



Disability Support Workforce

Community Engagement Summary

28 March 2023



All is for All

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In particular, we would also like to acknowledge the guidance, input and support provided by the community reference group in completing this mahi.

Ngā mihi nui ki a koutou.

Note that this project was originally commissioned by the Ministry of Health prior to the establishment of *Whaikaha – Ministry of Disabled People (Whaikaha)*.

The majority of the engagement was completed prior to June 2022, however, the analysis and this report were completed after 30 June and therefore provided to *Whaikaha*.

A note on terminology

Language evolves over time. We understand that people identify with a range of terminology for disability. This includes both person-first and identify-first language, as well as a range of terms such as neurodiverse. Similarly, in Māoridom, there are different preferences concerning what language is appropriate to identify disabled Māori people. Throughout this report we have chosen to use the terms “disabled people” and “tāngata whaikaha Māori”. We recognise that the Disabled People’s Organisations (DPOs) in Aotearoa New Zealand also prefer these terms.

Further information on key terms can be found in the Glossary.

Executive summary

Allen + Clarke and *All is for All* were commissioned by the Disability Directorate (Ministry of

Health) to complete community engagement to support the development of a Disability Support Workforce Strategy.

This report, jointly produced by *Allen + Clarke* and *All is For All*, summarises this engagement and is based upon interviews, focus groups and survey responses of stakeholders. Care was taken to capture the voice of those with lived experience of disability, family and whānau, disability support workers, service providers and representatives from other organisations who are involved in the sector. Consultancy *Te Amokura* assisted the project team to ensure that Māori voices were authentically captured.

Our approach was supplemented by a desk-based analysis of relevant information sources, such as industry workforce statistics.

What we found

- The current disability support workforce landscape is complex. There is no clear definition of the workforce or universal experience of the workforce making it difficult to create a single unifying strategy.
- There are currently a range of strategic initiatives in place which address parts of the workforce, but do not provide a sector wide cohesive (or joined-up) approach.
- The disability workforce is currently being heavily impacted by staff shortages affecting the entire health workforce. While this has been exacerbated by the impacts of COVID-19 and reduced immigration, there is an underlying issue with a lack of people entering the disability workforce.
- The disability sector is currently experiencing significant transformation triggered by the implementation of Enabling Good Lives and a shift to more disabled people using Individualised Funding. However, this transformation has not yet been embedded and the workforce needs further support to enable successful system change.

What we heard

Our engagement involved a series of questions designed to support an analysis of the challenges currently being experienced by the workforce and its users and investigation into the expected future workforce need.

We have summarised below the key messages that we heard from our engagements with stakeholders. The details of these engagements are outlined in the following sections.

Current challenges

- There are significant barriers to recruiting people into the disability workforce. Public perceptions of support work are often negative, and it is not viewed as an

attractive career choice. There are barriers to people with lived experience entering the workforce as the qualifications structure doesn't currently value lived experience.

- Development opportunities and pathways were a priority for members of the workforce. Service providers, support workers and disabled people generally agreed that current training and development opportunities do not meet needs and a number of gaps in training programmes were identified. Disabled people also identified that current training programmes were not inclusive for those with certain disabilities or learning needs.
- Significant issues were identified with retention across the sector, particularly amongst workers with more specialised skills and training. Changes are required to make the sector a more welcoming, effective and positive place for the workforce. This includes higher pay rates which are competitive with other similar sectors.

The emerging vision for the workforce

- is grounded in the principles of Enabling Good Lives, UNCRPD and Te Tiriti o Waitangi
- meets the needs of the disabled community by having the 'right' people available to provide services
- is seen as a worthwhile and attractive career
- offers sufficient respite, remuneration and flexibility and development opportunities to be attractive
- has a healthy balance of lived experience, appropriate qualifications and values underpinning it
- is supported by comprehensive data and information (both for the sector and for consumers)
- works with disabled people to respond to trends and future needs of the workforce.

Background

Purpose

The disabled community deserves high quality and well-funded care. The newly established *Whaikaha – Ministry of Disabled People* needs a vision for the disability support workforce and clear direction about the steps required to ensure that the workforce is appropriately developed.

To achieve this *Allen + Clarke* and *All is for All*, with support from *Te Amokura* worked together to complete initial engagement with the community to inform future workforce priorities. This required an analysis of the challenges currently being experienced by the workforce and investigation into the expected future need. This report seeks to:

- Summarise the context and key challenges of the current situation.
- Reflect the expectations of the diverse stakeholder groups engaged, including disabled people and Māori.
- Provide predictions about what will be required of the workforce to 2027 and beyond.
- Identify a set of key shifts that will be required to position the workforce to meet future needs of disabled people.
- Provide critical input into strategic workforce planning and the development of workforce priorities.

Scope

For the purposes of this project the Disability Directorate defined the disability support workforce as *“those people who work with people who are eligible for disability support and includes family caregivers who may or may not be paid.”*

Specifically, this included people:

- working for current providers – inpatient, child development, behaviour support, residential and home and community support, support workers, specialist roles under the High and Complex Framework, managers and supervisors
- working for emerging organisations and groups supporting disabled people in new ways
- employed or contracted by host organisations
- employed by community organisations
- employed or directly contracted by disabled people
- working in Needs Assessment and Service Coordination Service (NASC) roles and Kaitūhono/Connect roles in Enabling Good Lives services

- working in Disability Information and Advisory Services (DIAS) roles.

This includes a wide range of people with varying employment arrangements and responsibilities, qualifications and backgrounds.

We interviewed people in various employment arrangements, some who didn't feel part of the disability support workforce or were unsure if this terminology would cover them.

Further information is provided at Appendix D about the current demographics and size of the disability support workforce.

