Te Tau Tītoki

A framework for supporting people on the autism spectrum

Acknowledgements

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Autism Framework reference group members.

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The Ministry's commitment to work alongside organisations to provide better support was an important and significant driving force in the development of this framework. In addition, the Ministry provided the required funding and directly contributed to the co-design process. These resources and expertise were essential for making this endeavour successful.

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Foreword

In recent years, we have seen a significant increase in autism awareness. There has been a focus on developing autism-specific supports and bolstering a strong movement of people with lived experience that includes both people on the autism spectrum and their whānau.

In order to make the most of these positive developments, we need a workforce with an understanding of the full autism spectrum. They also require the skills to apply that knowledge in individual ways for the person they are supporting. A strong, well-equipped workforce is key to better support and improve outcomes for people with autism and their families.

We are pleased to support the publication of *Te Tau Tītoki*, which recognises the importance of having a competency framework for those professionals who support the autism community. It is critical to have a workforce who provide services that reflect the standards in the framework. This will contribute significantly to improved wellbeing and quality of life for people on the autism spectrum and their whānau.

We would like to acknowledge all who contributed to the development of this resource. *Te Tau Tītoki* reflects voices from across the disability sector and the community. We hope that the stories, ideas and expectations captured in this framework contribute to more informed, person-centred practices that support the wellbeing of autistic people and their whānau.

Dr Ashley Bloomfield
Director – General of Health

Introduction

Disabled people and those on the autism spectrum have long emphasised the importance of values, attitudes and relationships in the workforce.

When speaking with autistic people, many shared stories of good support and these conversations invariably led back to the attributes of those professionals and how it was just easier to talk to, spend time with, and build relationships with people who understood autism. Autistic people have been quite clear that when others know about autism, it makes it easier for them to be understood as individuals and that this essential knowledge is the foundation for the values, attitudes and relationships they desire.

Without question, living with autism and supporting someone on the autism spectrum can be both challenging and joyous, and for many the culmination of this experience is the development of a strong sense of advocacy.

In developing this resource, we employed a co-design process. I was lucky to receive the contributions of many staunch advocates and self-advocates, whom I cannot thank enough for their questions, challenges and support. I especially want to acknowledge Gabrielle Hogg for ensuring a platform was in place for autistic people who rely on disability support services to be part of the process and have their voices heard. Without her advocacy, much would have been lost and many of the voices reflected in the framework and accompanying stories would have remained silent.

Appropriately enough, many of those same individuals stressed how important it is to listen to autistic people and the duty we all share to be advocates and to promote self-advocacy in those we support. Possibly, above all else, it is this theme that should resonate loudest as we use this resource and seek to advance our knowledge and professional practice.

It is my hope that this resource is well-received by autistic people and those who love, care for and support them. I hope it will help organisations and individuals deliver high quality services and provide guidance so that all staff have the skills to support autistic people to the best of their abilities.

Most importantly, I hope this resource captures the aspirations and views of autistic people, honours the tireless commitment of parents and caregivers, and stokes the passion of professionals who work directly with people on the autism spectrum.

Ngā mihi nui

John Vogenthaler
Te Pou o te Whakaaro Nui

Takiwātanga

I feel honoured that so many people around Aotearoa and indeed, the world, can relate to my interpretation of autism in te reo Māori – takiwātanga. It is derived from the notion of "tōku/tōna anō takiwā," meaning "my/his/her own time and space".

For me, this is a way to honour the autistic whānau and friends I am privileged to have in my life. I hope it can be a source of strength for them and anyone that can relate to people being accepted for who they are and being allowed to have "their own time and space".

Te Tau Tītoki has this view of autism at its core and seeks to recognise and honour the view that autism is intrisically personal for every individual and whānau. The name is derived from the whakataukī, Ā te tau tītoki which means, "when the tītoki fruits".

The valued tītoki tree does not fruit regularly but does it in its own time, an allusion to autistic people blooming in their own time and space.

Nā

Keri Opai

About Te Tau Tītoki

Purpose of this framework

Te Tau Tītoki maps out the competencies required by professionals supporting autistic people within Disability Support Services funded by the Ministry of Health.

It is a response to gaps in knowledge and training that have been identified and evidenced across the sector, as well as providing an approach to addressing these gaps which is consistent with recommendations from the NZ Autism Spectrum Disorder Guideline.

It is hoped this framework will serve as a foundation for standardised learning and development which guides organisations and individual employers to take a consistent approach towards workforce development.

Competencies required for professional roles are presented in a manner that provides a direct link to evidence and the principles of quality service provision.

The goals of the framework are to:

- support employers to ensure staff are using practice that is reflective of a quality education in autism
- provide a pathway for ongoing professional development
- assist support providers to incorporate best practice in autism service delivery.

Who is Te Tau Tītoki for?

Te Tau Tītoki can be used in any environment which supports the wellbeing of autistic people or their whānau.

However, the framework sits most appropriately with employers and those in professional roles who directly support autistic people or are involved in service planning and design.

Additionally, it supports autistic people directly as they seek highly skilled professionals and advocate for quality services for themselves and their whānau.

It can also be used by individuals for planning their professional development, services and organisations in planning for strategic workforce development, as well as adding value more broadly across systems and communities.

Let's get real: Disability and how it relates to Te Tau Tītoki

The *Let's get real*: *Disability* framework describes the essential knowledge, skills, values and attitudes needed to deliver person-driven, high quality disability services.

It is designed to help organisations and individuals identify ways to strengthen the delivery of disability services to better meet the aspirations of disabled people, and their families, whānau and communities.

Let's get real: Disability is underpinned by a human rights approach, a social model of disability, Enabling Good Lives, and the New Zealand Disability Strategy. It is informed by the Treaty of Waitangi, the UN Convention on the Rights of Persons with Disabilities and the New Zealand Human Rights Act 1993, along with the approaches to working with disabled people encompassed in the social model of disability and whānau ora.

The fundamentals of *Let's get real: Disability* include a set of values embracing human rights, respect, service, communities and relationships. At the heart of this are objectives such as autonomy and self-determination, informed consent, non-discrimination, person-centred practices, full participation in society and healthy relationships in all spheres of activity for a disabled person.

Let's get real: Disability also describes a range of attitudes which should be demonstrated and embraced by people working in disability services.

Let's get real: Disability also outlines seven 'Real Skills' and the competencies required for each skill.

1. Working with disabled people.
2. Working with Māori.
3. Working with families and whānau.
4. Working within communities.
5. Challenging stigma, discrimination, and promoting value.
6. Upholding law, policy and practice.
7. Maintaining professional and personal development.

Let's get real: Disability has been adapted by Te Pou, in consultation with leaders from across the disability sector, including disabled people's organisations.

Te Tau Tītoki is meant to complement *Let's get real: Disability* by focusing on the required knowledge and skills that relate specifically to the autism spectrum, and how better understanding autism will enhance values-based practice.

Te Tau Tītoki was influenced by *Let's get real: Disability* and is intentionally structured in a similar format, using the same workforce groups and performance indicators related to specific domains.

Understanding Te Tau Tītoki

Workforce groups

The performance indicators in *Te Tau Tītoki* are divided into and described within four different levels of competency: Essential, Capable, Enhanced and Leader.

Each level reflects the expectations for staff with different degrees of experience and responsibility within the disability workforce.

In general, Essential and Capable levels focus on the skills needed for staff involved in individual and whānau support. Enhanced level focuses on the skills needed for overseeing practice and enhancing workforce capacity. Leader level focuses on the skills needed for guiding and developing organisational practice, managing service delivery and contributing to local and national policy.

Essential	Applies to all staff working in disability regardless of their role or profession, or the organisation for whom they work.
Capable	Applies to all staff working in disability whose roles involve fewer complex skills and knowledge, for example, disability support workers, community support workers and intensive support workers. Staff working at this level will demonstrate Essential and Capable level performance indicators, appropriate to their role.
Enhanced	Applies to all staff working at an advanced or senior level, whose roles involve complex skills and knowledge, for example whānau advisors, complex support advisors, professional practitioners and intensive support specialists. Staff working at this level will demonstrate Essential, Capable and Enhanced level performance indicators, appropriate to their role.
Leader	Applies to all staff who are team leaders, managers or service leaders. Staff working at this level will demonstrate Essential, Capable, Enhanced and Leader level performance indicators, appropriate to their role.

It is acknowledged that different providers use a range of organisational structures, job titles and responsibilities for different positions. The broadly-defined workforce groups in *Te Tau Tītoki* are meant to allow for flexibility and interpretation across organisations and existing structures.

Skill domains

Te Tau Tītoki consists of seven domains.

Domain 1

Knowledge of autism: key characteristics, understanding of the spectrum and co-occurring conditions

Includes broad indicators of a general understanding of the autism spectrum as well as other features of physical and mental health that may impact on an individual. Specific descriptors related to the core features of autism are found across the other domains.

Domain 2

Mental health, wellbeing and behaviour

Provides a description of the importance of mental health for autistic people and how an individual's wellbeing can be best supported. Likewise, challenging behaviours are presented within this context and discussed as a component of a person's overall quality of life.

Domain 3

Communication

Focuses on the specific communication style of the individual, how the ability to verbally communicate varies across the spectrum, the link between communication and behaviour and the impact of environmental factors on effective communication.

Domain 4

Predictability and structure

Describes how predictability can benefit autistic people and the need to balance flexibility and moderation within a structured support environment.

Domain 5

Repetitive behaviours or restricted interests

Focuses on why an individual may have repetitive behaviours or restricted interests and how this potentially contributes to or detracts from one's quality of life.

Domain 6

Sensory processing

Encourages others to think about an individual's sensory needs and how to promote self-awareness, coping mechanisms and therapeutic environments as a part of quality support.

Domain 7

Social and community interaction

Highlights the importance of relationships, community belonging and how advocacy and self-advocacy can be supported at all levels.

Evidence of skills

Within each skill domain *Te Tau Tītoki* outlines a set of performance indicators for each skill level. These are presented in the framework as 'evidence of skills' which can be gathered to show an individual displays an appropriate level of knowledge of autism in the workplace.

Evidence of skills can be gathered or sourced in the form of verbal or written discussions or feedback, workplace observations, and/or found in key documentation, such as organisational policies, processes and plans. As such, evidence of skills is presented in the framework under these three headings.

The specific role and experience of an individual may make it more appropriate to assess one type of skills evidence, than others. For example, a community support worker with little experience would most likely show competency by being able to describe autism in general terms and, as that employee develops their professional competency, you would expect to see that general knowledge being applied towards the individual being supported. For more experienced staff, we would expect most evidence to be through direct observation of active support. Likewise, normal record keeping, such as personal plans are consistently updated on a regular basis, and contributing to service delivery planning would reflect an evidence of knowledge and the use of skills related to autism.

