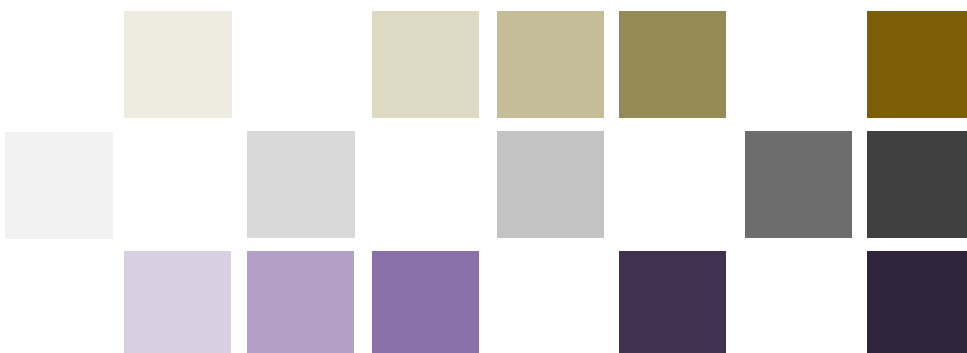


Quality and Safeguarding Frameworks

Research paper for Whaikaha Ministry of Disabled People and Disability Support Services (DSS) in the Ministry of Social Development (MSD)

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A note about terminology

Language around disability is important. There are different terms preferred by different people to refer to disabled people, family and whānau that support them, including within Te Ao Māori. This report uses the term 'disabled people' and 'disabled people and whānau' as an inclusive term, including disabled tamariki/children, rangatahi/young people, tāngata whaikaha Māori and whānau (including parents, caregivers and guardians), tagata sa'ilimalo and their aiga.

This report uses the term tāngata whaikaha Māori as a term for disabled Māori or Māori with lived experience of disability. We acknowledge that other terms are used such as whānau hauā.

We note that there is ongoing debate around the language used and individuals and groups will use the terms they feel most comfortable with. We are also conscious that not all members of the community identify with disability-focused language.

List of abbreviations

Abbreviation	Stands for
ARC	Aged residential care
ASA	(Australian) Adult Safeguarding Agencies
BC	British Columbia (Canada)
CHO	Community healthcare organisation (Ireland)
CQC	Care Quality Commission (England)
DAPAR	Disability Abuse Prevention and Response team
DPO	Disabled People's Organisation
DSS	Disability Support Services (a business group in the Ministry of Social Development)
EGL	Enabling Good Lives
EIF	Enhanced individualised funding
HCBS	(United States) Home and community-based services
HDC	Health and Disability Commissioner
HIQA	Health Information and Quality Agency (Ireland)
HSE	(Irish) Health Service Executive
IDCC&R	Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
IF	Individualised funding
IMM	Independent Monitoring Mechanism
KPI	Key Performance Indicator

Abbreviation	Stands for
MEAL	Monitoring, Evaluation, Analysis and Learning Strategic Framework
MSD	Ministry of Social Development
NAS	(Irish) National Advocacy Service
NASC	Needs Assessment (&) Service Coordination service
NDA	(Irish) National Disability Authority
NDIA	(Australian) National Disability Insurance Agency
NDIS	(Australian) National Disability Insurance Scheme
OSCAR	Out of School Care and Recreation
PB	Personal budget
SAB	Safeguarding Adults Board (England)
SAC	Severity Assessment Code
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
Wai 2575	Waitangi Tribunal Health Services and Outcomes Inquiry

Executive summary

For many disabled people, disability support services are essential to navigating and overcoming barriers and achieving their goals and aspirations. Over 50,000 people receive supports that are funded by Disability Support Services (DSS) within the Ministry of Social Development (MSD), with an approximately \$2.3 billion annual appropriation.

Quality disability supports are those that honour commitments under Te Tiriti o Waitangi, enable a good life and contribute to progressive realisation of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD). In other words, quality disability supports:

- ensure disabled people have more choice and control over their lives and disability supports and achieve goals that are meaningful to them
- drive better, equitable outcomes for disabled people, tāngata whaikaha Māori, and Pacific disabled people
- provide a good experience for disabled people and whānau
- are culturally safe, giving disabled people the power to be involved in decisions about their own care and give feedback without fear of bias, negative attitudes or assumptions, or prejudices from support providers
- keep disabled people safe from abuse and neglect.

Enlivening Te Tiriti principles in a quality framework

There are five principles of Te Tiriti o Waitangi that are assumed relevant to disability because they were identified by the Waitangi Tribunal in its *Hauora* report (Waitangi Tribunal, 2023) as part of the Health Services and Outcomes Kaupapa Inquiry (Wai 2575). Te Tiriti principles have broad implications for a quality framework, but some considerations have been identified as a starting point.

The guarantee of tino rangatiratanga

- Strong engagement to understand the needs and aspirations of tāngata whaikaha Māori and their whānau.
- Supporting Māori-led approaches to engagement and implementation of a quality framework (e.g. aspects that are Māori-led).
- Ensuring Māori scholarship and thinking on disability, disability supports, and quality are identified and included in all thinking.

The principle of equity

- Making it clear that there is an expectation of no discrimination for anyone entitled to DSS.
- Identifying equity as an overarching aim of the quality framework and monitoring its impact on tāngata whaikaha Māori.
- Having mechanisms in place to ensure that data is routinely monitored by ethnicity.

The principle of active protection

- Identifying where there might be gaps or issues through the quality framework that could exacerbate or maintain inequities and understanding any unintended consequences.

- Appropriately resourcing Māori-led or Māori-focused elements of the quality framework.
- Effective communication around how tāngata whaikaha Māori and whānau can engage with the framework.
- Interrogation of data collected through the framework, especially by ethnicity, in line with the principles of Māori data sovereignty.

The principle of options

- Concepts of quality to include an understanding (and expectation of) cultural safety in all services, including mainstream services, and high standards of cultural safety.
 - Māori individuals should have equal and fair protections wherever they access services.

The principle of partnership

- Consultation with Māori, in a way that does not “simply present Māori with its [the Crown’s] own solutions” (Waitangi Tribunal, 1999, p. 659).
- Governance arrangements that allow for Māori to have equal decision-making power in the decisions on the quality framework.
- Engagement with tāngata whaikaha Māori in the monitoring of the quality framework.

How a quality framework can support EGL system change

An important part of the EGL approach is that, as well as building new ways of doing things, disabled people have ways to check that it is working well for individuals, families and communities (i.e. check quality and outcomes). Disabled people have contributed to a number of seminal reports that have made recommendations about an EGL-based approach to quality.

- **The use of developmental evaluation**

Many reports have called for a comprehensive developmental evaluation process: development of disability standards, with appropriate outcomes-focused evaluation processes; ensuring that quality-of-life is measured and valued by giving people with disabilities and their families a significant role in the monitoring process.

- **Giving disabled people a voice**

Voice mechanisms help build the capacity of disabled people and enable them to have self-determination and more control of their lives. Independent voice mechanisms can help disabled people share their experiences and raise issues with current support arrangements. Specific regard should be given to ways for tāngata whaikaha Māori and whānau to have their voice heard. Crucially, there must be processes to act on what is heard.

- **Driving quality practice by focusing on what works**

The Putting People First report said that the Ministry should set out what quality practice and outcomes look like and monitor against it. Best practice should be actively supported including showcasing examples of good quality practice (Van Eden, 2013, p. 3). This includes peer review, developing and sharing new ideas, and providers working co-operatively with like-minded organisations to jointly develop and share resources, such as staff training.

- **Better complaints and issue resolution processes that influence change**

The Social Services Committee (2008) said that complaints processes should be made more accessible, including a pathway for verbal complaints. Putting People First (Van Eden, 2013) emphasised the need to ensure the safety of disabled people after laying a complaint. That report also called for timely and independent investigations of significant complaints using experts.

- **Improved data collection and outcomes measurement and reporting**

Contract performance monitoring reports should be focused on quality-of-life outcomes (Van Eden, 2013). Accountability would be promoted by making the evaluation of services readily available to the public (Social Services Committee, 2008). Drivers of exceptional performance should be identified, and key performance indicators designed around this to support positive behaviours and outcomes (Van Eden, 2013).

- **Safeguarding is paramount**

Putting People First (Van Eden, 2013) emphasised that there must be a policy of zero tolerance of the abuse of disabled people. It was seen that there is a need to ensure the legislation covering disabled people provides the necessary protection to keep disabled people safe from serious harm.

Quality measurement

Measuring the quality of services can be a difficult endeavour. There often isn't a universally accepted definition of what constitutes quality, how it should be measured, or how this process can help providers to make improvements. Emphasis should be placed on the impact that supports have on quality of life, supplemented by indicators that evaluate the structures and processes of services and providers.

There exists a body of literature on quality-of-life concepts and measurement. In New Zealand, developmental evaluation and quality-of-life survey tools have been co-developed with disabled people and whānau, grounded in EGL principles and relevant literature.

Little published on Indigenous approaches

There are limited publications on quality framework elements that are specifically relevant to Māori or other Indigenous peoples. One notable exception is a body of work from British Columbia (BC), Canada that identified nine core principles for an accessible and culturally appropriate complaints system (Health Quality BC, 2022).

There is a small (and growing) body of work that looks at the needs and aspirations of tāngata whaikaha Māori. Tāngata whaikaha Māori consider that quality services are accountable, accessible, and clearly communicated. The work of Ingham (2022) and others also emphasises the lack of cultural safety in many current services. There is a growing body of evidence on the use of cultural safety in health care as a dimension of ensuring quality at a practitioner and health organisation level.

The Australian NDIS experience

The National Disability Insurance Scheme (NDIS) was introduced in Australia in 2013 and provides funding directly to participants to choose their own providers.

The key regulatory functions proposed by the NDIS Quality and Safeguarding Framework were brought together under the independent NDIS Quality and Safeguards Commission (NDIS Commission). The NDIS Commission's role is to manage complaints about NDIS providers, improve the quality and safety of NDIS supports and services, regulate NDIS service providers and workers, and lead education, capacity building and development for disabled people, NDIS providers and workers.

Findings and recommendations from the NDIS review

An independent review into the NDIS was conducted in October 2023 (NDIS Review Panel, 2023). The review found that while the NDIS Commission developed important preventative and corrective mechanisms, the focus has almost exclusively been on regulatory arrangements. Not enough attention has been given to developmental supports, such as capacity building, support to strengthen natural safeguards, or supporting and encouraging providers to engage in quality improvement.

The review also found that the unanticipated growth of unregistered providers reduced the impact of preventative strategies and shifted responsibility for quality management back to participants, without enough investment in developmental strategies that would help support participants to make informed decisions.

The review has recommended expanding the coverage of the NDIS Commission, to include other Australian Government funded and commissioned disability supports. The review panel considered that expanding the Commission's coverage will provide consistent protections for disabled people accessing a range of supports, reduce regulatory burden for providers, and drive efficiencies. The review also recommended that a dedicated quality function be set up within the new Commission, to achieve a stronger focus on quality, including support to understand what good quality looks like and how to implement quality improvements.

A risk-proportionate model for the visibility and regulation of all providers

The review recommended a more graduated and risk-proportionate provider registration system, aiming to better prevent harm while continuing to support choice and control and enable a thriving provider market. The proposed model included four broad categories based on the risk associated with different types of supports and providers—enrolment (lowest risk with lightest touch requirements), basic, general and advanced registration (highest risk with greatest requirements). Proportionality could be achieved by simplifying practice standards where possible, recognising compliance in other regulatory systems, and using risk-based auditing and assessment approaches (NDIS Review Panel, 2023, pp. 178–179).

After the NDIS review, a taskforce provided advice on the design and implementation of a new provider regulation framework. The taskforce heard significant concerns that mandatory registration

for all NDIS providers would impact choice and control for participants, be costly or burdensome and limit or stifle innovation and different models of support. Features of the model proposed include:

- **Not all providers should be registered**
Providers that would not be required to be registered include providers of goods purchased off-the-shelf and providers supporting participants who self-direct their support.
- **A new self-directed support category**
NDIS participants self-directing their supports would register themselves with the NDIS Commission. Practice standards would not be applied to this category, but it would still be subject to review and auditing. NDIS participants under self-directed support registration would be required to have regular check-ins with the NDIS Commission.
- **Basic, general and advanced registration of other providers based on risk**
Worker screening and practice standards would only apply to the advanced and general registration categories (not basic registration).

Other regulatory frameworks

Other countries that we would compare ourselves to have legislation regarding disability service quality and safeguarding. For example, the English Care Act 2014 places a general duty on local authorities to promote the wellbeing of an individual receiving social care services. The Care Act says that where a local authority has reasonable cause to suspect that an adult in its area is experiencing, or is at risk of, abuse or neglect, and is unable to protect themselves, the local authority must make whatever enquiries it thinks necessary to be able to decide whether any action should be taken and, if so, what and by whom (Care Act 2014, 2015, Section 42).

Like the English legislation, the Wales Social Services and Well-being Act 2014 uses the concept of wellbeing. The Social Services and Well-being Act also imposes duties to give effect to certain key principles. Welsh ministers are required to issue a statement specifying the wellbeing outcomes that are to be achieved. The Act requires ministers to issue a code to help achieve the outcomes specified in the statement, which may include quality standards, performance measures and targets.

The Social Services and Well-Being Act has the same requirement and wording as the English Care Act relating to investigation where a local authority suspects that an adult with care and support needs is at risk of abuse or neglect. The Act provides for orders to authorise entry to premises so that an authorised officer of a local authority can assess whether an adult is at risk of abuse or neglect and, if so, what to do about it.

An evaluation of the Welsh Social Services and Well-Being Act found support for, and some positive impact of, its wellbeing principles, but identified that there can be a disconnect between legislative intent and operational reality.

In New Zealand, the recent report of the Royal Commission of Inquiry into Abuse in Care has made many recommendations, including legislation and a national care safety regulatory framework.

Some key points to take away

This report includes a large amount of material that can serve as a reference and input to the development of a revised, fit-for-purpose quality framework. Some key points include the following:

- A quality framework should contribute to the DSS commitment to the principles of Te Tiriti o Waitangi. Equity must be an overarching aim of the quality framework and impacts should be monitored.
 - There is a large body of work co-developed with disabled people and whānau that informs an EGL-based approach to quality. This work provides recommendations and tools that can be adopted.
 - Regulation may present as a solution to some problems, but it is costly, hard to get right and can detract from investment in important developmental approaches.
 - Enshrining principles in legislation can have a positive impact and legislation can set out obligations and powers to investigate and intervene when things may be going wrong.
- Design and delivery of a fit-for-purpose quality and safeguarding framework takes time and resourcing. A framework should be regularly revisited to ensure it remains fit-for-purpose and responds to the needs of the disabled people and whānau it serves.

1. Introduction

This research paper has been prepared by Sapere, with sections provided by Gabrielle Baker (sections 2.1 and 3).

1.1 About this paper

This paper is one input to inform the development of recommendations for an improved quality framework. It includes information from:

- a desktop review and targeted interviews to analyse the current state and opportunities for improvement
- a stocktake of existing work and reports relevant to quality and identification of findings and recommendations that remain relevant
- the findings from the literature on holistic, indigenous and Aotearoa New Zealand approaches to quality
- a literature scan of quality frameworks, regulation and mechanisms in overseas jurisdictions and other sectors.

The paper is organised into three parts:

- **Part one – foundations for a quality framework**
Part one sets out the pou (pillars) that underpin DSS's work. We discuss the principles of Te Tiriti o Waitangi and their implications for a quality framework. We set out the EGL principles and consider the ways in which a quality framework can support EGL system-change.
- **Part two – regulatory frameworks**
Part two describes the current authorising and legislative framework underpinning quality and safeguarding. We look at regulatory regimes in other countries, particularly Australia, and some features of regulatory arrangements in other sectors.
- **Part three – quality measurement**
Part three provides brief commentary from the literature on quality and outcome measurement within a broader quality framework.

1.2 Disabled people in New Zealand

Disabled people represent almost a quarter (24 per cent) of New Zealand's population—a large and diverse group of over one million people.

- Māori are the tāngata whenua of Aotearoa. Twenty-six per cent of Māori identified as disabled in 2013. Māori have a young population profile and when adjusted for age, the Māori disability rate is 32 per cent (Statistics New Zealand, 2015). We note that this is only part of the picture for tāngata whaikaha Māori, as there is a widely acknowledged gap in Māori disability research and

measurement of the impact of disability on Māori.¹ Tools for disability data collection are not culturally informed (Ingham et al., 2022).

- Pacific peoples make up a growing proportion of the country's population and of disabled people (19 per cent in 2013). Pacific peoples have a young population profile, and when adjusted for age, the Pacific disability rate is 26 per cent. Pacific peoples have the lowest median age of disability compared to other ethnic groups (39 years) (Statistics New Zealand, 2015).
- The employment rate for all disabled adults is 45 per cent, with an unemployment rate of 9 per cent. This contrasts with non-disabled adults who have an employment rate of 72 per cent and an unemployment rate of 5 per cent.
- 64 per cent of all disabled adults earn \$30,000 or less, compared with 45 per cent of non-disabled adults.
- 33 per cent of all disabled adults have no education qualification, compared with 15 per cent of non-disabled adults.

Tāngata whaikaha Māori experience unique and amplified challenges. Outcomes in education, employment, finance, justice, and accessibility signal the importance of recognising and developing a sophisticated understanding of the unique landscape of tāngata whaikaha Māori experiences of disability. Pacific peoples' considerations are also a material factor. A limited choice of culturally responsive disability services and negative traditional Pacific views of disability means Pacific peoples are under-represented in disability services.

1.3 A portion of the disabled population people receive DSS-funded disability support

Disabled people have the same rights as non-disabled people, to live a good life and fulfil their unique potential. New Zealand is not yet a non-disabling society,² so supports and services are, for many people, essential to navigating and overcoming barriers and achieving their goals and aspirations.

DSS commissions, and in some instances delivers through the Enabling Good Lives (EGL) sites, disability support services for people with a long-term physical, sensory disability, or autism that has been identified before the age of 65. DSS also commissions disability supports for people with an intellectual disability that has been identified before the age of 18. A proportion of disabled people—over 50,000 people—receive supports that are funded by DSS, funded by an approximately \$2.3 billion annual appropriation.

At the time of the last major review of the health and disability sector, around half of those using DSS-funded services had a principal impairment that is intellectual, around a quarter physical, and almost a quarter neurodiverse. The mix of people served is shifting towards those with higher needs and lower

¹ <https://www.hrc.govt.nz/resources/research-repository/te-ao-marama-disability-perspectives-tangata-whaikaha-maori>

² The New Zealand Disability Strategy's vision of a "non-disabling society" is 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).

average age, including a 20 per cent rise in the number of children of school age accessing support. The profile of needs and services used is markedly different for pre-school children, school age into young adulthood, and as adults of working age. Disability is reported among most people over 65, with access to home and community-based support and aged residential care among the supports and services more common for this age group (funded by Health New Zealand Te Whatu Ora).

Commissioning arrangements

Needs Assessment Service Coordination organisations (NASCs) work with disabled people to identify their strengths and support needs and outline what support is available.

DSS has around 800 contracts with over 470 disability support providers. Funded disability supports include equipment and modification services, personal care and household management supports, and residential 24/7 support, as well as supporting family caregivers. Support takes place across a range of settings, including communities, private homes, residential group homes and in specific circumstances in aged residential care (ARC) facilities.

Flexible funding (FF) gives disabled people and their whānau more choice in how they are supported to live their lives by providing them the option to purchase some disability supports themselves. Options for FF include individualised funding (IF), enhanced individualised funding (EIF), and Enabling Good Lives personal budgets (PB).

IF allows disabled people to purchase home and community support services and respite services themselves. Disabled people receiving IF manage their funding, purchase supports, become the employer of support workers, and are accountable for all expenditure (even if they appoint an agent to carry out some of these responsibilities).

IF is generally accessed through a NASC. The Ministry also contracts IF hosts to help disabled people organise, set up and manage their supports, administer payments, and manage their IF responsibilities. The Ministry is not a party to the relationship between an IF host and the disabled person.

