Why, what, when, who, and how?

Establishing a disability data and evidence collection framework for tamariki and rangatahi whaikaha engaging with Oranga Tamariki

August 2023

1. He Whakamihi/Acknowledgements

The Oranga Tamariki Evidence Centre works to build the evidence base that helps us better understand wellbeing and what works to improve outcomes for New Zealand's children, young people and their whānau.

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2. Ihirangi/Contents

3. <u>K</u>ā Kupu whakamārama/Glossary

Aggregated data: A process where data is combined and/or simplified (<u>Stats NZ, 2018a</u>).

Administrative data: Information gathered by organisations for the purpose of conducting and tracking the progress of programmes or services (<u>Office for Disability Issues, 2022a</u>). Generally, administrative data documents or tracks beneficiaries of a government policy and the general population, and is not for research purposes (<u>World Bank, 2023</u>).

Data sovereignty: The understanding that data is governed by the laws of the country in which it is stored. Māori data sovereignty refers to the idea that Māori data should be governed by Māori (<u>Te Mana Raraunga, 2018</u>).

Disaggregated data: The process of breaking data down into smaller units of information to enable a more detailed analysis with potential to identify intersectionality and multidimensionality (<u>Asian Development Bank, 2021</u>).

Duty bearer: Individuals and/or parties that have a responsibility to respect, uphold, and promote relevant human rights (<u>UNICEF, 2017</u>).

Individual models of disability: Models of disability that carry a negative view of disability and conceptualise disability as a problem within the individual. For example, the charity, moral, and medical models (Oliver, 1990).

Intersectionality: A concept and theoretical framework that facilitates the recognition of the complex ways in which social identities overlap and can create compounding experiences of discrimination and concurrent forms of oppression (<u>United Nations Network on Racial Discrimination and Protection of Minorities, 2022</u>).

Qualitative research: The study of things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2000).

Quantitative research: A set of strategies, techniques and assumptions used to study psychological, social and economic processes through the exploration of numeric patterns (<u>Coghlan & Brydon-Miller, 2014</u>).

Social model of disability: A model where disability is viewed as a social construct in which people are disabled by barriers in society (Oliver, 1990).

Supported decision making: Describes a process of decision making that enables disabled people to exercise their right to make decisions about their life in line with their will and preferences, and that the decision-making process is supported by a person of their choice (<u>Centre for Public Representation, 2023</u>).

Twin track data: Twin track is an approach that ensures mainstream services and supports are inclusive of, and accessible to, disabled people and that services and supports that are specific to disabled people are also available (<u>Office for Disability</u>

Issues, 2016). In the context of disability data and evidence, twin track data refers to general data that is inclusive of disability, as well as disability specific data.

Research paradigm: The philosophical framework that underpins and guides the way research/data collection is carried out (Denzin & Lincoln, 2011).

Rights holder: Describes an individual who is subject to human rights (UNICEF, 2017). For example, tamariki whaikaha are rights holders under international law because the New Zealand Government has signed and ratified international conventions.

4. K̲ā Kupu Whakamārama – Te Reo Māori

Hapū: Clusters of whānau where the whānau is usually an extended family grouping consisting of children, parents, often grandparents, and other closely related kin (Stats NZ, 2018b).

Iwi: An iwi, or Māori tribe, is one of the largest kinship groupings and is generally made up of several hapū that are all descended from a common ancestor (Stats NZ, 2018b).

Kaupapa: Principles and ideas that act as a base or foundation for action. A kaupapa is a set of values, principles, and plans which people have agreed on as a foundation for their actions (Te Ahukaramū Charles Royal, 2007).

Mahi: To work, do, perform, make, accomplish, practise (Te Aka Māori Dictionary, 2023).

Mātua: Parents (Te Aka Māori Dictionary, 2023).

Mātua whaikaha: Disabled parents.

Mana tamaiti: The intrinsic value and inherent dignity derived from a child's or young person's whakapapa (genealogy) and their belonging to a whānau, hapū, iwi, or family group, in accordance with tikanga Māori or its equivalent in the culture of the child or young person (Oranga Tamariki, 2023).

Mana tane: The power, strength, authority, rights, and leadership of a tane.

Mana wahine: The power, strength, authority, rights, and leadership of a wahine.

Tamaiti: A child (Te Aka Māori Dictionary, 2023).

Tamariki whaikaha: Disabled youth (children and teenagers).

Tāngata whaikaha: Disabled people (Te Aka Māori Dictionary, 2023). Term chosen for its inclusivity of tamariki whaikaha, rangatahi whaikaha, mātua whaikaha, and whānau.

Tino rak̲atirat̲ak̲a (tino rangatiratanga): Self-determination, sovereignty, independence, and autonomy. The term is rooted in a Māori worldview, and there is no one English term which fully encapsulates its meaning. Tino rangatiratanga speaks to Māori control over Māori lives (Te One & Clifford, 2021).

Tik̲a̲ka (tikanga): The customary system of values and practices that have developed over time and are deeply embedded in the social context (Te Aka Māori Dictionary, 2023).

Whānau: Immediate and/or wider extended family (Walker, 2011).

Whakapapa: The multi-generational kinship relationships that help to describe who the person is in terms of their mātua (parents), and tūpuna (ancestors), from whom they descend (Oranga Tamariki Act 1989 Children's and Young People's Well-being Act 1989).

Whanau̱kata̱ka (whanaungatanga): Forming and maintaining relationships and strengthening ties between kin and communities ([Independent Māori Statutory Board, n.d.)](#)

5. Kupu Rāpoto/Acronyms

DBI: Donald Beasley Institute

DDEWG: Disability Data and Evidence Working Group

DHS: Department of Human Services (Australia)

DPO: Disabled People's Organisations

DPUP: Data Protection and Use Policy

DRPI: Disability Rights Promotion International

EBP: Evidence-based Practice

EGL: Enabling Good Lives

NEAC: National Ethics Advisory Committee

NZDS: New Zealand Disability Strategy

OECD: Organisation for Economic Co-operation and Development

OHCHR: Office of the United Nations High Commissioner for Human Rights

OOHC: Out-of-Home Care

RCOI: Royal Commission of Inquiry into Abuse in Care

SDGs: Sustainable Development Goals

SDM: Supported Decision Making

SUPERU: Social Policy Research and Evaluation Unit

UNCROC: United Nations Convention on the Rights of the Child

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

UNDRIP: United Nations Declaration on the Rights of Indigenous Peoples

UNICEF: United Nations Children's Fund

WGDS: Washington Group on Disability Statistics

WGSS: Washington Group Short Set

6. He Kupu Whakataki/Introduction

Mā te rongo, ka mōhio,
Mā te mōhio, ka mārama,
Mā te mātau, ka ora.
Mā te mātau, ka ora.

From listening comes knowledge,
From knowledge comes understanding,
From understanding comes wisdom,
From wisdom comes wellbeing.

In this opening whakataukī, knowledge is recognised as the foundation of wellbeing. But to gain knowledge, we must first listen. Other interpretations of this whakataukī speak of cognisance, discussion, and awareness (Manatū Hauora, 2021; Tautoko Support Services, 2023) – words that all reflect the journey of research, whereby new knowledge is created, or, existing knowledge is used in a new and creative way to generate greater understandings (Western Sydney University, 2020). In 2022, following a research project conducted by the Donald Beasley Institute titled *Good practice for disabled tamariki and rangatahi in care: Literature Review* (Donald Beasley Institute, 2022a)*,* Oranga Tamariki sought additional research support. This new research is intended to help strengthen their commitment to Te Tiriti o Waitangi, the New Zealand Disability Strategy (NZDS) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) through the development of a foundational framework for the collection of disability-related data and evidence when engaging with tamariki and rangatahi.

Disability data and evidence is crucial in upholding the human rights of tamariki and rangatahi as it can be translated into meaningful insights that inform and transform policy and practice (Office for Disability Issues, 2022a). As this integrative literature shows, disability data and evidence not only informs policy and practice, but can also be used to honour Te Tiriti o Waitangi, monitor human rights progress, prevent abuse, and advance current models of thinking about disability. The review explores three key questions regarding: existing models and frameworks of data collection; the application of models and frameworks within the context of Aotearoa New Zealand; and the development of a data collection framework for Oranga Tamariki.

In *Part A*, summaries of informative and relevant treaties, conventions, strategies, policies, and documents are provided. In *Part B*, these frameworks are applied to the context of Aotearoa New Zealand as the why, what, when, who and how of disability data collection is discussed. *Part C* draws together the findings from Parts A and B, to provide a suggested framework for Oranga Tamariki to use when developing an organisational approach to collecting disability data and evidence. *Part C* also includes four hypothetical case studies that demonstrate how the framework might be used in practice.

7. Whano<u>k</u>a Pono/Values

This integrative literature review is based on the following documents and principles:

— Te Tiriti o Waitangi
— United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
— 2016-2026 New Zealand Disability Strategy (NZDS)
— The Social and Human Rights Models of Disability.

<u>K</u>ā Mātāpono (DBI Research Values) also underpin this mahi:

— Whakatinana – Honouring Te Tiriti o Waitangi through our practice
— Whakara<u>k</u>atira – Being Respectful
— Whakawhanau<u>k</u>ata<u>k</u>a – Being Relational
— Whakamana – Being Ethical
— Whakawhirinaki – Being Accountable
— Whakakotahi – Being Inclusive
— Whānau – Through uplifting whānau our journey will be one of prosperity

The DBI respects <u>K</u>āi Tahu dialect which replaces *ng* with a *k*. We have underlined the <u>k</u> whenever this has convention has been applied throughout the document. The exceptions to this are when we: refer to Oranga Tamariki; use the terms rangatahi or tāngata whaikaha; directly quote from an original source.

8. Take<u>k</u>a Mai/Background

In March 2021, Oranga Tamariki commissioned the Donald Beasley Institute (DBI) to develop a literature review focused on identifying good practice for disabled tamariki and rangatahi in out-of-home care (OOHC). The purpose of the literature review was to inform future planning and decision-making in relation to improving disability services and support provisions, while considering three key topics: models and systems; supports and services; participation and voice (Donald Beasley Institute, 2022a). This research has been made available on the Oranga Tamariki website and is informing ongoing mahi related to tamariki whaikaha [1] engaged with Oranga Tamariki.

The literature review noted that only 10 percent of tamariki and rangatahi whaikaha who interact with Oranga Tamariki can be reliably identified. It also noted that a lack of clarity about the identification of disability leads to undercounting of disabled tamariki, rangatahi (and mātua), making the true prevalence of disability experienced by those engaged (in some way) with Oranga Tamariki extremely difficult to establish (Donald Beasley Institute, 2022a). There are many children and young people with an unknown and/or unmet need, such as those who have impairments that are not yet diagnosed, who do not meet funding thresholds, or who are not in contact with services (Oranga Tamariki, 2020a). This means that even when tamariki and rangatahi are experiencing challenges that may relate to their disabilities, these challenges cannot effectively be addressed.

Currently, Oranga Tamariki does not have a standardised method of collecting data relating to disability (Oranga Tamariki, 2022a). While Oranga Tamariki is committed to improving disability data and evidence, as was highlighted in its response to the Royal Commission of Inquiry into Abuse in Care (Oranga Tamariki, 2022b), disability data is currently not held in a consistent, easily analysed format. Many tamariki and rangatahi known to Oranga Tamariki have not received a formal diagnosis, and consequently recorded data provides only a partial picture of the tamariki whaikaha in their care. According to the Oranga Tamariki Future Direction Action Plan (2021), there is a two-to-five-year commitment to ensuring robust data, research, and information flows that support ongoing transformation of the organisation. A commitment to the continued roll out of new performance reporting tools which make data and information available to operational staff to inform their decision-making was also made.

In 2022, Oranga Tamariki sought additional research support to help strengthen their commitment to Te Tiriti o Waitangi, the New Zealand Disability Strategy, and the UNCRPD in the form of a literature review. It was hoped that this research could support the development of a foundational framework for the collection of disability-related data when engaging with tamariki and rangatahi. The current review was therefore designed to identify literature that Oranga Tamariki can draw on for guidance, reasoning, and explanation when making decisions about **what data is collected, who it is collected from, why it is collected, and whom it is collected by**. By strengthening data collection processes, Oranga Tamariki will not only be

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[1] In this report the abbreviated term 'tamariki whaikaha' denotes both tamariki whaikaha and rangatahi. The te reo term is inclusive of children and young people of all ethnicities and cultures. When specifically referring to Māori disabled children, it is indicated as "tamariki whaikaha Māori". "Disabled children" or other terms that refer to tamariki whaikaha are used when these are direct quotes from literature.

progressively realising their data collection obligations under Article 31 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), but will also be contributing to upholding the human rights of the tamariki, rangatahi, family, and whānau they serve.

9. Aramahi/Method

The aim of this project was to answer the following research questions posed by Oranga Tamariki:

— What existing frameworks can inform Oranga Tamariki data collection processes relating to disability and impairment?
— How do existing frameworks hold up in the socio-political context of Aotearoa New Zealand?
— What does a social-, rights- and Te Tiriti o Waitangi-based approach to disability data collection look like in the context of Oranga Tamariki engagement with tamariki, rangatahi and whānau?

An integrative literature review was conducted to address these questions, with particular emphasis on the identification of existing frameworks and methods for data collection in Aotearoa New Zealand and abroad. The integrative literature review also sought to identify where data collection practices were falling short for disabled tamariki and rangatahi.

Integrative literature reviews enable the use of theoretical and empirical literature inclusive of 'grey' literature to provide "a more comprehensive understanding of a particular phenomenon or healthcare problem" (Whittemore & Knafl, 2005, p. 546). The inclusion of grey literature involves the use of information produced by academia, governments, non-governmental organisations, service providers, businesses, and industry (Lawrence, 2012). An additional feature of an integrative review includes the potential to inform evidence-based practice (EBP) (Toronto, 2020; Whittemore & Knafl, 2005).

As part of the integrative review process, a list of foundational documents was formulated consisting of relevant treaties, conventions, strategies, policies, and documents that could inform the key project questions. Twenty-two foundational documents and categories were identified by the research team. Subsequently, a search of the literature pertinent to each of the foundational documents (with specific reference to disability data and evidence) identified further frameworks, and additional considerations and shortfalls of the existing guidance. Of this search, 88 sources were identified and used to inform this review. Summaries of the foundational documents are presented in *Part A* of this report.

Relevant data from the identified literature was then extracted and analysed according to key components of understanding data collection. These included the why, what, when, who, and how of collecting disability data, as presented in *Part B* of this report. This process allowed the overarching research questions to be explored and addressed as presented in this report.

Finally, in *Part C* of this report the findings of the literature review are applied to hypothetical case studies. Within these cases studies, a Tiriti o Waitangi- and rights-based framework for data collection is applied in the context of: tamariki with existing and diagnosed disabilities; tamariki with invisible or undiagnosed disabilities; and disabled parents who engage with Oranga Tamariki.

10. Part A: Instructive conventions, policies, documents and guides

What existing frameworks should be used to inform Oranga Tamariki data collection processes relating to disability and impairment?

The primary documents most instructive when creating a framework for data collection were identified as Te Tiriti o Waitangi, the UNCRPD, and the 2016-2026 New Zealand Disability Strategy. These, along with additional conventions, policies, documents, and guides that can be used to inform Oranga Tamariki efforts to establish a disability data collection framework, are identified below. While the list is not exhaustive, the documents have been prioritised according to their relevance to the cultural context of Aotearoa New Zealand and their consideration of and specific directives in relation to:

- why disability data should be collected,
- what types of data should be collected,
- when it should be collected,
- who it should be collected by,
- and how it should be collected.