Having a range of ways to assess and interpret skill competency is important because the disability workforce continues to grow and evolve. It is also a diverse workforce when it comes to English fluency, learning ability and lived experience of disability, requiring a holistic approach to assessing and supporting professional knowledge and skill development.

The evidence of skills for each domain and workforce level have been set out in a structured way to assist organisations to align workforce development to quality service provision. Employers are encouraged to consider how practices and policies promote knowledge transfer across the workforce, support an organisational culture of learning, and develop and encourage workplace coaching and mentoring.

By aligning key documentation, observable evidence from active support and professional knowledge, *Te Tau Tītoki* will assist employers to connect service provision with workforce planning and record keeping.

Using Te Tau Tītoki

Skill development

Te Tau Tītoki is a hierarchical model, in that the evidence of skills competency ascribed to each workforce group (Essential, Capable, Enhanced, Leader) builds upon the preceding level.

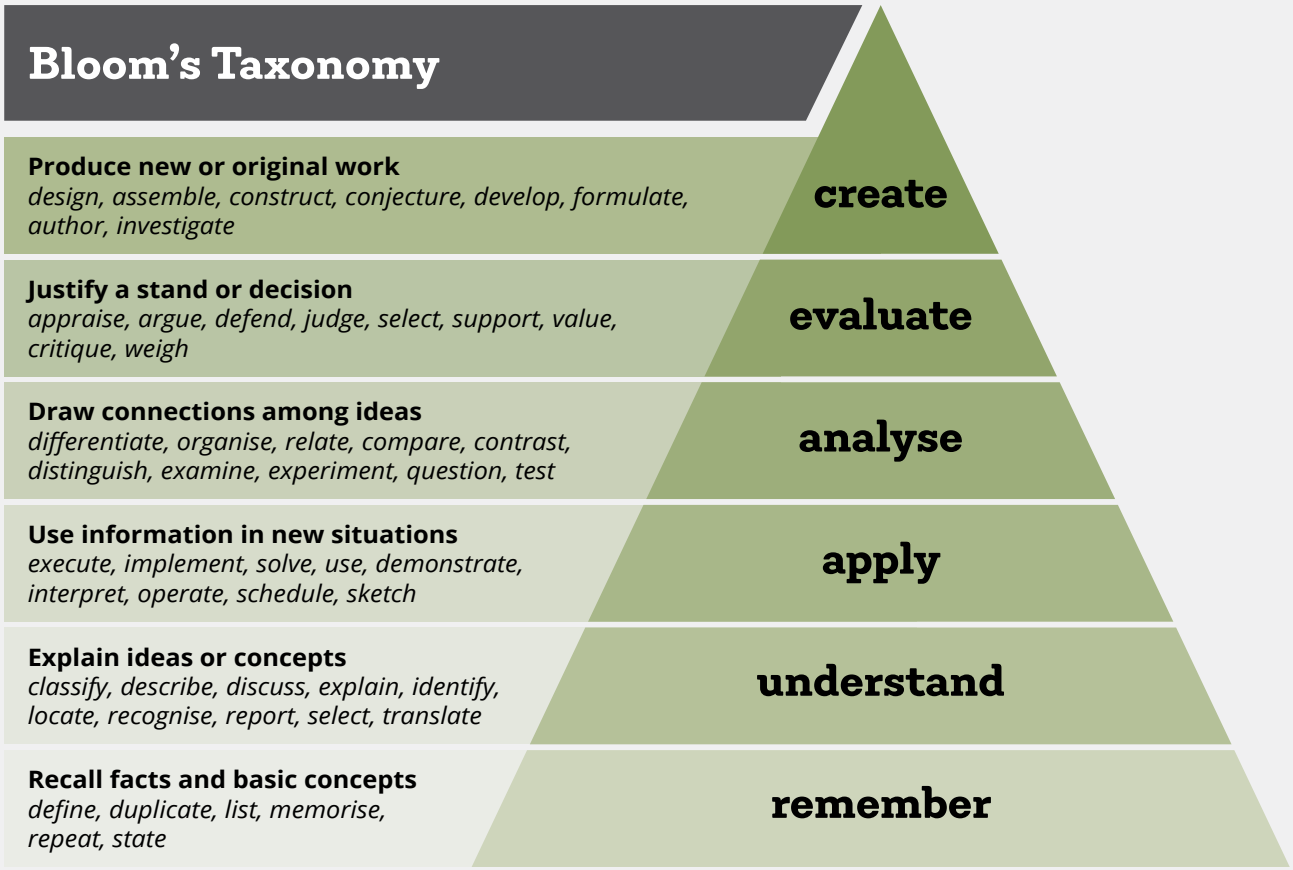
Individuals would therefore be expected to demonstrate the knowledge and skills of the workforce group to which they belong, in addition to the preceding levels.

In general terms, we would expect anyone supporting an autistic person or their whānau to have a general knowledge of the basic elements of autism and knowledge of the person they are working with. As the staff member develops more knowledge and skills, they will better understand the relationships between those basic elements and how they function together in the life of the person they are supporting.

One would then expect to see their growing knowledge being applied more practically, through active and ongoing support. Finally, individuals would develop an understanding that enables them to make sound judgements about service planning, as well as investigating changes in wellbeing and designing high quality services.

Learning theory and workforce development

This workforce development approach underpinning *Te Tau Tītoki* is based on Bloom's Taxonomy, an educational model describing the complexity of learning which is a widely accepted theoretical basis for teaching learners of all ages. It uses a hierarchical design to illustrate how foundation learning leads to higher order thinking skills.



https://cft.vanderbilt.edu/guides-sub-pages/blooms-taxonomy/

To follow is an interpretation of Bloom's Taxonomy applied to the support of autistic people.

Remember

State basic knowledge of autism.

Understand

Describe the person being supported.

Explain how autism affects them.

Recognise the person's strengths and abilities.

Apply

Demonstrate knowledge of autism in daily, active support.

Interpret behaviour, communication and changes in wellbeing.

Use knowledge of autism to meet the immediate needs of the individual.

Implement service delivery and behaviour support plans.

Schedule daily supports and useful strategies.

Analyse

Examine factors that contribute to quality of life.

Question how a person's wellbeing can be best supported.

Organise data collection and record keeping.

Relate new learning to support.

Evaluate

Support advocacy and self-advocacy.

Appraise the quality of service delivery plans and overall support.

Critique professional practices.

Defend the views of the autistic person and the evidence behind support strategies.

Create

Investigate changes in a person's wellbeing and causes of distress.

Author or contribute to service delivery and behaviour support plans.

Assemble supportive teams.

Design high quality services.

Limitations of Te Tau Tītoki

Knowledge

Te Tau Tītoki does not include everything you need to know to provide good support. Support is highly individualised, and it would be impossible to capture the complexity needed to respond to every individual in every situation. Additionally, there are a range of evidence-based specialist interventions and therapies which benefit autistic people that would require an advanced level of knowledge and skill which are out of the scope of this resource. However, *Te Tau Tītoki* does lay out expectations of knowledge and skills for most people in supportive roles. It offers what autistic people, families, service providers and specialists view as the foundation of a supportive environment.

Training

Te Tau Tītoki is not a mandated curriculum for training. It would be unwise to expect that a single workshop on autism would include all the content found in the performance indicators. However, *Te Tau Tītoki* could assist training providers to engage with service agencies to determine organisational and individual needs, and tailor training to those needs. It also offers a tool which can be used to review existing resources and training packages to ensure learning and development meets the needs of autistic people and those providing support.

Professional development

Te Tau Tītoki is not an assessment. However, this framework could be used for self-reflection, planning for one's own professional growth through learning and development, and guidance for recruiting or coaching other staff.

Service provision

Te Tau Tītoki is not a performance monitoring or service auditing tool. However, it can be used more broadly by managers and leaders to improve service quality. The layout of the framework includes key performance indicators presented as evidence of competency within a support environment. It allows employers to clearly and easily link workforce development to quality service provision, and guide reflection on service delivery and planning.

Listening to autistic people

Te Tau Tītoki is not a reflection of what every autistic person needs or believes. The views of autistic people are as varied as the neurotypical population. While a range of views were included in the development of this framework, it's impossible to capture every experience. However, the framework accurately reflects the comments, experiences and views of the individuals who advised its development, and hopefully these resonate with others who use and read it. If you have any doubts, just listen to the person you are supporting.

Skills for supporting autistic people:

A framework

Domain 1

Knowledge of autism: Key characteristics, understanding of the spectrum and co-occurring conditions

Performance indicators

Essential level

Verbal/written feedback

- Describes how autism is a spectrum and a life-long condition.
- Describes differences in back-and-forth social interaction, understanding emotions and relationships.
- Describes differences in communication.
- Describes limited interests or repetitive behaviours, movements or speech.
- Describes differences in sensory processing.
- Describes difficulties with transitions, changes in routines, plans or unexpected outcomes.
- Describes accepted prevalence rates of autism and higher rates of diagnosis among males.
- Names at least one physical or psychological condition that can often co-occur.
- Describes abilities, needs, strengths, gifts and interests for the person being supported.
- Describes how people across the autism spectrum experience disability in different ways.
- Acknowledges that only some autistic people have an intellectual disability.

Observation

- Actively engages in professional development to learn more about autism.
- Learns more about the autistic person they support and works on building a strong rapport with them.
- Adapts support based on knowledge of an individual's autism and co-occurring conditions.

Documentation

- Accesses documentation which describes how key characteristics of autism are relevant to the person being supported.
- Accesses important information about any known co-occurring conditions.

Capable level

Verbal/written feedback

- Describes how numerous factors impact on individuals differently (gender, ethnicity, social, cultural and religious environments).
- Explains the current understanding of the causes of autism.
- Explains Theory of Mind, Executive Functioning and Central Coherence.
- Describes the impact of known co-occurring conditions for the person they support.

Observation

- Provides support to help a person to have greater self-awareness.
- Models successful support strategies.
- Takes a lead role in helping others to better understand the autistic person.

Documentation

- Contributes to documentation reflecting the current strengths and abilities of the autistic person.
- Contributes to documentation which includes strategies to recognise and minimise negative impact of co-occurring conditions.
- Keeps accurate records.

Domain 1

Knowledge of autism: Key characteristics, understanding of the spectrum and co-occurring conditions

Performance indicators

› Enhanced level

Verbal/written feedback

- Describes varying perspectives of autism held by autistic people.
- Describes diverse views of identity held by autistic people.
- Describes a range of assessments available to support understanding of characteristics of autism.
- Describes gender differences in presentation and diagnosis of autism.
- Translates assessments from other professionals for application to an individual.
- Gives diverse audiences information and strategies related to understanding the spectrum.
- Describes best practice regarding use of medication.
- Explains how to interpret and apply NZ ASD Guidelines.