Our approach to this mahi

Nothing about us without us

One of the foundations of the UNCRPD is that disabled people will be closely consulted and actively involved by decision-makers in policy matters which affect their lives.¹ This principle is best described by the phrase 'nothing about us without us.' Our approach to engagement was grounded in this principle:

- *Our project team was a partnership between disabled and non-disabled people* – our project team was made up of representatives from *Allen + Clarke, All is for All* (who is led by disabled people) and *Te Amokura* (experts in tikanga Māori). *Allen + Clarke* played a co-ordinating role, ensuring those voices came together to inform this report.
- *Our engagement was guided by a reference group* – the reference group was formed to provide a sounding board for the project team from the voice of lived experience of disability and support work. The seven members of the reference group reflected a range of perspectives including disabled people, family and whānau and the workforce. Voices which have traditionally been marginalised were specifically included in the reference group for example tāngata whaikaha Māori, disabled people from rural areas and people with learning disabilities.
- *Consideration was given to Te Tiriti o Waitangi partnership responsibilities* – a dedicated consultancy *Te Amokura* was contracted to ensure the voice of tāngata whaikaha Māori and their whānau, carers and Māori disability support providers was well represented.
- *Our engagement incorporated wider community voices* – disabled people exist in all communities, so it was vital to include contributions from wider stakeholders, such as whānau, caregivers and allies. The disability support workforce deeply affected not only disabled people but their family, whānau and communities as well. These voices helped ensure we understood the wider impact of the workforce.

¹ Article 4(3) UNCRPD

Kua mua, ka muri

Our approach to this mahi was guided by the whakataukī – ka mua, ka muri. This is often translated into 'walking backwards into the future'. By focusing first on what has happened in the past, we can learn and adapt to bring about a better future.

This whakataukī informed our approach to engagement which aimed to elicit views from representatives across the community and uplift the voices of disabled people. The engagement focused on gaining perspectives and insights on the following:

- Key events and factors that have led to or shaped the current state and current challenges facing the disability support workforce.
- Current workforce landscape, including current workforce characteristics, capabilities (clinical and specialist), philosophies, approaches and methodologies.
- The future landscape and context.
- Barriers that are preventing key shifts.
- Current career pathways and supports for recruitment of a diverse workforce.
- Aspirations of the disabled community that can be supported through the disability workforce.
- Factors that are necessary to appropriately support, enable and empower the workforce to achieve the vision and to navigate system transformation successfully.

Engagement methodology

The insights in this report are based on our engagement with the disability community. These were collected through:

- 16 interviews
- 6 focus groups or small group sessions
- 2 workshops
- 3 wānanga
- Publicly available survey (686 respondents).

A primary consideration for our project team was that our engagements were inclusive and safe for participants. We adapted the format to meet the specific needs of disabled people (for example, a small group session was facilitated by People First with people with learning disabilities). We had processes in place (including professional support if needed) if people disclosed sensitive material.

Where possible our engagement material was made accessible including through translation into Easy Read format and NZ Sign Language.

A full list of interview and survey questions has been provided at Appendix B / Appendix C.

Perspectives we engaged with

Throughout the project we engaged with 82 people via online or in-person sessions. A further 686 people submitted responses to the survey. The diagram below gives an overview of the perspectives and people that we engaged with.



We asked participants whether they identified as disabled in our engagements. However, we did not ask them to share any details about the nature of their disability (although some people chose to do so).

Specific disabilities have been noted where:

- We spoke to a representative organisation associated with a particular type of disability for example we engaged with a representative of Parents of Vision Impaired.
- The Ministry explicitly requested that a certain perspective was included (through the contract or from discussions with the project team). For example – the Ministry explicitly noted the importance of engagement with people who are non-verbal, people with learning disabilities and people with Foetal Alcohol Syndrome.

A note on participant responses

The types and nature of services described by disabled people and their whānau differed greatly depending on whether:

- **they lived in an Enabling Good Lives pilot region**
- **they had access to Individualised funding**
- **they directly contracted their own support worker or used a service provider**

This made it difficult to synthesize any one experience of the disability support system either from a user or provider perspective.

Operating challenges facing the workforce

We have outlined below significant challenges currently facing the disability workforce.

These were the main environmental factors that stakeholders identified as affecting the sector. Other factors have been identified based on a forward-looking contextual analysis based on a range of sources as outlined in the Reference section.

There are significant staffing shortages

As noted elsewhere, the disability workforce is not the same as the health workforce. However more information is known about the general health workforce, and this provides useful context to draw inferences and meaning. While Aotearoa has many skilled, dedicated and professional health staff, there are significant staffing shortages across all health aligned professions. Specifically, there is a lack of people with the right skills, high turnover, uneven distribution of the workforce between rural and urban areas, and reliance on migrant workers (Ministry of Health, 2014). The current workforce is ageing with fewer young people entering health professions. There is long-standing global competition for a limited health workforce and the COVID-19 pandemic has placed further pressure on workforce availability, retention and wellbeing.

Māori and Pacific representation are low across all health professions, with slow growth (1 – 2% a year) especially in leadership positions (Health Workforce Advisory Board, 2022). The complex health workforce funding stream and lack of streamlined coordination are considered the main barriers to the growth of Māori and Pacific workforce.

COVID-19 has contributed to workforce shortages by:

- increasing the number of people choosing to leave the workforce because of burnout, negative working conditions or vaccine mandates
- boarder closures reducing the availability of immigrants who typically fill a number of roles.

However, while this has exacerbated the workforce shortages, we heard that the underlying issue of under-recruitment into the workforce has been a long-term persistent problem. There is an over reliance on immigration to bolster the workforce without significant enough investment in domestic recruitment and training programmes.

The disability workforce shares many of the same challenges as the wider health profession. These challenges result in increased unmet needs of disabled people, especially those requiring highly specialised care (Stats NZ, 2017).

We heard from service providers that this has created competition between overlapping health workforces particularly for more highly skilled roles. We understand this is particularly problematic for residential care facilities which currently struggle to find registered nurses. A significant contributor to the nursing shortage was higher pay rates for jobs with Te Whatu Ora (formerly District Health Boards), with other services struggling to offer competitive salaries. Sufficient numbers of registered nurses is vital for these facilities to remain open and provide the level of quality care expected for disabled people.

Certain aspects of disability support services are transforming but system transformation is slow and hasn't yet been embedded nationwide

The introduction of the Enabling Good Lives (EGL) approach and the EGL pilot programmes have changed the way disability support services are currently being provided.