10.1 - Foundational documents

10.1.1 - Te Tiriti o Waitangi

Te Tiriti o Waitangi is the foundational document of Aotearoa New Zealand. It affirms the belonging of land to Māori while offering belonging to the Crown and others. It also secures the Tino Rangatiratanga of Māori, which is "the right for Māori to make decisions for Māori" ([Matike Mai Aotearoa, 2016, p. 8](#)). With regards to data, measuring and monitoring wellbeing from a Te Ao Māori view requires data collection methods and measurements that are fit for purpose ([Independent Māori Statutory Board, 2019](#)).

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

The UNCRPD is an international agreement that ensures disabled people have access to the same human rights as non-disabled people. Article 31 of the UNCRPD (Statistics and Data Collection) states that State Parties must "undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" ([United Nations, 2006](#)). Collected data must be disaggregated; monitor the government's implementation of the Convention; identify and address barriers faced by disabled people in exercising their rights; and be disseminated in an accessible way.

10.1.3 - 2016–2026 New Zealand Disability Strategy

The 2016–2026 New Zealand Disability Strategy guides the work of all New Zealand government agencies on disability issues. The vision of the Strategy is: "New Zealand is a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make

this happen" ([Office for Disability Issues, 2016, p. 6](#)). The Strategy recognises that disabled people are often not counted, recognised, or understood, and that when this occurs their needs are not responded to. It is therefore critical to ensure that the right evidence is available at the right time to inform investment decisions.

10.2 - Other important conventions, treaties and strategies

10.2.1 - United Nations Declaration on the Rights of Indigenous People (UNDRIP)

The UNDRIP is a universal framework of minimum standards for the survival, dignity, and wellbeing of the indigenous peoples of the world. It elaborates on existing human rights standards and fundamental freedoms, as they apply to the specific situation of indigenous peoples. Article 3 of the UNDRIP articulates indigenous peoples' right to self-determine their political status and to pursue their economic, social, and cultural development, which includes the right to have data and information collected by them or jointly with them. Further commentary on Article 3 also considers data sovereignty, which refers to the right to maintain, control, protect and develop cultural heritage, traditional knowledge, and cultural expression, as well as the right to maintain, control, protect and develop their intellectual property over these ([Tauli-Corpuz, 2016](#)).

10.2.2 - United Nations Convention on the Rights of the Child (UNCROC)

The UNCROC is a human rights treaty that enshrines children's rights in international law. Adopted by the United Nations in 1989, UNCROC defines universal principles and standards for the status and treatment of children worldwide. While UNCROC does not explicitly reference data and evidence, Article 4 states that the New Zealand Government "shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention", while Article 12 holds that children have the right to be listened to and taken seriously ([United Nations, 1989](#)).

10.2.3 - Sustainable Development Goals (SDGs)

In 2015, the SDGs were adopted at the UN General Assembly with 17 specific goals that contribute to the overall goal of "leave no-one behind" ([Abualghaib et al., 2019](#); [Balestra & Fleischer, 2018](#)). The goal applies to all people in the world. Disabled people are one of their targeted populations, including recognition of the need for a specific approach to ensure disabled people have access to human rights on an equal basis with others ([Abualghaib et al., 2019](#)). *Transforming our world: the 2030 Agenda for Sustainable Development* states that "Quality, accessible, timely and reliable disaggregated data will be needed to help with the measurement of progress and to ensure that no one is left behind" ([United Nations, 2015, Para. 48](#)).

10.2.4 - New Zealand Government's Child and Youth Wellbeing Strategy

The Strategy's overall vision statement is "New Zealand is the best place in the world for children and young people" ([Department of the Prime Minister and Cabinet, 2022, p. 3](#)). The Strategy does not explicitly mention disabled children. It has recently been established that disabled children and young people, who often have greater needs, are over-represented in child poverty, ([Murray & Loveless, 2021](#)). Any monitoring of

progress of the Child and Youth Wellbeing Strategy must include measurement of the wellbeing of disabled children and young people to ensure that targeted supports can be provided.

10.2.5 - Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan

Whāia Te Ao Mārama is a culturally anchored approach to supporting Māori disabled people (tāngata whaikaha) and their whānau. It recognises that to reach the Action Plan's goals, agencies and organisations that provide services to tāngata whaikaha should collect data and evidence on the effectiveness of their services accessed by tāngata whaikaha, which will in turn drive service improvements (Manatū Hauora, 2018).

10.2.6 - Faiva Ora 2016- 2021 National Pasifika Disability Plan

Faiva Ora 2016–2021 sets out priority outcomes and actions to support and improve the lives of Pacific disabled people and their families. The Plan recognises that although quantitative information on Pasifika client demographics is available, there is a growing need for complementary qualitative information that would help to explain trends and patterns. For example, the combination of demographic information with in-depth qualitative information allows agencies to make evidence-based decisions about how best to deliver services to Pasifika disabled people and their families, as well as "provide insights and inform planning and funding decisions" (Manatū Hauora, 2017, p. 14).

10.2.7 - Tagata Sa'ilimalo Strategic Framework

Developed by the Tōfā Mamao Collective, the Tagata Sa'ilimalo Strategic Framework sets out a pathway to success for tagata sa'iliimalo (Pacific disabled people and their families/nofo-a-kainga and carers/supporters/tautua soifua in Aotearoa); "Tagata sa'ilimalo refers not only to an individual, but also to the family and community who surround them" (Tōfā Mamao, 2022, p. 5). While the Framework does not specifically reference data collection, it provides guidance on Pacific collectivism and inclusive ecosystems; shared authority; shared responsibility; shared outcomes and whakawhanaukataka. Three priority action areas include building consensus through informing and influencing; initiatives and interventions; and tagata sa'ilimalo-led service design.

10.2.8 - Oranga Tamariki Outcomes Framework

The Outcomes Framework provides an overview of the Oranga Tamariki operating model, which ensures that policies, practices, and services have regard for mana tamaiti (tamariki), the whakapapa of Māori children and young people, and the whanaungatanga responsibilities of their whānau, hapū and iwi. Specifically, with regards to its delivery, the Framework asks "How will we do it differently? We will conduct more accurate and meaningful assessments for the children, young people and whānau we work with" (Oranga Tamariki, 2020b, p. 1). Accurate and meaningful assessment processes are especially important for tamariki whaikaha as they determine the support and services they receive in the future.

10.2.9 - Washington Group on Disability Statistics

The Washington Group on Disability Statistics (WGDS) promotes and coordinates international cooperation in health statistics focusing on the development of disability measures suitable for census and national surveys. The major objective of the WGDS is to provide information on disability that is comparable throughout the world (Washington Group on Disability Statistics, 2022). The Washington Group question set is considered good practice when collecting administrative data on disability (Office for Disability Issues, 2022b), and underpins the approach taken in the New Zealand Disability Data Survey (Stats NZ, 2017). However, it has been noted that the WGDS do not accurately capture or measure the experiences of particular cohorts within the disability community, including tamariki whaikaha, people with learning disability, and people with psychosocial disability (Development Initiatives, 2020; Kaiwai & Allport, 2019; Stats NZ, 2015).

10.2.10 - Enabling Good Lives Principles

The Enabling Good Lives (EGL) approach is designed to allow disabled people and their whānau to have choice and control over their lives and the supports they receive. The EGL approach operates off a set of principles which guide decision-making and monitoring of progress. These include self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, and relationship building (Enabling Good Lives, n.d). Accurate data underpins transformation of the system in accordance with EGL principles. Equally, data collection guided by EGL principles upholds foundational documents.

10.2.11 - National Ethical Standards for Health and Disability Research and Quality Improvement

Kāhui Matatika o te Motu – National Ethics Advisory Committee (NEAC) produces the National Ethical Standards for Health and Disability Research and Quality Improvement, commonly referred to as the NEAC Standards (NEAC, 2022). The NEAC Standards provide a detailed blueprint for ethical data collection in Aotearoa New Zealand, including a specific chapter containing guidance in relation to disability research (Chapter 5). Whether undertaking internal data collection activities, or more comprehensive organisational research, all activities should align with the ethical guidance outlined in the NEAC Standards, and formal ethical approval from an accredited ethics committee should be gained in certain data collection contexts.

10.3 - Instructive reports

Outlined below are other instructive reports from Aotearoa New Zealand and abroad that have commented on disability and data collection in relevant contexts, and have instructed framework thinking:

— Tāwharautia: Pūrongo o te Wā Interim Report (Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions, 2020): **Key finding** – There is a lack of data on disabled people's experiences of institutional care.

— He Purapura Ora, he Māra Tipu – From Redress to Puretumu Torowhānui (Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions, 2021): **Key finding** – Redress data was not

disaggregated, making it unclear who was impacted by abuse in care, who has accessed redress, and who is likely to access redress in the future.

— [Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia](#). (Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability). **Key finding –** Data sources with the potential to develop an understanding of the nature and extent of violence, abuse and exploitation were limited. Specific data gaps were identified as relating to: definitional complexity; design and methodology; quality and utility; data accessibility; and opportunities for data linkage. Recommendations for improving data and information included: maximising the use of existing data; addressing definitional complexity in data; and enhancing and augmenting existing data collections.

— Final Recommendations ([Australian Royal Commission into Institutional Responses to Child Sexual Abuse, 2017](#)): **Key finding** – It was recommended that a nationally agreed set of key terms and definitions for the purpose of data collection and reporting, and a centralised database are implemented (Australia).

— Off the Record: An investigation into the Ministry of Health's collection, use, and reporting of information about the deaths of people with intellectual disabilities ([Boshier, 2020a](#)): **Key finding** – There is a lack of guidance, implementation, and consistency in reporting, collecting information and data regarding the deaths of people with learning disabilities who lived in residential homes.

— He Take Kōhukihuki | A Matter of Urgency ([Boshier, 2020b](#)): **Key finding** – There is no structural method for collecting data about applications made under section 78 of Oranga Tamariki Act 1989, and there is no clear method for distinguishing uplift notices made with or without notice. Similarly, it cannot be distinguished if the application was rejected by the court, or if it has been prepared but abandoned/ not filed.

— Disability Rights: How is New Zealand doing? ([Independent Monitoring Mechanism, 2022](#)): **Key finding** – While improvements have been made, there is an inconsistency and lack of disability data collection across government agencies. When data is available, it is not used efficiently to guide policy and progress work programmes to address the challenges experienced by the disability community. Data should be disaggregated and applied to real life contexts according to Article 31 of the UNCRPD.

The reports below provide examples of how disability data has been instructive to reporting or investigation activities undertaken within official agencies.

— Child and Youth Wellbeing Strategy Annual Report for the year ending 30 June 2021 ([Department of the Prime Minister and Cabinet, 2022](#)): **Key finding** – Fifty-two percent of disabled young people experienced psychosocial distress compared to 17 percent of non-disabled young people aged 15 to 24 years. There is a lack of "strength-based data for disabled children and young people" (p. 18).

— Treatment of disabled mother and removal of newborn child (Boshier, 2020c): **Key finding** – Evidence suggests that children have been uplifted from disabled parents, who had not been assessed to establish the supports they needed to parent effectively.

10.4 - Useful guides

The following list of documents has been adapted from a resource developed by the Disability Data and Evidence Working Group (DDEWG) as representing positive examples of the collection of disability data (Office for Disability Issues, 2022c):

— Statistics NZ – Improving New Zealand Disability Data

— Washington Group – Publications about Washington Group tools

— Washington Group – Disaggregation and Sustainable Development Goals

— Washington Group – The Social Model of Disability

— Public Service Commission – Standards of Workforce Information for Agencies in the State Services (Disability information)

— Social Wellbeing Agency – Using Integrated Data to understand mental health and addiction conditions

— World Health Organisation – Strengthening the collection of data on disability

— UNICEF – Three Methods for Collecting Data on Persons with Disabilities.

10.5 - Summary table[2]

Framework tiers	Document	Vision	Application
Foundational documents These documents act as constitutional underpinnings of the framework.	Te Tiriti o Waitangi	Measuring and monitoring wellbeing from a Te Ao Māori perspective requires data collection methods and measurements that are fit for purpose.[3] This includes kaupapa Māori approaches to data and evidence; tino rangatirataka is secured in data collection; and the inclusion of tamariki whaikaha Māori.	Measuring and monitoring wellbeing from a Te Ao Māori perspective utilises data collection methods and measurements that are fit for purpose.

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[2] Key references from the summary table have been included as footnotes. Further references can be found in the full text of Part A.

[3] (Independent Māori Statutory Board, 2019)

	United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)	Article 31 states that appropriate data must be collected to inform policies that give effect to UNCRPD.	Collected data is disaggregated; monitors the government's implementation of the Convention; identifies and addresses barriers experienced by disabled people in exercising their rights; and is disseminated in an accessible way.
	2016–2026 New Zealand Disability Strategy	Disabled people must be counted and understood so that their needs can be met.	The right evidence is available at the right time to inform investment decisions that meet the needs of disabled people.
Important conventions, treaties, and strategies	United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)	Article 3 articulates indigenous peoples' right to self-determine their political status and to pursue their economic, social, and cultural development. This includes the right to have data and information collected by them and/or jointly with them.	Indigenous people are involved in and/or leading data collection processes which are guided by data sovereignty[4] principles.
	United Nations Convention on the Rights of the Child (UNCROC)	Article 4 states that the Government "shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention". Article 12 states that children have the right to be listened to and taken seriously.	Data is collected to measure the implementation of the UNCROC so that the rights of children are upheld, they are listened to and their views are taken seriously.
	Sustainable Development Goals (SDGs)	The vision of the SDGs is to "leave no-one behind".	A specific approach must be implemented to ensure disabled

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[4] Data sovereignty refers to the right to maintain, control, protect and develop cultural heritage, traditional knowledge, and cultural expression, as well as the right to maintain, control, protect and develop their intellectual property over these (Tauli-Corpuz, 2016).

| | | | people have access to human rights on an equal basis as others.

Specifically, "[q]uality, accessible, timely and reliable disaggregated data will be needed to help with the measurement of progress and to ensure that no one is left behind."[5] |
	New Zealand Government's Child and Youth Wellbeing Strategy	The Strategy's vision is to ensure that Aotearoa New Zealand is the best place in the world for children and young people.	For the vision to be actualised, the wellbeing of children and young people must be measured.
	Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan	Tāngata whaikaha pursue a good life with support.[6]	Data and evidence is collected on the effectiveness of services accessed by tāngata whaikaha, which will in turn drive service improvements.
	Faiva Ora 2016–2021 National Pasifika Disability Plan	Pasifika disabled people and their families are supported to live the lives they choose.	Combining administrative data with qualitative data will ensure evidence-based decisions can be made about how best to commission services to Pasifika disabled people and their families.[7]
	Tagata Sa'ilimalo Strategic Framework	Pacific collectivism driving tagata sa'ilimalo wellbeing.	The Framework's vision in action includes Pacific collectivism and inclusive ecosystems; shared authority; shared responsibility; shared outcomes; whakawhanaungatanga a.

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[5] (United Nations, 2015, Para. 48).
[6] (Manatū Hauora, 2018).
[7] (Manatū Hauora, 2017).

	Oranga Tamariki Outcomes Framework	To ensure all tamariki are in loving whānau / families and communities where oranga tamariki can be realised.	Accurate and meaningful assessments are conducted for the tamariki, rangatahi and whānau Oranga Tamariki works with so they receive the support they need.
	Washington Group on Disability Statistics	The main objective of the Washington Group question set is to provide information on disability that is comparable throughout the world. The question set is considered good practice when collecting administrative data on disability, and underpins the approach taken in the New Zealand Disability Data Survey.[8]	The Washington Group question set is one aspect of collecting administrative data on disability.
	Enabling Good Lives (EGL) Principles	The EGL approach is designed to ensure disabled people and their whānau have choice and control over their lives and the supports they receive. The EGL principles are: self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, and relationship building.	Accurate data underpins transformation of the system in accordance with EGL principles. Therefore, data collection must be guided by EGL principles.
	Document	**Key findings**	**Recommendations**
Instructive reports The findings of these reports	Tāwharautia: Pūrongo o te Wā Interim Report	There is a lack of data on disabled people's experiences of institutional care.	Data collection must include the experiences of tamariki whaikaha in institutional/residential settings.