Alternatively, disabled people living in Waikato, Christchurch or MidCentral can access IF through the EGL sites. Disabled people in these sites discuss their needs with an assigned connector and a budget advisor (and possibly other support) to agree how their 'good life plan' can be structured to meet their goals. This involves the allocation of a PB with which they can purchase disability supports. PB funding can be provided directly to the disabled person, with some oversight by the EGL team, or disabled people can choose a host (the same as with an IF host) to help them manage their personal budget.

1.4 The quality framework project

In early 2024 Whaikaha Ministry of Disabled People embarked on a quality framework project, commissioning Sapere to develop a quality framework based on an Enabling Good Lives (EGL) approach which:

- is fit-for-purpose for a transformed disability support system

- supports the vision and principles of EGL, including that disabled people can make choices and take risks (including making mistakes)
- provides different ways of ensuring the high quality of Whaikaha-funded disability supports and to keep disabled people safe from abuse and neglect (safeguarding).

In August 2024 Cabinet decided to transfer responsibility for commissioning disability supports to a new business unit within MSD, called Disability Support Services (DSS). Therefore, this project was transferred to DSS. The framework will need to determine the extent to which DSS is responsible for quality and safeguarding oversight and provide for the range of ways disabled people access their disability support, from centrally contracted providers through to situations where disabled people and their whānau are the purchasers of support (e.g. through a personal budget).

1.4.1 What is quality?

Quality disability supports are those that honour commitments under Te Tiriti o Waitangi,³ enable a good life and contribute to progressive realisation of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD).

In other words, quality disability supports:

- ensure disabled people have more choice and control over their lives and disability supports and achieve goals that are meaningful to them
- drive better, equitable outcomes for disabled people, tāngata whaikaha Māori, and Pacific disabled people
- provide a good experience for disabled people and whānau
 - are culturally safe, giving disabled people the power to be involved in decisions about their own care and give feedback without fear of bias, negative attitudes or assumptions, or prejudices from support providers
 - keep disabled people safe from abuse and neglect.

1.4.2 What is safeguarding?

Safeguarding is a broad concept, with the protection of the human rights of children and adults at risk at its core. Safeguarding is more than just protecting a person from harm—it also includes measures to promote and protect people’s human rights, health, wellbeing and culture, and to empower people to help themselves. DSS and the providers it commissions have a role to play in safeguarding disabled people and preventing abuse, neglect and restrictive practices (seclusion and restraint).

DSS describes abuse as physical abuse or assault, psychological or emotional abuse, financial abuse, and sexual abuse or assault. Neglect is categorised as grossly inadequate care, failure to provide access to medical care, supervisory neglect, reckless disregard of a person, or failure to protect from harm or abuse.

³ For a more in-depth discussion on Te Tiriti of Waitangi and quality DSS services see section 2.1.

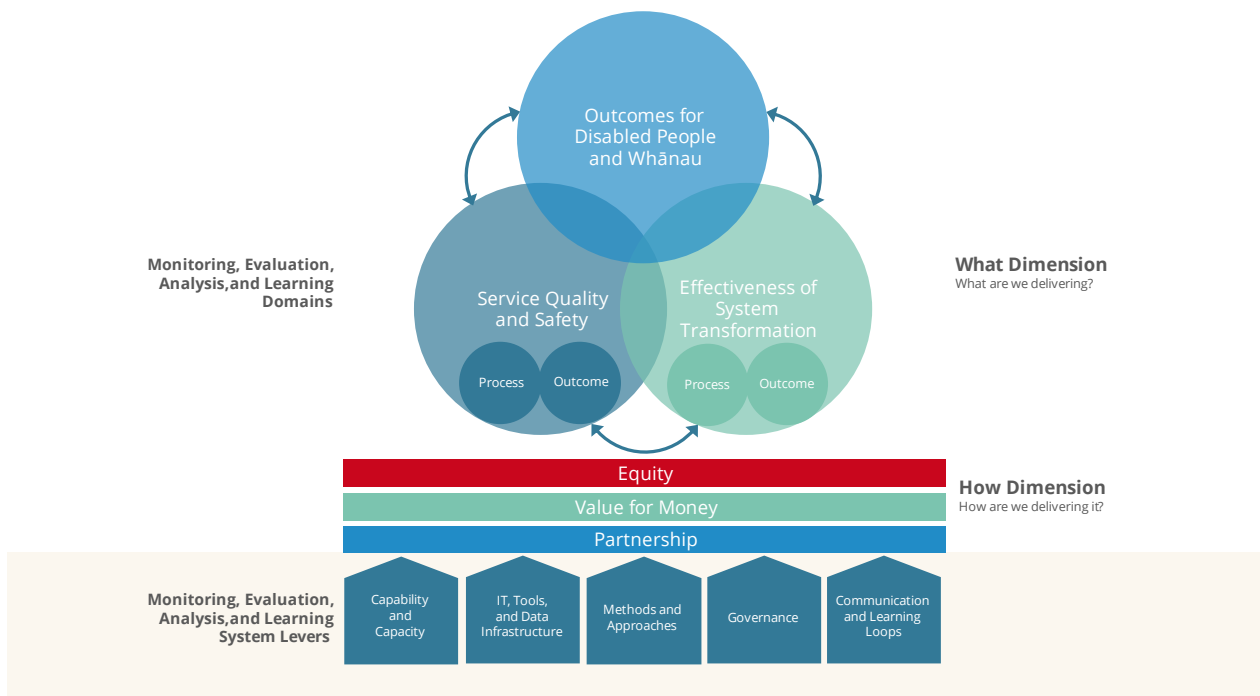
1.5 MEAL is the overarching umbrella

DSS’s Monitoring, Evaluation, Analysis and Learning Strategic Framework is the overarching umbrella for a quality framework. The MEAL framework promotes four key shifts (Whaikaha Ministry of Disabled People, 2023, p. 8). Quality systems, processes and activities can make an important contribution to realising these key shifts.

- Shift one – disability system monitoring, evaluation, analysis, and learning is led, designed, and conducted by and with disabled people, tāngata whaikaha Māori and whānau in partnership with the Crown.
- Shift two – disability system monitoring, evaluation, analysis, and learning approaches are guided by Te Tiriti o Waitangi.
- Shift three – disability system monitoring, evaluation, analysis, and learning provide a lever to create better outcomes for disabled people, tāngata whaikaha Māori and whānau.
- Shift four - disability system monitoring, evaluation, analysis, and learning use effective and appropriate tools and systems.

Service and safety is one of the key MEAL domains (Figure 1). An EGL-aligned MEAL system will provide greater accountability and critical information to disabled people and their whānau, enabling them to exercise control and improve the disability system through monitoring and evaluation processes, including quality processes.

Figure 1: Monitoring, Evaluation, Analysis and Learning domains



Source: (Whaikaha Ministry of Disabled People, 2023)

Part one: foundations for a quality framework

2. Three foundational pou

DSS's work, and any quality framework to be developed, is underpinned by three pou—Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disability, and the Enabling Good Lives principles.

2.1 Te Tiriti o Waitangi

This section is provided by Gabrielle Baker and explores how the development and operationalisation of a quality framework by DSS can contribute to the Ministry's commitment to the principles of Te Tiriti o Waitangi. It is based on published literature, government publications, opinion pieces and Waitangi Tribunal reports relevant to the health and disability systems.

There are five principles of Te Tiriti o Waitangi that are assumed relevant to disability because they were identified by the Waitangi Tribunal in its *Hauora* report (Waitangi Tribunal, 2023)—which related to primary health care—as part of the Health Services and Outcomes Kaupapa Inquiry (Wai 2575). The same Tribunal panel has not completed the disability phase of its inquiry, and it is possible they will amend or add to their list of relevant principles when they do. This reinforces the need for government agencies to constantly reflect on and, if necessary, change the way they are applying Te Tiriti o Waitangi principles in their work.

There are also some provisos when thinking about how to incorporate and meet Te Tiriti o Waitangi obligations through any government policy and implementation.

- An approach based on Te Tiriti principles is useful for understanding what the Crown can do to meet its obligations under Te Tiriti o Waitangi within the kawanatanga sphere. Applying the principles does not, however, represent the full expression of Te Tiriti o Waitangi. In other words, principles help with policy but don't necessarily address the constitutional issues of the relationship between Māori and the Crown.
- As important as the five principles identified in the *Hauora* report are, other principles have been used by the Courts and by government (Te Puni Kōkiri, 2001). It is, however, outside the scope of this paper to explore these.

2.1.1 The principles

Principle one: the guarantee of tino rangatiratanga

The guarantee of tino rangatiratanga as a principle of Te Tiriti o Waitangi is articulated in the *Hauora* report as providing “for Māori self-determination and mana motuhake in the design, delivery, and monitoring of primary health care” (Waitangi Tribunal, 2023, p. 180).

Cabinet guidance, though focused on an interpretation of Te Tiriti o Waitangi articles rather than principles, guides policy makers to reflect on whether proposals allow for the Māori exercise of rangatiratanga while recognising the right of the Crown to govern (Cabinet Office, 2019), and reflect on the following questions:

- Can/should the proposal or parts of it be led by Māori?

- What options/mechanisms are available to enable rangatiratanga?

The Cabinet guidance emphasises that Māori were guaranteed rangatiratanga and it is the duty of the Crown to respect the right of Māori to control decisions in relation to the things of value to them. There is limited guidance, however, on what options or mechanisms might be available to enable rangatiratanga outside of programmes (like Whānau Ora) where Māori organisations are funded to support whānau to have more control over the services they receive and build whānau strengths so that whānau are better able to achieve their own aspirations.

Academic writing on Te Tiriti o Waitangi and disability do not define the guarantee of tino rangatiratanga, but do indicate that action by the Crown under the banner of tino rangatiratanga is “nonperformative”—a concept developed by Sara Ahmed (2006) in the context of organisational anti-racism work. That is, the words used by the Crown (in its strategies, policies, public statements) in relation to rangatiratanga are rarely met with meaningful action because they conflate rangatiratanga with partnership or involvement on decision-making boards (Baker et al., 2021), they invisibilise the needs and aspirations of tāngata whaikaha Māori (King, 2019), or they are not based on the scholarly work of Māori academics or the practical experiences of kaupapa Māori disability providers (Came et al., 2022).

The principle of equity

The principle of equity is articulated in the *Hauora* report as requiring “the Crown to commit to achieving equitable health outcomes for Māori” (Waitangi Tribunal, 2023, p. 180). The Tribunal has also stated:

- “The principle of equity broadly guarantees freedom from discrimination, whether this discrimination is conscious or unconscious” (Waitangi Tribunal, 2023, p. 34).
- “A policy or service that establishes equal standards of treatment or care across the whole population may still result in inequitable outcomes for Māori” (Waitangi Tribunal, 2023, p. 34)—that is, that equity is not the same as equal access to services.

The main actions required of government agencies in response to the principle of equity include:

- identifying and eliminating discrimination of any kind in policy proposals and implementation
- stating, unambiguously, that equity is an outcome (in contrast to saying that a reduction in inequity is the objective) (Waitangi Tribunal, 2023)
 - collecting high quality disability and ethnicity data that is informed by tāngata whaikaha Māori understandings of disability, is made public, easily understandable, and accessible (subject to relevant legislation) (Waitangi Tribunal, 2021)
- having mechanisms in place to ensure that data is routinely monitored by ethnicity.

In the context of disability, the principle of equity compels a focus on the intersection between racism and ableism which impacts tāngata whaikaha Māori. This intersection amplifies inequitable access to the determinants of health and well-being and to health and disability care (Ingham et al., 2022).

Access to health and disability support and the lack of data available to DSS has been regularly raised in the evidence presented to the Waitangi Tribunal as part of the disability phase of Wai 2575, including evidence that “government in-depth surveys and other government datasets do not allow us to count the number of tāngata whaikaha Māori in New Zealand, nor do they allow us to provide

explanations for why inequities for tāngata whaikaha Māori persist, or how these inequities can be eliminated” (McGregor et al., 2023).

The principle of active protection

The principle of active protection requires the Crown to “act, to the fullest extent practicable, to achieve equitable health outcomes for Māori. This includes ensuring that it, its agents, and its treaty partner are well informed on the extent and nature of both Māori health outcomes and efforts to achieve Māori health equity” (Waitangi Tribunal, 2023, p. 34). In practice, active protection and equity are closely related, but the emphasis for active protection is more on the actions (rather than aspirations or targets) that agencies put in place to ensure equitable outcomes, and the advancement of Māori needs and aspirations.

Active protection requires government agencies to implement policies and programmes that adapt to different needs and preferences of tāngata whaikaha Māori. As the Waitangi Tribunal has said:

“A ‘one size fits all’ model tends in practice to suit the needs of the majority, who are rarely the group most in need of help” (Waitangi Tribunal, 2001, p. 175).

Active protection is demonstrated by tangible systems and processes to achieve equity (Baker et al., 2021). These can include:

- prioritising Māori outcomes (Waitangi Tribunal, 2023, p. 33)
- “provid[ing] resources or programmes” to appropriately ensure services to Māori (Waitangi Tribunal, 2001, p. 53)
 - closing the gaps between Māori and non-Māori outcomes (Waitangi Tribunal, 2015)
 - taking a culturally safe approach that recognises different approaches may need to be employed to be effective for Māori (Waitangi Tribunal, 2001, p. 175)
- ensuring equitable funding, for example in funding formulae and commissioning approaches (Baker et al., 2021)
- interrogation of data, especially by ethnicity (Bevin et al., 2023), in line with the principles of Māori data sovereignty (Te Kāhui Raraunga, 2023).

The principle of options

The principle of options requires the Crown to provide for and properly resource kaupapa Māori services, and ensure that its own mainstream services are culturally appropriate and recognise that for Māori, wellness and health are holistic concepts (Waitangi Tribunal, 2023, p. 180). In the Napier Hospital and Health Services Report, the Waitangi Tribunal also sees this principle as about Māori having “the right to choose their social and cultural path” (Waitangi Tribunal, 2001, p. 65).

At a system level, this principle reinforces the need for:

- equitable funding to Māori providers, which in turn requires a knowledge of who is a Māori provider, and what services they offer
 - cultural safety in all services, including mainstream services⁴

⁴ For a discussion on cultural safety, see Curtis et al. (2019).

- Māori individuals to have equal and fair protections wherever they access services, be that through Māori-led or mainstream providers (Waitangi Tribunal, 2021, p. 44).

A central issue with the way the Crown has expressed the principle of options in the context of disability is the lack of focus on kaupapa Māori disability support services, with only 3.4 per cent of disability support providers identifying as Māori-owned and Māori-governed in 2018 (King, 2019). When asked in April 2024 through the Waitangi Tribunal process if these figures had been updated, Crown officials noted that they “do not currently have a systematic way of identifying kaupapa Māori providers.”⁵

The principle of partnership

The principle of partnership requires the Crown to work with Māori “in partnership in the governance, design, delivery, and monitoring, of primary health services” (Waitangi Tribunal, 2023, p. 180).

While there is a substantial body of legal research on what this concept means to the wider relationship between the Crown and Māori, the Tribunal has noted that when it comes to state policy a central concept is that the Crown consult and partner with Māori genuinely, and that to do so the Crown must be willing to work through structures that Māori prefer in the circumstances, whether that be through iwi, hapū, whānau or some other organisation (Waitangi Tribunal, 2023, p. 28).

The expression of partnership is situation specific—sometimes it might be at a system level (how Māori and the Crown can partner on the design and operation of the health system for example) or at the level of a specific project or contract for services.

Examples of applying the principle of partnership include:

- the State providing “logistical and financial support and the Māori treaty partner exercising decision-making responsibility” (Waitangi Tribunal, 2011, p. 559)
- the creation of Māori entities to take responsibility for areas of government spending or implementation,⁶ or to monitor aspects of government performance⁷
 - consultation with Māori, in a way that does not “simply present Māori with its [the Crown’s] own solutions” (Waitangi Tribunal, 1999, p. 659)
 - governance arrangements that allow for Māori to have equal decision-making power over projects or organisations (Joseph & Benton, 2021)
- constant evaluation of actions that support partnership. The Waitangi Tribunal says, for example, that statements on the importance of engaging with Māori groups breach Te Tiriti o Waitangi principles if this commitment had not been realised through actual engagement.

While there are several calls for co-design with Māori as a way to achieve partnership, research evidence emphasises the need for caution when it comes to the use of this as a methodology to

⁵ Appendix 9, Tesoriero and Sarfati evidence L17 (2024).

⁶ As was the case for Whānau Ora commissioning agencies, or the former Māori Health Authority (Te Aka Whai Ora).

⁷ Te Ao Mārama Aotearoa (TAMA) is an example of this within the disability sphere when it was first set up (although it has since evolved into an independent entity), as are Iwi-Māori Partnership Boards established under the Pae Ora (Healthy Futures) Act 2022.

address Indigenous issues. In particular, there is a lack of clarity about what is meant by co-design and what it means to co-design ethically (King, 2021). While many of those in support of co-design have hopes that it is a part shift in power or move towards power sharing (which is a minimum requirement of the principle of partnership), this doesn't appear to happen in practice (King et al., 2022).

2.1.2 Implications for a quality framework

Applying the principles of Te Tiriti o Waitangi is not a tick-box exercise. It requires thoughtful consideration in design, implementation, and monitoring of policy-decisions. However, as a starting point, there are several considerations that must be addressed throughout the development and implementation of a quality framework for DSS.

The guarantee of tino rangatiratanga

- Strong engagement during the development of a quality framework so that DSS is well informed of the needs and aspirations of tāngata whaikaha Māori and their whānau and hears from them directly.
- Supporting Māori-led approaches to both the engagement with Māori on the quality framework, and to the implementation of the quality framework itself. Are there aspects that could be Māori-led? How could complaints resolution be Māori-led, if that was preferred by tāngata whaikaha Māori and their whānau?
- Ensuring that Māori scholarship and thinking on disability (and disability support services) and quality are identified and included in all thinking.

The principle of equity

- Making it clear (e.g. through contracts and public statements) that there is an expectation of no discrimination for anyone entitled to disability support services (which includes no ableism or racism in the way services are designed and delivered).
- Identifying equity as an overarching aim of the quality framework and monitoring the impact of the quality framework on tāngata whaikaha Māori, including the access or lack of access to the wider determinants of health and wellbeing.
- Having mechanisms in place to ensure that data, including data on complaints and use of the quality framework, is routinely monitored by ethnicity.

The principle of active protection

- Identifying and understanding where there might be gaps or issues through the quality framework that could exacerbate or maintain inequities, including an understanding of how the framework ensures Māori individuals have fair and equal protections regardless of how they access disability support services.
- Understanding the unintended consequences of a quality framework—including who will benefit from the framework and what can be done to minimise the negative unintended consequences and amplify the positive consequences (see the Health Equity Assessment Tool (Signal et al., 2008)).
- Appropriately resourcing Māori-led or Māori-focused elements of the quality framework. This might mean additional resource to support Māori-engagement on the framework once it is up

and running, or having aspects of the quality framework that are focused on Māori needs and aspirations.

- Flexibility in a way that enables a culturally safe approach to disability support services provision, including effective communication around the roll out of a quality framework and how tāngata whaikaha Māori and their whānau can engage with the framework.
- Ensuring equitable funding of services from the outset, for example in funding formulae and commissioning approaches.
 - Interrogation of data collected through the framework, especially by ethnicity, in line with the principles of Māori data sovereignty.

The principle of options

- Equitable funding to Māori providers, which in turn requires a knowledge of who is a Māori provider, and what services they offer.
- Concepts of quality to include an understanding (and expectation of) cultural safety in all services, including mainstream services, and high standards of cultural safety by all those working for DSS. Lessons on this approach could be taken from Ngā Paerewa Health and Disability Service Standard (Standards New Zealand, 2021).
 - While there needs to be flexibility and a ‘one size fits all’ approach avoided, Māori individuals should have equal and fair protections wherever they access services, be that through Māori-led or mainstream providers.

The principle of partnership

- Consultation with Māori, in a way that does not “simply present Māori with its [the Crown’s] own solutions” (Waitangi Tribunal, 1999, p. 659).
- Governance arrangements that allow for Māori to have equal decision-making power in the decisions on the quality framework (while the insights alliance plays a role in this during the development, part of the commitment to partnership is exploring whether this is the best arrangement for the oversight of the framework once it is in place).
- Engagement with tāngata whaikaha Māori groups in the monitoring of the quality framework once it is implemented.
- Constant evaluation of the effectiveness of actions undertaken in support of partnership.

