

# Equitable access to wellbeing

A shared framework for the disability and mental health and addiction workforces providing support for autistic people and people with learning disability who experience mental distress and addiction.



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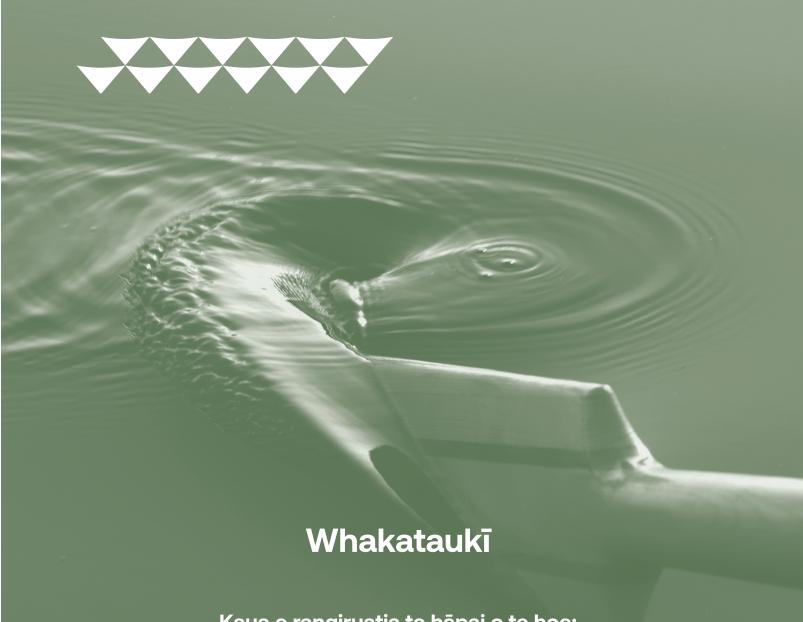
More than 160 people commented, representing a wide range of stakeholders including people with lived experience, whānau, Māori leaders, representatives from the health and disability workforces, specialist dual disability services, district health board clinical leaders and managers, Pasifika leaders, professional groups and associations, advocacy organisations and those from education and workforce development.

In particular, the authors would like to thank the 24 individuals with direct experience and their whānau who so courageously shared their stories.

To all of you, your generosity in sharing your thoughts and ideas has shaped the *Equitable Access to Wellbeing* framework.

E mihi nui nei ki a koutou katoa





Kaua e rangiruatia te hāpai o te hoe; e kore tō tātou waka e ū ki uta

Do not lift the paddle out of unison or our canoe will never reach the shore

This proverb serves to emphasise the importance of all working together to succeed in any joint project.

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# **Terms**

# Learning disability

Learning disability is usually referred to as intellectual disability by professionals. Through this document we use the term learning disability which is the preferred choice of People First New Zealand. Learning disability is a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behaviour**, which covers many everyday social and practical skills. This disability originates during the developmental period (AAIDD, 2021).

It is important to note that people with learning disability are a diverse group with a range of abilities, strengths and needs. The impact of learning disability on a person's life depends on the severity of their impairment and a range of personal and environmental factors (NSW Ministry of Health, 2017).

Mencap (n.d.), a UK network, offers the following definition which is reflective of the transforming disability agenda.

"A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

It's important to remember that with the right support, most people with a learning disability in the UK can lead independent lives."

Autistic people may also have learning disability, but many do not.



# **Autism**

Autism, or as it is formally diagnosed, Autism Spectrum Disorder (ASD), is a condition that affects communication, social interaction and adaptive behaviour functioning. Historically, there were separate diagnostic categories within autism these being autistic disorder, Asperger's disorder (Asperger syndrome), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS). In DSM5 these were combined into a single category of ASD.

The term ASD is still used widely internationally, however, increasingly many people (particularly adults) in the autism community, whether formally or self-diagnosed, prefer to use identity-first language to refer to themselves as being autistic, autists or Aspies. This recognises autism as a central part of their identity, rather than being a person "with autism". Some prefer to describe themselves as being on the autism spectrum, or as having autism or Asperger's. In this framework, the term "person on the autism spectrum" or "autistic person" is preferred and refers to someone understood to have met criteria for the diagnosis of ASD (Ministries of Health & Education, 2016).

# **Mental distress**

Mental distress (or psychological distress) is a term used, by some mental health practitioners and users of mental health services, to describe a range of symptoms and experiences that are held to be troubling, confusing or out of the ordinary. The American Psychological Association (n.d.) defines psychological distress as "a set of painful mental and physical symptoms that are associated with normal fluctuations of mood in most people. In some cases, however, psychological distress may indicate the beginning of major depressive disorder, anxiety disorder, schizophrenia, somatization disorder, or a variety of other clinical conditions. It is thought to be what is assessed by many putative self-report measures of depression and anxiety."

# Addiction

Addiction, in this framework, refers to a wide range of harms arising from substance use.



# Introduction

# Introduction

There are longstanding concerns in Aotearoa New Zealand regarding access to effective treatment and support for autistic people and people with learning disability who also experience mental distress and addiction. The Equitable Access to Wellbeing framework (the framework) has been developed in response to these concerns.

The framework is primarily to support the disability and mental health and addiction workforces. It sets out values, knowledge and skills needed by the health and disability workforces to support health and wellbeing for autistic people and people with learning disability and who experience mental distress and addiction, all of which may or may not be formally diagnosed. The framework has been developed collaboratively by people with lived experience and workforce stakeholders.

While the focus of the framework is autism and learning disability, our aim has been to 'design to the edges' rather than 'designing to the average' (TEDx Talks, 2013). Through this approach it is hoped that the framework will also benefit all disabled people and their whānau irrespective of the specific nature of their disability. For the workforces, the impact of the framework will benefit overall practice.

# Te Tiriti o Waitangi

The Māori text of The Treaty of Waitangi was the first official human rights document to be signed in Aotearoa New Zealand. It is known as the founding document of our country. The Māori text of the Treaty is recognised legally, both internationally and through the United Nations.

The Articles of the Māori text of The Treaty of Waitangi guide this framework and its implementation into a true partnership approach, as was agreed to in 1840.

In the context of this framework Te Tiriti Articles are identified as:

# 1. Kāwanatanga

> Partnership and shared decision-making

# 2. Rangatiratanga

> Protection and the revitalisation of Māori philosophy

### 3. Rite Tahi

- Equity
- > Participation
- > Equality and non-discrimination
- ) Improved outcomes in all sectors

Most Māori disabled people identify as Māori first. The importance of their cultural identity, which encompasses language, whānau, cultural principles, practices and linkages to the land through genealogy, is paramount to how they live their day to day lives in both Te Ao Māori and Te Ao Pakeha.

- New Zealand Disability Strategy 2016 to 2026

The framework seeks to support the wellbeing aspirations of Māori. It aims to support the actions outlined in the New Zealand Disability Strategy and contribute towards the vision of Whāia Te Ao Mārama 2018 to 2022: the Māori Disability Action Plan which is that tāngata whaikaha pursue a good life with support.

Whāia Te Ao Mārama confirms that tāngata whaikaha Māori would like to:

- participate in te Ao Māori (the Māori world)
- > live in a world that is non-disabling
- > have leadership, choice and control over their disability supports
- > be supported to thrive, flourish and live the life they want.

In alignment with Whāia Te Ao Mārama the framework seeks to contribute towards workforce practices and services that uphold the significance of te reo Māori, te Ao Māori and ensure access to Māori approaches to practice.

# Purpose of the framework

The framework aims to support autistic people and people with learning disability and the health and disability workforces to provide accessible and effective support and treatment so that people and their whānau are supported in their wellbeing and can have the lives they want.

The goals of the framework are to:

- describe best practice in support and treatment for autistic people and people with learning disability who experience mental health and addiction related needs
- outline a lived-experience perspective on best practice to support selfdetermination
- provide a map for ongoing professional development that can be used in education and training programmes and as a basis for individual and organisational development
- contribute towards workforce practices that promote equitable health outcomes for Māori and their whānau
- > support delivery of more inclusive mental health and addiction services through a more informed workforce
- support disability services to adequately meet the mental health and addiction needs of autistic people and people with learning disability, through a more informed workforce.

While acknowledging that there are diverse approaches and models, the framework seeks to provide shared values, knowledge and language, fostering an integrated way of working to support wellbeing regardless of approach, model, context and professional role.

The framework builds on and complements professional competencies, ethics, scopes of practice, and other skills frameworks. It draws on and reflects other key approaches including Whānau Ora, the Social Model of Disability, Wellbeing and Recovery, Enabling Good Lives, Te Whare Tapa Whā, the Fonofale model, Te Tau Titoki, and Let's get real. The Code of Health and Disability Services Consumers Rights is also acknowledged as a key document. The framework also draws on relevant international frameworks and research, adapting this to the Aotearoa New Zealand context.

# Who is the framework for?

The framework has two main audiences.

- The disability and mental health and addiction workforces.
- Whānau and autistic people and people with learning disability.

# The workforces: disability and mental health and addiction

The framework is for the disability workforce and the mental health and addiction workforce (working in primary, secondary and tertiary settings and services).

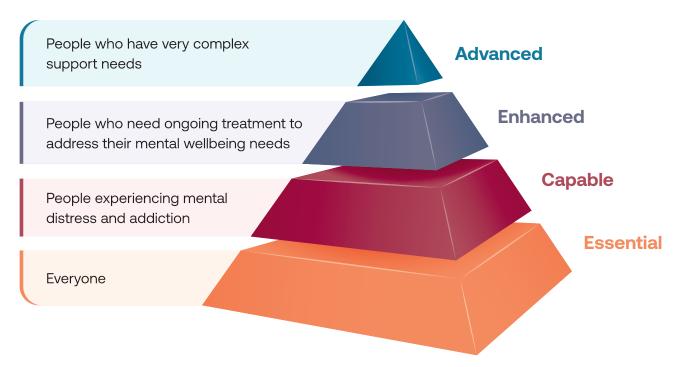
Autistic people and people with learning disability have the right to access effective mental health and addiction treatment and support. This should be available in all contexts in which such support is provided. Effective provision relies on skilled, confident, empathetic and supported workforces across the range of mental health and addiction services in all settings and all disability services. The framework seeks to support these workforces, recognising their commitment, professionalism and expertise, and acknowledging a need for further guidance, development, training and support.

While everyone in the health and disability workforces needs to respond effectively, the nature and complexity of the response can vary considerably. The framework recognises and outlines the differing responsibilities and requirements of different segments of the workforce.

- Those providing mental health and addiction related support and treatment need to understand how autism or learning disability may impact on a person's wellbeing. They also need to understand how to build on what they already know and do, to provide effective assessment, treatment and support for autistic people and people with learning disability in any setting where mental health and/or addiction support and treatment are provided.
- Those providing disability support and services need the skills to recognise the needs of people experiencing mental distress and/or addiction and know where and how to access appropriate input from mental health and addiction professionals when needed. This is so they can tailor support to address both disability and mental distress and addiction related needs.