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[8] ([Office for Disability Issues, 2022c](#))

identify shortfalls of data collection and provide lessons for improving data collection processes.	He Purapura Ora, he Māra Tipu – From Redress to Puretumu Torowhānui	Redress data was not disaggregated, making it unclear who was impacted by abuse in care, who has accessed redress, and who is likely to access redress in the future.	Data must be disaggregated to allow for deeper analysis and interpretation.
	Final Recommendations (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017)	There is no shared understanding of key terms and definitions relating to abuse and disability.	Nationally agreed key terms and definitions must be applied for the purpose of data collection and reporting, and a centralised database should be implemented.
	Off the Record: An investigation into the Ministry of Health's collection, use, and reporting of information about the deaths of people with intellectual disabilities	There is a lack of guidance, implementation, and consistency in reporting, collecting information and data regarding the deaths of people with learning disabilities who live in residential homes.	There must be an appropriate level of guidance, implementation, and consistency in reporting, collecting information across all residential settings.
	He Take Kōhukihuki | A Matter of Urgency	There is no structural method for collecting data about applications made under section 78 of Oranga Tamariki Act 1989, and no clear method for distinguishing uplift notices made with or without notice, or determining how they were responded to by the Family Court.	A structural approach to data collection must be implemented so that data about Oranga Tamariki practices (for example, court applications, uplifts, and so on) can be easily accessed and evaluated.
	Disability Rights: How is New Zealand doing?	There is an inconsistency and lack of data collection across government agencies. When data is available, it is not used efficiently to guide policy and progress work programmes to	Data must be disaggregated and applied to real life contexts according to Article 31 of the UNCRPD.

		address the challenges experienced by the disability community.	
	Child and Youth Wellbeing Strategy Annual Report for the year ending 30 June 2021	There is a lack of strength-based data related to tamariki whaikaha.	Strength-based data is collected regularly and intentionally from tamariki whaikaha.
	Treatment of disabled mother and removal of newborn child	Tamariki were uplifted from disabled parents, whose parenting support needs had not been assessed or met.	The support needs of disabled parents must be included in data collection processes so that disabled parents are supported to give effect to their right to home and family (Article 23).

11. Part B: Thinking about disability data

How do existing frameworks hold up in the socio-political context of Aotearoa New Zealand?

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), State Party agencies such as Oranga Tamariki have an obligation to collect data on the disabled people who engage with their services and programmes. As outlined above, there are many key documents and reports that assert why data should be collected, what types of data should be collected, when it should be collected, who it should be collected by, and how it should be collected. In combination, this literature can provide a framework for Oranga Tamariki to develop their own approach to disability data collection.

11.1 - Why should disability data be collected?

Disability refers to a wide range of experiences. Therefore, perhaps the most important aspect of developing a disability data collection framework is understanding the reason why disability data should be collected in the first place. As articulated by Madans and colleagues ([2017](#)):

> As disability is not a singular static state, there is no simple, singular way to collect disability data. There is also no gold standard by which to validate the data. To assure that appropriate and useful data are collected, it is necessary to identify the purposes for which the data are needed, and then to identify the appropriate data collection approach. When reporting or using disability data, it is always necessary to be explicit about the objectives underlying the collection, which aspects of disability are being addressed, and how they relate to the overall conceptualization of disability (pp. 1165-1166).

With this in mind, the key themes that were observed in the literature about why it is important to collect disability-related data and evidence are outlined below.

11.1.1 - Honouring Te Tiriti o Waitangi

Prior to colonisation, tamariki whaikaha Māori were a natural part of their whānau, hapū, and iwi ([Hickey & Wilson, 2017](#)). However, with colonisation many tamariki whaikaha and tamariki Māori were placed in State care ([Royal Commission of Inquiry into Abuse in Care, 2021](#)). Even so, there is very little data specifically on tamariki whaikaha Māori. As stated by Davis ([2016, p. 25](#)): it is "well understood that the existence of relevant information is a vital precondition for devising adequate policy responses to address inequalities and to monitor the effectiveness of measures to overcome discrimination." This is especially relevant for tamariki and rangatahi who experience intersecting identities ([Baker et al., 2021](#); [Oranga Tamariki, 2022a](#)). Further to this, measuring and monitoring wellbeing from a Te Ao Māori view requires data collection methods and measurements that are fit for purpose and in line with Te Tiriti o Waitangi ([Independent Māori Statutory Board, 2019](#)). As recently highlighted by Oranga Tamariki:

> It is important that we get better at how we collect data so we can see how disabled children are faring compared to the non-disabled population. Just as important is capturing data on the intersection of disabled and Māori and disabled and Pacific to understand the outcomes for these children (Oranga Tamariki, 2022a, p. 20).

Efforts to strengthen the protection and promotion of rights of indigenous disabled people is also supported by the UNDRIP. At the World Conference on Indigenous Peoples in 2014, a resolution was adopted to ensure:

> [p]olicy and institutional structures relating to indigenous peoples are inclusive of indigenous persons with disabilities, committing to prevent and eliminate violence, and committing to disaggregate data collection by disability and indigeneity (Harpur & Stein, 2018, p. 170).

Accurate data collection is central to equitable service delivery and outcomes for tamariki whaikaha Māori and for ensuring accountability (Came et al., 2021). If data is not properly disaggregated to identify the inequities experienced by tamariki whaikaha Māori, there is a risk of further entrenching the inequities they experience, in breach of Te Tiriti o Waitangi (Came et al., 2021; Baker et al., 2021). To avoid this, accurate data needs to be ingrained in policy advice, system design, and service delivery (Baker et al., 2021).

Disability data collection within Oranga Tamariki needs to be disaggregated to ensure tamariki whaikaha Māori are not further disadvantaged by intersectionality. Accurate data can inform Oranga Tamariki on how to best support tamariki whaikaha Māori and measure the outcomes of their approach.

11.1.2 - Preventing abuse

Data collection is also recognised as an important factor in efforts to prevent abuse (Royal Commission of Inquiry into Abuse in Care, 2021). In a broad sense, data is crucial for identifying the systemic issues that can underpin and lead to abuse. Furthermore, without accurate data, comparisons between the experiences of tamariki whaikaha Māori, tamariki whaikaha, and non-disabled children cannot be made. During the recent Royal Commission of Inquiry into Abuse in Care, Oranga Tamariki responded to questions posed by the Royal Commission, in the following way:

> 18.24 Gaps in data have been identified as a barrier to understanding the current and long-term impacts of the state care and protection system. Oranga Tamariki acknowledges that there are existing limitations in respect of the reliability of information held by it, and it requires ongoing work to address (2022b, p.135).

Historically, many disabled children were placed in institutional care away from their families – a direct result of the lack of supports and services that should have enabled them to live at home and in the community (Royal Commission of Inquiry into Abuse in Care, 2021). Many of these children experienced varying types and degrees of abuse within institutional settings. However, when opportunities for redress were presented, the lack of data on disability status meant understanding of the impact that institutions had on disabled people and the abuse they experienced was limited (Royal

Commission of Inquiry into Abuse in Care, 2021). The small group of disabled people who came forward to present at the Royal Commission of Inquiry into Abuse in Care were certain that the most important aspect of redress was ensuring that history did not repeat itself – that is, preventing abuse from occurring again. Their evidence brief is a crucial piece of disability data with the potential to inform policy and practice designed to prevent tamariki whaikaha from entering care.

> **Collecting current and accurate data on why tamariki whaikaha enter care can inform what community-based supports can and should be provided to families and whānau to prevent the past from being repeated. This has the potential to progress the goals of the Oranga Tamariki Outcomes Framework, particularly, "[c]hildren are safe and flourishing in their homes" (Oranga Tamariki, 2020b). Such information can also support the prevention of disproportionate abuse experienced by tamariki whaikaha.**

11.1.3 - Informing policy and practice

When data informs policy, it also informs frontline practice. Article 31 of the UNCRPD recognises that data is an integral part of implementing the Convention, including collecting "appropriate information" to enable States "to formulate and implement policies to give effect to" the UNCRPD (Article 31) (United Nations, 2006). According to Davies (2004, p. 3), evidence-based policymaking "helps people make well-informed decisions about policies, programmes and projects by putting the best available evidence from research at the heart of policy development and implementation". Accurate data can inform policymakers, create accountability within society, and measure the differences made by policies (Abualghaib et al., 2019). As summarised by the OECD:

> Data and indicators are key for strategic planning and decision making, and are tools for promoting informed dialogues across levels of government and sectors of society, integrating both a national and an international perspective (OECD, 2023).

According to Sutcliffe and Court (2005), better utilisation of evidence in policy and practice can help save lives, reduce poverty, and improve development processes. However, it is also important to consider, as this literature review does, the challenges of evidence-based policymaking and practice, including deciding what evidence should be used in a policymaking process (paying attention to "the quality, credibility, relevance and the cost of the policy"); how evidence is incorporated into policymaking; and acknowledgement that policymaking is an inherently political process (Sutcliffe & Court, 2005, p. IV).

In practical terms, evidence-based policy is likely to lead to evidence-based practice (EBP), which involves the conscientious, explicit, and judicious application of best research evidence to a range of domains (Gilgun, 2005). As a process, EBP within social work combines intervention research with clinical experience, ethics, client preferences, and culture to guide and inform the delivery of treatments and services (National Association of Social Workers, n.d.). Within the context of this literature review, this includes research and evidence that is informed by the UNCRPD and Te Tiriti o Waitangi; that is disability-led and/or disability inclusive; is tamariki whaikaha-centred; and that respects disability culture and other intersecting identities.

It is notable that in August 2022, the New Zealand government was examined for its implementation of the UNCRPD within Aotearoa New Zealand. The Committee on the Rights of Persons with Disabilities (2022, p. 3) raised concerns with "[t]he lack of disaggregated data collected on disabled children with disabilities, including by the Ministry of Education and Oranga Tamariki (Ministry for Children) to inform implementation of national frameworks on children, such as the Child and Youth Wellbeing Strategy". In response to this concern, the Committee on the Rights of the Child, and the Committee on the Rights of Persons with Disabilities (2022, p. 3) made a joint recommendation to the New Zealand government to:

(b) Strengthen the collection of comprehensive disaggregated data on children with disabilities, including on Māori children with disabilities to inform effective early intervention, particularly in the fields of education, care and protection and youth justice.

When a person comes to the attention of Oranga Tamariki, the usual protocol begins with an assessment, followed by intervention and evaluation, before the cycle continues. Disability data, research, and evidence not only informs how this cycle is delivered, but data gleaned from the cycle can also be used to continually inform and improve policy and practice.

11.1.4 - Monitoring progress

A second key reason for collecting data is to monitor progress against international and domestic instruments that give expression to the human rights of tamariki whaikaha (Office of the United Nations High Commissioner for Human Rights, 2021). Under Article 7 of the UNCRPD, disabled children must have "all human rights and fundamental freedoms on an equal basis with other children" (United Nations, 2006). Collecting data is essential for identifying gaps in rights implementation and the progressive realisation of UNCRPD and other instrumental international agreements (Office of the United Nations High Commissioner for Human Rights, 2021; Came et al., 2021; Muego, 2019). As highlighted by Abualghaib et al. (2019, p. 4) the "lack of consistent and good quality disability data in accessible forms [...] has limited the ability to analyse issues and evaluate progress."

An example of this can be found in the SDGs, which the New Zealand government signed in 2015 (Ministry of Foreign Affairs and Trade, n.a.). While the catchphrase of the SDGs is "leave no one behind", research continues to point towards tamariki whaikaha as being a group that is at high risk of being left behind. In 2021, research showed that households with disabled children were between 1.4 and 1.6 times more likely to be below poverty thresholds than households that only included non-disabled children (Murray & Loveless, 2021, p. 65). This directly contradicts Goal 1 of the SDGs, which aims to end poverty in all its forms everywhere. For this reason, disability data should routinely be used for monitoring purposes, including how the SDGs are or are not being realised for tamariki whaikaha. As highlighted by the SDGs Disability Data Portal, "it is no longer the case that policymakers can attribute lack of data as a reason for preventing policy change towards meaningful disability inclusion" (Abualghaib et al., 2019, p. 8).

Inclusive and accessible data collection regarding tamariki whaikaha and their whānau is needed to monitor the progressive implementation of the SDGs, as well as other human rights instruments (UNCROC, UNCRPD, and so on). This, in turn, can be used to inform evidence-based policymaking and evidence-based practice.

11.1.5 - Promoting and advancing current models of disability

When collecting disability data and evidence, collection frameworks and paradigms should uphold and promote contemporary concepts of disability (Cappa et al., 2015). Disability and impairment have existed throughout history, with records documenting its presence across all societies and cultures (Barnes et al., 1999; Oliver, 2009). However, each culture and society has their own way of understanding disability and impairment, influenced by the social and political context of the time.

Historically, individual models of disability have dominated societal perceptions of disability. These include the charity, moral, and medical models of disability, which all perpetuate the belief that disability is a negative life experience that is located in an individual (Oliver, 1990). Individual models of disability, particularly the medical model, are still prevalent in our society, and continue to influence the supports and services that are provided to tamariki whaikaha (Donald Beasley Institute, 2022b).

In contrast, the social model of disability was developed by disabled self-advocates during the disability rights movement (1960s onwards) to demonstrate that the challenges experienced by disabled people are created by inaccessible social structures and inequitable distribution of resources (Oliver, 2013). It highlights that individuals with impairments are disabled by socially constructed barriers which limit their ability to fully participate in society (Oliver, 2013). By shifting the root cause of disability from the individual to society, the social model of disability has been used as a powerful tool for advocacy. It recognises that it is society's responsibility to remove barriers so that disabled people have full and meaningful access to every part of society (Shakespeare, 2013).

From the social model of disability, the disability rights model then emerged. The disability rights model holds that disabled people have the same human rights as those that are guaranteed to non-disabled people (Johnstone, 2001). Through affirming the rights of disabled people, this model acknowledges that disability is a natural part of humanity (Skarstad, 2018). The disability rights model has since been cemented via the establishment of the UNCRPD. It emphasises the empowerment of disabled people as active stakeholders, while the accountability of duty bearers (public institutions and structures such as governments) to implement disabled people's human rights (rights holders), and to justify the pace and quality of implementation (Miller & Ziegler, 2006).

Collecting accurate disability data that is informed by, and reflective of, current thinking about disability presents an opportunity to further shift the practice of child protection so that it advances the human rights of tāngata whaikaha (Donald Beasley Institute, 2022a). As stated in the Oranga Tamariki Ministerial Advisory Board's report, "the importance of data, and its essential role in ensuring a fit-for-purpose care system [...] data and evidence-based experiences enables identification of systemic issues, such as systemic racism" (Oranga Tamariki, 2022b, p. 132). In this same way, the collection of disability data and evidence must actively challenge individual models of disability, while upholding and promoting current models of disability such as the social and rights models.

11.2 - What disability data should be collected?

As previously highlighted by Madans and colleagues (2017), there is no gold standard for disability data collection. This includes when thinking about what data should be collected. However, once the purpose of data collection has been established, the aforementioned conventions, policies, documents, and guides provide useful recommendations on data collection pathways that ensure findings are fit for purpose. This includes disaggregated data, qualitative and quantitative data, types of data, and sources of data (who data should be collected from).

