p. 433). While initially opposed by the TEC (Zepke, 2011), the use of Māori cultural literacy at Te Wānanga o Aotearoa has been valued internationally as an example of good practice (UNESCO, 2016).

Te Wānanga o Aotearoa has now departed from promoting Māori cultural literacies and weaves language, literacy, and numeracy into all of their programs using a kaupapa Māori approach instead (H. Ngatai, personal communication, 26 June, 2023). Note the weaving metaphor as distinct from the embedding metaphor that is used by the TEC (Mem Joe & Terrell, 2011). Encouragingly, the current *Tertiary Education Strategy* now includes a provision for delivering education that “sustains [learner] identities, languages and cultures” (Ministry of Education, 2020b, p. 2), which aligns with a Māori cultural literacy approach.

The following table presents coded excerpts of Māori cultural literacies from our research meetings.

Māori cultural literacies			
Code	English approximation	Example excerpt	Passioner
Kaitiakitanga	guardianship	Awa is our river, where we get our water.	Hōri
Karakia	prayer	Kia mai nau mai haere mai e whakatonga e haue e hunga e mai ane e whakatanga te hau ake ake amene.	AJ
Kīngitanga	Māori King Movement	Yeah, at coronation, every year and shaking the King’s hand.	Hōri

Knowing about <i>Te Tiriti o Waitangi</i>		I remember when we wrote a book up for <i>Te Tiriti o Waitangi</i> .	AJ
Poukai	Māori King Movement gathering	The poukai is just for the Māori Kīngitanga. And for the Queen. For the King to go all over the place and Tūrangawaewae ⁵³ and then we poukai in Tauranga, and you got Waingaro poukai. It's all over the place.	Hōri
Tikanga	correct procedure	You have a lady doing the <i>karanga</i> [welcome call] saying her thing to bring him in to like a <i>pōwhiri</i> [welcome ceremony].	Hōri
Wānanga	instruction	Just to learn what you want to learn on the marae.	AJ
Whakawhānaungatanga	process of establishing relationships	What's your whakapapa and what iwi you come from.	Hōri

7.3.2 Pākehā Cultural Literacies

I added the theme “Pākehā cultural literacies” as a counterpart to “Māori cultural literacies” in this research to identify and decentre Pākehā culture in line with a bicultural approach. This research does not advocate for the inclusion of Pākehā cultural literacies in policy or curriculum. Rather, it seeks to differentiate references to Pākehā culture to avoid normalising the dominant culture, which is a key tenant of racism (Awatere, 1984).

⁵³ A marae in Ngāruawāhia, headquarters for the Kīngitanga.

There were fewer instances in the transcripts that I could categorise as enabling Pākehā to live as Pākehā, compared to those I could categorise as enabling Māori to live as Māori. This is likely to be because I am Pākehā and immersed in Pākehā culture. Reflexive TA brought my Pākehā worldview into focus and gave me an opportunity to revise my assumptions about culture and leadership in this research, with expert guidance from my Māori cultural advisor. Pākehā cultural literacies were practiced by both Māori and Pākehā Passioners.

The following table presents coded excerpts of Pākehā cultural literacies from our research meetings.

Pākehā cultural literacies		
Code	Example excerpt	Passioner
Christmas	Jesus he um, that is his birthday, and his birthday is like to celebrate Christmas and the whole Christian times.	AJ
Independent learning	I need to do, do my own work.	Hōri
Pākehā ways of looking after the dead	I had to put me Mum in the back of the hearse to go to the funeral home and after that I was in the hearse to take her to the crematorium, it was not easy.	David

7.3.3 Learning Disability Cultural Literacies

This research applies the concept of cultural literacy to the culture of learning disability (see *Section 3.3*). While not identified by the Passioners or in existing literature, my understanding of learning disability culture fits within the wider category of disability culture and aligns with the affirmation model of disability.

The Passioners talked about and demonstrated objective and subjective aspects of their culture during our research meetings (Berry & Triandis, 2014). Objective culture includes visible elements, such as artworks, buildings, and rituals (Berry & Triandis, 2014). Examples of objective cultural elements discussed by the Passioners included easy read and the Special Olympics. There were fewer objective cultural elements than subjective cultural elements discussed in our research meetings.

Subjective culture includes invisible elements, such as “evaluations, beliefs, attitudes, stereotypes, expectations, norms, ideals, roles, tasks, and values” (Berry & Triandis, 2014, p. 48). The Passioners demonstrated subjective cultural elements including their approaches to time, support, mutual affirmation, and aspirations. The Passioners valued a leisurely approach to time, allowing ideas to flow naturally, “I am going to wait until something comes up in my head” (Hōri); “an easier way is to slow it down” (AJ). Transparency around the use of supports was evident, with Passioners openly acknowledging and engaging assistance from parents or support services, “how should it go, with support, yeah.” (Hōri); “Mum helped me do it” (John). They also encouraged each other to access support, “it’s better if you go to [supported employment service], they will get you a job” (Melissa). The Passioners demonstrated exceptional supportiveness towards one another, actively seeking opportunities to assist and uplift their peers, “helping those people who can’t help themselves as well” (Hōri). For example, John said he would like to write a song but he “wouldn’t know where to begin to do that.” AJ responded saying, “if you want to think of a title of a song or anything like any topic, if you want to know any more you can email me, and we can talk a bit more about song writing.” The Passioners embraced and celebrated all contributions, such as John saying the role play by AJ and Hōri was “brilliant, absolutely brilliant.” Goals and aspirations were frequently discussed, for example, to pursue professional photography and modelling or motivational speaking and becoming an entrepreneur. I identified numerous subjective cultural elements among the interactions of the Passioners, even though they did not expressly identify themselves as belonging to a unique culture.

The process of reflexive TA informed me that I recognise the Passioners as being part of a unique culture, even though they did not make the same observation. As someone who takes part in autistic culture⁵⁴, I noticed overlaps and similarities with cultural norms expressed by the Passioners, for example, direct communication and the inclusion of support people was evident. Therefore, I was mindful of refraining from imposing my cultural views as an autistic person onto data produced by people with learning disability in my construction of learning disability cultural literacy. This section now turns to a discussion of five learning disability cultural literacies I coded in data from our research meetings, being “self-advocacy”, “accommodations”, “choice and control over support”, “aspirations”, and “drama”.

7.3.3.1 Self-advocacy

Self-advocacy is a process whereby people understand and communicate their wants and needs to achieve choice and control in their life (Goodley, 2000). As a generic term, self-advocacy can occur formally or informally and individually or collectively. In the context of learning disability, self-advocacy is a social movement that often occurs in a group where people with learning disability come together to learn about their rights and strategize for personal and political empowerment (Goodley, 2000). People with learning disability have used self-advocacy to counter oppressive conditions within institutions and later in disability support services in Aotearoa New Zealand since the 1960s (McRae, 2014). There is a global organisation by and for people with learning disability to engage in self-advocacy called People First.

⁵⁴ Autistic culture often includes aspects of repetitive or routine activities, which can take the form of special interests. Communication is usually honest, direct, and efficient. Sensory preferences, such as comfortable clothes are often more important than other factors such as fashion and design in autistic culture. People in autistic culture commonly have gender and sexual role variances, reject widely used social norms and hierarchies, and use supports and accommodations.

People First began in Oregon, North America in 1974 (Goodley, 2000). The Aotearoa New Zealand chapter of the organisation was set up by the New Zealand Society for the Intellectually Handicapped (now IHC) in 1985, and they continued running People First until 1994, when members voted to become an independent organisation (Gosling & Gerzon, 1994). At least two of the Passioners were members of People First.

I am a member of the committee of People First regional team and I am one of the people who is in it and normally what happens, we talk about what business side, and Chris he is our President and he talks about what he has been up to as our President and then we take a break and then we go back and talk about what has been happening in our regions. (AJ)

While two of the Passioners were People First members, self-advocacy is not restricted to that organisation. The cultural literacy of self-advocacy involves practices such as taking part in a group or committee, making decisions, and “speak[ing] their mind” (AJ), to inform other people with learning disability, and to make things “better for us” (AJ). These practices enable people with learning disability to live as people with learning disability.

7.3.3.2 Accommodations

Accommodations are often discussed using the CRPD terminology of reasonable accommodations (see *Section 5.4*). However, the Passioners did not discuss accommodations using that framework. The Passioners described the accommodations they use in three categories: communication, tasks, and transport.

Communication accommodations can include low-tech options such as pictorial or simplified written instructions and communication boards (Flores et al., 2022; Goodwin et al., 2015; Oldreive & Waight, 2013), or higher-tech options such as speech to text or eye-gaze directed devices (Talklink, 2023). John explained why communication accommodations may be necessary, saying he was “not as good at interpreting certain things.” Hōri talked

about bringing his copy of the easy read research booklet to each meeting to maintain awareness of what is going on. “That is why I bring that information book that I have with me each time, because it has got all of the different ideas and different things in that book that I bring with me” (Hōri). AJ also talked about accessing easy read information outside of research meetings.

Task accommodations can include occupational modifications such as simplifying instructions, additional time, or creating a structured and predictable environment (Chi et al., 2018). Melissa talked about her task accommodation of having shorter shifts at work, being “three hours a day.” Hōri also suggested having additional instructions for learning new tasks, “another way to learn sometimes is to get someone to show you how to use it first and to go over it with you.”

Transport accommodations could include public transport design, priority parking and seating, and help with paying for transport (Community Law, 2024). David shared how he used transport accommodations to get to work, “I was catching the bus into town, into The Base, and then someone come pick me up and take me there and then they drop me off and I get the bus back home.” Negotiating accommodations is a form of learning disability cultural literacy.

The cultural literacy of accommodations involves people with learning disability identifying, communicating, and doing what could be done differently to support them to live as people with learning disability.

7.3.3.3 Choice and Control over Supports

Choice and control is one motif that reflects the right to “equal recognition before the law” expressed in the CRPD (United Nations, 2007, Article 12). Pallisera et al. (2021) interviewed people with learning disability about their choices as they accessed supported living

services⁵⁵ and the resulting control they had in their lives. Many participants exerted choice and control over their supports by co-designing support plans, asking for support, or saying no to support, clarifying the types and frequency of wanted supports, and using family members as advocates (Pallisera et al., 2021). Choice and control over supports were active processes for participants and those who did not employ strategies to maintain control in their lives experienced the consequence of having paternalistic and overbearing supports (Pallisera et al., 2021). As noted by Williams and Porter (2017), choice and control disrupts the status quo of disability support services having power over people with learning disability.

The Passioners reported asking for support, for example, “I can ask my staff to help me get stuff” (AJ) and “I will ask my support person tomorrow if she can do it” (Melissa). They were aware of the support they need, such as “I had a little bit of help from the staff, but I do a little bit, but not much” (Hōri). AJ encouraged communication with support workers to organise supports for positive outcomes, “talk to staff as well as the as a team of getting the right support and how you can get better.” David decided to delegate a task, “I think I would like you to do it.” John recognised that navigating support is a skill, “not everyone has the confidence to ask for help, even though they know they need help from others.” The Passioners discussed actioning choice and control over their supports in these excerpts.

The cultural literacy of choice and control over supports involves people with learning disability living as people with learning disability by asserting their needs and preferences for support and regulating the nature and extent of that support when necessary.

7.3.3.4 Aspirations

People with learning disability have similar aspirations as those held by their non-disabled peers (McMahon et al., 2020). While asserting that aspirations are likely to be similar, they

⁵⁵ Living independently with some support.

do not need to possess a likelihood of being actualised to be aspirational (Benoot et al., 2022). Benoot et al. (2022) gave an account of enabling factors for aspiration in people with learning disability, including having the ability and opportunity to tell their own story, and having that story taken seriously by others. Those enabling factors are important because people with learning disability have been known to have their aspirations discounted. As Espiner and Hartnett (2012, p. 66) explained, aspirational talk is met with “putdowns and discussion” in some disability services. In the same vein, some participants in Benoot et al. (2022) reported not sharing their aspirations with others because of their concerns about disapproval.

Benoot et al. (2022) also explored the aspirations of adults with learning disability alongside the presence or absence of conversion factors, such as personal resources and environmental conditions, required for those aspirations to become functioning realities. For example, one participant aspired to become a forklift driver but also understood that he was unable to obtain a driving licence due to his disability (Benoot et al., 2022). People with learning disability can be more or less aware of the need for conversion factors in realising their aspirations, for example, only one of four young people with learning disability interviewed by McMahon et al. (2020) recognised that they needed support. The incongruence between the aspirations of some people with learning disability and the availability of requisite conversion factors can prompt other people to seek to modify those aspirations to make them more achievable (Benoot et al., 2022; McMahon et al., 2020).

There are often differences between the aspirations of people with learning disability and the aspirations others hold for them. McMahon et al. (2020) reported on the career aspirations of young adults with learning disability compared with the perspectives of their mothers. The young adults aspired to pursue trajectories such as going to university and being a doctor or a farmer (McMahon et al., 2020). However, their mothers held more restrained aspirations for them, namely continuing with some disability-specific activities and working towards independent living with support (McMahon et al., 2020). Dearing (2022) confirmed the practice of disability service support staff using strategies such as

deferral, creating alternative achievements, listing barriers, and conflating therapeutic activities with employment to challenge the aspirations of job-seeking participants in line with what staff perceived as realistic for their clients. Investigating whether adults with learning disability find life satisfaction in working towards an alternative goal along the same theme as their aspirations could be a topic of further research.

The Passioners expressed numerous aspirations during our research meetings. Some aspirations were actionable in the near term, for example, “why don’t all of us and you meet up and have a coffee out somewhere” (Hōri). While others would require significant investment to be realised. For example, John said he “would like to do a song with [Avril Lavigne] or be in one of her videos,” and AJ said he was “thinking about being a model” and “a motivational speaker.” I had initially coded this group of excerpts as “aspirations and planning” to indicate the combination of what I considered to be unachievable and achievable ideas. I subsequently changed the code to “aspirations” to refrain from imposing evaluative distinctions based on my own view of what is possible for the Passioners.

Looking back at the transcripts, I found I had also used language discounting the aspirations of the Passioners. For example, I attempted to modify John’s aspiration to do a song with Avril Lavigne by saying “you could potentially get a support person who knows more about song writing,” meaning that he could work towards doing a song with a support worker instead of with the famous Canadian singer. Other times I neglected to meaningfully acknowledge the aspirations of the Passioners. For example, I said, “oh that’s cool” when John told me he wanted to become a professional photographer, and I said, “okay” after AJ expressed his aspirations for both modelling and motivational speaking. The coding of aspirations in the transcripts forced me to confront a level of ableism I still harbour. I questioned whether I would have considered an aspiration to become a professional photographer or start a makeup design business unrealistic if expressed by a person without learning disability, and how I might have responded differently in that instance. Given that I lacked attentiveness and supportiveness in engaging with the Passioners’ aspirations, even when I had a methodological imperative to be responsive, sensitive, and non-judgemental,

highlights the need for people with learning disability to maintain their “capacity to aspire” (Benoot et al., 2022, p. 1107). The capacity to aspire includes the ability to maintain aspirational thinking in the presence of scepticism communicated by others (Benoot et al., 2022; Dearing, 2022; Espiner & Hartnett, 2012; McMahon et al., 2020).

Aspiration is a cultural literacy that enables people with learning disability to live as people with learning disability by engaging in practices such as imagining a future different to the present and viewing the future as presenting new possibilities.

7.3.3.5 Drama

Music, dance, and drama are non-verbal forms of communication (Mino Roy et al., 2022). Trowsdale and Hayhow (2015, p. 1023) specifically highlighted drama as an “embodied exchange” that helps people with learning disability learn more about social roles. For Chesner (2020), drama can foster fun, group cohesion, self-determination, and the confidence to express oneself. Continuing with the social value of drama, Dickinson and Hutchinson (2019) said drama offers an opportunity for people with learning disability to engage in social interactions they are often otherwise excluded from.

The Passioners engaged in individual and group drama to explore social roles that may occur in the future. Hōri and AJ both practiced speeches ahead of upcoming events. Hōri gave an impromptu rendition of a speech he would “say in front of the people.” AJ practised a speech in which he planned to thank the facilitators and committee of a disability support provider at their Christmas party. AJ asserted his leadership in his speech, saying “I have done [disability support provider] for a very long time, nearly 12 years in [disability support provider], so I can answer some questions.” AJ and Hōri also performed a play about this research (see *Section 6.1.2*). John talked about his interest in costume performance art, “I got an outfit for a guy called Itachi Uchiha, so like for cosplayer sort of stuff,” which may have represented exploring an imagined social role.

Drama is a cultural literacy that enables people with learning disability to live as people with learning disability through practices such as exploring social roles and rehearsing for the future.

7.3.4 *Encoding and Decoding*

In this research, *encoding* means the conversion of thoughts and ideas into visual literacy, including but not limited to writing, and *decoding* is the reverse process, including but not limited to reading. I coded data to construct the Passioners as encoding by “writing English,” “writing te reo Māori,” “drawing symbols,” “producing easy read,” “selecting emoji,” doing “photography,” and “mapping”. I coded data to construct the Passioners as decoding by “reading te reo Māori,” “reading English,” “reading a tide chart,” “interpreting images,” and “consuming media”. Some of the coded data represents a demonstration of encoding or decoding and some represents descriptions of their experiences that occurred outside our research meetings. See figures 21, 22, 23, and 24 as examples of encoding by the Passioners.

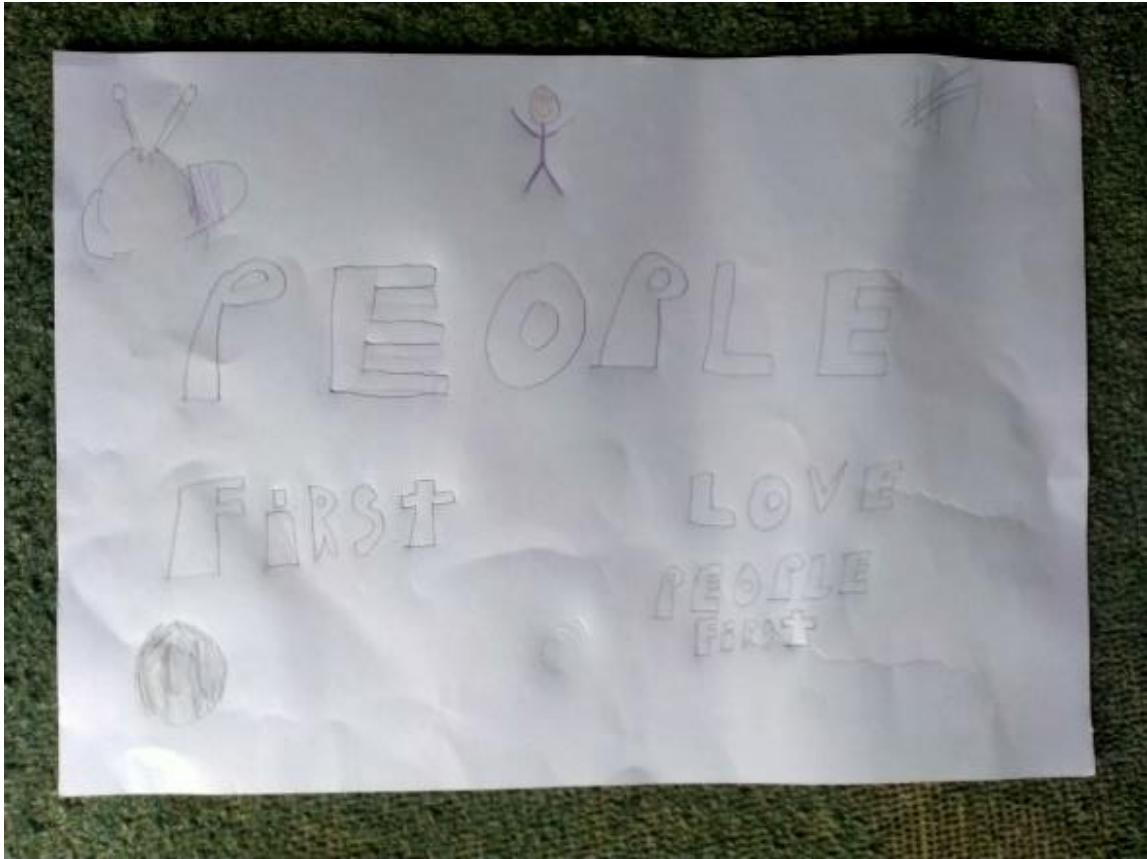


Figure 21 Poster by AJ, text reads PEOPLE FIRST LOVE PEOPLE FIRST, symbols represent people and butterflies (Photo: N. Newcombe).

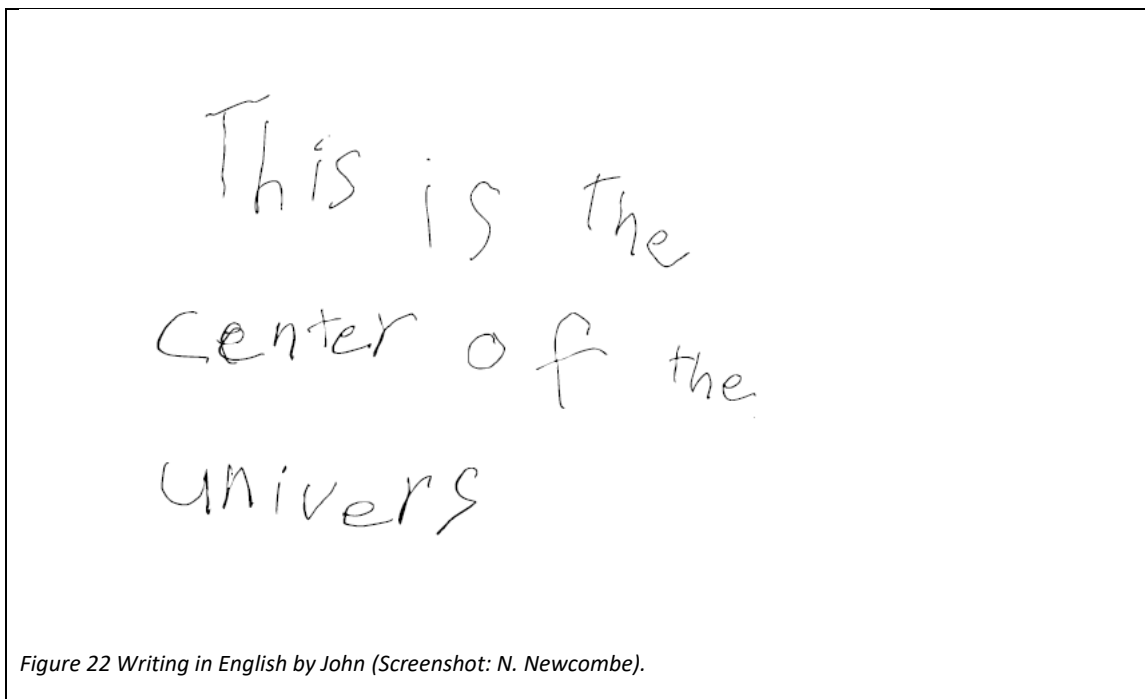


Figure 22 Writing in English by John (Screenshot: N. Newcombe).



I love food

Keep your teeth cleanen



They are happy

Keep you well



Figure 23 Easy read document by Melissa (Screenshot: N. Newcombe).

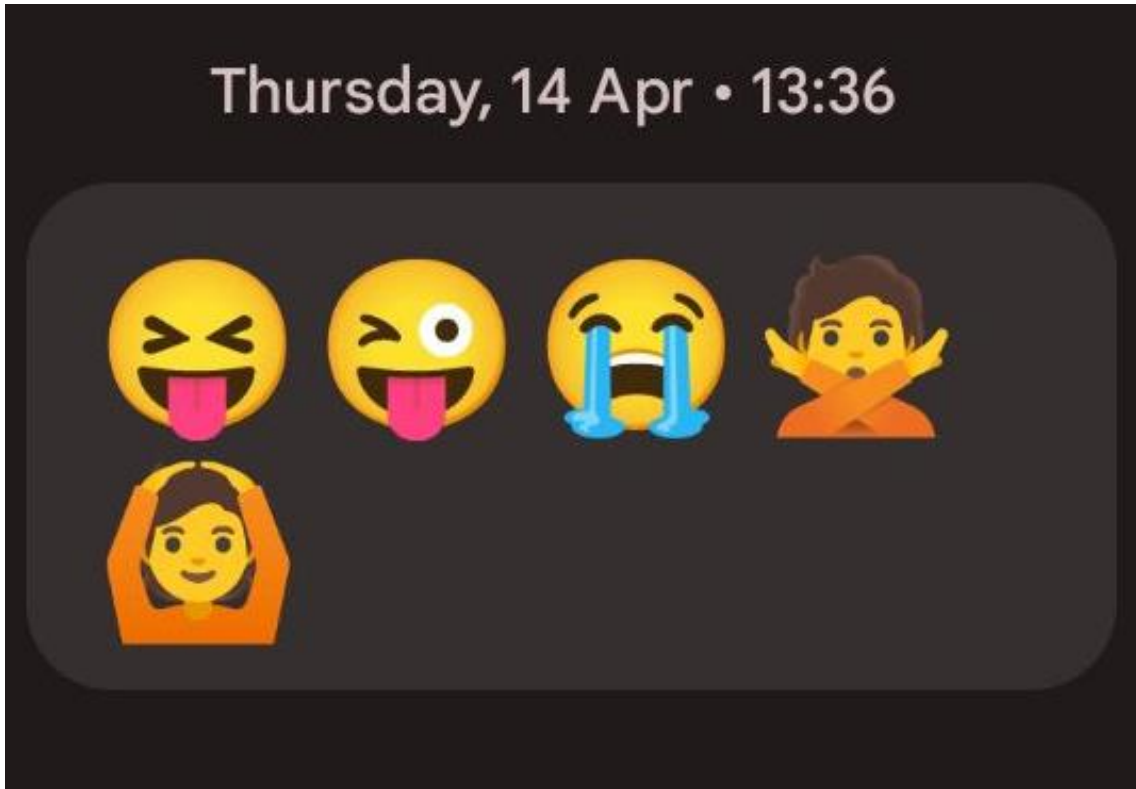


Figure 24 Emoji selection by John (Screenshot: N. Newcombe).



Figure 25 Photosymbols. (2022). Coffee break 1. www.photosymbols.com

In terms of decoding, the Passioners read slides aloud in English and whakataukī cards aloud in te reo Māori. I had initially used Photosymbols images throughout resources I designed for our research meetings, such as slides, handouts, and picture cards. The Passioners interpreted many of these images alongside the text, whereas I had often intended them to be decorative. Consequently, there are numerous examples of the Passioners decoding images in the transcripts. For example, the image in *Figure 25* was used in a slide with the words “what are we doing in this research?” Hōri interpreted the image, saying, “this could be a man that is asking a lady about her ideas and thoughts and the lady might be sharing this man some thoughts and ideas.” The Passioners recalled instances of decoding by reading a tide chart and consuming media in the forms of online streaming services, radio, and television from previous experiences, rather than demonstrating them in our research meetings.

I looked to see if any examples of literacy I coded as encoding or decoding could overlap with the steps, progressions, or strands in the *Learning Progressions* (TEC, 2008a). If there were convergences, my research meeting method could be further developed into an additional assessment process using the existing rubric established by the TEC. However, I was unable to align coded data with any of the learning progression strands, progressions, or steps. This is because, due to the collaborative nature of an IPAR methodology, I did not evaluate or interrogate what the Passioners said or did during our research meetings. For example, I did not ask John about his spelling of the word “univers” in his writing (see *Figure 22*), or to look for that word in a dictionary and revise his spelling. While doing so could have aligned with step two of the spelling progression in the strand known as write to communicate (TEC, 2008a), it would have run counter to the purpose of this research. The Passioners also used environmental print, such as scanning QR codes for the NZ COVID Tracer app, although this is part of *Starting Points* and not the *Learning Progressions*.

This section illustrates a wider view of visual literacy than reading and writing, which extends encoding and decoding to include symbols, images, maps, and charts, as well as well as an appreciation for consumptive media held by the Passioners.

7.3.5 *Social Media*

Social media are interactive digital communication applications that link users to a network of other users (Cunningham, 2012). Social media has democratised the relationship between media producers and consumers, allowing everyone (Cho et al., 2022; Cunningham, 2012), including people with learning disability, to share examples of their literacy practices with a potentially global audience.

Social media literacies go beyond technical skills to include creativity and an awareness of social and ethical dynamics (Manca et al., 2021). Cho et al. (2022) conceptualised social media literacy as the strategies used to construct and navigate an individualised version of reality within a social media world. Those strategies are made up of local and global skills (Manca et al., 2021). Local skills, such as making a Twitter list, are specific to one platform. Global skills, such as navigating through limitless content options, are transferable across multiple social media platforms. The Passioners discussed or demonstrated social media literacies in relation to the codes of “Facebook,” “online gaming,” “TikTok,” “YouTube,” and “Zoom.” For example, John talked about following Buckin' Billy Ray Smith and Jenny Desu on YouTube, revealing his skill in finding specific content of interest to him. Some of our research meetings occurred on Zoom, which resulted in an opportunity to connect with each other using social media.

Communication skills can form a barrier to social media for some people with learning disability (Caton & Chapman, 2016). For example, the social media content written by participants with learning disability in some studies reviewed by Caton and Chapman (2016) failed to generate engagement, such as likes, comments, or shares, from other users. John had a similar experience when he started a Facebook page with the intention of gaining feedback on his photography, “I initially made it [Facebook page] so that people could, you know, critique my work and tell me what I need to do to take better photos, but no one really says anything.” Caton and Chapman (2016) also found that uploading photos, as John

did, reduced the demand for reading and writing, compared with creating other types of content for social media.

AJ talked about his avid use of TikTok and played some of his TikTok videos during our research meetings, saying, “I will probably do a TikTok about something and I will probably do something for disabled people, that we are also part of our community and reaching forward to our dreams, our disabled life.” His intention to disclose his disability mirrored the findings of Caton and Chapman (2016), which suggested that people with learning disability frequently made their disabled status known on social media. Borgström et al. (2019) added that people with learning disability are more likely to express themselves in a setting where they feel safe and in control, such as on social media. Caton and Chapman (2016) and Borgström et al. (2019) also discussed people with learning disability concealing their disability online.

People with learning disability are at a greater risk of experiencing loneliness, which can lead them to seek connection via social media (Caton & Chapman, 2016). AJ and Melissa both used social media to engage with other people, “I’m always on Zoom, on online meetings” (AJ). Melissa enjoyed the portability of sending and receiving messages, saying, “I send text messages, means that you can text anybody and get a text on Facebook, and you can get some texts when you going to work where you are.” Social media proved to be a valuable tool for enhancing social connectedness for the Passioners.

While social media has many benefits, it also carries potential risks for people with learning disability, particularly involving misinformation, cyberbullying, unwanted sexual attention, and fraud (Caton & Chapman, 2016; Iglesias et al., 2019). The Passioners did not discuss any risks associated with social media, contrasting with eight out of ten studies reviewed by Caton and Chapman (2016) that raised safety as a concern regarding social media and people with learning disability. Iglesias et al. (2019) found that people with learning disability encountered the same amount of cyberbullying as people without learning disability, even though people without learning disability used social media more frequently

and for longer durations. It is not known whether the Passioners were not aware of the risks associated with social media or if they did not talk about them in our research meetings.

Social media literacies were less salient among Passioners affected by digital exclusion (see *Section 5.7.3.1*). Although lacking an internet connection at home, David still showed me how to take a selfie on his phone, “there is a face on the screen, the camera turns itself round and if you press it again it goes the opposite way.” The Passioners predominately interacted with older social media platforms, being Facebook 2004, YouTube 2005, Zoom 2011, and TikTok 2016. They had not yet adopted newer platforms such as Clubhouse 2020, Byte 2020, and Dispo 2021. None of the social media platforms developed specifically for people with learning disability, such as Amik@ (Martins et al., 2021) or SymbolChat (Keskinen et al., 2012), were mentioned in our research meetings.

Our research meetings occurred between November 2021 and April 2022, before artificial many intelligence systems, such as ChatGPT, were released (Bahaimiha, 2023). As ChatGPT is thought to be the most rapidly adopted digital technology of all time (Bahaimiha, 2023), future studies will be likely to include the applications and outcomes of artificial intelligence for people with learning disability.

Social media literacies may contain elements of literacy outlined in the Learning Progressions (TEC, 2008a), i.e. reading, writing, speaking, and listening, but social media literacies themselves are not part of adult literacy policies in Aotearoa New Zealand. In this way, Aotearoa New Zealand falls behind international bodies with policies that include social media literacies, such as *The Digital Competence Framework for Citizens* (Vuorikari et al., 2016) and *A Global Framework of Reference on Digital Literacy Skills* (UNESCO, 2018).

7.4 Reporting Back

I made an easy read booklet called *Telling People about this Research* to report my findings to the Passioners (see *Appendix I*).

The contents of *Telling People about this Research* are as follows.

Telling People about this Research	
Heading	Description
<i>Why</i>	Talks about the reasons I decided to do this research.
<i>Thinking about this research</i>	An explanation of inclusive research, PAR, and IPAR.
<i>Who took part</i>	The eligibility criteria and a note that participants called themselves the Passioners.
<i>What we did</i>	The consent process and methods used in this research.
<i>How did the research go?</i>	Research benefits.
<i>Thinking about what this research means</i>	Key terms that are used in the following pages.
<i>Analysis</i>	The picture card analysis done by the Passioners.
<i>What I did with the data</i>	My thematic analysis process.
<i>Working with my advisors</i>	Acknowledgements for Glen Terry and Te Atakura Ryan.
<i>What I found out</i>	The themes I identified in the data.
<i>What I think should happen now</i>	My recommendations.
<i>Have I got this right?</i>	A page for the Passioners to respond to my findings.

I attempted to visit all the Passioners, however, David had passed away since our research meetings, and John was not home when I had arranged to see him. Hōri had moved from

supported living services⁵⁶ into residential care⁵⁷ since our research meetings, demonstrating the pace of change in the lives of people with learning disability.

Interactions on my visit with Hōri confirmed my understanding of the learning disability cultural literacy of aspirations as he sought to extend my role as a researcher into one of being an advocate (see *Section 8.6.2*). Melissa and her supporter met me at McDonalds to go over *Telling People about this Research*. Her supporter was also very interested in my findings. AJ was the only Passioner who used the last page of the booklet to give feedback. He told me to write, “people will need support to do the research” and that people were “learning in a different way.” He also said this research was “helpful on a personal level,” and asked me when we can do more research meetings. I reminded him that our research meetings were finished.

7.5 Conclusion

Using a social constructionist lens, different systems of knowledge are valued equally. Therefore, reading and writing are not superior to other literacy practices that are also used by adults with learning disability. As *Te Kāwai Ora* begins, “nāu te rourou, nāku te rourou, ka ora te manuhiri⁵⁸” (Māori Adult Literacy Working Party, 2001, p. 5), emphasising that our society becomes stronger through diversity (Ake & Moorhouse, 2016), so adults with learning disability add their basket of literacy practices to our non-learning disabled baskets of literacy practices. Learning disability cultural literacies are one way their unique literacy practices could be categorised and sustained.

⁵⁶ Living independently with some support.

⁵⁷ Living with support all the time.

⁵⁸ From your food basket and from mine, the wellbeing of the people will be assured.

8 Chapter Eight: An Evaluation of my Inclusive Approach in This Research

This chapter undertakes an evaluation of the inclusive approach I employed in this research. In presenting the voices of adults with learning disability, this research supported the extension of “nothing about us without us” to include adult literacy policies. An evaluation clarifies how this research itself was “nothing about us without us,” because inclusive research can include people with learning disability in a range of ways. Research is made up of components that each contribute to or detract from inclusivity and cannot be generalised. In doing this evaluation I encourage inclusive researchers to consider the inclusivity of all aspects of the research, rather than focusing inclusion on the data collection phase. This evaluation also creates an opportunity to continue learning from this research about making research more inclusive. This approach is unique, and I invite other inclusive researcher to consider evaluating their approach in this way.

Inclusive research grew out of the social model of disability and aims to dismantle barriers to research for people with learning disability (Garratt et al., 2022; Milner & Frawley, 2019) (see *Section 5.6.1*). However, this research used the affirmation model of disability, which views disability as an identity, rather than a form of oppression on people who have an impairment (see *Section 2.5.3*). Affirmation model pioneers Swain and French (2000) argued that disablement presents an opportunity to challenge the status quo, in contrast to improving access to what is already not working for disabled people, as in the social model.

Taking cues from the affirmation model, this chapter seeks to identify where the Passioners have added value to this research by participating in ways that are distinctive from convention, and by necessitating responsive adjustments to embrace those differences. Using an adapted Wehipeihana (2019) method, I conducted this evaluation in relationship with my advisors by meeting with each of them at the start of the evaluation to seek their guidance on what I was planning to do, and at the end of the evaluation to talk about my

learnings and see how I could contribute back to their communities⁵⁹. My advisor with learning disability defined the determinants of inclusivity, being “to,” “for,” “with,” “by,” and “as,” but I made decisions about how this research aligned with those determinants and wrote the evaluation report. While I had carefully planned how this research would be as inclusive as possible in the earlier stages, I decided to conduct an evaluation later and faced more significant time constraints by that stage of my candidature, placing limitations on how closely I could work with the community affected by this research.

8.1 Aims

Within the context of doing a PhD, this research was initiated by my endeavour to ameliorate an issue I observed as affecting adults with learning disability. My observation arose from an outsider standpoint as I do not have a learning disability. While I engaged in preliminary consultation with five disabled people to explore beginning a research topic that would meet my objective (see *Section 1.1*), only one of those five people had a learning disability. Reviewing the transcripts of this consultation, I found we had had conversations about literacy and adults with learning disability, but that I had formulated the research topic myself. For these reasons, this part of the research was “for” people with learning disability. While I consulted with one person with a learning disability, I failed to facilitate that consultation in a way that would give him power to set the aim of this research.