2.2 United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international human rights treaty that sets out what is required to implement existing human rights as they relate to disabled people. It covers civil and political rights to equal treatment and freedom from discrimination, and social and economic rights in areas like education, healthcare, employment and transport. New Zealand was a leader in negotiating the UNCRPD including having representatives from the disability sector in the delegations to the United Nations. The Government ratified the UNCRPD in 2008.

New Zealand has an Independent Monitoring Mechanism (IMM), as required by Article 33(2) of the UNCRPD. The IMM independently monitors how the UNCRPD is implemented. The IMM partners are the Disabled People’s Organisation (DPO) Coalition, the Ombudsman, and the Human Rights Commission. In addition to whole-of-IMM work, IMM partners have autonomous roles to promote, protect and monitor disability rights in Aotearoa. The IMM make-up reflects Article 4(3) of the Disability Convention, which provides that decision-making processes affecting disabled people should actively include them.

The most recent IMM report identified issues relevant to quality including inconsistent and lack of data collection “preventing agencies from identifying and resolving the issues disabled people face. Where data and evidence is available, agencies are not consistently using this to inform disabled people’s needs or changes in ... service evaluation methodologies” (DPO Coalition, Ombudsman, Human Rights Commission, 2022, p. 7). The IMM also highlighted that disabled people have the right to access information in a way they can understand and pointed out that the digital divide needs to be recognised and understood, in order to be overcome (DPO Coalition, Ombudsman, Human Rights Commission, 2022, p. 23).

2.3 Enabling Good Lives

Between 2008 and 2013, hundreds of disabled people and their families contributed to the development of the EGL approach. The EGL approach is about disabled people and their families being able to direct their own lives, having supports that make things easier and having the ability to influence the system. The EGL approach overlaps with the Whānau Ora approach. It supports that all services and supports become appropriate for tāngata whaikaha Māori, and also that some things are developed by Māori for Māori (Enabling Good Lives, 2024).

The EGL principles are the basis of the approach. A principles-based approach is flexible, meaning that anyone can use them and work out what EGL looks like for them.

Box 1: EGL principles

Self-determination

Disabled people are in control of their lives

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural support; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

Person-centred

Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

Ordinary life outcomes

Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

Mana enhancing

The abilities and contributions of disabled people and their families are recognised and respected.

Easy to use

Disabled people have supports that are simple to use and flexible.

Relationship building

Supports build and strengthen relationships between disabled people, their whānau and community.

Changes are being made to the disability support system based on the EGL approach but will take time to roll out across the country. EGL-based system changes include the:

- role of an independent ally to help disabled people, their family and whānau to consider existing options and create new possibilities.
- creation and purpose of a 'good life plan,' which paid supports can be measured against
- use of flexible budgets where people can choose how they create a good life for themselves.

An important part of the EGL approach is that, as well as building new ways of doing things, disabled people have ways to check that it is working well for individuals, families and communities (i.e. check quality and outcomes).

2.3.1 How a quality framework can support EGL system change

The MEAL Strategic Framework described how an EGL-aligned approach embeds strengths-based approaches to monitoring and evaluation (Whaikaha Ministry of Disabled People, 2023, p. 7). In relation to quality, there needs to be:

- independent autonomous voice mechanisms for feeding the voice of disabled people into system improvement
- better complaints and issue resolution processes, with timely feedback loops and evidence of how those processes influence change
 - EGL-aligned developmental evaluation approaches and associated methodologies
 - improved data collection and outcomes measurement and reporting.

Disabled people have contributed to a number of seminal reports that have made recommendations about an EGL-based approach to quality. Many of the recommendations remain relevant today. This body of work represents a significant contribution by many disabled people and whānau, over many

years, and is an important starting point for information gathering. Some of the emerging themes and recommendations are summarised below.

The use of developmental evaluation

A developmental approach to evaluation of disability services in New Zealand has a history that spans back to the 1990s. Key elements of developmental evaluation, as described by the “Mid-Point” Developmental Evaluation Handbook (Ministry of Health, 2013), include:

- a multi-perspective approach
- service users are primary contributors to the evaluation
- disabled people and family have key roles in conducting the evaluation
- evaluation seeks to determine effectiveness
 - evaluation is framed as a constructive and collaborative process
- evaluation seeks to promote and cultivate excellence.

Many reports have called for a comprehensive developmental evaluation process as a core development and safeguarding approach.

- The Select Committee (Social Services Committee, 2008) noted its preference for developmental evaluations: development of disability standards, with appropriate outcomes-focused evaluation processes; ensuring that quality-of-life is measured and valued by giving people with disabilities and their families a significant role in the monitoring process.
- A single, outcomes-focused developmental evaluation approach was recommended in the EGL Canterbury Report (Boxall & Benjamin, 2012, p. 31): self-review by services and independent evaluations against the principles of Enabling Good Lives.
- The Putting People First report (Van Eden, 2013) recommended that the certification audit and developmental evaluation process be replaced with an enhanced developmental evaluation and comprehensive coverage across residential services.
- The Safeguarding Framework for the [EGL] prototype in MidCentral (Safeguarding Working Group, 2018) noted that a developmental evaluation approach supports a ‘try-learn-adjust’ approach being adopted by EGL MidCentral. Evaluators should be independent, have lived experience of disability (including whānau) and an excellent analysis of power and control and the dynamics of abuse of disabled people.

Capturing and responding to the voice of disabled people

The Machinery of Government Review Working Group’s 2019 paper *Mana, Self-determination and Voice* (Machinery of Government Working Group, 2019) provided guidance for how the voices of disabled people could be incorporated into system design.

- Voice is about capturing the voices of individuals and the collective, in an ongoing way. The collective is particularly important when people are not able to express their individual voice and rely on the power of the collective. Putting People First also said that the system needs to ensure those people who cannot represent themselves have others to do it for them.

- Voice mechanisms help build the capacity of disabled people and enable them to have self-determination and more control of their lives. The Select Committee also highlighted the need for building community capacity and support (Social Services Committee, 2008).
- Voice mechanisms can help disabled people share their experiences and raise issues with current support arrangements. Mechanisms should be available to allow voice to be heard through multiple different channels. People must have the autonomy to choose what best suits their individual needs and preferences.
- Specific regard should be given to ways for tāngata whaikaha Māori and whānau to have their voice heard. Māori concepts of disability and attitudes towards disability are intertwined with other concepts, beliefs and values such as whanaungatanga, āwhinatanga and manaakitanga, and there is a contrast between individualistic Western views of disability and Māori holistic concepts of hauora (Machinery of Government Working Group, 2019, p. 3).
- Crucially, there must be processes to act on what is heard through voice mechanisms. The Machinery of Government Working Group pointed out that new arrangements must actively listen, respond and justify decisions (Machinery of Government Working Group, 2019, p. 8).

The voice of disabled people was a key theme of the Putting People First report. In relation to quality and complaints processes, the report highlighted the need for disabled people to be able to speak out without fear of retribution. It recommended the creation of a support role—a group of trusted people who would build relationships with disabled people and support them to stay safe and speak out when needed.

Driving quality practice by focusing on what works

Putting People First said that the Ministry should set out what quality practice and outcomes look like and monitor against it. Best practice should be actively supported including showcasing examples of good quality practice (Van Eden, 2013, p. 3).

This includes peer review, developing and sharing new ideas, and providers working co-operatively with like-minded organisations to jointly develop and share resources, such as staff training. This concept of (resourced) communities of practice, with each organisation contributing to and supporting the others, was also recommended by the Royal Commission of Inquiry into Abuse in Care (Royal Commission of Inquiry into Abuse in Care, 2024).

Performance monitoring, management and accountability

Many findings and recommendations have been made, based on the input from disabled people, across several reviews and reports.

- DSS has a key role in setting direction and clearly defining and communicating what high standards of performance look like. The need for high-cost performance monitoring systems diminishes as providers put disabled people at the centre of their service and strive for excellence (Van Eden, 2013).
- Contract performance monitoring reports should be focused on quality-of-life outcomes, as well as challenges experienced, and improvements being put in place by service providers (Van Eden, 2013).

- Accountability would be promoted by making the evaluation of services readily available to the public, ensuring privacy of individuals is preserved (Social Services Committee, 2008).
- Drivers of exceptional performance should be identified, and key performance indicators (KPIs) designed around this to support positive behaviours and outcomes (Van Eden, 2013). Putting People First also cautioned that KPIs should reflect drivers of performance, not just the easily measurable.
 - Complaints process should be made more accessible by creating a pathway for verbal complaints about disability support to be lodged (Social Services Committee, 2008).
- The safety of disabled people after laying a complaint should be ensured, by: (i) removing the alleged perpetrator from contact with the disabled person if there is potential for that person to be re-harmed in any significant way, and (ii) providing supports that will enable them to overcome the effects of being abused (Van Eden, 2013, p. 15).
- There should be timely and independent investigations of significant complaints using experts (e.g. communicating with disabled people with cognitive impairments, knowledge and expertise relating to abuse, clinical knowledge, legal expertise). Investigation teams could also include appropriately skilled disabled people with a lived experience of the issues or abuse involved (Van Eden, 2013, p. 16).

Safeguarding is paramount

There must be a policy of zero tolerance of the abuse of disabled people (Van Eden, 2013, p. 13).

The Putting People First report noted that the Crimes Act and Domestic Violence Act⁸ might not always be applied due to lack of clarity or not meeting police thresholds. It was seen that there is a need to work with the Ministry of Justice to ensure the legislation covering disabled people provides the necessary protection to keep disabled people safe from serious harm (Van Eden, 2013, p. 17).

Commitment to an EGL-based approach takes resourcing

- Putting People First described the Ministry of Health (DSS Directorate) as “an organisation that is running to catch up with itself” (Van Eden, 2013, p. 4). The organisation was working on a large number of initiatives to deliver future improvements to the sector but without sufficient resources to keep services safe.
- The Ministry, and wider system, needs to be resourced to focus on the things that matter and maintain relationships.
 - Beyond the Ministry, both the Select Committee report and Putting People First recommended that there needed to be greater collaboration and information sharing between Government agencies responsible for disability support (Social Services Committee, 2008). There should be formal protocols and clear roles and responsibilities around sharing information, making joint decisions, and designing the processes to be followed when working jointly on a case (Van Eden, 2013).

⁸ Replaced by the Family Violence Act 2018

3. Indigenous approaches

This paper's aim was to identify areas for further investigation in the development of the quality framework, and it is not meant as a comprehensive review of quality, disability support, or Māori (or Indigenous) disability. This section is authored by Gabrielle Baker.

The web-based searches included academic databases and targeted searches of the websites of a selection of government agencies (Health Quality and Safety Commission | Te Tāhū Hauora, Te Whatu Ora, The Ministry of Health, and Whaikaha). Initially, key search terms were limited to terms directly relevant to the development of the quality framework (quality, framework, disability support, disabled people, Māori, tāngata whaikaha Māori, kapo Māori, tāngata turi, and whānau hauā). Following advice from researchers involved with Te Ao Mārama research programme (Otago University, Wellington), this was broadened to include a look at a wider range of service areas (including mental health services), as these might have insights for disabled Māori (mental health being a term many Māori with lived experience of disability relate to). The searches also looked at efforts to improve quality for Indigenous peoples with lived experience of disability in other jurisdictions (especially Australia and Canada).

In total, 35 documents were reviewed, a mixture of published academic articles, commissioned reports (usually commissioned by health agencies), tribunal findings (specifically the Waitangi Tribunal in Aotearoa), and government reports.

3.1 There is little published on quality framework elements that is directly relevant to Māori or other Indigenous peoples

Our review found no articles published on disability services and quality frameworks written with a focus on Indigenous populations. There were, however, some documents on primary health care. Specific to Aotearoa, the Waitangi Tribunal found several breaches in the application of the principles of the Treaty of Waitangi by the Crown in its 2019 report *Hauora* (Waitangi Tribunal, 2019). It recommended a set of five principles be adopted (see section 2.1.1). The Tribunal has also put the spotlight on the lack of disability data relevant to tāngata whaikaha Māori in relation to the roll-out of the Covid-19 vaccination programme (Waitangi Tribunal, 2021).

3.2 There are few examples of other jurisdictions critically examining quality issues from an Indigenous disability perspective

Looking Internationally at frameworks for disability or mental health, there are still few examples of jurisdictions showing how they have appropriately dealt with issues for Indigenous disabled peoples.

The few examples that were found could be considered nonperformative, in that they assert a specific population is important but do not translate this to meaningful action. For example, a Canadian review of mental health in primary health care settings states at the outset “unfortunately, meaningfully and

respectfully engaging with Indigenous knowledge keepers turned out to be beyond the capacity of this project” (Sunderji et al., 2019, p. 6). There was another example of Indigenous groups having a single seat at the table, but this was seen as separate from the ‘consumer voice.’ This was seen in a quality improvement initiative for case management in Australia where an Indigenous community worker was appointed as a representative on a guidelines approval group, as being a way of reflecting Indigenous needs and aspirations (Davies, 2015).

While in this case it was seen as “pivotal to the process” (Davies, 2015, p. 20), the lack of Aboriginal and Torres Strait Island disabled people on the group raises considerable questions about its effectiveness as a voice mechanism. Similarly, the level of impact of this group for Aboriginal and Torres Strait Island populations is minimal, with the only example given being the ability for Aboriginal clients to bring an Aboriginal support worker to an initial assessment.

3.2.1 Improving complaints processes for Indigenous populations

An exception to this general pattern is a body of work in British Columbia (BC), Canada following an investigation into Indigenous-specific racism in the healthcare system. Among other things, this investigation identified the need for an accessible and culturally appropriate complaints system. In response, Health Quality BC and the BC Ministry of Health held a “day of dialogue” to explore how to improve the complaints system. This identified nine core principles (Health Quality BC, 2022), outlining that a complaints system should:

- be grounded in Indigenous rights, cultural values, and traditional protocols (which includes an emphasis on cultural safety)
- be Indigenous patient- and family-centred (which aims to build trust and diminish the power imbalance usually at play)
- take a restorative and accountable approach (including building an understanding of the causes of the harms)
- remove unnecessary barriers to engaging in the patient feedback process (noting Indigenous people have found feedback processes inaccessible)
- be trauma- and violence-informed (including understanding intergenerational trauma)
- include Indigenous people in leadership and positions supporting the patient feedback process
- be responsive and provide clear, timely feedback (including asking Indigenous patients and families what information they want communicated and any language or terminology preferences they have)
 - provide Indigenous patients and families with an Indigenous support person
- provide an opportunity for Indigenous patients to identify their Indigenous/Aboriginal ancestry (i.e., self-identification).

3.3 Tāngata whaikaha Māori consider that quality services are accountable, accessible, and clearly communicated

The rapid review found a small (and growing) body of work that looks at the needs and aspirations of tāngata whaikaha Māori. For example, Ingham et al. (2022) provide a thematic analysis of interviews

with tāngata whaikaha Māori, which includes “differential quality of health and disability care” as a theme. The article includes direct quotes from interviews that highlight issues around lack of accountability, lack of clear information, and a mono-cultural approach to services. The following four quotes are given as examples from the article (Ingham et al., 2022):

“Lack of accountability as well, I think that that’s really all wrong. Māori who have reached out for disability help but not got it, and then they have [negative] consequences. They [health professionals] should be held accountable.” (participant)

“No one told us our [disability] entitlements, we would just go through [the whole process] without knowing what we are entitled to.” (participant)

“[Disability] providers, they run on the Pākehā, white, Western culture; not te ao Māori.” (participant)

3.4 Cultural safety is centrally important to quality disability support services

The work of Ingham (2022) and others also emphasises the lack of cultural safety in many current services. As one interview participant put it:

“Well actually the only time I become fricking disabled is when I’m accessing Pākehā services, you know, or the environment.” (participant)

This has been commented on and raised as an issue for tāngata whaikaha Māori for decades. A 2004 report on tāngata whaikaha Māori and disability support options interviewed Māori with lived experience of disability and found the most frequently commented on area for improvement was the need for more culturally sensitive staff and providers, and access to more Māori-centred activities (Nikora et al., 2004). These calls for culturally appropriate services have continued since 2004, within the disability system (Tupou et al., 2021), health care (Hale et al., 2018), and other sectors, for example education (Fortune, 2013).

There is a growing body of evidence on the use of cultural safety in health care as a dimension of ensuring quality at a practitioner and health organisation level. This body of work was initiated by Māori nurses in the 1990s (Ramsden, 2002) and continued by other Māori health professionals (e.g. (Curtis et al., 2019)), and internationally (e.g. (Lavery et al., 2017)). It also includes work by the Health Quality and Safety Commission to develop a cultural safety question set for inclusion in their patient experience surveys (Health Quality & Safety Commission, 2021).

Curtis et al. (2019) recommend the following definition of cultural safety:

“Cultural safety requires healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided. In doing so, cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing

culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity. Cultural safety requires healthcare professionals and their associated healthcare organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment.”

3.5 Quality improvement needs to be informed by the need for sustainable kaupapa Māori providers

The final topic area the rapid review identified was the impact of quality improvement activities on Indigenous providers.

The need for kaupapa Māori disability support services has been acknowledged by tāngata whaikaha Māori (McGregor et al., 2023) and by research commissioned by the Waitangi Tribunal (King, 2019), which found that only 33 of the 980 (at that time, Ministry of Health-funded) disability providers identified as Māori-owned and Māori-governed.

As Ingham et al. (2022) state:

“...our results indicate that the lack of access to kaupapa Māori providers creates a barrier to accessing levels of care and disability support that meet their needs, build connections (to communities, to whānau, and to culture) and support their aspirations.”

In 2021, Darr et al. also published a thematic analysis of papers on Australia and New Zealand primary health care to look at quality management in relation to the Aboriginal Community Controlled Health Service Sector (Darr et al., 2021). That analysis is more focused on individual practices/organisations rather than whole-of-system quality, but it highlighted the need to holistically measure the quality of care delivered by clinical teams and the need to avoid overburdening providers with “compliance standards and extraneous operating expenses at the cost of delivering quality health services” (Darr et al., 2021, p. 8).

Part two: regulatory frameworks

4. The current authorising and legislative framework underpinning quality and safeguards

The legislative framework for monitoring quality and safeguarding of people receiving DSS-funded disability supports in Aotearoa New Zealand is currently set out across several Acts and regulations. Key parts of the regulatory framework include:

- The **Pae Ora (Healthy Futures) Act 2022** which hosts the legislative basis for the New Zealand Disability Strategy 2016–2026.
- The **Health and Disability Services (Safety) Act 2001** which promotes the safe and quality provision of health and disability services to the public, including by setting standards and auditing performance.
- The Ngā Paerewa Health and Disability Services Standard (Ngā Paerewa), a standard under the Health and Disability Services (Safety) Act 2001, sets the minimum necessary requirements for fair and equitable health and disability services, including for restrictive practices. Residential disability services (with five or more beds) and aged care facilities that deliver 24/7 care for disabled people are required to meet and maintain certification under Ngā Paerewa.
- The **Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003** (IDCC&R) which provides a system for the compulsory care and rehabilitation of persons who have an intellectual disability and who have been charged with, or convicted of, an imprisonable offence in specific circumstances.
- The **Health and Disability Commissioner Act 1994** which promotes and protects the rights of health consumers and disability service consumers by establishing the Health and Disability Commissioner (HDC), a Code of Health and Disability Services Consumers Rights (the Code), a Consumer Advocacy Service, and investigations into complaints.

None of these Acts are administered by DSS, making the Ministry reliant to some extent on the exercise of functions by other agencies to monitor the quality of the services it funds, and the safeguarding of disabled people under these Acts. There can be confusion around different agencies' roles and sometimes overlapping responsibilities.

4.1 How DSS currently checks the quality of services it commissions

As the commissioner and funder of disability supports, DSS has a responsibility to ensure those support services are high quality and are keeping disabled people safe from abuse and neglect (safeguarding). At present, the key mechanisms to monitor quality that are covered in the contracts between DSS and disability support providers are:

- receiving and managing critical incident reports for all DSS contracted services

- receiving and managing notifications of deaths of disabled people in DSS-funded residential care
- auditing, evaluating and investigating DSS contracted providers
 - managing complaints about the quality of DSS contracted disability support.