As shown in Figure 1 below, the framework is based on the concept that as the complexity of people's wellbeing support and treatment needs increases, so should the skill levels of those providing support (Frieden, 2010).

Figure 1 People and workforce skills levels



# Notes to Figure 1.

# **Essential level (orange)**

Applies to all autistic people and people with learning disability and to the whole workforce, assuming everyone has knowledge of what makes a good life for people and how to get the best out of their talents. This level is about having/developing the skills to support people and whānau well, so they experience a high quality of life and therefore good mental health. It prompts the tailoring of supports to consider any previous trauma or mental distress. As an example, at this level the framework aims to support workforce development to ensure that practice reflects a values-informed approach, assessments are strengths based and resources are better targeted.

# Capable level (red)

Applies to autistic people and people with learning disability experiencing mental distress and addiction and those providing direct support to them. People included here may require additional assistance so they can reach their wellbeing goals. The workforces need more knowledge and skills to support their journey. As an example, at this level the framework aims to support a holistic approach to wellbeing so people can be confident they can have access to wellbeing based on what makes a good life for them.

# **Enhanced level (purple)**

Applies to a smaller group of autistic people and people with learning disability who need ongoing treatment to address their health and wellbeing needs, and the workforces providing that treatment and related support. As an example, at this level the framework aims to support the workforces to have a better understanding of enablers/disablers to people getting a good life and to ensure providers and supporters are equipped to play their part in the journey.

# Advanced level (blue)

Applies to a small number of people who need specialist treatment and support to access a good life, and those providing specialised treatment and support. As an example, the framework aims to support specialists to build capacity throughout the pyramid to minimise the need for interventions and maximise people's potential to live the life of their choice in the community through:

- identifying of best practice
- developing tools to implement best practice
- > providing input into generic and specialist training curricula.

# Whānau and autistic people and people with learning disability

The framework seeks to support whānau and autistic people and people with learning disability to:

- > develop their understanding of best practice responses to support wellbeing
- > strengthen their ability to participate as key partners in their support and treatment.

Noleen<sup>1</sup>, an autistic person who participated in stakeholder consultation, said she was keen to stay involved if the project continues. She stated "I feel proud to have shared my experiences, I am hopeful that it will help other people who have this (mental distress). It's ok to feel like this, never feel ashamed to be vulnerable."

Ricky, a person with learning disability who participated in stakeholder consultation, said he was keen to assist the project as it moves forward and was clear about the importance of the work. He stated, "We need change and we need it now!".

# Why is the framework needed?

Research overwhelmingly confirms that people with disability are much more likely to experience mental distress than the general population, however this is not reflected in the way related assessments, funding, supports, training, and services are provided in Aotearoa New Zealand.

People who are disabled and who experience mental distress and addiction have been caught between disability and mental health sectors, often resulting in them falling through the gaps and losing out both ways.

<sup>&</sup>lt;sup>1</sup> All names have been changed to protect the privacy of people who contributed to the quotes and examples in the framework.

Key considerations include the following:

- Autistic people and people with learning disability experience the same range of mental distress as the general population, but with significantly increased likelihood and higher incidence for some conditions.
- Addiction needs are often not recognised or addressed and disabled people are at risk of experiencing more negative consequences than non-disabled people.
- Autistic people and people with learning disability experience a higher rate of adverse life events than the general population, so good practice incorporates trauma informed care principles.
- Autism and learning disability can have a significant impact on communication, so alternative or augmentative communication skills are required.

# **System transformation**

This framework takes into account the principles of Enabling Good Lives and reflects the intent of the recommendations of He Ara Oranga and the aims and actions set out in Kia Manawanui Aotearoa: Long-term pathway to mental wellbeing.

Aotearoa New Zealand's health and disability system is undergoing change to better meet the wellbeing aspirations and needs of all New Zealanders. In 2021 the Government announced a new operating model made up of the Ministry of Health, in a stewardship role, Te Whatu Ora Health New Zealand, responsible for managing the health system, and Te Aka Whai Ora, responsible for ensuring the health system provides equitable outcomes for Māori. A newly established Whaikaha Ministry of Disabled People will work with these agencies and across Government, to create partnership between the disability community and Government and help drive ongoing transformation of the disability system in line with the Enabling Good Lives approach.

While there remains some uncertainty about how these changes will impact, the health and disability workforces will need the values, knowledge, and skills to effectively support disabled people experiencing mental distress and addiction.

Our tertiary vocational education sector is also undergoing transformation with work on the <u>Reform of Vocational Education</u> (RoVE) underway. This initiative is focused on skills that learners, employers and communities need to thrive, delivered by a unified, sustainable vocational education system that is fit for the future of work (Ministry of Education, 2019).

# **Equity**

The Ministry of Health defines equity as follows:

In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.

- Ministry of Health, 2019

Inequity is unacceptable and many factors that contribute to it are avoidable. People will experience better health outcomes when support is more easily accessed, more joined up and addresses social and cultural determinants that impact on wellbeing. All initiatives and efforts in health and disability must contribute towards achieving equity of outcomes for all. This means that those who experience disadvantage must be prioritised.

Disabled people experience inequity of outcomes, with those experiencing more than one disability being especially disadvantaged. Multiple environmental and social challenges impact on the health of disabled people, and on their access to health services. The United Nations Convention on the Rights of Persons with Disabilities aims to promote, protect and ensure the full and equal human rights and freedoms, and full participation of all disabled people, and to promote respect for disabled people's inherent dignity (Te Pou o te Whakaaro Nui & Ministry of Health, 2014). The Convention recognises mental health difficulties as a disability. It affirms that, among other rights, disabled people have a right to the same range, quality and standard of health care and programmes provided to non-disabled people. Further, it requires that health professionals provide care of the same quality to persons with disabilities as to others.

Māori are among those who experience the most disadvantage in New Zealand and addressing Māori health inequity is a key priority (Ministry of Health, 2021). Under Te Tiriti o Waitangi Māori have rights to have their health protected. A Waitangi Tribunal (2019) report (referred to as Wai 275) found that the Crown has systematically contravened obligations under Te Tiriti across the health sector.

Pasifika peoples also experience health inequity. The Ministry of Health has set an agenda to support the health and wellbeing of Pasifika communities in Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025.

While there is limited data on prevalence rates for autism and learning disability for Māori and Pasifika peoples, data on Aotearoa New Zealand disability rates, adjusted for age of population, indicates that Māori and Pasifika peoples have higher than average disability rates (Stats NZ, 2013). Data also suggests that Māori and Pasifika peoples experience compounding disadvantage. For example, for Māori, social and economic factors contribute to poorer disability outcomes i.e., lower income and poverty, higher unemployment and lack of education (Stats NZ, 2015). Further, the New Zealand ASD Guideline notes that "there is clear empirical evidence that Pacific people have poorer health status, are exposed to more risk factors for poor health and experience barriers to accessing services" (Ministries of Health & Education, 2016 p. 221). The impact of inequities in relation to the socioeconomic determinants of health is strongly reinforced by the Ministry of Health in Ola Manuia.

While there is limited data on the gender and sexual diversity of autistic people, the data available show that being members of rainbow communities<sup>2</sup> is more common among autistic people (Gender Minorities Aotearoa, n.d.). Equity includes access to gender affirming care, and gender and sexuality appropriate support services.

A focus on equity requires meaningful engagement with disadvantaged communities to understand their aspirations, worldviews, and requirements. It also requires workforces that can integrate cultural values, concepts, and practices, and eliminate racism, sexism, transphobia, homophobia and discrimination.

In this framework an equity lens has been applied to strengthen our workforces and services in contributing towards equitable outcomes for autistic people and people with learning disability.

<sup>&</sup>lt;sup>2</sup> Rainbow communities are defined as people who identify as lesbian, gay, bisexual, takatāpui, transgender, queer, intersex, asexual, and other non-hetero-non-cis identities.

# Overarching approaches

The Equitable Access to Wellbeing framework does not stand alone. It builds on the foundations of accepted best practice in health and disability.

In Aotearoa New Zealand key overarching approaches to disability and mental distress and addiction include:

- **> Whānau Ora:** a whānau-centred approach which has significantly influenced policy and practice over the past decade. Whanāu Ora requires integration across health, social and economic sectors.
- **The Social Model of Disability:** this model is widely adopted as an overarching approach in the disability sector.
- > The Wellbeing and Recovery approach: a key driver of policy and practice in the mental health and addiction sector.
- Penabling Good Lives: an approach currently offered in different ways in different regions. It will be rolled out nationally under the guidance of the newly created Ministry for Disabled People with a view to creating national system change to offer disabled people and whanau greater choice and control over their lives.

Each of these approaches has strong support from people with lived experience and whānau. Notably, cultural perspectives impact the way each approach is understood and applied.

This framework can be applied within any of these broader approaches. However, understanding the key concepts of each approach and their potential alignment is important. It helps us to work alongside people and whānau in an integrated way to support them to achieve wellbeing and have the lives they want. See Appendix 1. Table 1. which sets out key concepts within each approach and shows how they can align. It demonstrates that while key concepts for the approaches may not perfectly overlay each other, they can be complementary.



# Understanding the framework

# Understanding the framework

The framework sets out underpinning values and six skills.

Each skill is looked at from two perspectives.

# Lived experience perspective

The lived experience perspective shows the knowledge, skills, and outcomes expected by autistic people, people with learning disability and their whānau, to support their wellbeing.

# Workforce perspective

The workforce perspective gives the knowledge, skills and outcomes required to provide effective mental health and addiction support to autistic people and people with learning disability and their whānau.

Taken together they provide an overall picture of what is most important both to those receiving support and those delivering it.

The six skills have been informed by research alongside professional and lived experience. The framework can be used to inform the design and content of workforce development plans for everyone who is involved in supporting autistic people and people with learning disability who experience mental distress and addiction related needs.

Note: The aim is not to replace organisation or profession-specific values and competencies, but to reflect the shared values, knowledge, and skills that apply to all the workforces working specifically with autistic people and people with learning disability in relation to wellbeing, mental distress and addiction, across all health and disability settings and regardless of organisation, role or profession.

Equitable Access to Wellbeing provides a sub-set of the broader range of values, knowledge and skills needed to effectively support people and whānau. It adds to other relevant practice frameworks (such as *Let's get real*), professional competencies and codes, legal and regulatory requirements and organisational policies and procedures.

# Let's get real

Let's get real: Real Skills for working with people and whānau with mental health and addiction needs is a framework developed by people with lived experience and other stakeholders. It outlines values, attitudes, knowledge and seven Real Skills relevant to anyone working with people experiencing mental distress and addiction.

Let's get real provides a foundation for working with autistic people and people with learning disability who experience mental distress and addiction, so Equitable Access to Wellbeing has been intentionally built on Let's get real. It utilises the basic structure of Let's get real by setting out skills, outcomes and performance indicators at various levels. These are tailored for autistic people and people with learning disability as informed by research and stakeholder consultation.