11.2.1 - Disaggregated data

Disaggregation refers to the process of breaking data down into smaller units of information to enable a more detailed analysis with potential to identify intersectionality and multidimensionality (Asian Development Bank, 2021; Expert Group on International Statistical Classifications, 2000). Aggregation is a broader method in which it can identify a broad statistic by grouping data rather than breaking it down (Expert Group on International Statistical Classifications, 2000). For example, aggregated data may identify the number of tamariki engaged with Oranga Tamariki, but it cannot provide any further detail about 'who' those tamariki are. Conversely, disaggregation enables the exploration and identification of specific characteristics of those who make up the broad grouping of tamariki (for example, age and ethnicity).

Disaggregated data allows for inequities to be highlighted and erases the "invisibility of marginalised groups" (Abualghaib et al., 2019, p. 2). A key requirement of data disaggregation is that it must identify disability so that any barriers to the exercising of disabled people's rights can be identified and addressed (Office of the United Nations High Commissioner for Human Rights, 2021). General data must be disaggregated with the inclusion of "disability-specific data and the identification of barriers" (Office of the United Nations High Commissioner for Human Rights, 2021, p. 7). The Office of the United Nations High Commissioner for Human Rights (OHCHR) listed the following as disability-specific data:

— "information on the need for and the provision of assistive technologies and support services

— information on the accessibility and effectiveness of certain services, such as disability benefits and rehabilitation, among others

— information about the attitudinal, physical, informational, or institutional barriers that persons with disabilities face" (Office of the United Nations High Commissioner for Human Rights, 2021, p. 7).

Data disaggregation requires data be collected, not only on disability, but also other life aspects, such as income status and gender, to understand and plan for the needs of marginalised people (Abualghaib et al., 2019). Furthermore, the SDGs adopted by the UN General Assembly require data to be disaggregated by sex, income, ethnicity, race, age, migratory status, geographic location, disability "or other characteristics" to enable the monitoring of policy commitments (Balestra & Fleischer, 2018, p. 9; Abualghaib et al., 2019; Besio et al., 2022). A lack of disaggregated data exacerbates vulnerabilities of disabled people and prevents growth in understanding the exclusion and discrimination faced by disabled people (Besio et al., 2022). Aside from monitoring the SDGs, disaggregating data allows governments to identify priorities for national policy planning (Balestra & Fleischer, 2018). Additionally, data disaggregation enables monitoring of the implementation of key conventions including the UNCRPD, UNDRIP and UNCROC.

11.2.2 - Qualitative and quantitative data

Data collection must encompass both qualitative and quantitative methods. A key strength of quantitative data is that it provides evidence that supports examination of the scale and scope of an issue while identifying related factors (Office of the United Nations High Commissioner for Human Rights, 2021). On the other hand, qualitative data can explore and support understanding relating to the dynamics of life and its interactions through interviews, focus groups, visual recordings, and photographs (Office of the United Nations High Commissioner for Human Rights, 2021). Traditionally, there has been focus on quantitative data, which has been useful in exposing social inequalities, inequity and the maltreatment experienced by tamariki whaikaha. However, there is very little qualitative and mixed method research that has sought to capture the experiences of tamariki whaikaha in their own voices, and hear what they think might have led to better outcomes for them. Further to this, the repeated presentation of disadvantage through quantitative data, without being matched with lived experience stories through qualitative data, can serve to reinforce negative stigmas and bias associated with tamariki whaikaha (Stalker & McArthur, 2012). The need for mixed methods is also reinforced in the New Zealand Disability Strategy:

> Evidence is both quantitative (data) and qualitative (lived experience, or stories, directly from us and those who care for us). We know that both are equally important and need to be valued alike to ensure there is a good understanding of the problem (before deciding on solutions); what interventions work best for us; and to be able to measure results against the outcomes we are seeking (Office for Disability Issues, 2016, p. 20).

11.2.3 - Types of data

The three main categories of data include administrative data, survey data, and research data. Administrative data is typically collected by organisations to support the running and monitoring of services (Disability Data and Evidence Working Group,

2022). A key benefit of administrative data is accuracy across a large sample size. Because administrative data is already being collected, it can also reduce or eliminate the need to collect additional data, meaning that it is considered a cost and time effective approach to data collection (Innovations for Poverty Action, 2016). Survey data is collected from a sample of population and is typically intended to be representative of the sampled population (Disability Data and Evidence Working Group, 2022). Surveys are versatile in that they can be used to answer almost any type of research question. They can also be conducted remotely, and are considered to be cost-effective and generalisable. Research data, on the other hand, are broader in scope as they are gathered using a variety of methods:

> Disability research involves creative and systematic activity to increase disability-knowledge. It is regularly carried out by researchers in academia, disabled people, disability and community organisations and government agencies. Evidence gathered through high quality disability research is often translated into meaningful insights to inform and transform policy and practice (Disability Data and Working Evidence Group, 2022).

Even though these three types of data are beneficial in different contexts, it is important to consider their limitations. For example, in an administrative data report on *Children and Young People with Impairments,* Oranga Tamariki (2020a, p. 29) stated:

> It is important to acknowledge that administrative data does not reflect all aspects of children's wellbeing, including their emotional and spiritual wellbeing, connection to culture, and the strength of their relationships with family/whānau, friends and their communities. These are important parts of children's lives and further research to describe the experiences of children with impairments would be of significant value.

Acknowledging the limitations of administrative data listed above is vital in understanding the totality of needs and experiences of tamariki whaikaha and disabled children. While it is important to utilise the strengths of administrative data, data collection must also be conducted through other means, so all necessary information is captured.

The limitations of survey data have previously been identified, particularly regarding insufficient disability data within nationwide statistics (Office for Disability Issues, 2017a; Stats NZ, 2017). As such, The Washington Group Short Set (WGSS) has been introduced to several large national surveys to identify disability within the population; including the 2018 Census, General Social Survey, and the Household Labour Force Survey (Stats NZ, n.d). The WGSS is a list of six questions that ask participants if they have difficulty with "seeing, hearing, walking, cognition, self-care and communication" and includes response scales (Office for Disability Issues, 2017b, p. 3). The questions were not designed for collecting data about children and child development, and it has been suggested that the WG-UNICEF Module on Child Functioning is more appropriate for identifying disability in children (Washington Group on Disability Statistics, 2022). Other recognised limitations of the WGSS are its tendency to fail to capture responses from people who experience psychosocial disability, indigenous

disabled people and people with learning disability who are self-completing the questions (Development Initiatives, 2020; Kaiwai & Allport, 2019; Stats NZ, 2015).

Finally, the limitations of research data include the time required, costs involved, smaller sample sizes, skills required, and the absence of generalisable results (Choy, 2014).

11.2.4 - Data sources

11.2.4.1 Data from tamariki whaikaha

The UNCROC and the UNCRPD both affirm the rights of tamariki whaikaha to take part in decision-making and to contribute their views (Jenkin et al., 2020). As such, data must be collected from the perspective of the tamariki themselves for use in decision-making processes. This imperative is supported by the New Zealand Children's Commissioner (2022, p. 25) in their report to the United Nations Committee on the Rights of the Child, which recommended the New Zealand government:

> In line with Te Tiriti and the Children's Convention, embed legal obligations and practical expectations in policy development and government consultation processes to engage with mokopuna meaningfully and ethically, so they can be heard throughout Government decision making.

Government agencies providing services for tamariki whaikaha must create opportunities for the views of tamariki whaikaha to be collected, considered, and acted upon in policy and programme development (Children's Convention Monitoring Group, 2019). Tamariki whaikaha must be encouraged to speak for themselves. Data collected from proxies is not sufficient in considering the perspective of a tamaiti (Jenkin et al., 2020).

In 2021, Oranga Tamariki released *Te Mātātaki,* which reported findings from a survey that explored the experiences of tamariki and rangatahi in the care of Oranga Tamariki. As stated in the report, "caregivers were informed about the survey and could choose to opt out – that is, they could choose for the tamariki and rangatahi they care for to not take part" (Oranga Tamariki Voices of Children and Young People Team, 2021, p. 20). This approach undermines the participation and voice of tamariki and rangatahi in care and undermines the kaupapa of the data collection. Tamariki whaikaha must also be included in data collection, using methods that are inclusive, accessible and age-appropriate. Based on the reviewed literature, it can be assumed that any data collection process that prevents the participation of tamariki whaikaha undermines their human rights.

11.2.4.2 - Data from tamariki whaikaha Māori

To honour Te Tiriti o Waitangi, data collection must involve "high-quality ethnicity data, in order to understand inequities; to deliver equitable services to Māori; to act to address inequity; and to monitor progress on eliminating inequities" (Harris et al., 2022, p. 61). Collecting data about tamariki whaikaha Māori must not focus solely on their condition, function and/or capacity as this approach risks drawing an inaccurate

picture about their daily realities. A 2016 study, investigating how data is collected about indigenous people stated that:

a. Currently available data for the most part did not adequately explain social conditions; there are gaps to be addressed.

b. Currently available data did not adequately incorporate environmental concerns (Davis, 2013, p. 29).

To address this issue and gain an accurate picture of the reality of indigenous peoples, the author stated:

[m]easuring implementation of the human rights standards affirmed in UNDRIP will require the collection of both objective and subjective data (also referred to as 'fact-based' and 'judgement-based' data). These elements are complementary and mutually reinforcing, and both present important opportunities for the collection of data spearheaded by indigenous peoples themselves (Davis, 2016, p. 35).

This approach should also be applied within the context of Aotearoa New Zealand. Ratima and Ratima (2007) state that disability data collection from tāngata whaikaha must be consistent, and purposeful about culturally safe practice. It is important to measure outcomes and capture positive functioning and culturally-specific measures beyond individual functioning. Collecting Māori-specific data must be inclusive of cultural data such as "hapū and iwi affiliation, access to Māori networks, whānau support, and other information related to those factors that strengthen Māori identity and may reflect positive functioning within Māori cultural contexts" (Ratima & Ratima, 2007, p. 190).

11.2.4.3 - Data from disabled caregivers

Another important source of disability data comes from disabled parents or caregivers who engage with Oranga Tamariki. For example, parents with learning disabilities are over-represented in statistics related to the uplift of tamariki with and without notice, with a lack of appropriate supports and services being identified as a key factor in these uplifts (Boshier, 2020c). The Oranga Tamariki Outcomes Framework (Oranga Tamariki, 2020b) highlights actions to identify and coordinate support needed by whānau and to identify those needs as early as possible. Data pertaining to the experiences of disabled caregivers must also be collected at the earliest possible opportunity, i.e., when whānau and tamariki initially come into contact with Oranga Tamariki. The data collected must include consideration of the support needs of whānau and tamariki from a disability rights approach to prevent future harm to whānau and to avoid perpetuation of disability rights violations (for example, UNCRPD Article 23 – right to home and family).

11.2.4.4 - Data from whānau and close supporters

As highlighted in a previous report by the Donald Beasley Institute (2022), whānau may initiate contact with Oranga Tamariki if and when they feel they have reached a breaking point in providing care to their tamariki whaikaha. Once breaking point has been reached, it is possible for whānau in crisis to surrender care of their children to Oranga Tamariki. An Australian report entitled *Desperate measures: The*

relinquishment of children with disability into state care in Victoria made recommendations about the role of data collection in preventing relinquishment:

> A comprehensive system for identifying families at risk of relinquishment is an essential prerequisite for early intervention. The Commission welcomes the work initiated by disability service networks in north/northwest Melbourne to identify triggers for relinquishment, risks linked to the triggers and strategies to target such risks. Using this work as a starting point, a consistent approach to risk identification should be developed by DHS across all regions so that, regardless of where a family lives, a rapid and early response can be put in to place to prevent the family surrendering care. So that where risk is identified, appropriate and immediate support is provided (Victorian Equal Opportunity & Human Rights Commission, 2012, pp. 56-57).

Similarly, collecting data on the antecedents of relinquishment in the context of Aotearoa New Zealand would serve to identify the needs of whānau with tamariki whaikaha and ensure the provision of effective supports in their caregiving roles.

11.2.4.5 - Data from front-line workers

Within social work, front-line workers are expected to use a critical thinking framework in recognition that data collection (assessment) is not free from personal perspectives and biases (Sowers et al., 2008). Sowers et al. (2008, p. 47) identified two main ways inaccuracies can occur within social worker assessments. Observational bias can occur when "the practitioner, usually without awareness, looks at the client through conceptual lenses provided by the society and culture to which the practitioner belongs." Relatedly, context effect is a form of error that "occurs when the context in which a social worker practices influences what the practitioner pays attention to and how he or she interprets the information obtained from and about a client".

There is an inherent power imbalance between data collectors (often frontline workers) and data subjects (tamariki whaikaha, whānau, close supporters, and so on) (Sowers et al., 2008). Data from front-line workers can provide useful insights for policy and practice, it can also act as a tool for recognising power imbalances. When the role of data collector is transferred to data subject, greater insights into data collection processes can be made. This process can help identify factors that have influenced practitioner' approaches to data collection from tamariki whaikaha and their whānau, ensuring that critical self-reflection is embedded within their practice.

11.2.4.6 - Data from third parties

Oranga Tamariki can access data from third parties about tamariki whaikaha to gain broad and holistic information. However, third-party data collection is tightly controlled and monitored. While it is beyond the scope of this literature review to analyse legislation and privacy regulations regarding data collection from third parties, it is important to acknowledge how the data is collected by different ministries, agencies, departments and programmes. That is, identifying the frameworks that informed the collection of the data held. Not all available data are collected from a Tiriti o Waitangi

and disability rights-based approach. Understanding how data is collected by third parties is important for meaningful data analysis.

A Tiriti o Waitangi and rights-based approach would expect that tamariki whaikaha and their whānau are informed before data is sought from a third party. Discussions should include why data is being sought from another person or agency, who is providing the third-party data, what data they are providing, how it will be gathered, how it will be used, and how it will be stored and for how long. The NEAC Standards provide clear guidance about the parameters of third-party data collection, which often occurs for disabled people due to assumptions about their capacity to consent to data or research activities. A Tiriti o Waitangi and rights-based approach to data assumes that all people have capacity, and the right to participate in data collection activities on their own behalf. The NEAC Standards stipulate that Supported Decision Making strategies should be implemented to ensure that disabled people have sufficient information, presented in an accessible way, when they are being asked to take part in research (refer to NEAC Standards Chapters 5 and 7 for further information).

11.2.5. Evaluation

To ensure services are operating well and in line with their purpose, evaluation frameworks are necessary for providing data on service operation. Evaluation is a term used to describe a variety of activities "involving the systematic determination of the quality, value and importance of something" (Social Policy Evaluation and Research Unit [SUPERU], 2015, p. 15). Evaluation is typically conducted to improve implementation and management; for accountability to funders, stakeholders, and service users; to measure impact of service; and for future planning (SUPERU, 2017). One of the key considerations of evaluation is whether it is internal or an external/independent process, or both.

11.2.5.1 - Internal and external evaluation

The Evaluation Standards for Aotearoa New Zealand (SUPERU, 2015) assert that consideration must be given to the position of the evaluator and their ability to navigate their subjectivity and proximity to the context that is subject to evaluation. Further to this, consideration must be given to the interconnectedness of evaluators with their whānau and communities as well as their "ability to simultaneously conduct valid, reliable and rigorous evaluation" (SUPERU, 2015, p. 23). With this in mind, it is crucial to apply a disability rights lens when considering and clarifying who should conduct the evaluation, as internal and external/independent evaluators both hold insights and knowledge that differ and carry value depending on the context. Independent reviews are a type of evaluation that reduces the potential for bias as independent reviewers have no relationship with the processes or decisions that are being reviewed.

