Dear Special Rapporteur on the Rights of Persons with Disabilities,

Thank for you for the opportunity to provide input into your report addressing the theme “*Re-imagining services to give effect to the right to live independently and be included in the community for persons with disabilities. The report will seek to present good practices, emerging trends, existing challenges, and identified gaps in the interpretation, operationalization and engagement of the above obligations.”*

Please find the answers to your questions below. In some cases, we have provided additional contextual information and have also grouped questions to minimise duplication. We look forward to seeing the report.

**A: Policy Goals and Principles**

1. ***What are the primary principles and goals that govern services to people with disabilities in your State?***

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Te Tiriti o Waitangi (the Treaty of Waitangi), and the New Zealand Disability Strategy underpin disability policy and services in New Zealand. The lead agency focused on the outcomes of disabled people is Whaikaha – Ministry of Disabled People (Whaikaha). Whaikaha’s leadership of the disability support system will demonstrate Enabling Good Lives (EGL) and Whānau Ora principles, with a whole-of-life approach that supports disabled people to determine and tailor services to their everyday lives, goals and needs. The principles bring a focus to building the strengths of local communities, collective leadership and self-determination by disabled people and their whānau (family). They give effect to tino rangatiratanga (self-determination), enabling disabled people, tāngata whaikaha Māori (Māori disabled) and their whānau to have control over the services they receive.

Whaikaha is still developing internal processes and ongoing work programme and priorities. Whaikaha is based on a set of principles and goals that will improve outcomes for disabled people. These are detailed throughout this document.

Whaikaha is responsible for:

* 1. funding and contracting for most disability support services in New Zealand
  2. driving better outcomes for all disabled people;
  3. leading cross-government strategic disability policy;
  4. delivering and transforming Disability Support Services;
  5. leading cross-government work to address accessibility barriers, once accessibility legislation is passed (expected to be enacted by 1 July 2023), guided by a Ministerial Accessibility Committee made up of, and representing, disabled people.

The Office for Disability Issues (ODI) also forms part of Whaikaha. The ODI was established in 2002 to provide departmental functions and services directly to the Minister for Disability Issues and to support a whole of government response to disability issues.

The ODI’s functions include acting as the lead unit for the development and monitoring of the New Zealand Disability Strategy and the Disability Action Plan, providing advice on disability issues, and working in partnership with Disabled People’s Organisations in reviewing and monitoring the implementation of the UNCRPD.

1. ***Have these principles and goals been modified to take explicit account of Article 19 of the CRPD on the right to live independently and be included in the community (e.g., personalization of services, personal and human support, assistive technology, accessible transport, access to housing, expansion of community-based services, emphasis on personal empowerment and choice).***

Whaikaha intends to use its strategic policy function, to support the implementation of New Zealand’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to lead a future-focused and whole-of-government approach to disability and drive improved overall outcomes for disabled people.

It is anticipated that this will be done in a number of ways, including:

* 1. Beginning to lift the profile and visibility of disability and disability issues across all of government to ensure an alignment of services and policies with the Human Rights Act 1993, UNCRPD and the New Zealand Disability Strategy
  2. strengthening partnerships with disabled people, families, and whānau and ensuring their voices are embedded at all levels of decision-making. For example, continuing to work with the Disabled Persons Organisation (DPO) Coalition, I. Lead (a disabled youth network), the family/whānau network and other important groups to ensure we hear the voice of disabled people and their family
  3. strengthening disability rights approaches across a range of government strategies
  4. improving cross-government disability data and information, gathering, management and use
  5. ensuring effective cross government reporting and monitoring processes
  6. ensuring agencies are regularly reporting on progress against actions they have responsibility for through the Disability Action Plan (2019-2023) and Whāia Te Ao Mārama 2018-2022 – Māori Disability Action Plan.

The New Zealand Disability Strategy adopts the UNCRPD’s ‘social model’ of disability, applying it within a domestic context. The New Zealand Disability Strategy outlines that disability is created by barriers within the social and physical environment and that these barriers inhibit the ability of disabled people to participate fully in society. It identifies eight key outcome areas for improvement and works towards a barrier free society and the principles and approaches that should underpin the progress of the outcomes. This includes disabled people having more choice and control over their lives and supports.