The vision of the EGL approach is that in the future disabled adults, children and their families and whānau will have greater choice and control over their lives and how they are supported. There are two key aspects to the approach – the EGL vision and principles and the EGL pilot programmes.

Enabling Good Lives has eight core principles:

- Self-determination
- Beginning early
- Person-centred
- Ordinary life outcomes
- Mainstream first
- Mana enhancing
- Easy to use
- Relationship building

An EGL service approach is currently available to disabled people living in Christchurch, Waikato and in MidCentral (Mana Whaikaha). A key feature of the EGL service is the provision of an EGL Kaitūhono or Connector who works with disabled people and their whānau to make a plan for their future and connect them to services that suit them. This allows disabled people to self-direct their own future based on their preferences and aspirations.

Greater eligibility for Individualised Funding has also significantly changed the way that many disabled people and their whānau access services.

Many disabled people and whānau who were interviewed indicated they were unfamiliar with EGL or weren't sure what it meant. Generally disabled people and whānau were only familiar with EGL if they lived in a pilot region or had received an EGL service. Even where people were familiar with EGL, they confused or conflated its principles and service delivery functions. A significant group of interviewees thought Individualised Funding was only accessible through EGL.

Generally, people that provided disability support services (particularly where they were associated with a service provider) were aware of EGL and understood the principles. Survey results showed the workforce rated their familiarity levels with EGL approaches at six out of ten. However, many providers outside the EGL pilot regions didn't feel they were supported or had the necessary tools to apply an EGL approach. They didn't know what the future rollout of EGL nationwide would look like and how that would affect their services.

This was particularly true for service providers in providing residential or home and community support. They often felt that EGL were principles for 'mainstream disability' and didn't consider or cater to people with higher levels of need. While choice and control are important and highly possible in those contexts, the outcomes often look quite different and require different resourcing and skillsets. These providers didn't feel like they were included in EGL and questioned how the nation-wide rollout would affect their services.

Vision for the future workforce

We asked participants what they required and valued in the future disability support workforce. We have summarised their responses according to group as there were diverging perspectives.

Disabled people

Disabled people fundamentally want choice, empowerment and freedom from their disability support services. More than 80% of survey respondents who accessed DSS for themselves, or for someone in their care responded that choice and control over support options was most important to them. They described how service provision should be flexible and responsive, with supports tailored according to the individual and support staff that understand their needs and wants.

From a workforce perspective choice and control meant having:

- Control over the way a support worker provides their service (a relational rather than transactional approach).
- Choice over who their support worker is – being able to choose a support worker of a particular age, gender, ethnicity, skill set or with similar interests.
- Control over the activities a support person is prepared to assist the disabled person with (for example shopping trips, outings and budgeting).

Disabled people consistently told us they wanted a workforce that respected their will and preferences in both big and small matters.

Disabled people want to see more disabled peers in roles in the support workforce, particularly in information roles such as NASC or DIAS.

Tāngata whaikaha Māori

Tāngata whaikaha Māori felt strongly that being able to choose who they employ to deliver care and how they are supported is crucial. They felt this made them more empowered to set and achieve their individual goals and aspirations.

We also heard tāngata whaikaha Māori want a workforce strategy that incorporates intrinsic Māori values at the centre such as tika, aroha and pono and ensures the voice of tāngata whaikaha Māori living in urban and rural Aotearoa is reflected.

“My wife and whānau have learnt from each other. My wife is the main carer, but after 43 years, we’ve been able to build our own whānau support and capability. We contract and train people we need and want. It works for us.”

- Tāngata whaikaha Māori

“- “My mental wellbeing and relationship with carers must be positive. This happens by carers respecting my whare, being able to respectfully tell my carers how I want to be cared for, what my care looks like and more so, not walking into my home and being judgemental“.

- Tāngata whaikaha Māori

Family and whānau

Family and whānau had a range of different priorities depending on the care or support role they played.

Family and whānau felt it was important to prioritise employing carers that are well-trained, well-coordinated and who understand disability. Clear communication from support workers and agencies was seen as crucial to supporting disabled people and their whānau. It was also important to this group that support providers take into consideration the needs of family and whānau in the wider scheme of caring for disabled people.

Many family and whānau members in support roles wanted more recognition for the role that they played in providing care. Whānau carers wanted to be supported, have access to training and the ability to easily access respite.

For Māori, whānau are often considered the centre of care for tāngata whaikaha Māori. Māori felt it was important to ensure whānau are incentivised and supported to provide care. This means a system which pays the same rate for family and non-family carers, ensures accessible employment opportunities for whānau and builds capacity and capability through on-going training.

Service providers and support workers

Service providers and support workers had common goals and priorities for the sector including:

- Having access to a robust pipeline of support workers to alleviate staffing shortages.
- The support workforce being seen as a valuable career choice with career pathways, and exciting opportunities for growth. This included better pay for support workers across all levels.
- Many service providers were excited about the opportunities for system transformation but didn't know how to support their staff to move to new ways of working and approaches.

Māori disability service providers

Māori disability service providers spoke collectively about the need to integrate Māori systems and thinking into the workforce. There is a strong desire to include te ao Māori approaches as part of carer recruitment policy and capabilities. This included designing appropriate fit-for-purpose training to strengthen carers' cultural competency for example by integrating Te Whare Tapa Whā into day-to-day delivery of care.

"The training needs to be a hands-on approach and less from the pukapuka [lungs] ... So I developed our own assessment according to how we provide support, particularly support focused on mātauranga Māori."

- Māori disability provider

"We need more Māori advocates to help Māori to navigate the system."

- Māori disability provider

Strategic priorities

Once stakeholders had shared their vision for the future disability workforce, we asked them to:

- Outline current challenges or barriers faced by the workforce.
- Describe the changes they felt were needed to support the desired workforce transformation

We have themed our findings in this area into three broad areas (recruitment, retention and development). However, we acknowledge that all aspects of the workforce are interrelated and where possible we have attempted to draw connections between insights.

RECRUITMENT

We heard that there are significant barriers to recruiting people into the disability workforce

One of the most significant issues raised by stakeholders was an inability to recruit people into disability support jobs. This issue was raised by almost every stakeholder we spoke to and was seen by many as the most significant issue for the sector. We spent a significant amount of time with stakeholders discussing the causes of the inability to recruit people. These are outlined below.