Internal evaluation (or in-house evaluation) is useful for programme management and understanding the concerns and needs of an organisation's administrators, managers and staff, so that they have a better understanding of programme processes and outcomes. Compared to external evaluation, internal evaluation can reduce evaluation anxiety; be more targeted and effective, taking into account history and cultural norms; is cost effective; and ensures findings remain in-house (Youker, 2018). However, it can be difficult for internal reviewers to objectively review their own processes or decisions (Independent Complaint and Review Authority, n.d). Internal evaluation

should therefore have inbuilt safeguards that draw on external evaluation norms. Conley-Tyler (2005) put forward a checklist to support agency decision-making when considering the appropriateness of utilising internal or external evaluators or both. The checklist includes 15 factors to consider as well as guidelines that apply to each factor. Cost, availability, knowledge of processes and context, utilisation of evaluation, and organisational investment are factors that slightly favour internal evaluation. Perceived objectivity and "accountability for use of government funds" are factors that strongly favour external evaluation; ability to collect information and willingness to criticise are factors that slightly favour external evaluators (Conley-Tyler, 2005, p. 9). This highlights that both internal and external evaluation can be valuable depending on the characteristics of the organisation and the purpose of the evaluation. However, government agencies should seek independent evaluation for accountability, objectivity and for the ability to be critical. This is supported by Voyce – Whakarongo Mai, an organisation advocating for tamariki with care experiences:

> Ensuring true independence of the 'Independent' Children's Monitor is VOYCE's top priority. Government must not monitor government, and this independence is key in gaining any trust and positive engagement with the communities the Monitor is tasked with keeping safe (Voyce, 2022, para. 9).

Independent reviews into public agencies are sometimes sought by members of the public when their requests have been ignored by the public agency. The Ombudsman conducts independent investigations into public sector agencies and provides independent oversight (Boshier, 2020b). All government agencies are required by law to cooperate with investigations conducted by the Ombudsman (Ombudsman, 2020). Another independent evaluator is the Children's Commissioner which is responsible for monitoring the Oranga Tamariki youth justice system and places where tamariki and rangatahi are detained (Children's Commissioner, n.d).

Consideration of the position of evaluators also allows for selection based on appropriate experience. For example, article 33.3 of the UNCRPD stipulates that disabled people "must be involved and participate fully in monitoring the UNCRPD" (United Nations, 2006). This means that independent evaluation of the implementation of the UNCRPD must be carried out by disabled people. The Disability Rights Promotion International (DRPI) model is a methodology developed for this purpose – requiring the voices of disabled people to be recognised and valued throughout the monitoring process (Samson, 2015). Furthermore, involving disabled people in evaluation processes and ensuring those processes are disabled-led supports the disability rights mantra 'nothing about us, without us' (Francis Watene et al., 2021; Samson, 2015).

11.2.6 - Privacy

Privacy is a critical component of any data collection method. The importance of protecting a disabled person's private information is articulated in Article 22 and 31(1) of UNCRPD (United Nations, 2006). Data collection methods are required to adhere to international and domestic laws, policies, and ethical standards (Office of the United Nations High Commissioner for Human Rights, 2021). As highlighted by the United Nations Committee on the Rights of Persons with Disability, concerns have been raised about disabled people's right to privacy in multiple areas, including:

[T]he right to health, statistics and data collection, home and the family, children, protection of the integrity of the person, liberty and security of the person and in the banking sector. States should address these areas of concern so that persons with disabilities, including those in social care, psychiatric or other institutions, enjoy their right to privacy on an equal basis with others (Office of the United Nations High Commissioner, 2021, p. 12).

In Aotearoa New Zealand, the Privacy Act 2020, Section 7AA of the Oranga Tamariki Act and the guidance of the Data Protection and Use Policy (DPUP) provide a legal and policy framework guiding how information should be collected and protected appropriately and respectfully (Oranga Tamariki, 2019a). Tamariki whaikaha have the right to protection of privacy on an equal basis with others, but because of their potentially vulnerable position in society, protection of their privacy is particularly important (Office of the United Nations High Commissioner for Human Rights, 2021).

When collecting health-related information as part of disability data, guidelines stipulate consent must be obtained. Implementing a consent process ensures that privacy is protected, and "improves the efficacy and efficiency with which data is collected and used, as it supports defining human rights-based purposes and the provision of consent for data-collection processes" (Office of the United Nations High Commissioner for Human Rights, 2021, p. 11). The Health Research Council stipulates that consent should be obtained from children under age 16 if they have "the competence to understand the nature, risks and consequences of the research" and their consent is treated the same as consent of an adult (Health Research Council, n.d., p. 3).

For tamariki whaikaha and people with complex disability who are seen as unable to give their own informed consent, a Supported Decision Making (SDM) process can be utilised. SDM enables people who know the decision-maker to come together to agree on a decision they believe the person themselves would likely make. Integral to SDM is that primacy is given to the person's rights, will and preferences. Watson & Frawley (2023) identified key aspects of SDM with tamariki whaikaha as including the need for: *a positive attitude about the child's capacity to participate in decisions and communicate; a close relationship with the child; a deep knowledge of the child's history and life story; a circle of support that is collaborative and free of conflict; an understanding of the importance of the child taking some supported risks within decision making; a strong commitment to documentation including the use of video to ascertain the child's preferences.* (https://aifs.gov.au/resources/short-articles/engaging-children-disability-supported-decision-making.

11.2.7 - Data sovereignty

Data sovereignty typically refers to the understanding that data is subject to the laws of the nation within which it is stored, while Māori data sovereignty recognises that Māori data should be subject to Māori governance (Te Mana Raraunga, 2023). He Puapua – a report and roadmap that articulates what it would take to implement the UN Declaration of Rights of Indigenous Peoples in Aotearoa New Zealand – highlights that data currently available in Aotearoa New Zealand is often incomplete and/or unreliable. To address this, He Puapua recommends that:

- ▪ "Māori are involved in the governance of data repositories;
- ▪ data for and about Māori is safeguarded and protected by Māori;
- ▪ quality and integrity of Māori data and its collection is achieved by:
  - ○ meaningful disaggregation of data and
  - ○ supporting Māori to have their own data infrastructure and security systems" (Charters et al., 2019, p. 88).

These suggestions are supported by the idea of indigenous data sovereignty. Māori data sovereignty principles have been developed by Te Mana Raraunga, the Maori Data Sovereignty Network, which can be used as an operational guide to transform data practices (Kukutai & Cormack, 2019). The principles suggested by Te Mana Raraunga include rangatiratanga (authority); whakapapa (relationships); whanaungatanga (obligations); kotahitanga (collective benefit); manaakitanga (reciprocity); and kaitiakitanga (guardianship).

In this context, data includes qualitative and quantitative data as well as information and knowledge (Rainie et al., 2019). It asserts the self-determination and control of data collection, storage, analysis, and implementation for Māori by Māori (Walter & Carroll, 2020; Rainie et al., 2019). There is a global movement to advance the autonomy of indigenous people over data (Walter & Carroll, 2020). Often, data collected about indigenous people, especially by Crown organisations, tends to focus on negative statistics that do not represent their diverse realities. To shift the focus of how data is collected, Kukutai and Cormack (2020, p. 29) hold that:

> The foundation of these digital data systems needs to be built on our own tikanga (ethical principles, practices and processes for what is "tika" or right in a given context), mātauranga (knowledge systems and ways of knowing) and priorities [...] A tikanga-centred approach to creating collective data privacy frameworks, principles and protocols could protect group identities and collective privacy, build trust, reduce group harm in diverse social, cultural and environmental settings and resolve potential risks and tensions with individual data rights.

11.2.8 - Data collection barriers and risks

As discussed by Garfield (2021), there is a power imbalance that exists in the process of data collection, and that even the terms used to describe the data collection process can influence research practice. For example, by conceptualising people's lived experience as data that can be collected, researchers, and other practitioners, can exclude the autonomy and humanness of the person whose data is being collected:

> However, the term data "extraction" also fails to capture the full extent of this violence. It is not merely something being taken out of an individual, it is a complete refusal of a person as a person, it is data as exclusion. But there is also more to this violence than erasure. Reducing people to categories—the datafication and objectification inherent to data collection as conceived by "science, surveillance and selling", that is, academic, government and corporate interests (D'Ignazio and Klein 2020, p. 42) – imposes something external in its drive towards identification. Datafied identities are not only performed according to

cultural norms, binaries and hierarchies, but explicitly scripted to fit machine-readable periperformative contexts built on patriarchal, racist and ableist inequities (Garfield, 2021, p. 11).

For example, Scott and Faulkner (2019) allude to these potential risks when using a survey as a method of data collection, and highlight a range of factors that data collectors need to consider including:

— "What distress is the survey likely to cause for participants and interviewers?

— How can distress be minimised?

— What balance can be provided between the anonymity of study participants and disclosures of harm or wrongdoing?

— What harms are likely to occur with the circulation of outcomes of the study and how will the results be reported and used?

— What are potential unintended consequences (for example, stigmatisation of a minority group)?

— Do the benefits outweigh the potential harm to individuals?" (Scott & Faulkner, 2019, p. 264)

History shows that the collection of disability data has often resulted in negative consequences for disabled people (Mertens et al., 2011). For example, data collected through disability assessment, often conducted by social workers, has led to segregated living situations (Royal Commission of Inquiry into Abuse in Care, 2021) and forced sterilisation programmes (Abualghaib et al., 2019). As previously identified, collecting disability data can also reinforce negative stereotypes, such as the individual models of disability (Williams et al., 2018). In measuring disability, there is a risk of categorising tamariki whaikaha and potentially negating their unique life experiences. This risk is particularly high when the socially constructed perception of disability is negative, and negative traits or experiences are attributed to disability:

[…] a social label may group together people who are actually very different based on attributes being studied. Furthermore, referring to social categories may lend credence to beliefs in group inferiority or superiority or in ideas of "fixed biological or ethnic classification," or entrench cumulative disadvantage (Williams et al., 2018, p. 107).

Māori have been the subject of data collection for a long time and the risks of data collection and negative use of data experienced by Māori are well documented (Smith, 2012). Kukutai and Cormack (2020, p. 25) critiqued recent government policy that placed significant importance on data collection and evidence-based decisions, however, "the conceptualization of Māori as watchable and in need of watching within contemporary data regimes is a continuation of coloniality, not a departure."

Similar concerns have been shared in relation to the involvement of disabled people in big data sets:

Nevertheless, there continue to be warnings about the possible human rights violations stemming from the misuse of big data. Preliminary research has shown the disproportionately high risks to persons with disabilities arising from biased data sets and discriminatory algorithms that restrict persons with disabilities' access to and affordability of services in social protection and health, as well as their access to opportunities in employment and education. States should require greater transparency and accountability in respect of algorithms used in disability-related services, and adopt a human rights-based approach to big data, including on persons with disabilities and their human rights (Office of the United Nations High Commissioner for Human Rights, 2021, p. 12).

In Aotearoa New Zealand there are a range of standards and guidelines on how to avoid the issues of data collection identified above. For example, two sets of principles underpin the NEAC standards: Te Ara Tika principles and bioethics principles. Te Ara Tika is a set of Māori ethical principles (Tika, Manaakitanga, Whakapapa, Mana), which coupled with Bioethics principles (Beneficence, Non-maleficence, Respect for people, and Justice) apply to all people in Aotearoa New Zealand (refer to Chapter 2 of the NEAC standards for further information). When adhered to, these principles serve to mitigate actual and potential risks within data collection activities.

While the lack of agency data regarding disability is well known, a report by the Independent Monitoring Mechanism (2022) highlighted that even when data is available, it is not used effectively to inform policy. Collecting disability data has the potential to transform how support is provided to tamariki whaikaha. However, any data collection must adhere to ethical standards, consider the risks to individuals, and include strategies to mitigate any potential harm. The aim of all disability data collection must be to directly or indirectly lead to improvement in the wellbeing status of tamariki whaikaha. This requires critical thinking and embedding the suggested data collection framework within a policy and practice framework (Abualghaib et al., 2019). One of the ways to navigate risk for those who are the focus of data collection activities is to ensure that data collection is carried out using a human rights framework. Moreover, Garfield (2021) suggests that individuals should have the power to refuse to have their data collected. Data should also be governed by collectives who share the lived experiences of people whose data is being collected. These two suggestions align with a Te Tiriti o Waitangi and rights-based-framework as it promotes the self-determination and collective approach.

11.3 - Who should collect disability data?

Who should collect disability data is a question that has no one, right answer, but should be considered within the broader context of disability research and Critical Disability Studies commentary. With regards to Oranga Tamariki, any person who collects and documents information regarding individuals with diagnosed or undiagnosed disability is considered a data collector, and therefore has ethical responsibilities and requirements.

Historically, the collection of disability data and evidence has been primarily conducted by non-disabled people in positions of authority and power. This traditional expert model of disability research has been widely critiqued for its individualised and medical ideological underpinnings (see individual models of disability). Specifically, research conducted by non-disabled researchers has often served the agenda of the expert rather than the disability community, while failing to represent the knowledge and experiences of disabled people or to implement change (Oliver, 1992). As highlighted by Kitchin (2000, p. 26) "critically-formulated research (that with an emancipatory, political agenda) which adopts an expert model approach is paradoxically seeking change at one level (society), whilst at the same time reproducing unequal social relationships at another."

While disability data can be collected by anyone, the relationship between data collectors and the person sharing data should be considered as an outward expression of the underpinning paradigms and assumptions of data collection. Stone and Priestley (1996) suggest that a reformatted research strategy is one that:

-   Adopts the social model of disability;
-   Surrenders the claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;
-   Only undertakes research where it is of practical benefit to the self-empowerment of disabled people and the removal of barriers;
-   Ensures full accountability to disabled people and their organisations;
-   Gives voice to the personal as political;
-   Adopts a plurality of data collection and analysis methods.

Further work by Donna Mertens challenges power imbalances in research and data collection through the transformative paradigm,[9] the central tenet of which is that "power is an issue that must be addressed at each stage of the research process" (2007a, p. 213). When asking the question of who should collect disability data and evidence, the transformative paradigm holds that the marginalised community at the centre of research should actively be informing the socially constructed realities that underpin the research (ontological assumptions); the culture and power relations within the research (epistemological assumptions); the type of methods used to collect data (methodological assumptions); and issues of respect, beneficence, and justice (axiological assumptions). To do this, it is crucial to ensure community members are involved in research decisions as early as possible (Mertens, 2007a).

Regardless of whether the data being collected is administrative, survey or research, careful consideration must be given to power dynamics between the parties, including factors such as disability status (or non-status), ethnicity, age, and experience. Though not always possible, it is preferable for disability data to be collected by people with lived experience of disability. This can be achieved by ensuring disabled people are employed in roles right across an organisation. However, it is essential that anyone collecting data or informing a data collection process understands the Tiriti o Waitangi and rights-based framework, which harmonises the social and rights models of disability, the Disability Strategy and Te Tiriti o Waitangi as it pertains to tāngata whaikaha (Donald Beasley Institute, 2022a). This will not only ensure higher quality

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[9] The transformative paradigm is discussed further in section 11.5.1.3.

data and more positive ongoing relationships, but it also ensures that the process of data collection itself is empowering and affirming for tamariki whaikaha and their whānau.

11.4 - When should disability data be collected?

There are no set requirements when it comes to the timing of disability data collection. Decisions on periodicity depend on what data is being collected and the purpose of data collection. For example, if survey data are collected, how often should the data collection occur? What will happen if data is collected more frequently or less frequently than the utility of the data? Drawing on the DDEWG (2022) guidance on data collection, outlined below are considerations when thinking about when to collect different types of disability data.