Everyone utilising *Equitable Access to Wellbeing* is strongly encouraged to demonstrate the *Let's get real* values, attitudes, and the essential level seven Real Skills. Resources to support learning are available at <a href="www.tepou.co.nz/initiatives/lets-get-real">www.tepou.co.nz/initiatives/lets-get-real</a>. *Let's get real* provides the broader foundation needed to apply the skills in *Equitable Access to Wellbeing*.

# The structure of the skills in the framework

Each skill comprises the following.

- **Why we need this skill:** examples from interviews with people and/or whānau are provided to illustrate why the skill is needed.
- > Whakatauki: a proverb that captures the essence of the skill.
- > Overall summary statement: a summary of the skill in one or two sentences.
- Intended outcome: what we aim to achieve by applying the performance indicators associated with the skill.
- **Subheadings:** these are used in some skills to differentiate components of the skill.
- > Indicators: examples of the knowledge and/or skills that apply to each sub-heading at different levels: essential, capable, enhanced, and advanced.

# Indicator levels

The levels are defined as follows.

- > Essential: applies to everyone who interacts with, supports or provides treatment to autistic people or people with learning disability. This level applies to all, regardless of role or profession, setting or organisation.
- Capable: applies to those working in health and disability roles requiring the knowledge and skills to provide support to people experiencing mental distress and/or addiction related needs, for example experienced support workers. Those working at this level need to develop both the essential and capable levels as appropriate to their role.
- > Enhanced: applies to those working in roles requiring knowledge and skills to support people experiencing complex mental distress and addiction-related needs. For example, mental health clinicians, addiction practitioners, whānau advisors, complex support advisors, professional practitioners, and intensive support specialists. Those working at this level will also need to develop the essential, capable, and enhanced levels of the skills, as appropriate to their role.
- Advanced: applies to those providing treatment and support to people with mental distress and addiction related needs in specialist settings such as dual disability or forensic mental health services, and are providing supervision, mentoring, consultancy, and support to other professionals. Those working at this level will also need to develop the essential, capable, and enhanced levels of the Skills, as appropriate to their role.



# The importance of leadership

While workforce development activity can improve the knowledge and skills of the workforces, skilled leadership is vital to support implementation.

For this reason, a leadership statement has been included for each skill recognising the critical role of those who are able to influence and shape the structure, culture and climate of the context in which knowledge and skills are applied. It is acknowledged that this influence can extend beyond those in formal leadership roles.

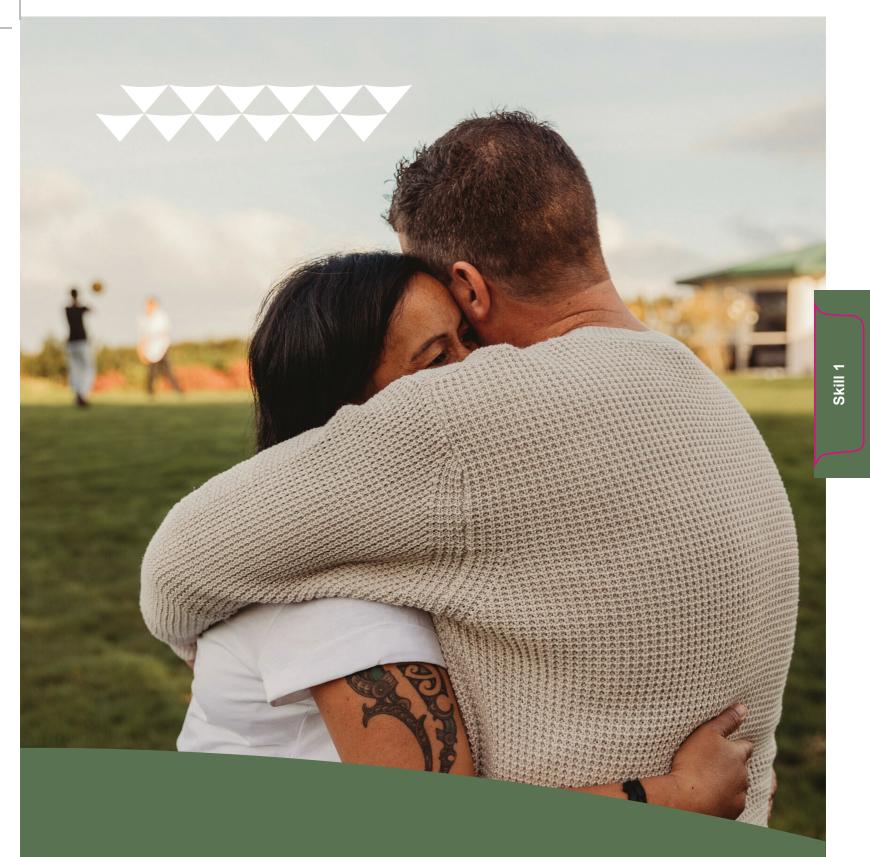
The challenges for leadership include fostering best practice and resolving many of the systemic issues that are known to create barriers to access and effective practice. These include siloed funding arrangements, inadequate technology, discriminatory service criteria, lack of clarity about roles, poor understanding between different approaches and services, a lack of cultural leadership and lack of leaders with lived experience.

# **Values**

Equitable Access to Wellbeing builds on the United Nations Millennium Values for Human Rights education. This collective kaupapa has been adapted for use in Aotearoa New Zealand.

- Aroha | Love
- > Whakaute | Respect
- Mana Motuhake | Freedom
- > Oritetanga | Equality
- > Whanaungatanga | Shared responsibility
- > Kotahitanga | Solidarity
- > Wairuatanga | Spirituality

The values help to guide our work in a way the reflects the intent of the Articles of Te Tiriti o Waitangi.



# Skill 1:

Understanding the barriers to people accessing supports and services to promote their wellbeing

# Skill 1 > Understanding the barriers to people accessing supports and services to promote their wellbeing

Why is this skill important?

Jan and her family have found little professional support to assist them to understand and have agency over their perspectives and diagnoses.

The internet has yielded some golden nuggets of information and resources that have assisted 'in spite of the system' and [personalised education] shows a way that personalised schooling can be offered, benefiting all pupils. The family see a complete change of life as being the next logical step to try to reduce the distress, particularly for their eldest who is clearly in crisis and at risk. They get good support from other family members and some friends/neighbours, where others don't understand or have been challenging. – Jan

Because of where he lives, Raymond can use his allocated resources for disability support more flexibly than elsewhere, so he could talk to his connector about switching some of his allocated resources towards sessions with a counsellor. An advocate could assist with this which [his support person] could arrange. Having someone he trusts who has the skills to understand both his autism and mental distress to assist in navigating his life journey may help Raymond to continue to make good decisions and achieve all that he wants to. – *Raymond* 



Contact with mental health services has been a disaster for Kerry over the past seven years. Their "rigid and narrow" diagnosis has been borderline personality disorder and everything they do (and perceive Kerry to do) then flows from that. Any questioning is countered by anyone in the mental health system as relating to Kerry's personality disorder and how things are 'manipulated' by her, leading to a vicious circle. Kerry's mental distress has been profound with many attempts on her own life up to a year ago (and one since then). By chance she then saw a health improvement practitioner (HIP) who happened to specialise in autism. Community health services were a barrier to any autism assessment but Kerry persisted and was diagnosed as being autistic. It was a pivotal moment for Kerry as she could now understand why she felt the way she did and acted as she did. With the diagnosis came support and an important connection with [service].

She soon found that her treatment from community mental health services was completely counter to what she needed. For example, being told to go out and socialise leading to over stimulation and 'autistic burnout'. Since then, Kerry's life has transformed. It is not easy but having people around her that she trusts and who work with her to address the daily challenges eg, remembering to eat (with timely prompts) and having strategies around how and when to shop, etc. These align well with the six skills required by the workforce (within the framework). – *Kerry* 

# Whāia te mātauranga, hei oranga mōu

# Attain knowledge for the benefit of your wellbeing

Everyone working in health and disability understands that autistic people and those with learning disability experience the same range of mental distress and addiction related needs as other people and have equal rights to support and treatment.

# **Expected outcome**

Autistic people and people with learning disability are supported in their wellbeing by skilled workforces.

# **Performance indicators**

# Lived experience perspective

# Awareness and knowledge of the barriers to wellbeing

# **Essential**

People in my life know about my culture and support me in a way that respects my culture/s.

I am involved in decisions about how I am supported to determine my health and wellbeing, so everyone close to me is clear about what I want and what I want to happen if I become unwell.

My whānau and I have good information, provided in the way I understand best so I can make informed decisions about addictive substances.

I am supported in a way that has regard to any bad experiences I have had in my life; this goes for my whānau as well.

People in my life respect me and take time to build a relationship with me, so they know what I like and what I am good at.

People in my life avoid doing things that make me upset or unwell.

People in my life can spot when things are not going well for me and know what to do to get the right help.

### **Essential continued**

People work at my place and at my pace.

People in my life respect my sexuality and gender, and support me to make my own choices in this aspect of my life.

# **Capable**

People respect my preferences about involving support that is relevant to my culture eg, whānau/elders etc.

If I need additional help with my wellbeing, managers/agencies know how I feel about involving family.

If you know me then you will be in a much better position to help me.

If you respond to my situation quickly then it may prevent me from becoming more unwell and we can build more trust.

If you use methods that are proven to work, then my wellbeing will improve faster.

If you don't have time to see me/support me in these ways, then I would like to have the opportunity to complain.

I would like to be able to access the same types of supports and services that are available to everyone else but for these to be tailored to my needs.

### **Enhanced**

I understand that I may need more specialised help sometimes.

People providing mental health and addiction treatment know what is best for me and advise the people who are close to me about how best to support my recovery/maintain my wellbeing.

# Performance indicators > Lived experience perspective continued

### **Advanced**

I expect to have access to people who are specialists in the things that support me and my wellbeing.

I want these specialists to be able to advise whānau and other people who are supporting me to have a good life about what is likely to work for me.

I want these specialists to monitor this work so I can have confidence that my whānau and I will not get forgotten about.

I want these specialists to believe in the rights of disabled people as set out in the UNCRPD.

I want these specialists to keep up with what works best to support someone in my circumstances to get the opportunity to have a good life.

# Trauma informed approach

### **Essential**

People in my life know that there's quite a high chance that I have had bad things happen in my life such as violence from others, sexual abuse, emotional abuse, financial abuse, neglect, and bullying.

People in my life know that people react to bad things that happen to them in different ways.

People in my life know that bad things don't just happen to people on their own; they can happen to whanau and groups and communities.

People in my life take the time to build trusting and supportive relationships with me. They check in to make sure I feel safe. They make sure I feel safe where I am.

### Capable

People supporting me show that they understand what might be going on for me (and my whānau) if bad things have happened to me/us.