The EGL vision and principles underpin Whaikaha’s work, both in the cross-government leadership of disability issues and in the transformation of funded Disability Support Services. EGL in aligning with the principles and approaches of Whānau Ora as a basis for government supports, will also enable a holistic whole-of-life, whole-of-whānau approach to addressing inequities and realising the aspirations of and opportunities for disabled people and whānau to live independently and be included in their communities. EGL is a rights-based approach that enables a shift away from a deficit-based model of disability towards a strengths-based approach and embeds the principles of self-determination, choice and control.

1. ***Are these goals linked directly to broader policy imperatives to ensure people with disabilities can take meaningful advantage of being in the community – such as the opportunity for employment and education, access to health care, promotion of natural or unpaid supports or community assets available to citizens without disabilities? If so, how?***

Both the EGL and Whānau Ora approaches bring a focus on building on the strengths of local community and whānau capacity, collective leadership and self-determination by disabled people. The principles and processes of both give effect to self- determination, enabling disabled people, tāngata whaikaha Māori and whānau to have control and make choices. In 2021 Cabinet agreed to implement the EGL approach to disability support services nationally.

Feedback from disabled people and whānau involved in the EGL demonstration sites has been positive. Those who have access to the new system report a greater ability to manage their own lives and to choose service providers that work within a culturally responsive context, aligning with disabled people’s cultural continuity and tino rangatiratanga of tāngata whaikaha Māori.

Evaluations have found that many have an increased sense of choice and control, social and community connectedness and have benefitted from the use of flexible approaches to funding to improve their lives and wellbeing.

**B: Service Delivery**

1. ***Who primarily delivers services to people with disabilities (State, local government, private providers commissioned by the State, religious organizations, other, or a mix?) How do you see this mix changing if at all as a result of the UN CRPD in your country?***
2. ***Who primarily pays for services to people with disabilities (State, local government, private providers commissioned by the State, religious organizations, other, or a mix?). How do you see this mix changing if at all?***

A key function of Whaikaha is funding Disability Support Services (DSS). DSS is currently available to people with a long-term physical, intellectual and/or sensory impairment or autism spectrum disorder[[1]](#footnote-2). The purpose of these supports is set out in the Pae Ora (Healthy Futures) Act 2022: to “promote [disabled people’s] inclusion and participation in society and their independence”.

A wide range of services are funded, ranging from equipment to support and retain independence, through to support with daily activities (e.g., personal care, shopping, cleaning etc), as well as support to family carers (payment for care and respite so they can take a break).

Disability support services are delivered by 484 providers holding 751 contracts for service. The main providers are the Needs Assessment and Service Coordination (NASC) residential support, home and community services, respite, supported living, disability information and advisory services, and services under the High and Complex framework. The number of people receiving disability supports is growing fast and expected to continue.

The national implementation of the EGL approach will significantly change how Disability Support Services are funded and provided over time.

A national model for delivery of the Disability System Transformation, based on the EGL approach and implementation plan, will show how the funding will be used and the phasing of the expenditure. Whaikaha intends to introduce greater flexibility for funding acknowledging that individuals are the experts in own lives and will be given greater choice and control.

Disability Support Services are delivered by both non-governmental organisations and government run organisations. The intention is for services to be developed to provide a more rights based flexible approach in line with system transformation.

1. ***Describe generally how community-based providers are paid for the services they deliver (e.g., through general grants, through per capita funding, based on specific services rendered, other names?). What changes, if any, are anticipated regarding the present payment methodology?***

Most providers are paid on a fee for service basis, primarily dependent on the number of hours of support they have delivered to specific individuals. Some services have an element of capacity funding where funding is guaranteed. This may be where there is limited workforce and certainty of cashflow is essential, or where Whaikaha’s ability to predict who might require a service is limited and there isn’t time to wait for an individual service to be developed (e.g., Intensive crisis placements).