11.4.1 - Administrative data

Administrative data is routinely collected by government agencies while implementing programmes and policies. As recommended by the Office of the United Nations High Commissioner for Human Rights (2021), governments should systemise administrative data collection processes to collect data on disability and identify gaps in policy implementation that prevent disabled people's human rights from being met (recommendation 57.e). This means collecting disability data from the outset of administrative data collection, i.e., from when a person first comes into contact with Oranga Tamariki, as well as throughout their engagement.

While collecting administrative data from someone who has been formally diagnosed with disability or a health condition is common sense, with the populations who engage with Oranga Tamariki it may not be immediately clear if someone has a disability or not, especially if they have not been formally diagnosed or have access to existing supports and services. Research shows that many people in Aotearoa New Zealand experience significant financial and attitudinal barriers when seeking formal diagnosis, which limits their ability to access treatments, interventions and funding (Donald Beasley Institute, 2022b).

Under Article 25 of the UNCRPD, the New Zealand government and its agencies have a responsibility to ensure tamariki whaikaha have the highest attainable standard of health, including:

> b) health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons (United Nations, 2006).

Access to early diagnosis is also articulated in Outcome 3 – Health and Wellbeing of the 2016-2026 New Zealand Disability Strategy. In the context of Oranga Tamariki work, Article 25 b of the UNCRPD and Outcome 3 of the Strategy recognise that if a tamaiti is thought to have disability but has not yet been diagnosed, the Oranga Tamariki approach to data collection should provide an easy and timely pathway to diagnosis (early identification), so that administrative data can then be effectively collected and monitored. Once diagnosed, administrative data should regularly

monitor the tamaiti to ensure timely access to supports and services. For tamaiti with a known disability, it is appropriate to utilise natural points of engagement or interaction during their dealings with Oranga Tamariki. For example, disability data collected during early engagement will help to inform a tailored response and service provision. Disability data collected during periodical evaluations and reviews, can help to determine whether the tamaiti's rights, will and preferences are being met under the UNCRPD. It should also be noted that disability is fluid and evolving, so a life-long approach to data collection should be utilised, to monitor changing needs over time.

11.4.2 - Survey data

While survey data is usually considered within the context of census data, the Disability Survey, or other data collection programmes, within Oranga Tamariki survey data might be considered in the context of staff awareness of disability. Periodically collecting data from Oranga Tamariki staff will ensure disability rights awareness is measured and monitored, and that professional development is relevant and meaningful. As previously identified, existing internal evaluation processes should collect data on Oranga Tamariki staff's knowledge of, and commitment to, disability rights, and the implementation of critical thinking. Ideally, periodic surveys will demonstrate an increase in staff knowledge on disability rights.

11.4.3 - Research and evidence

Disability research involves creative and systematic activities to increase disability knowledge. It is regularly carried out by researchers in academia, disabled people, disability and community organisations, and government agencies. Best practice research and evidence places disabled people at the centre of data collection – both as researchers and participants (DDEWG, 2022). Research and evidence often takes a more longitudinal approach to information than administrative and survey data, and is often collected through a series of limited engagements (for example, interviews). Qualitative in-depth data collected over an extended period can be used to inform policy and practice, and ensure the progressive realisation of disabled people's rights, will, and preferences.

11.5 - How should disability data be collected?

11.5.1 - Paradigms

The final question this literature review asked was how disability data should be collected. In some ways this leaves the most important question to last, while also providing an opportunity to draw together the previously discussed why, what, when and who of data collection. In the context of disability data and evidence, it is crucial to 1) establish and articulate underpinning research paradigm/s before 2) developing appropriate method/s of data collection.

A research paradigm is the philosophical framework that research is based on. This framework makes explicit the principles underpinning the research – or the "basic set of beliefs that guides action" (Guba, 1990, p. 19, as cited in Denzin & Lincoln, 2011). When taking a paradigmatic approach, researchers are expected to communicate their beliefs about ontology (the nature of reality), epistemology (the relationship between the inquirer and the known), and methodology (how knowledge is gained).

Methodology refers to the rationale for the research approach, and the lens through which the analysis occurs, while methods are the ways in which data is collected (Brookshier, 2018). While it is not uncommon for data collection methodology and methods to be developed without first considering and articulating underpinning paradigm/s (particularly in non-academic settings, such as the public sector), understanding and acknowledging the research paradigm underpinning a specific data collection activity is crucial for ensuring that methodology and data collection methods appropriately respond to the 'why' of disability data collection. This is not to say that research that has not consciously or outwardly acknowledged paradigm/s are absent of paradigms – in fact, quite the opposite. Status quo approaches to research and data collection regularly (subconsciously or consciously) draw on paradigms that can be in direct contradiction with Te Tiriti o Waitangi, the UNCRPD, and the NZDS. For example, positivist, interpretivist, and to some extent constructivist paradigms may all deliver useful information, but do not fundamentally change the relationship between the researcher and the (disabled person/people) being researched or have a specific focus on achieving change (Oliver, 1992). This does not mean these paradigms do not have a place in disability data collection and research, but careful consideration of the **'why'** of taking such an approach is critical. It is also important to consider **how** results and findings will be presented to avoid perpetuating negative or assumptive disability stereotypes.

In contrast, there are numerous paradigms and methodologies that lend themselves to a Tiriti-rights-based approach to disability data collection, or that have been developed in direct response to disability and indigenous rights movements. Outlined below are a selection of recommended research paradigms and methodologies that have been integral in advancing the rights of disabled people through data collection.

11.5.1.1 - Critical Theory Paradigm

The critical paradigm, at its core, is focused on power, inequality, and social change. This paradigm is underpinned by the belief that social research can never be truly objective or value-free and operates from the assumption that research should be conducted with the express goal of social change (Denzin & Lincoln, 2011). Researchers using a critical paradigm might begin with the knowledge that systems are biased against others (ableism, racism, sexism, and so on). Moreover, such research projects aim to foster positive change for the research participants themselves, the systems being studied, as well as collect important data. The critical paradigm not only studies power imbalances but also seeks to change them (Denzin & Lincoln, 2011).

11.5.1.2 - Critical Disability Studies Theory

Based on the social model of disability, traditional disability studies developed in response to the dominant deficit model of disability (see individualised models of disability). Critical disability studies, on the other hand, challenges the normative assumptions, focus, and direction traditionally found in disability studies. It does this by highlighting the limits, exclusions, and framing of traditional disability studies, and how this came about. As summarised by Hall (2019), concerns and objects of critique include disability studies' largely liberal approach; narrow consideration of physical disability; focus on the global North and independent living; downplay of pain and suffering; ties to or investment in class elitism; neoliberalism; masculinism;

materialism; somatophobia; and white supremacy. As a result, several notable sub-paradigms have emerged from critical disability studies that are useful for disability data collection.

— Crip Theory: Crip Theory emerged as a particular mode of doing disability studies, deeply in conversation with queer theory. Crip theory affirms lived, embodied experiences of disability and the knowledges (or cripistemologies) that emerge from such experiences; at the same time, it is critical of the ways in which certain identities materialise and become representative to the exclusion of others that may not fit neatly within dominant vocabularies of disability. Many works in Crip Theory focus on the supposed margins of disability identification as well as on the intersections where gender, race, sexuality, and disability come together (McRauer & Cassabaum, 2020).

— Disability Justice: The Disability Justice paradigm recognises that the disability rights movement has historically invisibilised the lives of disabled people of colour, immigrants, minority religions, LGBTQIA+, trans, and gender non-conforming people, homeless, incarcerated people, and people who have had their ancestral lands stolen, amongst others. A disability justice framework understands that all bodies are unique and essential; all bodies have strengths and needs that must be met; disabled people are powerful, not despite the complexities of our bodies, but because of them; all bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them (Berne, 2020).

— Indigenous and Post-colonial Theories: Understanding the intersections between race and disability calls for attention to indigenous persons (Hall, 2021). Disability scholars in Aotearoa New Zealand are among a growing number of academics advancing indigenous and post-colonial paradigms and theories; research that seeks to decolonise disability by centring the global South, challenging neo-colonialism in capitalism, culture, and discourse, and re-engaging questions of disability from a diversity of cultures (Hall, 2021; Hickey & Wilson, 2017; Hickey, 2020; Meekosha & Shuttleworth, 2009).

11.5.1.3 - Transformative Paradigm

The Transformative Paradigm provides a culturally-responsive, mixed-methods approach to addressing social injustice and inequality. It recognises the constructed nature of realities and questions whose reality is privileged in the research context (Mertens, 2007a). It acknowledges that while some individuals hold a greater level of power, there are individuals with different characteristics who may be more likely to be excluded (Mertens, 2007b). In simple terms, the Transformative Paradigm assumes that discrimination and oppression are pervasive, and that the knowledge generated through research must be used to ensure all people have their human rights met (Mertens, 1999; Romm, 2015).

11.5.1.4 - Kaupapa Māori approaches

Kaupapa Māori is both a paradigm and a research methodology – by Māori, for Māori, and with Māori. This makes it different from other forms of data collection in which Māori are participants, but may have no conceptual, design, methodological or

interpretative control. Crucially, kaupapa Māori research and data collection is guided by a set of principles which should underpin the way research involving Māori is thought about. Among these are whakapapa, te reo, tikanga Māori, rangatiratanga, mana wahine, and mana tane (Tuhiwai Smith, 2015).

When applying the kaupapa Māori paradigm in the context of disability data and evidence, for example, the way in which disability is understood can guide how disability data is collected. One of the te reo Māori kupu (words) for disability is whānau hauā. It places disability as a collective experience. The potential barriers experienced by a disabled person are not attributed back to the individual, rather it is seen as something that the collective work together to address (Hickey & Wilson, 2017). To reflect the meaning of the kupu in the data collection process, whānau must be involved in, and leading data collection processes. Another kupu for disability in te reo Māori is tāngata whaikaha, which recognises disabled people as having determination and strength (King, 2019). When data is collected using this paradigm, tamariki whaikaha have self-determination over the collection processes, analysis, and use of data (Kukutai & Cormack, 2020) as well as data sovereignty.

11.5.1.5 - Strength-based approach

The basic premise of any strengths-based theory or practice is that every individual, group, and organisation has strengths. Originating in the field of positive psychology, the strengths-based approach was soon picked up by social work practitioners, who saw the benefit of refocusing interventions away from 'need' and deficits and towards resources and 'strengths'. The overarching aim is to improve the lives and wellbeing of users and carers (Department for Health and Social Care, 2019). The strengths-based approach is being utilised by Oranga Tamariki, for example, in the strengths and needs assessment (Oranga Tamariki, 2019b).

11.5.2 - Methodologies

While the purpose of this review was not to provide recommendations on specific methods of data collection, outlined below are key points to consider when developing methodologies and methods for collecting data about disability.

11.5.2.1 - Accessible formats

It is important that disability data collection methods are accessible to people with a wide range of disabilities. The Accessibility Charter was developed by the Ministry of Social Development and the Disabled People's Organisations (DPOs), and is endorsed by public sector chief executives, including the Chief Executive of Oranga Tamariki. The Charter documents commitment to delivering on Article 9 – Accessibility of the UNCRPD. This means:

— meeting the New Zealand Government Web Accessibility Standard and the Web Usability Standard, as already agreed, by 1 July 2017
— ensuring that forms, correspondence, pamphlets, brochures, and other means of interacting with the public are available in a range of accessible formats including electronic, New Zealand Sign Language, Easy Read, braille, large print, audio, captioned and audio described videos, transcripts, and tools such as the Telephone Information Service

— complying with accessibility standards and requirements as a high priority deliverable from vendors

— responding positively when our customers draw our attention to instances of inaccessibility in our information and processes and working to resolve the situation

— adopting a flexible approach to interacting with the public where an individual may not otherwise be able to carry out their business with full independence and dignity (Office for Disablity Issues, 2018).

The Accessibility Charter should be applied to any and all data collection efforts, without compromise. This includes ensuring all administrative, survey, and research and evidence is collected and presented in the key accessible formats identified above.

11.5.2.2 - Twin track data

Another important aspect of data collection is the twin track approach, which is about ensuring mainstream services are disability responsive, while providing disability specific services when required (Office of Disability Issues, 2016). When considering data collection there are two ways of thinking about the twin track approach. Within the context of Oranga Tamariki, a twin track approach ensures general data collection procedures are inclusive of and accessible by tamariki whaikaha, while also ensuring there are data collection processes unique to the specific needs of tamariki whaikaha.

The twin track approach allows for data to be collected from tamariki whaikaha about their experiences within a mainstream environment, as well as any disability specific environments they have engaged with, while also being able to compare their experiences to non-disabled children. Madans and colleagues (2017, pp. 1166 - 1167) suggested the following method for measuring twin track data:

> This is done by collecting data that describe the disability continuum from none to very severe, and then by identifying a point along the continuum that distinguishes between those with and without disabilities according to established criteria. In order to determine if those with a disability have achieved equalized opportunities (in selected outcomes like education or employment), it is necessary to compare that subgroup of the population with disabilities   to   that without disabilities (again, according to established criteria). The complexity of the disability paradigm allows for the identification of multiple subpopulations, each describing different levels of disability.

11.5.2.3 - Life course approach

The needs of tamariki whaikaha change as they grow (Donald Beasley Institute, 2020; Donald Beasley Institute, 2022b). As outlined in the New Zealand Disability Strategy, taking a "whole-of-life and long-term approach to social investment" in the disability community is key to ensuring that tamariki whaikaha have access to appropriate support as their needs and situations change with age (Office of Disability Issues, 2017, p. 16). In the context of quantitative and qualitative data collection, it is important to have a lifelong and cyclical approach to identifying and addressing the gaps experienced by tamariki whaikaha (Goldman et al., 2020; Scott & Faulkner, 2019).

At the national level, global organisations should support and resource efforts to provide high-quality longitudinal data and information about family care, including information about children living without parental care, while ensuring that collection methods are ethical and support the privacy of children (Goldman et al., 2020, p. 616).

This is especially critical for rangatahi whaikaha who are transitioning between Oranga Tamariki and Whaikaha – Ministry of Disabled People. Rangatahi whaikaha are eligible to transition to adult disability services at the age of 18, however, it can take up to two years to complete a successful transition. It is suggested that transition planning starts before tamariki whaikaha turn 15 years of age. In order for the planning to happen early with consideration given to disability, it is important that disability data are collected appropriately and as early as possible (Oranga Tamariki, 2017).

11.6 - Summary table

Guidance from the literature	Themes	Key findings	System level application	Practical application[10]
Why should disability data be collected?	To honour Te Tiriti o Waitangi	Disability data collection within Oranga Tamariki needs to be disaggregated to ensure the needs of tamariki whaikaha Māori and intersectional experiences can be identified and responded to. Accurate data can inform Oranga Tamariki on how to best support tamariki whaikaha Māori and measure the outcomes of their approach.	Data is disaggregated to identify and attend to inequities experienced by tamariki whaikaha Māori.	I am open and transparent about the process of collecting data and how data is used. I ask honest and respectful questions about how tamariki whaikaha Māori identify themselves and their experience of identity.
	To prevent abuse	Data is crucial for identifying the systemic issues that can underpin and lead to abuse. Without accurate data, comparisons between the experiences of tamariki whaikaha Māori, tamariki whaikaha, and non-disabled children cannot be made.	The data that is collected accounts for reports/ complaints of abuse in care. The data is reviewed so that systemic issues that lead to abuse can be identified and responded to.	I record the complaints and reports of abuse and neglect of tamariki whaikaha in care so that it is accounted for in data.
	To inform policy and practice	Accurate data can inform policymakers, create accountability, and measure the differences made by policies.	Accurate data must be collected to inform policy and to measure and compare the effect of policies.	I know how data collected from tamariki whaikaha informs the wider policies that impacts them, and I share this information with them in a way they understand.