People supporting me know to check out what has happened to me, rather than looking for what is wrong with me.

People in my life respond positively to my choices around sexuality and gender.

People show that they understand that there can be a lot of bad things that happen for Māori people, such as colonisation, racism and discrimination, negative stereotyping, being told it's bad to be Māori and other bad things.

People know about the effects of colonisation including people losing ties with whakapapa, language, and cultural identity.

People know that being connected to your culture helps my wellbeing. They can help me get kaupapa Māori support and treatment if my whānau and I need that.

People know that Pasifika and other migrant groups have bad things happen because of being in a new place that is different from home.

People know about how important it is to build trusting relationships with Pasifika families.

People make my safety a priority. They listen respectfully and try to understand what it is like for me if I talk about bad things that have happened to me.

People get help from the right people if that's what I or my whanau need.

#### Performance indicators > Lived experience perspective continued

#### **Enhanced**

People helping me can recognise when I have had bad things happen to me; they let me know that me and my whānau can get well and heal.

People know how to work with me if bad things have happened to me.

- They help me to get support that fits my cultural world view and they know how important this is and that it is a right for Māori people.
- They know me and my whānau need to be strong in who we are and be connected to our culture.
- They know about the higher risks of me getting physical health problems and mental distress and problems with alcohol and other drugs.
- They support me in a way that fits with my strengths and needs.

#### **Advanced**

Specialists know a lot about what it can be like if bad things happen to people and what that might mean for me and my whānau.

Specialists know a lot about how to work with me and my whānau when we have had bad things happen to us.

Specialists support other people to work with me and my whānau when we have had bad things happen to us.

# Leadership performance indicators

- The people who support me show that they understand that my whanau and I are experts in and need control over our lives and experiences.
- ) I determine what makes a good life for me!
- > The people who support me work well together to ensure I can do the things I choose.
- > The people who support me respect my culture, values and beliefs.
- The people who support me respect my sexuality and gender.



#### **Performance indicators**

# Workforce perspective

# Awareness and knowledge of the barriers to wellbeing

#### **Essential**

Describes the difference between learning disability and mental distress.

Describes the difference between autism and mental distress.

Demonstrates understanding that autistic people and those with learning disability can experience mental distress and/or addiction related needs.

Describes at least one experience of mental distress and/or addiction related needs common to autistic people and people with learning disability.

Describes the impact of different factors on wellbeing for the person being supported (cultural, environmental, physical, economic, psychological, social, spiritual, sexual).

Demonstrates understanding of the importance of a person's gender, culture, age, ability, sexual orientation and spirituality.

Demonstrates understanding of the importance of whānau and wider support networks in supporting the wellbeing of autistic people and people with learning disability.

Demonstrates awareness that some autistic people and people with learning disability experience negative consequences related to use of alcohol and other drugs.

### Capable

Demonstrates understanding of the role of whānau and wider support networks regarding a person's wellbeing.

Describes a holistic view of wellbeing and is familiar with Te Whare Tapa Whā and Fonofale models of wellbeing.

Recognises that autistic people and people with learning disability require supports tailored to both their disability and their needs relating to mental distress and addiction.

Recognises early signs of mental distress and seeks advice on support options for the person.

Demonstrates understanding of the impact (positive or negative) of the support environment on the person's wellbeing.

Demonstrates understanding that alcohol and other drug use can be viewed as occurring on a continuum.

Demonstrates awareness of a harm reduction approach to supporting autistic people and people with learning disability with addiction needs.

Demonstrates awareness that addiction related needs can be masked by autism or learning disability.

Demonstrates understanding that autistic people and people with a learning disability have diverse sexualities and genders.

Demonstrates awareness that autistic people and people with learning disabilities can experience the need for gender related medical treatment.

#### Performance indicators > Workforce perspective continued

#### **Enhanced**

Demonstrates understanding that people with learning disability or autism experience higher rates of mental distress than the general population.

Responds to early signs of mental distress through tailored support strategies or referral for specialist help in collaboration with the person.

Demonstrates understanding that autistic people and people with learning disability may have atypical symptoms of mental distress and addiction, particularly those displayed through changes in behaviour.

Demonstrates understanding of specialist mental health and addiction assessments and integrates recommendations into support strategies.

Demonstrates understanding of key principles of a harm reduction approach to alcohol and other drug issues.

Demonstrates understanding that autistic people and people with learning disability are at greater risk of experiencing severe consequences from alcohol and other drug use.

- Increased social isolation.
- Problems with the criminal justice system.
- Victimisation while intoxicated.
- Increased cognitive problems.
- Reduced impulse control.
- > Health problems.
- Serious side effects from interactions with other medications.

Demonstrates awareness that best-practice affirming approaches to gender-related treatment and support are part of treating mental distress.

#### **Advanced**

Understands neurobiological impacts of learning disability or autism on vulnerability to mental distress.

Understands differential diagnosis of behaviour as a symptom of mental distress.

Understands syndrome-specific vulnerabilities and common co-occurring conditions.

Demonstrates ability to apply best practice national standards and pathways with reference to gender-related support and treatment.

Teaches others about best practice in supporting a person with complex mental health needs in addition to autism and/or learning disability.

# Trauma informed approach

#### **Essential**

Demonstrates understanding that autistic people and people with learning disability have increased vulnerability to adverse experiences. For example: violence from others, sexual abuse, emotional abuse, financial abuse, neglect, and bullying.

Demonstrates understanding that people experience trauma in different ways and that the impact of trauma is influenced by a person's past experiences and culture.

Demonstrates understanding that trauma can be experienced by individuals, whānau and groups and communities.

Demonstrates understanding of the importance of building trusting and compassionate relationships and establishing safety, including a safe environment, for autistic people and people with learning disability.

#### Performance indicators > Workforce perspective continued

### **Capable**

Demonstrates a basic understanding of the impact of trauma and loss on people's wellbeing.

Demonstrates understanding that trauma is not always obvious and that responses to trauma, for example behaviour, can be misunderstood. For example: behaviour, can be misunderstood.

Demonstrates understanding that autistic people and people with learning disability are at high risk of trauma around sexuality and gender, and that this is best treated with a best practice affirming approach.

Demonstrates understanding that Māori people can experience trauma related to colonisation, racism and discrimination, negative stereotyping, negative indoctrination about being Māori and other adverse experiences.

Describes effects of colonisation including severed ties with whakapapa, separation from language, and loss of cultural identity.

Demonstrates understanding that cultural connection, including access to kaupapa Māori support and treatment, contributes to better outcomes for Māori.

Demonstrates understanding that Pasifika and other migrant groups can experience trauma related to experiences of immigration, blending of two cultures, and loss of cultural identity.

Demonstrates understanding of the importance of building trusting relationships with Pasifika families.

Prioritises the person's safety and listens to understand if a person raises traumatic experiences; seeks skilled help as needed.

Seeks help from relevant skilled clinicians and/or cultural advisors when signs or potential signs of trauma are identified.

#### **Enhanced**

Demonstrates understanding of signs that autistic people and people with learning disability have experienced trauma and loss.

Recognises and validates trauma and communicates belief in a person or whānau's potential to heal.

Demonstrates knowledge of how to work in a trauma-informed way with autistic people and people with learning disability and whānau.

- > For Māori, ensures provision of trauma-informed approaches that reflect understanding of a Māori worldview and cultural experiences as Māori.
- Demonstrates understanding of the importance of strengthening cultural identity and supporting cultural connectedness in healing from trauma.
- Understands that the increased likelihood of being exposed to environmental stressors means people are at a higher risk of having their resilience compromised and developing physical health problems and mental distress and addiction.
- Adapts support strategies to take into account the person's needs arising from learning disability and/or autism and the effects of trauma.

#### **Advanced**

Demonstrates an in-depth knowledge of the impact of trauma on autistic people and those with learning disability.

Demonstrates in-depth understanding of how to work in a trauma-informed way with autistic people and people with learning disability and whānau.

Supports others to work in a trauma-informed way.

#### Performance indicators > Workforce perspective continued

# Leadership performance indicators

- Develops and maintains understanding of the barriers that prevent autistic people and people with learning disability accessing supports and services that optimise their wellbeing.
- Ensures systems, processes and resources enable staff to develop and maintain understanding of the needs of autistic people and people with learning disability.
- Identifies and works to address gaps in understanding of the needs of autistic people and people with learning disability to support service access and delivery and to enable staff to demonstrate best practice.
- Provides leadership to enable a holistic approach to the wellbeing of autistic people and people with learning disability and whānau.
- Fosters understanding of culturally responsive approaches, the importance of direct experience perspectives and a trauma informed approach when working alongside autistic people and people with learning disability and whānau.



# Skill 2:

Communication about mental distress and addiction

# Skill 2 > Communication about mental distress and addiction

Why is this skill important?

Rees seeks criticism from people he meets.

This includes the police who are sometimes called when Rees is distressed. He presents as being dishevelled and vulnerable when he seeks such criticism from strangers. The police usually deal with him well and often take him to the police station where they contact the crisis mental health team – "they [the mental health team] don't assist though".

Family perseverance to get help through the local MP and Rees's persistent and escalating threats of self-harm, finally resulted in admission to a mental health facility, but even then the facility was reluctant to admit him citing his Asperger's Syndrome being a barrier for them to support him.

Family pressure enabled a stay for three weeks but the Privacy Act was used to keep family at arm's length through this time. All in all, it has been a battle for family to engage with professionals rather than an alliance. Mum despairs at this and has volumes of files that record and emphasise her disappointment and feelings of being let down. She feels the family has been batted around between disability and mental health services with none really taking an interest or responsibility. She desperately wants local services to step up so she can step back. – **Rees** 



James also gets upset when he is treated badly. For example, if people speak to him as if he is a child. This can lead to him displaying anger and frustration (described as an outburst) and then feeling bad about how he reacted. He sometimes returns to the situation to apologise and try to make it clear why he was upset. James is a very capable and respected leader in the disability sector but, somewhat ironically, can often feel disempowered by staff who support him.

One example was when they didn't inform him a NASC assessor was visiting. Another was a new manager who was apparently allergic to cats so he was told his cat would have to be removed from the house so she could visit. There are many other examples and there is a pattern of the support provider not learning. – **James** 

Communication was and is the most important thing. When this goes wrong Mark displays high levels of anxiety and frustration. He received therapeutic support at school but there was a

disconnect between this and his everyday home life. The further Mark fell behind, the more frustrating it was for him and at age 12 he was receiving behavioural support services. The range of interventions from different professionals (Speech/Language, Occupational Therapy, Physiotherapy, Behaviour) often conflicted and they didn't necessarily listen to the expertise from the family. Advice seemed generic and not tailored. Mark's distress manifested in dangerous head banging on the floor.

Mark had a lot of health interventions. He had some sight but that has deteriorated irreversibly to the extent of now only having some light recognition. Time to support him develop coping strategies through that period was wasted/lost irretrievably. Escalating behaviour resulted in multiple police and ambulance interventions and 19 hospital admissions in one year. The focus on behaviour missed medical complications and the accompanying pain Mark was in.