We heard that people have negative perceptions of disability support work

Most stakeholders (including disabled people and service providers) felt that disability support work is not viewed positively as a career choice. This perception was seen as being created

and reinforced by the stigma surrounding disability. We heard that the impact of the Medical Model of disability means that the public are taught to 'other' disabled people; fear them or dismiss them. Barriers to entry for disabled people in many communities and employment sphere mean that often disabled people may not be visible to large segments of society, or they are visible in only negative or infantilising ways. This contributes to a lack of understanding of what disability support work is like.

The consistent view held was that many people still perceive disability one-dimensionally as a medical condition and conceptualise support work in the same sphere as health care. In particular, stakeholders felt that the negative perceptions of disability support work contributed to a lack of younger people choosing to enter this workforce.

We heard that many people are surprised to learn about the opportunities involved in support work – the flexibility that can be involved, the chance to travel or do leisure activities alongside a disabled person and the opportunities for downtime during a shift.

We heard from service providers there may also be negative perceptions of the disability support workforce related to perceived or actual workforce conditions. The sector is perceived to be low paid, with few opportunities for growth or development.

We heard there are barriers to people with lived experience entering the workforce

A variety of people told us about experiences of being unable to take up jobs in the sector due to a lack of qualifications. Many of these people had previously been whānau carers or had lived experience of disability with a desire to share their knowledge and learnings with others. However, from an employers' perspective they were 'unqualified' and could only take up low-paid positions. This was more likely to affect people from Asian, Pacific or Māori communities who may have extensive expertise in caring for disabled people in their community but were seen as less likely to take on mainstream qualifications.

In particular, disabled people wished to be part of this workforce and felt their lived experience of disability should be recognised as a skill or experience equivalent to a qualification. Forty three percent (43%) of survey respondents reported that having more disabled people working visibly in the system was one of their top three priorities for the future.

The qualifications system was seen as exclusionary to certain groups of people, such as people based rurally or people with certain disabilities or different learning styles. We understand there are a range of training courses available but many of these are delivered online and are not accessible for all people.

Another significant barrier to entry identified by disabled people is the presence of ableism in the sector. We heard that the systemic bias of low expectations for disabled people has impacted disabled people's ability to get jobs in this sector. One stakeholder recounted a time when she was rejected from an administration role with a support provider because she was unable to obtain a driver's license. The role she had applied for did not require her to drive but the support provider had a general requirement for all staff to have driver's licenses.

We heard that the processes required for support workers concerning police checks currently prevents people with minor offences (such as traffic violations and unpaid fines) from

participating in the workforce. While the regulations around police checks exist to support safety, in some rural areas or systemically disadvantaged areas this process creates a barrier to recruitment. Some stakeholders suggested that flexibility could be considered in this process, particularly in areas of significant need to help reduce the workforce pressures.

We heard that moving forward the focus needs to be on recruiting the 'right' people

We heard the right people have certain values

Disabled people consistently said they want people in the workforce with the right values. They described how this would support the development of high-trust, professional and respectful relationships between disabled people and their carers. They want people who:

- Understand they are there to give support to another person's will and preference.
- Listen to what the disabled person needs and wants, not substitute what they want to do.
- Treat the person they are engaging with as a priority and not just thinking about their next client.
- Act with empathy, kindness and patience.

These skills were also the types of skills that were identified by providers as being necessary to provide an EGL approach to support work. Both disabled people and providers felt that there was not enough emphasis placed on hiring for these softer skills. Many people talked about how other skills could be taught but it was difficult to teach people to display compassion or initiative.

Currently disabled people did not feel that all support workers had those values. Multiple people spoke about support workers being on their phones when they were meant to be engaging with the disabled person. They gave numerous examples of situations where they felt their support person's mind was on something other than the person in front of them.

We heard the 'right' workforce is diverse

Disabled people and their whānau want support workers who fit into their community or share similar characteristics or interests.

We heard that the majority of current support workers are middle-aged or older Pakeha women.² Men in care and support roles tended to be family members or to work in particular areas of the sector such as behavioural support roles.

² We were unable to confirm the accuracy of this perception with current available data. However this tracks with general trends in the support and care workforces and is also supported in data available from Australia where over 70% of the disability workforce is women and 44% aged over 45.

Disabled people and whānau wanted a more diverse workforce to suit their needs and preferences including:

- Māori and Pasifika support workers
- Male support workers
- Younger support workers
- People with disabilities or lived experience

In particular disabled people identified the need for diverse people to take on certain roles such as Needs Assessment, Information Advisory or navigation services.

Service providers also saw the need for a more diverse workforce, but struggled to recruit suitably diverse people to roles.

DEVELOPMENT

Across our engagement people had a wide variety of views about the importance and emphasis on formal training programmes and qualifications.

Some disabled people and whānau did not place a great deal of importance on formal training or qualifications. They felt that as long as a support person had the right values and attitude, they could teach them anything else they needed to know. In fact, some people had a preference to train their own support worker so they would provide care according to their needs and preferences.

Some other disabled people and their whānau placed a lot of importance on having skilled support workers.

In general support workers and service providers supported formal training and more directed career pathways. They felt this was crucial to contributing to the perceived value of support work and crucial for providing quality services to disabled people. However many of these stakeholders did not feel that current formal training pathways were sufficiently targeted or equipped to deal with current support needs.

We heard that there is a lack of career pathways in the sector

Support workers and service providers felt that once people are in the workforce there are limited pathways for them to develop over time. There are limited resources for training and the chronic understaffing often means people are unable to take up training or development opportunities. Some providers commented that the only way to progress in their organisation was by entering management which would not suit or meet the needs of everyone. This view is supported by 2017 – 2018 workforce data which showed that 29% of the workforce is unqualified.³

³ 2017 – 2018 pay equity data provided by MOH

We heard that the lack of recognition disability support work gets amongst training and certification programmes, especially in vocational training, means that it is not visible to the potential workforce when they are at a pivotal point in establishing their career pathways.