Some of these contracts are also covered under Ngā Paerewa Health and Disability Services Standard administered by the Ministry of Health Manatū Hauora.

There is limited ability to ensure safeguarding and safety of disabled people and quality of support for disabled people accessing disability support through individualised funding or personal budgets.

4.1.1 New steps being taken to improve quality and safeguarding

During 2022–2024 Whaikaha set up new quality and safeguarding initiatives to build the voice and safety of disabled people (note responsibility for these new initiatives transfers to DSS in December 2024):

- a community-led **Disability Abuse Prevention and Response (DAPAR)** team that responds to disabled people experiencing violence or who are unable to protect or remove themselves from abusive situations because of their need for disability support.
- The **People for Us** service will be staffed by disabled people, tāngata whaikaha Māori and whānau. It will work with disabled adults in residential services to help people with concerns connect to the right support pathways. The intention is that, over time, People for Us will expand beyond residential services.
- **Assisting Change** will provide targeted developmental support to providers who support the most at risk disabled people, and those identified to have a pattern of quality issues and who wish to develop their service in line with the EGL principles.

5. Royal Commission of Inquiry into Abuse in Care

The Royal Commission of Inquiry into Abuse in Care was the largest and most complex Royal Commission of Inquiry ever established in New Zealand. The Inquiry was asked to investigate the abuse and neglect of children, young people and adults who were in the care of state and faith-based institutions between 1950 and 1999. The Inquiry recognised the disproportionate representation of Māori and Pacific peoples in care and focused on the experiences of Deaf and disabled people who were abused in care.

The Inquiry found that leaders of state and faith-based institutions failed in their duty to nurture and protect the people in their care and failed to hold abusers to account. An estimated 200,000 children, young people and adults in care were exposed to pervasive abuse and neglect (Royal Commission of Inquiry into Abuse in Care, 2024).

Deaf and disabled people experienced abuse, were denied personhood and were often stripped of their dignity and autonomy. For tāngata whaikaha Māori, abuse was compounded by racism. They were denied access to their ability to practice mātauranga, tikanga, reo Māori, and the ability to connect to their whakapapa. Pacific peoples also experienced racial abuse and cultural neglect.

Care standards were inconsistent and routinely breached, workers were often inadequately vetted, trained or supervised, only some care settings had complaints processes and, when people did complain, they were often not believed. Complaints were not appropriately acted upon and there was limited independent oversight or monitoring of state and faith-based care.

The Inquiry found that many of the factors that contributed to the abuse and neglect persist, and its report says that fundamental changes are needed to safeguard people who are in care today.

5.1 The Inquiry made significant recommendations

The Inquiry made 138 recommendations, many of which have implications for DSS's quality and safeguarding approach.

Notably, the Inquiry recommended a new Care Safety Act and include any legislative measures required to establish a national care safety regulatory framework and give effect to the Inquiry's recommendations. The proposed Care Safety Act would:

- embed **12 Care Safety Principles** that people and organisations should be guided by when making decisions, performing functions, or exercising powers and duties in relation to people in care
- require a comprehensive **National Care Safety Strategy** on the prevention of and response to abuse and neglect in care, with clearly understood roles and responsibilities for different organisations and entities
- establish a new independent **Care Safety Agency** to lead and coordinate the care system, act as the regulatory agency, and promote public awareness of preventing and responding to abuse and neglect in care

- create a **duty of care**, and strengthen and clarify the accountabilities of all state and faith-based care providers and staff and care workers
- provide for the creation of **care standards**
- provide for an **accreditation scheme for care providers**
- provide for the **professional registration of staff and care workers** (including volunteers) who are not otherwise subject to a professional registration scheme
- provide for **penalties, sanctions and offences** for state and faith-based care providers and staff and care workers who fail to comply with statutory and non-statutory standards of care
 - provide for **mandatory reporting**
 - provide for a comprehensive and strengthened **pre-employment screening** and vetting regime for all staff and care workers.

As well as its regulatory functions, the Care Safety Agency would:

- promote a continuous improvement and learning culture in the care system, including facilitating regular forums and communities of practice and evaluation
 - undertake workforce development activities
- lead public awareness, education and prevention initiatives
 - undertake research, data analysis and horizon-scanning, including building evidence on the risk, extent and impact of abuse and neglect in care
 - publish data and statistics on complaints of abuse and neglect in care to promote transparency and measurability of outcomes.

Safeguarding

The Inquiry recommended that all state and faith-based entities providing care directly or indirectly should have safeguarding policies and procedures in place. The report set out a range of requirements for such policies and procedures, including expected content and consistency with new national principles, strategy, rules and standards, and best practice guidelines.

There were a number of recommendations to empower and support people in care, including government investment for independent advocacy.

Complaints

The Inquiry recommended that all state and faith-based entities providing care directly or indirectly to children, young people and adults in care and relevant professional registration bodies should ensure they have appropriate policies and procedures in place to respond in a proportionate way to complaints, disclosures or incidents of abuse and neglect. The report set out detailed expectations of provider complaints policies and procedures, including reporting of all complaints to the Care Safety Agency and public reporting of the number and outcome of complaints.

It is proposed that legislation should enable the Care Safety Agency to collate and keep a centralised database of complaints, disclosures or incidents of abuse and neglect of children, young people and adults in care. This would prevent proven perpetrators from moving between settings without detection and allow the identification of people subject to multiple complaints so that steps can be

taken if appropriate. A centralised database would also create an evidence base and allow data analysis that can inform new prevention and response strategies and practices.

Coherent institutional arrangements

The Inquiry recommended that independent oversight and monitoring is coherent and well-resourced, with collaboration and data sharing between bodies to enable a whole-of-system view.

The government should establish performance indicators for all entities providing care directly or indirectly on behalf of the state or faith-based entities, based on Aotearoa New Zealand's domestic and international obligations.

Finally, the Inquiry recommended the establishment of a Care System Office to lead implementation of its recommendations. In future, the Care System Office would become a ministry which would administer the Care Safety Act.

6. The Australian NDIS experience

The National Disability Insurance Scheme (NDIS) is Australia's first national scheme for disabled people. It was introduced in 2013 and provides funding directly to individuals aged under 65 years. In the new market-based system, participants choose their own providers, rather than providers being contracted by government agencies.

The national rollout of the NDIS was completed on 1 July 2023 and the scheme now supports over 500,000 Australians, including around 80,000 children with developmental delay (NDIS, 2024)

The National Disability Insurance Agency (NDIA) is an independent statutory agency. The NDIA decides whether someone is eligible to become an NDIS participant and how much funding people receive based on their needs. This is based on the National Disability Insurance Scheme Act 2013 (NDIS Act). Funding is paid directly to the registered participant, and they then decide how to manage their own NDIS funding. Participants can choose:

- self-management
- a plan manager
- an NDIA manager (paid for by the NDIA on behalf of the participant).

6.1 NDIS Quality and Safeguarding Framework

When the NDIS was launched, governments agreed that a nationally consistent approach to quality and safeguards would be a critical component of the scheme. The NDIS Quality and Safeguarding Framework (Department of Social Services, Australian Government, 2017) was developed for the transition to the new national scheme. The framework was intended to be a high-level policy document with significant work to be done on the implementation, design and rollout.

The framework was designed to promote high quality supports and safe environments for all NDIS participants, and was based on the following key principles:

- Human rights
- The presumption of capacity to exercise choice and control
 - National consistency
 - Proportionality and risk responsiveness
 - Efficiency and effectiveness

The Quality and Safeguarding Framework set out developmental, preventative, and corrective measures targeted at individuals, the workforce, and providers (Australian Government Department of Social Services, 2017):

- Mechanisms in the **developmental** domain are intended to strengthen the capability of disabled people, the workforce and providers. While these are not regulatory functions, they are included in the framework because they are fundamental to supporting quality and safeguarding.
 - Mechanisms in the **preventative** domain are intended to prevent harm and ensure quality services are delivered to people with disability.

- Mechanisms in the **corrective** domain are intended to resolve problems, enable improvements to be identified, and provide oversight of the system.

Table 1: Components of the NDIS Quality and Safeguarding Framework

Underpinning foundations		
<i>UN Convention on the Rights of Persons with Disabilities; National Disability Strategy 2010–2020; National Disability Insurance Scheme Act 2013</i>		
Components		
Developmental: Building capability and support systems	Preventative: Preventing harm and promoting quality	Corrective: Responding if things go wrong
Individuals: supporting and empowering people with disability		
Providing participants information for decision-making Providing accessible information on how the NDIS works, participant rights, providers and complaints processes	Safeguarding participants through planning, implementation and review processes Having formal safeguards in the NDIS planning, implementation and review processes	Responding to complaints NDIS complaints commissioner receiving and responding to complaints about NDIS-funded supports, as well as ensuring that all registered providers have an internal complaints system
Building participants' capability Supporting participants to build knowledge, skills and confidence to exercise choice and control	Funding advocacy services Funding formal individual and systemic advocacy services outside of the NDIS	Responding to serious incidents Providers reporting on and commissioner investigating dangerous situations
Strengthening natural supports Supporting participants to strengthen family and other support networks and participate fully in their community	Supporting self-managing participants Ensuring self-managing participants are equipped to manage their supports	Community visitors Continuing existing state and territory schemes during the transition and conducting a review to evaluate their role in full scheme
<i>Links to information, linkages and capacity building</i>	<i>Links to supported and substitute decision-making (guardianship systems) and National Disability Advocacy Framework</i>	<i>Links to universal protections outside the NDIS (e.g. police, other regulatory and complaints systems)</i>
Workforce: promoting a safe and competent workforce		
Building a skilled and safe workforce Supporting the development of a NDIS workforce with the attitudes and skills that meet the needs of participants	Screening workers Screening workers to help ensure they keep people with disability safe Ensuring workers have the skills for specific roles through provider quality assurance system and registration	Monitoring worker conduct Monitoring through employee screening functions, serious incident reports, complaints and breaches of the code of conduct
<i>Links to Integrated Market, Sector and Workforce Strategy</i>	<i>Links to National Framework for Protecting Australia's Children</i>	
Providers: encouraging safe, innovative, high-quality support provision		

<p>Building provider capacity and best practice</p> <p>Supporting the development of a diverse and sustainable provider market able to meet demand and provide safe and high-quality services</p>	<p>Reducing restrictive practices</p> <p>Ensuring restrictive practices are reduced or eliminated by introducing consistent quality requirements for behaviour support practitioners and relevant providers, and reporting. The senior practitioner will conduct an educative role in the reduction of restrictive practices</p>	<p>Investigating non-compliance with the code of conduct</p> <p>Investigating potential breaches of the code of conduct and taking appropriate action</p>
	<p>Ensuring provider safety and quality</p> <p>Having provider quality requirements proportionate to the type of support offered and the needs of participants, and that builds a culture of continuous improvement. This includes oversight of the NDIS market</p>	<p>De-register or bar as NDIS provider</p>
<p><i>Links to NDIS Sector Development Fund</i></p>	<p><i>Links to National Framework for Reducing and Eliminating Restrictive Practices</i></p>	

Source: reproduced from (Department of Social Services, Australian Government, 2017)

6.1.1 Regulatory components of the framework

The NDIS Quality and Safety Framework set out some key regulatory functions:

1. Complaints commissioner

The complaints commissioner will receive and support the resolution of complaints about providers, receive and investigate serious incident reports, and investigate potential breaches of the NDIS Code of Conduct.

2. Registrar

The NDIS registrar will register providers, manage NDIS' practice standards and certification scheme, monitor provider compliance and take action as required.

3. Senior practitioner

The senior practitioner will oversee approved behaviour support practitioners and providers, provide best practice advice, receive/review/report on use of restrictive practices, and follow up on serious incidents that suggest unmet behaviour support needs.

4. Risk-based worker screening

Responsibility for overall design and broad policy settings will sit with the registrar and operational responsibility—including the management and operation of worker screening units—will rest with the states and territories.

6.2 The NDIS Quality and Safeguards Commission

The key regulatory functions proposed by the NDIS Quality and Safeguarding Framework were brought together under the NDIS Quality and Safeguards Commission (NDIS Commission). The NDIS Commission is an independent agency created by a 2017 amendment to the National Disability Insurance Scheme Act.

The NDIS Commission's role is to manage complaints about NDIS providers, improve the quality and safety of NDIS supports and services, regulate NDIS service providers and workers, and lead education, capacity building and development for disabled people, NDIS providers and workers.

The NDIS Commission says that it:

- responds to concerns, complaints and reportable incidents, including abuse and neglect of NDIS participants
 - promotes the NDIS principles of choice and control, and works to empower participants to exercise their rights to access quality services as informed, protected consumers
 - requires NDIS providers to uphold participants' rights to be free from harm
 - registers and regulates NDIS providers and oversees the NDIS Code of Conduct and NDIS Practice Standards
- provides guidance and best practice information to NDIS providers on how to comply with their registration responsibilities
 - monitors compliance against the NDIS Code of Conduct and NDIS Practice Standards, including undertaking investigations and taking enforcement action
- monitors the use of restrictive practices within the NDIS with the aim of reducing and eliminating such practices
 - is working in collaboration with states and territories to design and implement nationally consistent NDIS worker screening
- focuses on education, capacity building and development for people with disability, NDIS providers and workers
 - facilitates information sharing with the National Disability Insurance Agency (NDIA), state and territory authorities and other Commonwealth regulatory bodies.

6.2.1 NDIS Code of Conduct

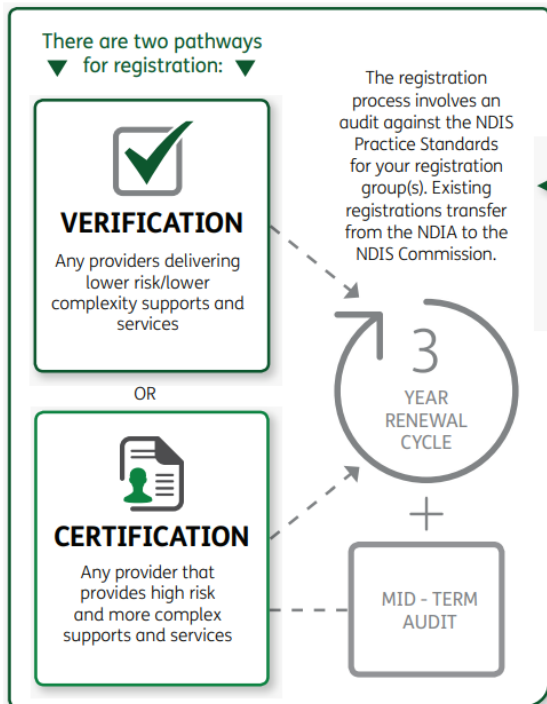
The NDIS Code of Conduct is set out in secondary legislation authorised by the NDIS Act (National Disability Insurance Scheme (Code of Conduct) Rules 2018, 2018). It requires workers and providers who deliver NDIS supports to:

- act with respect for individual rights to freedom of expression, self-determination, and decision-making in accordance with relevant laws and conventions
 - respect the privacy of people with disability
 - provide supports and services in a safe and competent manner with care and skill
 - act with integrity, honesty, and transparency
 - promptly take steps to raise and act on concerns about matters that might have an impact on the quality and safety of supports provided to people with disability
 - take all reasonable steps to prevent and respond to all forms of violence, exploitation, neglect, and abuse of people with disability
 - take all reasonable steps to prevent and respond to sexual misconduct
 - without a valid reason, not represent or charge a higher price for goods supplied to a NDIS participant that is higher than the price that would be supplied or charged to a person who is not a NDIS participant.

6.2.2 Provider registration and practice standards

A registered NDIS provider is registered with the NDIS Commission under the NDIS Act. Providers must be registered to deliver services and supports to NDIS participants who have their plan managed by the NDIA. Providers that deliver specialist disability accommodation, use restrictive practices, or develop behaviour support plans must also be registered. The registration process depends on providers' size and scope as well as service delivery risk.

Figure 2: NDIS provider registration process



Source: (NDIS Quality and Safeguards Commission, n.d.)

The NDIS Code of Conduct only describes high-level ethical expectations. It does not describe minimum acceptable standards for safe and appropriate service delivery, does not require any specific knowledge or expertise, and does not describe the standards and behaviours needed for a quality service.

The NDIS Practice Standards specify the quality standards to be met by registered NDIS providers. The core module applies to all providers, and supplementary modules apply to providers of specialised supports. The core module includes things like:

- risk management
- expected qualifications and competencies for employees
- complaints systems
- effective and inclusive governance.

Supplementary modules for more complex supports include:

- high intensity daily personal activities
- specialist behaviour support

- implementing behaviour support plans
- early childhood supports
- specialised support coordination
- specialised disability accommodation.

Not all providers are required to be registered, but choosing to be registered provides assurance to participants and families that it has met quality and safety criteria. Unregistered providers usually deliver lower risk supports to NDIS participants. Only participants who self-manage or plan-manage their NDIS funding can use unregistered providers. The code of conduct applies to unregistered NDIS providers and their employees as well as to registered NDIS providers and employees.

6.2.3 Worker screening

Registered NDIS providers must ensure that workers have a screening clearance that meets the requirements of the NDIS Practice Standards. The requirements relating to worker screening are set out in the NDIS (Practice Standards – Worker Screening) Rules 2018 (Australian Government, 2018).

All states and territories have now started implementing new NDIS worker screening arrangements as part of a national approach to worker screening.

6.2.4 Complaints and investigations

Every NDIS provider must have complaints management and resolution arrangements. When a person is unable to resolve issues with their NDIS provider or does not feel empowered to make a complaint directly, the NDIS Commission will receive and investigate complaints.

The NDIS Commission asks for voluntary provision of documents or information, but it also has legislative powers to obtain information to help with its investigations. These powers include:

- section 55A of the NDIS Act which gives the NDIS Commission the power to obtain information from others to ensure the integrity of the NDIS
- entering premises with consent under the Regulatory Powers (Standard Provisions) Act 2014
- executing monitoring or investigation warrants under the Regulatory Powers Act.

Following an investigation, the NDIS Commission can impose penalties including, in the most serious cases, banning workers or providers, de-registering providers and seeking civil penalties (i.e. fines).

6.3 NDIS independent review and recommendations

An independent review into the NDIS was conducted and a final report was published in October 2023 (NDIS Review Panel, 2023). The review report notes that problems with the NDIS have been well known in the disability community and the subject of several inquiries and reviews.

6.3.1 Framework not implemented as intended

The issues paper for the Australian NDIS Quality and Safeguarding Framework found that the NDIS framework did not appear to be directly used to guide the work of the NDIS commission and other

actors, leading to a lack of long-term, whole-of-scheme approaches. This also led to the framework not evolving and being updated to reflect changes (NDIS Review Panel, 2023).

The framework envisioned a balanced mix of developmental, preventative and corrective safeguards. While the NDIS Commission developed important preventative and corrective mechanisms, the focus has almost exclusively been on regulatory arrangements. Not enough attention has been given to developmental supports, such as capacity building, support to strengthen natural safeguards, or supporting and encouraging providers to engage in quality improvement (NDIS Review Panel, 2023).

The issues paper also found that the unanticipated growth of unregistered providers reduced the impact of preventative strategies and shifted responsibility for quality management back to participants, without enough investment in developmental strategies that would help support participants to make informed decisions (NDIS Review Panel, 2023).

In addition, the issues paper identified that there were a number of overlapping standards and frameworks regarding quality and safeguarding beyond the NDIS (e.g. for mental health). Having different approaches between NDIS and others led to inconsistent standards and confusion (NDIS Review Panel, 2023).

6.3.2 Effective quality and safeguarding institutions and architecture across the disability support ecosystem

In response to known problems that were highlighted in the review report, the review has recommended expanding the coverage of the NDIS Quality and Safeguards Commission and developing a new Disability Supports Quality and Safeguarding Framework.

A new National Disability Supports Quality and Safeguarding Commission would include all disability supports provided through the NDIS plus other Australian Government funded and commissioned disability supports (i.e. employment services, advocacy programme, etc.). The review considered that expanding the Commission's coverage will provide consistent protections for disabled people accessing a range of supports, reduce regulatory burden for providers, and drive efficiencies for government. The review also noted that the Australian Government should, over time, move towards a common approach for the regulation of the wider care and support sector (e.g. aged care, veterans, childcare).