1. ***In what ways are principles and service goals communicated to the service system (e.g., in laws, service standards, staff training, funding incentives, means for compensating/penalizing service providers, and /or for assessing the quality of services?). Please describe?***

The ‘Tier One’ service specification for all services includes the vision and principles that emphasise the rights of disabled people and their whānau, and a vision for their inclusion in society.

The EGL principles are now included in procurement processes, so that providers have a strong signal that they must be able to explain how what they are proposing aligns with the principles. There are a range of operational policy in development to support clear communication of expectations in an EGL setting.

The Monitoring, Evaluation, Analysis and Learning (MEAL) Framework emphasises an enhanced developmental evaluation approach that emphasises the voice of disabled people and ‘Peer monitoring’ by disabled people to communicate expectations and support provider development.

Whaikaha is exploring the potential of a Discretion for Results approach to enable better performing providers to have more discretion over how they manage their services.

There is also a Workforce Strategy under development and Whaikaha has invested in provider capability development to support providers to move to person-directed ways of working.

1. ***What new services, including those to support families, have been added to the available service array to advance principles consistent with Article 19?***

New Zealand has added a range of services that are progressively more flexible to support disabled people to live independently in the communities of their preference. These are primarily personal budget-based services and provide options for individuals to be more involved in the management and direction of their supports, via providers.

The next stage for New Zealand is to expand on the use of those options.

1. ***What practices, if any, have been adopted/encouraged to promote greater use of technology to personalize support to persons with disabilities (e.g., telehealth, remote monitoring, adaptive communication, artificial intelligence, etc.)?***

Whaikaha has increased the flexibility of purchasing rules that enables more than 25,000 of the 43,000 people we serve to purchase items and technology that would be of use to them in overcoming disability-related challenges. Whaikaha are also developing and trialling a guided decision support tool to make it more possible for people to access low and medium risk assistive technology through personal budgets without a face-to-face assessment.

***10. In what ways are caregivers (e.g., family members, other information caregivers) recognized and supported?***

Whaikaha has a range of services available to sustain caregivers/whānau and the roles they play in the lives of disabled whānau members. We have broadened the basis on which family members can be paid for their roles, and the most widely used flexible product we have is Carer Support, an allocation of funding that can be used flexibly for the purposes of sustaining balance in the whānau unit and enabling the disabled person and whānau to take a break from each other.

Whaikaha has work underway to better reflect how the roles whānau play now can create positive expectation for their future roles in the life of their disabled family member through funding allocation.

1. ***Do you have a policy of personalizing/tailoring services to individual needs? How is the policy implemented? (e.g., through individual planning requirements?)***

Disability system transformation is about fundamentally changing the purpose of the disability support system from being about provision of services to giving disabled people, tāngata whaikaha Māori and Pacific disabled people individual choice and control over their own lives and planning of their supports. A fundamental aspect of transformation is the implementation of the Enabling Good Lives approach across the system.

1. ***Describe how much control people with disabilities have regarding the services that they receive (e.g., choice of who provides support, choice of where they live and with who they live, control over budgets).***

The range of choices that disabled people have in the current system is mixed. It is expected that choices for disabled people will increase as the system transformation is progressed.

Whilst disabled people may be able to choose between providers and staff that choice narrows during times of workforce shortage (as is the case now) and may also become severely limited in particular situations. For example, a few people are on an individualised funding plan because no existing provider is able to work with them.

It is also the case that individual disabled people living in congregate care[[2]](#footnote-3) may have little or no choice over whom they live with, as compatibility is largely a judgement made by the service provider and the Needs Assessment Service Coordination (NASC) team.

Through EGL, Whaikaha is achieving much higher levels of choice and control by disabled people and their whānau, and works to reduce the use of congregate care settings and the associated conflicts of interest in how support is managed.

Overall, New Zealand has some way to go to ensure that choices made by or in the name of the disabled person genuinely reflect the disabled person’s will and preference, and that they have had appropriate support to form, express, test and enact that will and preference.

1. ***In some disability support structures, service users or families have an allocated budget which is devolved so they have control over how the funds are used to purchase eligible disability supports. Do you have or anticipate a policy of devolving budgets to the service user? Describe***

The Disability support system has personal budget options which devolve control over how funds are used to the disabled person. With the national rollout of EGL, we anticipate this will be expanded on, and we expect to progressively retire the use of less flexible funding lines in favour or personal budget-based products.