One example was a severe ear infection. Only Mum's insistence unravelled the ear infection which, once addressed, calmed Mark, but it took a long time. Then, by chance, he ended up on a mental health ward for the elderly which was a game-changer. The skills the staff had in working with people with dementia etc. worked with Mark. They also looked at Mark in a holistic way so they got to know him as a person and build trust and rapport. They could see the issues were more medical than psychiatric. For example, constipation was attended to and teeth were fixed. – *Mark* 

## Ko te kai a te Rangatira, he korero

#### Communication is the food of chiefs

Everyone working in health and disability considers the specific communication support needs of autistic people and people with learning disability and enables them to make decisions about their support and/or treatment.

## **Expected outcome**

Autistic people and people with learning disability have the support they need to give and receive information relevant to their mental health and addiction treatment and support.

#### **Performance indicators**

# Lived experience perspective

#### **Essential**

I have information in the way I understand best that describes my unique circumstances.

I am assisted to indicate to others when I feel distressed.

#### **Capable**

People/services tailor their response to my situation and take notice of where I feel safe and how I like to be communicated with.

People understand what my behaviour communicates and know what to do to ensure I feel safe, calm, and well supported.

#### Performance indicators > Lived experience perspective continued

#### **Enhanced**

I expect mental health and addiction professionals across all settings to take the time to make sure they know what is best in my circumstances and communicate this clearly to me.

I want people to be trained in the best supported decision-making practices, so I am empowered to exercise my rights and make decisions with or without people who are close to me including my whānau, as appropriate.

#### **Advanced**

I want the specialists to find ways to make sure that wherever I live in Aotearoa New Zealand, I can get the expertise I require at the time I need it and in forms I can understand and influence.

I want my experience to be collected and communicated anonymously in ways that improves what happens to people in the future.

# Leadership performance indicators

- I have everything I need to make decisions about how I live my life.
- I feel good about my authority in making decisions about how I live my life.
- My whānau are respected as partners in my treatment and support; they are appropriately engaged; their input is valued, and they are communicated with in timely and appropriate ways.

#### **Performance indicators**

# Workforce perspective

#### **Essential**

Describes how a person they support communicates when they are experiencing mental distress and/or addiction related needs.

Supports the person with strategies for communicating wellbeing needs to others.

#### **Capable**

Demonstrates understanding that behaviour is a form of communication.

Demonstrates understanding of the person's communication support needs and the impact of communication difficulties on their wellbeing.

#### **Enhanced**

Actively supports and empowers people to exercise their rights and make decisions about their wellbeing and life, which may require the involvement of whānau, guardians and/or other support people.

Takes the time needed to know the person and their context to support self-determination and shared decision making.

Demonstrates understanding of informed consent and applies a supported decision-making approach tailored to the person's needs to achieve this whenever possible.

#### Performance indicators > Workforce perspective continued

#### **Advanced**

Demonstrates the ability to assess the capacity of a person with learning disability to understand information and make decisions about their mental health care.

Confirms that the person, their whānau and support network are aware of the clinical process, and understand their right to be informed, give or withhold informed consent, and of their right to participate in their mental health care.

Develops tools to assist autistic people and people with learning disability and their supporters to monitor wellbeing.

Develops wellbeing plans, strategies and treatments in a format that can be understood by autistic people and people with learning disability and their supporters and communicates optimum implementation approaches with relevant people/services.

# Leadership performance indicators

- Ensures systems enable staff to demonstrate best practice in communicating with autistic people and people with learning disability and whānau about wellbeing.
- Addresses barriers which may prevent best practice in communication about wellbeing.



# Skill 3:

Support with living well: physical health and lifestyle

# Skill 3 > Support with living well: physical health and lifestyle

Why is this skill important?

Tracy had a serious health condition which caused chronic pain. This contributed to her experiencing severe mental distress. Tracy harmed herself which resulted in her being referred to the mental health system where, over time, she received diagnoses of both Bi-Polar Disorder and Borderline Personality Disorder. Her learning disability diagnosis was removed and, although now Tracy sees this as being correct, it had a disastrous impact of removing her access to disability supports at the time. There was also a clear mismatch between her mental health interventions and her autistic needs – the former not taking account of the latter – so things got worse. – *Tracy* 

Anna lives in a residential facility with three other women who are all non-verbal. As with any shared situation, there are tensions including around personal belongings. Staff are generally from different backgrounds and cultures. Wrong assumptions can be made about a resident's needs (eg, spiritual preferences with the example of assuming an Asian resident wanted to go the Temple as they didn't realise she was Catholic). House diets may reflect staff rather than resident likes. There is a high turnover and internal transfers which often don't fit well with what families want. – **Anna** 



Meri spoke about her experience of giving birth to her son when she was also struggling physically with Carpel Tunnel Syndrome. Her experience was that the midwife and most hospital staff didn't understand her learning needs or physical restriction and she felt blamed rather than supported to parent. One exception was the anesthetist who was initially horrible but became much more helpful when he realised Meri had a disability. Meri has a partner of six years who also has a learning disability. He was denied the opportunity to be at the birth of his son as they felt he wouldn't cope. – *Meri* 

#### Mauri tū mauri ora

#### An active soul, is a healthy soul

Everyone working in health and disability understands the impact of physical health and lifestyle choices on wellbeing.

### **Expected outcome**

Autistic people and people with learning disability receive support or treatment which promotes physical health, positive lifestyle choices, and activity to increase wellbeing.

#### **Performance indicators**

# Lived experience perspective

#### **Essential**

My life choices are decided by me with the support of people who are closest to me who I trust as evidenced by the supported decision-making process if needed.

#### **Capable**

People who support me are supported by their managers/agencies when I make my lifestyle choices.

People who support me know how I want my whānau involved and wherever possible they sort this out with me when I am well.

#### **Enhanced**

The side-effects and other consequences of any medication or other medical interventions are made clear to me.

My rights are fully considered when treatments are prescribed.

I am clear about the proven benefits and risks associated with my lifestyle choices.

I want to be really clear and participate in decisions which may require me to take medication or receive other health interventions.

I don't want to have to tell different people the same story.

I want people to regularly check whether medication or other health interventions are working and to change them if they are not.

#### **Advanced**

I want medication or other medical interventions to minimise risk to my physical health and maximise my ability to fully enjoy my lifestyle choices.

I want people and organisations involved in my health and wellbeing to work together for my benefit.

I want the specialists to devise a system that supports those less knowledgeable to learn.

# Leadership performance indicators

- I feel good about my lifestyle choices, including my culture, sexuality, and gender.
- I feel valued in my community.

#### **Performance indicators**

# Workforce perspective

#### **Essential**

Demonstrates understanding of a holistic approach to wellbeing.

Describes how lifestyle choices promote wellbeing (physical activity, diet, employment).

Works in partnership with the person and whānau to provide support for living well in a way that is responsive to the person's age, culture, strengths, preferences, environment, and context.

Supports the person to participate in activities which contribute to good mental health.

#### **Capable**

Describes individual and social factors that contribute to poor health outcomes.

Demonstrates understanding of the importance of equitable access to quality health care.

Demonstrates understanding that stigma, discrimination, and racism impact access to health care.

Demonstrates understanding of the risk that physical (and mental health) needs can be overlooked for autistic people and people with learning disability (diagnostic overshadowing).

Describes effective strategies for supporting a person's wellbeing.

Demonstrates understanding of cultural responses to restoring wellbeing.

Supports autistic people and people with learning disability to decide their own wellbeing goals and strategies.

#### **Enhanced**

Applies an in-depth understanding of a concept of wellbeing that encompasses all dimensions of health.

Works with the person, whanau and other health professionals to manage physical health and other lifestyle issues to maximise the person's overall health and wellbeing.

Provides information about cultural responses to restoring wellbeing and facilitates access to these as needed.

#### **Advanced**

Explains the importance of an evidence base for lifestyle choices and behaviours which improve wellbeing for people who are autistic and/or have learning disability.

Incorporates lifestyle choices and behaviours into a comprehensive support/treatment plan.

Demonstrates knowledge of health conditions commonly experienced by autistic people and people with learning disability eg, epilepsy, UTI, delirium, diabetes, gender dysphoria and ensures appropriate support and treatment is available.

Supports services and professionals providing cultural responses to restoring wellbeing to work effectively with autistic people and people with learning disability and whānau.

Ensures data is collected to inform how successful supports and treatments are performing.

Teaches others about best practice in supporting a person with complex mental health and addiction needs in addition to autism and/or learning disability.

## Performance indicators > Workforce perspective continued

# Leadership performance indicators

- > Ensures systems enable staff to demonstrate best practice in supporting autistic people and people with learning disability and whānau in living well/
- Addresses barriers which may prevent best practice. For example, identifies where additional resources are needed and works to obtain them.
- > Fosters relationships with services, groups, and communities to support autistic people and people with learning disability and whānau in living well.



Recognising and responding to mental distress and addiction

# Skill 4 Recognising and responding to mental distress and addiction

Why is this skill important?

Kim has insight into her mental distress, and the side-effects of medication. She separates out her experience of depression with something even more serious, which she calls the other thing. She knows she can become very unwell and lose touch with reality. This then affects her behaviour. At such times she is at the mercy of the system which responds to the then presenting crisis. She bounces between disability services, mental health crisis and the police. The responsibility then seems to pass back to disability services but without the skills needed to support her recovery and so the cycle continues, and Kim's chances of recovery are compromised. – *Kim* 

Maria's mental distress came about as a young adult and was initially diagnosed as schizophrenia although she is now clear it is PTSD and processing disorder. She is off medication and doesn't misuse alcohol and drugs now – being a Mum put paid to that. Her experience of services has been poor with her multiple diagnoses seeming to ensure she was always fobbed off by one (mental health) to the other (disability) and back again with no one agency taking responsibility or even coordinating effort. – *Maria* 



"Our oldest son had collapsed and fallen one day in May while getting off a bus, so we brought him home, and he fairly quickly began to get very unwell. As it turns out, his symptoms were related to significant anxiety which would cause him to shake uncontrollably and fall. What we saw was him having seizures. He had numerous hospital admissions following ambulance calls and it was all very high drama. They did thorough medical investigations to eliminate anything organic. They never used the word anxiety. In the end, they told us it was behavioural. Suppose someone has anxiety and no learning impairment. In that case, the person would be diagnosed with anxiety, stress, or depression, and the root cause would be worked through."

The family then sought international expertise and privately engaged psychology support.