We heard there needs to be more options for training

Stakeholders across all groups told us there needs to be more options for training and development. This included different training to cater to the structure and size of the provider, employer or carer in each case. For example, training to work in a residential setting needs to be very different to training for a parent caregiver. We heard that most providers prefer in-house training because it was cheaper and more efficient to deliver, and training provided by other providers were not seen as useful.

A survey completed by NZDSN in 2018 found that Level 3 and Level 4 qualifications were only meeting the needs of between one quarter and one third of service providers.⁴ Survey respondents also reported a preference for in-house training over other training providers.

However, in 2018 one third of organisations reported in the survey that they didn't receive funding for training and development. This was supported by our engagement where service providers reported they received no or inadequate funding to support training and development needs.

Many support workers reported they were unable to attend training because their service provider was understaffed.

"We want the right people in the right roles but the limitations on training and development make this much harder to do."

- Service provider

Disabled people commented that there should be greater alignment of services and service provider training for a more cohesive system. Often their support person might have been trained in a specific way by a provider and couldn't adapt to other ways of working.

We heard that there are specific gaps in current training programmes

Stakeholders across all groups indicated that training was needed or currently inadequate in a variety of areas:

- Being inside a disabled person's home (as your workplace)
- Dual training (for example disability and mental health)
- Navigating personal relationships with a disabled person (who is your employer)
This was particularly raised in relation to whānau caregivers who were trying to grapple with what effective self-directed funding and quasi-employment relationships between family members look like in practice.

⁴ NZDSN survey <https://nzdsn.org.nz/wp-content/uploads/2021/05/Workforce-Survey-Report.pdf>

- Responding to challenging behaviour
- Recognising and reporting abuse and neglect
- Specialist training for unique and complex needs
- Awareness of the EGL principles and how to apply these in real life settings

We heard that current training options do not cater for people with learning disabilities

Many stakeholders indicated to us that there needs to be better training, development, eligibility criteria and information aimed at people with learning disabilities.

In particular, training courses were often run online and were in a written format which is not accessible to a large number of people with learning disabilities.

RETENTION

We heard that changes are required to make the sector a more welcoming, effective and positive place for the workforce and the community they serve. We heard that many support workers are choosing to leave the sector to pursue opportunities either overseas or in other sectors. We heard that the current workforce environment is not conducive to people wanting to stay for a number of reasons including system-level policy issues.

Support workers reported low mental wellbeing

Support workers reported that burnout and low mental wellbeing were a significant concern. In a survey of over 1,600 carers most respondents reported experience of poor financial, physical and mental wellbeing as a result of being undervalued (Synergia, 2022). In our survey 71% of respondents reported that one of the biggest issues facing the sector was burnout or mental/emotional fatigue.

We heard that health and safety issues such as being overworked and burnt out are prevalent in the disability support sector. This has been exacerbated by COVID-19 but the problem was identified to be ongoing and long-term.

During the engagement period, a number of providers talked about the current strains with staff being absent from work due to COVID-19 or the seasonal flu.

We heard that burnout has a significant impact across the disability sector because if people choose to leave it places even more stress on an already fragile sector. There is a risk that people leaving the workforce because of burnout will not recommend disability support work to others, further damaging the reputation of the disability support workforce and contributing to negative perceptions of the work.

The wellbeing of the disability support workforce also impacts the disabled person who is receiving support. Throughout our engagement we heard from many disabled people who have been negatively impacted by the wellbeing of their support staff. This was most commonly reported as a lack of support due to workers being less available or not available at all. Disabled people also observed that the quality of care they received was lesser or didn't

meet their expected standards – they were less likely to be treated nicely or patiently when needed.

We heard there is an opportunity to provide greater wellbeing support

While the workforce acknowledged there are many challenges to ensuring the wellbeing of staff, many providers felt they did their best to ensure staff receive wellbeing support.

Some current or potential future initiatives identified included:

- Peer support
- Counselling
- Discounts for gym memberships
- Discounts at some retail stores

Some providers currently offer these kinds of benefits to staff but not all. However, family and whānau carers or independent disabled employers would struggle to offer their employees the same or similar benefits. It was suggested that any strategy to support workforce wellbeing should ensure there are a range of centralised tools and resources to support wellbeing.

We heard that family and whānau carers also need wellbeing support

Family and whānau carers (both paid and unpaid) reported low levels of mental wellbeing and reflected there was a lack of adequate on-going support.

The majority of family and whānau received wellbeing support through community or parent-to-parent organisations. While this support system is invaluable – we heard it is also shaped by experiences of trauma and mistrust. This has a negative impact on whānau entering the disability support system, and shapes the way they interact with support services going forward. Family and whānau did not feel like the support and wellbeing services provided through government were sufficient to cater for the depth and breadth of their wellbeing needs.

While some family carers were eligible for respite services, they often did not take respite because of a lack of trust in the respite services available. We heard that a number of respite services have closed, and there are some concerns about the quality of services provided to disabled people. There was a general perception that respite services needed to be more widely available, with appropriate funding to support quality care.

We heard that the lack of pay equity causes people to leave the sector

All stakeholders agreed that support workers are not currently paid enough to reflect the value of the work they do. Some support workers left the sector for other better paid opportunities or because they felt their work was not being valued. A 2019 workforce survey completed by

the NZ Work Research Institute showed that 68.3% of support workers were paid less than \$25.50.⁵

Competition was most strongly felt for more specialised or technical roles. One example was a residential care facility who reported they struggle to recruit or retain registered nurses due to low pay rates. They reported pay rates for nurses in the public health system was 22% higher than the rates for nurses in disability roles meaning they often lost staff to roles at public hospitals.

The impact on these care facilities is that they are understaffed and under pressure to care for some of the most vulnerable and high needs members of the disability community. We heard this effectively puts disabled people in their care at risk of not receiving adequate care.

Feedback on the service delivery model

We received a significant amount of feedback from stakeholders about the current model for provision of services. Although this feedback doesn't relate directly to the workforce it provides a picture of the future system the disability workforce will need to support. The workforce will need to have the skills and be able to adapt to this transformed system.