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[10] The Practical application column is intended to provide simple examples to show practitioners how the key findings can be applied in their practice. The examples presented here are not exhaustive of the ways in which the framework can be applied to practice.

		Evidenced-based policy is likely to lead to evidence-based practice (EBP), which involves the conscientious, explicit, and judicious application of best research evidence to a range of domains.	Policy and practice must be shaped by data and evidence.	My practice is based on evidence-based policy.
		It has been recommended that the New Zealand government: "(b) Strengthen the collection of comprehensive disaggregated data on children with disabilities, including on Māori children with disabilities to inform effective early intervention, particularly in the fields of education, care and protection and youth justice."[11]	Disaggregated data on tamariki whaikaha is collected to inform effective early intervention, particularly in the fields of education, care and protection, and youth justice.	I collect data in a way that can be easily disaggregated.
	To monitor progress	Inclusive and accessible data collection regarding tamariki whaikaha and their whānau is needed to monitor the progressive implementation of the SDGs, as well as other human rights instruments (UNCROC, UNCRPD, and so on). This, in turn, can be used to inform evidence-based policymaking and evidence-based practice.	The data that is collected must demonstrate whether the human rights of the tamaiti whaikaha have been recognised and respected.	I know how data collected from tamariki whaikaha is used to monitor the implementation of SDGs and other human rights instruments. I share this information with them in a way they understand.
	To promote and advance current models of disability	Collecting accurate disability data that is informed by, and reflective of, current thinking about disability presents an opportunity to further shift the practice of child protection so that it upholds the human rights of tamariki whaikaha.	Disability data is collected in alignment with social and rights models of disability to ensure the human rights of tamariki whaikaha are upheld at all times.	When I work with tamariki whaikaha and their whānau I collect information about their strengths, the barriers they experience, and their aspirations. I feel confident in my role as duty bearer.

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[11] (Committee on the Rights of Persons with Disabilities, 2022).

What disability data should be collected?	Disaggregated data	Disaggregation refers to the process of breaking data down into smaller units of information to enable a more detailed analysis with potential to identify intersectionality and multidimensionality.	Data must be disaggregated to enable detailed analysis. Intersectionality and multidimensionality must be identifiable from the data.	I know to record information from tamariki whaikaha in a way that is easily broken into smaller pieces of data.
	Qualitative and quantitative data	Qualitative data can explore the personal perspectives of tamariki whaikaha, including what their needs were in the past, and continue to be. Quantitative data can expose societal inequalities and maltreatment experienced by tamariki whaikaha on a large scale, while also relating these experiences to other interlinking factors. It is important to utilise both quantitative and qualitative approaches to data collection, as well as mixed methods, to gain both holistic and specific understandings.	Qualitative and quantitative methods should be used together where appropriate. Qualitative data includes the perspectives of tamariki whaikaha, as articulated by tamariki whaikaha.	I know the differences between quantitative and qualitative data and how each are collected and used. Both quantitative and qualitative data inform my practice. When I collect qualitative data from tamariki whaikaha, I make it clear that their stories are contributing to data.
	Types of data	The three main categories of data include administrative data, survey data, and research data: Administrative data is typically collected by organisations to support the running and monitoring of services. Survey data is collected from a sample of population and is typically intended to be representative of the sampled population. Research data is broader in scope and gathered using a variety of methods over longer periods of time.	When collecting data, a variety of methods should be used. Data collection methods must be appropriate for the administrative and research questions being asked.	The main data collection I use in my practice is administrative data which comes from assessment processes and case notes. Survey data and research data are typically conducted by the research office, but are important for informing my practice.

Data sources	**Data from tamariki whaikaha:** Tamariki whaikaha must be included in data collection, using methods that are inclusive, age appropriate and accessible. Based on the reviewed literature, it can be assumed that any data collection process that prevents the participation of tamariki whaikaha undermines their human rights.	The perspectives of tamariki whaikaha must be collected as part of data and evidence. Data collection processes must be inclusive and accessible.	I listen to tamariki whaikaha and record what they say as an important source of data.
	Data from tamariki whaikaha Māori: Data collection must involve "high-quality ethnicity data, in order to understand inequities; to deliver equitable services to Māori; to act to address inequity; and to monitor progress on eliminating inequities."[12] Māori specific data must also be collected inclusive of information that strengthens Māori identity.	Data must be collected to understand inequity. Data must be used to inform equitable service delivery and address inequity. Cultural data must be collected so that tamariki whaikaha Māori remain connected to their Māori networks and their identities are strengthened.	I ask tamariki whaikaha Māori open and transparent questions about their identity, experience with their identity, and their aspirations.
	Data from disabled caregivers: Disability data must be collected from disabled parents and/or caregivers who engage with Oranga Tamariki. The data collected must include consideration of the support needs (from a disability rights perspective) to prevent future harm to whānau and to avoid perpetuation of disability rights violations (for example, UNCRPD Article 23 – right to home and family).	Collected data must include the perspectives of disabled parents/ caregivers. The support needs of disabled parents/ caregivers must be included, recognising the right to home and family (Article 23, UNCRPD). When relinquishment of care occurs, data must be collected on the factors that led to relinquishment. This data informs	I listen to disabled parents/ caregivers about their experiences, needs and aspirations for themselves as parents, and as a whānau/ family.

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[12] (Harris et al., 2022, p. 61).

		supports required to prevent future relinquishment.	
	Data from whānau and close supporters: Data must be collected from whānau and close supporters about why and how their tamariki whaikaha have engaged with Oranga Tamariki to identify the needs of whānau with tamariki whaikaha and ensure the provision of effective supports in their caregiving roles.		I listen to whānau, family and close supporters of tamariki whaikaha who have engaged with Oranga Tamariki about their experiences, needs and aspirations for themselves as parents, and as a whānau/ family.
	Data from frontline workers: Frontline workers are expected to use a critical thinking framework in recognition that data collection (assessment) is not free from personal perspectives and biases. The inherent power imbalance between data collectors and data subjects is recognised in data collection processes.	Data should be collected from frontline workers in order to provide useful insights for policy and practice. Collecting data from frontline workers is a tool for reducing power imbalance and identifying potential bias.	I am open to sharing my own critical self-reflection and my thoughts that have guided my practice, as part of data collection.
	Data from third parties: Oranga Tamariki can access data from third parties about tamariki whaikaha to gain broad and holistic information.	A Tiriti o Waitangi and rights-based approach is used when collecting third-party data. Tamariki whaikaha and their whānau are informed before data is sought from a third party.	I am transparent with tamariki whaikaha and their whānau about what third parties I am collecting information from, what information I am collecting, and why.
Evaluation	Evaluation frameworks are necessary for providing data on service operation.	Consideration is given to the position of the evaluator: External evaluation is used to achieve greater objectivity.	I engage with, and contribute to, internal and external evaluations to improve the support we provide.

			Internal evaluation has built in safeguards through the inclusion of external evaluation.	
	Privacy	Tamariki whaikaha have the right to the protection of privacy on an equal basis with others, but because of their potentially vulnerable position in society, protection of their privacy is particularly important. In Aotearoa New Zealand, the Privacy Act 2020, Section 7AA of the Oranga Tamariki Act, and the guidance of the Data Protection and Use Policy (DPUP) provide a legal and policy framework for how information should be collected and protected appropriately and respectfully.	Data must be collected and protected appropriately and respectfully. When collecting data, consent must be gained from tamariki whaikaha. Supported Decision Making (SDM) must be implemented when the capacity to provide consent is in question.	I am open and transparent with tamariki whaikaha about why I collect information from them, and how it will be used. I provide support to tamariki whaikaha to make decisions for themselves about what they feel comfortable to share, and for me to record.
	Data sovereignty	Data is subject to the laws of the nation within which it is stored. Māori Data Sovereignty recognises that Māori data should be subject to Māori governance.	Data collected from tamariki whaikaha Māori adheres to Māori data sovereignty principles.[13]	I understand and respect tikanga and mātauranga Māori. I follow the direction of Māori governance when gathering information from tamariki whaikaha Māori and their whānau.
	Data collection barriers and risks	There is an inherent power imbalance in data collection process which can be harmful to the people whose data is being collected. There is a history of disability data leading to negative consequences for tāngata whaikaha.	Data collection adheres to Te Ara Tika principles and bioethics principles. A human rights framework must be used in all data collection activities.	I am aware of the power I hold in relation to the person I collect data from. People are able to refuse their data being collected and decide how they want the data to be used/stored.

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[13] (Te Mana Raraunga, 2018)

				I understand the Te Ara Tika principles and use a human rights framework to mitigate any risks of data collection.
Who should collect disability data?		It is preferable for disability data to be collected by people with lived experience of disability. If this is not possible, non-disabled data collectors should be trained in, and be familiar with, disability rights. The relationship between data collectors and the person sharing data should be considered an outward expression of the underpinning paradigms and assumptions of data collection.	Disabled people are employed in roles across the organisation. Data collection processes are underpinned by Te Tiriti o Waitangi and a rights-based framework, which is informed by the social and rights models of disability, the Disability Strategy and Te Tiriti o Waitangi as it pertains to tamariki whaikaha.	I incorporate a Te Tiriti o Waitangi and rights-based framework when collecting information from and with tamariki whaikaha. Relationship building with tamariki whaikaha is the foundation of data collection process.
When should disability data be collected?	Administrative data	If a tamaiti is thought to have disability but has not yet been diagnosed, the Oranga Tamariki approach to data collection should provide an easy and timely pathway to diagnosis (early identification), so that administrative data can then be effectively collected and monitored. Once diagnosed, administrative data should regularly monitor the tamaiti to ensure timely access to supports and services. For tamaiti with a known disability, it is appropriate to utilise natural points of engagement or interaction during their encounters with Oranga Tamariki to collect further data.	Data collected during early engagement helps to inform tailored responses and service provision. Disability data collected during periodical evaluations and reviews helps determine whether the rights, will and preferences of the tamaiti are being met under the UNCRPD.	I know that data collection process starts from the first interaction and continues until the tamaiti whaikaha leaves the Oranga Tamariki system.

	Survey data	Internal Oranga Tamariki evaluations (such as surveys) can document and monitor staff awareness of disability rights.	Internal evaluation processes collect data on Oranga Tamariki staff's knowledge of, and commitment to, disability rights, and the implementation of critical thinking. Periodical surveys demonstrate an increase in staff knowledge on disability rights.	I understand that answering survey questions about my knowledge of tamariki whaikaha and rights and strength-based practice contributes to improving the support we provide to tamariki whaikaha.
	Research and evidence	Research and evidence often take a more longitudinal and in-depth approach to data than administrative and survey data and is collected through a series of engagements (for example, interviews).	Qualitative in-depth data collected over an extended period is used to inform policy and practice, and ensure the progressive realisation of the rights, will and preferences of tamariki whaikaha.	I know that research contributes to evidence-based practice, and I am able to contribute to relevant research as needed.
How should disability data be collected?	**Paradigms** The philosophical framework that research is based on that outlines the principles underpinning the research	**Critical Theory Paradigm:** Focused on power, inequality, and social change. It is underpinned by the belief that social research can never be truly objective or value-free and operates from the assumption that research should be conducted with the express goal of social change.	Used in research projects that aim to foster positive change for the research participants, the systems being studied, and is used to collect important data.	I understand the power dynamics that exist between tamariki whaikaha and myself. I critically self-reflect to reduce my position of power when gathering information from them. I note my own reflections as an important part of data.
		Critical Disability Studies Theory: Responds to the dominant deficit model of disability. It challenges the normative assumptions, focus, and direction found in traditional disability studies by highlighting limitations, exclusions, and framing of disability studies, and how this came about. Sub-	Knowledge generated through research underpinned by Critical Disability Studies Theory is used to challenge ableism and disablism experienced by tamariki whaikaha	I challenge negative assumptions about disability. I value the lived experiences of disability.

		paradigms include: Crip Theory; Disability Justice; Indigenous and Post-colonial theories.	engaged with Oranga Tamariki; challenge deficit models; and to inform a human rights framework.	
		Transformative Paradigm: Provides a culturally responsive, mixed methods approach to addressing social injustice and inequality.	Knowledge generated through transformative research must be used to ensure the rights, will and preferences of tamariki whaikaha are met.	I take time to learn about knowledge generated through transformative research to inform my practice. I consider the principles of the transformative paradigm when collecting data.
		Kaupapa Māori: By Māori, for Māori and with Māori. Kaupapa Māori research and data collection is guided by principles that should underpin the way research involving Māori is thought about: whakapapa, te reo, tikanga Māori, rangatiratanga, mana wahine, and mana tane.	When data is collected using a kaupapa Māori paradigm, tamariki whaikaha have self-determination over the collection processes, analysis, and use of data as well as data sovereignty.	I follow the self-determination of tamariki whaikaha Māori regarding how they want their data collected and used.
		Strength-based approach: All tamariki whaikaha and their whānau have strengths. Rather than focusing on their needs, the overarching aim is to improve the lives and wellbeing of tamariki whaikaha and carers.	The strengths-based approach is utilised by Oranga Tamariki, for example, in the strengths and needs assessment.	My interactions with tamariki whaikaha focus on their strengths.
	Methodologies	**Accessible formats:** Disability data collection methods must be accessible to people with a wide range of disabilities. The Accessibility Charter documents commitment to delivering on Article 9 – Accessibility of the UNCRPD.	The Accessibility Charter must be applied to all data collection efforts. All administrative, survey and research and evidence must be collected and presented in accessible formats.	I will ensure information I present to tamariki whaikaha and their whānau are in a format that is accessible to them. For example, Te Reo Māori, NZSL, braille, Easy Read, audio, plain English and large print.

| | | **Twin Track Data**: Disability responsive general data, together with disability-specific data. | A twin track approach ensures general data collection procedures are inclusive of and accessible to tamariki whaikaha, while also ensuring there are data collection processes unique to the specific needs of tamariki whaikaha. | When I collect general data, it is inclusive of and responsive to the needs of tamariki whaikaha. There are also times when I collect disability-specific data from tamariki whaikaha.

I will also consider how tamariki whaikaha experience mainstream services, as well as disability specific services. |
| | Life course approach | The needs of tamariki whaikaha change as they grow. A whole-of-life and long-term approach is key to ensuring that tamariki whaikaha have access to appropriate support as their needs and situations change. This approach is endorsed by the NZDS. | A whole-of-life and long-term approach to data collection must be taken to identify and address the barriers experienced by tamariki whaikaha. | When I collect data from tamariki whaikaha, I give consideration to things that change in their lives as they age, and how their needs change. |

12. Part C: Applying a Tiriti o Waitangi and rights-based framework

What does a social-rights- and Te Tiriti o Waitangi-based approach to disability data collection look like in the context of Oranga Tamariki engagement with tamariki, rangatahi, and whānau?