"I can now see that we have all emerged, happier, more robust, and we are all here. Because we could pay, we chose to spend our money on therapy-with psychologists who had the expertise and who knew how to work with the family – and the individual. Some of our sons and daughters no longer live in the disability world where they are 'attached' to a contracted disability service provider. A small but growing community of families tries to keep a light footprint when interacting with disability services. We want access to expertise when needed from professionals who are easily accessed when our lives intersect with health and disability services." – **Nathan** 

### He aha te mea nui o te ao, he tangata he tangata he tangata

What is the most important thing in the world, it is people, it is people, it is people

Everyone working in health and disability recognises signs of mental distress for autistic people or those with learning disability, and understands and plays their role in support, treatment, or recovery.

# **Expected outcome**

Autistic people and people with learning disability who are experiencing mental distress have individualised support and/or treatment which is tailored to their needs as early as possible.

#### **Performance indicators**

# Lived experience perspective

# Recognising mental distress and addiction

#### **Essential**

I want people to know early on if I an becoming unwell.

I want to have trusting relationships with the people who support me.

I understand why records need to be kept if I need medication, so people know if it is working.

I have access to my records in a form me and my whānau understand.

#### **Capable**

I want my whanau and staff to be well trained to identify symptoms of unwellness.

I want people to be able to recognise when my wellbeing is being impacted by mental distress.

I want people to know when I need specialist assistance.

#### **Enhanced**

I want people to be skilled in assessing my wellbeing needs as related to my culture, gender, sexuality, circumstances, and lifestyle choices.

I want people to make sure they see me at a time and in an environment that works best for me, my whānau and my supporters.

I want people to help me understand everything that is going on.

I want people to work together to maximise my chances to have the lifestyle of my choice and minimise risks to my wellbeing.

I want to have timely access to specialist help if I need it.

#### **Advanced**

I want specialists to recognise the expertise of me and my whānau so we can work together to determine the best plan for me.

I want there to be a centre of expertise so all New Zealanders with disability can be confident that they will be treated with the best practice.

I want specialists to measure the things that are important to me (and others) like:

- > spending more time doing the things I like
- > spending less time doing the things I don't like or that others don't like
- fewer hospital stays and less time per stay
- > less medication that has bad side effects
- less need for specialists to be involved.

# Responding to mental distress and addiction

#### **Essential**

I want people close to me to know how to support me in living the life of my choice.

I want people close to me to support me in my daily activities in a way that minimises my risk of being mentally distressed.

I don't want to be restrained. I don't want to be secluded.

#### **Capable**

I want people to ensure I can live the life of my choice.

I want people to be available to help me in discussions with mental health professionals.

I want people to work with me to identify emotional and behavioural indicators of wellbeing.

#### **Enhanced**

I want clinicians to know me as an individual so it is less likely their interventions will adversely impact my lifestyle choices.

I want clinicians to help me understand how their interventions will help me to recover from mental distress.

I want interventions to respect my human rights.

I want clinicians to show me practical ways to stay well.

#### **Advanced**

I want specialists to take account of my ambitions when developing a treatment plan.

I want specialists to consider the things outside of their control that could assist my recovery so plans can be made to address these strategically.

I want treatment techniques to eliminate the need for restraint or seclusion.

I want specialists to support clinicians to implement treatment plans and to adapt them in light of my experience.

I want specialists to make sure the success of plans is measured and reviewed regularly.

## Leadership performance indicators

- > I feel well supported when I become mentally distressed.
- > My whānau is engaged in ways that have been agreed when I am well.
- The people/agencies in my life work well together to get the best treatment for me.
- My culture is respected at all times when I am being supported and treated.
- My gender and sexuality are respected at all times when I am being supported and treated.
- > The impact of bad things happening in my life influences my treatment.
- > Treatment doesn't prevent me from doing the things I want to do.

## **Performance indicators**

# Workforce perspective

# Recognising mental distress and addiction

#### **Essential**

Describes why it is important to report changes in wellbeing, including increased use of alcohol and other drugs.

Records changes in a person's wellbeing.

Records mental health and/or addiction support required for the person.

Collects data as necessary to determine needs and respond effectively.

Supports the person to recognise their mental distress and communicate how they are feeling.

### Capable

Describes the impact of stress on the wellbeing of the person they support.

Differentiates the role of mental health and addiction services and disability support services in maintaining wellbeing.

Identifies when changes to wellbeing (including use of alcohol and other drugs) require specialist assistance.

#### **Enhanced**

Identifies signs that a person may be autistic or have learning disability and seeks assistance as required to confirm disability through an appropriate assessment or obtaining existing assessment reports.

Makes necessary adjustments including for example:

- > preparing: finding out about the person's strengths and needs
- providing information in an accessible format
- > allocating adequate time
- > ensuring the physical environment is comfortable for the person
- establishing communication needs
- accommodating whanau, support people including cultural support, guardians, where required.

Demonstrates the importance of working in partnership with the person and whānau in order to understand and assess their needs, tailoring the approach to the strengths and capabilities of those involved.

Demonstrates the ability to understand and consider the potential risk factors and compounding conditions that may influence the mental state of an autistic person and /or a person with learning disability.

Identifies when support is required from specialist professionals, and actively seeks their support.

Recognises when someone may not have the capacity to consent and follows necessary procedures.

Works in a trauma-informed way.

Uses appropriate resources (relevant to role) such as screening and assessment tools to assist in recognising and responding to mental distress and/or addiction making any necessary adaptations eg, asking simple questions, using props and pictures in place of words.

#### Performance indicators > Workforce perspective continued

#### **Advanced**

Models working in partnership with the person and whānau in order to understand and assess their health needs, tailoring the approach to the strengths and capabilities of those involved.

Supports others to work in partnership with people and whānau and to tailor their approach as needed.

Undertakes specialist mental health and/or addiction assessments using appropriate tools.

Develops a working formulation and proposed intervention plan.

Uses assessment information to establish a baseline function for each individual, and the possible functional manifestations of mental distress and/or addiction.

Supports others to work in a trauma-informed way.

Teaches others about best practice in supporting a person with complex mental health and/or addiction needs in addition to autism and/or learning disability.



# Responding to mental distress and addiction

#### **Essential**

Works in partnership with autistic people and people with learning disability to support them to use strategies to maximise wellbeing.

Demonstrates aroha and respect when responding to people experiencing mental distress and/or addiction needs and their whānau.

Promotes choice wherever possible.

Supports autistic people and people with learning disability with strategies for communicating their mental distress and addiction related needs to others.

Supports the person to use strategies which help them cope with or reduce mental distress.

#### Performance indicators > Workforce perspective continued

#### **Capable**

Communicates important information regarding wellbeing and behaviour to others.

Supports autistic people and people with learning disability to use identified strategies for managing their wellbeing.

Participates in discussions with people and their mental health and/or addiction professionals and others involved in their support, to support an integrated approach.

Supports autistic people and people with learning disability to recognise emotional and behavioural indicators of wellbeing.

Supports autistic people and people with learning disability to recognise addiction related triggers.

#### **Enhanced**

Develops comprehensive treatment strategies that promote choices for the person and consider the broader biopsychosocial aspects relevant to the person including other interventions or treatments that they are receiving.

Involves whānau, other support people and/or guardians as an important component in prevention, early intervention, treatment, and recovery.

Identifies stressors/triggers and ways to support the recovery journey.

Makes skilled adaptations to tailor therapy to the needs of the person.

Actively promotes an integrated approach to treatment and support.

Teaches others about best practice in supporting a person with complex mental health and/or addiction needs in addition to autism and/or learning disability.

Recommends or develops effective monitoring tools which are tailored to the wellbeing needs of the person.

#### **Advanced**

Describes benefits and risks of pharmaceutical and therapeutic interventions for autistic people and people with learning disability experiencing mental health issues.

Offers choices and includes recovery and relapse prevention activities relevant to the person and whanau in their wellbeing plan.

Works with others involved with the person and whanau to provide an integrated approach to treatment and support.

## Leadership performance indicators

- > Ensures processes and resources are in place to enable staff to apply best practice in recognising and responding to mental distress.
- Promotes a collaborative approach, encouraging and enabling staff to work in an integrated way with other professionals and services and ensures systems are in place to support this.
- Fosters collaboration and integration with other services and sectors to enable best practice in recognising mental distress and providing effective responses to autistic people and people with learning disability and whānau.
- Personal Problem Probl
- > Fosters and enables sensitive and effective responses for autistic people and people with learning disability who have experienced trauma and loss.
- > Ensures that processes are in place to enable measurement of outcomes and fosters outcomes-focused service delivery.



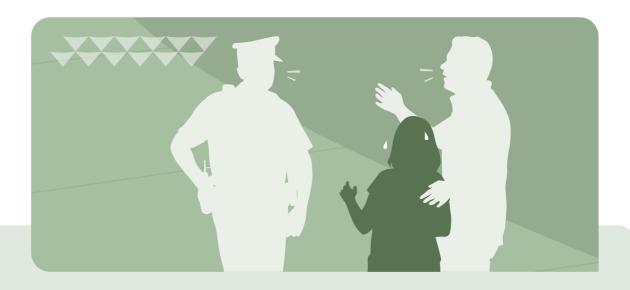


# Skill 5:

**Policy and Legislation** 

# Skill 5 > Policy and Legislation

# Why is this skill important?



"The day Stella and I [advocate] met is a story she is fond of telling. The community constable was on the footpath waiting for me to turn up - because the alternative was to arrest Stella. She was being evicted from her flat, the flat I later learned she had been living with her second and ex-husband – and she had nowhere to move to. Being arrested meant Stella would be fingerprinted, placed in the cells, the CAT team would be called, they would declare that Stella was not mentally unwell, and she would be discharged to the community - again, a very vulnerable person with very few reliable networks. Only this time Stella came to the attention of a new service. The criteria for support was that people with a diagnosed learning impairment who had offended under the Crimes Act – or who were at risk of offending, could be referred to the service for support and services. This was when I learned Stella was involved with Dual Disability Services - however it took some time to confirm which funding stream Stella came under - neither mental health services nor services for intellectually disabled people wanted to fund Stella's support arrangements- she was a person who fell through the cracks. Keeping Stella psychologically and medically well has been managed by disability services and the medical system. Has she had equitable access to support services for her mental health and addiction? The answer would have to be - not always and not consistently." - Stella

Ricky is a respected person and he told us that it was striking to him that he could feel so much of an outcast in his life at times, with bullying, teasing and loneliness central to that. He didn't feel like a citizen within his own country or part of his family, more like an outcast to both. Ricky spoke positively about receiving regular counselling which has been in place for just over a year and funded by ACC. This has resulted in a trusting relationship being developed which has helped Ricky share the trauma of the past 30 years. Whilst it doesn't take away from what has happened, he feels it helps him to understand and cope with it better. It is also a release for him, an alternative to the 'stiff upper lip' approach which just further bottles things up. There are still challenges though and Ricky spoke of the challenge of lockdown<sup>3</sup> which has brought back strong feelings about having to live in institutions both as a child and an adult. "They already locked us up once." He is also unable to wear a mask and, whilst carrying an exemption card, this doesn't prevent him being treated badly in public and in shops. He provided a contrast of the farming community where their mental distress as a community is recognised, and work is underway to address it - not for people with learning disability or the autistic community though. - Ricky

Harry is often misunderstood and sometimes this gets him into difficulties. He described an occasion when he took a photo of a dance group in public when he got told off by a policeman even though tourists doing the same didn't get told off. He sometimes feels picked on or singled out in this sort of way. – *Harry* 

<sup>&</sup>lt;sup>3</sup> Lockdowns were among the public health measures taken during the COVID-19 pandemic.