We heard that disabled people want more flexibility in funding and service provision

In addition to a more flexible workforce, disabled people spoke about their desire to have more flexible care arrangements, including funding, needs assessment and carer arrangements. Flexibility was desired regarding when and where they receive support services, such as being able to switch their support days around or change the type of support needed based on how they are feeling.

We heard that there is a need for support for disabled people and whānau to use Individualised Funding

We heard that while Individualised Funding should lead to more choice and control in theory, more management support was needed. There is a lack of development and resources for disabled people and their family to exercise control effectively – for example how to be a good employer. Some whānau had moved away from Individualised Funding during the pandemic because they felt unsure about how requirements such as vaccine mandates should be handled. We heard similar experiences from some caregivers in a National Disability Insurance Scheme context.

People said they wanted a meaningful choice between selecting Individualised Funding and working with a provider and the ability to choose what works best for that individual and family. Many people had a perception that directly employing a carer through Individualised Funding was the only way you could get any real choice or control.

⁵ See Appendix D.

We heard that there is a lack of information about available services

Disabled people want to be able to have ready access to advice and information about services they could receive, and clear processes to be able to obtain those services. Most commentaries from disabled people throughout the engagement signaled that information was hard to access, and they feel they are missing out on services. They sought an accessible and intuitive process with adequate communication and clear information on available supports and eligibility criteria.

People who had received EGL services emphasised the importance of the Kāituhono role to navigate the system.

Broader feedback

We heard frustrations around eligibility for services

Conditions such as Foetal Alcohol Spectrum Disorders (FASD) do not qualify for support despite the demonstrable impacts of not receiving support for relevant conditions.⁶ We heard from people with lived experience of FASD and their frustrations about eligibility criteria and other barriers associated with the significant stigma around FASD.

We hear there is poor sector level information

Strategic workforce management relies on having quality information about the workforce such as a breakdown by location, age, ethnicity, gender, role, skills and provider type. It was difficult to source this industry level information, highlighting a need to strengthen workforce data collection and analysis at the industry level. This was raised as a particular source of concern amongst workforce representatives and service providers.

We heard there are specific barriers for people with learning disabilities

We received feedback from people with learning disabilities and their caregivers that there were specific and compounding barriers relating to people with learning disabilities.

These included:

- The need for navigators to help support people with learning disabilities to make decisions without substituting their decisions.

⁶ Note that our scope of work explicitly included people with FASD despite their lack of eligibility for Disability Support Services at the time. This meant that the people providing them support were not expressly included in the definition of the workforce, but were treated as part of the workforce for the purposes of this report.

- A lack of understanding as to how specific conditions and impairments presented in individuals.
- Wider socio-economic issues (such as access to transport, heating and a safe secure home) affecting the delivery of good services and supports.
- Values relating to the social model of disability and lower expectations or aspirations for people with learning disabilities.

We heard there are barriers to care in specific communities

There are different providers offering different types of services to different people in rural and urban areas of Aotearoa New Zealand. We heard that there may be gaps in terms of access to workforce in different areas. There are also differences in the resources and ways of working for the workforce depending on whether a disabled person is in a residential setting, a flat, living with family or in their own house. We heard there were clear discrepancies between the levels of resourcing available such as more resourcing for people in residential settings.

Glossary

Term	Explanation
Ableism	Discrimination and social prejudice against people with disabilities or who are perceived to have disabilities. Ableism characterises persons as defined by their disabilities and as inferior to non-disabled persons. On this basis, people are assigned or denied certain perceived abilities, skills or character orientations.
Disabled People	Disabled people can include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. ⁷
DPO	Disabled People's Organisations
DSS	Disability Support Services
Enabling Good Lives	Enabling Good Lives is a partnership between the disability sector and government agencies to ensure that disabled people have greater control over their lives. The vision of the EGL approach is that in future disabled adults, children and their families and whānau will have greater choice and control over their lives and how they are supported. The eight core principles of EGL are outlined at https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/ .
Learning disability, neurodisability	Umbrella terms for several conditions and impairments including but not limited to Attention Deficit Hyperactivity Disorder (ADHD), Foetal

⁷ See Article 1 of the United Nations Convention on the Rights of Persons with Disabilities.

	<p>Alcohol Spectrum Disorders (FASD), traumatic brain injury, dyslexia, dyspraxia, dyscalculia and autism. Generally, this report uses:</p> <ul style="list-style-type: none">• Neurodiverse for people who have neurological differences like autism and dyslexia.• Learning disability for people who live with intellectual disabilities such as Down Syndrome.• “Invisible disabilities” to speak to other impairments.
Social Model of Disability	<p>A way of viewing the world, developed by disabled people. An example based on a social model of disability is the United Kingdom Scope’s Everyday Equality Strategy.⁸ The model states that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical (buildings without accessible toilets) or caused by attitudes (such as assuming disabled people can’t do certain things).</p> <p>The social model helps us recognise barriers that make life harder for disabled people. Removing these barriers creates equality and offers disabled people, more independence, choice and control.</p>
UNCRPD	<p>The United Nations Convention on the Rights of Persons with Disabilities. This was ratified by New Zealand in 2008 with no Reservations.</p>

⁸ <https://pwd.org.au/resources/models-of-disability/Scope> UK ‘Everyday Equality Our strategy 2017 – 2022’ accessed at <http://www.scope.org.uk/about-us/everyday-equality/>

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Appendix A: Summary of Engagements

Engagement method	Purpose	Number of engagements	Stakeholders involved
Reference Group	<p>To provide representation of key stakeholders and rights-holders.</p> <p>To provide consistent voice throughout the project.</p> <p>To add a disability rights and lived experience lens to all outputs.</p>	5	7
Interviews	<p>To gain insights into lived experience of receiving and providing disability support.</p> <p>To identify key factors shaping the current landscape and to understand aspirations for the future workforce.</p>	16	19
Focus groups	<p>Tailored engagement with specific groups to ensure their viewpoints are incorporated.</p> <p>Areas of discussion were formulated based on issues identified during interviews and with the Reference Group.</p>	6	25
Wānanga	<p>Wānanga were completed by Te Amokura Consultants to ensure the voice of Māori was reflected.</p>	3	20
Workshops	<p>To engage with organisations that often work together across the sector.</p>	2	11

Disability Support Workforce - Engagement Summary

TOTAL		32	82
Survey	To understand the current workforce landscape, challenges and barriers to workforce changes.		686 responses

Wānanga 1 was attended by 4 people who identify as tāngata whaikaha Māori.