8.2 Ethics

This research adhered to the *Regulations* at my university. While some forms of adherence could have resulted in this research becoming a closed/invited space, my intention was

⁵⁹ My Māori cultural advisor asked for information about a course for herself and adult literacy education for her clients and my advisor with learning disability could not think of anything else I could do.

always to work with the HREC to find solutions that would enable participant self-determination and positive outcomes. The strategies I used to minimise the likelihood of the Passioners experiencing harm in this research while upholding their right to non-discrimination (United Nations, 2007, Article 5) will now be evaluated.

8.2.1 Meeting with Prospective Participants and their Supporters Prior to Data Collection

Working with the Passioners involved careful consideration of research consent processes. One of the methods I employed to mitigate participant vulnerability in a manner that added value to this research was meeting with prospective participants in their homes or at a location of their choice at least twice before the research meetings, with one of the meetings needing to include their supporter (see *Section 6.3.3*). I explained the research and the consent process during these meetings, before prospective participants and supporters made their decision regarding giving consent. I agreed to as much contact as participants and their supporters required for them to be fully informed. For example, Hōri and his supporter consented after four phone calls and three meetings, but John and his supporter consented after one phone call and two meetings. This measure intended to accommodate the variable pace at which potential participants gain an understanding of the research and consent process (Cook & Inglis, 2012; Ho et al., 2018), rather than to prescribe an arbitrary number of meetings. Contact time prior to engaging in research meetings also served to build rapport with prospective participants and their supporters, and to better understand their accessibility needs. Contact with the Passioners and their supporters continued throughout data collection.

I conceptualise the meetings with prospective participants and their supporters prior to data collection as being research “with” people with learning disability. This is because I worked with HREC to decide how to conduct the consent process in line with the *Regulations* (University of Waikato, 2008), and prospective participants decided what they needed to

fully understand the research and consent. I demonstrated a willingness meet their needs by engaging *kanohi ki te kanohi* on multiple occasions, rather than merely adhering to the minimum requirement of formalising their consent on paper.

8.2.2 *Having Ongoing Discussions about Consent*

The second way that research processes were improved by working with the Passioners was that we discussed the concepts of research and consent during research meetings. I borrowed the idea of discussing research and consent from Cook and Inglis (2012), who did participatory research with men with learning disability. Cook and Inglis (2012, p. 95) had discussions about research, consent, and ethics with their participants because these are abstract concepts that can exist as “false understanding and meanings” for people with learning disability. The Passioners added value by discussing these topics, the outcomes of which are described in *Section 6.4.2.1*. The purpose of these conversations was to expose the Passioners to ideas about research and consent so they could understand more about an academic perspective. Furthermore, a workable understanding of research and consent may be needed for the Passioners to do their own research “as” people with learning disability in the future.

8.3 Research Design

One element of research design that added value to this research was using easy read documents to make words and information as accessible as possible for the Passioners. Easy read documents were used the whole way through this research (see *Appendix E, I, K, N, and O*), each being approved by my advisor who has a learning disability. Some research jargon was used, for example, “research,” “data,” and “analysis,” but these words were agreed to by my advisor, explained in easy read, and their meanings discussed during

research meetings. I created five easy read documents over the course of this research, totalling 71 pages. Creating easy read documents was research “with” people with learning disability because I worked with my advisor with learning disability to prepare each document.

8.4 Recruitment

The Passioners added value to the recruitment in this research. I initiated a participant recruitment method known as snowball sampling with two people with whom I had pre-existing relationships, being Hōri and John (see *Section 6.3.2*). Hōri added value to this research by responding enthusiastically to the offer of recruiting prospective participants. He quickly went about phoning some of his friends with assistance from his supporter. His contribution to recruitment appeared to be spontaneous and driven by mutual interest. This element seemed to be research “with” people with learning disability, in that I structured the recruitment method, and Hōri decided how to apply the practice of recruitment in his own way by calling his friends and inviting them to take part in this research.

8.5 Data Collection

Doing research with the Passioners added value to our data collection in three main ways.

8.5.1 Reciprocal Social Interactions

I was fortunate that the Passioners invited me into their spaces outside of our research meetings. Melissa texted me almost every day for months and invited me to apply for the same job as she had. John invited me and my son to visit his family holiday home and to

come to his birthday party, both of which we attended (see *Section 6.3.4.1*). Hōri invited the Passioners and I to a Christmas party at his house, although we were unable to go due to COVID-19 restrictions. In addition to the information and consent meetings, reflection meetings, and feedback meetings, AJ invited me to his house for lunch, and I went. These social interactions helped me build research relationships and better understand the significance of this research to the Passioners. I believe their enthusiasm in embracing me into their lives is unique to inclusive research, or at least forms of participatory research (see O'Brien, 2014), and was research “by” people with learning disability, in that I was able to engage in what Glen Terry called “actually being there, like being beside you” (personal communication, 30 August, 2023).

8.5.2 Making Methods More Accessible

The Passioners added value to this research by giving me their feedback so I could adapt research methods to be more accessible for them. For example, I modified our inclusive analysis method (see *Section 6.4.3*) after my explanation of the method was met with long silences and a hesitation on the part of the Passioners to engage. I assumed these responses from the Passioners to indicate the activity was more complex and metaphorical than their usual practices and preferences. This experience with the Passioners aligns with advice from Hollomotz (2018, p. 158), who said “metaphors and similarly ambiguous expressions should be avoided, to accommodate those who possess a literal rather than a figurative mode of expression” when working with participants with learning disability. I responded by modifying the inclusive analysis method according to their feedback. One of the ways I did this was my reducing the number of cards on the table from 22 to four. Hōri said the modified method was, “easy now, not so many [cards] around the whole table.” The Passioners opted not to use my research template in this research, but AJ said he would use the template later in his own research.

The process of making methods more accessible moved this element of the research from being “to” to “with” people with learning disability. As someone who tends towards

complexity, having participants who tend towards simplicity helped balance my approach. While at first, I presented my picture cards to the group, we then worked together to make the method easier for everyone. I think my research template is the most like research “for” people with learning disability. I constructed the template (in consultation with my advisor with learning disability) and the Passioners decided how they would engage with that template.

8.5.3 Learning Disabled Research Methods

The Passioners added value to this research by using their own research methods, which I have called learning disabled research methods. One example of a learning disabled research method was AJ making a poster. The poster contained the words “PEOPLE FiRst LOVE PEOPLE FiRst,” along with some symbols (see *Figure 21*). AJ showed the poster at several stages of its development and asked for contributions from the group. Discussions about the poster threaded through nearly every research meeting. The following excerpt shows how the poster formed an opportunity for leadership, group collaboration, and a way for AJ to record the research.

I am doing a poster for our group and the poster is about how you can share different ideas in this research and like you can say some words and I can put them in the poster that I am doing and it’s like helping each other each people in this room to see what we feel and what we are doing in this research.

AJ said the poster means “to feel connected with you Nicolina and with the group.” The poster also had research significance for me as I used it to draw conclusions about the role of self-advocacy groups, such as People First, in the lives of the Passioners (see *Section 7.4.3.1*).

Posters are an established method for presenting research information (Becker, 2014). They often convey the main points of a research project in a single-page format utilising visual data with limited text (Becker, 2014). According to MacIntosh-Murray (2007), posters are often regarded as being a more egalitarian form of academic communication with fewer conventions and more scope for creativity. These attributes could make posters an attractive method for people with learning disability. In inclusive research, Goodman (1998) used posters as a stimulus to develop participant thinking in focus groups and workshops with people with learning disability, and Jones (2019) displayed a group agreement poster about working together at her hui.

I conceptualise poster making as being research “as” people with learning disability. While AJ asked for support in the form of receiving a large piece of paper on which to create the poster, he completed the project in his own time and space without further intervention from people without learning disability. It was his idea to do a poster and he did it according to his own values and norms.

8.6 Outputs

The key outputs of this research so far have been two presentations at People First, easy read documents including a summary of findings called *Telling People about this Research* (see *Appendix I*), a doctoral thesis, one academic journal article (see *Appendix L*), and one academic conference presentation (Newcombe, 2021). I also intend to write further publications and make submissions based on this research in the future, which will be written inclusively where possible (see *Appendix P*)⁶⁰.

⁶⁰ My abstract to contribute an inclusive chapter in *The Routledge International Handbook of Disability Research and Enquiry*, which will be co-authored with my advisor with learning disability and PhD supervisor Dr Gretchen Good, has been accepted.

The Passioners and my advisor with learning disability added value to this research by creating their own research outputs. While relevant to this research, academic outputs may not be the most important output for the Passioners. People with learning disability generally report being more interested in outcomes, such as social and policy changes, than academic outputs, such as theses and journal articles (Riches et al., 2020). Furthermore, the latter outputs have typically comprised “a conversation of ‘us’ with ‘us’ about ‘them,’” *us* being academic researchers and *them* being the subjects of research (Cahill & Torre, 2007, p. 196). However, inclusive research presents an opportunity to produce a broader range of outputs (Riches et al., 2020).

8.6.1 Presentations at People First

The Passioners added value to this research by disseminating information about this research and findings to their community at People First meetings. Their method was like Riches et al. (2020), who noted that people with learning disability are more likely to contribute to non-academic outputs, such as group discussions, conference presentations, and video summaries. At the first People First meeting, the Passioners shared a PowerPoint presentation I made about this research, with my assistance. Two of the Passioners and my advisor who has a learning disability read out the slides and answered questions from the group.

Later, my advisor with learning disability suggested updating People First on our research progress. I assumed that I would be invited as a guest speaker, but my advisor said, “leave it to me” (G. Terry, personal communication, 30 August 2023). I was surprised to be informed that he had given a presentation about this research at another People First meeting. The organic dissemination of this research appears to be research “as” people with learning disability because a person with learning disability did that research task in his community.

While the output happened without my support, a People First local assistant provided support for the meeting.

8.6.2 *Easy Read Findings*

I reported my findings in an easy read booklet called *Telling People about this Research* (see *Appendix I*). My advisor with learning disability provided input in the creation of the booklet. When visiting the Passioners and reading out the booklet, Hōri stopped me at the point about having goals. He told me his four goals and asked if I could arrange for someone to say when he can do them. We subsequently spoke to one of his support workers who advised Hōri to do another organisational personal plan before she could move towards assisting him. As such, Hōri and I were able to use an output of this research to engage in advocacy and self-advocacy towards his pathways of choice. MacKenzie et al. (2015) found advocacy to be a research output that is relevant and meaningful to communities. The advocacy and self-advocacy that resulted from *Telling People about this Research* was research “with” people with learning disability, because I wrote the booklet (with input from my advisor with learning disability), and one of the Passioners decided how they would use that output.

8.6.3 *Academic Outputs*

It is challenging to produce academic outputs in an inclusive manner. I was unable to include the Passioners in writing my PhD thesis because it is required to be singularly authored by an enrolled student. Furthermore, some academic outputs from this research occurred early in my candidature (Newcombe, 2021, 2022). My experience of creating academic outputs independently of the Passioners mirrors the findings of Riches et al. (2020), who noted that researchers without learning disability write most academic journal articles about inclusive

research. This is, in part, because of barriers to people with learning disability publishing in academic journals, such as restrictive criteria for authorship, quick publishing timeframes, and exclusive writing conventions (Riches et al., 2020). The context of this research taking place so that I could complete a PhD qualification limited the inclusivity of the academic outputs that were produced. The academic outputs of this research have so far been “to” people with learning disability because I did these research tasks and presented a summary of my findings to the Passioners.

I assigned academic outputs in the lowest category in my graph of inclusivity (see *Figure 26*) because the completed academic outputs were done independently by me. Yet, there is clearly scope for inclusivity in academic outputs because other authors are learning disabled or have published with people with learning disability (Aspis, 2000; Chapko et al., 2020; Chapman & Townson, 2012; Garbutt et al., 2010; Riches et al., 2020; Vaccarino et al., 2023; White & Morgan, 2012).

8.7 Graph of Inclusivity

An adapted Wehipeihana (2019) model was useful to evaluate this research. I learned that inclusive research is not “with,” “by,” or “for” (Nind, 2014), or “on,” “with,” or “by” people with learning disability (Milner & Frawley, 2019), but comprises elements that can be represented by those metrics, and extended beyond them, with “to” and “as,” being added from Wehipeihana (2019). This research spans the entire spectrum of “to,” “for,” “with,” “by,” and “as” people with learning disability. Moreover, I identified one element of this research as transforming from “to” to “with,” and another element as having the potential to enable future research “as” people with learning disability. Thus, I constructed a graph to visually display the plot points described in this chapter.

Graph of inclusivity

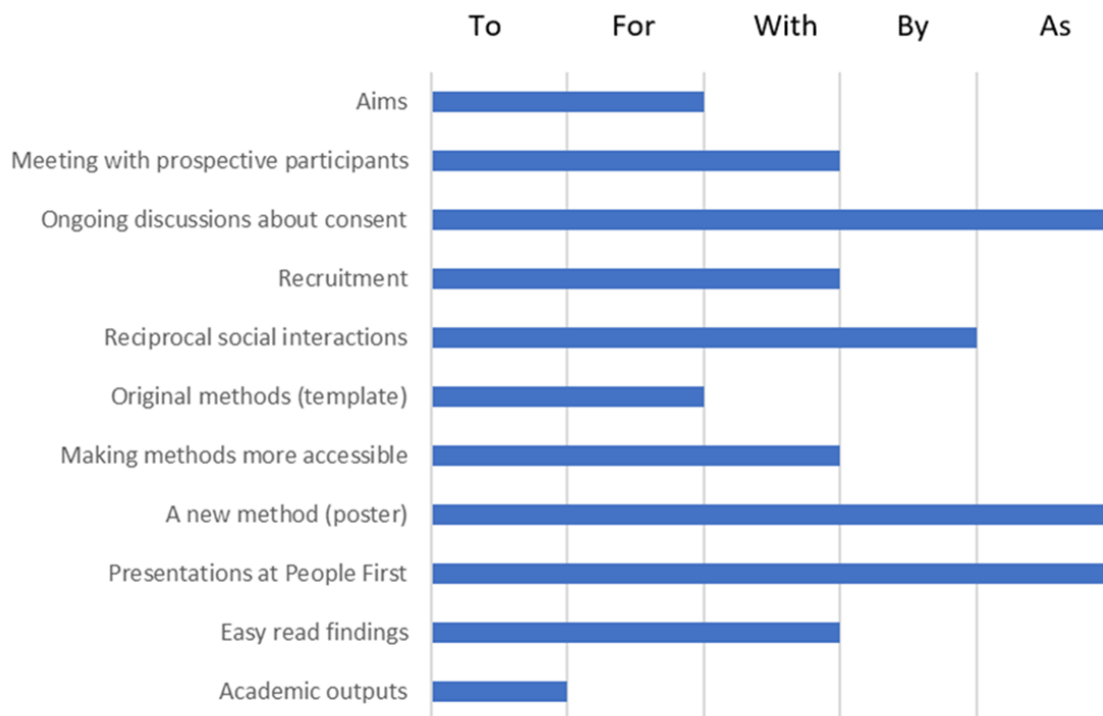


Figure 26 Graph of inclusivity.

8.8 Conclusion

I was privileged to work with the Passioners because they added value to this research and enabled methodological insights into making research more inclusive. The Passioners offered their own networks, attitudes, and methods, providing unique opportunities that could only be available through doing inclusive research with them. Their circumstances and particularities created challenges that were resolved by improving research processes, innovative research methods, making information more accessible, and acculturating myself in their worlds.

My evaluation demonstrates that inclusive research is made up of numerous actions and decisions that can be variously inclusive and remediated to become more inclusive where

necessary when those changes are permitted by the research conditions. This finding identifies the need for inclusive research to be transparent about how people with learning disability were involved in in all aspects of the research process, rather than generalising their involvement based on one or more parts of the research. Such as concentrating solely on recruitment and data collection as the focal points for inclusion.

This research did occur within the context of a PhD, which limited the decision-making powers that the Passioners and I had. However, this research was as inclusive as it could be considering my abilities, expectations, values, context, and the resources that were available. I will endeavour to continue an inclusive approach beyond this PhD by updating and seeking feedback from the Passioners as I create further outputs from this research in the future.

9 Chapter Nine: Discussion

This chapter addresses my research questions by providing a summary of research findings framed within the context of existing research. Following on from those findings, my adult literacy policy recommendations are prefaced by the policy changes that have already occurred during my candidature. Implications for researchers are then explored. Finally, the limitations of this study are discussed, and prospects for future research outlined.

The real-world problem at hand revolves around prevailing assumptions regarding the literacy of adults with learning disability and that these assumptions result in attitudes that often act as barriers to opportunities for them. While there is no statistical data to show whether adults with learning disability access adult literacy education equally with people without learning disability, the language of adult literacy policies presents them as a group of outliers and the policies do not guarantee their inclusion. Furthermore, the progressive and linear approach to literacy learning described in the adult literacy policies may not align with the needs of adults with learning disabilities, which exacerbates the challenges of exclusion faced by this demographic. These problems provide two compelling reasons for this research, one being rights-based, and the other ideological.

In terms of rights, people with learning disability have the right to access lifelong learning “on an equal basis with others,” and the right to have States Parties “closely consult with and actively involve” them “through their representative organizations,” when decisions about them made (United Nations, 2007, Article 25, Article 4.3). Yet these rights have not been realised in the adult literacy policies. Policymakers need to become aware of the standpoints of adults with learning disability, and form policies that will be inclusive of that group. One way to achieve this awareness is through research but to be effective, that research needs to involve relevant people in real world settings (Macfarlane et al., 2014).

In terms of ideology, the affirmation model of disability presents disability as an opportunity to challenge what is not working in our society (Barnes & Mercer, 2010) (see *Section 6.3.2*). The privileging of reading and writing as the delineator of who is literate in Aotearoa New

Zealand marginalises people with learning disability through its negative effect on educator attitudes about them as being capable literacy learners. In contrast, this research acknowledges the innate and inalienable literacy of all people and seeks to promote the inclusion of people with learning disability in their chosen pathways.

The origins of the notion of disability as other and less than, and the establishment of a standardised literacy in the form of reading and writing, can both be traced back to the Industrial Revolution. The Industrial Revolution necessitated a uniform approach to literacy to ensure effective communication among newly urbanised workers (Cook-Gumperz, 1986; Guar, 1984). For this reason, education in literacy via schooling was extended to all children, rather than being reserved for the elite (Cook-Gumperz, 1986; Guar, 1984). Levels of literacy then became precisely defined so that learner abilities could be measured. Evidencing the interconnectedness of literacy and learning disability, major diagnostic manuals used a descriptor of low literacy skills as a criterion for identifying individuals with varying levels of learning disability until 2013 (American Psychiatric Association & Task Force on DSM-IV, 2000; World Health Organization, 1980). While the corresponding current diagnostic manuals no longer reference literacy, the prominence of literacy within ways of thinking about learning disability has already been entrenched (Kliewer et al., 2016). This research highlights the link between literacy and learning disability to establish a foundation for changing that relationship into one that supports transformative equality. The goal is that adults with learning disability are recognised as literate members of the community and their equal access to lifelong learning is ensured.

The Aotearoa New Zealand adult literacy policies define adult literacy and inform how TEC funded adult literacy educational opportunities are apportioned, what qualifications educators will have, the andragogic approach they will use, and when and how learners will be tested on their literacy skills. These policies have an impact on adults with learning disability who have some of the lowest literacy outcomes when assessed using quantitative measures (Bochner et al., 2001; Moni et al., 2018; Morgan & Moni, 2008; The Roeher Institute, 1990, 1994; Trenholm & Mirenda, 2006). Yet, there has not been an opportunity

for adults with learning disability in Aotearoa New Zealand to inform adult literacy policies, directly in person, through their representative organisations, or indirectly via leading or participating in relevant research. I have responded to this omission by undertaking inclusive research with adults with learning disability so that it can be used to make recommendations for future adult literacy policies. As such, this research renders the voice of people with learning disability as being relevant to adult literacy policy development.

9.1 Summary of Findings

I derived findings from my policy analysis, analysis of our research meetings, and an evaluation of my inclusive approach used in this research. The policy analysis informed the need to undertake inclusive research, it did not inform the content of the research meetings because that was directed by the Passioners. Findings are summarised in the following three sections.

9.1.1 Policy Analysis

This research has identified and analysed current adult literacy policies in Aotearoa New Zealand to ascertain their impact on adults with learning disability. The language and values embedded in these policies shape understandings of what literacy is and who is considered literate in Aotearoa New Zealand, which effects the availability and nature of adult literacy educational opportunities, the determination of eligibility, and how progress is measured.

The adult literacy policies promote the notion of a typical learner and say that Deaf and disabled learners require specialised resources or programmes. However, it is evident that there are no specific resources or programmes for meeting the needs of adults with learning disability when they seek adult literacy education. Failing to incorporate research with participants with learning disability when developing the adult literacy policies has resulted

in policymaking that overlooks their valuable insights and perspectives that could provide a more inclusive way to understand literacy.

The adult literacy policies define literacy as reading, writing, speaking, and listening in English. While a continuum of competence is highlighted in the *Learning Progressions* (see *Section 5.3.2*), the TEC also influences attitudes by presenting literacy as a binary of skills partitioned by a literacy threshold⁶¹ that situates people as having the literacy skills to participate in the information age or as being considered to have low literacy skills. The adult literacy policies also promote the idea that learners progress through a universal developmental trajectory, demonstrating a lack of awareness about the needs of people with learning disability. Furthermore, the policies contribute to the normalisation of adults with learning disability by focusing on the enhancement of individual literacy skills, instead of providing environmental accommodations by improving accessibility to sites of literacy. As indicated in my literature review (see *Section 3.2.3*) and research (see *Section 7.4*), people with learning disability have a wider range of literacy practices, which are not always recognised by the learning progressions.

The adult literacy policies in Aotearoa New Zealand can be described as having competing ideologies, one being cost effectiveness, and the other being social wellbeing. These ideologies broadly reflect the direction of the governments that respective policies were formed under. While the policies are currently trending towards becoming more inclusive of adults with learning disability, the needs of those with learning difficulties, such as dyslexia and dysgraphia, appear to be taking precedence. Furthermore, after navigating a global pandemic and other unprecedented costly challenges, the political landscape in New Zealand is now focused on restoring fiscal equilibrium. Given the current context, it is unfortunate that any examination of our adult literacy policies would suggest that the concerns of disabled people are primarily addressed during periods of increased government spending.

⁶¹ Step 4 on the or above for reading in the *Learning Progressions*.

9.1.2 Analysis of our Research Meetings

The Passioners shared their literacy practices and perspectives in our research meetings. One of the findings was that the Passioners had different reasons for wanting to engage in adult literacy education than those described in the adult literacy policies. Reasons outlined in the policies are to improve learner skills in reading, writing, listening, and speaking to enable greater workplace productivity, progression to higher education, and more effective participation in society. In contrast, the Passioners wanted to take part in adult literacy education for its experiential benefits. Hōri described these benefits as being, “to see what it's like,” to “learn something,” and to “meet new people.” Zepke (2011) similarly found that differences between the adult literacy policies and the perspectives of Te Wananga o Aotearoa were about their contrasting purposes for the provision of adult literacy education (see *Section 7.4.1*).

The Passioners demonstrated an interest in reading and writing that appeared similar to existing research about some adults with learning disability having positive attitudes towards reading and others being reluctant to engage in that practice (Bochner et al., 2001; Morgan, 2013; Morgan & Moni, 2008). Two of the Passioners frequently offered to read slides and information out to the group, for example, “Yip I would like to do some [reading]” (AJ), whereas others were happier to listen. I cannot compare the reading strategies of the Passioners with the findings of Bochner et al. (2001) or Morgan et al. (2013), except to make a general observation that the Passioners tended to decode all the information on a page or screen by interpreting the pictures and reading the words together, rather than identifying the pictures as distinct from the text. This phenomenon could have implications for easy read design.

The Passioners all showed a preference for easy read, in alignment with existing research (Buell et al., 2020; Chinn, 2019; Fajardo et al., 2014; People First New Zealand, 2017; Turnpenny et al., 2018). For example, both Melissa and David produced an easy read

document using a Photosymbols template (see *Figure 23*) but did not do any other writing. Hōri brought his easy read *Research Booklet* to every research meeting.

The Passioners had similar and different literacy practices to those described as being used by adults with learning disability in *Section 3.2.3*. In contrast to Morgan et al. (2013), who found participants completing workbooks, the Passioners did not want to use a template (which could be seen as similar to a workbook). Copying other writing, as described by Morgan et al. (2013) and Trenholm and Mirenda (2006), did not occur in our research meetings. Forts and Luckasson (2011) used reading and writing to send cards and letters, whereas four out of five Passioners used the modern equivalent of these literacy practices in sending messages electronically via social media. John described being motivated to read and write as part of playing *Dungeons and Dragons*. He used reading and writing to fill in character sheets, find names, backstories, and personalities, and write about what army and weapons he is using. The Passioners enjoyed doing speeches and drama. John used drama as a means of connection, objecting to the idea of a single person role play as proposed by AJ, saying, “the thing about role play is doing it together, [that] is kind of the point about role play.” Photos were also a popular literacy practice, with John belonging to a photography club and having made a Facebook page about his photography. Melissa said she was taking a photo for the first time at our research meetings and took one photo. David showed us how to take a selfie. None of the Passioners used individualised communication systems (see *Section 3.2.3.3*), Makaton, New Zealand Sign Language, Augmented and Alternative Communication, or any other assistive technology.

The Passioners did not discuss any of the social media platforms developed specifically for people with learning disability, this may be because even I could not find a way to access these platforms using Google. Those who were less affected by the digital divide had more social media literacy skills. The Passioners used social media for interest, enjoyment, connection, and expression, in alignment with existing research about people with learning disability using social media (Borgström et al., 2019; Caton & Chapman, 2016; Iglesias et al., 2019).

Even though the Passioners did not identify themselves as having a culture, they demonstrated what I interpreted as being a learning disability culture (see *section 7.1.3*). My interpretation arose from parts of the transcripts that aligned with objective and subjective elements of culture (Berry & Triandis, 2014). Then, building on a foundation of what has been discussed about Māori cultural literacy in previous research (Leach et al., 2010; UNESCO, 2016; Zepke, 2011), I constructed five examples of learning disability cultural literacies from data created by the Passioners in our research meetings. These were self-advocacy, accommodations, choice and control over supports, aspirations, and drama.

The Passioners demonstrated an awareness of Māori cultural literacies in terms of *kaitiakitanga*, *karakia*, *Kīngitanga*, *poukai*, knowing about *Te Tiriti o Waitangi*, *tikanga*, *wānanga*, and *whakawhanaungatanga*, but did not bring up the Māori literacies of *moko*, *kōrero tuku iho*, or *whakario rākau* that were listed in *Section 3.2.1*. We never discussed the use of Pākehā cultural literacies, but I inferred these from the data on advice from my Māori cultural advisor, which arose in relation to a reflexive decentring of Pākehā culture in this research.

Findings garnered through analysis of our research meetings eschew the technological model of literacy because that model is key in restricting literacy to the narrow definition of reading and writing. Rather, the Passioners demonstrated a diverse range of multimodal literacy practices in alignment with the sociocultural model of literacy. This research only explored uses of language that resulted in communication. While the uses of language in learning disability cultural literacy extends the uses listed in *Section 3.1.4*. All lists of uses of language are necessarily partial and will continue to be constructed over time (Smith, 1983). Learning disability cultural literacy could be thought of as the functional literacy skills needed for people with learning disability to meet their unique needs in their unique contexts. However, such an application of functional literacy would require the redefinition of dominant understandings of the theory that focus on skills related to reading and writing.

9.1.3 Evaluation of my Inclusive Research Approach

I adapted an existing Wehipeihana (2019) model of evaluation to use in this research by substituting her definitions for the determinants of evaluation (to, for, with, by, or as) with definitions formulated by my advisor with learning disability, Glen Terry, to align the model with outcomes of importance to people with learning disability (see *Section 5.9*). This method explored how participants with learning disability added value to this research. I used outcomes from this evaluation to challenge and refine existing knowledge about inclusive research being on, with, by, or for people with learning disability (Milner & Frawley, 2019; Nind, 2014). Findings demonstrated that an inclusive research approach is contingent on researchers without learning disability being responsive and working to constrain our own roles within the research process. This evaluation supported me in acknowledging the research tasks done by the Passioners and their capability to do their own research now or in the future.

Any research process encompasses a variety of elements such as aims, participant recruitment, methods, analysis, and outputs. Some of those processes can be more easily completed in a more inclusive manner and some are more constrained by academic conventions. My evaluation has shown that each research process has its own limitations that present unique challenges to achieving comprehensive inclusivity. Therefore, this research continues conversations initiated by Nind (2014) and Milner and Frawley (2019). Nind (2014) explained how inclusive research signifies a shift in the dynamic between researchers with and without learning disabilities. Instead of continuing to make generalisations about inclusive research, this study underscores the need for a multi-faceted consideration of the inclusivity of each part of the research process.

My findings highlight specific instances where the Passioners added value to this research. Reflecting on my experience doing this research, I concur with Koenig (2012), who described how participants with learning disability contributed methodological insights that shaped the trajectory of his research and provided practical value through the sharing of their

experiences. Walmsley et al. (2018) further defined the added value of inclusive research, discussing its differentness and uniqueness. For Walmsley et al. (2018), doing research with people with learning disability impacts the quality of the research process and its outcomes and influences other researchers. The Passioners added value to this research by speaking from their standpoint, slowing the research process in a way that fostered my deeper understanding of concepts and data, and showed me how to make research methods more accessible. For example, while easy read documents were purposed to be more accessible for the Passioners, the act of writing them proved beneficial for me, by assisting me in breaking down and distilling my own understandings of this research. Koenig (2012) described the additional time and resources needed to enable people with learning disability to take part in his research as an investment into capacity building for future inclusive research. While Koenig (2012) elucidated one reason for enhancing the accessibility of inclusive research, as a disabled person and long-term disability advocate, accessibility and inclusion are part of my usual thinking and it would not make sense for me to approach research in any other way.

In doing this research, I found myself in agreement with Hollomotz (2018), who said the key attribute of an inclusive researcher is to be responsive. For example, people with learning disability might do something unexpected because they are not familiar with the unspoken boundaries or hierarchies of research. One instance of this happening was when AJ wanted to host another meeting to explain what we were doing to other local disabled people. Such a meeting could have had implications for my ethical approval, and I would also have had to respond to the outcomes of that meeting. While his potential actions may have enhanced this research, I did not feel able to manage such a deviation from existing plans. In summary, doing inclusive research necessitates responsiveness to the actions and reflections of participants, and being willing to make corresponding adjustments to research processes.

Importantly, this research has demonstrated that inclusive research significantly benefits from preexisting relationships and relationships developing within the research context. For

example, my preexisting relationships enabled me to easily organise doing preliminary consultation with appropriate people and to recruit expert advisors. I was also able to draw on my relationships with adults with learning disability to employ a critical perspective regarding their vulnerability (see *Section 5.10.2*). These relationships inspired me to counter the *Regulations* by implementing a two-tiered approach to consent that was more respectful for participants and better aligned to Article 12 of the CRPD (Newcombe, 2022) (see *Section 5.10.3*). Meeting with prospective participants at least twice before they joined the research was partly about building relationships with them and their supporters, part of which was to gain an understanding of their needs and communication styles. The Passioners and I enjoyed a trusting and egalitarian relationship. This was evidenced by them inviting me into their spaces outside of our research together (see *Section 8.5.1*), to the point of stretching my boundaries at times (see *Section 5.7.2.2*), their confidence in challenging me (see *Section 7.1.1*), in challenging the research processes I had planned (see *Section 7.1.3*), and in AJ offering to mentor me (see below). My advisor with learning disability reinforced the centralisation of relationships in inclusive research. He said my research was, “really well done.” When I asked him how he knows I have done a good job, he replied, “it's on how long you and I known each other, it's about the relationship and that bond that we have, we trust each other” (G. terry, personal communication, 26 February, 2024). Therefore, my relationships with people with learning disability facilitated practical aspects of this research as well as critical perspectives and meaningful collaboration.

My evaluation demonstrated that people without learning disability do not need to assume leadership in research to the degree I presupposed being necessary. For example, while I had initially planned some research methods, the Passioners also introduced their own research methods, such as the poster (see *Section 8.5.3*) and the role play (see *Section 7.1.2*), and rejected one of my methods, being the picture card analysis (see *Section 5.7.3.2*). Through this experience, I learned that researchers without learning disability should seek to minimise our role in the planning and development of research to the greatest extent

feasible. This approach would promote people with learning disability doing research “as” people with learning disability (see *Section 5.9*).

A key finding is that I needed active participation and feedback from people with learning disability to make the research more accessible. Therefore, reflection with participants needs to be an essential component of an inclusive research approach. I engaged in reflection with the Passioners between research meetings using Facebook messenger, email, and home visits. Sometimes the reflections were positive, such as “there was nothing hard about the zoom meeting. The zoom meeting was easy. Every person had their own opinion one at a time. Carry on the meeting as usual. No changes needed at the moment” (Hōri). Other times the reflections indicated that adjustments were necessary (see *Section 5.7.3.2*). Visiting the Passioners proved to be a more effective means of eliciting their reflections compared to email and messenger, while also enhancing our relationship building. Furthermore, I was able to hear participant voices directly during in person meetings, whereas I was unsure if written communication had been mediated via support people. Unfortunately, I did not record and transcribe reflective meetings as I had done for our research meetings, opting to write my recollection of participant reflections instead. A more accurate record of these reflections would have enabled greater insights to be garnered during the writing stage of this research.

Conducting an evaluation based on Wehipeihana (2019) made it easier for me to identify more of the research tasks undertaken by the Passioners. For example, Hōri took an active role in doing recruitment, John taught us how to use the digital camera, and AJ explained several slides and templates to the group. Even tasks such as leading the karakia could be described as an integral part of doing this research. AJ also offered to provide me with mentorship.

AJ. Nicolina, if you want any extra help with your research, I can help you out.

Nicolina. Okay, how would you like to do that?

AJ. I was thinking like I could mentor you.

Nicolina. Okay that would be great, for sure.

AJ. I know I have literacy experience and I can help you out.

Nicolina. Yip, that would be really appreciated.

These experiences with the Passioners challenged the three categories for approaches to inclusive research proposed by Bigby et al. (2014) (see *Section 5.6.1*). All three of these categories assumed that people with learning disability need involvement from people without learning disability. In contrast, there is no automatic inclusion of outsiders in Wehipeihana's model, as outsider involvement is subject to invitation.

For Wehipeihana (2019), it is more important that evaluators learn relationship skills than it is for the community to learn evaluation skills. On the one hand, it does not seem as if this evaluation measured up to the work of Wehipeihana in McKegg et al. (2016, p. 140) who said, "it is through relationships that the evaluation process unfolds," yet on the other hand those authors reported meeting fortnightly with staff from the educational initiative they were evaluating. Therefore, this evaluation may have been punctuated by the same meeting frequency as in McKegg et al. (2016) due to the smaller scale and scope of the evaluation in this research.

Finally, this research is consistent with the work of Goodley (2000), who discussed the productive reciprocity between self-advocacy groups and research. Some of the Passioners are long term People First members, through which they have ongoing opportunities for project work and leadership. They were able to bring transferable skills such as critical thinking, leadership, and ideas about how to reach their community from their experience at People First. Glen, my advisor with learning disability, also disseminated outputs in his community by leading a discussion about this research at a People First meeting.

9.2 The Evolution of Adult Literacy Policies During this Research

While the adult literacy policies that were current at the beginning of my doctoral journey in 2020 were a source of significant concern for me, several positive changes have occurred over the course of my candidature. My concerns revolved around the limited interventions offered almost exclusively to priority groups and the excessive assessment used to measure the impact of financial investment in adult literacy education. However, adult literacy and related policies published during the time I have been engaged in this research reflect a trend towards broader, rather than more specific, targets, and decentralisation with increased autonomy for educators, rather than more government control. These changes are favourable for adults with learning disability and align with the direction of the Sixth Labour Government, which secured a resounding mandate in the 2020 general election.

The *Literacy and Numeracy Implementation Strategy 2015–2019* (TEC, 2015) was one such policy that was in effect when I started this research. That strategy exclusively targeted Māori, Pasifika, young people, migrants and refugees, and people with learning challenges such as dyslexia. People with learning disability were excluded by omission. Although no new strategies specific to adult literacy have been published since then, the *Tertiary Education Strategy* has a more general orientation towards all learners, including those who are disabled or underserved (Ministry of Education, 2020b).

The Inclusive Literacy and Numeracy (ILN) fund is the adult literacy fund most likely to be applicable to adults with learning disability. It was restricted to 80 to 300 hours of delivery per learner at the start of my candidature (TEC, 2020). This would have been potentially problematic for adults with learning disability because research has shown they typically take longer to acquire new skills in reading and writing than adults without learning disability (Moni et al., 2018). In 2022, ILN changed from being capped per learner to being available as an average number of hours delivered per learner per year (TEC, 2021a). This was an outstanding improvement that transformed the ILN from a limited investment to a lifelong entitlement.

The *Guidelines for using the Literacy and Numeracy for Adults Assessment Tool* (TEC, 2017a) were updated in 2023 (TEC, 2023d) resulting in several progressive changes. The first of these changes was to reduce the use of prescriptive terms in favour of more flexible language. For example, in 2017 (p. 5) a list of educational actions was headed with “providers should,” whereas the same list begins with “your response may include” in 2023 (p. 5). Messaging around the online and paper versions of the LNAAT has also shifted. In 2017, the LNAAT was described as “predominantly online” (p. 4) and in 2023 it was described as “mostly online” (p. 4). The substitution of predominantly for mostly seemed to indicate a reduced emphasis on the online version. Given the significant digital exclusion facing people with learning disability (see *Section 5.7.3.1*), paper-based assessments may be better suited to some in this group. Further changes in the *2023 Guidelines* included that the description of people who use the LNAAT was expanded from foundation learners⁶² to all learners.

Importantly, targets for statistically significant gains were removed from the *2023 Guidelines*. This method was previously used to compare progress between two subsequent engagements with the LNAAT or SPAT by calculating the probability of an increase in learner results that is greater than zero (New Zealand Council for Educational Research, 2019). This information enabled the TEC to target funding to people who were more likely to improve their reading and writing skills during their enrolment period. However, it overlooked other benefits of adult literacy education, such as those experienced by adults with learning disability.