Observation

- Provides education and leadership on knowledge of the autism spectrum, key characteristics and co-occurring conditions.
- Provides information to help an individual and others understand autism.
- Conducts or participates in diagnosis of autism, as appropriate.
- Conducts or participates in assessments of skills, needs or features of autism.
- Suggests strategies that have an evidence-base.
- Accounts for gender in assessment, analysis and recommendations.
- Provides guidance on implementing support strategies, teaching new skills and personal planning.
- Models best practice support strategies.

Documentation

- Contributes to the development of key documentation describing the impact of autism on the person being supported and strategies for support.
- Demonstrates in written work an understanding of the individual and respectfully describes their needs and abilities.
- Uses a strengths-based planning and person-centred approach.
- Presents complex information in accessible terms.
- Contributes to the development of key documentation describing any co-occurring conditions for a person with autism.

Leader level

Verbal/written feedback

- Understands how greater content knowledge specific to autism impacts on service quality.
- Demonstrates to diverse audiences how organisational policies and practices align with current understanding and perspectives of autism.
- Describes how organisational systems and processes align with the NZ ASD Guidelines.
- Describes processes for seeking specialist guidance on autism

Observation

- Ensures policies reflect knowledge of the autism spectrum and best practice.
- Promotes an environment that values the continued development of knowledge related to autism.
- Provides appropriate resources to ensure ongoing staff education on autism.
- Develops and maintains relationships with autistic people and their whānau.

Documentation

- Current policies at a national and local level address the needs of people on the autism spectrum.
- Clearly articulated plans are in place to address workforce development in relation to knowledge of the autism spectrum, including induction, ongoing learning, and coaching/ mentoring.
- Language usage and terminology reflects current attitudes held by autistic people.
- Key documentation is in place which describes the impact of autism on the person and strategies for support.
- All documentation is up to date and accurate.

Domain
2

Wellbeing, mental health and behaviour

Performance indicators

Essential level

Verbal/written feedback

- Describes at least one mental health concern common to people with autism.
- Describes the impact of different factors on mental health and wellbeing for the person being supported (cultural, environmental, physical, economic, psychological, social, spiritual, sexual).
- Describes how lifestyle choices promote wellbeing (physical activity, diet, employment, etc.).
- Describes why it's important to report changes in mental health and wellbeing.
- Describes a range of emotional expressions.
- Identifies challenging behaviour for the person they support as well as factors which impact on behaviour.
- Describes how a person's behaviour is affected by the response of the person supporting them.
- Identifies at least one known trigger for anxiety as well as a supportive response.
- Describes basic de-escalation strategies that can be used to support a person with autism to calm.

Observation

- Support is provided to address factors which could potentially impact on mental health.
- Lifestyle choices that promote wellbeing are included as part of ongoing support.
- Follows established plans regarding mental health, wellbeing or behaviour.
- Uses proactive support focused on improving quality of life as a way of addressing challenging behaviour.

Documentation

- Accesses information regarding challenging behaviour and/or mental health concerns in personal records.

Capable level

Verbal/written feedback

- Understands the role of whānau and wider support networks regarding a person's mental health and wellbeing.
- Describes a holistic view of mental health and is familiar with Te Whare Tapa Wha and Fonofale models of wellbeing.
- Describes how characteristics of autism can be interpreted as challenging behaviour.
- Describes effective strategies for supporting a person's wellbeing.
- Describes triggers for anxiety or challenging behaviour and strategies used to support a person to calm.
- Describes the impact of stress on the wellbeing of the person they support.
- Differentiates the role of mental health services and disability support services in maintaining good mental health.
- Identifies when changes to mental health require specialist assistance.

Observation

- Supports the person with strategies for communicating mental health needs to others.
- Communicates important information regarding mental health, wellbeing and behaviour to others.
- Supports the person to use identified strategies for managing their mental wellbeing.
- Participates in discussions with the person and their mental health professionals.
- Supports the person to recognise emotional and behavioural indicators of mental wellbeing.
- Supports the person to use strategies to maximise mental wellbeing.
- Supports healthy relationships between the person with autism and their whānau or support network.
- Identifies common signs of anxiety and depression and uses appropriate support strategies.
- Models proactive support strategies.

Documentation

- Records changes in a person's wellbeing.
- Records mental health support required for a person with autism.
- Collects data as necessary.

Performance indicators

Enhanced level

Verbal/written feedback

- Understands specialist mental health assessments and interprets reports for diverse audiences.
- Describes benefits and risks of pharmaceutical and therapeutic interventions for a person experiencing mental health issues.
- Describes benefits and risks of using restraint minimisation strategies.
- Describes how various aspects of autism contribute to complex and challenging behaviour.
- Describes ways of positively supporting an individual's behaviour in different settings.
- Describes methods of collecting and analysing data to better understand the function of behaviour.
- Describes known reasons for behaviours based on evidence and data.
- Describes pathways for accessing behaviour support and other forms of specialist support.
- Describes pathways for accessing mental health and addiction support, education and training.
- Describes how behaviour specialists, mental health and addiction support workers as well as other specialists can best work together.

Observation

- Provides staff education and leadership on the mental health and wellbeing support needs of an individual.
- Provides guidance to others to better understand their role in the support of a person's mental health and wellbeing.
- Works collaboratively with other professionals and specialists.
- Provides guidance on how to best implement proactive behaviour support strategies focussed on increasing quality of life.
- Recommends strategies and provides guidance on how to minimise the escalation of anxiety and behaviour.
- Collects and analyses data to understand the function of behaviour.
- Provides information to help others understand the function of behaviour and recommends strategies to positively support an individual.
- Provides guidance on restraint minimisation strategies.
- Communicates complex behaviour and mental health information in accessible terms.
- Accesses information on the evidence-base behind different interventions.

Documentation

- Contributes to key documentation regarding the behavioural and mental health needs of a person as well as support strategies.
- Documented strategies for maximising the mental wellbeing of an individual include strategies related the mental wellbeing of the whānau or support network as well.
- Contributes to the development of key documentation which might include:
  - Functional Behavioural Assessment
  - Behaviour Support Plan
  - Risk Management Strategies
  - Strategies to support self-awareness and self-coping.
- Contributes to the development of personal plans.

› Leader level

Verbal/written feedback

- Identifies resources available for the support of a person's mental health and wellbeing.
- Describes how organisational and workplace culture includes a holistic view of wellbeing and proactive support for behaviour and mental health.

Observation

- Advocates for and participates in cross-sector activity between disability and mental health.
- Organisational practices meet the mental health and wellbeing needs of an individual.
- Advocates for access to specialist support.
- Ensures that support is based on strengths-based and person-centred plans.

Documentation

- Key documentation is in place which describes the impact of autism on the person's mental health, wellbeing and behaviour as well as strategies for support.
- Planning is person-centred and aims to maximise an individual's wellbeing.
- All documentation is up to date and accurate.

Domain 3

Communication

Performance indicators

Essential level

Verbal/written feedback

- Describes the impact of autism on communication.
- Describes benefits of seeking a person's views.
- Describes general communication strategies such as simplified language, visuals and assistive technology.
- Describes ways to help a person process information.
- Describes a person's communication preferences and support strategies.

Observation

- Uses simple and/or direct language when supporting a person with autism.
- Uses appropriate forms of augmentative and alternative communication (AAC), both aided and unaided for the person they support.
- Adjusts their own communication to suit a person's ability to process information.
- Checks for understanding as a routine part of communication.
- Follows established plans regarding a person's communication preferences.

Documentation

- Accesses relevant information about communication strategies for the person being supported.

Capable level

Verbal/written feedback

- Gives an example of when the person they support has used behaviour to communicate or express emotion.
- Explains how changing one's own body language, verbal and non-verbal communication style can support effective communication.

Observation

- Supports an individual to communicate aspirations and choices for community participation.
- Supports an individual to express their own strengths, goals and support needs.
- Supports the use of a robust core vocabulary which takes into account the different functions of language.
- Applies general understanding about communication to a specific person.
- Models communication using the person's AAC system.

Documentation

- Contributes to accurate record keeping regarding communication skills and strategies.
- Plans are available to the person being supported in a format that is best understood by them.

Domain 3

Communication

Performance indicators

Enhanced level

Verbal/written feedback

- Describes specific communication disorders commonly experienced by people with autism.
- Describes additional support and how to access it.

Observation

- Provides education and leadership on how a person's communication is impacted by autism.
- Provides education on communication strategies.
- Supports the use of both low and high technology options of AAC.
- Provides support to understanding the link between communication and behaviour.
- Models best practice on how to simplify language and use other communication strategies including AAC.

Documentation

- Contributes to key documentation which describes the communication needs and abilities of an individual.

Leader level

Verbal/written feedback

- Understands that a person's ability to communicate impacts on the quality of services they receive.
- Describes how to seek input and feedback regarding service development from people with autism.
- Describes how to best share information contained in key documentation with the autistic person.

Observation

- Promotes an organisational and/or team environment that values the opinions, values and choices of a person with autism.
- Ensures implementation of practices which support the development of communication skills within different support settings.
- Facilitates access to specialists and provides appropriate resources towards enhanced communication strategies.
- Service delivery reflects the values and aspirations of autistic people and their whānau.

Documentation

- Key documentation is in place which describes the impact of autism on the person's ability to communicate and strategies for support.
- All documentation is up to date and accurate.

Domain
4

Predictability and structure

Performance indicators

Essential level

Verbal/written feedback

- Describes the benefits of predictability for a person with autism.
- Names at least one example of how structure and routine is part of a person's programme or day.
- Names at least one strategy used to support a person facing a transition or change in routine.

Observation

- Communicates upcoming activities or transitions and checks for understanding.
- Supports the person to understand routines and develop greater independence.
- Follows established routines.

Documentation

- Accesses documents that describe predictability and structure for the person being supported.

Capable level

Verbal/written feedback

- Describes how structure and routine is balanced with flexibility and moderation and why this is important.
- Describes a person's ability to manage transitions and changes as well as effective support strategies.
- Describes how a person with autism has been or would be supported with a life milestone or a traumatic event.

Observation

- Plans new activities and communicates new routines.
- Provides support to understand and manage unexpected changes.
- Embeds structure and routine in a person's programme or day.
- Supports moderation and flexibility alongside routines.
- Assesses and manages risk in new or changed environments.

Documentation

- Contributes to accurate record keeping regarding predictability and structure.
- Records necessary data.
- Personal plans are available to the person being supported in a format that is best understood by them.

Domain
4

Predictability and structure

Performance indicators

Enhanced level

Verbal/written feedback

- Describes how highly structured support reflects best practice in supporting a person with autism.

Observation

- Provides education and leadership on the importance of predictability and structure.
- Provides guidance to include predictability and structure in a person's day.
- Recommends strategies that promote flexibility.
- Teaches self-management of transitions.
- Communicates information about structure and predictability in accessible terms.