6.3.3 Continuous quality improvement supported by a dedicated quality function

The review recommended that an appropriately resourced quality function be set up within the new National Disability Supports Quality and Safeguarding Commission, led by a dedicated Deputy Commissioner for Quality. This recommendation supports a much stronger focus on quality, including support to understand what good quality looks like and how to implement quality improvements. Quality improvement would become a priority in capacity building initiatives and audit processes.

The review also recommended that the new commission should implement an approach to measure and publish metrics of registered provider performance. This action would show providers how they

are performing, help incentivise providers to improve quality, and empower disabled people and their supporters to be active and informed consumers.

6.3.4 Safeguarding that is empowering and tailored to individuals, their service needs and environments

The review recommended a series of actions to achieve an empowered and individualised safeguarding approach that better responds to all disabled people, but particularly those facing intersectional discrimination and inequity. Safeguarding should prioritise building capacity, natural safeguards and community connections. This would be balanced with targeted, more intensive options for people at particular risk of harm or with more limited natural safeguards.

Adult Safeguarding Agencies (ASAs), as recommended by the Australian Law Reform Commission, are an emerging service in Australia. The review recommended that state and territory governments should establish or improve ASAs to deliver a universal service offering for the safeguarding of all people at risk of harm, including disabled people (NDIS Review Panel, 2023).

6.3.5 A risk-proportionate model for the visibility and regulation of all providers and workers

It was originally envisioned that most participants would be managed by the NDIA and therefore most providers would be registered. However, the number of participants who self-manage or use a plan manager has grown substantially, resulting in a large, unregistered provider market. The NDIS Commission has limited visibility of the market and few tools to respond to quality issues. Even if issues are detected, there is limited availability to act because unregistered providers are not required to meet any specific standards beyond the basic ethical expectations in the code of conduct.

The independent review noted that registered and unregistered providers can often deliver similar supports which results in inequitable regulatory requirements. Registered providers feel more scrutinised and subject to greater obligations than unregistered providers, who they are competing with to deliver similar supports. This is compounded by providers not seeing the registration process (and in particular the auditing process) to be of value to them or as something that contributes to the quality of their support (NDIS Review Panel, 2023). The review also noted that many participants highly value access to the unregistered provider market, particularly because of a perception that unregistered providers can be more flexible and innovative.

The review recommendations set out the panel's vision for a more graduated and risk-proportionate provider registration system. Its aim is to better prevent harm while continuing to support choice and control and enable a thriving provider market. The proposed model is built around four broad categories based on the risk associated with different types of supports and providers:

- **Advanced registration** for all high-risk supports, applying more intensive regulatory requirements and oversight where supports may pose an inherently high-risk or require high-level technical competence.
 - For example, supports delivered in high-risk settings, such as daily living supports delivered in formal closed settings like group homes.

- **General registration** for all medium risk supports, applying graduated approaches to regulatory requirements and oversight, depending on factors impacting the level of risk.
- For example, high intensity supports (such as high intensity daily personal activities), supports that require additional skill and training (such as complex bowel care or injections), and supports involving significant one-on-one contact with people with disability.
- **Basic registration** for all lower risk supports, applying lighter-touch registration requirements, while still allowing for regulatory oversight against practice standards, when required.
 - For example, sole traders and smaller organisations, supports such as social and community participation, and supports involving more limited one-on-one contact with people with disability.
- **Enrolment** of all providers of lowest risk supports, providing full visibility of the market and applying lightest-touch requirements through a simple online process.
 - For example, supports where general protections available under Australian consumer law are sufficient, such as consumables, equipment, technology, and home and vehicle modifications.

Proportionality could be achieved by simplifying practice standards where possible, recognising compliance in other regulatory systems (such as aged care), using risk-based auditing and assessment approaches (combining observational with desktop and self-assessments) and targeting audits on the most relevant and important issues (NDIS Review Panel, 2023, pp. 178–179).

Table 2 sets out the proposed provider obligations and processes for the four categories of registration.

Table 2: Graduated and risk-proportionate provider registration and enrolment

	A. Advanced registration In-depth registration for high risk supports	B. General registration Graduated registration for medium risk supports	C. Basic registration Light-touch registration for lower risk supports	D. Enrolment Basic visibility and requirements for lowest risk supports
Code of conduct	YES	YES	YES	YES
Worker screening (Action 17.4)	YES Workers in risk-assessed roles	YES Workers in risk-assessed roles	YES Workers in risk-assessed roles	YES Workers directly delivering specified supports or services, or who have more than incidental contact with people with disability
Subject to complaints process	YES	YES	YES	NO
Report incidents	YES General standards and support specific standards for all support types	YES General standards for all support types and support specific standards where needed	YES Simplified general standards for all support types	NO

	A. Advanced registration In-depth registration for high risk supports	B. General registration Graduated registration for medium risk supports	C. Basic registration Light-touch registration for lower risk supports	D. Enrolment Basic visibility and requirements for lowest risk supports
Performance measurement (Action 12.3)	YES	YES	YES	NO
Processes				
Application, identity verification and code of conduct and worker screening attestation	YES <ul style="list-style-type: none"> Provider completes online application form, integrated with centralised online platform and NDIS payments system (Actions 10.1 and 10.3) to provide the NDIA and new National Disability Supports Quality and Safeguards Commission with visibility of all providers and data on payments Application form collects basic information (e.g. business name, ABN or Digital ID, bank account details, location, contact details, support types delivered) Business identity is verified leveraging existing government systems and processes (such as myGovID) Provider attests to understanding obligations under code of conduct and worker screening requirements 			
Audit of compliance with practice standards	YES <ul style="list-style-type: none"> In-depth observational audit of compliance with relevant practice standard Streamlining where appropriate based on risk, such as the use of desktop auditing, self-assessment and attestation, and mutual recognition of compliance in other regulatory systems 	YES <ul style="list-style-type: none"> Graduated and proportionate audit of compliance with relevant practice standards, including observational and/or desktop auditing Streamlining where appropriate based on risk, such as the use of desktop auditing, self-assessment and attestation, and mutual recognition of compliance in other regulatory systems 	NO <ul style="list-style-type: none"> But includes a self-assessment and attestation of compliance with practice standards, in place of an audit 	NO
Suitability assessment of provider and key personnel	YES	YES	YES	NO
Ongoing monitoring and compliance	YES The National Disability Supports Commission undertakes:			

	A. Advanced registration In-depth registration for high risk supports	B. General registration Graduated registration for medium risk supports	C. Basic registration Light-touch registration for lower risk supports	D. Enrolment Basic visibility and requirements for lowest risk supports
	<ul style="list-style-type: none"> • Risk-based monitoring, investigation and regulatory intelligence gathering (including through provider outreach and information sharing with other regulators) • Corrective action in response to breaches of the code of conduct (registered and enrolled providers) and practice standards (registered providers only) 			

Source: reproduced from (NDIS Review Panel, 2023, p. 214)

6.4 Advice from the NDIS Provider and Worker Registration Taskforce

The NDIS Provider and Worker Registration Taskforce (the Taskforce) was established to provide advice on the design and implementation of the new graduated risk-proportionate regulatory model proposed in the NDIS Review Final Report, in consultation with the disability community. The Taskforce was supported by subject matter experts who formed advisory working groups to co-design specific activity in areas of concern.

The Taskforce heard significant concerns that mandatory registration for all NDIS providers would (Wade et al., 2024, p. 13):

- significantly impact choice and control for NDIS participants
 - be costly or burdensome to providers, particularly smaller providers, causing some to leave the NDIS market
 - limit or stifle innovation and different models of supports.

The Taskforce’s advice was published in August 2024 (Wade et al., 2024) and made 11 recommendations with 10 implementation actions with consideration to these concerns and the ideas and feedback heard during consultations. Some of the key points of difference from the NDIS review proposals are summarised below.

6.4.1 Recommended modifications to the proposed provider registration scheme

The Taskforce agreed that the registration categories as outlined in the NDIS review report should be the basis for most provider registration. However, the Taskforce recommends some changes:

- **Not all providers, as defined in the NDIS Act, should be registered.** Those who would not be registered include:

- unregistered providers who provide support to participants who self-direct⁹ their support
- goods purchased off-the-shelf from mainstream providers, as visibility through proof of purchase should be sufficient.
- A new category whereby **NDIS participants self-directing their supports register themselves with the NDIS Commission**. Practice standards would not be applied to the self-directed support category, but it would still be subject to review and auditing consistent with arrangements for other providers. NDIS participants under self-directed support registration would be required to have regular check-ins with the NDIS Commission, with the nature of those check-ins to be co-designed with the disability community and be flexible and respectful of people's right to privacy.
- The government should invest in offering **peer support and capacity building programmes** to engage in the NDIS regulatory framework, including for participants who self-direct their supports.
- The **code of conduct should be reviewed and co-designed** with disabled people, the disability community and sector. The Taskforce recommended the Code should be strengthened to reflect the disproportionate rates of violence, abuse, neglect and exploitation faced by disabled people, but also to better realise the right of disabled people to make their own choices, including through supported decision making frameworks (Wade et al., 2024, pp. 65–66)
 - **Worker screening would be applied to all workers in risk assessed roles for advanced and general registration** (not basic registration).
- **Practice standards would apply only to the advanced and general registration categories** (not basic registration). The legislative rules should require that **practice standards are co-designed**.
- Group homes should be required to have advanced registration and be subject to unannounced visits. The **NDIS Commission would have a statutory right to enter group home premises**. The Taskforce heard, and learnt through previous inquiries, including Australia's Disability Royal Commission, that disabled people living in many group homes can have little connection to community, little choice in their everyday lives including what they eat, where they go and what they do, and are often socialised together (Wade et al., 2024, pp. 49–50).

6.4.2 Other recommendations

Although not within the Taskforce's terms of reference, stakeholders shared their ideas about what a worker registration scheme could look like. The Taskforce recommended a worker registration scheme, underpinned by worker screening, as an important safeguarding step to a better system and improved outcomes (Wade et al., 2024, p. 92). Many aspects would need to be considered and co-designed, but key features of a worker registration scheme would include:

- a public register of workers

⁹ Self-directed support is a way of managing your supports, usually through direct employment. It is different to self-management, which is the financial management of the NDIS plan.

- professional development requirements
- a training and qualifications framework.

Practitioners that hold professional registration (e.g. allied health) would have that registration recognised and only be required to meet any additional obligations to provide NDIS supports.

The Taskforce also suggested an **innovation community of practice and working groups**. This would support and grow quality and innovation within the NDIS, led by the NDIS Commission.

The Taskforce recommended the establishment of a project group to consider the utility of the introduction and mandating of individual safeguarding plans for NDIS participants without individual natural safeguarding relationships and/or for those people in group care settings or clusters supported by a single provider.

7. What do other countries and sectors do?

7.1 England

Social care and support in England is usually paid for by the local council's social services department (although there is means testing), based on a needs assessment and a care and support plan. Eligible people are given a personal budget to spend on things that meet their agreed care plan. People can choose how they receive their personal budget—either the council:

- manages the budget for them
- pays the money to another organisation, such as a care provider
- pays the money directly to the person or someone they choose—this is known as a direct payment.

The Care Act 2014

The Care Act 2014 replaced most previous laws regarding both carers and people being cared for. The Act sets out how care and support should be provided to adults with care needs, how it is paid for, placed a number of duties on local authorities, and established new rights for people accessing services and carers.

The Care Act supports personalisation of care services, putting the person at the centre of the process. The Act places a general duty on local authorities to promote an individual's wellbeing, and the responsibility to ensure the availability of a wide variety of good quality social care services for people who need them. This means that local authorities should always have a person's wellbeing in mind when making decisions about them or planning services (Carers UK, n.d.).

Wellbeing can relate to (Care Act 2014, 2015, Section 2):

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support)
- participation in work, education, training or recreation
 - social and economic wellbeing
- domestic, family and personal relationships
 - suitability of living accommodation
 - the individual's contribution to society.

The Act requires that every council area must have a board tasked with:

- promoting individual well-being
- preventing needs for care and support
- promoting integration of care and support with health services
- providing information and advice
- promoting diversity and quality in provision of services

- assessing people's needs and deciding how to meet them
- planning care and support and reviewing those plans
- safeguarding adults.

The Care Act is mainly for adults and their adult carers. Provision for care and support for children is contained in the Children and Families Act 2014.

Safeguarding requirements

Although local authorities had been responsible for safeguarding for many years, there wasn't a clear set of laws behind it. As a result, it was often unclear who was responsible for what in practice. The Care Act created a legal framework so that key organisations and individuals with responsibilities for adult safeguarding can agree on how they must work together and what roles they must play to keep adults at risk safe (United Kingdom Government, 2016).

Safeguarding adults boards

The Care Act requires local authorities to set up a Safeguarding Adults Board (SAB) in their area, giving these boards a clear basis in law for the first time. The Act says that the SAB must:

- include the local authority, the NHS and the police, who should meet regularly to discuss and act upon local safeguarding issues
 - develop shared plans for safeguarding, working with local people to decide how best to protect adults in vulnerable situations
 - publish this safeguarding plan and report to the public annually on its progress, so that different organisations can make sure they are working together in the best way.

Safeguarding enquiries by local authorities

The Care Act says that where a local authority has reasonable cause to suspect that an adult in its area is experiencing, or is at risk of, abuse or neglect, and is unable to protect themselves, the local authority must make whatever enquiries it thinks necessary to be able to decide whether any action should be taken and, if so, what and by whom (Care Act 2014, 2015, Section 42). This applies whether or not the authority is actually providing any care and support services to that adult.

Safeguarding adult reviews

SABs must arrange a safeguarding adults review in some circumstances, for instance, if an adult with care and support needs dies as a result of abuse or neglect and there is concern about how members of the SAB acted. The reviews are about learning lessons for the future, and will make sure SABs get the full picture of what went wrong, so that all organisations involved can improve as a result (United Kingdom Government, 2016).

Independent advocacy

The local authority will arrange for an independent advocate to represent and support a person who is the subject of a safeguarding enquiry or a safeguarding adult review, if they need help to understand and take part in the enquiry or review and to express their views, wishes, or feelings (United Kingdom Government, 2016).

Supply of information

The Care Act requires people to supply information in order for an SAB to exercise its functions (Care Act 2014, 2015, Section 45).

The Care Quality Commission

The Care Quality Commission (CQC) regulates health and adult social care in England. Personal care and residential care are regulated activities under the Health and Social Care Act 2008 and providers must be registered with the CQC if they provide regulated activities. The regulations are set out in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 and Care Quality Commission (Registration) Regulations 2009.

The CQC is using a new approach to assessment. There are five key questions and a four-point rating scale, with services assessed against quality statements. The CQC now uses inspections to support a range of different ways to gather evidence (including people's experiences of services), rather than inspections being the primary way to collect evidence. There are a range of enforcement options available for non-compliance with registration regulatory requirements.

Assessing how local authorities meet their duties under Part 1 of the Care Act is a new responsibility for the CQC, required by a 2023 amendment to the Health and Social Care Act.

7.2 Wales

Many aspects of the Welsh system are similar to the English system. Local authorities undertake needs assessments and develop care and support plans with disabled people and others eligible for formal support. Direct payments allow people to receive payment from their local authority so they can arrange their own care services. Local authorities must provide appropriate, accessible information and support to enable people to decide whether they want direct payments.

The relevant legislation in Wales is the Social Services and Well-being Act 2014. Like the English legislation, the Act uses the concept of wellbeing and requires anyone exercising functions under the Act to seek to promote the wellbeing of people who need care and support, and carers who need support. The Act defines wellbeing in relation to any of the following:

- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- education, training and recreation
- domestic, family and personal relationships
 - contribution made to society
 - securing rights and entitlements
 - social and economic wellbeing
 - suitability of living accommodation.

In relation to a child, wellbeing also includes:

- physical, intellectual, emotional, social and behavioural development
 - 'welfare' as that word is interpreted for the purposes of the Children Act 1989.

In relation to an adult, wellbeing also includes:

- control over day-to day-life
- participation in work.

The Social Services and Well-being Act also imposes duties to give effect to certain key principles. The fundamental principles of the Act are (Welsh Government, n.d.):

- **Voice and control** – putting the individual and their needs at the centre of their care, and giving them a voice in, and control over, reaching the outcomes that help them achieve well-being.
- **Prevention and early intervention** – increasing preventative services within the community to minimise the escalation of critical need.
- **Wellbeing** – supporting people to achieve their own wellbeing and measuring the success of care and support.
- **Co-production** – encouraging individuals to become more involved in the design and delivery of services.

Welsh ministers are required to issue a statement specifying the wellbeing outcomes that are to be achieved for people who need care and support to specify outcome measures. The Act requires ministers to issue a code to help achieve the outcomes specified in the statement, which may include quality standards, performance measures and targets.

The Regulation and Inspection of Social Care (Wales) Act 2016 established a regulatory regime which supports the Act. The Care Inspectorate Wales is the regulator for social care. It also put in place Social Care Wales, an organisation to drive improvement and regulate the sector workforce.

Safeguarding requirements

Safeguarding enquiries by local authorities

The Social Services and Well-Being Act has the same requirement and wording as the English Care Act relating to investigation where a local authority suspects that an adult with care and support needs is at risk of abuse or neglect (Social Services and Well-Being (Wales) Act 2014, n.d., Section 126).

Local authorities' duties to investigate children at risk are provided for under the Children Act 1989.

Protection and support orders

An authorised officer may apply to a justice of the peace for an adult protection and support order. The Act provides for orders to authorise entry to premises so that an authorised officer of a local authority can assess whether an adult is at risk of abuse or neglect and, if so, what to do about it (Social Services and Well-Being (Wales) Act 2014, n.d., Section 127).

Safeguarding boards

Regulations set out the areas in Wales that need to have safeguarding boards for adults and children. The Act also establishes a National Independent Safeguarding Board to provide support and advice to ensure the effectiveness of safeguarding boards.

Evaluation

The Welsh Government commissioned a partnership of academics across four universities in Wales and expert advisers to deliver an evaluation of the Social Services and Well-Being Act (Llewellyn et al., 2023). Some of the summary assessments made by the evaluators include the following:

- “The evaluation data showed support for the principles from service users and carers and across the workforce” (Llewellyn et al., 2023, p. 43).
- “The relevance of having clear definitions of the key principles of the Act is that this reduces potential confusion...about their purpose of objectives. An example is wellbeing where there is scope to determine a more precise definition...that reflects the literature underpinning its use in policy...the outcomes framework offers insight as to what the government considers determinants of wellbeing to be, but this does not constitute a definition of the concept” (Llewellyn et al., 2023, p. 42).
- “In determining what aspects of life contribute to wellbeing, the National Outcomes Framework operates sufficiently well to guide practice; however, evidence that the framework is deployed to guide practice beyond initial training is scant. Beyond practice, the definition and guidance around wellbeing under the Act has implications for how the wellbeing of people accessing social care is measured, tracked and reported in Wales” (Llewellyn et al., 2023, p. 42).
- “From the workforce perspective, we have seen evidence of positive implementation of social services resulting from a focus on the principles. Equally, the general ethos of the Act, giving people more voice and control and approaches such as ‘what matters’ conversations, have helped cross divides that may exist within workforce cultures, albeit not always consistently. This has enabled workers to work beyond prescribed boundaries and explore wider options” (Llewellyn et al., 2023, p. 56).
 - “There was a view from both the perspectives of service users and carers and from some workforce participants, that implementation has not been as successful as envisaged. There is a disconnect between legislative rhetoric and operational reality, especially when faced with the tensions between local flexibility and interpretation versus centralised control and resource constraints” (Llewellyn et al., 2023, p. 56).
 - “There remains...a distance between the highly aspirational rhetoric of individual agency under the Act and the extremely complex and, often, imperfect matter of enacting this in individual cases which can create frustration and stress.” (Llewellyn et al., 2023, p. 72).

7.3 Ireland

Disability services in Ireland are merged with health services and overseen by the Irish Health Service Executive (HSE) (Giedraityt, 2020). The HSE delivers a limited number of services itself but mostly funds provision by locally based voluntary, non-government organisations. Nine community healthcare organisations (CHOs) plan and manage disability service delivery in their areas.

The HSE is working to reform disability services away from traditional models of segregated provision towards more community-based and person-centred models of support, through a process known as Transforming Lives (National Disability Authority, 2022).