The *2023 Guidelines* now include initiatives to support student wellbeing. For example, asking providers to consider how learners feel by checking in with their readiness for assessment and taking action to minimise their anxiety. There are also references to new resources, such as videos about the LNAAT that are now available in te reo Māori, Samoan and Tongan languages, and guides to support neurodivergent learners. In 2023, the fund-specific requirements for the LNAAT were moved from the funding conditions catalogues to

⁶² Learners accessing pre-degree TEC funded education that is not vocational and not research.

the new *Guidelines* so that future funding conditions could be more flexible and responsive (TEC, 2023e).

Another policy change made by the TEC was expanding the range of qualifications that can be held by adult literacy educators teaching Employer-led Workplace Literacy and Numeracy, Intensive Literacy and Numeracy, and Workplace Literacy and Numeracy TEO-led courses (TEC, 2023g). These now include a choice of certificate level adult literacy education qualifications and qualifications in combination with professional development (such as micro-credentials and digital badges), any adult literacy education qualification at degree level or above, and any general teaching qualification with specific professional development. Exemptions are available for some educators who can demonstrate competence and have five or more years of practical experience.

The term “special education” was changed to “inclusive education” in the *2024 Funding Conditions Catalogue*. This term appears in reference to the Special Supplementary Grant (SSG). The term “learning gain” has also been removed in line with funds holders no longer being required to report on statistically significant gain (TEC, 2024). The LNAAT is still required as part of learner eligibility for some foundation funds but is no longer required to evidence progress (TEC, 2023e). Finally, tertiary education organisations are now able to apply for approval to deliver ILN for fewer than five hours per week, rather than a five hour minimum (TEC, 2023b), which may have been too intense for some adults with learning disability.

Some of the changes described in this section are transformative and provide an avenue towards the realisation of recommendations that I will make the next section. The policy direction expressed in the Tertiary Education Strategy to “reduce barriers to education for all” also indicates the timeliness of a conversation about educational inclusivity for adults with learning disability (Ministry of Education, 2020b, p. 2).

9.3 Adult Literacy Policy Recommendations

This section outlines policy recommendations based on findings from this research that would value adults with learning disability as literate members of the community and improve their access to adult literacy education “on an equal basis with others” (United Nations, 2007, Article 24.5). Recommendations are broadly divided into four categories, which are intended to enable the adult literacy policies to move from a needs-based to a rights-based distribution of adult literacy education. As will be discussed, adjustments in policy consultation, content, and terminology could enhance the inclusivity of adult literacy policies for adults with learning disability. Many of these changes do not require substantial financial resources. Rather, they demand political will to prioritise a group of people who may not yield a return on investment in terms of increased taxation revenue or improve indicators for reporting to the OECD.

9.3.1 *Recognise Adults with Learning Disability as Literate*

The TEC defines literacy as reading, writing, speaking, and listening. This narrow definition does not recognise many of the literacy practices discussed or demonstrated by the Passioners in our research meetings (see *Section 7.3*) and therefore has the potential to represent them as having low literacy skills. Replacing the word literacy in the adult literacy policies with specific skills or skill levels would avoid using language that appears to negate the inherent literacy of all people. The adult literacy policies already name skills in some instances, such as, “New Zealand adults require a certain level of expertise in listening, speaking, reading and writing” (TEC, 2008a, p. 4). However, continued use of specific language would be useful in other instances, such rewording, “a learner who... has low skill levels in literacy” (TEC, 2024, p. 53), to *a learner whose LNAAT results enable them to meet the eligibility criteria for this fund*. Using more specific language rather than the more

general term “literacy” would enable adults with learning disability to be recognised as literate in the adult literacy policies.

The TEC has already stopped requiring formative use of the LNAAT for all but Foundation funds (no assessment is required to access ACE) and stopped requiring the LNAAT to be used for progress assessments (see *Section 9.2*). Going further by removing any compulsion to use the LNAAT or SPAT would better recognise the right to education, rather than using assessment to ascertain the presence of need. It would also avoid the presentation of an outcome that may conflict with the Passioners’ assertions of the of themselves as literate. One of the Passioners described his experience doing the LNAAT,

That test, it started off easy, but a little bit hard. But once you know what you are doing. My staff who taught me this test, she said what is going to happen in the test to write down what you think will happen. And the test was like a lot of questions that you can help know some of these. Or learn what question you have done, so you can look at it like right, this is this question. And how you gonna in your perspective way and about we write stuff down in words (AJ).

Educators can still be encouraged to utilise the LNAAT as a tool when it is suitable for and beneficial to individual learners.

Instead of focusing solely on the quantitative outcomes of adult literacy education as described in adult literacy policies (see *Section 6.2.3*), the Passioners experienced or aspired to participate in adult literacy education for the inherent purpose of engaging in the event itself. As a quantitative tool, the LNAAT does not have a mechanism for appreciating the scope of functions and advantages of adult literacy education for adults with learning disability. The Passioners expressed their purposes for engaging with or wanting to engage with adult literacy education in our research meetings, which were to have new experiences, to connect with other people, and to learn. In response, I recommend the implementation of a qualitative purpose and feedback process, akin to the wellbeing

framework developed by Furness and Hunter (2019). This process would enable learners to identify why they want to participate in adult literacy education and what they hope to gain from it, then give them an opportunity to reflect what has worked well in meeting those aims and what needs to happen differently in the future. The results of this process would capture the outcomes of adult literacy education in way that highlights the benefits for adults with learning disability.

Recognising adults with learning disability as literate by employing language that distinguishes their reading and writing skills from their overall literacy status could enhance access to adult literacy education by influencing educator attitudes. Furthermore, if educators were permitted to consider the success of learners in adult literacy education based on subjective purposes, rather than solely on completing a course with reasonable accommodations or, until 2023, on achieving statistically significant gains, they may be more inclined to facilitate their access. Shifting towards capturing how learners fulfil their objectives, while restricting the use of quantitative testing to instances where it benefits the learner, would enable educators to focus on what is important for everyone, including adults with learning disabilities.

9.3.2 Recognise Adults with Learning Disability Within the Main Narrative of the Adult Literacy Policies

The policy analysis presented in this thesis shows that adults with learning disability are not recognised within the main narrative of the adult literacy policies. Instead, their needs are referred to in a manner I have constructed as categorising them to be outliers (see *Section 6.2.4.3*). The adult literacy policies are also not informed by any research about people with learning disability (see *Section 6.2.5*) and their stories are not represented in the case studies (see *Section 6.2.4.1*).

The adult literacy policies currently fund reading, writing, listening, and speaking remediation that responds to the needs of most adult learners (see *Section 6.2.4.2*). Conversely, they construct Deaf and disabled people as outliers who may need “specialist resources or programmes” and “specialist assistance” (TEC, 2008d, p. 8) (as discussed in *Section 6.2.4.3*). In doing so, the adult literacy policies read as if meeting the needs of adults with learning disability is exceptional and therefore optional. A more inclusive approach could be to ensure all adult literacy education opportunities are accessible for Deaf and disabled learners rather than only for most learners.

Another example of where adults with learning disability are omitted from the adult literacy policies is in the *Starting Points* case studies. As discussed in *Section 6.2.4.1*, these case studies tell the stories of seven fictional characters to inform educators about the circumstances that may have led those learners to access literacy education as an adult and all appear to describe non-disabled people. Although the adult literacy policies do reference research that is specific to English for speakers of other languages and dyslexic learners, they do not appear to reference any research that includes adults with learning disability (see *Section 6.2.5*). Incorporating case studies about adults with learning disability could help educators develop a better understanding of their histories and contexts. Additional case studies could be based on contributions from the two adults with learning disability who took part in consultation for the current *Tertiary Education Strategy*. They described experiencing problems with education in reading and writing, a lack of AAC and other ways to express their literacy, not having enough learning support, and issues with unsafe learning environments (see *Appendix C*).

Recognising adults with learning disability within the main narrative of adult literacy policies would be a step towards transformative equality because it establishes an expectation that adults with learning disability will be included in literacy education. This approach seeks to incorporate the practices, perspectives, and experiences of adults with learning disability in the adult literacy policies using knowledge in an effort to change educator attitudes about them.

Another way that adults with learning disability may be constructed as outliers is in the naming of the assessment tool options, currently titled *Adult*, *Youth*, *Te Ata Hāpara*, and *Starting Points*. The *Adult* version of the LNAAT is described in the adult literacy policies as the “default option” and “recommended for most learners” (TEC, 2023d, p. 13). As noted in *Section 6.1.4*, adults with learning disability are often infantilised and being unable to access the *Adult* version of the LNAAT may be seen as pejorative to them. Therefore, the *Adult* version of the LNAAT could be changed to better include and represent adults with learning disability. Options include the *Pākehā* version, contrasting *Te Ata Hāpara* with the aim of decentring Pākehā culture, or to a more neutral name, such as the *Original* version.

9.3.3 *Consult or Actively Involve People with Learning Disability in the Development of Adult Literacy Policies*

In the process of reading the adult literacy policies, I became concerned that people with learning disability may not have been consulted or actively involved in their development. After being unable to find evidence of their consultation or involvement, the TEC confirmed my concerns to be true (see *Appendix A*). Then, I read through the reference lists in the adult literacy policies and found they have also not drawn on any research specific to adults with learning disability (see *Section 6.2.5*). This oversight may have occurred because the TEC does not deem people with learning disability as necessarily affected by the adult literacy policies, but rather, by curriculum development undertaken by Te Pūkenga (see *Section 6.2.4.3*). As was said in a statement by Tim Fowler, Chief Executive of the TEC, obtained under an OIA request (see *Appendix A*).

There are some specific programmes of learning that are designed for learners with intellectual disabilities which have different structures and expectations. For example, there is the New Zealand Certificate in Skills for Living for Supported Learners. It is these programmes which I would expect to see co-developed with the sector.

As adults with learning disability have lower results in quantitative literacy assessments than people without learning disability (Bochner et al., 2001; Moni et al., 2018; Morgan & Moni, 2008; Trenholm & Mirenda, 2006), I argue that the adult literacy policies are of relevance and importance to their group. My recommendation is for policymakers to be explicit about, review, and justify their threshold for honouring CRPD Article 4.3, which promotes consultation with and active involvement of disabled people when developing and implementing decision-making processes in matters that affect them. In doing so, policymakers will benefit from the experiential insights of adults with learning disability in developing policies that are inclusive of their needs.

9.3.4 Improve Access to Adult Literacy Education for Adults with Learning Disability

This section recommends improving access to adult literacy education for adults with learning disability. First, by creating a database of TEC funded adult literacy education and resources. Second, by extending the purview of the SSG to contribute to the costs of a wider range of reasonable accommodations for use by all adult literacy education providers.

Recognising that the adult literacy policies recommend specialist resources, programs, and assistance for Deaf and disabled learners (see *Section 6.2.4.3*), I searched for examples of these supports to include them in this thesis. However, it was difficult for me to find out what was available in this regard. After phoning the TEC and a number of Tertiary Education Organisations, searching on the Ako Aotearoa website and Google, I submitted an Official Information Act request to the TEC for a list of ILN providers in a bid to obtain a comprehensive list (see *Appendix A*). Furness et al. (2021) also found many adult literacy education providers in Aotearoa New Zealand, especially small charitable trusts, challenging to locate. Therefore, my recommendation is for the TEC to establish a database of adult literacy education and specialist resources, programs, and assistance, searchable by area, eligibility criteria, and capacity to include people with learning disability. While the ostensible purpose of this database would be for prospective learners to match themselves

with educational opportunities, it could also be used to identify where learners are likely to be underserved. Highlighting these gaps could inform the TEC in working towards the CRPD aspiration of access to lifelong education “on an equal basis with others” (United Nations, 2007, Article 24.5).

On analysing the adult literacy policies, I also found that the SSG is only for additional tutorial support at Te Pūkenga for qualifications on the New Zealand Qualifications and Credentials Framework (NZQCF) (TEC, 2017b), and that those courses are not accessible for many people with learning disability (see sections 1.1 and 6.2.4.3). To remedy this point of discrimination, my next recommendation is to widen the scope of reasonable accommodations that can be paid for using the SSG. The SSG, has already been used more creatively for other purposes, including to support independent travel (TEC, 2023h). The TEC could improve access for people with learning disability by encouraging all adult literacy education providers to use the SSG to address all barriers to adult education, for example, communication, task, and transport barriers, as described by the Passioners (see *Section 7.3.3*).

A more flexible approach to SSG funding could ultimately reduce barriers to education for adults with learning disability. One way this could occur is by increasing access to digital technology, including assistive technology used by some people with learning disability (see *Section 3.2.3.4*). Examples of such technology include digital notetakers, digital pens, and accessibility browsers. Furthermore, the funding could support the development and acquisition of specialist literacy resources and programs, including age-appropriate resources for adult literacy education. It could also facilitate professional development for educators, the employment of additional educators with learning disability, the promotion of education to adults with learning disability, and the implementation of universal design in existing andragogy.

9.4 Limitations of my Policy Analysis

A major limitation of this research is that the content of the adult literacy policies provides no insight to their application. Policy analysis occurs in abstraction and cannot transform the experience of affected people unless that knowledge becomes applied (Brownson & Jones, 2009). Yet there is an “applicability gap” between research, policy, and practice (Lawrence, 2015, p. 78). The disconnect between policies and their real-world interpretation stems from the varying power and perspectives of researchers, policymakers, and practitioners arising from the social, knowledge, and values divisions between these three groups (Lawrence, 2015). Furthermore, it is challenging to ascertain how adult literacy policies are being implemented for adults with learning disability because of the absence of statistical information regarding their participation.

My policy analysis asks what impact the current adult literacy policies have on adults with learning disability. Knowledge about this topic is largely anecdotal or inferred because the only comparative data disaggregated by impairment type is a survey of highest qualification attained. This excludes information about learning where qualifications are not recorded, whether through adult literacy education that is not part of the NZQCF or learning that did not result in a completed qualification. Furthermore, highest qualification statistics disaggregated by disability type are inconsistent, difficult to obtain, and subject to high sampling errors.

There appear to be significant discrepancies in relevant data about adults with learning disability. Beltran-Castillon and McLeod (2023) used the *2018 Administrative Population Census* to find that 43.3 percent of adults with learning disability have a qualification. In contrast, Stats NZ reported a figure of 59 percent for the same demographic (see *Appendix G*)⁶³. Even estimates of the number of people with learning disability in Aotearoa New Zealand vary significantly, which highlights the challenges in determining the impact of

⁶³ Compared with 88.8 percent of adults in the total population as reported in the 2013 census.

current adult literacy policies on this group. Statistics from the *2018 Administrative Population Census* acquired by Beltran-Castillon and McLeod (2023) suggest there are 47,000 people with learning disability in Aotearoa New Zealand, whereas the post-census survey administered by Stats NZ indicates 89,000, nearly double the former figure (see *Appendix G*). Stats NZ Statistical and Data Analyst Dean Edwards explained that their data contain a “subjective element” as it is based on respondent perceptions (personal communication, 27 March, 2023). It may also have a moderate to substantial level of deviation from the true population and “should be used with caution” (D. Edwards, personal communication, 2 February, 2024). Furthermore, I found obtaining available data costly and complex. For example, Stats NZ Customised Data Services charged \$356.50 to disaggregate their highest qualification data by disability type (see *Appendix G*), and the *2018 Administrative Population Census* “is not easy to access, partly for security reasons and partly because it is so complex” (K. McLeod, personal communication, 13 February, 2024). The only other data that could provide insight to adults with learning disability accessing lifelong learning is that 485 people with what was termed “intellectual/cognitive impairment” accessed disability services at a university, Te Pūkenga division, or Wānanga in 2022 (TEC, 2022a).

Anecdotal evidence suggests that people with learning disability do not access lifelong learning “on an equal basis with others” (United Nations, 2007, Article 24.5) (see *Section 1.1*). However, this research was limited by the strength of assertions it could make about the realisation of the right to education, and more specifically regarding the impact of adult literacy policies on the relevant demographic. These limitations stem from the lack of available statistics and the problems associated with the data where it is available.

9.5 Limitations of our Research Meetings

The number and demographic of participants recruited in this research created limitations for this research relating to group diversity, dynamic, and research generalisability. I had

originally planned to recruit two sets of four to six participants and that each set of participants would engage in five research meetings. However, only five people with learning disability participated in this research. The number of participants in this research was comparable to other inclusive research projects. Group based inclusive research cited in this research had a range of three to eight and an average of six participants (Chapko et al., 2020; Cook & Inglis, 2012; Garbutt et al., 2010; Jones, 2019; Morgan, 2013; Ollerton, 2012; Townson et al., 2004). The purpose of this small group was to enable meaningful contribution from each participant and to be pragmatic about the expected level of complexity involved in facilitating research with participants with learning disability.

The Passioners expressed a desire to expand the size of the group. AJ said, “try and get some more people to come in,” followed by Hōri saying, “and join up as well.” AJ later said, “more people can help in the research.” While having more participants would have enabled more voices to be heard, I decided to conduct a second set of research meetings with the same group instead of recruiting a second group. This was so they could analyse their data collaboratively and because the Passioners wanted to continue with the research meetings.

In contrast to demographic information from the most recent *Disability Survey* (Stats NZ, 2014), the Passioners did not represent anyone over 65 years old or anyone from two major ethnic groups in Aotearoa New Zealand, Pacifica and Asian peoples. Four out of five Passioners were male. While this was an overrepresentation, males are twice as likely to have a learning disability than females in Aotearoa New Zealand (Stats NZ, 2014). Half of disabled people in Aotearoa New Zealand have more than one impairment, yet I was not aware of any of the Passioners having multiple disabilities. Two of the Passioners shared information about their chronic health conditions. I did not ask the Passioners about their intersectionality regarding gender, sexuality, health status, housing, or income. The Passioners disclosed their age and ethnicity on their consent form, but categorisations of their gender were made by observation. A greater diversity of participants could have

engaged perspectives more representative of people with learning disability in Aotearoa New Zealand and contributed to the generalisability of this research.

The participation criteria in this research said that people needed to have a learning disability but did not circumscribe anything about that disability. I was hoping to attract one or more participants with significant needs for support because I assumed that people with different challenges would draw from a more diverse palette of literacy practices, for example by using AAC. However, my recruitment method resulted in everyone who took part in this research using spoken language and having minimal needs for support. My experience is congruent with Walmsley and Johnson (2003, p. 205) who acknowledged that, “we lack the skill and/or techniques to include people with severe learning disability as equal partners” in research.

In addition to being a small group, the Passioners were never all present at any one research meeting. One participant had serious health concerns and was hospitalised part way through our research meetings. There were also challenges with connectivity, and one of the Passioners opted not to come to most of the research meetings.

Participant attendance and reasons for non-attendance are summarised in the table below.

Participant attendance and reasons for non-attendance					
Research meeting	John	AJ	Hōri	Melissa	David
1	✓	✓	✓	No device/No support during COVID-19	✓
2	✓	✓	✓	No device/No support during COVID-19	Problems with internet connectivity

3	✓	✓	✓	No device/No support during COVID-19	Problems with internet connectivity
4	✓	✓	✓	✓	Isolating for COVID-19
5	✓	✓	✓	Not interested	Isolating for COVID-19
6	✓	Busy	Unwell	✓	✓
7	✓	✓	✓	Not interested	Unwell
8	✓	✓	✓	Not interested	Unwell
9	✓	✓	✓	Not interested	Unwell
10	✓	✓	✓	✓	Unwell

The composition of the group, coupled with frequent absences from two of the Passioners, may have had a limiting effect on the group dynamic in our research meetings. Our group dynamic was also influenced by several other factors. For example, one of the Passioners was preoccupied by his recent bereavement, and two of the Passioners were more loquacious than the others. A more egalitarian group dynamic could have resulted in the two remaining Passioners having more opportunities to share their voices. However, all the Passioners seemed to contribute what they wanted to the research meetings. Passioners who were more confident utilised intervals between the times when others were speaking by engaging in dialogue.

The small size and restricted diversity among the Passioners limited this research in its potential lack of generalisability. *Generalisability* describes the relationship between the uniqueness of an individual study and the typical characteristics in the context it represents (Tight, 2017). Research that is more generalisable is often of interest to a broader audience and can be applicable in a greater range of circumstances (Tight, 2017). As Cook and Inglis

(2012) suggested, a small sample size is common to inclusive research and often constrains its generalisability. Tight (2017) agreed that generalisability is a common weakness of smaller studies. While being less generalisable according to a traditional definition, this research may possess a strength in what Fine (2008, p. 227) called *provocative generalisability*, the “extent to which a piece of research provokes readers or audiences, across contexts... to rethink and reimagine current arrangements.” This research is generalisable to what is not working in society for people with learning disability and how their practices and perspectives can be used to challenge that status quo, as per the affirmation model of disability.

There were also limitations to this research posed by the academic context in which it occurred. Walmsley and Johnson (2003) understand academia as constraining the inclusivity of research. Additionally, Milner and Frawley (2019) highlighted the impact of the competing interests between the university and people with learning disability on inclusive research. One example of a competing interest is that students are required produce research that “displays intellectual independence” (University of Waikato, 2021, requirements for the degree), which conflicts with the interests of people with learning disability to control research about themselves (Townson et al., 2004). Furthermore, inclusive research that occurs as part of student work is inherently limited by inequality because only one person in the inclusive research group receives the privilege of being conferred a qualification for their efforts (Morgan et al., 2014). In this research, the Passioners were given a certificate that I made up because Hōri asked if they would get one (see *Appendix H*). Another limitation caused by researching in an academic context arose because of ethical requirements for research with disabled people in Aotearoa New Zealand. The *Human Research Ethics Application* necessitated I explain my topic, question, or objectives; recruitment process; research activities, including the submission of all research instruments; and method of analysis, prior to contacting prospective participants. Controversially, Fine (2008) claimed such actions are taken by the academy to limit the generation of knowledge by unconventional researchers. While my ethics application

contained numerous caveats about the co-construction of our research meetings, the inclusivity of this research was limited by the extent of the research design required to be completed before I received approval to begin recruitment.

9.6 Implications for Researchers

This research reinforces the importance of doing research with people impacted by the subject of the research, in this case, adults with learning disability. Research about people with learning disability needs to be as inclusive as possible to facilitate their meaningful contributions, leading to a decentralisation of expertise traditionally valued in Western cultures, to bring about transformational change. Implications for future research have also arisen from the challenges and experiences that occurred within this research. For example, that some participants with learning disability experience a digital divide (see *Section 5.7.3.1*) or rapid personal changes (see *Section 7.4*). Another example is that research ethics regulations may not be updated often enough to maintain currency with how people with learning disability experience rights in other areas of their lives (see *Section 5.10.3* and *9.1.3*).

Section 5.6.1 Inclusive Research explains the value of including people with learning disability in research about them. Inclusive research benefits people with learning disability (Walmsley & Johnson, 2003), helps achieve non-discrimination (Durham et al., 2014; Ollerton & Horsfall, 2013), and supports researchers without learning disability to learn inclusive research skills (Atkinson, 1993; Garbutt et al., 2010; Hollomotz, 2018; Ollerton, 2012; Townson et al., 2004; White & Morgan, 2012). It also enables people without learning disability to benefit from the strengths, abilities, and lived experiences of people with learning disability (Townson et al., 2004).

Section 5.6.2 Participatory Action Research describes the importance of collaboration with the community affected by the research as exemplified by PAR, which sets out to challenge

existing patterns of values ascribed to the distribution of knowledge (Fine, 2008, 2015; Kindon et al., 2007; Liamputtong & Ezzy, 2013; McFarlane & Hasen, 2007; McGuirk, 2012). As Fine (2015) explained, diverging from the dominant narrative, in this case about literacy, necessitates recognising the significance of the voices of marginalised peoples, in this case adults with learning disability. Furthermore, research has to be conducted with the people it seeks to represent in order to challenge oppression and effect change (McFarlane & Hasen, 2007).

The amalgamation of inclusive research and PAR into Inclusive Participatory Action Research (Ollerton, 2012) (see *Section 5.6.3*) has been indispensable in this research. A key example of this methodological pairing was the use of cycles of reflection and action to iteratively revise research methods to make them more inclusive. (see *Sections 5.7.3.2* and *9.1.3*). The application of this approach has now produced a unique contribution to knowledge from a group whose literacy practices and perspectives were previously unresearched.

Although comprising a small sample size of five participants, this research demonstrated challenges involved in the connectivity, hardware, and support they needed for using an online application such as Zoom from home. These issues were exacerbated by the reason why we were doing research online, which was a COVID-19 lockdown. As many adults with learning disability experience a digital divide, the implication for inclusive research that may occur online is that we should undertake advanced planning for solutions to ensure the same set of participants can take part online as would have been able to take part in person.

Between finishing conducting data collection (14 February 2022) and beginning reporting back to the Passioners (29 August 2023), one of the five Passioners had died, and another had moved from supported living into residential care. The implication for inclusive researchers is that we need to be responsive to the dynamic pace of change in the lives of people with learning disability.

Finally, I faced an unexpected challenge in obtaining ethical approval for this research because of the differential wording of the CRPD and the University of Waikato (2008)

Regulations, which were published in the same year as Aotearoa New Zealand ratified the CRPD (Newcombe, 2022). The implication from this occurrence is for researchers to advocate to research ethics boards to review or interpret their regulations in line with the CRPD.

9.7 Future Research

This research highlighted the need for additional data to ascertain the current level of and facilitate the future access of adults with learning disability to lifelong learning “on an equal basis with others” (United Nations, 2007, Article 24.5). There were also topics that would be interesting to investigate but were not explored in this research.

A survey of adults with learning disability regarding their participation in adult literacy education and tertiary education independent of highest qualification would be beneficial for monitoring implementation of the CRPD. Further research into their unmet aspirations to participate, as well as the barriers they have encountered or are likely to encounter, would be beneficial for advancing efforts to promote their access.

The research meetings used an IPAR methodology collaboratively led by participants with learning disability. Because of this approach, the Passioners did not explore all the topics I had previously been interested in pursuing. For example, I have observed people with learning disability understanding the literacy of other people with learning disability in ways that are less likely to occur for people without learning disability, but this was not discussed in the research meetings. I noticed this phenomenon when Hōri interpreted for one of his flatmates when I was visiting. I could not understand the utterance of Hōri’s flatmate, yet Hōri effortlessly clarified, “he is saying *truck*.” This enhanced capacity for interpretation was documented by the biographer of Sir Robert Martin, the first person with a learning disability to be elected to a United Nations Human Rights Treaty Body. Sir Robert Martin is said to have exceptional skills in understanding people with learning disability, with McRae

(2014, p. 104) saying, “he knew how to read a shrug or a grimace. He could find meaning in a wail or a grunt.” I had hoped to explore possible spiritual dimensions of literacy, such as telekinesis. I also did not collect data on how the Passioners might like to be supported in TEC funded adult literacy education because the research meetings were collaboratively led by the Passioners, and this did not come up as a topic of discussion.

9.8 Conclusion

The TEC and adults with learning disability have their own separate and overlapping literacy practices, and meanings and purposes for adult literacy education. However, only the TEC currently has the means to fund their vision of adult literacy into action, creating a power dynamic in which the adult literacy policies override the practices and perspectives of adults with learning disability. The affirmation model of disability encourages policymakers to transcend beyond reasonable accommodations, harnessing transformative equality to address the underlying reasons that necessitate accommodations, as in, to change the status quo of power relations. A rights-based approach is helpful in this instance to emphasise the inalienability of the right to education underpinning access to adult literacy education for people with learning disability.

Implementing the recommendations outlined in this chapter would value adults with learning disability as literate members of the community and better align with their literacy practices and perspectives. This research encourages open mindedness towards adult learners, a suspension of judgement regarding what constitutes literacy, and a move towards learner-centred approaches that appreciate different ways of learning and being literate. This research has also provided evaluative insights into how research could continue to become more inclusive.

10 Statement of image use in the appendices

All images in these appendices were created by the author or participants in this research or downloaded from Photosymbols in accordance with their licence agreement, except:

Appendix J: Information for Supporters

- A map on page 342 taken as a screenshot from the University of Waikato website and used in accordance with attribution guidelines provided by OpenStreetMap.
- A screenshot from busit.co.nz on page 345 (permission pending).

Appendix N: Research at COVID Alert Level 2

- Images on pages 356-358 downloaded from the Ministry of Health COVID-19 Resource Toolkit in accordance with their terms of use.

11 Appendix A: TEC 2024 OIA Response OI-24-00085



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Ref: OI-24-00085

14 February 2024

Nicolina Newcombe

By email: nin1@students.waikato.ac.nz

Tēnā koe Nicolina

Thank you for your requests, received on 06 February 2024, for the following information under the Official Information Act 1982 (the Act):

My question is, has the Tertiary Education Commission ever consulted with people with intellectual disabilities in the development of any adult literacy policy?

Here is a list of policies I consider to be the adult literacy policies:

- *Literacy, Language and Numeracy Action Plan 2008–2012*
- *Getting Results in Literacy and Numeracy*
- *Adult Literacy and Numeracy Implementation Strategy*
- *Literacy and Numeracy Implementation Strategy*
- *Learning progressions for adult literacy*

The answers to each question are as follows:

My question is, has the Tertiary Education Commission ever consulted with people with intellectual disabilities in the development of any adult literacy policy?

Due to the age of these strategies, the Tertiary Education Commission (TEC) holds no evidence of specific consultation with people with intellectual disabilities.



We ensure New Zealand's future success.

- *Starting points: Supporting the learning progressions for adult literacy*
- *Starting points: Assessment guide*
- *Guidelines for using the Literacy and Numeracy for Adults Assessment Tool 2017 and 2023*

Also....

My question is, can you provide me with a list of organisations with which you hold an Intensive Literacy and Numeracy contract in Palmerston North.

TERTIARY EDUCATION REPORT: ADULT LITERACY AND PEOPLE WITH INTELLECTUAL DISABILITIES

TEC literacy and numeracy funds such as ILN are in place to support the literacy and numeracy skill development of adults who did not develop these skills in school. These funds are not specifically designed to support learners with intellectual disabilities, though some TEOs do still use them for this purpose, and this can be a positive learning opportunity for the participants.

There are some specific programmes of learning that are designed for learners with intellectual disabilities which have different structures and expectations. For example, there is the New Zealand Certificate in Skills for Living for Supported Learners. It is these programmes which I would expect to see co-developed with the sector. Information on the consultation around the qualification design would be with NZQA, or for programme design, with the delivering TEO.

My question is, can you provide me with a list of organisations with which you hold an Intensive Literacy and Numeracy contract in Palmerston North.

Funding is allocated under a statutory process, and as such the TEC does not "contract" or hold contracts with providers. Below is a list of providers who have committed to delivery Intensive Literacy and Numeracy provision in Palmerston North:

- Land Based Training Limited
- Education & Training Consultants New Zealand Limited
- Achievement NZ Limited
- National Council of YMCAs of New Zealand Incorporated

Can I also have a list of organisations with which you hold an Intensive Literacy and Numeracy contract in Hamilton.

Below is a list of providers who have committed to delivery Intensive Literacy and Numeracy provision in Hamilton:

- Literacy Aotearoa Charitable Trust
- New Zealand School of Education Limited
- Personalised Education Limited
- Vision College Limited
- K2 Corporation Limited

You have the right to seek an investigation and review by the Ombudsman of this decision. Information about how to make a complaint is available at www.ombudsman.parliament.nz or freephone 0800 802 602.

Nāku noa, nā

A handwritten signature in blue ink, appearing to read 'Tim Fowler', with a stylized flourish at the end.

Tim Fowler
Chief Executive
Tertiary Education Commission

12 Appendix B: Literacy Assessments used with Children with Learning Disability

In an assessment involving a child with learning disabilities, Benson-Goldberg and Erickson (2021) used a PCEye Go eye tracker system and Gaze Viewer software to record eye fixations on Tar Heel Reader⁶⁴ stories that were displayed on a laptop screen. This assessment sought to better understand viewing patterns across images, text, and other visual features, such as blank space, prior and following the introduction of *print referencing*, i.e. pointing to the text. The study by Benson-Goldberg and Erickson (2021) found that eye fixations on the text doubled in response to print referencing.

McIlroy (2017) used an innovative narrative assessment strategy with children with learning disability in her doctoral research in Aotearoa New Zealand. Noticing a discrepancy between the literacy capabilities she observed among her participants and those identified via previous assessments, her research found that current assessment practices fail to demonstrate the capabilities of primary school students with learning disability. She experimented with semi-structured interviews involving students and a team of people who support them, including friends, teachers, teacher aides and parents. They discussed one narrative assessment for each child that contained one or more of photographs, artwork, pictures, symbols, and words (McIlroy, 2017). McIlroy (2017, p. 230) found this process to “override assumptions based on a pedagogy of difference” and ultimately recognise learning success.

⁶⁴ An online library of easy to read books that can be accessed using a mouse, keyboard, or switches.

13 Appendix C: Ministry of Education 2021 OIA response: Ref 1263757

Respondent 1

If you were the boss of education in New Zealand, what would you do first?

This is the writing of an adult educated in NZ. They have an intellectual impairment and hearing impairment. These are their words. I added info in ()

Please start

Reading teachers
Tar heel (reader website with books to read)
Touch chat (app)
Sign Language

Please Stop

bullying
Make video (making videos)
Typing
Maths

Please more

waiting, how to write, co-writer (app)

What does a successful student of the future look like to you?

read, write, talk on the phone, have friends, be happy, know things

What will they need to know and be able to do?

use ipads, write with keyboard, get around (i.e., drive my wheelchair), make plans with friends, send emails and texts, stand up for myself when people yell

What things need to be in place to make sure every learner is successful?

nice teachers
no more yelling teachers, no mean adults.
more teaching reading and writing

Respondent 2

If you were the boss of education in New Zealand, what would you do first?

(This is submitted in list format as that is how this adult with intellectual disabilities wrote it and asked me to enter type this in with their permission)

school need more:

cowriter (assistive tech for writing)
teaching reading
sports
believe I'm smart
thinking time
wheelchair driving
speech practice
test
nice teachers
puppets
board games
band/music

School should stop

mean kids
art (They describe too much boring art that was more about filling the time)
mean adults

smells from recycling bins
stop yelling at me when I'm on computer
bad teachers (They shared a lot about this which they didn't give me permission to share)
learning with other kids
yelling

Start:
iPad
sign language
reading time
cooking
let me teach
ask me questions
tar heel reader
disco
TouchChat (AAC)
go out in van
waiting
teaching writing
bend and stretch (an activity in her adult life)
laughter yoga

Released under the Official Information Act 1982

14 Appendix D: Ministry of Education 2021 OIA response: Ref 1264249

Meeting with Office for Disability Issues and the Disabled Peoples Organisations Coalition about the Tertiary Education Strategy

When:

- 3:00 PM on 31/05/2019

Where:

- Comfort Hotel conference room

Attendees:

- **ODI** – Jacinda Keith (Senior Advisor)
- **DPO coalition** (4 members)
Rose Wilkinson (Chief Executive at Blind Citizens NZ),
Gaylene Te Rauna (President of Kāpō Māori Aotearoa NZ),
Joanne Dacombe (Disabled Persons Assembly NZ),
9(2)(a) [did not hear what organisation she represents - check]
- **MoE** – Ewan Delaney (Manager, TES representative) and Lauren Bell (APA, A&P policy team)

Ewan outlined the basics of the TES – it is a requirement and it provides direction to the Tec. In its current draft form, the TES has three priorities. Key priority of interest was one relating to 'Equity for all learners'

He asked for feedback from the DPOs coalition and ODI regarding: 'what are the shifts we need to see in the tertiary system?', and 'how would we invest differently?'

He also asked for specific feedback on the proposed priorities:

'Do the priorities work?'

'Is something missing or do we need a new priority?' and

'If these priorities are right, then what needs to change in the system?'

DPO coalition wanted clarification around what 'Equity for all learners' meant and encompassed.

Ewan indicated that we are speaking in terms of equitable outcomes.

DPO coalition (in particular, Joanna) asked how we will work towards these outcomes and how will we address the actual needs (i.e. in response to the diversity of disabilities).

Ewan asked **DPO coalition** to indicate where there are weaknesses in the current system – i.e. support services. He gave examples regarding inadequate funding of te reo (action will be to review this funding)¹ and the need for better career advice (action will be to create qualifications for career advisors (?)).

¹ Near the closing of the meeting one of the **DPO coalition** members (Rose) brought up this point in relation to NZSL. It is also one of our national languages and many people want to learn it. Could the review extend to NZSL?

DPO coalition responded to Ewan's point by highlighted that the improved careers advice and services will also greatly help disabled people (as they currently experience poor transitions into tertiary education and employment).

ODI (Jacinda) drew focus to the Government's ***New Zealand Disability Strategy*** (NZDS). Outcome 1 of the strategy is about education (see Annex 1). The NZDS should be consulted and considered when thinking about tertiary education for disabled people.

DPO coalition highlighted that changes for disabled people should not just consider students. It needs to be wider than that – needs to consider everyone in, and who is influenced by, the system (i.e. staff and family members too). For instance, the system needs to consider how we support teachers and staff with disabilities, and also ensure that teachers and staff are responsive to, inclusive of, and competent in the needs of, disabled learners. Also need to support family (i.e. information access).

DPO coalition also highlighted that transitions are a real issue for disabled learners. This includes transitions from secondary to tertiary, and from tertiary into employment.

One **DPO coalition** member (b)(2)(a) discussed how disabled women are often worse off than disabled men (this is the case in NZ, and around the globe). As such, disabled women experience a 'double-bias' – they are discriminated against for being a woman AND disabled.

One **DPO coalition** member (Rose) indicated that disabled people want to know about other disabled people who have been successful (both in education and employment). Maybe this could be linked into improved careers advice and services (mentioned earlier by **Ewan**).

ODI (Jacinda) and the **DPO coalition** then went on to talk about the importance of ***reasonable accommodations***². There is a guide on reasonable accommodation of persons with disabilities (see Annex 2), which was published in 2015 by NZ's Independent Monitoring Mechanism (comprising the Office of the Ombudsman, the Human Rights Commission and the Convention Coalition Monitoring Group).