Wānanga 2 was attended by 12 people from Māori disability service providers.

Wānanga 3 was attended by 4 people who are whānau carers.

Appendix B: Engagement questions

Interviews, focus groups and wānanga were conducted as open conversations loosely structured around six key points. Questions were tailored to the participant/s and their role/experience with Disability Support Services.

1. Understanding the types of support the participant currently (or previously) had accessed or provided OR the role the participant played in the sector.
2. Understanding the participant/s' perspective on what a good support system would look like.
3. Understanding the participant/s' perspective on what is good about current Disability Support Services.
4. Identifying areas of Disability Support Services which the participant felt could be improved.
5. Identifying challenges the participant/s has faced in receiving or providing Disability Support Services and identifying challenges facing the workforce.
6. Asking participants if there was anything else they wanted to share about Disability Support Services.

Appendix C: Engagement Survey

Methodology

To complement the information being gathered via interviews, wānanga and focus groups, we designed a survey to capture the views of a larger cohort of interested stakeholders.

We chose the SurveyMonkey tool for questionnaire development and data collection as the accessibility and intuitive design enabled ease of use by respondents and the data formatting and exporting options were effective for analysis.

A web-link to the survey was shared through various channels (email, Facebook advertising, and key influencers in the disability sector informing their networks). The target audience for the survey were disabled people, family and whānau, and disability support workers. The survey included written questions in English and video recorded questions in New Zealand Sign Language, with options for typed or video-recorded signed responses.

The survey was live for over eight weeks and garnered a total of 686 responses. We regularly monitored survey uptake and made appropriate changes to improve coverage and responses.

Survey questions

Questions	Available responses
Do you identify as disabled?	Yes / No / Prefer not to say / I identify with another term
Are you a parent or caregiver?	Yes / No / Prefer not to say
How old are you?	Under 18 / 18 – 24 / 25 – 34 / 35 – 44 / 45 – 54 / 55 – 64 / 65+ / Prefer not to say
Please select your ethnicity (<i>tick as many as you want</i>)	NZ European / Māori / Pacific Peoples / Asian / MELAA (Middle Eastern, Latin American or African) / Prefer not to say / Other (please specify)
Which of the following previously or current applies to you? <i>Please select the option that best describes your experience.</i>	I access disability support services for myself / for someone in my care / on behalf of my child I am eligible for disability support services but do not access them I provide disability support services (<i>this includes family/whānau caregivers regardless of whether you are paid for these services</i>) Other, please give details
<i>The following questions were asked if the respondent had identified as disabled OR as a parent / caregiver of someone who receives disability support services.</i>	

<p>Which of the following best describes the disability support services you currently or have previously accessed? <i>Please tick all that apply</i></p>	<p>Personal Care Support / Home Help / Individual Supported Living / Modification to Housing or Vehicles / Respite / Community Day Services / Community Residential Support Services / Autism Spectrum Support / Behaviour Support / Child Development / Hearing and Vision Services / Other (please specify)</p>
<p>How are your disability support services funded? <i>Please tick all that apply</i></p>	<p>Individualised Funding / Mana Whaikaha / Enhanced Individualised Funding / Enabling Good Lives / Choice in Community Living / Carer Support / I choose / I'm not sure / Other (please specify)</p>
<p>What is most important to you when accessing quality disability support services? <i>Please select up to three options.</i></p>	<p>Choice and control over support options (including planning and funding) Family / whānau involvement Directly choosing and contracting my service Support from an independent facilitator or navigator Opportunities to develop other supports (e.g. participation in community activity or community life) Working well with other benefits or supports Services or supports being provided by people with lived experience of disability A good appeal process to review decisions and entitlements Other, please specify</p>
<p>What does your current disability support provider do well?</p>	<p><i>(Free text answer)</i></p>
<p>What changes would you like to see in future to enable you to receive good support services. <i>Please tick all that apply</i></p>	<p>Greater choice of disability support service options Greater understanding of the Enabling Good Lives amongst disability support service providers Greater investment in workforce development More disabled people working visibly in the disability system Greater leadership from disabled people over strategic direction Greater support for family/whānau caregivers Greater support and acknowledgement of parents Prefer not to answer Other, please specify</p>
<p>Is there anything else you would like to comment on with regards to disability support services?</p>	<p><i>(Free text answer)</i></p>

<p><i>The following questions were asked if the respondents had identified as a provider of disability support services.</i></p>	
<p>Which of the following best describes your role in providing disability support services?</p>	<p>Support worker / registered nurse / paid family or whānau caregiver / unpaid family or whānau caregiver / support co-ordinator (including NASC, Kaitūhono & Connectors and Disability Information and Advisory Services (DIAS)) / Other (please specify)</p>
<p>How would you rate your understanding of the Enabling Good Lives approach? <i>A short summary of EGL was included with a link to the official website.</i></p>	<p>I understand it really well I understand it but still some stuff to learn I know a bit about it but not too much I don't know much about it Never heard of it</p>
<p>What types of skills do you think are most important in providing support services in line with an EGL approach?</p>	<p><i>(Free text answer)</i></p>
<p>What do you think are the current challenges facing the disability workforce?</p>	<p>Lack of funding or people to work in jobs Lack of expertise and experience Lack of awareness around available qualifications Lack of diversity amongst support workers Lack of culturally appropriate support services Clinical and specialist disability workforce requirements Ageing workforce Not enough development opportunities Lack of incentives for support worker career pathways Burn out or mental & emotional fatigue Lack of visibility of disabled people in the workforce Other (please specify)</p>
<p>What changes would you like to see in future to enable quality disability support services? <i>Please tick all that apply</i></p>	<p>Greater variety of disability support service options Greater support for disability support service providers to understand the EGL approach Greater investment in workforce development Greater support for family & whānau caregivers Other (please specify)</p>
<p>Is there anything else you would like to comment on with regards to disability support services?</p>	