#### Te toia, te haumatia

#### Nothing can be achieved without a plan, workforce and way of doing things

Everyone working in health and disability implements legislation, regulations, standards, codes and policies relevant to their role in a way that supports autistic people and people with learning disability and whānau in their wellbeing.

### **Expected outcome**

Human rights, autonomy and self-determination of autistic people and people with learning disability and whānau accessing health services are promoted and upheld.

#### **Performance indicators**

# Lived experience perspective

#### **Essential**

I want my culture, values, and beliefs to be respected by everyone who supports me.

I want the people who support me to have values that reflect my rights as underpinned by the United Nations Convention of the Rights of Persons with Disabilities, United Nations Declaration on the Rights of Indigenous Peoples and within the Code of Health and Disability Consumers' Rights.

I want the people who support me to have the skills and knowledge to do this in a way that aligns with the principles of Enabling Good Lives.

I want people who support me to learn about my strengths and likes and how to ensure I can create an environment of safety and comfort.

I want any resources allocated to me to be able to be used flexibly to enable me to live the life of my choice.

## Capable

I want staff to be inducted and trained in Te Tiriti o Waitangi, UNCRPD, the principles of Enabling Good Lives and relevant legislation, codes and models of practice.

I want people to know about trauma informed practices.

I want people to review how my support is being delivered and attend to any shortcomings.

I want people and services to identify abuse or restrictive practices against me.

I want a safe place for me to make complaints and sees these as learning opportunities.

I want people to prioritise a safe environment for me.

#### **Enhanced**

I want clinicians to recognise that a one size fits all approach is not appropriate for me.

I want clinicians to provide care, support, and treatment to me and my whānau within the boundaries prescribed by law, professional standards, evidence-based best practice, and codes of ethical practice.

I want clinicians to believe that I have capacity.

I want clinicians to recognise when I may not have the capacity to consent and ensures that best practice methods to enable supported decisionmaking is utilised.

#### **Advanced**

I want specialists to see me as an equal citizen.

I want specialists to be prepared to be flexible in order to fit my circumstances.

I want specialists to have a detailed knowledge of relevant legislation, particularly:

- Mental Health Act
- Substance Addiction (Compulsory Assessment and Treatment) Act
- Intellectual Disability (Compulsory Care and Rehabilitation) Act
- Protection of Personal Property and Rights Act
- Criminal Procedure (Mentally Impaired Persons) Act
- Crimes Act (S195 Protection of vulnerable adults)
- > The Privacy Act
- The Vulnerable Children Act
- Human Rights Act (1993).

I want specialists to be skilled in finding the right solution for me.

I want specialists to regularly review my intervention plans.

I want specialists to keep up to date with best practice.

# Leadership performance indicators

- My support and treatment respect my culture, gender, sexuality, values and beliefs.
- My human rights are respected.
- I can access the right support, at the right time, in the right place.
- My opinion matters.

#### **Performance indicators**

# Workforce perspective

#### **Essential**

Respects the relationship between the government and tangata whenua and upholds the principles of Te Tiriti o Waitangi.

Demonstrates understanding of health policy, legislation and standards of practice that recognise the significance of te reo Māori, te ao Māori and Māori models of practice.

Upholds the principles set out in the United Nations Convention on the Rights of Persons with Disabilities, including the right to autonomy and self-determination, the right to be free from coercion and the right to be treated in a non-discriminatory way.

Upholds the principles set out in the United Nations Declaration on the Rights of Indigenous Peoples.

Recognises and respects the rights of people under the Code of Health and Disability Services Consumers' Rights.

Works to support implementation of Whakamaua: Māori Health Action Plan 2020-2025 as appropriate to role.

Provides information to people about their rights in a way that supports them to understand.

Understands least restrictive practice principles.

Understands and adheres to legislation, regulations, standards, codes and policies, appropriate to role.

Promotes equity, eg, demonstrates understanding of the impact of institutional racism and unconscious bias and takes steps to prevent and eliminate it, seeking support from others as needed.

Demonstrates understanding that further inequity can occur for some groups from the intersection of ethnicity, mental health, addiction, and physical health.

#### **Capable**

Describes how they apply Te Tiriti o Waitangi in their role of supporting autistic people and people with learning disability.

Supports people to advocate for their own rights and interests when seeking support and treatment for mental distress and/or addiction and/or effectively advocates on behalf of the person to ensure treatment and support needs are met.

Acts to prevent and eliminate institutional racism and unconscious bias.

Acts to prevent and eliminate institutional transphobia, intersexphobia and homophobia.

#### **Enhanced**

Provides care, support and treatment to autistic people and people with learning disability, whānau, and guardians within the boundaries prescribed by law, professional standards, and codes of ethical practice.

Recognises when people may not have the capacity to consent and follows necessary procedures.

Demonstrates knowledge of relevant legislation, particularly:

- Mental Health Act
- > Substance Addiction (Compulsory Assessment and Treatment) Act
- Intellectual Disability (Compulsory Care and Rehabilitation) Act
- Protection of Personal Property and Rights Act
- Criminal Procedure (Mentally Impaired Persons) Act
- Crimes Act (S195 Protection of vulnerable adults)
- > The Crimes Act (S 195 Protection of vulnerable adults
- The Privacy Act
- > The Vulnerable Children Act.

#### **Advanced**

Demonstrates detailed knowledge of relevant legislation, particularly:

- Mental Health Act
- > Substance Addiction (Compulsory Assessment and Treatment) Act
- Intellectual Disability (Compulsory Care and Rehabilitation) Act
- Protection of Personal Property and Rights Act
- Criminal Procedure (Mentally Impaired Persons) Act Crimes Act (S195 Vulnerable Adults)
- > The Crimes Act (S 195 Protection of vulnerable adults
- > The Privacy Act
- The Vulnerable Children Act
- > Human Rights Act (1993).

Provides advice and support to others regarding capacity to consent.

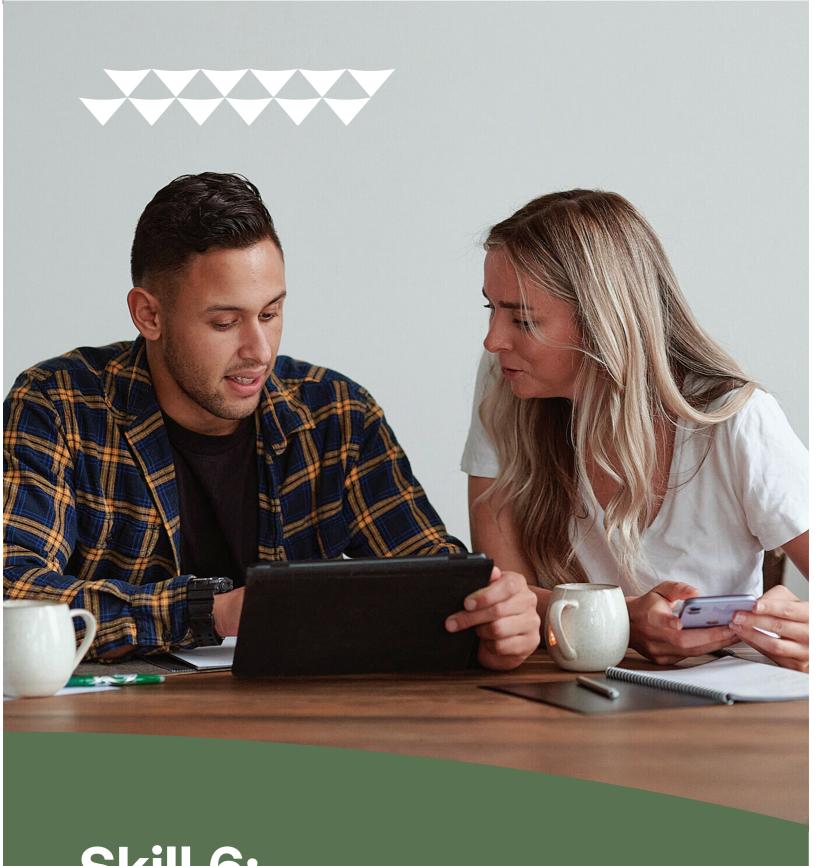
Provides support and guidance to others to support them to practice within the boundaries prescribed by law, professional standards, and codes of ethical practice.

Supports others to identify, prevent and eliminate institutional racism and unconscious bias.

#### Performance indicators > Workforce perspective continued

## Leadership performance indicators

- Provides leadership and ensures resources are in place to implement Te Tiriti o Waitangi.
- Provides leadership and ensures resources to enable implementation of and adherence to relevant legislation, standards, codes and policies.
- Promotes inclusion of autistic people and people with learning disability in service scopes and actively ensures autistic people and people with learning disability are not excluded from accessing services, support and treatment to support their wellbeing.
- > Contributes to positive legislative change and policy development impacting on the wellbeing of autistic people and people with learning disability and whānau.
- Provides leadership and works to identify, prevent, and eliminate institutional racism and unconscious bias.
- Provides leadership and works to identify, prevent, and eliminate institutional sexism, cissexism and homophobia.



# Skill 6:

**Learning and Development** 

# Skill 6 > Learning and Development

# Why is this skill important?

Tommie [a support person] confirmed how the team can work with Tracy to understand triggers and likely times of stress (for example, after being over stimulated by work) when pre-agreed processes can be enacted. Everyone is different so knowing the person well is crucial. The person should have full agency in terms of what happens when. Tommie said, "Knowing Tracy enables us to find other things that calm her down." Tommie is experienced with great values but not qualified clinically. She spoke of other practical interventions (for example, a weighted dog) that also helped to anticipate and reduce times of distress.

"The wait list for either of these services does not assist when you are in a crisis and needing something more immediate. GPs are not equipped with the knowledge of medications for people with intellectual and autism disabilities and so I have just suggested a particular medication that may have worked in the past as we are still waiting 1 year on for dual disability to contact. If we were to need [behavioural service] again the waitlist is over 18 months I think at present. We have currently been on the waitlist for [agency specialising in communication aids] 2.5 years and this has just come through." – **Tracy** 



Vic likes routine and predictability. Having a team around him that know him and his likes and dislikes is important. He currently has a great team of both paid staff and friends. Vic gets really down at times. He is then the opposite to usual, shutting down and not wanting to engage with anyone. It is a dark place and hard to get out of. This is when the people who know him, help the most so he can reengage and return to his routines safely and without stigma.