ODI (Jacinda) and the **DPO coalition** suggest that the reasonable accommodations guide is a good place for education providers to start. Could be that providers incorporate guide into BAU.

² The term reasonable accommodation refers to an adjustment made in a system and based on a proven need to accommodate an individual with a disability.

Went on to highlight that currently disabled learners are not getting the support that they need, during their whole experience through tertiary education.

One **DPO coalition** member (Gaylene) indicated that some of her members did not receive the right *level* of support – specifically, they were babied (tutors/helpers were too involved, removing key opportunities for independent learning) or they did not have reasonable accommodations of support. Suggested that in some circumstances staff are not competent to work with disabled learners.

Ewan highlighted that there is an equity based approach for Māori and Pacific learners put forward by Universities New Zealand. He asked whether there is a similar initiative or approach for disability.

DPO coalition suggested that a good approach would be:

- **Reasonable accommodations** – all educational providers should provide reasonable accommodations for their disabled learners
- **Awareness raising** – specifically around the notion that many disabled people are highly capable and independent (i.e. address and break down long-standing stereotypes regarding disabled learners),
- **Accessibility Accreditation** – it is expected that all government agencies will sign the Accessibility Charter³ (launched by ODI in 2018). Agencies and organisations that sign the Charter must work towards ensuring that all their information intended for the public is accessible to everyone (i.e. available in a range of accessible formats). More information on the Charter is in Annex 3.
 - The **DPO coalition** suggest that this expectation to sign the Charter be extended to all education providers. This would be the ideal 'first-step' approach.
 - Related to accessibility, the online interface for tertiary education needs to be easier to navigate. Joanne highlighted that some disabled learners find it hard to navigate through the complexities of some online interfaces (this can include provider websites and student support websites – like StudyLink).
- **Disability Action Plans** – we spoke about the work TEC has done around good practice in other countries, which includes a requirement for Australian tertiary education providers to issue Disability Action Plans as a requirement for funding [may need to check details with **s(2)(a)** at TEC]. DPO coalition and ODI (Jacinda) had talked to TEC about this idea. They agree that it would be a good direction to take, but would like to see some examples first.

³ Note that MoE has signed this Charter

Ewan detailed how he and his team have heard so far that education providers need to '*meet learners where they are*'. This means being able to accommodate for learners when they enter into tertiary education.

In terms of what to do next, we discussed possible people/providers to get in touch with as well as specific next steps.

Possible people/providers to get in touch with:

- Anne Hawker – Principal Disability Advisor (MSD)
- Victoria University of Wellington - Disability services, including the disability and inclusion advisors [Jacinda and Rose said they would track down her name?]
- AUT – DPO coalition and ODI (Jacinda) suggest that best practice regarding disability services are provided here.
- Canterbury also has some good contacts.

Next steps:

- We will come back with a draft TES, and will have a two month period for consultation (during July and August).
- Work on getting the consultation documents accessible – Sort with Sally Jackson (MoE). Need roughly a two month lead in.

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15 Appendix E: Research Booklet

Nicolina Newcombe



Research about literacy and adults with learning disabilities



You can watch this read out on YouTube.

- <https://youtu.be/kZFNy3Iy4pE>
- https://youtu.be/SklOV_Xpf2I
- <https://youtu.be/3OURUW-wuYI>
- https://youtu.be/h8DSXG_G02k



My name is **Nicolina Newcombe**

I am doing research about literacy and adults with learning disabilities



Research is:

- Looking for an answer to a question
- Finding out how to do things better

The University of Waikato logo

This research is part of my **PhD in Education** at the **University of Waikato**

If you want to know more about this research



If you want to know more about this research you can:

Call or text me on
027 512 1226



Email me on
Nin1@students.waikato.ac.nz

Or

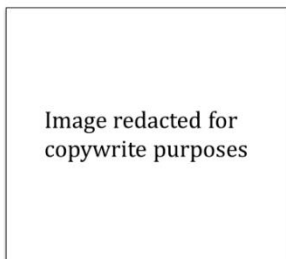


Tell the person who gave you this Easy Read form that they can give me your phone number or email

You could take part in this research if you:



Have a learning disability



Are 21 years old or older



Live in Hamilton



Are interested in literacy



Have a support person who can stay in contact with me and support you with making decisions if you need it.

This person could be a

- Family or whānau person
- Friend
- Support person



If you want to take part in this research, you will need to tell me the name and phone number of a support person and say it is okay for me to call them.



I will call your supporter and tell them you would like to take part in this research.



I will tell you if too many people say they would like to take part in this research and some people cannot take part in this research.

In this research we can



Meet in a group up to four times
for two hours



Talk about what research is

Talk about what literacy is



Use **digital technology** like a

- Camera
- Video camera
- Tablet
- Recorder
- Zoom

At this research



There will be lunch at the workshops



I will pay for transport for people to get to and from the workshops



I will try to make the workshops accessible for everyone especially if people are Deaf for have a disability

People who take part in this research might



Have fun

Express themselves

Learn new things



People could also remember something that upsets them

Some people know me



I have done many jobs with people with disabilities.

I might have met you or worked with you at places like:

The logos of Idea Services, People First, Enabling Good Lives, Interactionz, Career Moves, and CCS Disability Action

- Idea Services
- People First
- Enabling Good Lives
- Interactionz
- Career Moves
- CCS Disability Action



Taking part in this research is your choice even if I have met you or worked with you in the past.



I will write to you and your supporter about any times I have met you or worked with you in the past.



I will treat you the same as everyone else

Nothing bad will happen if you decide not to take part in this research.

Consenting to take part in this Research



There are two ways to consent to take part in this research.

If you normally have support to make decisions about things like

- Opening a bank account
- Becoming a tenant
- Getting a job

And

You normally have support to sign forms

Then

You can ask your support person to sign your consent form.





If you normally make your own decisions about things like

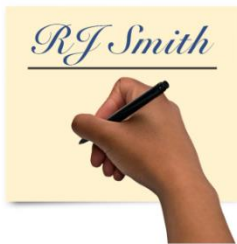
- Opening a bank account
- Becoming a tenant
- Getting a job

And

You normally sign your own forms

Then

You can sign your own consent form.



Your support person will still need to sign the Declaration for Supporters.



I will meet with you at least two times before you join the workshops so we can:

- Get to know each other
- Talk about understanding the research
- Talk about consent



You can choose to include your support person in these meetings.



If you need support at the workshops we can talk about how this could work.

Consent form



Taking part in workshops about literacy and adults with learning disabilities with Nicolina Newcombe



I understand what this research is about

	
<input type="checkbox"/>	<input type="checkbox"/>
Yes	No



I have had enough time to think about if I want to take part this research

	
<input type="checkbox"/>	<input type="checkbox"/>
Yes	No



I have been able to talk with my supporter about taking part in this research

	
<input type="checkbox"/>	<input type="checkbox"/>
Yes	No



I know who to ask if I have more questions



Yes



No



I know my name and my picture will not be used in this research



Yes



No



It is okay for Nicolina to record what I say and do in the workshops



Yes



No



I know taking part in this research is my choice



Yes



No



I will only answer the questions I want to answer



Yes



No



I know I can choose to leave the workshops at any time and I do not have to say why



Yes



No



I know if I stop being part of this research nothing bad will happen



Yes



No



I know Nicolina will use what I have said and done in the workshops even if I stop being part of this research



Yes



No



Nicolina can use the things I have said and done in the workshops to

- Talk at different places.
- Write different things
- Write a big book called a thesis



Yes



No



Nicolina will keep a copy of things I have said and done in the research for five years.



Yes



No



I can ask Nicolina for a copy of things I have said and done in the research anytime in the next five years.



Yes



No



Confidentiality



I will not talk about who else is at the workshops



Yes



No

I will not talk about what about other people said or did at the workshops



I would like to take part in this research

My name is _____ This is my signature.

I am _____ years old.

The date today is _____



If you want to talk to someone about this research



Nicolina Newcombe
027 512 1226
Nin1@students.waikato.ac.nz



Diana is the Chief Supervisor
Diana is like the boss of Nicolina
Dr Diana Amundsen
07 262 0582
diana.amundsen@waikato.ac.nz



The Human Research Ethics
Committee said it is okay for
Nicolina to do this research
humanethics@waikato.ac.nz

16 Appendix F: Schooling for Children with learning disability in Aotearoa New Zealand

All disabled children in Aotearoa New Zealand were extended the right to attend their local school by the *New Zealand Education Act* in 1989 (Powell, 2012). Then, the *Special Education 2000* policy set an intention to include all disabled children in mainstream schooling and to phase out special schools in Aotearoa New Zealand (McMenamin, 2014). Day and residential specialist schools⁶⁵ remain in operation for students with very high needs (Ministry of Education, 2022), although the continuance of residential specialist schools is under review (Roden, 2023). Hungary, Peru, Belgium, Portugal, and France made comments that Aotearoa New Zealand does not meet international inclusive education in the most recent Universal Periodic Review⁶⁶, which promotes mainstream schooling for all children (Human Rights Council Working Group on the Universal Periodic Review, 2019).

While *inclusive education*, children with and without disabilities sharing the same classrooms and curriculums in mainstream schools (Johnson, 2023), can provide social and academic benefits for disabled children (Selvaraj, 2015), and improvements in their literacy outcomes (Bochner et al., 2001), the practice can be problematic in other ways. As Melvin et al. (2023, p. 375) explain, “it appears that students with intellectual disability (ID) are more frequently absent from school compared with students without ID.” This can be caused by *school refusal*, absences that occur in response to student experiences of emotional distress or anxiety while at school, truancy, exclusion, or withdrawal (Melvin et al., 2023; Totsika et al., 2023). Recent statistics show that disabled children in Aotearoa New Zealand (not broken down by disability type) move to a different school 1.8 times more often and are up to three times more likely to be suspended from school than non-disabled children (Mhuru, 2020). These issues can occur for a range of reasons, but Mhuru (2020) asserts that the

⁶⁵ Special schools were renamed specialist schools in the Education and Training Act 2020 to better reflect their role within the wider school system Ministry of Education. (2024). *Education and Training Act 2020: Renaming “special schools” as “specialist schools.”* <https://www.education.govt.nz/our-work/legislation/education-and-training-act-2020/renaming-special-schools-as-specialist-schools/>

⁶⁶ A monitoring review of human rights in United Nations Member States standards

differential rates are likely to be an indicator that many schools do not meet the needs of disabled students. The IHC (2022)⁶⁷ reported that 35% of parent survey respondents said their disabled child was regularly sent home for part of the school day, and 31% said one or more schools had refused to enrol or placed conditions on the enrolment of their disabled child in the previous three to five years. More generally, Williams et al. (2019) found issues with social marginalisation, accessibility, and the attitudes of non-disabled students contributing to diminished self-esteem and wellbeing for autistic students who attended mainstream school. These findings may also hold relevance for children with learning disability.

School refusal is gaining attention from academics and advocacy groups. Totsika et al. (2023) found that school refusal was the most common reason for absence from school in students with learning disabilities. Although Melvin et al. (2023) questioned whether higher school attendance yields the best outcomes for students with learning disabilities, or if the benefits of including some rest days are more advantageous to them overall. It should be noted that advocacy groups do not use the term school refusal as it is thought to indicate choice, rather the term *school can't* is favoured instead to represent that some children are unable to attend schools that are not inclusive of their needs (Home Education Network, 2022; School Can't Australia, n.d).

There are multiple views about school choice for children with learning disability. Selvaraj (2015) in Aotearoa New Zealand and Johnson (2023) in the Republic of Ireland agree the success of inclusive education depends on appropriate learning and awareness of educators, and proper resourcing of mainstream schools where children with learning disability attend. Judith Nel, former president of the Special Education Principals' Association of New Zealand, reports that many schools are not ready to accommodate diverse needs, and that mainstream schooling can be abusive for some children (Nel, n.d). Furthermore, that special schools lead to "positive learning outcomes" because they have teachers with significant

⁶⁷ IHC own a group of charities that advocate for and support people with learning disability in Aotearoa New Zealand.

additional training (Nel, n.d, p. 3). The Ministry of Education is trending towards mainstream schooling for all children (McMenamin, 2014; Roden, 2023).

17 Appendix G: 2013 Disability Survey: Highest Qualification of Intellectually Disabled Adults (obtained under CONZUL Job 12325)

2013 Disability Survey	
Prepared for Barbara Rainier of The Council of New Zealand University Librarians	
Job Reference: JOB-12325	
<i>T1-counts</i>	File: T1_Education_Counts.csv
<i>Number of disabled people with Intellectual - detailed impairment type by highest qualification for people in private households</i>	
<i>Column</i>	<i>Notes</i>
Disability	Intellectual detailed impairment type
Highest Qualification	
Count	Estimates of disabled people rounded to the nearest thousand.
Quality Flag	* Relative sampling error is 30 percent or more, and less than 50 percent ** Relative sampling error is 50 percent or more
General notes:	
Not applicable. Estimates less than 1000 are suppressed (..S) as they are subject to sampling errors too high for most practical	
Estimates are rounded to the nearest thousand.	
Owing to rounding, individual figures may not always sum to give the stated totals.	
Symbol:	
* Relative sampling error is 30 percent or more, and less than 50 percent	
** Relative sampling error is 50 percent or more	
Source: Stats NZ	

Disability	Highest Qualification	Count	Quality Flag
Intellectual impairment	1 No qualification	24,000	
Intellectual impairment	2 School qualification	14,000	
Intellectual impairment	3 Post-school qualification	9,000	*
Intellectual impairment	4 Bachelor's or higher qualificat	3,000	**
Intellectual impairment	5 Qualification not specified	9,000	*
Intellectual impairment	Total	59,000	
Disability	Highest Qualification	Rate (%)	Percentage
Intellectual impairment	1 No qualification	41	
Intellectual impairment	2 School qualification	23	
Intellectual impairment	3 Post-school qualification	16	
Intellectual impairment	4 Bachelor's or higher qualificat	6	
Intellectual impairment	5 Qualification not specified	15	
Intellectual impairment	Total	100	

Table 13.02

Selected measures of disability for people in private households⁽¹⁾ (numbers)

By region

2013

Measure	Total private household population	Region											
		Northland	Auckland	Waikato	Bay of Plenty	Gisborne / Hawke's Bay	Taranaki	Manawatu-Wanganui	Wellington	Canterbury	Otago	Southland	Rest of South Island ⁽²⁾
Number (000)													
Total private household population	4379	153	1419	423	268	200	121	243	514	575	201	105	155
Detailed impairment type⁽³⁾													
Hearing	362	17 *	94	34	26	17	14	24	36	55	20	11 *	14
Seeing	154	S	42	15	11	6 *	4 *	10 *	17	24	7 *	6 *	5 *
Mobility	528	24	137	57	39	26	17	36	56	71	26	15	23
Agility	290	16	70	30	21	15	8 *	20	33	38	16	10 *	14
Intellectual	81	S	26	8	6	5 *	1 *	5 *	7	9	4 *	S	4 *
Psychiatric/psychological	229	7 *	60	24	15	11	7 *	15	26	38	13	5 *	7
Speaking	116	5 *	31	12	9	7 *	3 *	7 *	12	16	5 *	4 *	5 *
Learning	195	11 *	52	22	13	11	6 *	12	20	25	10 *	4 *	8
Memory ⁽⁴⁾	148	7 *	40	15	11	7 *	S	9	16	21	7 *	4 *	7 *
Developmental delay ⁽⁵⁾	6	S	S	S	S	S	S	S	S	S	S	S	S
Total	1020	44	271	105	73	46	36	67	114	143	52	27	41
Number (000)													
Single/multiple impairments													
Single	495	20	138	48	36	19	21	31	58	70	25	10 *	19
Multiple	524	24	133	57	37	26	15	36	56	73	28	17	22
Cause of impairment⁽⁶⁾													
Disease or illness	392	20	100	37	25	19	12	27	45	59	22	11	17
Accident or injury	312	15	74	35	26	16	12 *	22	31	43	15 *	10 *	15
Existed at birth	138	5 *	37	14	11	8 *	3 *	11	15	18	7 *	S	5 *
Ageing ⁽⁷⁾	264	12 *	71	29	18	10	6 *	15	30	38	17	8 *	10 *
Other	244	9 *	68	25	18	10	10 *	14	30	36	8 *	7 *	9 *
Not specified	36	S	11 *	S	S	S	S	S	S	S	S	S	S
Total	1,020	44	271	105	73	46	36	67	114	143	52	27	41

1. Includes adults and children surveyed in the Household Disability Survey. This does not include people living in residential care facilities.

2. 'Rest of South Island' contains the Tasman, Nelson, Marlborough, and West Coast regions.

3. Any individual may appear in more than one detailed level impairment type.

4. 'Remembering' is only asked of adults aged 15+ years.

5. 'Developmental delay' is only asked of children aged 0-14 years.

6. Any individual may appear in more than one cause of impairment group. Percentages for these groups exclude individuals who did not specify a cause of impairment.

7. 'Ageing' is only asked of adults aged 15+ years.

Note: Numbers may not sum to the stated totals because: a) individuals were counted in each applicable detailed level impairment type and cause of impairment, and b) numbers are rounded.**Symbols:**

S Suppressed

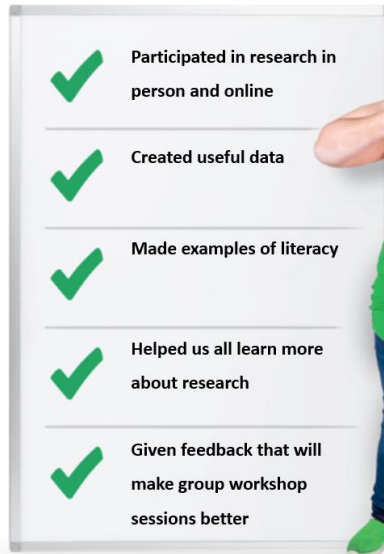
* Relative sampling error is 30 percent or more, and less than 50 percent

Source: Statistics New Zealand

18 Appendix H: Certificate for the Passioners

Thank You

for taking part in research about literacy
for adults with learning disabilities



Research about literacy and adults with learning disabilities



Telling people about this research
by
Nicolina Newcombe

Why

Image redacted for
copywrite purposes



Years ago I supported Jim* to ask about going to learn at a polytech.

The people at the polytech told Jim he needed to do a literacy course.

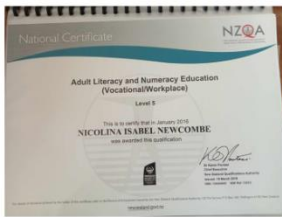
The people at the polytech did not know anything about Jim and his literacy.

I wondered if they thought Jim needed to do a literacy course because he had a learning disability.



Then I wrote a book with some people with learning disabilities.

I thought these people with learning disabilities were good at helping to write a book.



I also have a certificate for teaching literacy to adults.

I was worried that what I learned about teaching literacy to adults might not be the best for adults with learning disabilities.

Image redacted for copywrite purposes

These experiences made me want to do some research on different ways to think about literacy for people with a learning disability.

Thinking about this research



I tried to make this research right for people with learning disabilities.

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Inclusive research
Jan Walmsley and others tried to make research right for people with learning disabilities.

They came up with a way of doing research called inclusive research.



Inclusive research

- Comes from
- Works with
- Helps
- Is easy to understand for People with learning disabilities.

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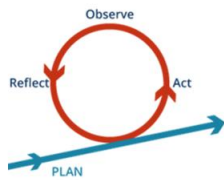


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Participatory action research

Other people have tried to make research right for people in communities.

They came up with a way of doing research called participatory action research. We can call it PAR.

PAR has three parts

- Taking action
- Thinking about what happened
- Planning to take action again

Inclusive PAR

Janice Ollerton came up with an idea to make inclusive research even better by using PAR as well.

This research is inclusive PAR

I did research with and for people with learning disabilities that went in loops of action, thinking and planning.

Who took part



The people who took part in this research

- Have a learning disability

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- Are 21 years old or older

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copyright purposes

- Live in Hamilton



- Are interested in literacy



- Had a support person who could stay in contact with me and help with making decisions if needed.

Passioners

The people who took part in this research called themselves the Passioners.

What we did

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copyright purposes

Snowball sampling

I asked two people if they wanted to take part in this research. Those two people asked other people if they wanted to join in too.



Having meetings

I met with people who said they wanted to take part in this research and their supporter.



We talked about what could happen in this research.

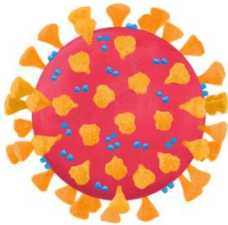


Consent

People who said they wanted to take part in this research

- Made a choice to take part in this research
- Signed a form that talks about their rights.

Their supporter signed a form as well.



Covid-19

Then Covid-19 came along.

We decided to stay safe from Covid-19 and do some research using Zoom.



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Research meetings on Zoom

We had three research meetings on Zoom.

Zoom was hard to use for some of the Passioners.

Some supporters and I helped some of the Passioners learn to use Zoom.

I gave computer parts to Passioners who needed them.

The Zoom meetings were good but the Passioners still wanted to meet in person.



Research meetings in person

We had six research meetings in person.

The in person meeting happened at the University of Waikato.



Here are some of the things we did.

Sharing examples of literacy

Some of the Passioners brought things from home like books and magazines.



Speeches and role-plays

Some of the Passioners did speeches and role-plays for the group.



Using digital technology

The Passioners used a camera, tablet and a dictaphone to record each other.

How did the research go?



Thank You

for taking part in research about literacy
for adults with learning difficulties



Some good things happened for the Passioners

- They met as a group and had food together
- They said what they think
- They may have learned more about using digital technology
- They may have learned more about research
- Some people were given computer parts
- They got certificates

**Here are some things the
Passioners said about taking part
in this research**



'Doing this course [research] is helpful in a way to me'.

'I have learned something from it'.



'You're inspiring me to do my own research'.

'It gets me out of the house'.

'I enjoyed coming here'.

Thinking about what the research means

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copyright purposes

I will be using two research words

1. Data
2. Analysis



The **data** is

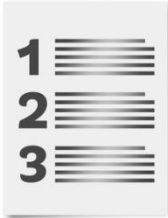
What the Passioners said and did at the research meetings.



Analysis is

1. Looking closely at the data
2. Choosing parts of the data
3. Saying what those parts mean

Analysis



I did some of the research jobs for analysis.



The Passioners did some of the research jobs for analysis.

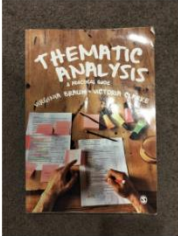


Picture card analysis

I asked the Passioners to think about what the data means by doing two things.

1. Looking at slides of what they did
2. Looking at different picture cards.

What I did with the data



Thematic analysis

I used thematic analysis to come up with ideas about what I think the data means.



Thematic analysis is:

1. Creating patterns in data



2. Thinking about how I think about what something means.



1. Creating patterns in data

I wrote out the data and read it lots of times.



I highlighted parts of the data that might answer my research question.



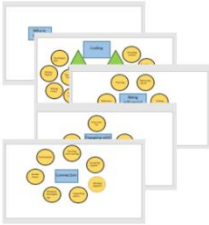
I cut out the highlighted parts.



I stuck the highlighted parts onto a big piece of paper.



I wrote words about what I thought might be happening on sticky notes.



I copied all my work onto PowerPoint slides.



I changed my mind a lot of times.



I wrote about what we did and what I think the data means in my big book called a thesis.



2. Thinking about how I think about what something means

Thematic analysis says we do research and analysis using our own ways of thinking.

Who I am changes

- What ideas I thought were most important
- What I came up with in the end.



I wrote about things like that

- I am autistic
- I can do different things and get treated in different ways than most people who have a learning disability
- I think about my disability as my culture



Working with my advisors

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TeAtakura Ryan

TeAtakura Ryan is my Māori Cultural Advisor.

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We talked about the data and Māori culture.

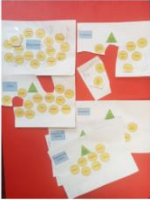


TeAtakura helped me think about my Pākehā culture and how I think about what things mean.



Glen Terry

Glen Terry is my advisor with a learning disability.



Glen asked me to change some of my ideas.



Glen told me some of my words were not easy to read.



I changed some of my words.

What I found out

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copyright purposes

Image redacted for
copyright purposes

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copyright purposes

Learning disability culture

I think learning disability is a culture.

One way to think about culture is

The things that make someone similar
to people who are part of their culture
and

Different from people who are not part
of their culture.

Cultural literacy

Cultural literacy helps us do well in our
worlds.

For example

- Whenua (land)
- Marae (meeting houses)



Learning disability cultural literacy

Learning disability cultural literacy helps people with learning disabilities do well in learning disability worlds.

For example,

- Places where people with learning disabilities can take part in making their rights real.
- Places where people with learning disabilities can get support.

Learning disability cultural literacy is a new idea.

Here are 5 parts of learning disability cultural literacy that I came up with from the data.



Self-advocacy

Telling people what you want and need and getting more choice and control in your life.



Changing things to fit

Making things easier to use or easier to do.



Guiding support

Telling people how to support you and when to stop supporting you.



Having goals

Having ideas about what you want to do and telling people about those ideas.



Doing drama

Using pretend play to try new ideas and show other people what you want and how you feel.



Other literacies

I also came up with other literacies from the data.



Māori cultural literacy

Māori cultural literacy helps Māori do well in the Māori world.



Some of the Passioners had skills in:

- Kaitiakitanga
- Karakia
- Tikanga
- Wānanga

and other things in te ao Māori.



Pākehā cultural literacy

Pākehā cultural literacy helps Pākehā do well in the Pākehā world.

Some of the Passioners had skills in:

- Independent learning
 - Pākehā festivals
 - Pākehā ways of looking after the dead
- and other things in Pākehā world.



Social media literacy

Some of the Passioners used social media to

- Make videos
- Watch videos
- Talk to people
- Get feedback

They used things like

- Zoom
- Email
- TikTok
- Facebook
- YouTube



Image redacted for
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School literacy

Some of the Passioners used the same literacy as they learned at school

Writing

Some of the Passioners wrote in te reo Māori and English.

Reading

Some of the Passioners read in te reo Māori and English.

Drawing

Some of the Passioners did drawings and symbols.

Have I got
this right?



20 Appendix J: Information for Supporters

The person you support has an opportunity to participate in four **group workshop sessions** about literacy with myself and three to five other adults with learning disabilities.

These workshops will be in the **McLaren Meeting Room TT.1.12**

11 am until 2 pm

- **26 August**
- **2 September**
- **9 September**
- **16 September**

Lunch will be provided.

Please advise if the person you support has any dietary requirements.

What I am asking supporters to do

- Engage in the consent process with participants. This means either consenting for the person you support or agreeing to support the person you support to take part in this research (See *Declaration by Supporter*).
- Advise me of any dietary or other wellbeing requirements applicable to the person you support.
- Be available to discuss any issues that may arise regarding the person you support.
- Work with me to ensure participants have safe transport to and from group workshop sessions. Transport costs will be reimbursed upon receipt.
- Support participants to make decisions such as deciding to take part in or withdraw from this research as required.

You are not required to attend the group workshop sessions unless the person you support has specific support needs such as assistance with personal care, assistance with eating and drinking and interpreting the language of the participant or other agreed supports.

Participants are welcome to bring support if they require support to attend group workshop sessions, such as assistance with personal care, assistance with eating and drinking and interpreting the language of the participant or other agreed supports.

Supporters will need to complete the *Agreement for Supporters Attending Group Workshop Sessions* section before attending any workshop session, including dropping off and picking up participants if this occurs inside the meeting room.

Ethics approval

This research has received full approval from the University of Waikato Human Research Ethics Committee (application number HREC(Health)2021#41).

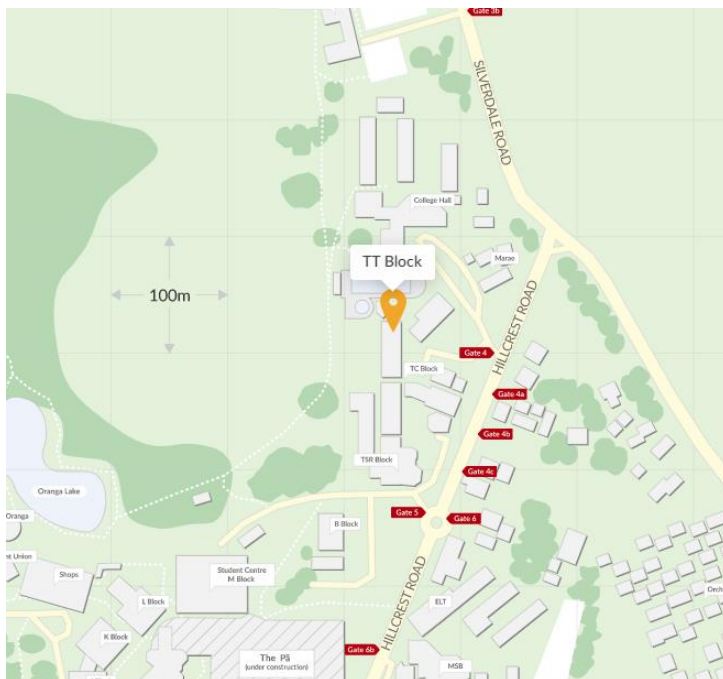
Contacts for if you have a question or concern

Please do not hesitate to contact me, Nicolina Newcombe, on 027 512 1226 or nin1@students.waikato.ac.nz

If you have further questions or concerns my Chief Supervisor is Dr Diana Amundsen and can be contacted on 07 262 0582 or diana.amundsen@waikato.ac.nz.

The Human Research Ethics Committee can be contacted via email at humanethics@waikato.ac.nz.

Getting there



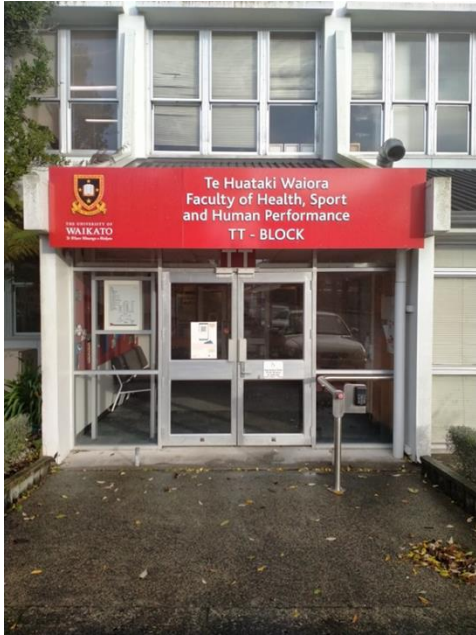
Feel free to discuss your travel plans with me so that I can provide any assistance I can.

Here is a map of the TT block surrounding area.

OpenStreetMap



If you are arriving from outside campus turn into Gate 4 on Hillcrest Road



Upon entering Gate 4 look straight ahead to the TT building

Enter these doors and turn right.

The McLaren room is the first door on your right.



If you get lost please call or text me on 027 512 1226!

Bus Information

The Orbiter bus route will **not** be servicing Knighton Road during the time I have scheduled the group workshop sessions.

Due to major roadworks along Ruakura Road, Orbiter buses will be on diversion via Wairere Drive

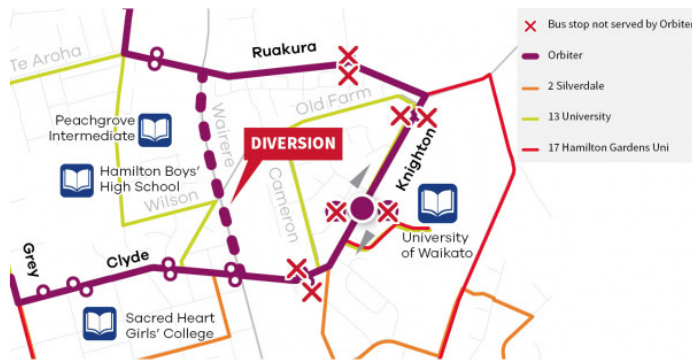
During this time, the Orbiter will be unable to serve the southern end of Ruakura Road (near Innovation Park), Knighton Road (near the university) and the first part of Clyde Street (near Hillcrest Warehouse). Buses will instead travel from Ruakura Road, onto Wairere Drive and then back onto Clyde Street.

Four sets of stops will not be served by the Orbiter during this time

- Both sides of Ruakura Road, near Innovation Park.
- 189 and opposite 187 Knighton Road.
- 129 and opposite 129 Knighton Road, near University Gate 2.
- 271 and 272 Clyde Street, near Hillcrest Warehouse.

For bus services to these areas, please use the 2 Silverdale, 13 University or 17 Hamilton Gardens Uni buses.

The Orbiter timetable may be affected during this diversion – please use the Transit app, or call 0800 205 305 for real time bus arrival times at your stop.



For people travelling by bus the best bus to take is the **Hamilton East University route 17** from the Anglesea St Transport Centre.

Complete your trip at **Opposite 196 Hillcrest Road**.

Then make your way across the road to Gate 4

Declaration by Supporter

Option A

I give consent for----- to take part in this research

AND OR (delete one)

Option B

I agree to support ----- to take part in this research by assisting them with supported decision-making and remaining in contact with Nicolina Newcombe regarding their wellbeing for the duration of this research project

Name: _____

Phone Number: _____

Email: _____

Signature: _____

Date: _____

Dietary intollerances and other wellbeing requirements:

Agreement for supporters attending group workshop sessions

Dear _____

Thank you for supporting _____ to participate in group workshop sessions.

This letter is to confirm the nature of your role attending group workshop sessions in writing.

Your role in attending group workshop sessions is to (circle as applicable):

- Drop off to and pick up from inside the meeting room
 - Provide assistance with personal care
 - Provide assistance with eating and drinking
 - Interpret the language of the participant, i.e. New Zealand Sign Language, AAC
 - Other
-
- No supporter will contribute data to this research.
 - Please do not make suggestions to the participant you are supporting even if you think it is something they might say with prompting.
 - Group workshop sessions are confidential, what happens in the group workshop sessions stays in the group workshop sessions.
 - If you report to a third party, for example by writing in a communication book or completing a running record for your employer, please restrict this reporting to your support of the participant and do not include any description of the research or data created by the participant you are supporting.

Signed

Date

Thinking about what our research means



Working with this book



You can write in this book if you want to.

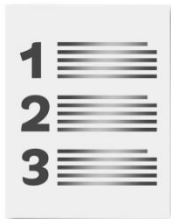


I am recording what we are saying on a Dictaphone.

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copyright purposes

If will keep a list of what people say and do in the research.

Working together in this research



I am doing some of the research jobs



You can do some of the research jobs



We will work through the jobs step by step

We are going to work on analysis



Analysis is

1. Looking closely at info



2. Choosing parts of the info



3. Thinking and talking about what those parts mean

Step 1: Looking closely at info

We are going to look at info made by the Passioners.



I have:

- Looked at info made by the Passioners
- Listened to info made by the Passioners
- Read what the Passioners said.



I have made a slide show of some things the Passioners said that were about literacy and some photos we took that were about literacy.



We are going to watch the slide show to see the info the Passioners made.

Step 2: Choosing parts of the info



You can choose parts of the info you think are interesting.

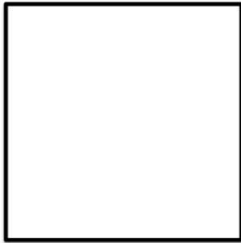


You can decide where a part begins.



You can decide where a part ends.

Step 3: Thinking about what those parts mean



You can look at a part you think is interesting and answer the question:

“What is going on right now”?



Then you can look at a part you think is interesting and answer the question:

“what else could be going on”?



You can look at a part you think is interesting again and again and think of lots of different things that could be going on.

Analysis Form



We are going to watch the slide show to see the info the Passioners made.



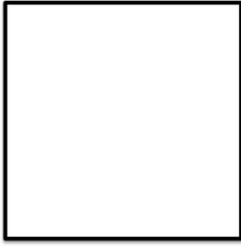
Find a part you think is interesting.

The part I think is interesting starts at:



The part I think is interesting ends at:

The part I think is interesting starts and ends because:



Have a look at the part you think is interesting and answer the question:

“what is going on right now”?



Now look at the part you think is interesting and answer the question:

“what else could be going on”?



The first thing that could be going on in the part I think is interesting is:



Now look at the part you think is interesting again and again and think of lots of different things that could be going on.



Another thing that could be going on in the part I think is interesting is:



Another thing that could be going on in the part I think is interesting is:



Another thing that could be going on in the part I think is interesting is:



Another thing that could be going on in the part I think is interesting is:

An example of analysis



I am looking at what the Passioners said.

Stoney Bay is a
really
awesome
beach up in the
Coromandel

I found a part I think is interesting.

Stoney Bay is a
really
awesome
beach up in the
Coromandel

The part I think is interesting begins at the start of the word Stoney Bay and ends at the end of the word Coromandel.



I am going to look at the part I think is interesting and answer the question:
"what is going on right now"?

I think the answer to that question is:

Talk.



Now I am going to look at the part I think is interesting and answer the question:

"what else could be going on"?



The first thing that could be going on in the part I think is interesting is this could be remembering.

Someone might be remembering a time they went to Stoney Bay.



Now I am going to look at the part I think is interesting again and again and think of lots of different things that could be going on.



Another thing that could be going on in the part I think is interesting is this could be a map.

Someone might be telling me how to find Stoney bay.



Another thing that could be going on in the part I think is interesting is this could be a practice.

Someone might be practicing a sentence.



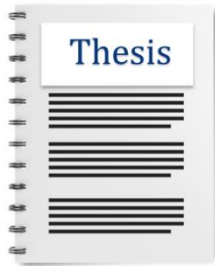
Another thing that could be going on in the part I think is interesting is this could be a plan.

Someone might be planning to go to Stoney Bay.

What happens next



I, Nicolina, will also do my own analysis.



I will write:

- Your analysis
- and
- My analysis

In a big book called a thesis.



I will also write what I found out in an easy way.