1. ***If budgets are devolved to the user, what kinds of supports are available to assist them, how are the administrative tasks minimized and is the individual given wide discretion on how the funds are spent?***

The rules for personal budgets are broadly that the funding is:

* used in line with the intent or purpose for which it was allocated, at an outcomes level
* used to address disability related challenges to inclusion, participation and independence
* used in a way that is cost-effective – primarily that higher purchases early will not compromise the ability to be supported later in the life of the personal budget
* Used for things another agency funds only if what that agency offers won’t be available in a timely way or will otherwise not be appropriate.

This approach affords a significant scope for flexibility.

The High-Level design of the transformed system, which has and is being developed with disabled people, includes a wide range of options to support disabled people and whānau with the management of their personal budgets. These range through:

* The disabled person (or in the case of a minor, their parents) managing the funding themselves
* Being coached to manage the funding
* A trusted person managing the funding on the disabled person’s behalf
* A provider managing the funding, directed by the will and preference of the disabled person.

These options are available to a variable extent across New Zealand.

1. ***Have you adopted any positive “wealth accumulation strategies” (e.g., innovative trust funds) to complement social provision? Describe.***

Generally, there has not been adoption of these kinds of strategies in New Zealand. We have some initial actions to undertake, that will support disabled people to understand their personal finances in a way that is meaningful to them, and to achieve enrolment early in state supported retirement and first home saving initiatives.

**C. Monitoring and Oversight**

1. ***Describe the types of data you collect on people with disabilities receiving services (e.g., numbers of service users, types of disability, service utilization, costs per persons, quality of life, outcomes, health outcomes, incidence of abuse, neglect and exploitation). Are these data gathered and reported in aggregate only or may it be disaggregated per person?***

Whaikaha collects information from its providers in regular reporting processes that are part of those providers' obligations. Information includes the reporting of critical incidents such as when harm has occurred to a person being supported and any death of a disabled person supported under residential care services. Whaikaha will also collect information outside of reporting cycles where there have been quality concerns raised about providers.

Additional information is collected by each NASC and recorded in a case management platform. This information allows reporting on service users, disability types, and service utilisation. This case management platform connects to multiple financial management systems, so costs can be attributed to people with disability, contracts, and service providers.

Regular audits and evaluations of services also occur and measure aspects of service quality and quality of life such as identity, autonomy, health and wellness of the disabled people, safeguards in place and upholding of rights. The information from these reports is used to assess how well providers are delivering quality supports to disabled people.

Audits and evaluations also include checks of provider's processes for vetting of staff, complaint management, and identifying and responding to abuse and neglect. The experiences of disabled people and their family are an essential component to the audit and evaluation process and services are also measured against the principles of EGL.

Whaikaha can commission an independent issues-based audit (with or without notice) to investigate a complaint or quality concern about the service a contracted provider is delivering. There are an average of 120 audits and evaluations commissioned each year. Audits provide a clear set of remedial requirements for a provider to address. Whaikaha can also review a provider’s contract based on performance. Whaikaha will produce a monthly quality dashboard presenting a summary of the trend of the month’s critical incidents, deaths, complaints, quality concerns and developmental evaluations and audits to inform the Ministry.

Whaikaha recognises there needs to be significant improvement to data collection for disabled people. Currently there is no mechanism to collect self-identified disability status. The lack of a consistent identifier makes it difficult to compare inequity in health outcomes for disabled New Zealanders.

From 2019, the New Zealand Health Survey has included results by disability status to better understand disabled people’s health outcomes.

Government agencies are working to improve data collection and analysis for disabled people. Work to date includes encouraging disaggregation of data by disability and other demographics including ethnicity as well as working with disabled people to understand how we can better monitor outcomes, particularly from a te Ao Māori lens. Work is also underway to develop a ‘disability indicator’ to inform future data collection. This work will further allow government agencies to better identify gaps in data and apply key considerations for disabled people in terms of data collection, analysis, and dissemination.