Documentation

- Contributes to the development of key documentation about strategies for managing changes, how structure could be included in the person's activities and routine, and how these can be communicated to the person with autism.

Leader level

Verbal/written feedback

- Describes how organisational policies and procedures encourage predictability and structure for the person receiving support.

Observation

- Develops systems designed to create and maintain predictability and structure.
- Ensures staff are supported to balance flexibility with predictability.
- Changes to routines and structure are made in consultation with the autistic person.

Documentation

- Transitions are planned and documented.
- Key documentation is in place which describes the individual's need for predictability as well as strategies for support.
- All documentation is up to date and accurate.

Domain
5

Repetitive behaviours or restricted interests

Performance indicators

Essential level

Verbal/written feedback

- Names at least one way an individual shows repetitive behaviours, movements or speech.
- Describes topics or activities that the person being supported enjoys.

Observation

- Follows established plans regarding repetitive behaviours or restricted interests.

Documentation

- Accesses information about repetitive behaviours or restricted interests in personal files and plans.

Capable level

Verbal/written feedback

- Describes how repetitive behaviours or limited interests affect a person's quality of life.
- Describes a range of strategies used to support a person around repetitive behaviours or limited interests.

Observation

- Supports the person with moderation and self-control.
- Uses limited interests in a positive way to achieve personal goals.

Documentation

- Contributes to accurate record keeping regarding repetitive behaviours or limited interests.

Enhanced level

Verbal/written feedback

- Describes known reasons for repetitive behaviours based on evidence and data.
- Describes positive attributes of restricted interests alongside challenges.

Observation

- Collects and analyses data to understand the function of repetitive behaviour or restricted interests.
- Provides education to understand the function of repetitive behaviour and restricted interests.
- Recommends strategies for supporting a person with repetitive behaviours or restricted interests.
- Provides guidance on how to include restricted interests towards achieving personal goals.
- Communicates complex information about repetitive behaviours and restricted interests in accessible terms.
- Recommends strategies to use limited interests in a positive way to achieve personal goals.

Documentation

- Contributes to the development of key documentation, which includes how to:
  - support displays of repetitive motor movements, speech patterns, or interest in topics or objects
  -manage the impact of repetitive behaviours or restricted interests.

Leader level

Verbal/written feedback

- Describes how repetitive behaviours and restricted interests are included in a proactive support plan.

Observation

- Ensures staff have access to assistance to understand and support repetitive behaviours and restricted interests when needed.
- Works with staff to proactively incorporate repetitive behaviours and restricted interests as part of a person's support plan.

Documentation

- Key documentation is in place which details repetitive behaviours and restricted interests as well as proactive support strategies.
- All documentation is up to date and accurate.

Domain
6

Sensory processing

Performance indicators

Essential level

Verbal/written feedback

- Describes general differences in sensory processing (under and over sensitivity).
- Gives examples of the sensory preferences of the person being supported.

Observation

- Follows established plans regarding a person's sensory preferences.

Documentation

- Accesses information about a person's sensory processing needs and management strategies.

Capable level

Verbal/written feedback

- Describes sensory processing needs for the person with autism across all senses: touch, taste, sight, hearing, smell, movement (vestibular) and position (proprioceptive) and interoception.
- Explains how to reduce sensory overload or increase sensory stimulation.

Observation

- Adapts exposure to sensory experiences according to the person's needs.
- Ensures that support includes positive sensory experiences.
- Prepares the person for difficult sensory environments and supports self-management.
- Creates sensory profiles to help others better understand the autistic person.

Documentation

- Contributes to accurate record keeping regarding sensory processing needs and support.

Enhanced level

Verbal/written feedback

- Describes an individual's sensory preferences based on evidence and data.
- Describes available resources for specialist assessment and management of sensory processing styles.

Observation

- Demonstrates effective collection and analysis of data to understand an individual's sensory processing style.
- Provides staff education and leadership on sensory processing and its impacts on an autistic person.
- Provides guidance on how to positively support a person's sensory processing style and adapt the environment.
- Communicates complex information about sensory processing in accessible terms.

Documentation

- Contributes to the development of key documentation which includes guidance on the management of an individual's sensory processing needs.

Leader level

Verbal/written feedback

- Describes how organisational procedures and physical environments contribute to therapeutic support for a person's sensory processing needs.

Observation

- Ensures that staff have support to understand a person's sensory processing style.
- Adapts the physical and sensory environment to meet each person's needs.
- Provides resources to access specialist support when needed.
- Plans services to best accommodate individual sensory needs.

Documentation

- Key documentation is in place which describes the sensory processing needs of the person as well as support strategies.
- All documentation is up to date and accurate.

Domain
7

Social and community interaction

Performance indicators

Essential level

Verbal/written feedback

- Describes how an individual's ability to socialise or participate in community activities is impacted by autism.
- Names important relationships for the person they support (family, friend, community, cultural and intimate relationships).
- Describes how supporting positive relationships fits within their role.

Observation

- Builds a relationship with the person they support.
- Follows established plans regarding social and community interaction.

Documentation

- Accesses relevant plans and information.

Capable level

Verbal/written feedback

- Describes the impact of community values and attitudes on autistic people.
- Describes why important relationships are valuable to the person they support.
- Describes how to support an individual to socialise or participate in community activities.
- Describes how to support an individual to protect themselves from harm.

Observation

- Supports relationships, friendships and being a part of the community.
- Supports development of social interaction skills.
- Provides information to help others understand a person's autism.
- Provides support to minimise the vulnerability of people with autism.

Documentation

- Contributes to accurate record keeping regarding social and community interaction, particularly in the context of personal goals.

Domain 7

Social and community interaction

Performance indicators

Enhanced level

Verbal/written feedback

- Describes barriers that an autistic person might face in forming intimate relationships.
- Describes available support and resources in the community which promote healthy intimate relationships.
- Describes the relationship between social and community interaction and communication, behaviour and wellbeing.

Observation

- Provides education on social and community interaction and how these are impacted by autism.
- Provides guidance on how to best support social interaction and community inclusion.
- Provides guidance on how to best support an autistic person's needs related to intimacy and sexuality.
- Provides education and leadership on advocacy and self-advocacy.
- Communicates complex information about social and community interaction in accessible terms.

Documentation

- Contributes to planning for social and community interaction.
- Ensures that planning includes goals related to socialisation, community inclusion or establishing/ maintaining relationships.

Leader level

Verbal/written feedback

- Understands staff will have varying levels of skill in advocacy and facilitates access to local and national advocacy support, if and when required
- Explains how the UNCRPD, NZ Code of Rights, Treaty of Waitangi and Human Rights Act align to organisational practices regarding self-advocacy and community inclusion.
- Describes how policies promote social inclusion for autistic people.

Observation

- Actively supports communities to better understand autism.
- Actively networks and collaborates across sectors to promote inclusion for people with autism.
- Develops organisational processes that prioritise inclusive communities.
- Provides support for advocacy and self-advocacy.
- Ensures that planning includes social and community interaction and is aligned to the person's likes and aspirations.

Documentation

- Records include important people and relationships in the life of a person with autism.
- Personal plans include exploring and building a person's cultural identity.
- Personal plans intend to maximise community inclusion.
- All documentation is up to date and accurate.

Stories from lived expertise

Introduction

In my experiences I have found a lack of skills in the workforce, particularly regarding knowledge of the autism spectrum. This is one of the reasons why I'm pleased to be included in this project and why I see the development of a competency and skills framework as beneficial for autistic people.

It is my hope that *Te Tau Tītoki* will guide providers and others towards where they should focus and to determine what support workers and managers need to know and understand when working with and supporting an autistic person, and their families and whānau.

One of the framework's strengths is its co-design, which was a process that allowed ideas to be joined together; in our case it was autistic individuals, parents and whānau as well as organisations. We also included the Ministry of Health and it was really good to all be around the table together at the same time.

It was great to be involved in the early stages of development and to be at the top of the co-design process. This is beneficial because when this framework goes out into the community, people will understand that it's been co-designed with autistic people as well as whānau, and hopefully they will have more respect for it.

I also valued the additional consultation that took place outside the reference group by going into different community settings – people's homes, libraries, universities – and talking to autistic people and families. Having real life stories alongside the competency framework will make *Te Tau Tītoki* come alive. It also gave people a chance to tell their stories, whether it's been a struggle or a positive story, and we had a bit of everything in our conversations.

What stood out for me in people's stories was the focus on advocacy and self-advocacy. We also heard about the importance of understanding mental health and behaviour, and the role of behaviour support, how autistic people need to be listened to, and how autism affects girls and women. Another thing that stood out for me was the importance of ensuring support workers are trained and knowledgeable before they are introduced to the autistic person. This is something I strongly identify with, and I think it's essential for support workers, or whoever is coming in, to have an understanding of the individual they will be supporting.

It's not surprising that advocacy was mentioned so often because advocacy is really important in the autism community.

New Zealand has signed and ratified the optional protocol of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and one of the main components is around advocacy and self-advocacy. This means people knowing their rights and having support people, paid employees and family members, with the skills to support them to speak up for themselves. It's critical for support workers and managers to have a basic understanding of the UNCRPD.

I encourage people to get involved with Disabled People's Organisations, to learn more about their rights and to speak up. One easy way to be better advocates is to use supported decision-making resources, promote the use of Augmentative and Alternative Communication (AAC), and support

autistic people to make choices in their own lives, even if it's as simple as choosing which clothes to wear or what to eat. Advocacy makes me feel extremely confident and this is important because there have been many times, especially when I was younger, that I wasn't heard, I wasn't listened to and I wasn't respected.

Now, when I'm given a platform to be supported as an advocate, it's a real confidence boost and it greatly improves my self-esteem. We know many autistic individuals experience depression and anxiety, so having something they're good at, and promoting that, can make a big difference in their lives.

When I have support workers who understand autism, they treat me as an individual and they support my communication and sensory needs. They support me to use my communication device at the right times and I feel more confident going out into the community because I know they will be able to respond to different situations.

Some of the people we talked with, and a lot of the families that I know with young autistic kids, struggle with behaviours that challenge other people. Adults face challenges too, especially around mental health, and we know research overseas shows we have higher rates of suicide, especially in autistic women.

Having a holistic view of behaviour, mental health and overall wellbeing is the best way to provide support for everyone. This means getting the right support people, including mental health professionals, speech language therapists, behaviour specialists and others around the same table to take a unified approach to understanding and responding to the unique needs of autistic people.

Respecting the views of the person and understanding and supporting their communication is absolutely critical for this support to work. This is my personal view, which was reflected over and over again by other autistic members of the co-design group and the individuals we interviewed as well.