In Part A of this integrative literature review, a range of documents were presented that are overtly instructive in their thinking around disability data collection. Part B provided commentary and analysis on how, in practical terms, these documents can be utilised and applied during data collection. In this section, Part C, the findings of the literature review are applied to hypothetical case studies, which apply a Tiriti o Waitangi and rights-based framework for data collection in the context of tamariki with existing and diagnosed disabilities, tamariki with invisible or undiagnosed disabilities, and disabled parents who engage with Oranga Tamariki.
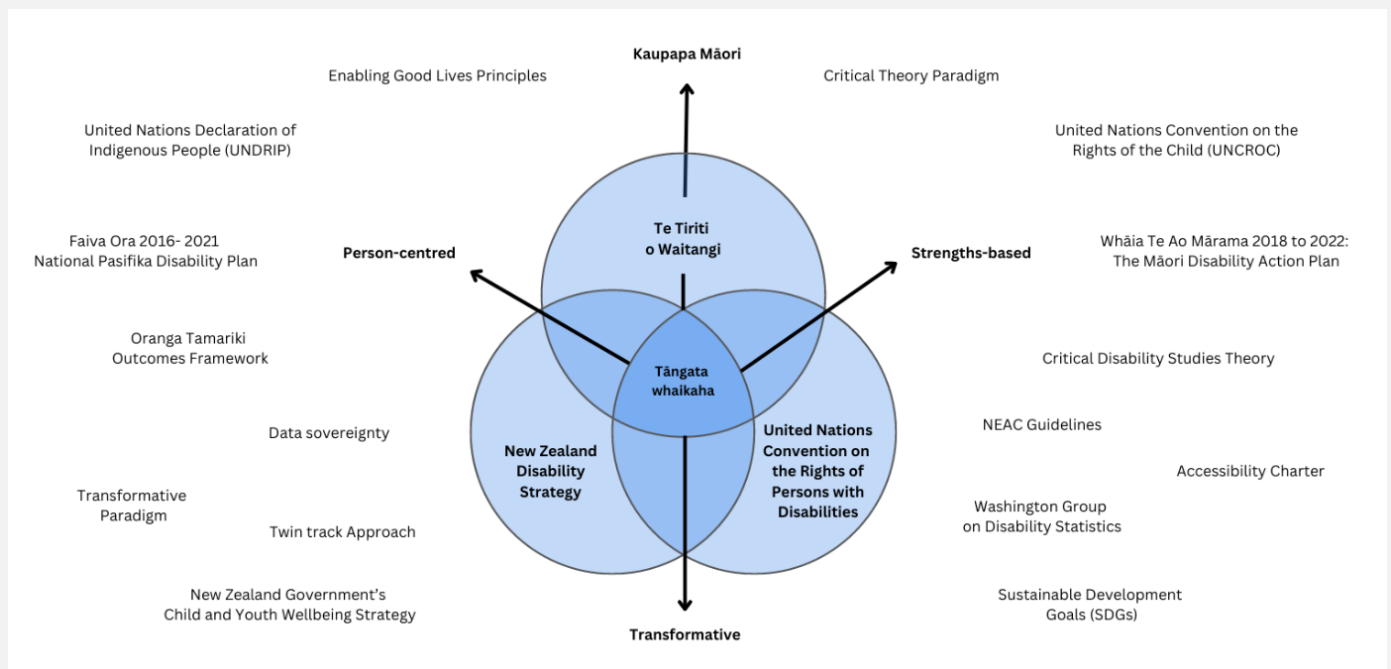

Figure 1. A Tiriti o Waitangi and rights-based framework for disability data collection

During analysis, the DBI team drew extensively on the knowledge of our disabled and non-disabled researchers and kairakahau Māori, disability data and evidence experts and the findings of this literature review, to workshop and formulate a data collection framework for Oranga Tamariki to use when strengthening and establishing future data collection processes. During this process, varying degrees of four key values were found to be woven throughout the literature and findings. These were that disability data collection best practice is person-centred, strengths-based, transformative, and embodies the values of kaupapa Māori approaches.

As shown in the Venn diagram, tāngata whaikaha (term chosen for its inclusivity of tamariki whaikaha, rangatahi whaikaha, mātua whaikaha, and whānau) are at the very centre of the framework. This is because data is people, so disability data collection processes must also be person-centred. The strengths-based value relates to how disability and tāngata whaikaha are perceived and treated throughout the various

stages of data collection. In all the reviewed literature, disabled people are recognised and respected for their strengths, not their deficits. The next key value, kaupapa Māori, holds that data collection should be guided by Kaupapa principles such as whakapapa, te reo, tikanga Māori, rangatiratanga, and mana wahine and mana tane. And finally, all efforts to collect disability data and evidence should ultimately lead to transformation. That is, better outcomes for tamariki whaikaha and their whānau.

This literature review has presented a range of potential paradigms and models that draw on these values, and therefore can and should be integrated into data collection processes. While this list is not exhaustive, it demonstrates the importance of ensuring that whichever paradigms and models underpin data collection, they should always be guided by the values identified above. Further to this, Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disabilities and the New Zealand Disability Strategy must always be observed, respected, upheld, and implemented throughout all stages of data collection. Hence, these three agreements remain front and centre in the Venn diagram of the proposed framework, with tāngata whaikaha at their intersection.

This final aspect of the review presents four hypothetical scenarios, and how a Tiriti o Waitangi and rights-based approach to data collection might be applied. The summaries are not exhaustive but provide examples of how some of the different aspects of data collection could be considered and implemented in the context of the everyday mahi of Oranga Tamariki.

12.1 - Case study 1

Chris is a 9-year-old boy who has been in the care of Oranga Tamariki for three years. Chris came to the attention of Oranga Tamariki due to care and protection concerns raised by an extended whānau member. Chris currently lives with a foster family. The school has raised concerns about Chris' behaviour at school, which includes distracting self and others during class, angry outbursts, and truancy.

As Chris does not have an official diagnosis, he is currently not considered 'disabled' within the care and education systems. However, the concerns raised by his school indicate that something is not working for him. Taking a rights- and strengths-based approach is important for exploring whether he has a disability, and which of his needs are and are not being met. Identification of disability is not only about determining cause, but also taking a person-centred approach to finding solutions and interventions that work for him as an individual, and in the context of his whānau. Chris must be informed about why the assessment/s are taking place, and how the information will be used in a way that he understands. Taking a Supported Decision Making approach would ensure Chris' right to be actively involved in decisions that are about him. If he meets the criteria for a disability diagnosis, it is important that the response is quick, unique to his needs, and primarily based on conversations with Chris himself. In some circumstances, it is appropriate to draw on responses that have worked for other tamariki with similar diagnoses, but this approach should only be

secondary to Chris' will and preferences. Data relating to his experience of disability, and subsequent interventions should be anonymised if it informs organisation data sets.

Collecting data in this way is overtly person-centred and transformative as the purpose is to improve and enhance Chris' experiences and outcomes. It also aligns with the UNCRPD, by ensuring that Chris has access to early identification and intervention (Article 25.b). This is also in alignment with the UNCROC (Article 12.a) by ensuring Chris has the opportunity to express his will and preferences.

12.1.1 - Key points for practice

- **I am open and transparent about my role, the process of my involvement and the use of information gained from Chris and key people in his life.**
- **I ask about his will and preference every step of the way using a Supported Decision Making process.**
- **I am curious and attentive to Chris's strengths, as well as challenges, during the assessment process.**

12.2 - Case study 2

Tane is a single father with a learning disability. Tane comes from a large whānau. His partner recently passed away, leaving him the primary caregiver of their four children. The oldest daughter is 16 years old, the twin boys are 14, and the youngest son is 11 years old. The whānau came to the attention of Oranga Tamariki following reports of concern from neighbours who had heard loud yelling on several occasions.

From the outset, data should be collected in a way that is respectful of Te Ao Māori and Te Tiriti o Waitangi. A kaupapa Māori approach considers who collects information and data from Tane and his whānau, what questions are asked, how that information is used, and data sovereignty. A strengths- and rights-based approach to data collection focuses on what supports are useful to Tane and his tamariki, while also noting Tane's disability and ethnicity among other demographics so that the disaggregated data can be used to compare, contrast, and measure progress. Given the high rate of uplift from disabled parents, it is important that the intent of data collection is communicated in a way that Tane understands (using the Supported Decision Making approach to ensure Tane understands the purpose of data collection and provides genuine informed consent), to ensure that he feels safe, and that sharing information with Oranga Tamariki will not automatically lead to the uplift of his children (provided there are no safety concerns). Even when there are safety concerns, these must be raised with him and the root cause of the concerns identified before any action is taken. It is also important to monitor whether he feels respected throughout the process. If Tane does not feel like his dignity and rights have been respected, the data collection processes must adapt in accordance with a person-centred approach. This is to ensure his rights continue to be met in a full and meaningful way. Any data

collected about Tane and his whānau should be governed by a high-level Māori/disability advisory group within the Oranga Tamariki decision making structure.

Collecting data using a kaupapa Māori, strengths and rights-based approach aligns with the UNCRPD by ensuring that Tane is supported in his parenting duties (Article 23.2) as well as Te Tiriti o Waitangi and the UNDRIP. This is also in alignment with the Oranga Tamariki Outcomes Framework as it enables any gaps in support needs to be identified early so that support can be provided, with the goal of ensuring tamariki thrive in their own home. Collecting data to support Tane and his tamariki to thrive in their home is transformative as the data collection process benefits the whānau and improves their outcomes.

12.2.1 - Key points for practice

- **I will be guided by tikanga and kaupapa Māori approach when collecting information from Tane.**
- **I follow Tane's direction about if and how he would like his information collected and used to contribute to the wider data set of Oranga Tamariki.**
- **I focus on his strengths and prioritise relationship building.**

12.3 - Case study 3

> **Rosie and Phil have been married for 15 years. They have three children, aged 11, 6, and 5. One boy and two girls close in age.**
> **Their son, Tom (11), has multiple and complex disabilities.**
> **Rosie is the primary caregiver for Tom, while Phil works full-time to support the family. Rosie has been struggling with her mental health for the past 12 months and feels as though she is nearing breaking point with Tom's care. Rosie and Phil have decided to contact Oranga Tamariki to ask for help.**

Research shows there is a lack of disability support services for families, who, as a result, often find themselves nearing breaking point when supporting a family member with complex disability (Donald Beasley Institute, 2022a). Data collection is a vital tool in identifying where gaps are, including where there is a lack of support for families impacted by disability. A strengths- and rights-based approach to data collection focuses on what supports are and are not available to the family, with the data informing how the Oranga Tamariki response can best enhance their access to support. This also aligns with a person-centred approach by tailoring support to the specific needs of the family.

In this context, data contributes to transformative practice that enables tamariki whaikaha wellbeing by addressing parent/caregiver wellbeing. This aligns with the Oranga Tamariki Outcomes Framework by ensuring tamariki can flourish in their homes because their needs have been understood and met. This also aligns with the UNCRPD (Article 23.3) by preventing the separation of whānau based on disability and by ensuring that comprehensive information, support, and services are provided to tamariki whaikaha and their whānau.

12.3.1 - Key points for practice

- **I explore what supports Rosie and her family already have access to, and how to enhance access to supports.**
- **I consider Rosie's holistic wellbeing and how this impacts the wellbeing of her family.**
- **I am transparent about the use of data that I collect from them.**

12.4 - Case study 4

> **Susan is a social worker for Oranga Tamariki in the intake team. However, she has not had specific training around disability rights. One day she comes into contact with a mother and a daughter. The mother experiences addiction issues and has been neglectful, while the daughter is known to be withdrawn. Susan is struggling to work with the mother and daughter, especially as she feels like the mother is being uncooperative.**

As highlighted in the 'who' section of Part B (8.3), there are often power imbalances between people who collect data and people whose data is being collected. Research shows power imbalance is also commonly experienced between social workers and their clients (Sowers et al., 2008). As a way to challenge perceived power imbalances, Susan's response and reflections about working with the family should be included in data collection. While social workers have mandatory confidential supervision sessions, an open record of self-reflection can create accountability and generate a fuller picture around the justification of decisions and responses made about a family. Evaluation processes will also monitor Susan's professional development in the disability rights area. This type of data collection is in line with the transformative paradigm in that it responds to the position of privilege and power in the data collection process. In addition, it is transformative by identifying where professional development is needed and helping to improve service provision.

This practice reflects the social model of disability, whereby the barriers tamariki whaikaha experience are understood as being socially constructed. Implementing self-reflection practice as part of the data collection process can provide opportunities to identify and explore barriers created by the biases of social workers and ableist policies. Equally, key elements of positive social work examples with tamariki whaikaha can be recognised. These are all important parts of realising disabled people's rights under the UNCRPD, particularly Article 7 (Rights of disabled children) and Article 23 (Respect for home and the family).

12.4.1 - Key points for practice

- **My critical self-reflection is supported through open record collection.**
- **Transparent communication is encouraged with colleagues, supervisors and the mother and daughter I work with.**
- **I explore immediate challenges as well as structural issues impacting the mother and daughter I work with.**

13. Kupu whakamutuka/Concluding remarks

Historically, disability data and evidence has been collected about tāngata whaikaha, but very rarely with or by them. Moreover, collecting data often led to negative outcomes for tāngata whaikaha and whānau. Over the past few decades, however, indigenous and disability rights movements have produced tools, models and paradigms that have been critical in ensuring the progressive realisation of their human rights and improved wellbeing.

This review has touched on a wide range of literature – strategies, conventions, reports, guides, models, and paradigms – that can be used to guide Oranga Tamariki work and strengthen their commitment to improving disability data and evidence under Article 31 of the UNCRPD. Part A of the review provided brief summaries of documents that are overtly instructive when it comes to disability data collection. The purpose of Part B was to explore these documents within the context of Aotearoa New Zealand, by drawing on additional academic and grey literature for context and analysis.

Part B began with the question: Why should disability data be collected? According to the literature, disability data can help inform policy and practice, monitor human rights progress, prevent abuse, honour Te Tiriti o Waitangi, while also advancing current models of thinking about disability. The second question asked what disability data should be collected. While the goal was not to suggest specific research methods and interview/survey/assessment frameworks, this section examined different considerations when deciding what data to collect. This included, disaggregated data, qualitative and quantitative data, types of data, data sources, evaluation, privacy, and data sovereignty. The section concluded with a cautionary note on the risks of collecting disability data. Who should collect data and when disability data should be collected were discussed. While there is no single or correct answer to the questions of who and when data should be collected, it is important to consider the diversity of staffing and whether data collectors are trained in inclusion, accessibility, and disability rights, as well as ensuring data collection processes enable early pathways to diagnosis, supports and services. Lastly, Part B asked: How should disability data be collected? An argument for establishing appropriate data paradigms at the outset of data collection design is made, while emphasising the importance of ensuring that methods are accessible, and responsive to the twin track and life course approaches.

In Part C, the Donald Beasley Institute drew on the extensive knowledge of our disabled and non-disabled researchers and kairangahau Māori, disability data and evidence experts, together with the findings from Parts A and B of the literature review, to workshop and formulate a data collection framework for Oranga Tamariki to use when strengthening and establishing future data collection practices. Through this process, four key values were identified as being raised consistently throughout the literature. The first being that disability data collection is person-centred. Second, that it is strength-based. Third, that it is guided by kaupapa Māori principles. And fourth, disability data is transformative. A framework was conceptualised, which placed tāngata whaikaha at the centre and surrounded by intersections of Te Titiri o Waitangi, the UNCRPD and the NZDS. The four key themes are highlighted, with the framework encompassed by the reviewed documents, paradigms, approaches, and models that can be used as tools and reasoning when developing data collection methods, specific

to the individuals Oranga Tamariki engage with, and the data systems that are being developed.

With the knowledge gained from the reviewed literature at the forefront of our minds, we return to the opening whakataukī:

Mā te rongo, ka mōhio,
Mā te mōhio, ka mārama,
Mā te mārama, ka mātau,
Mā te mātau, ka ora.

This review has demonstrated the importance of carefully considering the ethics of knowledge production when collecting disability data and evidence. It reaffirms that when we listen to tamariki whaikaha and their whānau, meaningful knowledge is gained. From this knowledge comes greater understanding. From greater understanding comes wisdom. From wisdom comes wellbeing – for tamariki whaikaha, whānau and all of Aotearoa New Zealand.

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