Summary of respondent data

Highlights

Self-identification	27% of respondents identified as disabled 5% of respondents identified with another term such as neurodiverse 61% of respondents identified as a parent or caregiver
Age	68% of respondents were over the age of 45
Ethnicity	76% of respondents identified as NZ European 16% of respondents identified as Māori 4% of respondents identified as Pacific Peoples 4% of respondents identified as Asian
Role in disability support workforce	37% of respondents reported they provide DSS 15% of respondents access DSS for themselves 23% of respondents access DSS on behalf of their child 6% of respondents access DSS for someone in their care (not a child) 4% of respondents were eligible for DSS but don't access it 14% of respondents selected the 'other' option citing instances such as not being eligible for DSS or working in the disability sector but not directly providing DSS

Summary of key survey responses

Question	Responses
<p>What is most important to you when accessing quality disability support services (select up to 3)</p>	<p>Responses from disabled people and family/whānau</p> <p>82.81% selected choice and control</p> <p>44.80% selected family/whānau involvement</p> <p>38.01% selected opportunities to develop other supports (e.g., participation in community activity)</p> <p>19.00% selected services or supports being provided by people with lived experience of disability</p> <p>20.8% selected support from independent facilitator or navigator</p> <p>23.08% selected directly procuring support</p> <p>13.12% selected alignment with other benefits or supports</p> <p>9.95% selected other</p> <p>Responses included:</p> <ul style="list-style-type: none"> - Respite - Co-ordinated approach - Training - Equity - Understanding of disabilities
<p>What changes would you like to see in future to enable you to receive quality support services? (Tick all that apply)</p>	<p>Responses from disabled people and family/whānau</p> <p>69.68% selected greater choice of disability support service options</p> <p>67.87% selected greater support for family/whānau caregivers</p> <p>57.92% selected greater support and acknowledgement of parents</p> <p>52.94% selected greater investment in workforce development</p> <p>50.68% selected greater understanding of the EGL approach amongst disability support service providers</p> <p>43.44% selected more disabled people working visibly in the disability system</p> <p>38.46% selected greater leadership from disabled people over strategic direction</p>
<p>How would you rate your understanding of the Enabling Good Lives (EGL) approach?</p>	<p>231 respondents who identified as support workers answered this question</p> <p>The average answer was 6 / 10</p>

<p>What do you think are the current challenges facing the disability workforce? (Please tick all that apply)</p>	<p>Responses from workforce</p> <p>80.60% selected lack of resourcing</p> <p>70.69% selected burnout or mental/emotional fatigue</p> <p>61.64% selected lack of experience and expertise</p> <p>55.17% selected lack of incentives for support worker career pathways</p> <p>46.98% selected lack of culturally appropriate services</p> <p>44.83% selected clinical and specialist skills shortages</p> <p>44.40% selected insufficient development opportunities</p> <p>40.52% selected ageing workforce</p> <p>37.03% selected lack of diversity amongst support workers</p> <p>36.64% selected lack of awareness around available qualifications frameworks and pathways</p> <p>37.93% selected other</p> <p>Responses included:</p> <ul style="list-style-type: none">- Lack of respite- Pay rates (over 60% of free text answers mentioned pay rates).
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Appendix D: Profile of current disability support workforce

We have provided below some additional information about the current disability support workforce. However, we note that the different definitions of care and support workers are used by various sources, and these do not match the definition adopted in this report. Although organisations are increasingly reporting on the care and support workforce there is still very limited publicly available data that tracks trends in the work conditions of this workforce. Regardless, this information adds some further context to understand the current profile of the workforce.

In 2019 the New Zealand Work Research Institute surveyed 2,373 care and support workers, nurses and managers who work in various community support services. Of those 557 participants worked in the disability support sector, including 459 care and support workers, 15 nurses and 83 managers.

Demographics findings:

	<i>Highlights</i>
Gender	Only 15.9% of disability support workers identified as male
Country of birth	71% of disability support workers were born in NZ
Ethnicity	70.2% of disability support workers identified as NZ European 19.8% of disability support identified as Māori
Hours of work	40% of disability support workers worked 40 – 49 paid hours 30% of disability support workers worked 30 – 39 paid hours 20% of disability support workers worked over 50 paid hours
Hourly paid	31.7% of disability support workers were paid \$25.50 or more and the rest were paid lower ⁹
Employment status	75.9% of disability support workers were employed on permanent full-time contracts 15.7% of disability support workers were employed on permanent part-time contracts

⁹ At the time of the survey the adult minimum wage was \$17.70.

The Impact of the Pay Equity Settlement report (New Zealand Work Research Institute, 2022) concluded that most disability support workers (83.0%) remained with the same employer since the pay equity settlement.

Appendix E: Frameworks and Strategic Plans impacting on the Disability Support Workforce

The multitude of frameworks demonstrate the diversity of the workforce and the various priorities for funding and attention from different sectors and groups.

As a result of these different strategic initiatives there are a number of disjointed programmes aimed at various aspects of the workforce and other parts of the disability sector.

Framework or Strategic Plan	Impact
Enabling Good Lives and Whānau Ora frameworks	Facilitate an environment where disabled people and their whānau have greater choice and control over their lives and supports.
Kaiāwhina Workforce Action Plan 2020 – 2025	Focusses on building cultural capability by lifting cultural competence, valuing the impact of lived experience, growing whanaungatanga and sharing this knowledge with the public. Other priorities include scaling up successful innovative ways of working, building workforce knowledge and data and developing a diverse workforce.
New Zealand Carers Strategy Action Plan 2019 – 2023	Plays a crucial role in developing awareness of carer roles, improving carers' wellbeing, supporting them in their role and ensuring they are at the forefront of policy development and decision-making.
Whaiā Te Ao Mārama: the Māori Disability Action Plan	Prioritises efforts to encourage Māori to enter health careers, support the Māori health sector to attract, retain, develop and utilise the workforce effectively and develop a workforce that reflects the Māori population, values and models of practice.
Faiva Ora – the National Pasifika Disability Plan	Prioritises efforts to attract Pasifika people to work in disability support services, which would enable the application of Pasifika models of support and lead to better outcomes for Pasifika disabled people and their aiga.



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