22 Appendix L: Reflecting on an Unexpected Challenge in Obtaining Ethical Approval for Research With Adults With Learning Disabilities



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Reflecting on an unexpected challenge in obtaining ethical approval for research with adults with learning disabilities

Nicolina Newcombe

Editors: Laura Gurney, Hossein Hosseini, Nicolina Newcombe and Kerry Earl Rinehart

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Abstract

Obtaining ethical approval for my PhD research with adults with learning (intellectual) disabilities presented an unexpected challenge of learning to work with two sets of guidance: the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and the Ethical Conduct in Human Research and Related Activities Regulations (HRR). The CRPD binds States Parties to progress equal rights for people with disabilities of which Article 12, equal recognition before the law, disconnects mental capacity from legal capacity. The HRR protects participants, researchers and institutions and recognises mental capacity as a component of informed consent. In applying the CRPD and the HRR as complementary safeguards, and looking through the lens of edgewalking, I gained an appreciation for positively encountering complexity and incorporating multiple points of view. This article will

describe how my challenging experience enabled skill building to develop a more strategic academic voice and will be of interest to student and other researchers.

Keywords

Consent; CRPD; inclusive research; research ethics

Introduction

This article unpacks experiences gained in PhD research to offer new insights about ethical research with adults with learning disabilities in New Zealand. My PhD research is about redefining literacy for adults with learning (intellectual) disabilities in New Zealand. Data collection involves a series of weekly Zoom or in-person group workshop sessions with adults with learning disabilities, using an inclusive participatory action research methodology (Ollerton, 2012). Including adults with learning disabilities as research participants aims to gain perspectives currently missing from the literature on this topic, and to uphold the disability rights movement dictum “nothing about us without us” (Charlton, 1998). While people with learning disabilities have been researched “on” within positivist inquiry, the social model of disability heralded new paradigms for research “with” and “by” people with learning disabilities and generated new ethical dilemmas (Milner & Frawley, 2019). One particular issue is balancing autonomy with protection (Douglass, 2016; Douglass & Ballantyne, 2019) for a group that is not inherently vulnerable (Doody, 2018) but whose members are more likely to experience vulnerability (Bracken-Roche et al., 2017).

Obtaining ethical approval for PhD research normally comprises expected challenges, but my experience was unexpectedly challenging because I had to navigate two sets of guidance: the *Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations, 2007), and the *Ethical Conduct in Human Research and Related Activities Regulations* (HRR) (University of Waikato [UoW], 2008). I commenced the approval process with an unexamined bias for, and an advocacy informed understanding of, the CRPD. However, the increased level of detail required for PhD research, and the standards of University of Waikato Human Research Ethics Committee, obliged me to revisit my understanding of the CRPD through wider reading. I will describe how this process enabled me to build a more nuanced and neutral academic voice that acknowledges and transcends my personal ideologies. Then, I will consider my experience alongside Stewart-Withers’ (2016) interpretation of *edgewalking*, the practice of contending with competing claims and building bridges between multiple realities. In this article, I reflect on learning the boundaries of academia and advocacy while cultivating accessibility and agency for participants in my research.

Research with people with learning disabilities

Historically, many people with learning disabilities have encountered research as subjects (Milner & Frawley, 2019; Walmsley & Johnson, 2003) and injustices have occurred involving both participation in and exclusion from research (Bracken-Roche et al., 2017). Then, *inclusive research* developed as a methodology that involves, rather than acts on, people with learning disabilities (Walmsley & Johnson, 2003). Inclusive research uses the *social model of disability*, which understands disability as constructed through interactions between an individual with impairment and barriers that exist within

society (Oliver, 1990), transforming how people with learning disabilities take part in research (Walmsley & Johnson, 2003).

Convention on the Rights of Persons with Disabilities

New Zealand ratified the CRPD in 2008, progressing equal rights for people with disabilities within the canon of human rights conventions. The CRPD grants people with disabilities “equality and nondiscrimination” (United Nations, 2007, Article 5). Where individuals meet recruitment criteria, equality and non-discrimination encompass participation in research (Nilsson & Broström, 2019).

Several articles in the CRPD imply rights and protections for research participants with disabilities, of which Article 12 has particular salience to consent for people who have learning disabilities (Mirfin-Veitch, 2016; Nilsson & Broström, 2019). Article 12 sanctions equal recognition before the law, confirming the right to legal capacity for people with disabilities (United Nations, 2007). This approach drives a wedge between *legal capacity*, the recognition of decisions as legally effective by others, and *mental capacity*, the cognitive abilities of the decision-maker, asserting that the former cannot be contingent on the latter (Nilsson & Series, 2018).

States Parties are responsible for providing support to realise Article 12, and safeguards to avoid abuse (United Nations, 2007). People with learning disabilities can experience difficulty understanding, remembering and weighing information, foreseeing consequences and communicating decisions (Office for Disability Issues, 2017). Therefore, some research participants may require *support for decisionmaking*, such as environmental and informational adaptations (Mirfin-Veitch, 2016), and *supported decision-making*, which exists when the “presence of support extends a person’s ability for decision making” (Office for Disability Issues, 2017, p. 3). Support for decision-making and supported decision *Reflecting on an unexpected challenge in obtaining ethical approval for research with adults 29* making processes aim to empower adults with learning disabilities to maintain control in their lives (Mirfin-Veitch, 2016; Office for Disability Issues, 2017).

Human research ethics in New Zealand and regulations at the University of Waikato

New Zealand law charges universities with ensuring the ethical conduct of their researchers who are working with human subjects (Gillett & Douglass, 2012; West-McGruer, 2020). These research ethics requirements draw on Western biomedical standards and closely align with existing legislation (such as Health and Disability Commissioner, 1996; Ministry of Health, 2002) (Stewart-Withers, 2016; WestMcGruer, 2020). As a result, research ethics in New Zealand presume competence, recognise mental capacity as a component of legal capacity, and have a best interest standard for research with people thought to lack capacity for consent (Douglass, 2016; Douglass & Ballantyne, 2019; Mirfin-Veitch, 2016).

The HRR outlines the ethical research policies of the University of Waikato (where I am undertaking my doctoral study) in line with guiding frameworks. Regarding consent, the HRR uses “reasonable judgement” to decide if a prospective participant is capable of giving informed consent, or, if proxy consent should be sought “from the person who has responsibility for the prospective participant's welfare” (UoW, 2008, Article 9.4.e). When proxy consent is sought, researchers “must make all

reasonable effort to involve the prospective participant themselves in the process and the decision about consent” (UoW, 2008, Article 9.4.f).

An unexpected challenge

The wording of the HRR was unexpectedly challenging for me and prompted a series of questions. I wondered, “if a prospective participant is reasonably judged incapable of giving informed consent” (UoW, 2008, article 9.4.e), what constitutes “reasonable judgement,” whose judgement should be involved, and how would I know if someone was incapable of giving informed consent? As Douglass (2016, p. 12) says, “Capacity can be difficult to assess, may not be clear-cut and involves value judgements about people’s preferences and beliefs.” People with learning disabilities are, as Nilsson and Broström (2019, p. 8) argue, “more vulnerable than others, all else being equal,” and their capacity to consent has been examined in many forums. If required to obtain proxy consent, I was unsure what that would entail, or where it would fall on a spectrum of decision-making approaches in light of the CRPD call for a paradigm shift from substitute decision making to supported decision-making (Mirfin-Veitch,

2016). The HRR states proxy consent must come “from the person who has responsibility for the prospective participant's welfare” (UoW, 2008, Article 9.4.e). However, as more people with learning disabilities are living self-directed lives in the community, I was unsure whom, if anyone, would have responsibility for their welfare.

My supervisors strongly encouraged me to engage with research that unpacks the CRPD and problematise an otherwise straightforward reading of the CRPD articles. This process enabled me to identify my positionality, or, where my “personal and field life bleed into one another” (Billo & Hiemstra, 2013, p. 315). Specific feedback directed my attention to the academic debate surrounding terms and concepts. The CRPD is characterised by strategic ambiguity and key terms, such as legal capacity and support, which are not defined within the text, for example, as Nilsson and Series (2018, p. 384) articulate,

In the final analysis, much comes down to what ‘substituted decision-making,’

‘supported decision-making,’ and ‘exercising legal capacity’ are taken to mean. These should be recognized as terms of art within the literature on universal legal capacity; it should not be assumed that they carry their intuitive or traditional meaning.

Ultimately, I was able to appreciate the common intent of the CRPD and the HRR and draw on the HRR as a protective counterbalance for the CRPD, as the latter lacks local and research specificity (Nilsson & Series, 2018).

My response

I responded to CRPD and HRR framings of capacity to consent by designing my recruitment and consent protocols to meet their calls for autonomy and safeguarding (Nilsson & Broström, 2019). I ensured each participant had a nominated support person who agreed to assist with supported decision-making. Participant autonomy was promoted by involving their support person to inform and

enhance individually tailored recruitment and consent processes. Then, I conducted at least two home visits with each participant to gain rapport and better understand their preferences and needs. I focused engagement around *Easy Read* information and consent forms. Easy Read is a communicative format intended to be more accessible for adults with learning disabilities and align more effectively with their preferences (Chinn, 2019; for example see Newcombe, 2019). This style can contribute to an enhanced understanding of research processes for some people with learning disabilities (Hurtado et al., 2014). I asked participants if they wanted to consent independently or with support, providing illustrations of other serious decisions and encouraging them to decide whether to participate in line with how they normally make and communicate similar decisions.

I promoted participant protection by using a *Declaration for Supporters* (DfS) that works alongside the Easy Read forms and allows a support person to give consent for and/or agree to support someone to participate in this research. I made the DfS as unobtrusive as possible by fitting it on one page in black and white, contrasting with the nineteen-page full-colour image-rich and large font participant information and consent forms. The DfS provides an additional safeguard to mitigate vulnerability for those who chose to sign their consent form and constitutes proxy consent for those who chose their supporter to provide consent. These accommodations to the recruitment and consent process enabled me to implement a research-informed example of how the CRPD and HRR work together.

Edgewalking

Reflecting on my experience, I came across feminist psychologist Krebs (1999), who coined the term edgewalkers (sic) to describe people who embrace complexity and difference. These people identify and cultivate edgewalking qualities, such as an appetite for change, innovation and risk; and courage in welcoming unfamiliarity, ambiguity and dialogue. Stewart-Withers (2016) applied edgewalking to ethics review in a New Zealand context. In her analysis, edgewalkers bridge the biomedical paradigm regulating ethics committees with the visceral dynamic of working with people in social sciences, as I found myself doing to achieve ethical approval. For Stewart-Withers (2016, p. 40), self-awareness is an important component of edgewalking because “ethics in practice can generate high expressed emotion where people have a tendency to position themselves one way or the other.” I found myself edgewalking as I negotiated consent processes with stakeholders, including participants, their supporters, my supervisors, and the University of Waikato Human Research Ethics Committee; incorporated my experiences of living and working alongside many people with disabilities, and indeed, being disabled; appreciated the adaptability of words and phrases in the CRPD and the HRR; and ultimately created something new, integrating the CRPD and HRR as complementary safeguards. In all, confronting my previously held assumptions provided me with an opportunity to be an edgewalker and move forward with a new understanding of managing complexity.

Conclusion

Including adults with learning disabilities in research requires appropriately balanced measures and processes. The CRPD and the HRR were written for different purposes, sit within different legislative contexts and construct risks in different ways. This article considers their contributions to consent in my research within the context of inclusive research. Understanding two sets of guidance as complementary has empowered me to accept ambiguity and multiple points of view. This unexpected

challenge enabled creative solutions to address tensions between my previous way of working and a new way of working, and personal growth in learning to be an edgewalker.

Acknowledgement

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References

- Billo, E., & Hiemstra, N. (2013). Mediating messiness: Expanding ideas of flexibility, reflexivity, and embodiment in fieldwork. *Gender, Place & Culture*, 20(3), 313–328. <https://doi.org/10.1080/0966369X.2012.674929>
- Bracken-Roche, D., Bell, E., Macdonald, M. E., & Racine, E. (2017). The concept of 'vulnerability' in research ethics: An in-depth analysis of policies and guidelines. *Health Research Policy and Systems*, 15(8) <https://doi.org/10.1186/s12961-016-0164-6>
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.
- Chinn, D. (2019). Talking to producers of Easy Read health information for people with intellectual disability: Production practices, textual features, and imagined audiences. *Journal of Intellectual & Developmental Disability*, 44(4), 410–420. <https://doi.org/10.3109/13668250.2019.1577640>
- Doody, O. (2018). Ethical challenges in intellectual disability research. *Mathews Journal of Nursing and Health Care*, 1(1), 1–11. <https://www.mathewsopenaccess.com/full-text/ethical><https://www.mathewsopenaccess.com/full-text/ethical-challenges-in-intellectual-disability-research>
- Douglass, A. (2016, July 4). *Mental capacity: Updating New Zealand's law and practice*. The Law Foundation New Zealand. <http://www.alisondouglass.co.nz/>
- Douglass, A., & Ballantyne, A. (2019). From protectionism to inclusion: A New Zealand perspective on health-related research involving adults incapable of giving informed consent. *Bioethics*, 33(3), 384–392. <https://doi.org/10.1111/bioe.12509>
- Gillett, G., & Douglass, A. (2012). Ethics committees in New Zealand. *Journal of Law and Medicine*, 20(2), 266–272.
- Health and Disability Commissioner. (1996). *Code of health and disability services consumers' rights*. <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services><https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/consumers-rights/>
- Hurtado, B., Jones, L., & Burniston, F. (2014). Is easy read information really easier to read? *Journal of Intellectual Disability Research*, 58(9), 822–829. <https://doi.org/10.1111/jir.12097>
- Krebs, N. (1999). *Edgewalkers: Defusing cultural boundaries on the new global frontier*. New Horizon Press.
- Milner, P., & Frawley, P. (2019). From 'on' to 'with' to 'by': People with a learning disability creating a space for the third wave of inclusive research. *Qualitative Research*, 19(4), 382–398. <https://doi.org/10.1177/1468794118781385>
- Ministry of Health. (2002). *Operational standard for ethics committees*.

- [www.moh.govt.nz/notebook/nbbooks.nsf/0/5ee9b561282cac41cc2578ae000c48d1/\\$FILE/OperationalStandard_final.pdf](http://www.moh.govt.nz/notebook/nbbooks.nsf/0/5ee9b561282cac41cc2578ae000c48d1/$FILE/OperationalStandard_final.pdf)
- Mirfin-Veitch, B. (2016). *Exploring article 12 of the United Nations convention on the rights of persons with disabilities: An integrative literature review*. Donald Beasley Institute. <https://www.odi.govt.nz/assets/Whats-happening-files/exploring-article-12-literature-review><https://www.odi.govt.nz/assets/Whats-happening-files/exploring-article-12-literature-review-october-2016.pdf>
- Newcombe, N. (2019). *The easy read book about the Treaty of Waitangi*. Tangata Tiriti – Treaty People.
- Nilsson, A., & Broström, L. (2019). Participation in research and the CRPD. *International Journal of Mental Health and Capacity Law*, 25, 1–78.
- Nilsson, A., & Series, L. (2018). Art.12 CRPD equal recognition before the law. In I. Bantekas, M. Stein, & D. Anastasiou (Eds.), *The UN convention on the rights of persons with disabilities: A commentary*. (pp. 339–382). Oxford University Press. <https://doi.org/10.1093/law/9780198810667.001.0001>
- Office for Disability Issues. (2017). *Summary of progress on improving disabled people's exercise of legal capacity*. <https://www.odi.govt.nz/summary-of-progress-on-improving-disabled-peoples-exercise-of-legal-capacity/>
- Oliver, M. (1990). *The politics of disablement*. Palgrave Macmillan.
- Ollerton, J. (2012). Ipar: An inclusive disability research methodology with accessible analytical tools. *International Practice Development Journal*, 2(2). <https://www.kennispleingehandicaptensector.nl/docs/KNP/KNP%20GS/Gewoon%20Bijzondere/Inclusive-research.pdf>
- Stewart-Withers, R. (2016). Edge walking ethics. *New Zealand Sociology*, 31(4), 28–42.
- United Nations. (2007). *United Nations convention on the rights of persons with disabilities*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>
- University of Waikato. (2008). *Ethical conduct in human research and related activities regulations*. <https://calendar.waikato.ac.nz/research-assessment-graduation/ethical-conduct>
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities past, present, and futures*. Kingsley Publishers.
- West-McGruer, K. (2020). There's 'consent' and then there's consent: Mobilising Māori and indigenous research ethics to problematise the western biomedical model. *Journal of Sociology*, 56(2), 184–196. <https://doi.org/10.1177/1440783319893523>

23 Appendix M: Ethics Approval Letter

The University of Waikato
Private Bag 3105
Gate 1, Knighton Road
Hamilton, New Zealand Human
Research Ethics Committee
Roger Moltzen
Telephone: +64021658119
Email: humanethics@waikato.ac.nz



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

14 July 2021

Nicolina Newcombe
School of Education
By email: nin1@students.waikato.ac.nz

Dear Nicolina

HREC(Health)2021#41: Redefining Literacy Competencies for Adults with Intellectual Disability in New Zealand

Thank you for your responses to the Committee feedback.

We are now pleased to provide formal approval for your project.

Please contact the Committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,

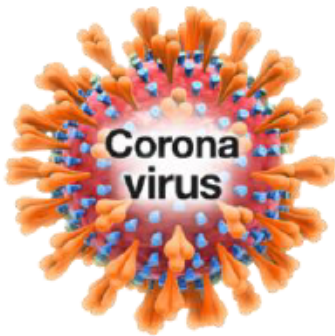
A handwritten signature in black ink, appearing to be 'RM' followed by a flourish.

**Emeritus Professor Roger Moltzen MNZM Chairperson
University of Waikato Human Research Ethics Committee**

Research at Covid-19 Alert Level 2



We are at Covid-19 Alert Level 2.



Research about literacy and adults with learning disabilities will happen differently at Alert Level 2.



You can take part in this research at Alert Level 2 or wait and take part later.



At Alert Level 2

Stay Home if you are Sick

Stay home if you are sick.



I will cancel a group workshop session if I am sick.



Contact Tracing

Everyone will scan the QR code with a phone or write down their name.



This means people could find out you took part in the research.



Wearing a mask

I will wear a mask.



I will ask you to wear a mask unless you have a reason that makes it hard for you to wear a mask.



Staying 1 metre apart

Only 3 people will take part in the research at one time.



We will stay 1 metre apart.

There will be tape on the table and floors to help us stay 1 metre apart.

Being safe

Image redacted for
copyright purposes

We will all use hand sanitiser at the
group workshop sessions

Image redacted for
copyright purposes

I will wipe the pens and equipment with
a new wipe every time someone uses
them.

Image redacted for
copyright purposes

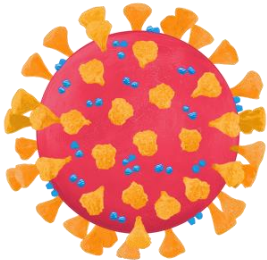
I will put your lunch on a plate and bring
it to your table.

25 Appendix O: Research about literacy and adults with learning disabilities at COVID-19
Traffic Light Red

Research about literacy and adults with learning disabilities at COVID-19 Traffic Light Red



We are at COVID-19 Traffic Light Red



Research about literacy and adults with learning disabilities will happen differently at Traffic Light Red.



You can choose to take part in this research at Traffic Light Red or wait and take part in a different way.

Staying safe at Traffic Light Red



Stay home if you are sick.

I will cancel a group workshop session if I am sick.



Scan the QR tracer code



We have a large meeting room.

We can social distance.



We can wear a mask.



We have a bathroom with our meeting room.

We can wash our hands for 20 seconds.



We can use hand sanitiser.



I will put lunch on plates for each person.

26 Appendix P: Accepted Abstract Submission to *The Routledge International Handbook of Disability Research and Enquiry*.

By Nicolina Newcombe, Glen Terry, and Gretchen Good.

This chapter describes our inclusive approach to research undertaken by three disabled disability researchers in Aotearoa New Zealand. The research was part of Nicolina Newcombe doing her PhD in Education, Glen Terry was her advisor with learning [intellectual] disability, and Dr Gretchen Good was one of her supervisors. We worked together as a team because people without learning disability need help from people with learning disability to do research in ways that include them.

Nicolina found out that no one with learning disability had ever been consulted or involved in the development of any adult literacy policy in Aotearoa New Zealand. This went against the *United Nations Convention on the Rights of Persons with Disabilities*, which says no one in the government should make decisions about disabled people without disabled people. Nicolina also heard that lots of people with learning disability were being excluded from adult literacy education. She decided to do research with people with learning disability to hear about their literacy practices and perspectives. This information helped Nicolina say things about how adult literacy policies could be better for people with learning disability.

A way of doing research called Inclusive Participatory Action Research was used for Nicolina to have 10 research meetings with five adults with learning disability. People who took part in the research called themselves the *Passioners*. Glen helped by telling Nicolina how to organise the research meetings and checking all the research information to make sure it was easy for the Passioners to read and understand. The Passioners helped by giving feedback about the research so Nicolina could make it easier for them to share their voices. Gretchen helped by encouraging Nicolina and talking about what she has learned from doing research in the past and from being a mother of two children with learning disability.

Nicolina did an evaluation of our inclusive approach to find out what was good about it and what could be improved. Glen told Nicolina what the evaluation words 'to,' 'for,' 'with,' 'by,'

and 'as' should mean so Nicolina could look for parts of our inclusive approach that would be important to people with learning disability. Those parts were easy read information, social relationships, making methods more accessible, using methods created by the Passioners, and Glen leading one of the outputs by presenting about the research at a People First meeting.

For Glen, it was important to do research together because of the knowledge people with learning disability have about who they are and what they believe in. It also helps people with learning disability learn how to do research, especially if their talent is speaking up. People with learning disability can see other people with learning disability doing research and realise they can do it too.

27 References

- Access Advisors. (2021). *A history of digital accessibility in Aotearoa*.
<https://accessadvisors.nz/news/a-history-of-digital-accessibility-in-aotearoa/>
- ACE Aotearoa. (2023). *Adult community education*. <https://www.aceaotearoa.org.nz/>
- Achieve. (2023). *Kia Ōrite Toolkit for Achieving an Inclusive and Equitable Tertiary Education Environment for Disabled Learners*. <https://www.achieve.org.nz/kia-orite-toolkit/nz-code-of-practice-2021-22/>
- Aho, T. N. (2017). Active citizenship, liberalism, and labor-normativity: Queercrip resistance, sanist anxiety, and racialized ableism in viewer responses to Here Comes Honey Boo Boo. *Journal of Literary & Cultural Disability Studies*, 11(3), 321-337.
<https://doi.org/10.3828/jlcds.2017.25>
- Ake, T., & Moorhouse, L. (2016). *Focus on whakataukī practice guide: Translating Māori knowledge and values into practice applications*. Koromiko Resources.
- Alkema, A., & Rean, J. (2013). *Adult literacy and numeracy: An overview of the evidence: Annotated bibliography*. <https://thehub.swa.govt.nz/assets/documents/Adult-Literacy-and-Numeracy-An-Overview.pdf>
- Altmann, G. T. M. (1998). *The ascent of Babel: An exploration of language, mind, and understanding*. Oxford University Press. <https://doi.org/10.1093/acprof:oso/9780198523772.001.0001>
- American Foundation for the Blind. (2006). New Zealand adopts Unified English Braille Code. *Journal of Visual Impairment & Blindness*, 100(1), 56.
<https://www.proquest.com/docview/222079407?parentSessionId=xRut4nHTFJvihlpOUu2PMOKljdbdWh3%2F7gISZ500ltQ%3D&pq-origsite=primo&accountid=17287&sourcetype=Scholarly%20Journals>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*.
- American Psychiatric Association, & Task Force on Dsm-iv. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR* (Revised ed.).
- American Psychological Association. (2020). *Publication manual of the American Psychological Association: The official guide to APA style* (7th ed.).
- Aspis, S. (2000). Researching our history: Who is in charge? In L. Brigham, D. Atkinson, M. Jackson, S. Rolph, & J. Walmsley (Eds.), *Crossing boundaries: Continuity and change in the history of learning disability* (pp. 1-6). Bild.
- Atkinson, D. (1993). Relating. In P. Shakespeare, D. Atkinson, & S. French (Eds.), *Reflecting on research practice: Issues in health and social welfare* (pp. 58-69). Open University Press.
- Atkinson, D., & Williams, F. (Eds.). (1989). *"Know me as I am": An anthology of prose, poetry and art by people with learning difficulties*. Hodder & Stoughton in association with the Open University.
- Atrey, A., Fredman, A., Campbell, M., Samtani, S., Brickhill, J., & Ramalekana, N. (2017). *Achieving transformative equality for persons with disabilities: Submission to the CRPD Committee for General Comment No.6 on Article 5 of the UN Convention on the Rights of Persons with Disabilities* Oxford Human Rights Hub. <http://ohrh.law.ox.ac.uk/publications/sandra-fredman-meghan-campbell-shreya-atrey-jason-brickhill-sanya-samtani-and-nomfundo-ramalenka-achieving-transformative-equality-for-persons-with-disabilities-submission-to-the-committee-of/>
- Avinera, N., & Harasta, J. (2021). Introduction: Exploring agency, ideology, and semiotics of language across communities. In J. Harasta & N. Avinera (Eds.), *Metalinguistic communities: Case*

- studies of agency, ideology, and symbolic uses of language*. Springer International Publishing. <https://doi.org/10.1007/978-3-030-76900-0>
- Awatere, D. (1984). *Maori sovereignty*. Broadsheet.
- Baaijens, M. (2011). *The abc for inclusive tertiary art education*. <https://ako.ac.nz/assets/Knowledge-centre/RHPF-c41-The-ABCs-for-inclusive-tertiary-art-education/RESEARCH-REPORT-The-ABCs-for-Inclusive-Tertiary-Art-Education.pdf>
- Bacchi, C. (2009). *Analysing policy: What's the problem represented to be?* Pearson.
- Bahaimiha, S. (2023). ChatGPT may be the fastest-growing consumer app in internet history, reaching 100 million users in just over 2 months, UBS report says. *Insider*. <https://www.businessinsider.com/chatgpt-may-be-fastest-growing-app-in-history-ubs-study-2023-2>
- Ballantyne, T. (2010). Culture and colonization: Revisiting the place of writing in colonial New Zealand. *Journal of New Zealand Studies*(9), 1-21. <https://search.informit-org.ezproxy.waikato.ac.nz/doi/abs/10.3316/informit.029901214293297>
- Banas, J. R., Magasi, S., The, K., & Victorson, D. E. (2019). Recruiting and retaining people with disabilities for qualitative health research: Challenges and solutions. *Qualitative Health Research*, 29(7), 1056-1064. <https://doi.org/10.1177/1049732319833361>
- Barnes, C., & Mercer, G. (2010). *Exploring disability* (2nd ed.). Polity.
- Barton, D., & Hamilton, M. (2005). Literacy practices. In M. Hamilton, R. Ivanic, & D. Barton (Eds.), *Situated literacies: Reading and writing in context* (pp. 7-14). Routledge. <https://doi.org/https://doi-org.ezproxy.waikato.ac.nz/10.4324/9780203984963>
- Beltran-Castillon, L., & McLeod, K. (2023). *From data to dignity: Health and wellbeing indicators for New Zealanders with intellectual disability: Mai i te raraunga ki te rangatiratanga o te noho: Ngā tūtohu hauora, toiora hoki mō te hunga whai kaha o Aotearoa*. https://assets-global.website-files.com/628455c1cd53af649dec6493/6584cc68cbd28550e09d0397_Full_IDI%20report_final_web.pdf
- Benoot, T., Roose, R., Dursin, W., Verschuere, & McKenzie, J. (2022). Aspirations of people with intellectual disabilities living in a care organization. *Journal of Social Work*, 22(4), 1105-1122. <https://doi.org/https://doi.org/10.1177/14680173211053087>
- Benseman, J. (2008). Foundation learning in New Zealand: An overview. In J. Benseman & A. Sutton (Eds.), *Facing the challenge: Foundation learning for adults in Aotearoa New Zealand* (pp. 11-28). Dunmore Publishing.
- Benson-Goldberg, S., & Erickson, K. (2021). Eye-trackers, digital-libraries, and print-referencing: A single case study in CDKL5. *Research in Developmental Disabilities*, 112, 103913-103913. <https://doi.org/10.1016/j.ridd.2021.103913>
- Berger, P., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Allen Lane.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234. <https://doi.org/10.1177/1468794112468475>
- Berger, R. J. (2013). *Introducing disability studies*. Lynne Rienner Publishers.
- Berry, J., & Triandis, H. (2014). Culture. In K. Pawlik & G. r. d'Ydewalle (Eds.), *Psychological concepts: An international historical perspective* (pp. 47-62). Taylor and Francis.
- Best, K. L., Mortenson, W. B., Lauzière-Fitzgerald, Z., & Smith, E. M. (2022). Language matters! The long-standing debate between identity-first language and person first language. *Assistive Technology*, 34(2), 127-128. <https://doi.org/10.1080/10400435.2022.2058315>

- Bevan-Brown, J. (1996). Special abilities: A Māori perspective. In D. McAlpine & R. Moltzen (Eds.), *Gifted and talented: New Zealand perspectives* (pp. 91-110). ERDC Press Massey University.
- Bevan-Brown, J. (2010). *Maori learners with special needs: Culturally appropriate, effective provisions*. Lambert Academic Publishing.
- Bevan-Brown, J. (2013). Including people with disabilities: An Indigenous perspective. *International Journal of Inclusive Education*, 17(6), 571-583.
<https://doi.org/10.1080/13603116.2012.694483>
- Bevan-Brown, J. (2015a). Intellectual disability: Looking through a Māori lens. In M. Berryman, H. Hickey, S. Macfarlane, K. Smiler, & T. Walker (Eds.), *Working with Māori children with special education needs: He mahi whakahirahira* (pp. 149-173). NZCER Press.
- Bevan-Brown, J. (2015b). Introduction. In J. Bevan-Brown, M. Berryman, H. Hickey, S. Macfarlane, K. Smiler, & T. Walker (Eds.), *Working with Māori children with special education needs: He mahi whakahirahira* (pp. 3-29). NZCER Press.
- Bigby, C., & Frawley, P. (2010). Reflections on doing inclusive research in the “making life good in the community” study. *Journal of Intellectual and Developmental Disability*, 35(2), 53-61.
<https://doi.org/10.3109/13668251003716425>
- Bigby, C., & Frawley, P. (2015). Conceptualizing inclusive research: A participatory research approach with people with intellectual disability: Paradigm or method? In G. Higginbottom & P. Liamputtong (Eds.), *Participatory qualitative research methodologies in health* (pp. 136-160). Sage. <https://doi.org/10.4135/9781473919945.n8>
- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3-12.
<https://doi.org/10.1111/jar.12083>
- Biklen, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review*, 60(3), 291-314. <https://doi.org/10.17763/haer.60.3.013h5022862vu732>
- Biklen, D., & Burke, J. (2006). Presuming competence. *Equity & Excellence in Education*, 39(2), 166-175. <https://doi.org/10.1080/10665680500540376>
- Bindah, E. V. (2019). *Adoption of snowball sampling technique in an exploratory study of disabled entrepreneurship*. Sage.
- Blind Low Vision NZ. (2023). *Braille*. <https://blindlowvision.org.nz/our-services/daily-living-skills/braille/>
- Blum, A., Goldstein, H., & Guérin-Pace, F. (2001). International Adult Literacy Survey (IALS): An analysis of international comparisons of adult literacy. *Assessment in Education: Principles, Policy & Practice*, 8(2), 225-246. <https://doi.org/10.1080/09695940123977>
- Bochner, S., Outhred, L., & Pieterse, M. (2001). A study of functional literacy skills in young adults with Down syndrome. *International Journal of Disability, Development, and Education*, 48(1), 67-90. <https://doi.org/10.1080/10349120120036314>
- Bogart, K. R., & Dunn, D. S. (2019). Ableism: Special issue introduction. *Journal of Social Issues*, 75(3), 650-664. <https://doi.org/10.1111/josi.12354>
- Borgström, Å., Daneback, K., & Molin, M. (2019). Young people with intellectual disabilities and social media: A literature review and thematic analysis. *Scandinavian Journal of Disability Research*, 21(1), 129-140. <https://doi.org/10.16993/sjdr.549>
- Borland, E. (2020). Standpoint theory. In Britannica Academic (Ed.), *Encyclopedia of gender and society*. <https://academic-eb-com.ezproxy.waikato.ac.nz/levels/collegiate/article/standpoint-theory/607855#article-contributors>

- Botha, M., Hanlon, J., & Williams, G. L. (2023). Does language matter? Identity-first versus person-first language use in autism research: A response to Vivanti. *Journal of Autism and Developmental Disorders*, 53(2), 870-878. <https://doi.org/10.1007/s10803-020-04858-w>
- Boudard, E., & Jones, S. (2003). The IALS approach to defining and measuring literacy skills. *International Journal of Educational Research*, 39(3), 191-204. <https://doi.org/10.1016/j.ijer.2004.04.003>
- Bracken-Roche, D., Bell, E., Macdonald, M. E., & Racine, E. (2017). The concept of 'vulnerability' in research ethics: An in-depth analysis of policies and guidelines. *Health Research Policy and Systems*, 15(1), 1-18. <https://doi.org/10.1186/s12961-016-0164-6>
- Brandon, T., & Pritchard, G. (2011). 'Being fat': A conceptual analysis using three models of disability. *Disability & Society*, 26(1), 79-92. <https://doi.org/10.1080/09687599.2011.529669>
- Brandt, D., & Clinton, K. (2002). Limits of the local: Expanding perspectives on literacy as a social practice. *Journal of Literacy Research*, 34(3), 337-356. https://doi.org/10.1207/s15548430jlr3403_4
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. Sage.
- Brownson, R. C., & Jones, E. (2009). Bridging the gap: Translating research into policy and practice. *Preventive Medicine*, 49(4), 313-315. <https://doi.org/10.1016/j.ypmed.2009.06.008>
- Buell, S., Langdon, P. E., Pounds, G., & Bunning, K. (2020). An open randomized controlled trial of the effects of linguistic simplification and mediation on the comprehension of 'easy read' text by people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(2), 219-231. <https://doi.org/10.1111/jar.12666>
- Bull, G., & Anstey, M. (2018). *Elaborating multiliteracies with multimodal texts: Changing classroom practices and developing teacher pedagogies*. Routledge.
- Burnett, C., & Merchant, G. (2020). Literacy-as-event: Accounting for relationality in literacy research. *Discourse: Studies in the Cultural Politics of Education*, 41(1), 45-56. <https://doi.org/10.1080/01596306.2018.1460318>
- Burr, V. (2015). *Social constructionism* (3rd ed.). Routledge.
- Cahill, C., & Torre, M. (2007). Beyond the journal article: Representations, audience, and the presentation of participatory action research. In S. L. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods: Connecting people, participation, and place* (pp. 196-205). Routledge.
- Cameron, C. (2007). Whose problem? Disability narratives and available identities. *Community Development Journal*, 42(4), 501-511. <https://doi.org/10.1093/cdj/bsm040>
- Cameron, C. (2010). *Does anybody like being disabled? A critical exploration of impairment, identity, media and everyday experience in a disabling society* [Doctoral thesis, Edinburgh, Scotland: Queen Margaret University]. QMU Repositories. <https://eresearch.qmu.ac.uk/handle/20.500.12289/7340>
- Cameron, C. (2011). Nothing to do with me: Everything to do with me: Disability, self and identity. *Disability Arts Online*, 1-11. http://www.disabilityartsonline.org.uk/domains/disabilityarts.org/local/media/audio/Nothing_To_Do_With_Me_FINAL.pdf
- Cameron, C. (2019). Disability arts: From the social model to the affirmative model. *A Blade of Grass*(3), 14-23. <http://abladeofgrass.org/articles/disability-arts-social-model-affirmative-model/>

- Cameron, C. (2023). Some things never seem to change: Further towards an affirmation model. *Disability & Society*, 1-6. <https://doi.org/10.1080/09687599.2023.2295799>
- Cameron, C., & Lingwood, L. (2020). What's wrong with 'seeing the person first'? *British Journal of Nursing*, 29(5), 314-317. <https://doi.org/10.12968/bjon.2020.29.5.314>
- Campbell, F. (2009). *Contours of ableism: The production of disability and abledness*. Palgrave Macmillan UK. <https://doi.org/10.1057/9780230245181>
- Campbell, F. (2015). Legislating disability: Negative ontologies and the government of legal identities. In S. Tremain (Ed.), *Foucault and the government of disability* (Revised ed., pp. 108-132). University of Michigan Press.
- Carey, M. A., & Asbury, J.-E. (2012). *Focus group research*. Left Coast Press.
- Carrucan, E. (2021). Ki te ture hei matua mō te tangata whaikaha. *LawTalk*, 946, 28-33. <https://www.lawsociety.org.nz/news/publications/lawtalk/lawtalk-issue-946/ki-te-ture-hei-matua-mo-te-tangata-whaikaha/>
- Carson, C. (2008). *The supported training programme: Supporting learners with intellectual disabilities*. <https://ako.ac.nz/assets/Knowledge-centre/good-practice-publications/GOOD-PRACTICE-PUBLICATION-the-supported-training-programme-supporting-learners-with-intellectual-disabilities.pdf>
- Carson, V. (1992). Submitting to great inconveniences: Early missionary education for Maori women and girls. In R. Glen (Ed.), *Mission and moko: Aspects of the work of the Church Missionary Society in New Zealand 1814-1882* (pp. 56-72). Latimer Fellowship of New Zealand.
- Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual & Developmental Disability*, 41(2), 125-139. <https://doi.org/10.3109/13668250.2016.1153052>
- Chalachanová, A., Nind, M., Østby, M., Power, A., Tilley, L., Walmsley, J., Westergård, B.-E., Heia, T., Gerhardsen, A. M., Oterhals, O. M., & King, M. (2020). Building relationships in inclusive research in diverse contexts. *Scandinavian Journal of Disability Research*, 22(1), 147-157. <https://doi.org/10.16993/SJDR.681>
- Chapko, D., Frumiento, P., Edwards, N., Emeh, L., Kennedy, D., McNicholas, D., Overton, M., Snead, M., Steward, R., Sutton, J. M., Jeffreys, E., Long, C., Croll-Knight, J., Connors, B., Castell-Ward, S., Coke, D., McPeake, B., Renel, W., McGinley, C., . . . Grierson, M. (2020, April 25-30). "We have been magnified for years: Now you are under the microscope!": Co-researchers with learning disabilities created an online survey to challenge public understanding of learning disabilities [Conference presentation]. CHI 2020, Honolulu, HI, United States. <https://doi.org/10.1145/3313831.3376278>
- Chapman, R. (2020). Neurodiversity, disability, wellbeing. In N. Chown, A. Stenning, & H. Bertilsson Rosqvist (Eds.), *Neurodiversity studies: A new critical paradigm* (pp. 57-72). Taylor and Francis.
- Chapman, R., & Townson, L. (2012). Researching together: Pooling ideas, strengths and experiences. In C. Davies, J. Walmsley, & M. Hales (Eds.), *Better health in harder times: Active citizens and innovation on the frontline* (pp. 69-72). Policy Press. <https://doi.org/10.51952/9781447306955>
- Chappell, A. L. (1992). Towards a sociological critique of the normalisation principle. *Disability, Handicap & Society*, 7(1), 35-51. <https://doi.org/10.1080/02674649266780041>
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.
- Chesner, A. (2020). *Creative drama groupwork for people with learning difficulties*. Taylor & Francis. <https://doi.org/10.4324/9780429486180>