The Transforming Lives programme includes piloting personalised budgets. Personalised budgets are still only in the pilot stage—the first stage of the project commenced in October 2019, and the second started in September 2020.

Health Information and Quality Authority

The Irish Health Act 2007 establishes and sets out the functions of the Health Information and Quality Authority (HIQA). The HIQA is an independent authority established to drive continuous improvement in Ireland’s health and personal social care services, monitor the safety and quality of these services and promote person-centred care for the benefit of the public.

Residential and residential respite centres are prescribed as ‘designated centres’ in the Health Act 2007. The HIQA has statutory authority to regulate the quality of service provided in designated centres for disabled adults and children. The HIQA’s disability inspection team is legally responsible under the Health Act 2007 for the monitoring, inspection and registration of designated centres

The HIQA sets national standards, including the National Standards for Residential Services for Children and Adults with Disabilities (Health Information and Quality Authority, 2013) and the National Standards for Adult Safeguarding (Health Information and Quality Authority & Mental Health Commission, 2019).

For other types of disability support services, quality assurance and monitoring arrangements are set out in service agreements with the CHO or HSE, including fulfilment of HIQA standards when applicable.

Safeguarding

The HSE operates an Adult Safeguarding Policy within older persons services and services for people with disabilities. The Safeguarding Vulnerable Persons at Risk of Abuse - National Policy and Procedures policy, which applies to all HSE and HSE funded services, outlines a number of principles to promote the welfare of vulnerable people and safeguard them from abuse (Health Services Executive, n.d.).

In each CHO, a Safeguarding and Protection Team (Vulnerable Persons) supports the objectives of the safeguarding policy. The Safeguarding and Protection Team will:

- receive reports of concerns and complaints regarding the abuse of vulnerable persons
 - support services and professionals to assess and investigate the concern(s) or complaint(s) and develop intervention approaches and protection plans
 - directly assess particularly complex complaints and coordinate service responses
 - support, through training and information, the development of a culture which promotes the welfare of vulnerable persons, and the development of practices which respond appropriately to concerns or allegations of abuse of vulnerable persons
- maintain appropriate records.

Safeguarding Ireland was established to promote the safeguarding of adults who may be vulnerable, protect them from all forms of abuse by persons, organisations and institutions and develop a national plan for promoting their welfare.

We note that the Adult Safeguarding Bill 2017 is at the committee stage. The purpose of the Bill is to make further and better provision for the care and protection of adults who are at risk, to establish a National Adult Safeguarding Authority and to require reporting to that authority.

The National Disability Authority

The National Disability Authority (NDA) is an independent statutory body, providing evidence-based advice and research to the Irish Government on disability policy and practice, and promoting universal design.¹⁰

The functions of the NDA are set out in the National Disability Authority Act 1999 and the Disability Act 2005. The main statutory functions of the NDA are:

- research and statistics
- assisting in the development of standards
 - creating codes of practice
- monitoring the implementation of disability related standards, codes and strategies,
 - promoting universal design.

The NDA supported a Task Force on Personalised Budgets and joined the Demonstration Projects Oversight Group in an advisory capacity. The NDA is responsible for commissioning an independent evaluation of the personalised budgets pilots.

Advocacy services

The National Advocacy Service for People with Disabilities (NAS)¹¹ provides independent, free and confidential advocacy services. The NAS helps disabled people to identify and understand their needs and options and secure their entitlements to social services. It has a particular remit to work with disabled people who are in particularly vulnerable situations. This includes disabled people who live in residential services, who attend day-services, who live in inappropriate accommodation, who have communication differences, who are isolated from their communities or who have limited natural supports.

The NAS is part of a framework of services funded and supported by the Irish Citizens Information Board. The board has specific functions under the Comhairle Act 2000 as amended by the Citizens Information Act 2007, to:

- support the provision of, or, where the Board of the Citizens Information Board considers it appropriate, directly provide independent information, advice and advocacy services to ensure that individuals have access to accurate, comprehensive and clear information relating to social services and are referred to the relevant services

¹⁰ "Universal design means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design" (United Nations Convention of the Rights of Persons with Disabilities, 2006, Article 2).

¹¹ <https://advocacy.ie/>

- assist and support individuals, in particular those with disabilities, in identifying and understanding their needs and options and in accessing their entitlements to social services
- promote greater accessibility, co-ordination and public awareness of social services and of information, advice and advocacy services provided in relation to such services whether by a statutory body or a voluntary body
 - support, promote and develop the provision of information on the effectiveness of current social policy and services, and to highlight issues which are of concern to users of those services.

7.4 Canada

Disability policy including safeguarding and quality in Canada is made up of multiple legislation, regulations and programs, crossing many departments within government and multiple layers of jurisdiction. There are 38 federal statutes relating to disability, as well as many others that have implications for people with disabilities even though they are not specifically stated.

In Canada, adult protection is primarily addressed at the provincial and territorial level and the various jurisdictions have taken different approaches to addressing the problem of adult abuse and neglect.

Legislation also exists in each of the 13 provincial and territorial jurisdictions, and municipalities also play a role in administering disability programmes and standards.

Disability policy is perceived by many people with disabilities as impenetrable and complex. It is a patchwork of legislation, regulations, programmes, and providers.

Unlike other Western democracies, such as the US, UK and Australia, there is no explicit national disability legislation in Canada.

Basic Assurances Certification

Basic Assurances Certification was developed by the Council on Quality and Leadership in Canada. This certification aims to look at the provision of safeguards from an individual perspective, where the effectiveness of a system is determined in practice, person by person.¹² The tool evaluates the success of operations involving the health and safety of people receiving services, and also looks at areas such as natural supports, social networks and employment. The certification is structured around factors, indicators (Table 3) and hundreds of probes. Both the system and actual practice are examined and measured.

¹² <https://www.c-q-l.org/tools/basic-assurances/>

Table 3: Council on Quality and Leadership Basic Assurances Indicators

Basic Assurances® Indicators

Rights protection and promotion

- The organisation implements policies and procedures that promote people's rights
- The organisation supports people to exercise their rights and responsibilities
- Staff recognise and honour people's rights
- The organisation upholds due process requirements
- Decision-making supports are provided to people as needed

Dignity and respect

- People are treated as people first
- The organisation respects people's concerns and responds accordingly
- People have privacy
- Supports and services enhance dignity and respect
- People have meaningful work and activity choices

Natural support networks

- Policies and practices facilitate continuity of natural support systems
- The organisation recognises emerging support networks
- Communication occurs among people, their support staff and their families
- The organisation facilitates each person's desire for natural supports

Protection from abuse, neglect, mistreatment and exploitation

- The organisation implements policies and procedures that define, prohibit and prevent abuse, neglect, mistreatment and exploitation
- People are free from abuse, neglect, mistreatment and exploitation
- The organisation implements systems for reviewing and analysing trends, potential risks and sentinel events including allegations of abuse, neglect, mistreatment and exploitation, and injuries of unknown origin and deaths
- Support staff know how to prevent, detect and report allegations of abuse, neglect, mistreatment and exploitation
- The organisation ensures objective, prompt and thorough investigations of each allegation of abuse, neglect, mistreatment and exploitation, and of each injury, particularly injuries of unknown origin
- The organisation ensures thorough, appropriate and prompt responses to substantiated cases of abuse, neglect, mistreatment and exploitation, and to other associated issues identified in the investigation

Best possible health

- People have supports to manage their own health care
- People access quality health care
- Data and documentation support education of health care objectives and promote continuity of services and supports
- Acute health needs are addressed in a timely manner
- People receive medications and treatments safely and effectively
- Staff immediately recognise and respond to medical emergencies

Safe environments

- The organisation provides individualised safety supports
 - The physical environment promotes people's health, safety and independence
-

-
- The organisation has individualised emergency plans
 - Routine inspections ensure that environments are sanitary and hazard free

Staff resources and supports

- The organisation implements a system for staff recruitment and retention
- The organisation implements an ongoing staff development program
- The support needs of individuals shape the hiring, training, and assignment of all staff
- The organisation implements systems that promote continuity and consistency of direct support professionals
- The organisation treats its employees with dignity, fairness and respect

Positive services and supports

- People's individual plans lead to person-centred and person-directed services and supports
 - The organisation provides continuous and consistent services and supports for each person
 - The organisation provides positive behavioural supports to people
-

Source: reproduced from Friedman, 2022

7.5 Sweden

The legal framework affords protection from discrimination and gives the right to assistance. The government periodically adopts a new strategy for the implementation of disability policy.

In Sweden, as in many other countries, policy concerning people with disabilities is expressed in terms of integration, full participation, and equality.

The basic philosophy upon which the Swedish welfare system is grounded is that of providing a system of general support for society and supplementing it with individualised support for persons with disabilities.

Swedish health services for persons with disabilities are organised in three hierarchical political and administrative levels—the state at a national level, the county council at a regional level, and the local authority at the municipality level.

7.6 United States

The US has shifted away from a fee-for-service system to a risk-based, capitated model, where managed care organisations receive a fixed per member/per month payment for home and community-based services (HCBS) (Caldwell & Machledt, 2022). This model financially rewards managed care plans that spend less on care.

The Final Settings Rule for HCBS was published in 2014, and establishes an outcome-oriented definition of HCBS that supports the self-determination and choice of the recipient (Roberts & Abery, 2023). The transition period for compliance was March 17, 2023. The final rule (Department of Health & Human Services, 2014) requires that all home and community-based settings meet certain qualifications to be funded, including that the setting:

- is integrated in and supports full access to the greater community
- is selected by the individual from among setting options

- ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint
- optimises autonomy and independence in making life choices
- facilitates choice regarding services and who provides them.

7.7 Regulation of other sectors

This section provides a brief summary of regulatory arrangements in other sectors.

7.7.1 Te Kāhui Kāhu social services accreditation

Te Kāhui Kāhu is an independent government business unit that provides social services accreditation. Accreditation is intended to provide assurance that organisations can safely deliver social services to their community.

The unit has been known by different names over the past 35 years and historically it worked only for Child, Youth and Family and the Ministry of Social Development. Now, Te Kāhui Kāhu has taken on a social sector-wide accreditation role and other oversight functions for government agencies. There are a range of government agencies that need organisations to be accredited for a variety of reasons, the most common of which is to receive funding or a contract. Agencies that fund Te Kāhui Kāhu to provide social services accreditation include:

- Department of Corrections
- Ministry of Housing and Urban Development
- Ministry of Justice
- Ministry for Pacific Peoples
- Ministry of Social Development
- Oranga Tamariki Ministry for Children.

Levels of accreditation

Accreditation standards have four levels of accreditation. Level one accreditation has the highest level of compliance. Services are assessed against 10 social sector accreditation standards and against any relevant specialist standards. They are visited at least every two years by Te Kāhui Kāhu. Compliance requirements reduce with the lowest level—level four—having a reasonable level of compliance involving assessment against six social sector standards but no visits by Te Kāhui Kāhu (Te Kāhui Kāhu, 2022).

If issues or concerns are raised about an organisation's accreditation, Te Kāhui Kāhu will talk to the relevant contracting agency/agencies. Te Kāhui Kāhu may suspend accreditation and ask the provider to address areas of concern. If issues aren't addressed, then accreditation can be revoked. If the issue is very serious, or there are concerns for people's safety and wellbeing, accreditation may be revoked immediately.

Accreditation standards

There are two types of standards. Social Sector Accreditation Standards are the core standards that every organisation must meet to be accredited. The full suite of core standards includes (Te Kāhui Kāhu, 2021):

- client-centred services
- community wellbeing
- cultural competence
- staffing
- health and safety
- governance and management structure and systems
- financial management and systems
 - complaints resolution
 - quality improvement
 - client services and programmes.

Specialist standards are for organisations that deliver specialised services or programmes or are required to meet specific legislation or policies.

Unregulated social services can choose to use the Social Sector Accreditation Standards. For example, the Out of School Care and Recreation (OSCAR) sector is not governed by any specific regulations, although services must comply with relevant legislation (health and safety, employment, privacy etc.). The Social Sector Accreditation Standards (including specialist standards) are a set of voluntary operating requirements which are in place over a large proportion of the OSCAR sector.

Once an OSCAR service has social sector accreditation, eligible parents may apply to Work and Income for the OSCAR fee subsidy. Accreditation is also a requirement for OSCAR services that receive operating grants from the Ministry of Social Development.

Use of Te Kāhui Kāhu can achieve consistency with other social services and uses an existing process. The disadvantage for disability support services is that the core standards are not as clear and relevant in relation to safeguarding adults from abuse or neglect. Bespoke disability standards would need to be developed and added to the existing Social Sector Accreditation Standards.

7.7.2 Early childhood education licensing

New Zealand early childhood education providers are regulated by the Education and Training Act 2020. Service providers operating an early childhood education and care centre must be licensed in accordance with regulations made under the Act. Home-based education providers may, but do not need to, be licensed. The Act requires that services must obtain police vetts of workers. The licensing arrangements are set out in the Education (Early Childhood Services) Regulations 2008.

All early learning services, and any person or organisation that is contracted or funded to provide children's services, must have a child protection policy.

7.7.3 Statutory powers of Oranga Tamariki

The Oranga Tamariki Act 1989 confers certain duties and powers to Oranga Tamariki. The purpose of the Act is to promote the wellbeing of children, young persons, and their families, whānau, hapū, iwi and family groups through a range of support and protection activities, and to provide for care and protection arrangements when necessary. The Act states that the “wellbeing and best interests of the child or young person are the first and paramount consideration, having regard to the principles set out [in certain sections of the Act]” (Oranga Tamariki Act 1989, n.d., Section 4A).

The Act provides for significant powers in relation to suspected abuse or neglect:

- A judge from the District Court or Family Court can issue what’s called a “place of safety” warrant to an Oranga Tamariki social worker or the police, allowing them to come into the home (and car if necessary) to search for a child and check up on them (Oranga Tamariki Act 1989, n.d., Section 39).
- To get one of these warrants from a judge, Oranga Tamariki or the police must satisfy the judge that there is good reason to suspect the child is being ill-treated, neglected, abused or harmed, or to suspect that this is likely to happen. They also must convince the judge that there is no other way of protecting the child.
- They can then take a child away, only in serious cases. They must have a reasonable belief—not just a reasonable suspicion—that removing the child is necessary. Also, if the risk they are concerned about is “neglect, deprivation or harm,” rather than abuse or ill-treatment, it has to be serious neglect, deprivation or harm (Oranga Tamariki Act 1989, n.d., Section 39(1)(b)).
- In some situations, the police—but not Oranga Tamariki social workers—may be able to enter the home and take the child away without first getting permission from a judge through a warrant—allowed in only the most urgent and exceptional cases (Oranga Tamariki Act 1989, n.d., Section 42).
- When the police use this emergency power, they must show their police ID and state that they are using this specific power under section 42 of the Oranga Tamariki Act.
 - There is a separate power for the District Court or Family Court to issue a warrant to remove a child from their carers once Oranga Tamariki has applied for care or protection orders (Oranga Tamariki Act 1989, n.d., Section 40). But the judge must first be satisfied that there are reasonable grounds to believe:
 - that the child is suffering (or is likely to suffer) ill-treatment or abuse, or serious neglect, deprivation or harm; or
 - that the child is so seriously disturbed that they’re likely to act in a way that’s harmful to themselves or someone else, or likely to cause serious damage to property.

7.8 Te Tāhū Hauora Health Quality and Safety Commission

7.8.1 A new adverse events policy

Adverse events are events in which a person receiving health care experienced harm. The national adverse events policy (Health Quality & Safety Commission, 2023) provides a national framework for health and disability providers to continually improve the quality and safety of services for consumers, whānau and health care workers. It provides a consistent way to understand and improve through reporting, reviewing and learning from all types of harm.

The updated policy seeks to adopt a relational approach to health care, focused on meeting the needs of the people within the system. The previous policy highlighted that consumers should be involved in the investigation process, but their participation was often limited to providing their perspective of an adverse event and then receiving an apology and a report at the end. The aim of the 2023 policy is to improve consumer and worker safety by supporting organisations to heal, learn and improve following harm that occurs in health and disability services. The policy embeds Te Tiriti o Waitangi and a te ao Māori worldview, and puts a focus on relationships through whānau engagement, equity, restorative practice and hohou te rongo (peace-making) restorative responses.

The Aotearoa New Zealand national adverse event rating scale (see Figure 3) is applied to all events where harm has occurred.

Figure 3: Severity Assessment Code (SAC) descriptors

SAC descriptors for the rating of harm			
<p>SAC 1: severe</p> <p>Death or harm causing severe loss of function and/or requiring life-saving intervention</p> <ul style="list-style-type: none"> Not related to natural course of illness or treatment Differs from immediate expected outcome of care Can be physical, psychological, cultural or spiritual 	<p>SAC 2: major</p> <p>Harm causing major loss of function and/or requiring significant intervention</p> <ul style="list-style-type: none"> Not related to natural course of illness or treatment Differs from immediate expected outcome of care Can be physical, psychological, cultural or spiritual 	<p>SAC 3: moderate</p> <p>Harm causing short-term loss of function and/or requiring moderate additional intervention</p> <ul style="list-style-type: none"> Not related to natural course of illness or treatment Differs from immediate expected outcome of care Can be physical, psychological, cultural or spiritual 	<p>SAC 4: minor</p> <p>Harm causing no loss of function and requiring little or no intervention</p> <ul style="list-style-type: none"> Not related to natural course of illness or treatment Extra investigation or observation Review by another clinician Minor treatment Can be physical, psychological, cultural or spiritual <p>Includes near misses</p>

Source: (Health Quality & Safety Commission, 2023, p. 17)

The national process for reporting events to Te Tāhū Hauora must meet the following requirements:

- An initial notification (part A) of any SAC 1, SAC 2 or 'always report and review' (ARR) event will occur within 30 working days of the event being notified.
- A review will be undertaken using an approved review methodology.
- An anonymised final report (part B) highlighting the system learning opportunities and actions taken will be forwarded to Te Tāhū Hauora within 120 working days of the event being reported to the provider.

Lower levels of harm (SAC 3 and 4) will be analysed to create actions for improvement within a provider organisation.

7.8.2 A desire to implement restorative initiatives

The development of restorative initiatives is emerging in health and disability services globally. Restorative systems are distinguished by an emphasis on relational principles, practices and goals that promote and restore human dignity and wellbeing (The National Collaborative for Restorative Initiatives in Health, 2023).

The National Collaborative for Restorative Initiatives in Health (the Collaborative) formed in 2020 to nurture and guide the development of restorative initiatives within the New Zealand health and disability sector. The Collaborative engages with experts in mātauranga Māori, kawa and tikanga, and has foundational roots at Te Ngāpara Centre for Restorative Practice (Victoria University of Wellington, Te Herenga Waka) and Manatū Hauora Ministry of Health.

The Collaborative notes that in Aotearoa New Zealand, restorative systems and organisations are underpinned by five principles (The National Collaborative for Restorative Initiatives in Health, 2023, p. 10):

- Whakawhanaungatanga – systems are comprised of people and relationships
 - Whakapapa – human wellbeing and relationships are interdependent
- Tapu – restorative systems maintain and enhance dignity through relationships
 - Taiao – contextual conditions affect people and their relationships
 - Mahi Tahi – relationships are enhanced by co-production and co-design.

Restorative responses involve honest dialogue in a psychologically safe environment and are guided by a concern to address harms, meet needs, restore trust, mitigate repetition, and promote repair.

The Collaborative facilitated the development of policy and practice recommendations published in He Maungarongo ki Ngā Iwi: Envisioning a Restorative Health System in Aotearoa New Zealand (The National Collaborative for Restorative Initiatives in Health, 2023). The engagement process critiqued the status quo as costly, slow, and confrontational, proposing that responses perpetuated inequity, colonisation and injustice. Many people suggested that responses to harm could be traumatising, particularly when multiple drawn out processes were involved.

Te ao Māori has its own restorative response of hohou te rongo (peace-making from a te ao Māori worldview). Hohou te rongo is a kawa.¹³ This kawa exists widely throughout Aotearoa NZ and tikanga varies from iwi to iwi, hapū to hapū.