I'm very grateful to have been involved in the development of *Te Tau Tītoki* and for my role in consulting with other autistic people on their views of support. I'm especially happy we were able to talk with a range of people, including children, whose voices are so often ignored. I want to thank everyone that took the time to speak with us. I think their stories truly reflect what we're trying to bring across in this competency and skills framework.

Ngā mihi nui
Gabrielle Hogg

The supports people access

The individuals whose stories are presented here have accessed, or are currently using, a range of different supports.

These include Enabling Good Lives, Supported Independent Living, Community Residential Support, Home Support, Behaviour Support Services, Carer Relief, Parent Education, Supported Employment and a range of services through the Ministry of Education.

People were asked to comment on some of their best and worst experiences, and these stories reflect what they chose to share. These individual experiences are uniquely theirs and shouldn't be generalised. Ultimately, these stories demonstrate the need to develop an understanding of the autism spectrum for everyone who works with autistic people and their families, regardless of role or service.

Trish, Pat, Bradley, Emily and Katie

Trish is a teacher and former special education needs coordinator (SENCO) raising two children on the autism spectrum and another who is undergoing diagnosis. Trish, son Bradley (14) and daughters Emily (11) and Katie (9) talk about their experiences at school, home and the community and the impact support has had on them as individuals and as a whānau.

Much of the support Trish and her family have received has related to understanding and managing challenging behaviour. They're able to offer detailed insights on the role of a specialist worker and the differences highly skilled staff can make for people's wellbeing.

"When you get the right people in your life, they're great, and if you don't get the right people, it causes problems," Trish said.

Trish frequently talks to her kids about autism and says it's important for them to understand the autism spectrum, "it's just part of who they are".

The kids happily share what autism means to them and what they think others should know. "It's a [type of] special needs that's common, but not common. We're very picky. We go through a lot of stuff. We want what we want, when we want," Emily said.

"And if we don't get them, then we have a tantrum," Bradley adds.

Emily continues, "people don't believe that most of us have it, like me and Bradley. Like, when I say it, people don't believe me".

This lack of awareness, understanding and acceptance has had a profound effect on their family and led to a host of problems for the kids. When asked if she thinks it's important for other people to know about autism, Emily quickly responds, "yeah, they can understand us better".

Trish said many people, in various roles at school and at home, have worked extraordinarily well with them as individuals and as a family.

"If I compare the attributes that they have, they are that we're being listened to. And those people are listening knowing that we are advocating for our child – that we actually know best of all."

Trish said something that can't be overstated is the importance of clear communication, particularly with the autistic person. This often means checking for understanding and ensuring messages are conveyed correctly. It can also include changing how we communicate.

Bradley has an after-school job delivering pamphlets and his boss exemplifies this well.

"If Bradley's boss needs to give him a message, he does it in pictures. Bradley really responds to that because that's how he remembers. It's that acceptance and knowledge of how he works." Trish said this is in a large part due to showing respect and developing a meaningful relationship.

"... we're putting people into roles where they should be highly skilled and trained, as well as continually supported, and they're not."

Emily describes one of her favourite teachers. "She understood a lot about me and she knew what I liked and didn't like. She knew what I'm capable of. She knew what would be wrong in every situation and she would talk to me about it. She would take me into her room and talk to me about stuff."

Trish feels that not all professionals have the knowledge, skills or attitude to support her children's success. She offers examples of times that Bradley has been misunderstood at school and how people's responses have escalated situations that could have been managed much more proactively. This has resulted in physical restraint, exclusion and what she sees as unnecessary services to address his behaviour.

Bradley recounts an example of a time where he wasn't following the teacher's directions, which resulted in removal from the classroom. Then, during a meeting with the principal, he was yelled at and approached in an aggressive, confrontational way, which made him more feel more anxious and agitated. This escalation ultimately led to physical restraint and exclusion from school. Bradley said the things that triggered his response included being talked to in disrespectful ways, aggressive body language and teachers grabbing hold of him and his possessions.

Trish said additional support in school was largely ineffective because, according to her, "he was seen as 'behaviour.' It was all about behaviour". Compounding this problem was a lack of cooperation between them, as parents, and the school leadership.

"The principal was 'right', and we were 'wrong.' End of story. It was her way or the highway." She said this reactive approach had a damaging and unnecessary effect.

Trish feels professional training and development is one reason why the support offered at school was ineffective for her family.

"In my experience, because I'm an educator, very few teacher aides receive the professional development they need. If you're really lucky, you'll get one that's passionate and will go and do their own research or has had life experience, so they would have learned that way and are empathetic. Otherwise, we're putting people into roles where they should be highly skilled and trained, as well as continually supported, and they're not."

In addition to school-based support, the family has also received Ministry of Health-funded support at home and in the community, including specialist support through Behaviour Support Services. Trish, Bradley, Katie and Emily describe a much different experience, focussed on individual and household wellbeing, a strength-based and person-centred approach, calm interactions and skill building.

"I cannot speak highly enough about Explore," Trish said. "Ollie [a Behaviour Support specialist worker]

"We're so worried about health and safety in the workplace and people who slip and fall over and things like that, but I haven't heard an awful lot about people's wellbeing, especially in relation to mental health."

worked around the needs of the family." She gestures towards the kids sitting together across the room. "They're both sitting on the same couch together. That could not have happened 18 months ago."

Both Emily and Bradley have received specialist support from Ollie.

"He helped me understand things," Emily said. She mentions developing a better understanding of her brother and sister as well as herself. For instance, she's learned about misophonia and the effects certain sounds have on her body.

Trish said that even though she's a professional, it's often difficult to apply that knowledge in her personal life. With the help of Behaviour Support, she and her husband have been better able to understand triggers for certain behaviours and support the kids in more therapeutic ways.

Trish discusses some of the skills Ollie demonstrated, that she feels should be essential for this segment of the workforce. In addition to putting the needs of the family first, she really appreciated his strength-based approach and his ability to support a better connection between home, school and the community. "He linked up school and our personal life through sport."

Ollie advocated for Trish when she needed support.

"He would go in and just reiterate everything that I had said. It was very empowering from that perspective."

He also helped everyone at home understand why some of the behaviours were occurring and gave practical advice along with simple, measurable goals.

The result has been a happier family and a much calmer way of interacting with one another. Trish feels this has been truly transformative and is something that should receive much greater emphasis.

"We're so worried about health and safety in the workplace and people who slip and fall over and things like that, but I haven't heard an awful lot about people's wellbeing, especially in relation to mental health," Trish said.

Understanding the function of behaviour and how challenging behaviour develops is critical when supporting autistic people and Trish thinks some of the examples of Bradley's verbal and physical aggression illustrate this. She feels all professionals need to have a much better grasp of the various factors influencing challenging behaviour, as well as specific environmental triggers, including their own actions.

"It's anxiety that drives behaviour and you have to figure out what's driving the anxiety. I think there needs to be far more awareness of it."

Trish acknowledges that behaviour can be incredibly complex, and we need to learn about the person and what purpose the behaviour serves for them.

"People have to listen, and you have teach them to look. They need to use their eyes way more than they

use their mouth because when you look at the behaviours you start to understand why they're acting the way they are. Behaviour is a form of communication, but a lot of people don't get that."

Trish has learned a great deal from specialist support and others about how best to respond.

"We've learned not to sweat the small stuff," she said, emphasising the importance of remaining calm.

"He asked, 'What are your priorities? What would you like to work on?' And we felt empowered, because we owned it."

"Actually, I don't mind a bit of noise. When they're really killing each other I really want to do something but, you know, they're actually within reason and functioning the way that a family should!"

Everyone in the family agrees this way of supporting and responding to Bradley works best. They point to an important person who worked with Bradley at school.

"All behaviour issues with him were treated as 'it's fine.' Everything was just very calm. And then Bradley's really good about being able to say, 'I need to put this right.' It's a nice restorative process and it's really quiet."

This approach was reinforced by the behaviour specialist and it was a skill that Trish and her husband Pat needed to learn themselves.

"This is the stuff that we need to do much more of. We weren't always well-skilled at that, especially Pat. It would be, 'Oy! Stop! Rah, rah, rah!' and then time-out. Whereas now it's more like, 'you've got these two choices, so think about the consequences of your actions. Will this get you what you want?' It's just changing the language, but it's really effective."

Trish said autistic people, particularly those who display challenging behaviour, could be much better supported and the fundamental challenge around behaviour is connecting with the person and using their strengths to develop skills.

"Why are we teaching the whole penal thing, the whole penal system? I just don't get that. It's actually about restoration and building relationships."

Trish reflects on the specialist support her family received and what was most beneficial to her and the kids. She says the first conversation the family had with Ollie became the foundation for all the work they completed together. She hopes more professionals deliver the same message when they approach their work with other families.

"There was no judgement, no judgement at all. What he saw is what he got, and it wasn't, 'all you need to do is…' or something. He asked, 'What are your priorities? What would you like to work on?' And we felt empowered, because we owned it."

Important themes

- We need to understand the function of behaviour and respond in calm, therapeutic ways.
- There should be greater focus on the wellbeing of individuals and families.
- Specialists need to educate and advocate.
- Specialists can help people understand themselves and their family member better.
- Let families lead support – ask about their priorities.

Bethany

Bethany is a young woman supported through Enabling Good Lives. Bethany's current support worker Tanwen is a university student undertaking Honours research related to autism spectrum disorder. The two women have developed a special personal connection. Bethany said the support she receives from Tanwen is vital to increasing her independence, preparing for university life and connecting to other services.

For Bethany, sharing her experiences and ideas is a way of providing an insight for people wanting to improve the way they support people on the autism spectrum. She describes support work as a highly skilled role which requires advanced knowledge of autism and the right combination of attitude and personality.

"When I first met Tanwen, she didn't try to shake my hand. She didn't stare at me constantly and she knew the right thing to say," Bethany said.

"I was really uncomfortable about youth group and she knew exactly what to do about it. There was no pressure at all. Ever since then, Tanwen has just been really good about that kind of stuff. She always knows what I need and she doesn't get offended if I accidently say something that shouldn't be said, which happens often.

"She's very friendly and comfortable around me and we have a connection because we go to youth group together – she goes to university and that's the direction I want to head in, so we have something in common."

Bethany sees this connection as vital to building a relationship and establishing meaningful support. She's also been able to do this with others within the service.

"I have something in common with Sharon too because she is a major fan of Dr Who, and I like Dr Who, so there was the connection. You couldn't put complete opposites, personality-wise, together. You really have to put people together in a specific way."

Aside from common interests and experiences, Bethany values Tanwen's knowledge of autism and sees a clear link between that knowledge, their connection and her ability to provide high-quality support.

"Tanwen told me, 'I'm going to university and I'm studying autism' and I thought 'Hallelujah!' She wasn't just being a support worker as, like, something to do. I think it was important to have that kind of investment in there so that it's not just you doing that to get paid."