- Chi, C., Dewi, R., Jang, Y., & Liu, H. (2018). Workplace accommodation for workers with intellectual or psychiatric disabilities. *International Journal of Industrial Ergonomics*, *68*, 1-7. <https://doi.org/doi.org/10.1016/j.ergon.2018.06.001>
- Chinn, D. (2019). Talking to producers of easy read health information for people with intellectual disability: Production practices, textual features, and imagined audiences. *Journal of Intellectual & Developmental Disability*, *44*(4), 410-420. <https://doi.org/10.3109/13668250.2019.1577640>
- Cho, H., Cannon, J., Lopez, R., & Li, W. (2022). Social media literacy: A conceptual framework. *New Media & Society*. <https://doi.org/10.1177/14614448211068530>
- Clouser, L. (n.d). *A timeline of learning disability history*. <https://ldaamerica.org/a-timeline-of-learning-disability-history/>
- Cohen, D., Plaza, M., Perez-Diaz, F., Lanthier, O., Chauvin, D., Hambourg, N., Wilson, A. J., Basquin, M., Mazet, P., & Rivière, J. P. (2006). Individual cognitive training of reading disability improves word identification and sentence comprehension in adults with mild mental retardation. *Research in Developmental Disabilities*, *27*(5), 501-516. <https://doi.org/10.1016/j.ridd.2004.07.008>
- Cohn, T. (2018). Assent. In N. Salkind (Ed.), *Encyclopedia of research design* (pp. 45-46). Sage. <https://doi.org/10.4135/9781412961288>
- Colebatch, H. K. (1998). *Policy*. Open University Press.
- Collin, R. (2013). Revisiting Jack Goody to rethink determinisms in literacy studies. *Reading Research Quarterly*, *48*(1), 27-38. <https://doi.org/10.1002/rrq.036>
- Collins, K. (2011). "My mom says I'm really creative!": Dis/ability, positioning, and resistance in multimodal instructional contexts. *Language Arts*, *88*(6), 409-418. <https://www-jstor-org.ezproxy.waikato.ac.nz/stable/41804300?sid=primo>
- Community Law. (2024). *Access to transport*. <https://communitylaw.org.nz/community-law-manual/chapter-17-disability-rights/access-to-shops-transport-and-other-services/access-to-transport/#:~:text=Those%20laws%20require%20transport%20operators,the%20services%20these%20companies%20provide.>
- Community Sector Taskforce. (2006). *A new way of working for the tangata whenua, community and voluntary sector in Aotearoa/New Zealand*. <https://trc.org.nz/sites/trc.org.nz/files/Application/A-New-Way-of-Working.pdf>
- Cook-Gumperz, J. (1986). Literacy and schooling: An unchanging equation? In J. Cook-Gumperz (Ed.), *The social construction of literacy* (pp. 16-44). Cambridge University Press.
- Cook, T., & Inglis, P. (2012). Participatory research with men with learning disability: Informed consent. *Tizard Learning Disability Review*, *17*(2), 92-101. <https://doi.org/10.1108/13595471211218875>
- Cope, B., & Kalantzis, M. (2000). Introduction: Multiliteracies: The beginnings of an idea. In B. Cope & M. Kalantzis (Eds.), *Multiliteracies: Literacy learning and the design of social futures* (pp. 3-8). Macmillan.
- Copeland, S. R., McCord, J. A., & Kruger, A. (2016). A review of literacy interventions for adults with extensive needs for supports. *Journal of Adolescent & Adult Literacy*, *60*(2), 173-184. <https://doi.org/10.1002/jaal.548>
- Copeland, S. R., & Zagona, A. L. (2022). Literacy learning among students with complex support needs in postsecondary education programs: A scoping literature review. *Inclusion*, *10*(2), 118-133. <https://doi.org/10.1352/2326-6988-10.2.118>
- Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine*, *41*(12), 1667-1676. [https://doi.org/10.1016/0277-9536\(95\)00127-S](https://doi.org/10.1016/0277-9536(95)00127-S)

- Crawford, H., & Newcombe, N. (2023). On the colour spectrum. *Altogether Autism Journal*, 28-29. Altogether Autism.
- Cross, K. (2022). Platitudes and toxic positivity: Notes from the editor. *Journal of Palliative Medicine*, 25(8), 1174. <https://doi.org/10.1089/jpm.2022.0295>
- Culham, A., & Nind, M. (2003). Deconstructing normalisation: Clearing the way for inclusion. *Journal of Intellectual & Developmental Disability*, 28(1), 65-78. <https://doi.org/10.1080/1366825031000086902>
- Cunningham, C. (2012). Social media. In M. Kosut (Ed.), *Encyclopedia of gender in media* (pp. 356-359). Sage. <https://ebookcentral-proquest-com.ezproxy.waikato.ac.nz/lib/waikato/reader.action?docID=996572>
- Danielsson, K., & Selander, S. (2021). *Multimodal texts in disciplinary education: A comprehensive framework*. Springer International Publishing.
- Danker, J., Dreyfus, S., Strnadová, I., & Pilkinton, M. (2023). Scoping review on communication systems used by adults with severe/profound intellectual disability for functional communication. *Journal of Applied Research in Intellectual Disabilities*, 36(5), 951-965. <https://doi.org/10.1111/jar.13133>
- Davies, J. (2012). *The importance of suffering: The value and meaning of emotional discontent*. Routledge. <https://doi.org/10.4324/9780203137789>
- Davis, L. J. (1997). Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century. In L. J. Davis (Ed.), *The disability studies reader* (pp. 9-28). Routledge.
- de Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences*, 11(4), 1-13. <https://doi.org/10.3390/socsci11040159>
- de la Iglesia, C. J. F., Buceta, J. M., & Campos, A. (2005). Prose learning in children and adults with Down syndrome: The use of visual and mental image strategies to improve recall. *Journal of Intellectual & Developmental Disability*, 30(4), 199-206. <https://doi.org/10.1080/13668250500349391>
- de Schauwer, E., Van de Putte, I., Van Goidsenhoven, L., Blockmans, I., Vandecasteele, M., & Davies, B. (2017). Animating disability differently: Mobilizing a heterotopian imagination. *Qualitative Inquiry*, 23(4), 276-286. <https://doi.org/10.1177/1077800416684871>
- Deaf Aotearoa. (2023). *Fact sheet: What is Deaf culture?* <https://www.deaf.org.nz/resource/fact-sheet-what-is-deaf-culture/>
- Dearing, K. (2022). Work aspirations, intellectual disability and 'cruelling out' the mark in the job club. *The Sociological Review*, 70(3), 564-579. <https://doi.org/doi.org/10.1177/003802612111044619>
- Dennis, R. (2002). Nonverbal narratives: Listening to people with severe intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 27(4), 239-249. <https://doi.org/10.2511/rpsd.27.4.239>
- Denzin, N. K., & Lincoln, Y. S. (2013). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research* (4th ed., pp. 1-42). Sage.
- Department of Further and Higher Education Research Innovation and Science. (2023). *PATH 4 project roll-out for universal design, autistic students and students with an intellectual disability announced by Minister Harris*. <https://www.gov.ie/en/press-release/50387-path-4-project-roll-out-for-universal-design-autistic-students-and-students-with-an-intellectual-disability-announced-by-minister-harris/>

- Derby, M. (2021). A history of Māori literacy success. *Journal of Indigenous Research*, 9, 1-10. <https://hdl.handle.net/10289/14574>
- Dickinson, D., & Hutchinson, N. (2019). Changes in understandings and perceptions of individuals, significant others and community supporters involved in a theatre company for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 691-705. <https://doi.org/10.1111/jar.12564>
- Digital Government. (2021a). *Digital inclusion user insights: Disabled people*. <https://www.digital.govt.nz/dmsdocument/170~digital-inclusion-user-insights-for-disabled-people/html>
- Digital Government. (2021b). *Te mahere mō te whakaurunga matihiko: The digital inclusion blueprint*. <https://www.digital.govt.nz/dmsdocument/113-digital-inclusion-blueprint-te-mahere-mo-te-whakaurunga-matihiko/html#disabilities>
- Digital Inclusion Research Group. (2017). Digital New Zealanders: The pulse of our nation. <https://www.mbie.govt.nz/dmsdocument/3228-digital-new-zealanders-the-pulse-of-our-nation-pdf>
- Dionisio, R., & Macfarlane, A. H. (2021). Tikanga rua: Bicultural spatial governance in Aotearoa New Zealand. *New Zealand Geographer*, 77(2), 55-62. <https://doi.org/10.1111/nzg.12303>
- Donaghy, C., & Anderson, E. (2015, March 25-28). *Bowel health and screening: A resource for people with learning disabilities and their carers* [Poster abstract] 15th International Conference on Integrated Care, Edinburgh, UK. <https://www.readcube.com/articles/10.5334%2Fijic.2068>
- Donnellan, A. M. (1984). The criterion of the least dangerous assumption. *Behavioral Disorders*, 9(2), 141-150. <https://doi.org/10.1177/019874298400900201>
- Doody, O. (2018). Ethical challenges in intellectual disability research. *Mathews Journal of Nursing and Health Care*, 1(1), 1-11. <https://www.mathewsoopenaccess.com/full-text/ethical-challenges-in-intellectual-disability-research>
- Douglass, A., & Ballantyne, A. (2019). From protectionism to inclusion: A New Zealand perspective on health related research involving adults incapable of giving informed consent. *Bioethics*, 33(3), 384-392. <https://doi.org/10.1111/bioe.12509>
- Downing, J., Hanreddy, A., & Peckham-Hardin, K. D. (2015). *Teaching communication skills to students with severe disabilities* (3rd ed.). Paul H. Brookes Publishing.
- Dowse, L. (2009). 'It's like being in a zoo': Researching with people with intellectual disability. *Journal of Research in Special Educational Needs*, 9(3), 141-153. <https://doi.org/10.1111/j.1471-3802.2009.01131.x>
- DPO Coalition, Human Rights Commission, & Office of the Ombudsman. (2023). *Removing barriers: Reasonable accommodation of disabled people in Aotearoa*. <https://www.ombudsman.parliament.nz/resources/removing-barriers-reasonable-accommodation-disabled-people-aotearoa#:~:text=This%20guide%20helps%20people%20to,Rights%20of%20Persons%20with%20Disabilities.>
- Duckworth, S. (2020). *Wheel of power/privilage*. https://www.thisshowyoucan.com/post/__wheel_of_power_and_privilege
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264. <https://doi.org/10.1037/a0038636>
- Dunn, L. M., & Dunn, D. M. (1997). *Peabody picture vocabulary test: Form IIIA (PPVT)*. American Guidance Service.

- Durgunoglu, A. Y., & Oney, B. (2002). Phonological awareness in literacy acquisition: It's not only for children. *Scientific Studies of Reading, 6*(3), 245-266.
https://doi.org/10.1207/S1532799XSSR0603_3
- Durham, F., & Carpenter, J. (2015). The face of multiculturalism in Korea: Media ritual as framing in news coverage of Jasmine Lee. *Journalism, 16*(8), 975-992.
<https://doi.org/10.1177/1464884914550137>
- Durham, J., Brolan, C. E., & Mukandi, B. (2014). The Convention on the Rights of Persons with Disabilities: A foundation for ethical disability and health research in developing countries. *American Journal of Public Health, 104*(11), 2037-2043.
<https://doi.org/10.2105/AJPH.2014.302006>
- Durie, M. (1998). *Whaiora: Māori health development* (2nd ed.). Oxford University Press.
- Durie, M. (2003). *The hui taumata mātauranga: Progress and platforms for Māori educational advancement*. Huia Publishers.
- Dyslexia Foundation of New Zealand. (2014). *Dyslexia: Recognition understanding action*
https://www.dyslexiafoundation.org.nz/pdf/DFNZ_Brochure_2014_web.pdf
- Education Gazette Editors. (2020). 'We are kanohi ki te kanohi people': Keeping Māori students connected during Covid-19. *New Zealand Education Gazette, 99*(6), 6-9.
<https://gazette.education.govt.nz/articles/we-are-kanohi-ki-te-kanohi-people-keeping-maori-students-connected-during-covid-19/>
- Edwards, S. (2010). Matauranga Maori literacies: Indigenous literacy as epistemological freedom v. eurocentric imperialism. *WINHEC: International Journal of Indigenous Education Scholarship, 1*, 26-37. <https://journals.uvic.ca/index.php/winhec/article/view/18628>
- Edwards, S. J. L., Kirchin, S., & Huxtable, R. (2004). Research ethics committees and paternalism. *Journal of Medical Ethics, 30*(1), 88-91. <https://doi.org/10.1136/jme.2002.000166>
- Elliott, P. (2020). *Politics of kindness: Exploring the political discourse of kindness articulated by Ardern in New Zealand* [Master's thesis, Hamilton, New Zealand: University of Waikato]. Research Commons Thesis Collection.
<https://researchcommons.waikato.ac.nz/bitstream/handle/10289/14087/thesis.pdf?sequence=4&isAllowed=y>
- Ellis, N. (2014). Ki tō ringa ki ngā rākau ā te Pākehā? Drawings and signatures of moko by Māori in the early 19th century. *Journal of the Polynesian Society, 123*(1), 29-66.
<https://doi.org/10.15286/jps.123.1.29-66>
- Ellsworth, E. (1989). Why doesn't this feel empowering? Working through the repressive myths of critical pedagogy. *Harvard Educational Review, 59*(3), 297-325.
<https://doi.org/10.17763/haer.59.3.058342114k266250>
- Emery, W., & Kākahi Consulting. (2017). *Te Ata Hāpara: Creating contexts for culturally responsive assessment and learning* [Video]. <https://www.youtube.com/watch?v=zmilpOeTliE&t=120s>
- Employment New Zealand. (2024). *Reasonable accommodation (measures)*.
<https://www.employment.govt.nz/workplace-policies/employment-for-disabled-people/reasonable-accommodation-measures/>
- Enabling Good Lives. (2023). *Enabling Good Lives*. www.enablinggoodlives.co.nz
- Erevelles, N. (2015). Signs of reason: Riviere, facilitated communication, and the crisis of the subject. In S. Tremain (Ed.), *Foucault and the government of disability* (Revised ed., pp. 45-64). University of Michigan Press.
- Espinero, D., & Hartnett, F. (2012). 'I felt I was in control of the meeting': Facilitating planning with adults with an intellectual disability. *British Journal of Learning Disabilities, 40*(1), 62-70.
<https://doi.org/https://doi.org/10.1111/j.1468-3156.2011.00684.x>

- Evans, C. (2021). Teaching literacy to adults with mild intellectual disability. *Fine Print*, 44(3), 14-18. <https://doi.org/10.3316/informit.215726873663757>
- Explore Hāpainga Ora. (n.d). *Neurodevelopmental assessment*. https://explorewellbeing.org.nz/neurodevelopmental-assessment/?fbclid=IwAR3ThpeWn7X8s7S7bEfbjhXRmBgZQSC0rGbTLEqHKLo8UPgKHSv2_jk7iYw
- Fabio, R. A., Bhattacharya, U., Wei, X., & Canegallo, V. (2023). Reading and writing in severe intellectual disability: A systematic review. *Current Developmental Disorders Reports*, 10(1), 1-13. <https://doi.org/10.1007/s40474-023-00269-5>
- Fajardo, I., Ávila, V., Ferrer, A., Tavares, G., Gómez, M., & Hernández, A. (2014). Easy-to-read texts for students with intellectual disability: Linguistic factors affecting comprehension. *Journal of Applied Research in Intellectual Disabilities*, 27(3), 212-225. <https://doi.org/10.1111/jar.12065>
- Farrar, J. (2022). *The social model and its relationship with Enabling Good Lives*. <https://www.enablinggoodlives.co.nz/negl/national-leadership-group-position-statements/the-social-model-and-its-relationship-with-enabling-good-lives/>
- Fine, M. (2008). An epilogue, of sorts. In J. Cammarota & M. Fine (Eds.), *Revolutionizing education: Youth participatory action research in motion* (pp. 213-234). Routledge. <https://ebookcentral-proquest-com.ezproxy.waikato.ac.nz/lib/waikato/detail.action?pq-origsite=primo&docID=325551>
- Fine, M. (2015). Decolonizing knowledge: Toward a critical research justice praxis in the urban sphere. In A. J. Jolivet (Ed.), *Research justice: Methodologies for social change* (pp. 199-204). Policy Press. <https://doi.org/10.2307/j.ctt1t89jrt>
- Flores, A. L., Meunier, J., & Peacock, G. (2022). "Include me": Implementing inclusive and accessible communication in public health. *Assistive Technology Outcomes and Benefits*, 16(2), 104-110. <https://www.proquest.com/docview/2712296571/fulltextPDF/F4340770E08843DAPQ1?acountid=17287&sourcetype=Scholarly%20Journals>
- Fluyt, L., Delafontaine, J., & Nijs, S. (2023). Stakeholders' perspectives on the decision-making process regarding reasonable accommodations for students with SEN: A concept mapping study. *International Journal of Inclusive Education*, 1-24. <https://doi.org/10.1080/13603116.2023.2223633>
- Foley, K. R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., Einfeld, S., Llewellyn, G., Parmenter, T. R., & Leonard, H. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: Care, Health and Development*, 39(6), 789-800. <https://doi.org/10.1111/cch.12019>
- Forts, A. M., & Luckasson, R. (2011). Reading, writing, and friendship: Adult implications of effective literacy instruction for students with intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 36(3-4), 121-125. <https://doi.org/10.2511/027494811800824417>
- Freire, P. (1970). *Pedagogy of the oppressed*. Penguin Books.
- French, S., & Swain, J. (1997). Changing disability research: Participating and emancipatory research with disabled people. *Physiotherapy*, 83(1), 26-32. [https://doi.org/10.1016/S0031-9406\(05\)66107-X](https://doi.org/10.1016/S0031-9406(05)66107-X)
- French, S., & Swain, J. (2008). There but for fortune. In J. Swain & S. French (Eds.), *Disability on equal terms* (pp. 7-20). Sage.

- Fugard, A., & Potts, H. W. W. (2019). Thematic analysis. In P. Atkinson, S. Delamont, A. Cernat, J. Sakshaug, & R. Williams (Eds.), *Sage research methods foundations*. Sage.
<https://doi.org/10.4135/9781526421036858333>
- Furness, J., Hedges, M., & Piercy-Cameron, G. (2021). *Adult literacy and numeracy intervention landscape in Aotearoa New Zealand*. NZ Work Research Institute.
https://workresearch.aut.ac.nz/__data/assets/pdf_file/0004/549607/ADULT-LITERACY-AND-NUMERACY-INTERVENTION-LANDSCAPE-IN-AOTEAROA-NEW-ZEALAND_3.pdf
- Furness, J. A., & Hunter, J. (2018). Adult literacy in Aotearoa New Zealand: Policy, potential and pitfalls. *New Zealand Annual Review of Education*, 22, 66-77.
<https://doi.org/doi.org/10.26686/nzaroe.v22i0.4149>
- Furness, J. A., & Hunter, J. (2019). *Using a wellbeing framework to recognise, value, and enhance the broad range of outcomes for learners in adult literacy and numeracy programmes*. Teaching and Learning Research Initiative.
www.tlri.org.nz/sites/default/files/projects/TLRI%20Summary_Furness%26Hunter.pdf
- Furness, J. A., Nikora, L. W., Hodgetts, D., & Robertson, N. (2015). Beyond ethics to morality: Choices and relationships in bicultural research settings. *Journal of Community & Applied Social Psychology*, 26(1), 75-88. <https://doi.org/10.1002/casp.2239>
- Fyson, R., & Fox, L. (2014). Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning. *Disability & Society*, 29(2), 239-254.
<https://doi.org/10.1080/09687599.2013.776491>
- Gair, S. (2012). Feeling their stories: Contemplating empathy, insider/outsider positionings, and enriching qualitative research. *Qualitative Health Research*, 22(1), 134-143.
<https://doi.org/10.1177/1049732311420580>
- Gallagher, S. (2002). 'A curious document': Ta moko as evidence of pre-European textual culture in New Zealand. *Bibliographical Society of Australia & New Zealand*, 27(3 & 4), 39-47.
https://www.bsanz.org/publications/script-and-print/past-issues/?ee=1&eeFolder=Bulletin-1970_2004%2FBulletin_27_2003%2FVolume-27_No-3-4&eeListID=1
- Gallaher, K. M., van Kraayenoord, C. E., Jobling, A., & Moni, K. B. (2002). Reading with Abby: A case study of individual tutoring with a young adult with Down syndrome. *Down Syndrome Research and Practice*, 8(2), 59-66. <https://doi.org/doi:10.3104>
- Gappmayer, G. (2019). Exploring neoliberalism in care for people with intellectual disabilities: A practice theory approach. *Journal of Occupational Science*, 26(2), 258-274.
<https://doi.org/10.1080/14427591.2019.1596830>
- Gappmayer, G. (2021). Disentangling disablism and ableism: The social norm of being able and its influence on social interactions with people with intellectual disabilities. *Journal of Occupational Science*, 28(1), 102-113. <https://doi.org/10.1080/14427591.2020.1814394>
- Garbutt, R., Tattersall, J., Dunn, J., & Boycott-Garnett, R. (2010). Accessible article: Involving people with learning disabilities in research. *British Journal of Learning Disabilities*, 38(1), 21-34.
<https://doi.org/10.1111/j.1468-3156.2009.00556.x>
- García Ochoa, G., & McDonald, S. (2020). *Cultural literacy and empathy in education practice*. Springer International Publishing. <https://doi.org/10.1007/978-3-030-59904-1>
- Garland-Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. Columbia University Press.
- Garratt, D., Johnson, K., Millea, A., Picken, S., Slattery, J., & Walmsley, J. (2022). Celebrating thirty years of inclusive research. *Social Sciences*, 11(9), 1-14.
<https://doi.org/10.3390/socsci11090385>

- Gatenio Gabel, S. (2016). *A rights-based approach to social policy analysis*. Springer International Publishing. <https://doi.org/10.1007/978-3-319-24412-9>
- Gaur, A. (1984). *A history of writing*. British Library.
- Gee, J. (2015). The new literacy studies. In J. Rowsell & K. Pahl (Eds.), *The Routledge handbook of literacy studies* (pp. 35-48). Routledge. <https://doi.org/doi/10.4324/9781315717647>
- Gernsbacher, M. A. (2017). Editorial perspective: The use of person first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859-861. <https://doi.org/10.1111/jcpp.12706>
- Gibbons, P. (2002). Cultural colonization and national identity. *New Zealand Journal of History*, 36(1), 5-17. <http://www.nzjh.auckland.ac.nz.ezproxy.waikato.ac.nz/document.php?wid=316&action=nul>
- Gillovic, B. (2019). *Experiences of care at the nexus of intellectual disability and leisure travel* [Doctoral thesis, Hamilton, New Zealand: University of Waikato]. Research Commons Thesis Collection. <https://researchcommons.waikato.ac.nz/handle/10289/12833>
- Gilmore, A., Croft, C., & Reid, R. (1981). *Burt word reading test: New Zealand revision*. NZCER Press.
- Goethals, T., De Schauwer, E., & Van Hove, G. (2015). Weaving intersectionality into disability studies research: Inclusion, reflexivity and anti-essentialism. *Journal of Diversity and Gender Studies*, 2(1-2), 75-94. <https://doi.org/doi.org/10.11116/jdivegendstud.2.1-2.0075>
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.
- Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*. Harper & Row.
- Gómez-Carrillo de Castro, M. (2023). A journey together: Co-creation and experiential knowledge of people with intellectual disabilities in social policy. In S. Robinson & K. Fisher (Eds.), *Research handbook on disability policy* (pp. 33-48). Edward Elgar Publishing.
- Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties: The politics of resilience*. Open University Press.
- Goodley, D. (2014). *Dis/ability studies: Theorising disablism and ableism*. Routledge. <https://doi.org/10.4324/9780203366974>
- Goodley, D. (2017). *Disability studies: An interdisciplinary introduction* (2nd ed.). Sage.
- Goodwin, J., Mason, V., Williams, V., & Townsley, R. (2015). Easy information about research: Getting the message out to people with learning disabilities. *British Journal of Learning Disabilities*, 43(2), 93-99. <https://doi.org/10.1111/bld.12128>
- Goody, J. (1968). *Literacy in traditional societies*. Cambridge University Press.
- Goody, J. (2000). *The power of the written tradition*. Smithsonian Institution Press.
- Goody, J., & Watt, I. (1963). The consequences of literacy. *Comparative Studies in Society and History*, 5(3), 304-345. <https://doi.org/doi.org/10.1017/S0010417500001730>
- Gordon Pershey, M., & Gilbert, T. W. (2002). Christine: A case study of literacy acquisition by an adult with developmental disabilities. *Mental Retardation*, 40(3), 219-234. <https://doi.org/doi:10.1352/0047-6765>
- Gosling, D. S., & Gerzon, R. (1994). *Barriers to a dream: Issues of power and control in the self-advocacy movement of people with intellectual disabilities in New Zealand*.
- Gould, S. J. (1997). *The mismeasure of man*. Penguin Books.
- Graber, S. (2018). The bathroom boogeyman. *Journalism Practice*, 12(7), 870-887. <https://doi.org/10.1080/17512786.2017.1358651>
- Graff, H. J., & Duffy, J. (2011). The literacy myth. In H. J. Graff (Ed.), *Literacy myths, legacies, and lessons: New studies on literacy* (pp. 35-48). Transaction Publishers.

- Graham, R., Masters Awatere, B., & Cowan, C. (2023). What do we know about the intersection of being blind and being Māori in Aotearoa New Zealand? Taking an applied community psychology approach to a systematic review of the published literature. *Journal of Community & Applied Social Psychology*, 33(5), 1171-1197. <https://doi.org/10.1002/casp.2700>
- Grant, A., & Kara, H. (2021). Considering the autistic advantage in qualitative research: The strengths of autistic researchers. *Contemporary Social Science*, 16(5), 589-603. <https://doi.org/10.1080/21582041.2021.1998589>
- Grant, J., Perez-y-Prez, M., & Cook, T.-A. (2019). *Work active: Supporting the “forgotten learners” in their journey to work*. <https://ako.ac.nz/assets/Knowledge-centre/RHPF-s1802-Work-active/Work-Active-FInal-Report.pdf>
- Grimes, A., & White, D. (2019). *Digital inclusion and wellbeing in New Zealand*. Motu Economic & Public Policy Research. https://motu-www.motu.org.nz/wpapers/19_17.pdf
- Grundy, A. L., Pollon, D. E., & McGinn, M. K. (2003). The participant as transcriptionist: Methodological advantages of a collaborative and inclusive research practice. *International Journal of Qualitative Methods*, 2(2), 23-32. doi.org/10.1177/160940690300200203
- Haegele, J. A., & Hodge, S. (2016). Disability discourse: Overview and critiques of the medical and social models. *Quest*, 68(2), 193-206. <https://doi.org/10.1080/00336297.2016.1143849>
- Halliday, M. A. K. (1973). Explorations in the functions of language. In P. Doughty & G. Thornton (Eds.), *Explorations in language study* (pp. 9-21). Edward Arnold.
- Hambrook, C. (2009). *Further towards an affirmative model of disability*. <https://disabilityarts.online/magazine/opinion/towards-affirmative-model-disability/>
- Hamilton, M. (2005). Expanding the new literacy studies: Using photographs to explore literacy as social practice. In M. Hamilton, R. Ivanic, & D. Barton (Eds.), *Situated literacies: Reading and writing in context* (pp. 15-32). Routledge. <https://doi.org/https://doi-org.ezproxy.waikato.ac.nz/10.4324/9780203984963>
- Hamilton, M., & Barton, D. (2000). The International Adult Literacy Survey: What does it really measure? *International Review of Education*, 46(5), 377-389. <https://doi.org/10.1023/A:1004125413660>
- Hand, L. (2021). *Perspectives on the use of sign with non-deaf children with communication difficulties* [Master's thesis, Auckland, New Zealand: University of Auckland].
- Hart, S. M., Gaffney, J. S., & Hill, M. F. (2017). Critical reflections on emancipatory partnerships in transition research: Discerning perspectives of New Zealand students on the autism spectrum. *Disability & Society*, 32(6), 831-852. <https://doi.org/10.1080/09687599.2017.1329710>
- Hart, S. M., Pascucci, M., Sood, S., & Barrett, E. M. (2020). Value, vulnerability and voice: An integrative review on research assent. *British Journal of Learning Disabilities*, 48(2), 154-161. <https://doi.org/10.1111/bld.12309>
- Haynes, N. (1995). How skewed is the bell curve? *Journal of Black Psychology*, 21(3), 275-292. <https://doi.org/10.1177/00957984950213005>
- Hayward, C. (2010, August). *Panel session* [Conference session]. NZCER Conference, Wellington, New Zealand.
- Health and Disability Commissioner. (n.d). *My health passport*. <https://shop.hdc.org.nz/uploads/product/full/cTVQOL7U/j006079%20hdc%20health%20passport%20easy%20read%20english.pdf>
- Heath, S. (1986). The functions and uses of literacy. In S. De Castell, A. Luke, & K. Egan (Eds.), *Literacy, society, and schooling: A reader* (pp. 15-26). Cambridge University Press.

- Hefferon, K. A. (2020). *Recognising autistic women: A minority within a minority* [Master's thesis, Hamilton, New Zealand: University of Waikato]. Research Commons Thesis Collection. <https://researchcommons.waikato.ac.nz/handle/10289/13417>
- Henry, E., & Wolfgramm, R. (2018). Relational leadership: An Indigenous Māori perspective. *Leadership, 14*(2), 203-219. <https://doi.org/10.1177/1742715015616282>
- Herrnstein, R. J., & Murray, C. A. (1994). *The bell curve: Intelligence and class structure in American life*. Free Press.
- Hetaraka, M., Meiklejohn-Whiu, S., Webber, M., & Jesson, R. (2023). Tiritiria: Understanding Māori children as inherently and inherited-ly literate: Towards a conceptual position. *New Zealand Journal of Educational Studies, 60*-72. <https://doi.org/10.1007/s40841-023-00290-7>
- Hetzroni, O. E. (2004). AAC and literacy. *Disability and Rehabilitation, 26*(21-22), 1305-1312. <https://doi.org/10.1080/09638280412331280334>
- Hevey, D. (1993). The tragedy principle: Strategies for change in the representation of disabled people. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers: Enabling environments* (pp. 116-121). Open University Press.
- Heyman, A. (2018). What do young adult carers learn through supporting family members? Extending the affirmation model. *Disability & Society, 33*(8), 1191-1211. <https://doi.org/10.1080/09687599.2018.1481014>
- Hickey, H. (2006). Replacing medical and social models of disability by a communities-based model of equal access for people of differing abilities: A Māori perspective. *He Puna Korero: Journal of Māori and Pacific Development, 7*, 35-47. <https://doi.org/doi/10.3316/informit.285940984141502>
- Hickey, H. (2014). Indigenous people with disabilities: The missing link. In M. Schulze & M. Sabatello (Eds.), *Human rights and disability advocacy* (pp. 157-169). University of Pennsylvania Press. <https://doi.org/10.9783/9780812208740.157>
- Hickey, H. (2015). Tātau tātau: Engaging with whānau hauā from within a cultural framework. In M. Berryman, H. Hickey, S. Macfarlane, K. Smiler, & T. Walker (Eds.), *Working with Māori children with special education needs: He mahi whakahirahira* (pp. 70-84). NZCER Press.
- Hickey, H., & Collins, A. (2006). *The role of whānau in the lives of Māori with physical disabilities*. <https://thehub.swa.govt.nz/resources/the-role-of-whanau-in-the-lives-of-maori-with-physical-disabilities/>
- Hickey, H., & Wilson, D. (2017). Whānau hauā. *MAI Journal, 6*(1), 82-94. <https://doi.org/10.20507/MAIJournal.2017.6.1.7>
- Higginbottom, G., & Liamputtong, P. (2015). What is participatory research? Why do it? In G. Higginbottom & P. Liamputtong (Eds.), *Participatory qualitative research methodologies in health*. Sage.
- Highmore, B. (2016). *Culture*. Routledge. <https://doi.org/10.4324/9780203129470>
- Hindle, R., & Matthewman, S. (2017). Māori literacies: Ecological perspectives. *Set*(3), 32-37. <https://doi.org/doi.org/10.18296/set.0090>
- Hirsch, E. D. (1984, January 19-20). *Cultural literacy* [Conference presentation]. National Adult Literacy Conference, Washington, DC, United States. <https://files.eric.ed.gov/fulltext/ED241697.pdf>
- Hirsch, E. D. (1988). *Cultural literacy: What every American needs to know*. Vintage Books.
- Hirsch, E. D., Kett, J., & Trefil, J. (2002). *The new dictionary of cultural literacy: What every American needs to know*. Houghton Mifflin.