“The kawa is understood here as a process for addressing harm by restoring the mana (power and authority) and tapu of people, the environment and spiritual connections, and the relationships between them. The special relationship between the Crown and Māori under Te Tiriti o Waitangi has relevance for hohou te rongo, as hohou te rongo is a form of knowledge that is a taonga under Article II and the Article III obligation for the Crown to ensure equitable outcomes for Māori in responses to harm. The Crown has an obligation to resource iwi and hapū to protect and develop this mātauranga under their mana Motuhake.” (The National Collaborative for Restorative Initiatives in Health, 2023, p. 11).

The Collaborative made the following recommendations (The National Collaborative for Restorative Initiatives in Health, 2023):

- Restorative principles should be embedded across policy, programme delivery and practice standards that intend to mitigate and respond to healthcare harm.
- A navigation service for all serious harms should be provided (Tatau pounamu—the green stone door, the safe space).
- There should be partnership with educational providers, restorative practitioners, iwi and Māori to build capability and capacity in restorative practices and hohou te rongo.
 - There should be partnership with agencies, regulators, and other bodies to review the pursuit of restorative initiatives within current legislation to thus inform how legislation might be enhanced.
- Processes and practices that promote healing, learning and improving should be developed.
 - Restorative initiatives should be evaluated to develop evidence-based practice that appreciates what works, for whom, how and in what contexts will differ.

Importantly, the overarching principle for the inclusion of hohou te rongo in the framework is that it be developed within the Mātauranga Māori Directorate of Te Aka Whai Ora¹⁴ and guided by Iwi Māori Partnership Boards.

¹³ Kawa is the collective and agreed values, principles and protocols that connect whānau, hapū, iwi and Māori communities. There are other local terms including hohou rongo, hohou te rongopai, and hohou te rongo. The local term should take precedence in any reference to this kawa.

¹⁴ Te Aka Whai Ora has been disestablished and its functions transferred to the Hauora Māori Directorate of Te Whatu Ora Health New Zealand.

Part three: quality measurement

8. Quality measurement

This section provides brief commentary from the literature on quality and outcome measurement within a broader quality framework.

“When developing a quality framework, the focus needs to be on the impact that the service has on the quality-of-life of the people it supports primarily. This is referred to in the literature as outcomes and these outcomes need to be based on rights established in the UNCRPD and centred on the quality-of-life concept. This combined with indicators that look at the structures of a service, such as the resources available, staff ratio, equipment, facilities among others, as well as processes such as the way support is provided, will help in providing a comprehensive picture of the service’s quality...

...measuring the quality of services for persons with disabilities is a challenging mission for most service providers. The challenges arise not only from the lack of a mutually agreed definition on what quality is but also on how it can be measured and how this process can further support services to improve. Even if, in most of the countries, the assessment of quality in services is set out in legislation, they do not specify methodologies, indicators, and do not define quality, as well as translating the findings into practical recommendations and actions. In certain countries, also, the assessment of quality follows procedures, such as formal inspection visits, that are often closer to administrative processes in nature and do not provide services with the necessary means to develop and improve.” (European Association of Service providers for Persons with Disabilities, 2022)

8.1 Concepts for measuring quality and outcomes

Organisational factors, in addition to individual factors, impact the quality-of-life of people with disability, with provider quality playing a significant role in personal outcomes (Friedman, 2022). However, relying too much on process measures means that outcomes experienced by the individual, and measurement of progress towards individual goals are missed. Process-based measures can be criticised as too prescriptive, where compliance does not equate to quality, and there is no focus on continuous quality improvement (Bradley & Hiersteiner, 2022).

Traditional methods of monitoring public services measure inputs (e.g. funding, staffing) and outputs (e.g. programmes delivered, number of persons supported). However, there is a trend to develop person-centred models and quality improvement processes focusing on achieving personal outcomes—placing outcomes at the centre of design and accountability (National Disability Authority, 2019).

A commonly used concept of service quality has been Donabedian’s Structures-Process-Outcomes model (Donabedian, 1988). Donabedian suggested that the quality of services should be judged by the outcomes they produce and identifies three groups whose outcomes should be considered—those who use services, their families, and the staff that support them. For defining outcomes, the concept and principles of ‘quality-of-life’ have been widely applied.

Schalock and Verdugo (2014) identify five conceptualisation principles of quality-of-life:

1. Quality-of-life is made up of the same factors and relationships for all people (i.e. for those with and without disabilities).
2. Quality-of-life happens when we both have our needs met and have the opportunity to pursue life enrichment in the same life settings as others.
3. Quality-of-life has both subjective and objective elements but is primarily concerned with the views and perceptions of the individual on their life.
4. Quality-of-life is based on individual needs, choices and control.
5. Quality-of-life is a "multidimensional construct influenced by personal and environmental factors."

The European Association of Service Providers for Persons with Disabilities (2021) mapped quality-of-life domains identified by the Schalock et al. international consensus on quality-of-life (Schalock et al., 2002) to articles of the UNCRPD (either directly or indirectly).

Table 4: Quality-of-life domains with example indicators and relevant UNCRPD articles

Domain	Examples of indicators	UNCRPD articles
Rights (R)	Human rights, e.g. respect, dignity, equality, privacy, family life, freedom from harm Legal or civil rights, e.g. citizenship, access, due process, voting	5, 6, 7, 10, 11, 12, 13, 14, 15, 16, 18, 21, 22
Self-determination (SD)	Choices/decisions, autonomy, personal control, personal goals	9, 12, 14, 19, 21
Interpersonal relationships (IR)	Access to family, positive interactions with others, intimate and personal relationships, friendship, participating in social activities and events	23, 30
Social inclusion (SI)	Community presence/integration and participation in activities in the community Community roles and contributions	8, 9, 18, 19, 20, 21, 24, 27, 29, 30
Personal development (PD)	Access to education Skill development Meaningful occupation and demonstrating competence	24, 26, 27
Material wellbeing (MW)	Financial status Employment status Housing status Possessions	27, 28
Physical wellbeing (PW)	Health status, nutrition, recreation and physical activity, physical safety from abuse and basic physical needs met	11, 16, 17, 23, 25, 26, 30
Emotional wellbeing (EW)	Safety and security, happiness and contentment, positive experiences and self-esteem, lack of stress	15, 16, 17, 25, 26

Source: Reproduced from European Association of Service providers for Persons with Disabilities, 2022

There may be differences in how people with a disability conceptualise quality-of-life compared to people without a disability. An Australian survey study investigated whether there was a difference in

the ranked order of importance of quality-of-life dimensions between people with a disability and people without. It looked at differencing in the empirical rankings of key quality-of-life dimensions in three preference-based instruments. The study found that people with a disability placed higher importance on broader quality-of-life dimensions (e.g. control, independence, self-care) relative to health status focused dimensions (e.g. vision, hearing, physical mobility) (Crocker et al., 2021).

When creating outcome measures, designers need to take into account that just because one approach of measurement works for a selected sample, this does not mean it will work for everyone (Swenson, 2022). However, this flexibility can create issues.

For example, the US has Medicaid-funded Home and Community-Based Services (HCBS) for people with intellectual and developmental disabilities. States that operate this programme are required to measure and improve performance, and there was flexibility in choosing how they monitored compliance using their own performance measures. This flexibility introduced challenges in conceptualising and measuring quality at a national scale and hindered state comparisons of outcomes (Bogenschutz et al., 2022).

The European Association of Service providers for Persons with Disabilities (2021) suggested that there needs to be a toolkit of different measures, able to be tailored to specific services and individuals, rather than one set tool to be used across all settings.

8.2 Approaches across different countries

A scoping review and template synthesis (Beadle-Brown et al., 2023) gathered information on different countries' methods of defining and measuring quality in services for disabled people, and mapped them against the quality-of-life domains identified by the Schalock et al. international consensus on quality-of-life (Schalock et al., 2002).

Table 5: Different countries' frameworks mapped to quality-of-life domains

Framework/tool	To which Schalock et al. QoL domains could at least some domains or indicators be mapped?							
	PD	IR	R	SI	SD	MW	PW	EW
Frameworks where whole domains could be mapped								
Bigby et al. (2014, Australia)	X	X	X	X	X	X	X	X
The quality cube (Netherlands)	X	X	X	X	X	X	X	X
ASCOT – Social care related quality of life (UK and internationally)	X	X	X	X	X	X	X	X
Changing our lives quality of life standards (UK)	X	X	X	X	X	X	X	X
Social services quality standards (Czechia)	X	X	X	X	X	X	X	X
Personal outcomes measure (the US and internationally)	[X]	X	X	X	X			X
National quality forum framework AND the home and community-based services outcomes (US)	X	X	X	X	X	[X]		
National core indicators (US)	X	X		X	X	[X]		X
Quality of life outcomes domain framework (Ireland)	X	X	X	X	X	[X]	X	X

Framework/tool	To which Schallock et al. QoL domains could at least some domains or indicators be mapped?							
	PD	IR	R	SI	SD	MW	PW	EW
Frameworks where individual indicators, standards, or parts of domains could be mapped								
National standards for residential services for children and adults with disabilities (Ireland)	X	X	X	X	X		X	X
EQUASS (Europe)			X	X	X		X	
Guidance on a human rights-based approach in health and social care health services. By health information and quality authority (Ireland)			X	X	X		X	
National longitudinal transition study. Shrogen et al. (US)	X	X			X	X	X	X
Standards New Zealand health and disability services standard NZS 8134: 2021	X	X	X	X	X	X	X	X
Quality of life impact of services tool (QOLIS) (Europe)	X	X		X	X	[X]		X
Saska et al. (2021, Czech Republic)	X	X	X	X	X	X	X	X
National standards for disability services (Australia)	X		X	X	X		X	
NDIS Practice Standards and quality indicators (Australia)		X	X		X	X	X	X
Person-centred advocacy, vision, and education (US)	X	X	[X]	X	X	[X]	X	[X]

Note: SD (self-determination). MW (material wellbeing). R (rights). PD (personal development, including meaningful occupation). PW (physical wellbeing). SI (social inclusion). IR (interpersonal relationships). EW (emotional wellbeing). [X] (link is indirect or related to one indicator only, e.g. employment).

Source: reproduced from Beadle-Brown et al., 2023

The European Association of Service Providers for Persons with Disabilities explored the models of service quality used in a range of different social systems. There were differences between countries in terms of formal and informal systems of measuring the quality of services. However, most countries included appeared to have the assessment of service quality set out only as an overarching objective in legislation, rather than with definitions of methodologies specified. Where quality standards existed, they typically comprised rights, participation and self-determination, complaints, service management, and emergency situations. In the countries in which a set of quality indicators was applied, the focus was predominately on structures and processes rather than on individual outcomes (European Association of Service providers for Persons with Disabilities, 2022).

8.3 Putting quality measurement into practice

The use of observation to evaluate quality-of-life is time consuming and difficult to standardise, but there is growing interest in using it as part of the toolbox. Observation involves directly witnessing the experience of people and providing descriptions that are unconstrained by concepts and categories. This method can be particularly important in evaluating the quality of services for people with severe intellectual disabilities (National Disability Authority, 2019).

Person-reported measures are not equivalent to person-centred measures. Person-centred measures are not always suitable for benchmarking as they should be defined by the individual and not generalised (Roberts & Abery, 2023).

A literature review on outcome measurements found that developing tools to effectively measure outcomes relating to the individual (e.g. full societal participation) is challenging as operationalising these concepts is difficult. Additionally, designing measures of abstract or complex concepts that are able to take into account individual variations can be challenging (National Disability Authority, 2019).

The National Disability Authority of Ireland (2019) illustrated possible methods for outcome measurement for different purposes, noting that every purpose contains an individual outcomes evaluation to ensure outcome measurement always aligns with and promotes a person-centred culture.

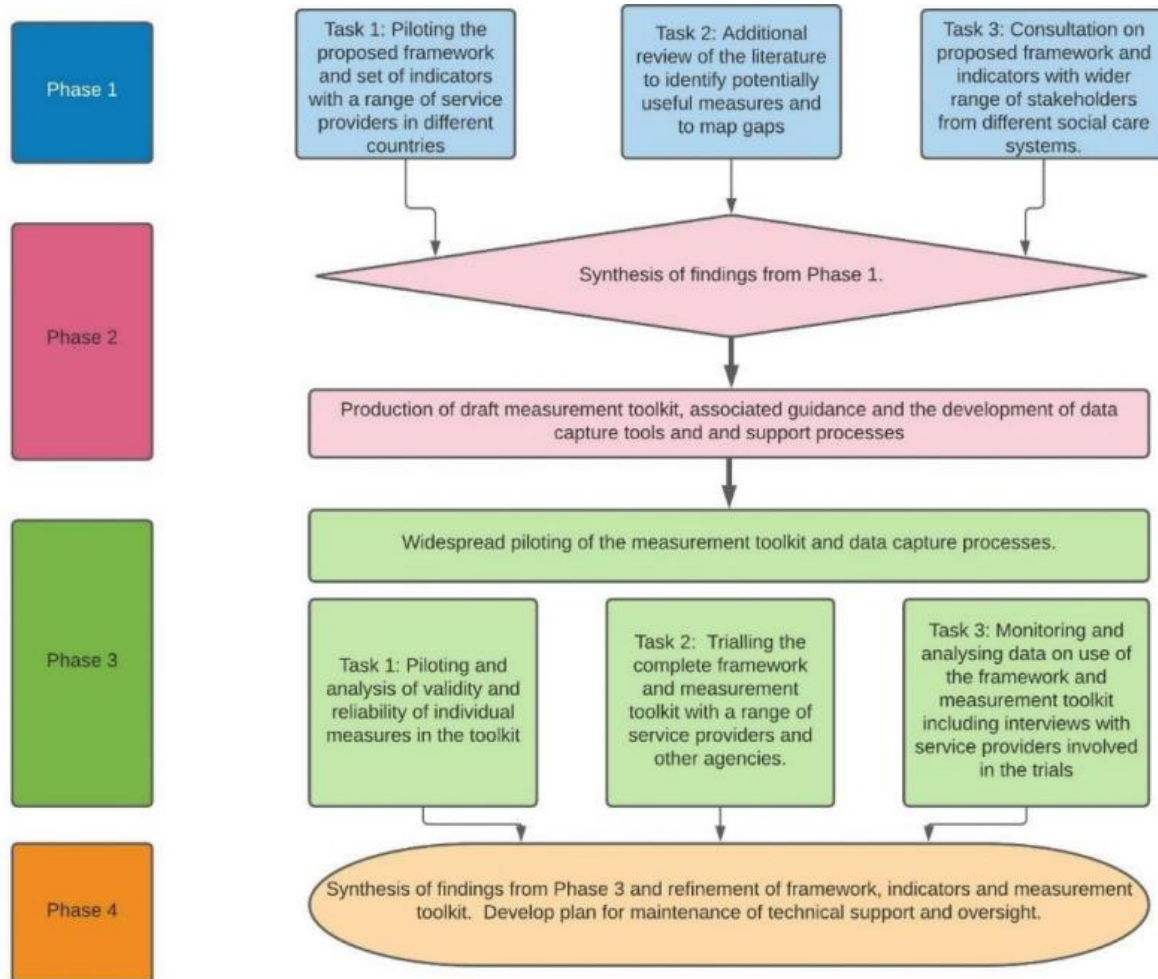
Table 6: Outcome measurement for different purposes

Evaluating individual quality-of-life outcomes	Evaluating quality of disability services	Quality improvement systems	Quality assurance
Evaluate quality of person-centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview + Interviews (where possible) + Observation + The use of standardised outcome indicators	Evaluate quality of person-centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview + Interviews (where possible) + Observation + The use of standardised outcome indicators + Evaluate presence or absence of outcome predictors	Evaluate quality of person-centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview + Interviews (where possible) + Observation + The use of standardised outcome indicators + Evaluate presence or absence of outcome predictors + Feedback from quality assurance processes + Plan and implement changes to services based on findings	Evaluate quality of person-centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview + Interviews (where possible) + Observation + The use of standardised outcome indicators + Evaluate presence or absence of outcome predictors + Standardised quality assurance tools (management responsibility, structures of management systems, etc.)

Source: reproduced from (National Disability Authority, 2019)

The European Association of Service providers for Persons with Disabilities states that frameworks, including design, developments and implementation, should be guided by a co-production approach, centralised around the “nothing about us without us” principle (European Association of Service providers for Persons with Disabilities, 2022). The group set out a suggested process for development, outlined in Figure 4.

Figure 4: Summary of process for the further development of a disability quality framework



Source: (European Association of Service providers for Persons with Disabilities, 2022)

8.4 Co-development of quality and outcome measurement approaches in Aotearoa New Zealand

In New Zealand, developmental evaluation and quality of life survey tools have been co-developed with disabled people and whānau, based on EGL principles and the relevant literature.

A high-level evaluation approach was designed for the system transformation prototype in MidCentral. The evaluation approach envisaged two components—longitudinal outcomes evaluation and social cost-benefit analysis. A baseline study was undertaken with one of its objectives to understand and measure the current experiences and life outcomes of disabled people and whānau in the MidCentral area (Standards and Monitoring Services, n.d., p. 5). Survey tools were developed to

gather data from disabled people, families and whānau, support workers and providers. The tools were linked to the EGL principles and Māori Disability Action Plan; and drew from other sources such as:

- the Treasury's Wellbeing Framework
- other quality of life surveys and questionnaires, including that developed by Schalock and Keith (1993)
 - evaluation frames of reference co-developed with disabled people and their whānau and previously used by Standards and Monitoring Services to assess life outcomes and quality of support (Standards and Monitoring Services, n.d.).

Developmental evaluation methodologies and tools support the 'Try, Learn and Adjust' approach to help drive meaningful change. There are four elements of the current outcome focussed evaluation tools for developmental evaluation (Ministry of Health, n.d.):

- quality of life outcomes for disabled people
- experience of disability supports
- organisational health
- value for money.

The tool has a range of indicators aligned to outcomes in seven areas:

- identity
- self-authority
- connections
- wellbeing
- contribution
- support
- resources.

9. Summary remarks

This section sets out some summary remarks based on the material compiled for this report.

New Zealand has ratified the UNCRPD, providing a fundamental rights basis for an improved quality framework. In Aotearoa New Zealand, Te Tiriti principles identified by the Waitangi Tribunal in its *Hauora* report are instructive for any DSS policy design, implementation and monitoring. Section 2.1.2 of this paper sets out some considerations as a starting point for a quality framework. However, there is a need for government agencies to constantly reflect on and, if necessary, change the way they are applying Te Tiriti o Waitangi principles in their work.

The EGL vision and principles provide the foundation for DSS development in New Zealand. There is an existing body of work that has made recommendations about an EGL-based approach to quality, representing a significant contribution by many disabled people and whānau, over many years. In relation to quality, there has been a call for independent voice mechanisms, better complaints and issue resolution processes that influence change, developmental evaluation, and improved data collection, outcomes measurement and reporting.

There is little published on quality framework elements that is directly relevant to Māori or other Indigenous peoples. An exception to this general pattern is a body of work in Canada exploring principles for an accessible and culturally appropriate complaints system. The lack of cultural safety for tāngata whaikaha Māori and calls for culturally appropriate services have continued for decades. The development of restorative initiatives is emerging in health and disability services with potential for inclusion of restorative responses from te ao Māori (to be led by Māori).

Other countries that we would compare ourselves to have legislation regarding disability service quality and safeguarding (e.g. the UK, Australia). Legislation places certain obligations on various actors in the system and can provide powers to investigate and intervene. Enshrining principles in legislation imposes duties to give effect to those principles when carrying out functions under the act. An evaluation of the Welsh Social Services and Well-Being Act found support for, and some positive impact of, its wellbeing principles, but identified that there can be a disconnect between legislative intent and operational reality.

The independent review into the Australian NDIS reveals issues with the implementation of a quality and safeguarding framework and regulatory regime. The focus has almost exclusively been on regulatory arrangements, with little attention to developmental supports such as capacity building, support to strengthen natural safeguards, and quality improvement initiatives. The review also noted the need for a quality framework to evolve and be updated to reflect changes. The review identified that the NDIS Commission has limited visibility of the market and few tools to respond to quality issues and recommended a more graduated and risk-proportionate provider registration system. However, the review and subsequent NDIS Provider and Worker Registration Taskforce noted the frustrations with the existing registration system and differing views on how a revised system should apply in practice. A large amount of work and consultation has occurred through both the review and taskforce, but further design work, in partnership with disabled people and the sector, is required. These processes are large and iterative undertakings.