Bethany said the personal investment Tanwen made in learning about autism not only led to her being good in her role, it also showed she was passionate about helping autistic people lead more independent and dignified lives. Support workers like Tanwen will also be able to improve services to make sure they're more responsive to the needs of people across the autism spectrum.

"Tanwen told me, 'I'm going to university and I'm studying about autism' and I thought 'Hallelujah!'"

Bethany said the impact of Tanwen's knowledge is obvious. "She understands me and she doesn't get offended by the things I say. Tanwen is very good, she knows what she's doing."

"She understands me and she doesn't get offended by the things I say."

When Bethany was first introduced to disability support services, she experienced a sense of disengagement and isolation.

"I was uncomfortable with my first support worker because I had no decision about that and I personally didn't get along with her. I found she made me uncomfortable as a person and being around her was uncomfortable. There was no connection there. It was obvious she had no clue about autism, how it affected people or what it was. She had no idea how to deal with an autistic person and she treated me like I was five."

This caused Bethany to disengage from services and avoid interacting with the person who was supposed to be supporting her to achieve the goal of planning what she wanted to do in life.

"I used to hide in my room every time mum said she was coming."

Bethany said anyone who works with autistic people should have a sound understanding of the autism spectrum. They should also be properly trained and initiated into their role.

"They should learn about autism before they jump straight into it, they should be understanding about things. It's what they say as well. They shouldn't take it straight to heart because sometimes autistic people will say something, and they don't mean for it to be offensive. They'll see it as some kind of emotional nonsense attack, which most autistics don't really do. If I say something, it's probably because it's a logical fact."

Bethany also points out there is a wide range of ability across the spectrum. Professionals need to be able to work with people who have a learning disability as well as those without, adapting their support accordingly.

"There is a big range of autistic people and I think they should be aware, that's important."

Support staff need to be able to understand when a potential meltdown is going to happen and work proactively to prevent it. When they are new to the role or struggling, they should work closely with more experienced staff who are able to provide guidance.

"I think a manager has to be able to do the job of the support workers themselves. They have to have those skills themselves before they try to employ someone else."

Both women agree proper training and initiation has a very real effect.

"We are trying to introduce transitional and handover guidelines, particularly for clients with autism. We're getting there slowly," Tanwen said.

Bethany does not think new support workers should go straight into working with one person and be the main person they connect to.

"When you have a support worker, one you like, you really connect with them. When I have a problem, my first thing is to see what Tanwen thinks. You do make that connection if you find someone that understands you. You want them to be there a lot, it's kind of like a security blanket sort of thing."

Bethany said the ability to support autistic people also extends to organisational managers and leaders.

"I think a manager has to be able to do the job of the support workers themselves. They have to have those skills themselves before they try to employ someone else."

Bethany feels confident approaching a manager if she is unhappy with any aspect of her support.

"Karen is Tanwen's boss and I get on with her because she is really easy to talk to as well," she said.

Bethany also feels that managers should know what additional support is available and facilitate greater support across services. This comes down to establishing a rapport, valuing relationships with disabled people and providing opportunities for people to use their voice. She said autistic people can be empowered when they are listened to and advocacy can drive systemic change.

Bethany believes taking an organisational approach to workforce development and providing better support is straightforward.

"If we could just follow that pattern – be understanding and have the knowledge of what they need to do before they start working with me. Employers themselves should recognise those traits as well. If they don't have them, they should acquire them somehow. Take a course or something."

Important themes

- Strong relationships are the foundation of meaningful support.
- Knowledge of autism is essential when supporting an autistic person.
- Education and training lead to great support.
- Managers should have at least the same level of skill as their staff.

Chelsea

Chelsea and Craig, who is the manager of the disability service supporting Chelsea, talk about the impact of responding in calm, therapeutic ways and how critical it is to understand disabled people. The conversation also focusses on the ways their relationship has been the foundation for good support and how to best encourage self-advocacy.

"There are certain types of people that will get along very well with Chelsea," Craig said. "It's people who can remain calm and open-minded and accept the fact that Chelsea, although she doesn't look like she has a disability, has autism. So, there's going to be times where she is going to fixate on certain topics, and that's going to happen forever. And, if you handle it the right way, we won't have any problems."

"She knows my 'in's-and-out's' and my personality. She's calm and understanding to me."

Chelsea agrees and tells us about Annaliese, a support worker who exemplifies these points.

"She understands me and because she's known me for such a long time, she knows my 'ins-and-outs' and my personality. She's calm and understanding to me. When I'm upset she helps me to settle down, she talks to me and she gives me hugs."

Chelsea and Annaliese bonded quickly because they're close in age and share many common interests. Chelsea said they like to have fun and joke with each other. "She's more like a friend to me than a support worker, because we have a special relationship, it's really special."

She also said that Annaliese understands autism, particularly the importance of routines and her own sensory needs.

When talking about Annaliese and other support staff that have worked well with her, Chelsea said they all had a great understanding of her as a person.

"She's more like a friend to me than a support worker, because we have a special relationship."

"Understanding means they are calm and they listen to me and I think they know me, my autism and my personality," she said.

Craig agrees. "Chelsea can become anxious around certain things. And, these people don't respond in a way that's going to set her off even further. Because they do know Chelsea and they do have some understanding of autism, they are able to talk to her and explain things through. They can be completely black and white and just say something for what it is, without Chelsea having to think about things in an anxious state. They do that very well and I think that's what you're trying to say when you say they understand you and your personality."

Chelsea reiterates over and over again the importance of understanding her as a person and how vital it is for those supporting her to remain calm. "Unfortunately, that's not a follow-on with everybody," Craig adds.

Chelsea recounts different experiences from her life across numerous living arrangements and disability services, detailing experiences when staff members were completely disengaged and times when people used aversive techniques. Examples include being locked out of the house and having things like internet access used in threatening and coercive ways. She also describes being bullied, punished, talked to in disrespectful ways and, in one case, restrained.

Many of these examples of poor support are historic and through these negative experiences Chelsea has developed a strong sense of self-advocacy. Now, when she is unhappy with any aspect of her support, she's proactive about engaging with her support provider so they can work together on a solution.

"I tell Chelsea that it's not just about making the complaint, it's actually about learning as well, for all of the people involved. Chelsea said to me one day that she doesn't want to be known as the 'complaint girl,' but that's not what it's about. This is actually about how we want to establish some clear practice about what's going on in the houses and services," Craig said.

Chelsea feels a sense of empowerment in being listened to and seeing that her views are held in high regard. She knows her self-advocacy will lead to action. Craig ensures Chelsea is integral in any process that follows.

Chelsea described how she filed a complaint and was then part of sorting it. This involved a meeting that included Chelsea and the support worker she wasn't happy with because, as Craig explains, "we just needed to be sure that these two reconnected in a way that they both were happy with, and they both wanted to give it another shot."

It is clear there is a close relationship between Craig and Chelsea. He's able to confidently elaborate on what Chelsea wants to talk about and provides encouragement for her to share her views openly.

"He [Craig] does his job well. I reckon he's done a fantastic job. He's been in my life a long time and he is just a really nice, calm person," Chelsea said.

She agrees that Craig is one of the people who has a great understanding of her and she appreciates his honesty and willingness to share with her the details of any conversation he has regarding her support, which Craig said is vital.

> *"He's been in my life a long time and he is just a really nice, calm person."*

"If you don't, Chelsea will suspect and ask questions, so it's best to just be transparent, black-and-white. Chelsea is a very literal thinker so if you say something that's a bit around-the-bush, it's just going to escalate things. Chelsea can handle news, even if it's not the news that she wants to hear, if it's delivered in the right, calm, direct way. So, everything about her support we talk about, even the financial stuff. At the end of the day our focus, my focus in particular, is to get all of the people we support on board with any aspect of their life."

Chelsea is thankful she has someone like Craig playing such an integral role in how her support is delivered and she is looking forward to the future. "He says he will never give up on me."

Important themes

- Professionals need to recognise anxiety and remain calm at all times.
- Understanding autism is key to understanding the person.
- It's crucial to support self-advocacy.
- Professionals need to listen to autistic people and respond.
- Good managers exemplify good support.

Claire

"I just want to be treated like a normal person, but maybe with a tiny bit more empathy and understanding." Through years of support and numerous support workers, Claire is keenly aware of the importance of attitude for people supporting those on the autism spectrum.

Claire talks about how critical it is to approach working alongside autistic people with a non-judgemental approach, honesty and tact. For Claire, it is a strong personal connection that leads to high quality support.

"I just need a support worker to have fun and make jokes, but if I've said something inappropriate or something, just speak up." Otherwise, poor outcomes become more likely, such as when a staff member, "got really irritated at me, which pushed her over the edge. I never saw her again after that; she just quit on the spot." Ideally, Claire would like to have a "friendship-type relationship, not to be friends but have that comfort level," while still maintaining professional boundaries. This includes having a strong rapport, being able to offer emotional support, allowing her space to cry when she needs it and telling her if she does something inappropriate or is pushing boundaries.

"One of the problems with a support person, like when you just meet them, is that they have to get to know you,"

She insists that having the right approach rests largely on the support worker's knowledge of autism and experience supporting autistic people. If someone has a good understanding of the autism spectrum, they will know that only some autistic people have a learning disability. "otherwise they might treat me a bit stupid or they might think I'm a bit less intelligent."

Claire also wants to remind people that she's a unique individual and that everyone is unique. "No two Aspies are two peas from the same pod, we're just as different as anybody else."

When a professional has a thorough understanding of autism, it makes it easier to understand the person they're supporting.

"One of the problems with a support person, like when you just meet them, is that they have to get to know you," Claire said. She adds that support workers need to be observant and pay attention and that it's not up to her to teach others about autism or herself.

"They'll help me figure out what I can do and then I can just do it by myself."

"A lot of the time I don't want to teach, I just want to get on with whatever it is we're supposed to do, especially when time is limited."

Claire acknowledges that support work is quite complex, requiring a great amount of skill to manage difficult situations. She acknowledges that mistakes do happen to everyone. "If you're with a difficult client, it's pretty hard to stay in professional mode. If something goes wrong, just don't do it again."

Claire says if two people have a good relationship then they should be able to work through difficult situations together. For her, the best support staff are fun people who maintain professional boundaries while encouraging independence. "They'll help me figure out what I can do and then I can just do it by myself."

Claire has a bit of advice for anyone thinking about supporting disabled people. "Don't go in with any preconceived expectations. And just realise that everyone is different and just be open-minded." Preparation is vital because support workers need to, "expect the unexpected and be ready for just about anything". When supporting an autistic person, this is especially true. That's why Claire insists that it's crucial to know about autism. "But also see us as just people. Don't look at us like there's neurotypicals here and everyone else here. Hey, we're all homo sapiens, aren't we?"