- Ho, P., Downs, J., Bulsara, C., Patman, S., & Hill, A. M. (2018). Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disabilities, 46*(2), 92-100. <https://doi.org/10.1111/bld.12217>
- Hodgson, J., & Harris, A. (2022). The genealogy of 'cultural literacy.' *Changing English, 29*(4), 382-395. <https://doi.org/10.1080/1358684X.2022.2081530>
- Hollomotz, A. (2013). Disability, oppression and violence: Towards a sociological explanation. *Sociology, 47*(3), 477-493. <https://doi.org/10.1177/0038038512448561>
- Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research, 18*(2), 153-170. <https://doi.org/10.1177/1468794117713810>
- Holtmatt, R. (2013). The CEDAW: A holistic approach to women's equality and freedom. In A. Hellum & H. S. Aasen (Eds.), *Women's human rights: CEDAW in international, regional, and national law* (pp. 95-123). Cambridge University Press.
<http://ebookcentral.proquest.com/lib/waikato/detail.action?docID=1303706>
- Home Education Network. (2022). *School can't*. <https://home-ed.vic.edu.au/school-cant/>
- House, S. (1981). A radical feminist model of psychological disability. *Off Our Backs: A Women's Newsjournal, 11*(5), 34-35. <https://www.jstor.org/stable/25774071?seq=1>
- Hua, Y., Hendrickson, J. M., Therrien, W. J., Woods-Groves, S., Ries, P. S., & Shaw, J. J. (2012). Effects of combined reading and question generation on reading fluency and comprehension of three young adults with autism and intellectual disability. *Focus on Autism and Other Developmental Disabilities, 27*(3), 135-146. <https://doi.org/10.1177/1088357612448421>
- Hua, Y., Therrien, W. J., Hendrickson, J. M., Woods-Groves, S., Ries, P. S., & Shaw, J. W. (2012). Effects of combined repeated reading and question generation intervention on young adults with cognitive disabilities. *Education and Training in Autism and Developmental Disabilities, 47*(1), 72-83. <https://doi.org/https://www.jstor.org/stable/23880563>
- Hua, Y., Woods-Groves, S., Kaldenberg, E. R., & Scheidecker, B. J. (2013). Effects of vocabulary instruction using constant time delay on expository reading of young adults with intellectual disability. *Focus on Autism and Other Developmental Disabilities, 28*(2), 89-100. <https://doi.org/10.1177/1088357613477473>
- Human Rights Commission. (2013). *A new era in the right to sign: He houhanga rongu te tika ki te reo tūri*. <https://tikatangata.org.nz/our-work/a-new-era-in-the-right-to-sign>
- Human Rights Council Working Group on the Universal Periodic Review. (2019). *National report submitted in accordance with paragraph 5 of the annex to Human Rights Council resolution 16/21: New Zealand*. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/338/73/PDF/G1833873.pdf?OpenElement>
- Hunter, J. (2016). Critical revisioning: The construction of practitioners in Aotearoa New Zealand's literacy campaign. In K. Yasukawa & S. Black (Eds.), *Beyond economic interests: Critical perspectives on adult literacy and numeracy in a globalised world* (pp. 223-237). Brill. <https://doi.org/10.1007/978-94-6300-444-2>
- Hurst, M. J. (1990). *The voice of the child in American literature*. The University of Kentucky.
- Hurst, S. A. (2008). Vulnerability in research and health care: Describing the elephant in the room? *Bioethics, 22*(4), 191-202. <https://doi.org/10.1111/j.1467-8519.2008.00631.x>
- Hurtado, B., Jones, L., & Burniston, F. (2014). Is easy read information really easier to read? *Journal of Intellectual Disability Research, 58*(9), 822-829. <https://doi.org/10.1111/jir.12097>
- Hutchings, J., & Ikin, K. (2016). *Haea te pū ata: A national strategy for Māori adult literacy and numeracy: 2016–2020 (and beyond)*. https://www.nzcer.org.nz/system/files/Haea_Te_Pu_Atata_English_digital_1.pdf

- Hutchings, J., Yates, B., Isaacs, P., Whatman, J., & Bright, N. (2013). *Hei ara ako ki te oranga: A model for measuring wellbeing outcomes from literacy programmes*. Ako Aotearoa.
<https://ako.ac.nz/assets/Knowledge-centre/NPF-10-006-Hei-Ara-Ako-ki-te-Oranga/RESEARCH-REPORT-Hei-Ara-Ako-ki-te-Oranga-A-Model-for-Measuring-Wellbeing-Outcomes-from-Literacy-Programmes.pdf>
- Iglesias, O. B., Sánchez, L. E. G., & Rodríguez, M. Á. A. (2019). Do young people with Asperger syndrome or intellectual disability use social media and are they cyberbullied or cyberbullies in the same way as their peers? *Psicothema*, *31*(1), 30-37.
<https://doi.org/10.7334/psicothema2018.243>
- IHC. (2022). IHC inclusive education survey. https://assets-global.website-files.com/628455c1cd53af649dec6493/642cf4cf6c45ae2a37fa94ca_220715%202022%20IHC%20Inclusive%20Education%20Survey.pdf
- Ingham, T. R., Jones, B., Perry, M., King, P. T., Baker, G., Hickey, H., Pouwhare, R., & Nikora, L. W. (2022). The multidimensional impacts of inequities for tāngata whaikaha Māori (Indigenous Māori with lived experience of disability) in Aotearoa, New Zealand. *International Journal of Environmental Research and Public Health*, *19*(20), 1-16.
<https://doi.org/10.3390/ijerph192013558>
- Inglis, P., & Cook, T. (2011). Ten top tips for effectively involving people with a learning disability in research. *Journal of Learning Disabilities and Offending Behaviour*, *2*(2), 98-104.
<https://doi.org/10.1108/20420921111152441>
- International Federation of Library Association and Institutions. (2010). *Guidelines for easy-to-read materials*. <https://www.ifla.org/wp-content/uploads/2019/05/assets/hq/publications/professional-report/120.pdf>
- Isl collective. (n.d). *Rat research project*. <https://en.islcollective.com/english-esl-worksheets/general-topic/movies-and-tv-series/rat-research-project/34339>
- Jackson, B., & Jones, O. S. (2012). Promoting better public services leadership: An appreciative critique. *Policy Quarterly*, *8*(3), 34-40. <https://ojs.victoria.ac.nz/pq/article/view/4423/3914>
- Jansen-van Vuuren, J., & Aldersey, H. M. (2020). Stigma, acceptance and belonging for people with IDD across cultures. *Current Developmental Disorders Reports*, *7*(3), 163-172.
<https://doi.org/10.1007/s40474-020-00206-w>
- Jarrett, S., & Tilley, E. (2022). The history of the history of learning disability. *British Journal of Learning Disabilities*, *50*(2), 132-142. <https://doi.org/10.1111/bld.12461>
- Jenkins, K. (1993). *Becoming literate, becoming English: A research into the beginnings of English literacy within Maori society*. Research Unit for Maori Education.
- Jerome, M. K., & Ainsworth, M. K. (2020). Acquisition for students with severe disabilities: Making it happen through assistive technology. *Teaching Exceptional Children*, *53*(1), 80-83.
<https://doi.org/10.1177/0040059920945590>
- Johnson, D. J., Jaeger, E., Randolph, S. M., Cauce, A. M., & Ward, J. (2003). Studying the effects of early child care experiences on the development of children of color in the United States: Toward a more inclusive research agenda. *Child Development*, *74*(5), 1227-1244.
doi.org/10.1111/1467-8624.00604
- Johnson, G. (2004). *Adult literacy and economic growth*. NZ Treasury working paper.
<https://www.treasury.govt.nz/sites/default/files/2007-09/twp04-24.pdf>
- Johnson, K. (2009). No longer researching about us without us: A researcher's reflection on rights and inclusive research in Ireland. *British Journal of Learning Disabilities*, *37*(4), 250-256.
<https://doi.org/10.1111/j.1468-3156.2009.00579.x>

- Johnson, K. (2023). Education and learning. In L. Tilly & J. Walmsley (Eds.), *Rights in practice for people with a learning disability* (pp. 13-44). Palgrave Macmillan. https://doi.org/doi.org/10.1007/978-981-99-5563-3_2
- Join In. (n.d). European Network for Inclusive Higher Education. <https://joinin.education/>
- Jones, A., & Hoskins, T. K. (2016). A mark on paper: The matter of indigenous–settler history. In C. Taylor, C. Hughes, & H. Mizuta (Eds.), *Posthuman research practices in education* (pp. 75-92). Palgrave Macmillan. <https://doi.org/10.1057/9781137453082>
- Jones, B., King, P. T., Baker, G., Nikora, L. W., Hickey, H., Perry, M., Pouwhare, R., & Ingham, T. R. (2023). Karanga rua, karanga maha: Māori with lived experience of disability self-determining their own identities. *Kōtuitui: New Zealand Journal of Social Sciences Online*, 19(1), 45-64. <https://doi.org/10.1080/1177083X.2023.2224422>
- Jones, F. W., Long, K., & Finlay, W. M. L. (2007). Symbols can improve the reading comprehension of adults with learning disabilities. *Journal of Intellectual Disability Research*, 51(7), 545-550. <https://doi.org/10.1111/j.1365-2788.2006.00926.x>
- Jones, I. R. (2019). *Disability as an entanglement: A new materialist reimagination of disability* [Doctoral thesis, Hamilton, New Zealand: University of Waikato]. Research Commons Thesis Collection. <https://researchcommons.waikato.ac.nz/handle/10289/12433>
- Jones, K. (2020). *Bridging the research gap: A toolkit on inclusive research and development practices*. The Chicago Council on Global Affairs. <https://www.jstor.org/stable/resrep24850>
- Jordan, S., & Kapoor, D. (2016). Re-politicizing participatory action research: Unmasking neoliberalism and the illusions of participation. *Educational Action Research*, 24(1), 134-149. <https://doi.org/10.1080/09650792.2015.1105145>
- Joyce, T., & Borgwaldt, S. R. (2013). Introduction. In S. R. Borgwaldt & T. Joyce (Eds.), *Typology of writing systems* (pp. 1-12). John Benjamins Publishing. <https://ebookcentral-proquest-com.ezproxy.waikato.ac.nz/lib/waikato/reader.action?docID=1209571&ppg=9>
- Kaiwaik, H., & Allport, T. (2019). *Māori with disabilities (part two): Report commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575)*. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150473583/Wai%202575%2C%20B023.pdf
- Kasa-Hendrickson, C. (2005). 'There's no way this kid's retarded': Teachers' optimistic constructions of students' ability. *International Journal of Inclusive Education*, 9(1), 55-69. <https://doi.org/10.1080/1360311042000253591>
- Kaufert, D. (1989). Cultural literacy: A critique of Hirsch and an alternative theory. *ADE Bulletin*, 94, 23-28. <https://www.maps.mla.org/bulletin/article/ade.94.23/>
- Keefe, E. B., & Copeland, S. R. (2011). What is literacy? The power of a definition. *Research and Practice for Persons with Severe Disabilities*, 36(3-4), 92-99. <https://doi.org/10.2511/027494811800824507>
- Kelsey, J. (1995). *The New Zealand experiment: A world model for structural adjustment?* Auckland University Press with Bridget Williams Books.
- Kesby, M., Kindon, S. L., & Pain, R. (2007). Participation as a form of power: Retheorising empowerment and spatialising participatory action research. In S. L. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods: Connecting people, participation, and place* (pp. 19-25). Routledge.
- Keskinen, T., Heimonen, T., Turunen, M., Rajaniemi, J.-P., & Kauppinen, S. (2012). SymbolChat: A flexible picture-based communication platform for users with intellectual disabilities. *Interacting with Computers*, 24(5), 374-386. <https://doi.org/10.1016/j.intcom.2012.06.003>

- Khanlou, N., Khan, A., Vazquez, L. M., & Zangeneh, M. (2021). Digital literacy, access to technology and inclusion for young adults with developmental disabilities. *Journal of Developmental and Physical Disabilities*, 33(1), 1-25. <https://doi.org/10.1007/s10882-020-09738-w>
- Kiddle, R. (2012). Uncovering the sensory experience. In J. Hendry & L. Fitznor (Eds.), *Anthropologists, Indigenous scholars and the research endeavour: Seeking bridges towards mutual respect* (pp. 199-207). Routledge. <https://doi.org/10.4324/9780203122136>
- Kindon, S. L. (2012). *'Thinking-through-complicity' with Te Iwi o Ngāti Hauiti: Towards a critical use of participatory video for research* [Doctoral thesis, Hamilton, New Zealand: University of Waikato]. Research Commons Thesis Collection. <https://researchcommons.waikato.ac.nz/handle/10289/6286>
- Kindon, S. L., Pain, R., & Kesby, M. (2007). Participatory action research: Origins, approaches and methods. In S. L. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods: Connecting people, participation, and place* (pp. 9-18). Routledge.
- King, P. (2019). *Māori with lived experience of disability: Part I: Commissioned by the Waitangi Tribunal for Stage Two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry*. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575%2C%20B022.pdf
- Kingi, J., & Bray, A. (2000). *Māori concepts of disability* <https://www.donaldbeasley.org.nz/publications/haua-maori/>
- Kirsch, I., & Guthrie, J. T. (1977). The concept and measurement of functional literacy. *Reading Research Quarterly*, 13(4), 485-507. <https://doi.org/10.2307/747509>
- Kittay, E. F. (2015). Centering justice on dependency and recovering freedom. *Hypatia*, 30(1), 285-291. <https://doi.org/10.1111/hypa.12131>
- Kliewer, C. (1998). Citizenship in the literate community: An ethnography of children with Down syndrome and the written word. *Exceptional Children*, 64(2), 167-180. <https://doi.org/10.1177/001440299806400202>
- Kliewer, C. (2008). Joining the literacy flow: Fostering symbol and written language learning in young children with significant developmental disabilities through the four currents of literacy. *Research and Practice for Persons with Severe Disabilities*, 33(3), 103-121. <https://doi.org/10.2511/rpsd.33.3.103>
- Kliewer, C., & Biklen, D. (2007). Enacting literacy: Local understanding, significant disability, and a new frame for educational opportunity. *Teachers College Record*, 109(12), 1-19. <https://doi.org/https://doi-org.ezproxy.waikato.ac.nz/10.1177/016146810710901202>
- Kliewer, C., Biklen, D., & Kasa-Hendrickson, C. (2016). Who may be literate? Disability and resistance to the cultural denial of competence. *American Educational Research Journal*, 43(2), 163-192. <https://doi.org/10.3102/00028312043002163>
- Kliewer, C., Fitzgerald, L. M., & Meyer-Mork, J. (2004). Citizenship for all in the literate community: An ethnography of young children with significant disabilities in inclusive early childhood settings. *Harvard Educational Review*, 74(4), 373-403. <https://doi.org/10.17763/haer.74.4.p46171013714642x>
- Koenig, O. (2012). Any added value? Co-constructing life stories of and with people with intellectual disabilities. *British Journal of Learning Disabilities*, 40(3), 213-221. <https://doi.org/10.1111/j.1468-3156.2011.00695.x>
- Köhler, T., Smith, A., & Bhakoo, V. (2022). Templates in qualitative research methods: Origins, limitations, and new directions. *Organizational Research Methods*, 25(2), 183-210. <https://doi.org/10.1177/10944281211060710>

- Kramer, J. M., Kramer, J. C., García-Iriarte, E., & Hammel, J. (2011). Following through to the end: The use of inclusive strategies to analyse and interpret data in participatory action research with individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24(3), 263-273. <https://doi.org/10.1111/j.1468-3148.2010.00602.x>
- Kress, G. (2010). *Multimodality: A social semiotic approach to contemporary communication*. Routledge.
- Kress, G., & Jewitt, C. (2003). Introduction. In C. Jewitt & G. Kress (Eds.), *Multimodal literacy* (pp. 1-18). Peter Lang.
- Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Sage.
- Laes, T. (2017). Beyond participation: A reflexive narrative of the inclusive potentials of activist scholarship in music education. *Bulletin of the Council for Research in Music Education*, 210, 137-151. <https://doi.org/doi.org/10.5406/bulcoursmusedu.210-211.0137>
- Lankshear, C., & Knobel, M. (1997). Critical literacy and active citizenship. In S. Muspratt, A. Luke, & P. Freebody (Eds.), *Constructing critical literacies: Teaching and learning textual practice* (pp. 95-124). Hampton Press.
- Law, J. (2021). *A dictionary of nursing* (8th ed.). Oxford University Press. <https://www-oxfordreference-com.ezproxy.waikato.ac.nz/display/10.1093/acref/9780198864646.001.0001/acref-9780198864646-e-10107>
- Lawrence, R. J. (2015). Mind the gap: Bridging the divide between knowledge, policy and practice. In H. Barton, S. Thompson, S. Burgess, & M. Grant (Eds.), *The Routledge handbook of planning for health and well-being* (pp. 108-118). Routledge. <https://doi.org/10.4324/9781315728261-16>
- Leach, L., Zepke, N., Haworth, P., & Isaacs, P. (2010). *'One size does not fit all': How five tertiary education organisations embed literacy, language and numeracy: Case study findings* https://www.educationcounts.govt.nz/__data/assets/pdf_file/0006/77280/oneSize-doesNot-Case-76974-15062010.pdf
- Learning Disability Wales. (2020). *How to use Zoom*. <https://www.ldw.org.uk/wp-content/uploads/2020/04/How-to-use-Zoom.pdf>
- Lee, C. (2014). Systemic colonization of the educational lifeworld: An example in literacy education. *Educational Philosophy and Theory*, 46(1), 87-99. <https://doi.org/10.1111/j.1469-5812.2011.00812.x>
- Lettington, J., & Van Herwegen, J. (2024). Home literacy environment and literacy outcomes in individuals with Williams syndrome and Down syndrome. *Journal of Intellectual & Developmental Disability*, 49(1), 67-83. <https://doi.org/10.3109/13668250.2023.2226917>
- Liamputtong, P., & Ezzy, D. (2013). *Qualitative research methods* (4th ed.). Oxford University Press.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York University Press. <https://doi.org/10.18574/9780814765043>
- Lock, A., & Strong, T. (2010). *Social constructionism: Sources and stirrings in theory and practice*. Cambridge University Press. <https://doi.org/10.1017/CBO9780511815454>
- Loseke, D. R., & Green, S. E. (2019). Introduction: Exploring narrative as a social science framework on disability and disabled people. In S. E. Green & D. R. Loseke (Eds.), *New narratives of disability: Constructions, clashes, and controversies*. Emerald Publishing.
- Luke, A. (2018). The social construction of literacy in the primary school. In *Critical literacy, schooling, and social justice: The selected works of Allan Luke* (pp. 28-74). Routledge. <https://doi.org/10.4324/9781315100951-2>

- Lumsden, K. (2019). *Reflexivity: Theory, method, and practice*. Taylor and Francis.
<https://doi.org/10.4324/9781315692319>
- Lynch, J. (2013). A case study of a volunteer-based literacy class with adults with developmental disabilities. *Australian Journal of Adult Learning*, 53(2), 302-325.
<https://files.eric.ed.gov/fulltext/EJ1013645.pdf>
- Lytle, S. L. (1991). Living literacy: Rethinking development in adulthood. *Linguistics and Education*, 3(2), 109-138. [https://doi.org/10.1016/0898-5898\(91\)90002-Z](https://doi.org/10.1016/0898-5898(91)90002-Z)
- Macfarlane, A., Macfarlane, S., & Gillon, G. (2014). Inclusion, disability and culture: The nexus of potential and opportunity for policy development. In R. Wills, M. Morton, M. McLean, M. Stephenson, & R. Slee (Eds.), *Tales from school: Learning disability and state education after administrative reform* (pp. 255-270). Birkhäuser. <https://doi.org/10.1007/978-94-6209-893-0>
- MacIntosh-Murray, A. (2007). Poster presentations as a genre in knowledge communication: A case study of forms, norms, and values. *Science Communication*, 28(3), 347-376.
<https://doi.org/10.1177/1075547006298251>
- MacKenzie, C. A., Christensen, J., & Turner, S. (2015). Advocating beyond the academy: Dilemmas of communicating relevant research results. *Qualitative Research*, 15(1), 105-121.
<https://doi.org/10.1177/1468794113509261>
- Manca, S., Bocconi, S., & Gleason, B. (2021). "Think globally, act locally": A glocal approach to the development of social media literacy. *Computers and Education*, 160, 1-17.
<https://doi.org/10.1016/j.compedu.2020.104025>
- Mander, A. (2022). The stories that cripple us: The consequences of the medical model of disability in the legal sphere. *Victoria University of Wellington Law Review*, 53(2), 337-362.
<https://doi.org/10.26686/vuwlr.v53i2.7765>
- Māori Adult Literacy Working Party. (2001). *Te kāwai ora: Reading the world, reading the word, being the world*. www.beehive.govt.nz/030908TeKawaiOraReport
- Marsden, M. (1992). God, man and universe: A Maori view. In M. King (Ed.), *Te ao hurihuri: Aspects of Maoritanga* (pp. 118-138). Reed.
- Martins, A. P., Freitas, C., Cristina, M., Pereira, S., & Santos, C. (2021). "amik@": Social media platform for people with intellectual disability. *Procedia Computer Science*, 181, 716-721.
<https://doi.org/10.1016/j.procs.2021.01.223>
- May, S., Jang-Jones, A., McGregor, A., & Ministry of Education. (2019). *PISA 2018: Summary report: System performance and equity*.
<https://www.educationcounts.govt.nz/publications/series/PISA/pisa-2018/pisa-2018-summary-report>
- Mazzeschi, R. P. (2021). *International human rights law: Theory and practice*. Springer International Publishing. <https://link-springer-com.ezproxy.waikato.ac.nz/book/10.1007/978-3-030-77032-7>
- Mazzeschi, R. P. (2022). The United Nations system. In F. Felder, L. Davy, & R. Kayess (Eds.), *Disability law and human rights: Theory and policy* (pp. 179-210). Palgrave Macmillan. https://link-springer-com.ezproxy.waikato.ac.nz/chapter/10.1007/978-3-030-77032-7_10
- McFarlane, H., & Hasen, N. (2007). Inclusive methodologies: Including disabled people in participatory action research in Scotland and Canada. In S. L. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods: Connecting people, participation, and place* (pp. 88-94). Routledge.
- McGuirk, E. (2012). Studying time banking: Exploring participatory action research in Aotearoa. *Sites*, 9(2), 142-171. <https://doi.org/doi.org/10.11157/sites-vol9iss2id207>

- McIlroy, A.-M. (2017). *'The myth of inability': Exploring children's capability and belonging at primary school through narrative assessment* [Doctoral thesis, Christchurch, New Zealand: University of Canterbury]. UC Research Repository. <https://ir.canterbury.ac.nz/items/8b0b0eb6-d15d-4f2d-884e-7810dd495dbd>
- McKee, R. L. (2011). Action pending: Four years on from the New Zealand Sign Language Act 2006. *Victoria University of Wellington Law Review*, 42(2), 277-297. <https://doi.org/10.26686/vuwlr.v42i2.5133>
- McKegg, K., Wehipeihana, N., Becroft, M., & Gill, J. (2016). Developmental evaluation's role in supporting community led solutions for Māori and Pacific young people's educational success In M. Q. Patton, K. McKegg, & N. Wehipeihana (Eds.), *Developmental evaluation exemplars: Principles in practice* (pp. 125-142). The Guilford Press.
- McKenzie, D. (1987). The sociology of a text: Oral culture, literacy and print in early New Zealand. In P. Burke & R. Porter (Eds.), *The social history of language* (pp. 161-197). Cambridge University Press.
- McMahon, M., Moni, K., Cuskelly, M., Lloyd, J., & Jobling, A. (2020). Aspirations held by young adults with intellectual disabilities and their mothers. *Australian Journal of Career Development*, 29(2), 107-116. <https://doi.org/https://doi.org/10.1177/1038416220916813>
- McMenamin, T. (2014). Neither confirmed nor denied: Special school provision in New Zealand's Special Education 2000 policy. *British Journal of Special Education*, 41(1), 25-41. <https://doi.org/10.1111/1467-8578.12053>
- McRae, J. (2014). *Becoming a person: The biography of Robert Martin*. Craig Potton Publishing.
- McRae, J. (2017). *Māori oral tradition: He kōrero nō te ao tawhito*. Auckland University Press.
- Mead, S. M. (1997). *Landmarks, bridges and visions: Aspects of Maori culture*. Victoria University Press.
- Mellifont, D., & Smith-Merry, J. (2016). Laying or delaying the groundwork? A critical framing analysis of Australia's National Disability Strategy from an implementation planning perspective. *Disability & Society*, 31(7), 929-947. <https://doi.org/10.1080/09687599.2016.1216392>
- Melvin, G. A., Freeman, M., Ashford, L. J., Hastings, R. P., Heyne, D., Tonge, B. J., Bailey, T., Totsika, V., & Gray, K. M. (2023). Types and correlates of school absenteeism among students with intellectual disability. *Journal of Intellectual Disability Research*, 67(4), 375-386. <https://doi.org/10.1111/jir.13011>
- Mem Joe, M., & Terrell, J. (2011, June 30). *Embedding in a Māori context* [Conference presentation]. National Centre of Literacy & Numeracy for Adults Symposium, Hamilton, New Zealand. <https://ako.ac.nz/assets/Knowledge-centre/ALNACC-Resources/Embedding-literacy-and-numeracy-in-a-Maori-context/Embedding-LN-in-a-Maori-context.pdf>.
- Mhuru, M. (2020). *The educational experiences of disabled learners*. https://www.educationcounts.govt.nz/__data/assets/pdf_file/0004/199030/He-Whakaaro-the-educational-experiences-of-disabled-learners.pdf
- Middleton, A. (2019). *Pēwhairangi: Bay of Islands missions and Māori 1814 to 1845*. Otago University Press.
- Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 26(1), 5-19. www.researchgate.net/publication/230853055_Integrated_employment_or_sheltered_workshops_Preferences_of_adults_with_intellectual_disabilities_their_families_and_staff

- Mika, J. P., & O'Sullivan, J. G. (2014). A Māori approach to management: Contrasting traditional and modern Māori management practices in Aotearoa New Zealand. *Journal of Management & Organization*, 20(5), 648-670. <https://doi.org/10.1017/jmo.2014.48>
- Miller, S. M., & van Heumen, L. (2021). Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: Technological adaptations. *Journal of Enabling Technologies*, 15(2), 122-135. <https://doi.org/10.1108/JET-12-2020-0051>
- Milner, P., & Frawley, P. (2019). From 'on' to 'with' to 'by': People with a learning disability creating a space for the third wave of inclusive research. *Qualitative Research*, 19(4), 382-398. <https://doi.org/10.1177/1468794118781385>
- Milner, P., Mirfn-Veitch, B., Tikao, K., & Frawley, P. (2019). "Mean as!" *The story of creating an online library about relationships and sexuality told and read by whaikaha Māori and men and women with a learning disability.* <https://www.donaldbeasley.org.nz/assets/projects/Mean-As/Mean-As-Academic-Report.pdf>
- Ministry of Education. (2001). *More than words: The New Zealand adult literacy strategy: Kei tua atu i te kupu: Te mahere rautaki whiringa ako o Aotearoa.* <https://englishonline.tki.org.nz/Users/Editors-Literacy-English/MN-Files/More-Than-Words-The-New-Zealand-Adult-Literacy-Strategy-PDF>
- Ministry of Education. (2019). *Evidence brief for the Tertiary Education Strategy.* <https://conversation.education.govt.nz/assets/TES/16-Sept-2019-Annex-2-Draft-Evidence-Brief-003.pdf>
- Ministry of Education. (2020a). *Education and Training Act* <https://www.legislation.govt.nz/act/public/2020/0038/latest/LMS170676.html>
- Ministry of Education. (2020b). *The statement of national education and learning priorities (NELP) & tertiary education strategy (TES).* <https://education.govt.nz/assets/Documents/NELP-TES-documents/FULL-TES-2020.pdf>
- Ministry of Education. (2022). *Specialist schools.* <https://www.education.govt.nz/school/student-support/special-education/specialist-schools-for-students-with-high-needs/>
- Ministry of Education. (2024). *Education and Training Act 2020: Renaming "special schools" as "specialist schools."* <https://www.education.govt.nz/our-work/legislation/education-and-training-act-2020/renaming-special-schools-as-specialist-schools/>
- Ministry of Education. (n.d-a). *The future of education: Results from an online survey on people with disabilities or learning support needs: Easy read.* <https://conversation-space.s3-ap-southeast-2.amazonaws.com/Voices+of+People+With+Disabilites+Survey+Report+Easy+Read.pdf>
- Ministry of Education. (n.d-b). *Pacific and Pasifika terminology.* <https://tapasa.tki.org.nz/about/tapasa/pacific-and-pasifika-terminology/#:~:text=The%20terms%20%E2%80%9CPasifika%E2%80%9D%20and%20%E2%80%9C,Pacific%20regions%20and%20their%20descendants.>
- Ministry of Education, & TEC. (2024). *2024 Single data return: A manual for tertiary education organisations and student management system developers: Specifications of the Ministry of Education and Tertiary Education Commission data requirements for the single data return for the 2024 academic year.* https://edapps-live-storagestack-1ms-assetstorages3bucket-eoqkiztmvgxu.s3.amazonaws.com/s3fs-public/2024-01/SDR%20Manual%202024%20ver%201.0_1.pdf?VersionId=kvaJecwRKWcV_Zxnly83E0k4qi2K5QhI
- Ministry of Health. (2003). *Intellectual Disability (Compulsory Care and Rehabilitation) Act.* <https://www.legislation.govt.nz/act/public/2003/0116/latest/DLM224578.html>

- Ministry of Health. (2015). Disability support services: Tier one service specification. <https://www.whaikaha.govt.nz/get-involved/information-for-service-providers/contracts-and-service-specifications/#national-contracts>
- Ministry of Health. (2018). *Whāia te ao Mārama 2018 to 2022: The Māori Disability Action Plan*. <https://www.health.govt.nz/system/files/documents/publications/whaia-te-ao-marama-2018-to-2022.pdf>
- Ministry of Health. (2019). *Demographic report for clients allocated the Ministry of Health's Disability Support Services: 2018 update*. https://www.health.govt.nz/system/files/documents/publications/demographic-report-for-client-allocated-ministry-of-health-disability-support_services-2018-update14nov2019.pdf
- Ministry of Health. (2020). *Contracts and service specifications*. <https://www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/contracts-and-service-specifications>
- Minkowitz, T. (2017). CRPD and transformative equality. *International Journal of Law in Context*, 13(1), 77-86. <https://doi.org/10.1017/S1744552316000483>
- Mino Roy, J., St Jean, J., Lemus Folgar, O., Caron, K., Constant Nolett, O., Després, J. P., & Gauthier Boudreault, C. (2022). Effects of music, dance and drama therapies for people with an intellectual disability: A scoping review. *British Journal of Learning Disabilities*, 50(3), 385-401. <https://doi.org/10.1111/bld.12402>
- Mirfin-Veitch, B. (2003). *Education for adults with an intellectual disability (including transition to adulthood): Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability*. <https://www.donaldbeasley.org.nz/assets/publications/literature-reviews/NHC-Educ.pdf>
- Moni, K., Jobling, A., & Baffour, B. (2018). Literacy learning outcomes in a longitudinal study of a postschool literacy education program for young adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(2), 155-165. <https://doi.org/10.1111/jppi.12247>
- Moni, K. B., Jobling, A., & Van Kraayenoord, C. E. (2007). 'They're a lot cleverer than I thought': Challenging perceptions of disability support staff as they tutor in an adult literacy program. *International Journal of Lifelong Education*, 26(4), 439-459. <https://doi.org/10.1080/02601370701417269>
- Montenegro, M., & Greenhill, B. (2015). Evaluating 'FREDA Challenge': A coproduced human rights board game in services for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28(3), 223-237. <https://doi.org/10.1111/jar.12124>
- Moon, P. (2018). King's 1793 'vocabulary': The culture, politics and linguistics behind the development of an early Māori lexicon. *History Australia*, 15(1), 78-88. <https://doi.org/10.1080/14490854.2017.1413944>
- Moon, P. (2019). Missionaries and the Māori language in nineteenth century New Zealand: A mixed inheritance. *Journal of Religious History*, 43(4), 495-510. <https://doi.org/10.1111/1467-9809.12632>
- Moorfield, J. (2024). *Te aka online Māori dictionary*. <https://maoridictionary.co.nz/>
- More, C. (2000). *Understanding the Industrial Revolution*. Routledge. <https://doi.org/10.4324/9780203136973>
- Morgan, M. (2013). *Using participatory research to investigate what literacy looks like for adults with intellectual disability* [Doctoral Thesis, Brisbane, Australia: University of Queensland]. UQ eSpace. <https://espace.library.uq.edu.au/view/UQ:318995>

- Morgan, M., Moni, K., & Jobling, A. (2004). What's it all about? Investigating reading comprehension strategies in young adults with Down syndrome. *Down Syndrome Research and Practice*, 9(2), 37–44. <https://doi.org/doi:10.3104/reports.290>
- Morgan, M., Moni, K. B., & Jobling, M. A. (2006). Code-breaker: Developing phonics with a young adult with an intellectual disability. *Journal of Adolescent & Adult Literacy*, 50(1), 52-65. <https://doi.org/10.1598/JAAL.50.1.6>
- Morgan, M. F., Cuskelly, M., & Moni, K. B. (2011). Broadening the conceptualization of literacy in the lives of adults with intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 36(3-4), 112-120. <https://doi.org/10.2511/027494811800824516>
- Morgan, M. F., Cuskelly, M., & Moni, K. B. (2014). Unanticipated ethical issues in a participatory research project with individuals with intellectual disability. *Disability & Society*, 29(8), 1305-1318. <https://doi.org/10.1080/09687599.2014.934440>
- Morgan, M. F., & Moni, K. B. (2008). Literacy: Meeting the challenge of limited literacy resources for adolescents and adults with intellectual disabilities. *British Journal of Special Education*, 35(2), 92-101. <https://doi.org/10.1111/j.1467-8578.2008.00378.x>
- Morgan, M. F., Moni, K. B., & Cuskelly, M. (2013). Literacy strategies used by adults with intellectual disability in negotiating their everyday community environments. *Australian Journal of Adult Learning*, 53(3), 411-435. <https://espace.library.uq.edu.au/view/UQ:313218>
- Morton, M. (2012). Who will be heard? Qualitative research and legal decisions about facilitated communication. In S. Steinberg & G. Cannella (Eds.), *Critical qualitative research reader* (pp. 246-256). Peter Lang.
- Mulholland, M., & Bargh, R. (2015). *Māori carving: The art of recording Māori history*. Huia Publishers.
- Nafatali, R. (2023). *"E lē ma'i, o le malosi!" = (he's not sick, he's strong!): Pacific parents' journey of raising autistic children in Aotearoa* [Doctoral thesis, Auckland, New Zealand: Massey University]. <https://mro.massey.ac.nz/items/7beaf5ec-e2d0-4c73-8d81-9430a82c0334>
- Nario-Redmond, M. R. (2019). *Ableism*. John Wiley & Sons.
- Neale, M. D. (1989). *The Neale analysis of reading ability: Revised*. NFER.
- Nel, J. (n.d). *The role of New Zealand special schools in a climate of inclusion: A futurist perspective: Supporting learners with significant learning support needs & strengthening the capacity of mainstream settings*. <https://www.educationaleaders.govt.nz/content/download/81210/664632/file/Judith%20Nel%20-%20special%20schools%20-%20sabbatical%20report%202017.pdf>
- Neuralink. (2023). *Neuralink*. www.neuralink.com
- New London Group. (2000). A pedagogy of multiliteracies designing social futures. In B. Cope & M. Kalantzis (Eds.), *Multiliteracies literacy learning and the design of social futures* (pp. 9-38). Macmillan.
- New Zealand Council for Educational Research. (2018a). *Background and overview (LNAAT)*. <http://assessforadults.nzcer.org.nz/support/solutions/articles/4000124694-background-and-overview>
- New Zealand Council for Educational Research. (2018b). *The learner report, or the end of assessment report*. <https://assessforadults.nzcer.org.nz/support/solutions/articles/4000125032-the-learner-report-or-the-end-of-assessment-report>
- New Zealand Council for Educational Research. (2018c). *What is the difference between the youth assessment option and the adult option?* <http://assessforadults.nzcer.org.nz/support/solutions/articles/4000121825-what-is-the-difference-between-the-youth-assessment-option-and-the-adult-option-if-i-have-a-mixed-ag>

- New Zealand Council for Educational Research. (2018d). *What will happen to all the data being collected?* <https://assessforadults.nzcer.org.nz/support/solutions/articles/4000121827-what-will-happen-to-all-the-data-being-collected->
- New Zealand Council for Educational Research. (2019). *Introducing the gain report.* <https://assessforadults.nzcer.org.nz/support/solutions/articles/4000125031-the-gain-report>
- New Zealand Foreign Affairs & Trade Manatū Aorere. (n.d). *International organisations.* <https://www.mfat.govt.nz/en/about-us/who-we-work-with/international-organisations>
- New Zealand Qualifications Authority. (2023). *New Zealand Certificate in Skills for Living for Supported Learners (Level 1).* <https://www.nzqa.govt.nz/nzqf/search/displayQualificationOverViewWidgetJS.do?&selecteItemKey=2853>
- Newcombe, N. (2015). The attribute of verbal diversity. *Parent to Parent Magazine*, 8-9. Parent to Parent. https://issuu.com/parenttoparentnz/docs/parenttoparent_magazine_summer15
- Newcombe, N. (2021). *The ableism of a singular literacy* [Conference presentation]. Disability Studies Conference, Auckland, New Zealand.
- Newcombe, N. (2022). Reflecting on an unexpected challenge in obtaining ethical approval for research with adults with learning disabilities. *Waikato Journal of Education*, 27(2), 27-32. <https://doi.org/10.15663/wje.v27i2.920>
- Newcombe, N. I. (2019). *The easy read book about the Treaty of Waitangi.* Tangata Tiriti.
- Newman, K. (2010). *Bible & treaty: Missionaries among the Māori: A new perspective.* Penguin Books.
- Nicholas, A. M. (1978). Semantography as a system of communication: Its relevance to special education. *The Exceptional Child*, 25(3), 149-156. <https://doi.org/10.1080/0156655780250302>
- Nind, M. (2011). Participatory data analysis: A step too far? *Qualitative Research*, 11(4), 349-363. <https://doi.org/10.1177/1468794111404310>
- Nind, M. (2014). *What is inclusive research?* Bloomsbury Academic. <https://doi.org/10.5040/9781849668149.ch-001>
- Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, 17(3), 278-288. <https://doi.org/10.1177/1468794117708123>
- Nind, M., Chapman, R., Seale, J., & Tilley, L. (2016). The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities* 29(6), 542-551. <https://doi.org/10.1111/jar.12213>
- Nind, M., & Vinha, H. (2012). *Doing research inclusively, doing research well? Report of the study: Quality and capacity in inclusive research with people with learning disabilities.* https://www.southampton.ac.uk/assets/imported/transforms/content-block/UsefulDownloads_Download/97706C004C4F4E68A8B54DB90EE0977D/full_report_doing_research.pdf
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102-109. <https://doi.org/10.1111/bld.12013>
- Nind, M., & Vinha, H. (2016). Creative interactions with data: Using visual and metaphorical devices in repeated focus groups. *Qualitative Research*, 16(1), 9-26. <https://doi.org/10.1177/1468794114557993>
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1-13. <https://doi.org/10.1177/1609406917733847>

- Noy, C. (2008). Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. *International Journal of Social Research Methodology*, 11(4), 327-344. <https://doi.org/10.1080/13645570701401305>
- NZ Assessment Tool. (2019). *NZCER Starting Points Reading Assessment* [Video]. <https://www.youtube.com/watch?v=LEVzrwJKvVM&t=1s>
- O'Brien, M. (2020). Social investment in Aotearoa/New Zealand: Meaning and implications. *Social Sciences*, 9(7), 111. <https://doi.org/10.3390/SOCSCI9070111>
- O'Brien, V. (2014). *Collaborative visual ethnography: Practical issues in cross-cultural research*. Sage.
- OECD. (2000). *Literacy in the information age: Final report of the international adult literacy survey*. <https://doi.org/10.1787/9789264181762-en>
- OECD. (2005). *The definition and selection of key competencies: Executive summary*. <https://www.oecd.org/pisa/35070367.pdf>
- OECD. (2013). *OECD skills outlook 2013: First results from the survey of adult skills*.
- OECD. (2016). *Skills matter: Further results from the Survey of Adult Skills: New Zealand*. <https://www.oecd.org/skills/piaac/Skills-Matter-New-Zealand.pdf>
- Office for Disability Issues. (2016). *New Zealand disability strategy 2016-2026*. <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf>
- Office for Disability Issues. (2020). *Disability etiquette*. <https://www.odi.govt.nz/home/about-disability/disability-etiquette/>
- Office for Disability Issues. (2022). *Running accessible meetings*. <https://www.odi.govt.nz/guidance-and-resources/running-accessible-meetings/>
- Olaszi, P., Koutny, I., & Kálmán, S. L. (2002). From Bliss symbols to grammatically correct voice output: A communication tool for people with disabilities. *International Journal of Speech Technology*, 5(1), 49-56. <https://doi.org/10.1023/A:1013682632553>
- Oldreive, W., & Waight, M. (2013). Enabling access to information by people with learning disabilities. *Tizard Learning Disability Review*, 18(1), 5-15. <https://doi.org/10.1108/13595471311295950>
- Oliver, M. (1990). *The politics of disablement*. Macmillan Education.
- Oliver, M. J. (1999). Capitalism, disability, and ideology: A materialist critique of the normalization principle. In R. Flynn & R. Lemay (Eds.), *A quarter-century of normalization and social role valorization* (pp. 163-173). University of Ottawa Press. www.jstor.org/stable/j.ctt1cn6s45.8
- Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity & Ethnic Minority Psychology*, 8(2), 130-137. <https://doi.org/10.1037/1099-9809.8.2.130>
- Ollerton, J. (2012). IPAR: An inclusive disability research methodology with accessible analytical tools. *International Practice Development Journal*, 2(3), 1-20. <https://www.kennispleingehandicaptensector.nl/docs/KNP/KNP%20GS/Gewoon%20Bijzonder/Inclusive-research.pdf>
- Ollerton, J., & Horsfall, D. (2013). Rights to research: Utilising the Convention on the Rights of Persons with Disabilities as an inclusive participatory action research tool. *Disability & Society*, 28(5), 616-630. <https://doi.org/10.1080/09687599.2012.717881>
- Ouellette-Kuntz, H., Burge, P., Brown, H. K., & Arsenault, E. (2010). Public attitudes towards individuals with intellectual disabilities as measured by the concept of social distance. *Journal of Applied Research in Intellectual Disabilities*, 23(2), 132-142. <https://doi.org/10.1111/j.1468-3148.2009.00514.x>

- Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health & Illness*, 37(3), 385-403. <https://doi.org/10.1111/1467-9566.12199>
- Pallisera, M., Vilà, M., Fullana, J., & Valls, M. J. (2021). Being in control: Choice and control of support received in supported living: A study based on the narratives of people with intellectual disability and support staff. *Journal of Intellectual & Developmental Disability*, 46(2), 164-174. <https://doi.org/https://doi.org/10.3109/13668250.2020.1802812>
- Pangestu, Y. P. D. A., Aliifah, J., Jati, P., Amalia, C., & Situmorang, D. D. B. (2022). Analysis of the generation z's viewpoint from the faith-based educational institutions on the toxic positivity phenomena: How and why? *Journal of Pastoral Care & Counseling*, 76(2), 97-104. <https://doi.org/10.1177/15423050221090861>
- Pardoe, S. (2005). Respect and the pursuit of 'symmetry' in researching literacy and student writing. In M. Hamilton, R. Ivanic, & D. Barton (Eds.), *Situated literacies: Reading and writing in context* (pp. 147-164). Routledge. <https://doi.org/https://doi.org.ezproxy.waikato.ac.nz/10.4324/9780203984963>
- Parliamentary Counsel Office. (2022). *Accessibility for New Zealanders Bill*. <https://www.legislation.govt.nz/bill/government/2022/0153/latest/LMS727091.html>
- Parr, C. (1961). A missionary library: Printed attempts to instruct the Māori: 1815-1845. *Journal of the Polynesian Society*, 70(4), 429-450. <https://www.jstor.org/stable/20703937>
- Parsons, D. W. (1995). *Public policy: An introduction to the theory and practice of policy analysis*. Edward Elgar.
- Parsons, I. (1999). *Cripples, coons, fags, and fems*. Villamanta Legal Service.
- Paterson, L. (2020). Māori literacy practices in colonial New Zealand. In T. Ballantyne, L. Paterson, & A. Wanhalla (Eds.), *Indigenous textual cultures: Reading and writing in the age of global empire* (pp. 80-98). Duke University Press.
- Paulus, T., Woodside, M., & Ziegler, M. (2008). Extending the conversation: Qualitative research as dialogic collaborative process. *The Qualitative Report*, 13(2), 226-243. https://go-gale-com.ezproxy.waikato.ac.nz/ps/retrieve.do?tabID=T002&resultListType=RESULT_LIST&searchResultsType=SingleTab&retrievalId=3d3cfd39-ab17-4e97-9f96-de609c74fec7&hitCount=1&searchType=AdvancedSearchForm¤tPosition=1&docId=GALE%7CA212371679&docType=Article&sort=RELEVANCE&contentSegment=ZONE-MOD1&prodId=AONE&pageNum=1&contentSet=GALE%7CA212371679&searchId=R1&userGroupName=waikato&inPS=true
- Payne, G. (2006). Re-counting illiteracy: Literacy skills in the sociology of social inequality. *British Journal of Sociology*, 57(2), 219-240. <https://doi.org/10.1111/j.1468-4446.2006.00107.x>
- People First New Zealand. (2017). *Make it clear: A guide to making easy read information*. <https://www.peoplefirst.org.nz/news-and-resources/easy-read-resources/>
- People First New Zealand. (2018). *Submission to the code of banking practice*. <https://www.nzba.org.nz/wp-content/uploads/2018/05/People-First-NZ-submission.pdf>
- People First New Zealand. (n.d-a). *Easy read information*. <https://www.peoplefirst.org.nz/news-and-resources/easy-read-resources/>
- People First New Zealand. (n.d-b). *History of the international self-advocacy movement*. <https://www.peoplefirst.org.nz/who-what-where/who-is-people-first/international-people-first-history/>
- Pfeifer, W. (2023). *From 'nothing about us without us' to 'nothing without us.'* www.ndi.org/our-stories/nothing-about-us-without-us-nothing-without-us
- Photosymbols. (2023). *We are Photosymbols*. <https://www.photosymbols.com/>

- Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education*, 16(2), 175-196. <https://doi.org/10.1080/0951839032000060635>
- Player, J. (2012). The glory and dismay football literacy programme. In J. Crowther, M. Hamilton, & L. Tett (Eds.), *More powerful literacies* (pp. 179-192). NIACE.
- Pool, I., & Kukutai, T. (2018). *Taupori Māori: Māori population change*. <https://teara.govt.nz/en/taupori-maori-maori-population-change/page-1>
- Powell, D. (2012). A review of inclusive education in New Zealand. *Electronic Journal for Inclusive Education*, 2(10), 1-24. <https://corescholar.libraries.wright.edu/cgi/viewcontent.cgi?article=1147&context=ejie>
- Preissle, J., & deMarrais, K. (2015). Teaching reflexivity in qualitative research: Fostering a research life style. In N. K. Denzin & M. D. Giardina (Eds.), *Qualitative inquiry and the politics of research* (pp. 189-196). Left Coast Press. <https://doi-org.ezproxy.waikato.ac.nz/10.4324/9781315421377>
- Ramcharan, P., Grant, G., & Flynn, M. (2004). Emancipatory and participatory research: How far have we come? In E. Emerson, C. Hatton, T. Parmenter, & T. Thompson (Eds.), *International handbook of applied research in intellectual disabilities*. Wiley. <https://doi.org/10.1002/9780470713198>
- Rangihuna, D., Kopua, M., & Tipene-Leach, D. (2018). Te mahi a atua. *Journal of Primary Health Care*, 10(1), 16-17. <https://doi.org/10.1071/HC17076>
- Rangiwai, B. (2020). Facebook as a substitute for kanohi ki te kanohi in the Master of Applied Indigenous Knowledge programme at Te Wānanga o Aotearoa in Māngere. *Te Kaharoa*, 15(1), 1-17. <https://doi.org/10.24135/tekaharoa.v15i1.309>
- Rangiwai, B. (2023a, October 12-13). *ADHD, two PhDs and boredom! A kaupapa Māori approach to completing large academic projects while living with ADHD*. [Conference presentation]. Neuroability Symposium, Dunedin, New Zealand.
- Rangiwai, B. (2023b). Reflections on being an academic with ADHD. *Te Kaharoa*, 16(1), 1-16. https://www.tekaharoa.com/index.php/tekaharoa/article/view/419/370?fbclid=IwAR1BD5hOpZPtYNkw2tNo4skpKMGcEIVec1Kyri_QjEGr9C7WzG0PJRJSiboE
- Riches, T. N., O'Brien, P. M., & The CDS Inclusive Research Network. (2020). Can we publish inclusive research inclusively? Researchers with intellectual disabilities interview authors of inclusive studies. *British Journal of Learning Disabilities*, 48(4), 272-280. <https://doi.org/10.1111/bld.12324>
- Rinaldi, J. (2013). Reflexivity in research: Disability between the lines. *Disability Studies Quarterly*, 33(2). <https://doi.org/10.18061/dsq.v33i2.3711>
- Robey, K. L., Beckley, L., & Kirschner, M. (2006). Implicit infantilizing attitudes about disability. *Journal of Developmental and Physical Disabilities*, 18(4), 441-453. <https://doi.org/10.1007/s10882-006-9027-3>
- Roden, J. (2023). *Future of NZ's schools for students with high needs remains in limbo*. <https://www.1news.co.nz/2023/09/20/future-of-nzs-schools-for-students-with-high-needs-remains-in-limbo/>
- Roiha, A., & Ikkänen, P. (2022). The salience of a prior relationship between researcher and participants: Reflecting on acquaintance interviews. *Research Methods in Applied Linguistics*, 1(1), 1-9. <https://doi.org/10.1016/j.rmal.2021.100003>
- Rolph, S. (1999). *The history of community care for people with learning difficulties in Norfolk 1930-1980: The role of two hostels* [Doctoral thesis, Milton Keynes, England: The Open University]. Open Research Online. <http://oro.open.ac.uk/19859/1/pdf83.pdf>

- Ross, L. (2018). From the fundamental attribution error to the truly fundamental attribution error and beyond: My research journey. *Perspectives on Psychological Science*, 13(6), 750-769. <https://doi.org/10.1177/1745691618769855>
- Royal, T. A. C. (1998). *Te whare tapere: Towards a model for Māori performance art* [Doctoral thesis, Wellington, New Zealand: Victoria University of Wellington].
- Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood*, 1(2), 124-133. <https://doi.org/10.1089/aut.2018.0035>
- Saltillo. (n.d). *TouchChat*. <https://touchchatapp.com/>
- Saunders, C. H., Sierpe, A., von Plessen, C., Kennedy, A. M., Leviton, L. C., Bernstein, S. L., Goldwag, J., King, J. R., Marx, C. M., Pogue, J. A., Saunders, R. K., Van Citters, A., Yen, R. W., Elwyn, G., Leyenaar, J. K., Acquilano, S. C., Doherty, J., Forcino, R. C., Foster, T., . . . Thomeer, R. P. (2023). Practical thematic analysis: a guide for multidisciplinary health services research teams engaging in qualitative analysis. *British Medical Journal*, 381, 1-23. <https://doi.org/10.1136/bmj-2022-074256>
- School Can't Australia. (n.d). *School Can't Australia*. www.schoolcantaustralia.com.au/
- Schroeder, D., & Gefenas, E. (2009). Vulnerability: Too vague and too broad? *Cambridge Quarterly of Healthcare Ethics*, 18(2), 113-121. <https://doi.org/10.1017/S0963180109090203>
- Selvaraj, J. (2015). Inclusive education in New Zealand: Policies, politics and contradictions. *International Journal of Inclusive Education*, 19(1), 86-101. <https://doi.org/10.1080/13603116.2014.907584>
- Sepeloni, C. (2020). *Social Wellbeing Agency replaces Social Investment Agency with new approach*. <https://www.beehive.govt.nz/release/social-wellbeing-agency-replaces-social-investment-agency-new-approach>
- Shafritz, J. M. (2004). *Dictionary of public policy and administration*. Westview Press.
- Shakespeare, T. (2013). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (4th ed., pp. 214-221). Taylor and Francis.
- Shaw, R., & Eichbaum, C. (2011). *Public policy in New Zealand: Institutions, processes and outcomes* (3rd ed.). Pearson Education New Zealand.
- Shaywitz, S. E. (2003). *Overcoming dyslexia: A new and complete science-based program for reading problems at any level*. Vintage Books.
- Siebers, T. (2006). Disability studies and the future of identity politics In S. P. Mohanty (Ed.), *Identity politics reconsidered*. Palgrave Macmillan. <https://doi.org/10.1057/9781403983398>
- Sim, J., & Waterfield, J. (2019). Focus group methodology: Some ethical challenges. *Quality & Quantity*, 53(6), 3003-3022. <https://doi.org/10.1007/s11135-019-00914-5>
- Simmons, W. P., Boynton, J., & Landman, T. (2021). Facilitated communication, neurodiversity, and human rights. *Human Rights Quarterly*, 43(1), 138-167. <https://doi.org/10.1353/hrq.2021.0005>
- Simon, C. A. (2007). *Public policy: Preferences and outcomes*. Pearson Longman.
- Sinason, V. (2010). *Mental handicap and the human condition: An analytical approach to intellectual disability*. Free Association Books.
- Singer, J. (2017). *Neurodiversity: The birth of an idea*.
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics*, 155A(10), 2360-2369. <https://doi.org/10.1002/ajmg.a.34235>
- Smith, F. (1983). *Essays into literacy*. Heinemann.

- Smith, G. H. (1999). Paulo Freire: Lessons in transformative praxis. In P. Roberts (Ed.), *Paulo Freire, politics and pedagogy: Reflections from Aotearoa-New Zealand* (pp. 35-42). Dunmore Press.
- Smith, L. T. (2021). *Decolonizing methodologies: Research and Indigenous peoples* (3rd ed.). Bloomsbury.
- Snyder, S. L., & Mitchell, D. T. (2006). *Cultural locations of disability*. University of Chicago Press.
- Social Sector Board. (2016). *Briefing for the incoming minister responsible for social investment*. <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/corporate/bims/final-version-social-investment-bim-07-02-2017.pdf>
- Solinski, C. (2010). *Coping with stigma: An adult learners perspective* [Master's thesis, Indiana, United States of America: Indiana University]. <https://scholarworks.iupui.edu/server/api/core/bitstreams/e7f56d26-034d-4bf0-8e52-49e63d16422d/content#:~:text=The%20low%20literacy%20stigma%20acts,process%2C%20and%20living%20more%20independently>
- Spehar, A. (2015). Gender equality for whom? A critical frame analysis of the 2007 Swedish domestic services tax reform. *Critical Social Policy, 35*(3), 350-368. <https://doi.org/10.1177/0261018315578107>
- Speld NZ. (n.d). *Specific learning disability definitions*. <https://www.speld.org.nz/specific-learning-disability-definitions>
- Spelman, A. (2013). *A relationships framework for organisational responsiveness to Te Tiriti/Treaty of Waitangi in the work of groups and organisations in the community and the public sector of Aotearoa New Zealand* [Master's thesis, Hamilton, New Zealand: University of Waikato]. Research Commons Thesis Collection. <https://researchcommons.waikato.ac.nz/handle/10289/8319>
- Spooner, F., Kemp-Inman, A., Ahlgrim-Delzell, L., Wood, L., & Ley Davis, L. (2015). Generalization of literacy skills through portable technology for students with severe disabilities. *Research and Practice for Persons with Severe Disabilities, 40*(1), 52-70. <https://doi.org/10.1177/1540796915586190>
- Stats NZ. (2014). *Disability survey: 2013*. <https://www.stats.govt.nz/information-releases/disability-survey-2013/>
- Stats NZ. (2018). Pacific Peoples ethnic group. <https://www.stats.govt.nz/tools/2018-census-ethnic-group-summaries/pacific-peoples>
- Stats NZ. (2023). *Household labour force survey*. <https://cdn.livechat-files.com/api/file/lc/att-old/6093951/3b614f3789cc6f642a043fa0aee595e6/emp%20rate%202013.JPG>
- Stewart-Withers, R. (2016). Edge walking ethics. *New Zealand Sociology, 31*(4), 28-42. <https://doi.org/doi/abs/10.3316/informit.339360749751193>
- Stone, D. A. (1984). *The disabled state*. Macmillan.
- Street, B. (1984). *Literacy in theory and practice*. Cambridge University Press.
- Street, B. (1993). The new literacy studies. In E. Cushman, E. Kintgen, B. Kroll, & M. Rose (Eds.), *Literacy: A critical sourcebook* (pp. 430-442). Bedford St. Martin's.
- Stromer, R., Mackay, H. A., Howell, S. R., McVay, A. A., & Flusser, D. (1996). Teaching computer-based spelling to individuals with developmental and hearing disabilities: Transfer of stimulus control to writing tasks. *Journal of Applied Behavior Analysis, 29*(1), 25-42. <https://doi.org/10.1901/jaba.1996.29-25>
- Stubbs, M. (1983). *Discourse analysis: The sociolinguistic analysis of natural language*. University of Chicago Press.
- Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society, 15*(4), 569-582. <https://doi.org/10.1080/09687590050058189>

- Swain, J., & French, S. (2008). Affirming identity. In J. Swain & S. French (Eds.), *Disability on equal terms* (pp. 65-78). Sage.
- Tafa, T., Fotu, M., & Group, P. T. (2009). *The popao model: A Pacific recovery and strength concept in mental health*. <https://www.leva.co.nz/wp-content/uploads/2019/10/popao-model-a-pacific-recovery-and-strength-concept-in-mental-health.pdf>
- Talklink. (2023). *Assistive technology*. <https://talklink.org.nz/assistive-technology>
- Tang, Q. (2015). *Goal 4: Education in the post-2015 Sustainable Development Agenda*. <https://www.un.org/en/chronicle/article/goal-4-education-post-2015-sustainable-development-agenda>
- Tar Heel Reader. (n.d). *Tar heel reader*. <https://tarheelreader.org/>
- Taylor, A. (2020). The metaphor of civic threat: Intellectual disability and education for citizenship. In L. Ware (Ed.), *Critical readings in interdisciplinary disability studies (dis)assemblages* (pp. 53-67). Springer International Publishing.
- Te Awēkotuku, N. (2009). *Memento Maori: Moko and memory*. <https://researchcommons.waikato.ac.nz/bitstream/handle/10289/3486/Awekotuku%20Nov09%20Memento%20Mori.pdf?sequence=1&isAllowed=y>
- Te Kawa Mataaho Public Service Commission. (2023). *Better public services*. <https://www.publicservice.govt.nz/publications/better-public-services/>
- Te Pūkenga. (2023). *New Zealand Certificate in Skills for Learning and Working, for supported learners*. <https://www.careers.govt.nz/qualifications/view/4373/6683>
- Te Tai Ōhanga The Treasury. (2015). *Better public services*. <https://www.treasury.govt.nz/information-and-services/state-sector-leadership/cross-agency-initiatives/better-public-services>
- Te Tai Ōhanga The Treasury. (2017). *Social investment*. <https://www.treasury.govt.nz/information-and-services/state-sector-leadership/cross-agency-initiatives/social-investment>
- Tertiary Education Commission. (2008a). *Learning progressions for adult literacy*. <http://assessforadults.nzcer.org.nz/support/solutions/articles/4000125030-the-learning-progressions>
- Tertiary Education Commission. (2008b). *Learning progressions for adult literacy and numeracy: Background information*. <https://epale.ec.europa.eu/sites/default/files/learning-progressions-numeracy-background.pdf>
- Tertiary Education Commission. (2008c). *Literacy, language and numeracy action plan 2008–2012: Raising the literacy, language and numeracy skills of the workforce*. <https://www.tec.govt.nz/assets/Publications-and-others/6f1ad78212/Literacy-language-numeracy-action-plan-2008-2012.pdf>
- Tertiary Education Commission. (2008d). *Starting points: Supporting the learning progressions for adult literacy*. <https://www.tec.govt.nz/assets/Publications-and-others/3fce0fa4eb/Learning-progressions-starting-points.pdf>
- Tertiary Education Commission. (2008e). *Teaching adults to read with understanding: Using the learning progression*. <https://ako.ac.nz/assets/Knowledge-centre/ALNACC-Resources/Learning-progressions/Learning-progressions-read-with-understanding.pdf>
- Tertiary Education Commission. (2010a). *Getting results in literacy and numeracy*. <https://www.voced.edu.au/content/ngv%3A43951>
- Tertiary Education Commission. (2010b). *Starting points: Assessment guide*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/9d04b07e57/Learning-Progressions-Starting-Points-assessment-guide.pdf>

- Tertiary Education Commission. (2012). *Adult literacy and numeracy implementation strategy*. <https://docplayer.net/15862757-Adult-literacy-and-numeracy-implementation-strategy-september-2012.html>
- Tertiary Education Commission. (2015). *Literacy and numeracy implementation strategy 2015–2019*. <https://www.tec.govt.nz/assets/Publications-and-others/c74aff1b80/Literacy-and-Numeracy-Implementation-Strategy-2015-2019.pdf>
- Tertiary Education Commission. (2017a). *Guidelines for using the literacy and numeracy for adults assessment tool*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/0869eb24/Guidelines-for-using-the-Literacy-and-Numeracy-for-Adults-Assessment-Tool.pdf>
- Tertiary Education Commission. (2017b). *Special supplementary grant: Special education*. <https://www.tec.govt.nz/funding/funding-and-performance/funding/fund-finder/ssg/>
- Tertiary Education Commission. (2020). *2020 Funding conditions catalogue*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/2020-Funding-Conditions-Catalogue-V4.pdf>
- Tertiary Education Commission. (2021a). *2022 Funding conditions catalogue*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/Funding-Conditions-Catalogue-2022.pdf>
- Tertiary Education Commission. (2021b). *Disability action plans: A guide for the tertiary education sector*. <https://www.tec.govt.nz/assets/Oritetanga/DAP-Guidance-for-TEOs-July-2021.pdf>
- Tertiary Education Commission. (2022a). *2022 Equity funding for tertiary students with disabilities: Tertiary Education Institutions data reporting* <https://www.tec.govt.nz/assets/Reports/2022-Equity-funding-for-tertiary-students-with-disabilities-Tertiary-Education-Institutions-data-reporting.pdf>
- Tertiary Education Commission. (2022b). *Special supplementary grant (SSG) funding report 2020 and 2021*. <https://www.tec.govt.nz/assets/Reports/SSG-202021-Report-2022>Returns.pdf>
- Tertiary Education Commission. (2023a). *2023 Funding conditions catalogue*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/2023-Funding-Conditions-Catalogue.pdf>
- Tertiary Education Commission. (2023b). *2024 funding conditions changes*. <https://www.tec.govt.nz/funding/funding-and-performance/funding/funding-conditions-by-year/2024-funding-conditions-changes/>
- Tertiary Education Commission. (2023c). *Equity fund*. <https://www.tec.govt.nz/funding/funding-and-performance/funding/fund-finder/equity-funding/>
- Tertiary Education Commission. (2023d). *Guidelines for using the Literacy and Numeracy for Adults Assessment Tool 2023*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/Guidelines-for-using-the-Literacy-and-Numeracy-for-Adults-Assessment-Tool-v2.pdf>
- Tertiary Education Commission. (2023e). *Key messages: LNAAT guidelines update 2023*. Author.
- Tertiary Education Commission. (2023f). *Plan guidance for providers submitting plans for funding from 1 January 2024*. <https://www.tec.govt.nz/assets/Forms-templates-and-guides/Plan-guidance-and-toolkit-2024/Plan-Guidance-for-2024-FINAL-PDF.pdf>
- Tertiary Education Commission. (2023g). *Qualifications required of educators who teach foundation-level literacy and numeracy*. <https://www.tec.govt.nz/funding/funding-and-performance/funding/funding-conditions-by-year/minimum-qualification-requirements>
- Tertiary Education Commission. (2023h). *Special supplementary grant (SSG) funding report 2022*. <https://www.tec.govt.nz/assets/Publications-and-others/Special-Supplementary-Grant-Funding-Report-2023-2022-Data.pdf>

- Tertiary Education Commission. (2024). *2024 Funding conditions catalogue*.
<https://www.tec.govt.nz/assets/Publications-and-others/2024-Funding-Conditions-Catalogue.pdf>
- Tertiary Education Commission. (n.d-a). *Glossary*. <https://www.tec.govt.nz/footer/about-our-site/glossary/>
- Tertiary Education Commission. (n.d-b). *Pathways awarua*. www.pathwaysawarua.com/
- The Critical Methodologies Collective. (2022). Introduction. In The Critical Methodologies Collective (Ed.), *Politics and ethics of representation in qualitative research* (pp. 1-8). Routledge.
<https://library.oapen.org/bitstream/handle/20.500.12657/50455/9781000410747.pdf;jsessionid=539B910BBE77C10A08B3E9BE104A15F3?sequence=1>
- The Makaton Charity. (2023). *What is Makaton?*
https://www.makaton.org/TMC/TMC/About_Makaton/What_is_Makaton.aspx?hkey=b275ea4d-55a9-40c3-8f10-a40f71f2395e
- The Roeher Institute. (1990). *Literacy and labels: A look at literacy policy and people with a mental handicap*. <https://files.eric.ed.gov/fulltext/ED337953.pdf>
- The Roeher Institute. (1994). *Literacy in motion: A guide to inclusive literacy education*.
- Think College Institute for Community Inclusion. (2023). *College search*.
<https://thinkcollege.net/college-search>
- Thomas, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, 86(3), 1155-1156. <https://doi.org/10.2466/pr0.86.3.1155-1156>
- Thomas, G., Johnston, M., & Ward, J. (2014). *Alignment of literacy and numeracy measures: Research for the Tertiary Education Commission*.
<https://www.tec.govt.nz/assets/Reports/c6fd843620/Alignment-of-Literacy-and-Numeracy-Measures.pdf>
- Thomson, F. (2007). Are methodologies for children keeping them in their place? *Children's Geographies*, 5(3), 207-218. <https://doi.org/10.1080/14733280701445762>
- Ticket to Work. (2021). *Inclusive higher education for young people with intellectual disability: An overview of the literature and outcomes*.
https://tickettowork.org.au/media/submissions_researches_buttons/Inclusive_higher_education_for_young_people.pdf
- Tight, M. (2017). *Understanding case study research: Small-scale research with meaning*. Sage.
<https://doi.org/https://doi.org/10.4135/9781473920118>
- Tikao, K., Higgins, N., & Phillips, H. (2009). Kāpo (blind) Māori in the ancient world. *MAI Journal*, 2(4), 1-14. <http://www.review.mai.ac.nz/mrindex/MR/article/view/237/271.html>
- Titchen, A. (2015). Action research: Genesis, evolution and orientations. *International Practice Development Journal*, 5(1), 1-15. <http://www.fons.org/library/journal.aspx>
- Tōfā Mamao. (2023). *Tōfā Mamao Collective*. <https://www.tofamamao.com/about>
- Together 4 Change. (2023). *People First*. <https://www.peoplefirst.org/>
- Totsika, V., Kouroupa, A., Timmerman, A., Allard, A., Gray, K. M., Hastings, R. P., Heyne, D., Melvin, G. A., & Tonge, B. (2023). School attendance problems among children with neurodevelopmental conditions one year following the start of the COVID-19 pandemic. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-023-06025-3>
- Townson, L., Macauley, S., Harkness, E., Chapman, R., Docherty, A., Dias, J., Eardley, M., & McNulty, N. (2004). We are all in the same boat: Doing people-led research. *British Journal of Learning Disabilities*, 32(2), 72-76. <https://doi.org/10.1111/j.1468-3156.2004.00282.x>

- Travers, J., & Ayres, K. (2015). A critique of presuming competence of learners with autism or other developmental disabilities. *Education and Training in Autism and Developmental Disabilities*, 50(4), 371-387. <https://www.jstor.org/stable/10.2307/26420347>
- Trenholm, B., & Miranda, P. (2006). Home and community literacy experiences of individuals with Down syndrome. *Down Syndrome Research and Practice*, 10(1), 30-40. <https://doi.org/10.3104/reports.303>
- Tringo, J. L. (1970). The hierarchy of preference toward disability groups. *Journal of Special Education*, 4(3), 295-306. <https://doi.org/10.1177/002246697000400306>
- Trowsdale, J., & Hayhow, R. (2015). Psycho-physical theatre practice as embodied learning for young people with learning disabilities. *International Journal of Inclusive Education*, 19(10), 1022-1036. <https://doi.org/10.1080/13603116.2015.1031832>
- Turia, T. (2003). *Turia launches Maori literacy report* <https://www.beehive.govt.nz/release/turia-launches-maori-literacy-report>
- Turnpenny, A., Caiels, J., Whelton, B., Richardson, L., Beadle-Brown, J., Crowther, T., Forder, J., Apps, J., & Rand, S. (2018). Developing an easy read version of the Adult Social Care Outcomes Toolkit (ASCOT). *Journal of Applied Research in Intellectual Disabilities*, 31(1), 36-48. <https://doi.org/10.1111/jar.12294>
- Twinkl. (n.d). *My research map template*. <https://www.twinkl.co.nz/resource/t-he-006-my-research-map-template>
- UNESCO. (1970). *Functional literacy: Why and how*.
- UNESCO. (2000). *World education report: The right to education: Towards education for all throughout life*. https://www.right-to-education.org/sites/right-to-education.org/files/resource-attachments/UNESCO_World_Education_Report_The_RTE_Towards_Education_For_All_Throughout_Life_2000_En.pdf
- UNESCO. (2011). *Creating and sustaining literate environments*. https://unesdoc.unesco.org/in/documentViewer.xhtml?v=2.1.196&id=p::usmarcdef_0000214653&file=/in/rest/annotationSVC/DownloadWatermarkedAttachment/attach_import_e9cd989d-4f61-4a15-b75e-6fc03fc2f5ed%3F_%3D214653eng.pdf&locale=en&multi=true&ark=/ark:/48223/pf0000214653/PDF/214653eng.pdf#Creating-23Nov.indd%3A.16688
- UNESCO. (2013). *Literacy from a right to education perspective*. <https://pihatennisclub.files.wordpress.com/2019/02/uprdraftretnzupr3.pdf>
- UNESCO. (2016). *Wānanga embedded literacy: New Zealand*. <https://uil.unesco.org/case-study/effective-practices-database-litbase-0/wananga-embedded-literacy-new-zealand>
- UNESCO. (2018). *A global framework of reference on digital literacy skills for indicator 4.4.2*. <http://uis.unesco.org/sites/default/files/documents/ip51-global-framework-reference-digital-literacy-skills-2018-en.pdf>
- UNESCO. (2019). *UNESCO strategy for youth and adult literacy (2020-2025)*. <https://en.unesco.org/themes/literacy/strategy>
- United Nations. (2007). *United Nations Convention on the Rights of Persons with Disabilities*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>
- United Nations. (2015). *The 17 goals*. <https://sdgs.un.org/goals>
- University of Waikato. (2008). *Ethical conduct in human research and related activities regulations*. <https://www.waikato.ac.nz/students/research-degrees/legal-issues/ethics/>

- University of Waikato. (2021). *Doctor of Philosophy*.
<https://calendar.waikato.ac.nz/regulations/higher/phd>
- UPIAS. (1975). *Fundamental principles of disability*. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf>
- Vaccarino, F., Vaccarino, Z., Armstrong, D., Borkin, E., Hewitt, A., Oswin, A., Quick, C., Smith, E., & Glew, A. (2023). Self-advocates with Down syndrome research the lived experiences of COVID-19 lockdowns in Aotearoa New Zealand. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 300-309. <https://doi.org/doi.org/10.1111/jar.13059>
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405. <https://doi.org/10.1111/nhs.12048>
- Vaka Tautua. (2022). Tagata sa'ilimalo: A shared vision for and by Pacific disabled people. <https://www.vakatautua.co.nz/news/tagata-sailimalo-a-shared-vision-for-and-by-pacific-disabled-people>
- Vallianatos, H. (2015). Designing participatory research projects. In G. Higginbottom & P. Liamputtong (Eds.), *Participatory qualitative research methodologies in health* (pp. 1-20). Sage. <https://doi.org/10.4135/9781473919945.n8>
- van den Bos, K. P., Nakken, H., Nicolay, P. G., & Van Houten, E. J. (2007). Adults with mild intellectual disabilities: Can their reading comprehension ability be improved? *Journal of Intellectual Disability Research*, 51(11), 835-849. <https://doi.org/10.1111/j.1365-2788.2006.00921.x>
- van der Westhuizen, D. W., & Pacheco, G. (2016). *Disability, education and the labour market: A longitudinal portrait for New Zealand*. <http://api.digitalnz.org/records/45263183/source>
- van Kraayenoord, C. (1994). Literacy for adults with an intellectual disability in Australia. *Journal of Reading*, 37(7), 608-610. <https://www.jstor.org/stable/20172366>
- Vasey, S. (1989). *Disability culture: It's a way of life*. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Vasey-Disability-Culture.pdf>
- Vincent, A. (2010). *Modern political ideologies* (3rd ed.). Wiley-Blackwell.
https://books.google.co.nz/books?id=igrwb3rsOOUC&pg=PA337&redir_esc=y#v=onepage&q&f=false
- Vuorikari, R., Punie, Y., Carretero, S., & Van den Brande, L. (2016). *DigComp 2.0: The digital competence framework for citizens*. <https://publications.jrc.ec.europa.eu/JRC101254>
- Waikato District Health Board. (2021). *Whānau hauā disabled peoples health and wellbeing profile*. <https://www.waikatodhb.health.nz/assets/Docs/About-Us/Key-Publications/Plans/Waikato-DHB-Whanau-Haua-Disabled-Peoples-Health-Wellbeing-Profile-2021.pdf?fbclid=IwAR2vzwx9r8U7VHNJF5qFqz6OzGEMt49ugCQpgEShYUJbiExv942HP5nSQqA>
- Waikato District Health Board, & Disability Support Link. (n.d). *Initial/comprehensive assessment*.
- Walker, M., Udy, K., & Pole, N. (1996). *Adult literacy in New Zealand: Results from the International Adult Literacy Survey*.
https://www.educationcounts.govt.nz/__data/assets/pdf_file/0006/9474/IALS-brochure.pdf
- Walmsley, J. (2004). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32(2), 65-71. <https://doi.org/10.1111/j.1468-3156.2004.00281.x>
- Walmsley, J. (2013). Commentary on 'enabling access to information by people with learning disabilities.' *Tizard Learning Disability Review*, 18(1), 16-19.
<https://doi.org/10.1108/13595471311295969>

- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities past, present, and futures*. Kingsley Publishers.
- Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 751-759. <https://doi.org/10.1111/jar.12431>
- Wansart, W. L. (1995). Teaching as a way of knowing: Observing and responding to students' abilities. *Remedial and Special Education*, 16(3), 166-177. <https://doi.org/10.1177/074193259501600306>
- Wehipeihana, N. (2019). Increasing cultural competence in support of Indigenous-led evaluation: A necessary step toward Indigenous-led evaluation. *Canadian Journal of Program Evaluation*, 34(2), 368-384. <https://doi.org/10.3138/cjpe.68444>
- Wehipeihana, N., McKegg, K., Thompson, V., & Pipi, K. (2016). Cultural responsiveness through developmental evaluation. In M. Q. Patton, K. McKegg, & N. Wehipeihana (Eds.), *Developmental evaluation exemplars: Principles in practice* (pp. 25-44). The Guilford Press.
- Wehmeyer, M., Bersani, H., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st Century. *Focus on Autism and Other Developmental Disabilities*, 15(2), 106-115. <https://doi.org/10.1177/108835760001500206>
- Weinberg, D. (2014). *Contemporary social constructionism: Key themes*. Temple University Press.
- Whaanga, H., Wehi, P., Cox, M., Roa, T., & Kusabs, I. (2018). Māori oral traditions record and convey indigenous knowledge of marine and freshwater resources. *New Zealand Journal of Marine and Freshwater Research*, 52(4), 487-496. <https://doi.org/10.1080/00288330.2018.1488749>
- Whaikaha Ministry of Disabled People. (n.d). *Our whakapapa*. <https://www.whaikaha.govt.nz/about-us/our-whakapapa/>
- White, E. L., & Morgan, M. F. (2012). Yes! I am a researcher: The research story of a young adult with Down syndrome. *British Journal of Learning Disabilities*, 40(2), 101-108. <https://doi.org/10.1111/j.1468-3156.2012.00745.x>
- Williams, E. I., Gleeson, K., & Jones, B. E. (2019). How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. *Autism*, 23(1), 8-28. <https://doi.org/10.1177/1362361317723836>
- Williams, P. (2022). *Consultation with the Deaf community on potential amendments to the New Zealand Sign Language Act 2006*. <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/information-releases/cabinet-papers/2022/consultation-on-potential-amendments-to-the-nzsl-act-2006/paper-consultation-with-the-deaf-community-on-potential-amendments-to-the-new-zealand-sign-language-act-2006.pdf>
- Williams, V. (2011). *Disability and discourse: Analysing inclusive conversation with people with intellectual disabilities*. Wiley. <https://doi.org/10.1002/9780470977934>
- Williams, V., & Porter, S. (2017). The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, 30(1), 97-108. <https://doi.org/10.1111/jar.12222>
- Wolbring, G., Deloria, R., Lillywhite, A., & Villamil, V. (2019). Ability expectation and ableism peace. *Peace Review*, 31(4), 449-458. <https://doi.org/10.1080/10402659.2019.1800929>
- Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21, 234-239. <https://doi.org/10.1352/1934-9556-49.6.435>
- Wolfensberger, W. (2011). Social role valorization and, or versus, 'empowerment.' *Intellectual and Developmental Disabilities*, 49(6), 469-476. <https://doi.org/10.1352/1934-9556-49.6.469>

- Wolfensberger, W., & Tullman, S. (1982). A brief outline of the principle of normalization. *Rehabilitation Psychology, 27*(3), 131-145. <https://doi.org/10.1037/h0090973>
- World Health Organization. (1980). *International classification of impairments, disabilities, and handicaps: A manual of classification relating to the consequences of disease*.
- World Health Organization. (2023). *International classification of diseases* (11th ed.) <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/605267007>
- Wyeth, E. H., Derrett, S., Hokowhitu, B., Hall, C., & Langley, J. (2010). Rangatiratanga and ōritetanga: Responses to the Treaty of Waitangi in a New Zealand study. *Ethnicity & Health, 15*(3), 303-316. <https://doi.org/10.1080/13557851003721194>
- YMCA New Zealand. (2023). *Y-Skills for Life: Te Kakāno* <https://ycentral.nz/wp-content/uploads/2023/09/2023-ILN-Programme-Information-Sheet-A4.pdf>
- Zdravkova, K., Krasniqi, V., Dalipi, F., & Ferati, M. (2022). Cutting-edge communication and learning assistive technologies for disabled children: An artificial intelligence perspective. *Frontiers in Artificial Intelligence, 5*, 1-14. <https://doi.org/10.3389/frai.2022.970430>
- Zepke, N. (2011). Navigating between Māori particularism and economic universalism in adult literacy provision in Aotearoa New Zealand: The case of a Wānanga. *Discourse: Studies in the Cultural Politics of Education, 32*(3), 431-442. <https://doi.org/10.1080/01596306.2011.573259>