1. ***How do you enforce standards as they apply to service delivery providers (law, standards, incentives)? What do these standards focus on in the main? How are they measured?***

Once a provider is contracted by Whaikaha for disability support services, they are subject to multiple oversight, monitoring, and evaluation processes. These include:

1. **Portfolio Managers –** Portfolio managers visit providers, discussing the service, and ensuring issues raised at previous meetings or audits are resolved. Depending on the findings from a specific meeting, Portfolio Managers may schedule extra visits, initiate an audit, or change the provider’s risk level.
2. **HealthCERT** – Residential care provided in any premises (including aged care premises) for five or more disabled people must be audited by independent designated auditing agencies, and to be certified by HealthCERT. Providers are audited on a regular cycle by HealthCERT and are certified for between one and five years, dependent on findings. Ongoing audit concerns lead to increased contract and monitoring by the Portfolio Manager and the Quality and Performance Team at Whaikaha.
3. **Audit and evaluation** *-* Whaikaha commissions external evaluations and audits of disability providers, using independent and experienced auditors and evaluators. Audits and evaluations funded by Whaikaha work in alignment with the audits against the legislatively required Health and Disability Safety Standards, managed by HealthCERT.These contractors identify areas that require improvement to better the quality of services and to ensure the achievement of quality-of-life outcomes and the safety of people who use the service.

Whaikaha has co-developed a Monitoring Evaluation Analysis and Learning Strategy with the community, for the transformation of disability support services. This strategy aims to ensure a developmental approach to monitoring and evaluation, providing stronger opportunities for safeguarding responses. The approach of the strategy is supported by the disability community and will be implemented incrementally from 2022.

The Minister of Health has approved the updated Ngā Paerewa Health and Disability Services Standard (Ngā Paerewa) for use under the Health and Disability Services (Safety) Act 2001. Ngā Paerewa came into effect on 28 February 2022, and apply to all providers of residential care, disability services and home and community support services.

Ngā Paerewa reflects the shift towards more person- and whānau-centred health and disability services. People are empowered to make decisions about their own care and support in order to achieve their goals, with a stronger focus on outcomes for people receiving support.

Among the outcomes for providers, Ngā Paerewa seeks to ensure that individuals are safe, with effective safeguards to protect from discrimination, abuse, neglect, and re-victimisation. Additionally, individuals are informed, have effective communication channels, and the ability to make complaints.

A safeguarding framework has also been developed as part of the Mana Whaikaha prototype in the Mid-Central region in 2018. Connectors in Mana Whaikaha have been trained in the safeguarding framework. Further work has been undertaken within the development of Kaitūhono (Connector) guides to strengthen capability in this area.

People with intellectual disabilities who are supported under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 have a specific set of rights that are monitored by District Inspectors, lawyers appointed under the Act to ensure that their rights are not breached. These rights include access to company, communication, and healthcare. There are also additional safeguards around the use of restrictive practices.

Audits and evaluations check the provider’s performance against their contract and include checks of their processes for vetting of staff, complaint management, identifying and responding to abuse and neglect, and meeting statutory and regulatory requirements under the Human Rights Act 1993.

1. ***Do your compliance rules make it possible to disqualify those providers in breach of the standards from competing for future State support?***

A substantial number of discussions and checks occur prior to contracting of providers. Contracted providers are walked through multiple guidelines that they must agree to, observe, and be audited on. These include guidelines around abuse and neglect. This also includes requirements around minimum standards for staffing and legal checks.

Using the Enabling Good Lives approach Whaikaha will be developing a new model of support for residential services including national best practice guidelines and a code of conduct. This work will include a review of the current service specifications and contract wording to develop the new model of support and a learning and monitoring system that promotes effective compliance.

**D. Re-Shaping the Market/Challenges and Opportunities**

1. ***Describe the major challenges you face in endeavouring to reform your system of services and supports for people with disabilities. Barriers might include workforce shortages, inadequate resources, lack of knowledge and training, weak infrastructure, and/history of institutionalization.***

Workforce challenges

New Zealand is experiencing a significant workforce shortage right now that places pressure on our ability to reduce congregate care services in favour of individualised supports. This does not mean it is impossible but will require careful management and phasing to achieve that change.