Important themes

- Professionals need to understand the full spectrum and how to support people without learning disabilities.
- Be honest and understanding.
- Show empathy and respect.
- The best support looks and feels like friendship.

Karleigh-Jayne

The desire to be listened to and have more influence over how she is supported has caused Karleigh-Jayne some frustration in the past and led to her seeking out new models of support. Now that she's eligible to receive Enhanced Individualised Funding she's chosen a good friend to be her key support worker. As an autistic employer, she offers a unique perspective on support to other professionals.

"It's all about the attitude of the staff and how willing they are to listen,"

"Don't assume someone's capabilities."

"It's all about the attitude of the staff and how willing they are to listen," Karleigh-Jayne said. She wishes more professionals would think about the people they support as if it was one of their own family members. "How would you like them to be treated? You would listen to someone in your family, so try listening to the people that you work with.

"Don't assume someone's capabilities. I would like to be treated with respect and dignity. And to be treated like somebody who is capable of doing stuff, but also take into account that I need help to do things sometime."

Karleigh-Jayne said others need to know about autism but the important thing is to see past the diagnosis to know the person. "Everyone is diverse. If you get to know the person and how to work with them as an individual, their culture and where they come from, you'll find that you end up with a really good relationship.

"This is what we learned about in human development; it's all about time, place and culture. I feel that relates to work with people as well, because there's no one theory or way of working that suits everybody."

Speaking of the role autism plays in a person's identity, Karleigh-Jayne said, "some people are really proud and out about being autistic and some people are like, 'mate, you're dreaming!'".

Karleigh-Jayne chose to employ her current support worker precisely because of her ability to see her as an individual and build a strong relationship.

"Greer is really amazing because she treats me with respect and knows I need support with some things but that I'm really capable of doing a lot of things. We get along really well and we have shared interests. She really understands what I'm like and what I dislike."

"Everyone is diverse. If you get to know the person and how to work with them as an individual, their culture and where they come from, you'll find that you end up with a really good relationship."

As soon as Karleigh-Jayne had the ability to employ her own staff through Enhanced Individualised Funding, she chose to employ someone that she already knew quite well.

"Greer did a psychology degree when she lived in the UK before coming to New Zealand. She's also worked in the disability sector in the UK. We've been friends for three years and she's learned a lot about me from doing animal care together. What drew her to me was my brains and now we have a relationship like sisters. She's like a sister to me."

Karleigh-Jayne has had other positive experiences with support workers in the past as well.

"I had one really good support worker and we clicked over our mutual love of roller derby. She helped me through some really difficult times flatting. She took me out to scrimmages on Wednesday nights and even now, if I have the time, I would skate and officiate. I thought I was pretty good at officiating and people really respected me for some of the little quirks I did. For example, I do a little hand signal when I announce, 'Five seconds until the jam's starting.' That support worker is deaf so I did that for her and other people came up to me and said how much they like it."

She said there are characteristics that exemplary support workers shared.

"They were awesome. They treated me with respect. They were willing to let my interests lead them."

Karleigh-Jayne said the effect of this person-centred approach to support and the ability to let the disabled person lead the process has had a profound effect.

"My support worker got to go with me on Tenacious, the big tall ship. She was raving about it and her workmate said, 'oh, can I come?' and she said, 'no! I'm Karleigh's friend!' Hearing that actually made me feel good because I never really knew how much of an impact I had on people until then."

Karleigh-Jayne talks about how disability support providers should strive to deliver better services to people on the autism spectrum. She said it really starts with valuing autistic people and giving them an opportunity to express their views.

“Services don’t listen! And it’s caused a whole lot of problems. I remember one manager said that I don’t need visuals when I asked for visuals.”

This left Karleigh-Jayne feeling a sense of disempowerment and ultimately led her to the conclusion that she wasn’t getting the support that she was looking for. She also found it difficult when her regular staff couldn’t be there for a shift, leaving her with inconsistent or non-existent support.

“Sometimes I had no one. Sometimes I would have another support worker show-up but it was just a bit unnerving.” One of the things she really values in her current support structure is the flexibility it affords. “It’s hard working with agencies because you have to be on their timetable.” She admits that now, as an employer, things still aren’t perfect because she is busy with study, as is her support worker, but “that’s okay with me because I know it’s just life”.

“A really good support worker would listen to me, be really clear and succinct, be able to tell me things in a way that I understand, and if it means using visuals, then do it. Respect me and don’t criticise me if I need space.”

Karleigh-Jayne’s message is clear. The focus really comes down to respect for the individual, offering opportunities to be heard and responding to peoples’ needs. She reiterates that a good support person is someone who shares common interests and can connect personally. She said it is important to have knowledge of autism and disabilities but a person’s values and attitude are far more important.

“It’s all about respect. You could know so much about autism but still be a crap support worker.”

Important themes

- Listen to autistic people.
- Ask people how they want to be supported.
- Get to know the person and their culture.
- Recognise and build on peoples’ strengths.
- Be respectful.

Sam

Sam discusses how the key to providing good support to autistic adults is to start early in life. He also shares his thoughts on developing a more inclusive society through improving knowledge and understanding of autism.

Sam can easily recognise the interconnectedness of things that others may view in isolation. For him, the connections between school, employment and personal life are clear. He draws a connection between his struggles at school, difficulty finding meaningful employment and the bullying and misunderstanding that he still regularly encounters.

"The problem could be that people aren't learning how to integrate with people with disabilities. We have a real fractured market when it comes to schools and jobs for disability. I had to go to four or five schools before they could fit me in one. They just don't have enough advocates or incentives to encourage equal learning and to work with peoples' learning abilities," Sam said.

When Sam tried to find employment, he found his support people were part of 'the system' and seemed to want to discourage others from taking someone on with a disability.

"They need to connect with people, more around what their interest is or what their skills are. People just need to connect more with that special interest and I think they'll have great workers."

"They need to connect with people, more around what their interest is or what their skills are. People just need to connect more with that special interest and I think they'll have great workers," he said.

Sam believes the key to providing good support to autistic adults starts much earlier in life and a major focus should be on making everyone more aware of autism and different forms of disability. In this way, professionals will develop competency through a greater understanding of autism and disability, and society will become more inclusive.

"There should definitely be a focus on raising the knowledge and skills of those working directly with disabled people, but that shouldn't be seen as a final goal – it's a starting point in creating a more understanding and accessible community," Sam said.

"Like the disability advocates programme they're starting to do at university and learning about different disabilities. They also did a really good one for primary schools about different disabilities and some ways you can help."

Sam also mentions some very specific aspects of autism that are often misunderstood. Most importantly, neurotypical people need to understand how autistic people communicate and make sure they are communicating in clear ways themselves. A good example is body language.

"You need to explain that with autism. Like the head, or the hands, or anything, how do they actually talk? I haven't found a voice box in these things yet, so I don't know what they're talking about. Apparently, there are messages that are being given off, but the hand hasn't told me anything, so I don't know what your hands are talking about."

He explains that understanding communication is critical, especially when an autistic person is experiencing anxiety. When an autistic person has difficulty talking about what's bothering them, they're reliant on that other person to fit the pieces together. The only way to be able to do this is to know about autism and have a good understanding of the person being supported.

"One of the problems is that initially the brain tries to analyse something, and it can come up with awkward blanks. Then the brain needs to re-start and re-analyse. So, it could actually be like 20 minutes before you have an emotional reaction and realise that something is wrong."

"My brain shuts off when I don't know what is happening next, so I just avoid it."

For Sam, predictability is a key aspect of supporting an autistic person. Unpredictable environments, anxiety and physical responses to stress can trigger a sense of shutting down and a feeling of disconnection from his own body..

"My brain shuts off when I don't know what is happening next, so I just avoid it." He also feels people on the autism spectrum tend to need support with managing stress.

"With autistics, it all goes internal and, actually, your body doesn't know how to respond. It just goes a bit chaotic inside, it's all internalised and kind of complicated to externalise it. It happens, but it's like punching the walls, and it's hard to show people how it's all connected.

"The hand takes all of the stress, it just leaves my body. It's hard to explain." This disconnection can lead to a lack of remorse. Sam describes an episode from when he was younger. "The first reaction was, 'do you feel sorry?' And I was like, 'my hand does not feel sorry right now!' Because my hand is the one that did it, the feeling went through my body to the hand and it reacted, that was pretty much it. 'Sorry' is a hard reaction to connect with."

Sam's example demonstrates how people in support roles need to understand behaviour and how stress and anxiety can lead to a crisis. The support person needs to have an in-depth knowledge of the person being supported – the key is to recognise the early warning signs and intervene early.

The key for Sam is to get support early so he can externalise some of the internal chaos in more appropriate ways. It's important that the support person and the person with autism have a meaningful relationship and can communicate with each other.

"It all comes down to words, really, it's all sitting down and talking with people." Another major focus for Sam is bullying and the role of advocates. "Bullying happens too easily with autism. Someone says, 'hey give me that!' And automatically you give whatever they're asking. It's very hard to think if it's right or wrong, so there's kind of a blur, you just sort of know how you're feeling and you don't always have the time to analyse why you're feeling that way."

Sam believes that, as well as having knowledge of disability, being able to advocate and teach self-advocacy and resiliency are vital to good support. It's important to support people to recognise when others are trying to bully or take advantage. He offers an example of a programme that he participated in through People First.

"Bullying happens too easily with autism."

"It was all about advocacy. We got these 'Feeling Safe' cards, which I've got at home. The cards are very useful. It shows if something is happening to you, you can point to the pictures and say, 'could you help me here?' And that's really good."

Sam hopes to see much better services for autistic people in the future, using a 'person-centred, strengths-based' approach. He wants professionals working with people of all ages to be more knowledgeable of disability and to see how various aspects of support and society connect across a person's life. It starts early and encompasses how society views autism and other forms of disability.

"I think it's better if they [health and education services] assess people with autism, particularly at school, on their ability. They would get the grades they deserve at schools and universities and get the jobs that they really want," he says.

Sam would also like a societal rethink about the role disabled people play in terms of paid employment. "Auckland is one of the biggest Pacific cities in the world and there's a lot of creativity! So, why not be more creative? That's people with disabilities and people without. They should be asking more questions, using more creative ideas and coming up with more creative jobs."

Important themes

- Supports are connected across the community and a person's lifespan.
- It's vital to understand how to best communicate with a person.
- Everyone needs to know how stress and anxiety can lead to physical behaviours.
- It's essential to support self-advocacy.
- It's essential to have a knowledge of autism and other disabilities.

Lealofi, Migi, Senele and Iosua

Lealofi and Migi have had a long and difficult journey with their autistic sons Senele and Iosua. They share some of the challenges they have faced through the process of diagnosis, receiving support and finding high quality services. Their story is a reminder of the role that professionals often play in educating parents about autism, how to better understand their children and how to best manage difficult situations at home. They also openly share their experience of how autism can affect parents' and caregivers' mental health and the impact that supportive environments and skilled professionals can have on a family's wellbeing.