In New Zealand, the recent report of the Royal Commission of Inquiry into Abuse in Care has made many recommendations, including legislation and a national care safety regulatory framework.

Measuring the quality of services can be a challenging mission. There may be a lack of a mutually agreed definition on what quality is, how it can be measured and how this process can be used to support providers to improve. There needs to be a focus on the impact supports have on quality of life, supplemented with indicators that look at the structures and processes of services and providers.

There is a body of literature on quality-of-life concepts and measurement. In New Zealand, developmental evaluation and quality of life survey tools have been co-developed with disabled people and whānau, based on EGL principles and the relevant literature.

Finally, we hope that this report serves as a useful reference and input to progression of an improved quality framework over time.

References

- Ahmed, S. (2006). The Nonperformativity of Antiracism. *Meridians*, 7(1), 104–126.
- Australian Government. (2018). *National Disability Insurance Scheme (Practice Standards—Worker Screening) Rules 2018*. <https://www.legislation.gov.au/F2018L00887/latest>
- Australian Government Department of Social Services. (2017, April 13). *NDIS Quality and Safeguarding Framework*. <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework-0>
- Baker, G., King, P. T., Jones, B., & Ingham, T. R. (2021). Meeting the Crown's te Tiriti o Waitangi commitments and obligations to Māori with lived experience of disability through the Health and Disability System Review. *The New Zealand Medical Journal (Online)*, 134(1535), 44–54.
- Beadle-Brown, J., Šiška, J., & Káňová, Š. (2023). Mapping frameworks and approaches to measuring the quality of transition support services for young people with intellectual and developmental disabilities. *Frontiers in Rehabilitation Sciences*, 4, 1043564. <https://doi.org/10.3389/fresc.2023.1043564>
- Bevin, N., Eggleton, K., & Herbert, S. (2023). Envisioning a Tiriti-responsive New Zealand Health Plan: Lessons from district health boards' annual plans. *New Zealand Medical Journal*, 136(1580). <https://nzmj.org.nz/media/pages/journal/vol-136-no-1580/envisioning-a-tiriti-responsive-new-zealand-health-plan-lessons-from-district-health-boards-annual-plans/34a0cbc014-1696474628/envisioning-a-tiriti-responsive-new-zealand-health-plan-lessons-from-district-health-boards-annual-plans.pdf>
- Bogenschutz, M., Dinora, P., Lineberry, S., Prohn, S., Broda, M., & West, A. (2022). Promising Practices in the Frontiers of Quality Outcome Measurement for Intellectual and Developmental Disability Services. *Frontiers in Rehabilitation Sciences*, 3, 871178. <https://doi.org/10.3389/fresc.2022.871178>
- Boxall, G., & Benjamin, M. (2012). *Enabling Good Lives in Canterbury*.
- Bradley, V., & Hiersteiner, D. (2022). Quality monitoring of intellectual and developmental disabilities systems in the US: Assessing the utility and applicability of selected National Core Indicators to national and state priorities. *Frontiers in Rehabilitation Sciences*, 3, 960996. <https://doi.org/10.3389/fresc.2022.960996>

- Cabinet Office. (2019). *CO (19) 5: Te Tiriti o Waitangi / Treaty of Waitangi Guidance*. Department of the Prime Minister and Cabinet. <https://www.dpmc.govt.nz/publications/co-19-5-te-tiriti-o-waitangi-treaty-waitangi-guidance>
- Caldwell, J., & Machledt, D. (2022). Advancing Policy and Practice in Medicaid Home and Community-Based Services Quality. *Frontiers in Rehabilitation Sciences, 3*, 876871. <https://doi.org/10.3389/fresc.2022.876871>
- Came, H., Manson, L., & McCreanor, T. (2022). A Critical Tiriti Analysis of the New Zealand Disability Strategy 2016-2026. *Review of Disability Studies: An International Journal, 18*(1 & 2). <https://www.rdsjournal.org/index.php/journal/article/download/1081/2587/8597>
- Care Act 2014 (2015). <https://www.legislation.gov.uk/ukpga/2014/23/contents>
- Carers UK. (n.d.). *Your guide to the Care Act (England)*. Your Guide to the Care Act (England). Retrieved 26 August 2024, from <https://www.carersuk.org/help-and-advice/guides-and-tools/your-guide-to-the-care-act-england/>
- Crocker, M., Hutchinson, C., Mpundu-Kaambwa, C., Walker, R., Chen, G., & Ratcliffe, J. (2021). Assessing the relative importance of key quality of life dimensions for people with and without a disability: An empirical ranking comparison study. *Health and Quality of Life Outcomes, 19*(1), Article 1. <https://doi.org/10.1186/s12955-021-01901-x>
- Curtis, E., Jones, R., Tipene-Leach, D., Walker, C., Loring, B., Paine, S.-J., & Reid, P. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health, 18*(1), 174. <https://doi.org/10.1186/s12939-019-1082-3>
- Darr, J. O., Franklin, R. C., McBain-Rigg, K. E., Larkins, S., Roe, Y., Panaretto, K., Saunders, V., & Crowe, M. (2021). Quality management systems in Aboriginal Community Controlled Health Services: A review of the literature. *BMJ Open Quality, 10*(3), e001091. <https://doi.org/10.1136/bmjopen-2020-001091>
- Davies, D. J. (2015). Quality improvement initiatives in a case management service: Case study. *Australian Journal of Primary Health, 21*(1), 14–21. <https://doi.org/10.1071/PY13111>
- Department of Health & Human Services. (2014, January 10). *Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule*. <https://www.medicare.gov/medicaid/home-community-based-services/downloads/hcbs-setting-fact-sheet.pdf>

- Department of Social Services, Australian Government. (2017). *NDIS Quality and Safeguarding Framework*. <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework-0>
- Donabedian, A. (1988). The quality of care. How can it be assessed? *JAMA*, 260(12), 1743–1748. <https://doi.org/10.1001/jama.260.12.1743>
- DPO Coalition, Ombudsman, Human Rights Commission. (2022). *Disability Rights: How is New Zealand doing? An update report about the state of disability rights in New Zealand*.
- Enabling Good Lives. (2024). *Summary of the Enabling Good Lives (EGL) approach*. <https://www.enablinggoodlives.co.nz/about-egl/egl-approach/enabling-good-lives-summary/>
- European Association of Service providers for Persons with Disabilities. (2021). *Innovative Frameworks for measuring the Quality of services for Persons with Disabilities*. <https://easpd.eu/resources-detail/report-on-innovative-frameworks-for-measuring-the-quality-of-services-for-persons-with-disabilities/>
- European Association of Service providers for Persons with Disabilities. (2022). *EU Framework on Social Services of Excellence for persons with disabilities Input of the Taskforce on Quality of Social Services for Persons with Disabilities First Reflections—December 2022*. https://easpd.eu/fileadmin/user_upload/Publications/First_Reflections_on_EU_Framework_on_Social_Services_of_Excellence_for_persons_with_disabilities.pdf
- Fortune, K. (2013). The impact of policy and legislation on Maori children with special needs in Aotearoa/New Zealand. *Support for Learning*, 28(1), 41–46. <https://doi.org/10.1111/1467-9604.12014>
- Friedman, C. (2022). The Impact of Human Service Provider Quality on the Personal Outcomes of People With Intellectual and Developmental Disabilities. *Frontiers in Rehabilitation Sciences*, 2, 780168. <https://doi.org/10.3389/fresc.2021.780168>
- Giedraityt, I. (2020). *Fact Sheet. Ireland. Financing of Care Services for Persons with Disabilities*. European Association of Service Providers for Persons with Disabilities.
- Hale, L., Bryant, K. P., Ward, A. L., Falloon, A., Montgomery, A., Mirfin-Veitch, B., Tikao, K., & Milosavljevic, S. (2018). Organisational views on health care access for hauā (disabled) Māori in Murihiku (Southland), Aotearoa New Zealand: A mixed methods approach. *New Zealand Journal of Physiotherapy*, 46(2), Article 2. <https://doi.org/10.15619/NZJP/46.2.03>

Health and Disability Commissioner. (2023). *Health & Disability Commissioner Annual Report 2023*.
<https://www.hdc.org.nz/media/wzpdch0g/hdc-annual-report-2023.pdf>

Health and Disability Commissioner. (2024a). *Report on complaints to HDC about Residential Disability Support Services*.

Health and Disability Commissioner. (2024b, April). *Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Service Consumers' Rights. A summary consultation document*.

Health Information and Quality Authority. (2013). *National Standards for Residential Services for Children and Adults with Disabilities*. <https://www.hiqa.ie/sites/default/files/2017-02/Standards-Disabilities-Children-Adults.pdf>

Health Information and Quality Authority & Mental Health Commission. (2019). *National Standards for Adult Safeguarding*.

Health Quality & Safety Commission. (2021). *Measuring culturally safe care through the patient experience surveys* (Safety Commission PO Box 25496). Health Quality & Safety Commission.
<https://www.hqsc.govt.nz/resources/resource-library/measuring-culturally-safe-care-through-the-patient-experience-surveys/>

Health Quality & Safety Commission. (2023). *Healing, learning and improving from harm. National adverse events policy*. Health Quality & Safety Commission.
https://www.hqsc.govt.nz/assets/Our-work/System-safety/Adverse-events/Publications-resources/AdverseEventsPolicy2023_Eng_Feb24update_WEB.pdf

Health Quality BC. (2022). *Sharing Concerns: Principles to Guide the Development of an Indigenous Patient Feedback Process*. <https://healthqualitybc.ca/resources/sharing-concerns-principles-to-guide-the-development-of-an-indigenous-patient-feedback-process/>

Health Services Executive. (n.d.). *Safeguarding Vulnerable Persons at Risk of Abuse National Policy & Procedures*.

Ingham, T. R., Jones, B., Perry, M., King, P. T., Baker, G., Hickey, H., Pouwhare, R., & Nikora, L. W. (2022). The Multidimensional Impacts of Inequities for Tāngata Whaikaha Māori (Indigenous Māori with Lived Experience of Disability) in Aotearoa, New Zealand. *International Journal of Environmental Research and Public Health*, 19(20), 13558.
<https://doi.org/10.3390/ijerph192013558>

- Joseph, R., & Benton, R. (2021). *Waking the Taniwha: Maori Governance in the 21st Century*. Thompson Reuters NZ Ltd. <http://store.thomsonreuters.co.nz/waking-the-taniwha-maori-governance-in-the-21st-century-ebk/productdetail/126608>
- King, P. T. (2019). *Māori with lived experience of disability – Part I* (WAI 2575; p. 22). Waitangi Tribunal. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575%2C%20B022.pdf
- King, P. T. (2021). *Oranga Mokopuna. Ethical co-designing for the pluriverse* [Doctoral Thesis., University of Otago]. <https://ourarchive.otago.ac.nz/esploro/outputs/doctoral/Oranga-Mokopuna-Ethical-co-designing-for-the/9926479033801891>
- King, P. T., Cormack, D., Edwards, R., Harris, R., & Paine, S.-J. (2022). Co-design for indigenous and other children and young people from priority social groups: A systematic review. *SSM - Population Health*, 18, 101077. <https://doi.org/10.1016/j.ssmph.2022.101077>
- Laverty, M., McDermott, D. R., & Calma, T. (2017). Embedding cultural safety in Australia's main health care standards. *The Medical Journal of Australia*, 207(1), 15–16. <https://doi.org/10.5694/mja17.00328>
- Llewellyn, M., Verity, F., Wallace, S., Calder, G., Garthwaite, T., Lyttleton-Smith, J., & Read, S. (2023). *From Act to Impact? Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014*.
- Machinery of Government Working Group. (2019). *Mana, Self-determination and Voice*.
- McGregor, B., Jones, B., Baker, G., & Tuuta, M. (2023). *Less talking, more action: Views and Experiences of Tāngata Whaikaha Māori in Wairarapa*. Te Aka Whai Ora. https://tekaruoteika.co.nz/wp-content/uploads/2024/02/2023_03_Less-Talking-More-Action-Views-and-Experiences-of-Tangata-Whaikaha-Maori-in-Wairarapa.pdf
- Ministry of Health. (n.d.). *Outcome Focussed Evaluation Tool for Community Residential Services for People with an Intellectual, Physical or Sensory Disability*. <https://www.whaikaha.govt.nz/for-service-providers/audits-and-evaluation/templates-and-tools-for-evaluators>
- Ministry of Health. (2013). *'Mid-Point' Developmental Evaluation Handbook*.
- National Disability Authority. (2019). *Outcome Measurement in Evaluating the Quality of Disability Services*. <https://nda.ie/publications/discussion-paper-outcome-measurement-in-evaluating-the-quality-of-disability-services>

National Disability Authority. (2022). *Transforming Disability Services*. National Disability Authority.
<https://nda.ie/transforming-disability-services>

National Disability Insurance Scheme (Code of Conduct) Rules 2018 (2018).
<https://www.legislation.gov.au/F2018L00629/latest>

NDIS. (2024). *What is the NDIS?* <https://www.ndis.gov.au/understanding/what-ndis>

NDIS Quality and Safeguards Commission. (n.d.). *NDIS Quality and Safeguards Commission: What does this mean for providers?* <https://www.ndiscommission.gov.au/providers/registered-ndis-providers/registered-provider-obligations-and-requirements#paragraph-id-2536>

NDIS Review Panel. (2023). *Working together to deliver the NDIS: Final Report*. Department of the Prime Minister and Cabinet, Australia.
<https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf>

Nikora, L., Karapu, R., Hickey, H., & Te Awekotuku, N. (2004). *Disabled Maori and Disability Support Options—A Report to the Ministry of Health*. University of Waikato.
<https://researchcommons.waikato.ac.nz/items/7ce6731c-363c-4e1b-916c-6580d071e3cc>

Office for Disability Issues. (2016). *New Zealand Disability Strategy 2016–2026*. Ministry of Social Development. <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf>

Oranga Tamariki Act 1989.

Ramsden, I. (2002). *Cultural Safety and Nursing Education in Aotearoa and Te Waipounamu, in Nursing* [Victoria University of Wellington: Wellington]. https://www.iue.net.nz/wp-content/uploads/2024/01/RAMSDEN-I-Cultural-Safety_Full.pdf

Roberts, M. A., & Abery, B. H. (2023). A person-centered approach to home and community-based services outcome measurement. *Frontiers in Rehabilitation Sciences*, 4, 1056530.
<https://doi.org/10.3389/fresc.2023.1056530>

Royal Commission of Inquiry into Abuse in Care. (2024). *Whanaketia Through Pain and Trauma, From Darkness to Light*.

Safeguarding Working Group. (2018). *Safeguarding Framework for the Prototype in MidCentral*.

- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6), 457–470. [https://doi.org/10.1352/0047-6765\(2002\)040<0457:CMAAQ>2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040<0457:CMAAQ>2.0.CO;2)
- Schalock, R. L., & Keith, K. D. (1993). *Quality of Life Questionnaire (QOL. Q)* [Dataset]. APA PsycTests.
- Schalock, R. L., & Verdugo, M. (2014). Quality of life as a change agent. *Int Public Health J*, 6(2), 19–34.
- Schmidt-McCleave, R. (2023). *Review for Whaikaha of policies, processes, and practices for managing complaints about IDEA Services Limited*.
- Signal, L., Cram, M. J., & Robson, B. (2008). *Health Equity Assessment Tool: A user's guide*. Ministry of Health. <https://www.health.govt.nz/system/files/2011-12/health-equity-assessment-tool-guide.pdf>
- Social Services and Well-Being (Wales) Act 2014.
- Social Services Committee. (2008). *Inquiry into the quality of care and service provision for people with disabilities*.
- Standards and Monitoring Services. (n.d.). *Baseline Study of the Disability Support System in the MidCentral Area: Survey Tools*.
- Standards New Zealand. (2021). *Ngā paerewa Health and disability services standard (NZS 8134:2021)*. Standards New Zealand.
- Statistics New Zealand. (2015). *He hauā Māori: Findings from the 2013 Disability Survey*. <https://www.stats.govt.nz/reports/he-haua-maori-findings-from-the-2013-disability-survey>
- Sunderji, N., Ion, A., Tang, V., Menear, M., Jansz, G., Wener, P., & Ghavam-Rassoul. (2019). *Advancing Collaborative Mental Health Care in Canada's Primary Care Settings: A National Quality Framework with Recommended Measures*. Mental Health Commission of Canada. <https://mentalhealthcommission.ca/wp-content/uploads/2022/11/Advancing-Collaborative-Mental-Health-Care-in-Canadas-Primary-Care-Settings.pdf>
- Swenson, S. (2022). Don't Look Down: The Limits of Meroscopic Measurement. *Frontiers in Rehabilitation Sciences*, 3, 873325. <https://doi.org/10.3389/fresc.2022.873325>

- Te Kāhui Kāhu. (2021). *Social Sector Accreditation Standards Level 1 (Version 5.5.2)*. <https://xn--tekhuikhu-7bbe.govt.nz/documents/what-is-accreditation/accreditation-standards/level-1-social-sector-accreditation-standards.pdf>
- Te Kāhui Kāhu. (2022, November 8). *Accreditation Levels*. <https://xn--tekhuikhu-7bbe.govt.nz/accreditation/levels.html>
- Te Kāhui Raraunga. (2023). *Māori Data Governance Model*. Te Kahui Raraunga. https://www.kahuiraraunga.io/_files/ugd/b8e45c_803c03ffe532414183afcd8b9ced10dc.pdf
- Te Puni Kōkiri. (2001). *He Tirohanga o Kawa ki te Tiriti o Waitangi*. Te Puni Kōkiri. <http://www.tpk.govt.nz/en/o-matou-mohiotanga/crownmaori-relations/he-tirohanga-o-kawa-ki-te-tiriti-o-waitangi/>
- The National Collaborative for Restorative Initiatives in Health. (2023). *He Maungarongo ki Ngā Iwi: Envisioning a Restorative Health System in Aotearoa New Zealand*.
- Tupou, J., Curtis, S., Taare-Smith, D., Glasgow, A., & Waddington, H. (2021). Māori and autism: A scoping review. *Autism: The International Journal of Research and Practice*, 25(7), 1844–1858. <https://doi.org/10.1177/13623613211018649>
- United Kingdom Government. (2016, April). *Care Act factsheets*. GOV.UK. <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets>
- United Nations Convention of the Rights of Persons with Disabilities (2006). <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Van Eden, K. (2013). *Putting People First. A Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services*.
- Wade, N., Borowick, M., O'Halloran, V., & Fels, A. (2024). *NDIS Provider and Worker Registration Taskforce Advice*.
- Waitangi Tribunal. (1999). *Te Urewera, part VI*. Legislation Direct.
- Waitangi Tribunal. (2001). *The Napier Hospital and health services report (WAI 692; Waitangi Tribunal Report 2001)*. Waitangi Tribunal. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_68596252/Wai692.pdf

Waitangi Tribunal. (2011). *Ko Aotearoa Tenei. A Report into Claims Concerning New Zealand Law and Policy Affecting Māori Culture and Identity* (WAI 262; Waitangi Tribunal Report 2011). Waitangi Tribunal.

https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_68356054/KoAotearoaTeneiTT1W.pdf

Waitangi Tribunal. (2015). *He Whiritaunoka: The Whanganui Lands Report*. Legislation Direct.

Waitangi Tribunal. (2019). *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry* (WAI 2575). Legislation Direct.

Waitangi Tribunal. (2021). *Haumarū: The COVID-19 Priority Report* (WAI 2575). Waitangi Tribunal.

https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_203737436/Haumarū%20W.pdf

Waitangi Tribunal. (2023). *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (reprint and update of 2019 report)* (WAI 2575; Waitangi Tribunal Report 2023).

Legislation Direct.

https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_195476216/Hauora%202023%20W.pdf

Welsh Government. (n.d.). *Social Services and Well-being (Wales) Act 2014 The Essentials*. Retrieved 26 August 2024, from <https://www.gov.wales/sites/default/files/publications/2019-05/social-services-and-well-being-wales-act-2014-the-essentials.pdf>

Whaikaha Ministry of Disabled People. (2023). *Monitoring, Evaluation, Analysis and Learning (MEAL) Detailed Strategic Framework*.

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