There is not a strong consensus across the whole of the disability community that reducing reliance on congregate care – rather than expanding congregate care – is the right thing to do. Greater choice and control are seen by some to mean that we might go backwards into reopening or re-creating institutional options. We have some work to do to ensure that expanded choice will always lead to greater inclusion, participation, and independence.

Substituted Decision Making

New Zealand’s legislative framework continues to use a substituted decision-making model rather than a supported decision making model. Recent case law has formed contesting the ability of the Ministry to rely on disabled people as decision makers about their supports. Whilst these judgements have generally favoured improving the support to families of disabled people, it comes with some collateral damage to the rights of disabled people to direct how they live their lives and are supported to make decisions about their disability supports.

The Government has commissioned independent advice from the Law Commission on how current legislation can be changed to better reflect supported decision making approaches.

In the meantime work is underway on practical implementation of supported decision making in service provision and family/whanau contexts.

Achieving change in line with the UN convention whilst navigating the existing legal framework will continue to pose challenges.

1. ***How is the COVID-19 pandemic and its aftermath reshaping the service delivery market? Explain in terms of changes in service expectations among service recipients and regarding impacts of the services available.***

For some disabled people, contracting COVID-19 remains a considerable risk because of their associated health conditions. The COVID-19 pandemic and its aftermath has provided several learnings, which are helping to reshape service delivery improvements including:

* 1. the continued need for risk mitigation and management strategies for disabled people as the government reduces COVID-19 mandates: mask exemption; vaccination mandates; testing and home isolation; access to therapeutics and care provided in the community.
  2. Highlighting the ongoing need to ensure effective and targeted communications, in accessible formats for disabled people and their whānau to stay safe and mitigate the concerns they might have about reduced COVID-19 protection measures.
  3. The need for a more flexible and person-centred approach to funded disability support services. This included developing purchasing guidelines for carer support payments more flexible and changes so access to respite could be more flexible.
  4. Need for engagement and partnership with disabled people, tāngata whaikaha Māori and their whānau to ensure lived experience informs future policy (Article 4 UNCRPD[[3]](#footnote-4)). COVID-19 engagement is facilitated by Whaikaha through the Office for Disability Issues for government officials to provide information on upcoming or past decisions feedback.
  5. Ensuring a twin-track approach to COVID-19 services is retained. A twin track approach ensures mainstream services and supports are inclusive of and accessible to disabled people and that services and supports specific to disabled people are also available.
  6. It has been identified that a data and evidence framework is required to ensure pandemic planning and future public health responses are disability data informed (Article 4,1, e UNCRDP). This will ensure that policy changes do not disproportionately impact disabled people and are working for disabled people. The priority is to establish a data dashboard including mortality; hospitalisation; vaccination; mask mandate; missed carer appointment.

1. ***Do you pro-actively seek out new kinds of service providers with new business models that emphasize person-centred practices?***

Whaikaha enables such providers to enter the market through the expansion of personal budgets. With the disabled person managing their own supports through their personal budgets, providers must prove themselves to the disabled people to receive the funding.

Disability Support Services has not undertaken active procurement for new providers for some time. This is due both to constraints in our financial position limiting our ability to take on many new things, and the need to provide continuity of support services through the recent establishment of Whaikaha which has been our main priority.

1. ***Do you encourage service providers to adopt a ‘business and human rights approach’ to their endeavours?***

Whaikaha is actively engaged with a number of providers on the need to see a stronger emphasis on human rights within their business model.

1. ***How do you incentivize innovative person-centred new providers to enter the market? Describe***

Our experience is that it is enough to create the opportunity for them to enter. Where we have used financial incentives, this has often led to medium term disruption when those are phased down into business as usual.

1. ***Do minimum wage laws apply in this sector? Is there a career advancement structure for workers in the sector?***

Yes. Both general minimum wage laws and specific minimum wage laws for care and support workers. The minimum wage rates for care and support workers are attached to different qualification levels, supporting a career advancement structure.