Lealofi begins by explaining how the family sought assistance to understand what was happening for their sons. "We could start to see some of the markers of him getting really anxious. We didn't really think anything of it until a couple of years later when we sought some support, some advice from Migi's cousin. Then we went to the GP for a referral. The GP said it was normal and then we talked to a family member and she said we have the right to ask for a second opinion and to get a referral for a specialist. So, we went to a specialist and there were a number of things that we found out."

After receiving an autism diagnosis from a specialist in Auckland, the family returned home to Wellington, where they engaged with a local Needs Assessment Service Coordination (NASC) provider.

"They wanted to know how we got the diagnosis and we got into a bit of an argument because it was like they were accusing us of self-diagnosing Senele. So, I did the arguing, the advocating, for our family. Then we got some support through a Pacific person who was familiar with us and she supported us with the NASC process. The only reason we went that way was because we got the diagnosis and no one really told us about supports or linked us to the NASC," Lealofi said.

Later, when they were referred for parent education and support, they were confronted with long waiting lists and limited options. So, they resorted to managing the situation on their own. Difficulty navigating the system affected the family again when they decided to relocate to Auckland. Lealofi and Migi were unaware of the required process for transferring the supports they were relying on.

"We had issues because, at the time, when we transferred from the NASC in Wellington to Auckland, we didn't know the process. We had 52 carer days down there and then we came up here and only had five. "I found out later that what you're supposed to do is transfer and then adjust it later to let the family settle in. Finding that out three years after we moved didn't help us at the time – it caused us a lot of stress," Lealofi said.

A misunderstanding of rights and processes continued to cause problems. Lealofi received an employment offer, but felt he needed to put the needs of his sons first. "I couldn't start until the boys had settled in, but we didn't apply for a benefit because I didn't know what the process was."

Much of the support the family received early on helped Lealofi and Migi learn about autism. The couple took part in a formal parent education programme and learned a lot from the knowledgeable staff at their early childhood education centre.

"We had an experience where we brought them to a preschool that was really good. We found certain trains, especially diesel trains, would set him off," Migi said. At this stage, Lealofi and Migi admit, they were still unsure about autism and were keen to know more about their sons' skills, why they displayed certain behaviours and how they could best manage them at home. "I guess we were still learning about the boys when we were down in Wellington," Lealofi said.

The difficulty with diagnosis, accessing support and not knowing how to navigate a complex system only seemed to make things worse. The stress of the situation had many impacts on their own wellbeing and family life.

"I just saw a change in Migi's presentation. So, I guess for me, because I work in mental health, I would come home and all the markers would be there around depression and all that, and you would just miss it altogether. Mum was doing a bit of self-blame. She thought it was her fault.

"All of the markers would be there around depression and all that, and you would just miss it altogether. Mum was doing a bit of self-blame. She thought it was her fault."

"It caused a lot of stress. At one point we almost called it quits, but then we went back to our vows," Lealofi said. Fortunately, things improved as the family learned more about autism and found support that worked for them. Lealofi and Migi started to notice that professionals who were knowledgeable about autism provided much better services. The boys seemed to respond better too. Although Iosua and Senele have limited verbal communication, they show how they're feeling through their behaviour.

"They don't talk and tell us, so it's certain behaviours that tell us if a set-up works," Lealofi explained. This became particularly clear when the family had to move early childhood education centres for financial reasons. "You could notice the difference and how they reacted. They wouldn't get out of the car. We noticed it was the skill level and the teachers' knowledge around autism behaviours. That was a cheaper day-care and financially it worked for us, but it caused a lot of issues when we would go

home. You don't realise that cheaper is not necessarily better, it just means that you shift the problem elsewhere – but it seems to impact even more," Lealofi said.

After an unsuccessful transition to school for Senele, the family decided to seek better services for their sons and made the decision to move to Auckland.

"Senele was going to school and it looked like he was just going and coming back. Migi went and saw him and they were just singing songs, and no one was monitoring intentional learning. So, we had a discussion and decided to move up to Auckland.

"I was Googling and found out that there was this school up here that had some expertise around autism. Then we had to find out the boundaries for health because the boundaries for health are different from the boundaries for education." Ultimately, the need to find skilled people who were knowledgeable in autism became the foundation for where the family chose to live and work. "It's funny because we had to live on this side of the motorway to access some of them. That's why we looked for a place here… we were just so focused on the autistic boys," Lealofi said.

Over the years the family has learned much more about autism and how it affects Iosua and Senele. They've accessed a range of different support services including behaviour support, music therapy, sensory workshops, speech therapy and a parent education programme.

The family's current focus is on developing communication skills. Lealofi said developing effective communication is making a real difference for both sons, who are experiencing improvements in their wellbeing and ability to self-manage some of their challenging behaviours.

"What we're finding is that, as we've seen with Iosua, as he gets more language or is able to communicate to us through his device, he is able to regulate himself more and he gets calmer."

"What we're finding is that, as we've seen with Iosua, as he gets more language or is able to communicate to us through his device, he is able to regulate himself more and he gets calmer." As parents, they're able to pick up on subtle cues and recognise nonverbal forms of communication, but it's often difficult to transfer that knowledge to others.

"We notice now with Iosua, there are certain sounds that if he sings in a high tone, then he's in a happy mood but if it's a growl, then he's not. You just have to notice the tone. I think, as a family we've learned what the triggers are, but it's difficult to communicate to someone else what it is."

Lealofi and Migi also employ support workers through Individualised Funding (IF), who provide direct support to Iosua and Senele. They say the best support workers have been able to connect with their sons because they understand autism or have had experience supporting disabled people.

One worker stood out. "You could tell that she just got him. She knew what his interests were and she was there for him. They had a really good connection and she and Iosua really gelled. He would stim and she would do the same thing, like play drumming," Lealofi said.

That connection meant she could ride in the family car, which is usually a challenge for anyone outside the immediate family. This allowed Iosua to be supported to attend church, which was something important for the family.

Migi discusses another support worker who has achieved success in her work with the family.

"She has experience in early childhood and she's brilliant. She knows how to communicate with Senele and Iosua and she sort of walks alongside them, which is quite good. It's a big difference when you have someone who's a bit more qualified than someone who's not.

She knows how to communicate with Senele and Iosua and she sort of walks alongside them, which is quite good.

"Another person has a bit more experience and she knows how to put them to bed and she just has a knack for getting them ready. The ones that come in just because they need extra cash, they don't work out too well," Migi said. Lealofi and Migi have devised a way to use their combined supports to seek out individuals who connect with their sons and provide good support. "When we get carers, we normally use our carer support days to test out people. We see if our boys have a relationship with them or not and if we see that it's positive then we shift them into IF," Migi said.

A key learning has been the importance of using the boys' interests and strengths as the basis of support. Lealofi and Migi show off a number of Iosua's drawings and reflect on how this interest is contributing to the development of independent living skills.

"He would go to bed at night and then in the morning the whole bed would be covered with paper. He must climb out of bed, find all the paper and bring it back. While he's drawing, it's like he's got so much on his mind that he just draws and puts it all down. That seems to be how he self-regulates and once he starts doing the drawings, then he's calm and can fall asleep."

Lealofi and Migi acknowledge that their journey with Iosua and Senele has been difficult and stressful. However, they've also learned quite a bit about autism and the qualities of a good support worker, as well as the importance of advocating for their children. Perhaps the thing that stands out most is how professionals can support the wellbeing of the family through teaching essential skills to them and their sons.

Important themes

- Skilled people deliver quality services.
- Families need assistance navigating systems and linking to other support.
- Families rely on professionals to learn about autism.
- People will go to extraordinary lengths to find good support.
- Knowledge and meaningful support can greatly improve family wellbeing.

Important considerations

Providing high quality support requires a wide-ranging skill set, and the qualities many autistic people seek go beyond what we consider to be knowledge of autism. Conversations with autistic people revealed additional areas that should be considered when seeking out other learning opportunities to complement autism workforce development.

Wellbeing and mental health

There is an increasing body of evidence which shows autistic people and those with learning disabilities are more likely to be affected by mental health issues and prescribed medication for the management of their mental health. Likewise, research indicates that autistic people are much more likely to experience the most adverse effects of declining mental health, particularly related to suicide. Many of the people who contributed to this resource discussed the importance of supporting every individual's wellbeing and emphasised that a competent workforce requires in-depth knowledge of mental health and wellbeing alongside skills related to the autism spectrum.

Positive Behaviour Support

Positive Behaviour Support (PBS) is an overarching framework for supporting disabled people and others who display behaviours that challenge. PBS uses evidence-based methodology to understand why behaviours occur, focusses on a person's human rights and utilises a strengths-based, person-centred approach to intervene proactively. A well-designed PBS plan focuses on building relationships and teaching skills to improve an individual's overall quality of life. The goal of PBS is to create a supportive environment which reduces a person's need to use behaviours that challenge. This requires everyone working together with a shared knowledge of behaviour and an understanding of how that relates to the person being supported.

Culture

For many people, culture is a critical component of wellbeing and a vital part of connecting to their communities. Cultural knowledge emphasises respect for the person, and supports a positive connection and the development of a meaningful relationship between an autistic person and their support person. It also enables people to be supported in a way that values their identity.

Communication

Communication needs will be specific to the individual. Specialist assessment, advice and, where necessary, intervention or therapy, should be sought if there are any concerns. A range of low-tech and high-tech forms of Augmentative and Alternative Communication (AAC) strategies require varying levels of knowledge and skill. Advice to understand and support someone's communication needs is best carried out by a professional with specialist skills and knowledge, and communication support will require varying levels of skill depending on the specific recommended interventions.

Sensory processing

Some autistic people require significant support to minimise and cope with the disabling effects of differences in sensory processing, and this is a crucial aspect of their support. For individuals experiencing negative effects of sensory processing, specialist assessment, planning and intervention is critical and best carried out by qualified professionals. People in supportive roles would require at least a capable level of knowledge and skill to intervene in meaningful ways.

Specific therapies

There are numerous therapies available which could be beneficial to autistic people. These therapies should be carried out by appropriately qualified professionals and underpinned by researched evidence. Therapists will most likely be registered with a professional body and subject to professional standards, for example social workers, psychologists or speech language therapists. Autistic people, whānau, carers and support staff have the right to know that therapies are evidence-based and that the person conducting these interventions is appropriately trained and qualified.

Human rights

Human rights are at the forefront of enabling, accessible communities, and developing an understanding of peoples' fundamental rights is essential for all advocates and self-advocates. A human rights-based approach also comprises a critical component of the knowledge and skills required by everyone supporting people on the autism spectrum and all disabled people.

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