He has been prescribed anti-depressants which he uses as he feels the need for rather than as directed (otherwise he can feel like a "cabbage"). He has had stronger anti-psychotropic medication when younger. A local art studio also provides a safe space to explore his artistic talents and connect with people. Vic has developed a range of coping strategies for when he feels down or upset. These include listening to music, walking and sketching. He has a traffic light system with 'Team Vic' so has agency in terms of how he is supported even if not engaging – a sort of advanced directive. – **Vic** 

#### Mā te ako ka mōhio

#### From learning comes knowledge

Everyone working in health and disability participates in learning and development to enable them to respond effectively to autistic people and people with learning disability.

### **Expected outcome**

Autistic people and people with learning disability and whānau receive effective responses from skilled workforces.

#### **Performance indicators**

# Lived experience perspective

#### **Essential**

I want to have opportunities to use my expertise through my experience.

I want people who are close to me to recognise the importance of my culture and beliefs.

I want people who are close to me to reflect on their culture and beliefs and how this impacts those they engage with so they can make sure they respect mine.

#### **Capable**

I want managers/agencies to ensure my unique situation means I am supported equitably including advocating for access to additional skills and resources as required.

#### **Enhanced**

I want clinicians to ensure they work with me to design creative ways for me to get the life of my choice.

I want clinicians to look beyond my diagnosis to find practical solutions that can discover my strengths and likes.

I don't need clinicians to like me but I do need them to value who I am and who I can become.

I do need clinicians to assist those close to me to bring the best out of me which will help create a safe environment.

I need clinicians to see the value of supporting me at times and in places they might not usually work.

I need clinicians to not give up on me or make it feel that it is my fault.

#### **Advanced**

I need specialists to ensure their practice reflects an ability to work with me, my whānau and close supporters in culturally respectful and responsive ways.

I want specialists to recognise the expertise I can offer to help make for better supports and services for other people who are in similar circumstances to me.

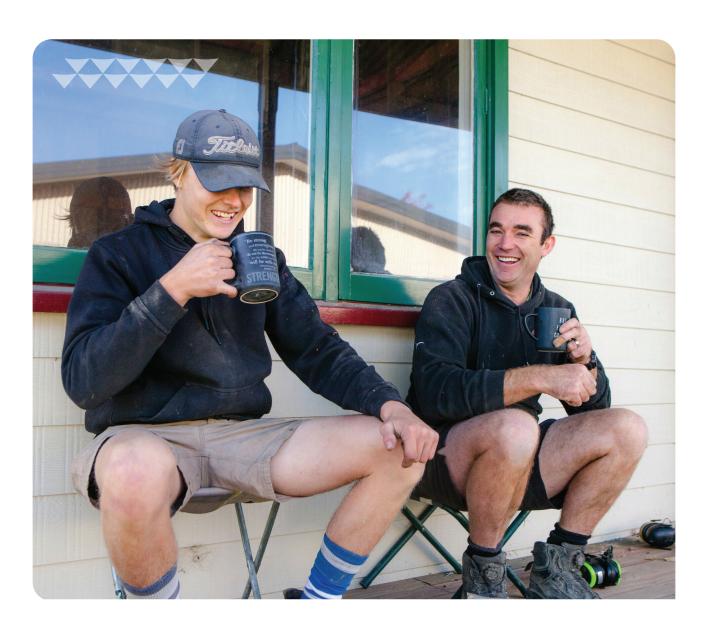
I want the culture and diversity of specialists to reflect the communities they work within.

I want New Zealand to be the best example in the world of how to support people who are in similar circumstances to me.

## Performance indicators > Lived experience perspective continued

# Leadership performance indicators

- People involved in my support and treatment seek to get better at supporting me over time.
- I am able to be involved in the design of training and qualifications.
- > I feel fairly treated.
- > People involved in my support and treatment don't give up on me.
- > People involved in my support and treatment work well together.



#### **Performance indicators**

# Workforce perspective

## **Professional development**

#### **Essential**

Demonstrates knowledge of a range of personal and institutional values and beliefs about disability and about mental distress and addiction.

Engages in ongoing reflection about their own values and beliefs about disability and about mental distress and addiction.

Engages in professional development opportunities to enhance cultural responsiveness.

Seeks cultural advice and guidance when working with people from another culture.

Learns how to recognise transphobia, intersexphobia and homophobia as sources of mental distress.

#### **Capable**

Seeks and takes up professional development opportunities to develop their understanding the barriers to people accessing supports and services to promote their wellbeing.

#### Performance indicators > Workforce perspective continued

#### **Enhanced**

Examines the extent and limits of their understanding of autism and/or learning disability and mental distress and addiction and seeks support to address this.

Demonstrates the ability to determine how the person relates to their own abilities and disability.

Acknowledges and articulates how personal beliefs and emotional reactions toward people with a disability might influence their clinical practice.

Supports and guides co-workers to gain knowledge and understanding of people who are experiencing mental distress and/or addiction.

Works collaboratively with mainstream/specialist mental health services, health services and other support services to meet the needs of people.

Works to engage people and to ensure service entry criteria do not exclude them unfairly.

#### **Advanced**

Addresses barriers to engaging autistic people and people with learning disability, whānau and support people from culturally and linguistically diverse backgrounds.

Acknowledges the varying views of autism and learning disability within different cultures and the impact that this may have on access and participation in services.

Consults with cultural groups to identify strategies to deliver culturally respectful and responsive services.

Facilitates professional development and learning for team members, professional colleagues, and other audiences.

## Wellbeing at work

#### **Essential**

Demonstrates understanding that what happens in our personal lives and at work affects our wellbeing.

Describes positive coping strategies that help to look after own wellbeing in times of stress eg, taking regular breaks, talking with trusted people etc.

Demonstrates understanding of the importance of setting appropriate limits and boundaries.

Asks for support from a trusted person, if needed, to look after own wellbeing.

#### **Capable**

Understands the concept of compassion fatigue and can name some key signs.

Describes ways to set and maintain boundaries.

Regularly reflects on own wellbeing, for example, using a model such as Te Whare Tapa Whā or Fonofale Model.

Describes personalised self-care strategies and practices these to look after own wellbeing.

#### Performance indicators > Workforce perspective continued

#### **Enhanced**

Models self-care practices.

Supports colleagues to look after their wellbeing.

Demonstrates understanding of the potential for vicarious trauma.

Works to prevent and/or intervene early to minimise the impact of vicarious trauma.

#### **Advanced**

Supports others to prevent and/or manage the impact of vicarious trauma.

Takes account of worker wellbeing when guiding and supporting others in their professional practice.

Includes wellbeing at work as a component of relevant training and education programmes.

## Leadership performance indicators

- Supports learning and development opportunities for self and staff to develop and maintain the values, attitudes, knowledge and skills to effectively support autistic people and people with learning disability and whānau.
- Advocates for and contributes towards the development of formal training and qualifications to support best practice, ensuring autistic people and people with learning disability are involved in design and delivery.
- Models non-discriminatory approaches to autistic people and people with learning disability.
- > Fosters cultural responsivity in service provision.
- Actively supports integrated service provision.
- Fosters a workplace culture which prioritises practices that support wellbeing at work.
- Responds effectively to staff who seek help and support to maintain their wellbeing at work.

# Appendix 1 ➤ Alignment of overarching approaches

In the Aoteoroa New Zealand context key overarching approaches to disability and mental distress and addiction are:

- **> Whānau Ora:** a whānau-centred approach which has significantly influenced policy and practice over the past decade.<sup>4</sup> Whanāu Ora requires integration across health, social and economic sectors.
- > The Social Model of Disability: this model is widely adopted as an overarching approach in the disability sector.
- > The Wellbeing and Recovery approach: a key driver of policy and practice in the mental health and addiction sector.
- Enabling Good Lives: is an approach currently being demonstrated in different ways in different regions with a view to creating national system change to guide service and sector-wide development to better meet the aspirations and needs of disabled people. There is high expectation that more details on how government will be progressing this during the period of consultation on this framework.

Table 1 sets out key concepts within each approach and shows how they can align. It demonstrates that while key concepts for the approaches may not perfectly overlay each other, they can be complementary.

<sup>&</sup>lt;sup>4</sup> For example, a Whānau Ora approach to working with Māori and Pasifika was mandated in Rising to the Challenge Mental Health and Addiction Service Development Plan 2012-2017.

Table 1 Whānau ora, Social Model of Disability, Recovery/Wellbeing

	Whānau Ora	Social Mode of Disability	Wellbeing and recovery approach	Enabling Good Lives
Social focus	Economic, cultural, environmental, and social factors are all relevant to whānau wellbeing  Wellbeing is achieved collectively, not individually. Interdependence and interconnectedness of whānau is central to wellbeing for the individual and the whānau	Disability is a set of barriers created by society, not an individual problem  It is the environment and people's attitudes that create disability  Change the environment and attitudes so everyone can participate in communities of their choice	Accepting and enabling social environments are necessary for wellbeing and recovery; health interventions alone are not enough  Social attitudes can impose limits on people experiencing mental health and addiction needs	<ul> <li>5 Elements for system change:</li> <li>&gt; Building knowledge and skills of disabled people</li> <li>&gt; Investment in families</li> <li>&gt; Changes in communities</li> <li>&gt; Changes to service provision</li> <li>&gt; Changes to government systems and processes</li> </ul>
People and whānau decide what matters to them	Whānau decide what they want to achieve; whānau aspirations guide practice and service provision  Whānau are at the core of decision making about their future	Disabled people choosing for themselves  Solutions differ according to where people live, what they want for themselves, their circumstances, and their culture	People decide what is a worthwhile life, whether or not they continue to experience distress  Recovery is not a destination, not a one size fits all	Self-directed planning and facilitation Strengthening families or whānau
Strengths	Whānau strengths and capabilities are the starting point for realising whānau potential	Strengths are the focus	Focus on what is strong not what is wrong; see abilities, strengths, skills, passions	Build knowledge and skills of disabled people

	Whānau Ora	Social Mode of Disability	Wellbeing and recovery approach	Enabling Good Lives
Inclusive, non- discriminatory	Inclusive: empowers whānau as a whole; intergenerational; flexible, available to all families in need	All of us: inclusion – valuing; no one left behind	Social inclusion and community connection. Challenge stigma and discrimination	Community building to develop natural supports
Partnership	Whānau skills, knowledge and experiences are the platform for building their wellbeing and resilience	Expertise: People have different kinds of knowledge	People are the experts in their own wellbeing and recovery  Working in partnership is key	Cross- government individualised and portable funding
Rights based	Whānau- centred, self- determination tino rangatiratanga; built on a Māori cultural foundation	Rights based; citizenship	Empowerment based; promotes the rights and responsibilities of citizenship	Considering the person in their wider context, not the context of funded supports
Community based	Oriented to whānau participating fully in community and society, participating confidently in Te Ao Māori	Community oriented (not institutionalised)	Community oriented (not institutionalised)	Community oriented (not institutionalised)

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