**E. Process of Reform**

1. ***What lessons have been learned to build momentum, while minimizing resistance, for systems change consistent with Article 19?***

Implementation of the Enabling Good Lives (EGL) Approach in three regions of Aotearoa New Zealand commenced in 2013 and has enabled disabled people and tāngata whaikaha Māori to be leaders in systems change. Disabled people involved have not only led change in their regions but taken on national leadership roles to ensure all disabled people can benefit from the EGL approach. Momentum for change is resulting in disabled people expecting full recognition of their rights under Article 19.

Whaikaha has learned that disabled people receiving personal budgets through the EGL approach are experiencing choice and control over where they live and with whom they live. They are purchasing the supports they need – often directly from their community rather than disability service providers.

Disabled people are sharing their successes and learnings with each other and with whānau and families - which has the effect of building momentum for system change.

Both disabled people and whānau and families need assistance to understand what moving from traditional service provision to genuine choice and control under Article 19 could look like.

Resistance to systems change comes from disability service providers and some family and whānau. To move forward a range of different strategies are needed – the most successful are where disabled people share their experiences of the change process and the positive difference it has made in their lives.

While implementing Article 19 the most powerful learning has been that disabled people, when working in partnership with Government, can bring about significant change – this is exemplified in the establishment of Whaikaha.

Evaluation has demonstrated working early with communities and establishing a genuine relationship of engagement with disability groups is critical to the success of any system change. This includes disabled person community development, easy to use information that is accessible and readily available as well as having tangible regional disability leadership in each area.

This enables an independent voice in the process separate to the government. Where this has been done most effectively over longer periods of time have led to more robust and sustainable outcomes for disabled people.

1. ***Did you have an initiative to re-imagine services that includes service users (e.g., have you commissioned a Task Force?)***

Systems transformation work under the leadership of Whaikaha is done in partnership with disabled people and family members. A range of partnership and advisory arrangements are in place at national and regional levels. Through these arrangements disabled people are paid to give advice which influences policy and operational decisions.

Much of the redesign of the system has been led by the disability community and embraces Enabling Good Lives principles which were developed by the disability community and allies. The high level co-design has inspired the prototype of large system scaling in the mid-central region of EGL. This prototype is now the model for a national roll out.

1. ***In what ways do you solicit the input of people with disabilities and family members in policy making, program oversight, strategic planning etc. (e.g., national advisory councils, regional/local forums, surveys, webinars, etc).***

Whaikaha engages in multiple ways with the disability community. A leadership framework is currently being developed to ensure an independent voice mechanism is engaged and influencing key decisions for Whaikaha. This is based on a tripartite framework of Disabled People, Tangata Whaikaha Māori and government officials.

Decision making is negotiated, and the mutual responsibilities of all parties are honoured. The Disabled Person’s Organisation Coalition (national network of disabled people organisations) is heavily involved in the overall strategic and action planning. Meetings are also held with Pacific people and Māori disabled people.

1. ***What are the two or three strategic objectives you have to enhance quality, availability, and effectiveness of services to people with disabilities in your State?***

Whaikaha was established to work in partnership with the disability community, Māori, and Government to drive change towards a better, more independent future for disabled people, tāngata whaikaha and their whānau. This was in response to the disability community asking for a Ministry which focuses on improving the outcomes for disabled people in Aotearoa New Zealand.

A key intent of Whaikaha is that it gives full effect to the individual and collective voices of disabled people, tāngata whaikaha Māori, whānau, and the wider disability community.

Whaikaha’s role is to:

* Lift the profile of disability and drive better outcomes for all disabled people, by accelerating the realisation of the Disability Strategy, Disability Action Plan, New Zealand Sign Language Strategy 2018 -2023, and implementation of the UNCRPD.
* Lead work on cross-government strategic policy, stewardship, and public sector capacity and capability building.
* Support government agencies to incorporate disability perspectives and needs into their work to meet their own responsibilities to disabled people and whānau.
* Transform Disability Support Services in line with the Enabling Good Lives approach.

[[1]](https://auc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en%2DNZ&rs=en%2DNZ&wopisrc=https%3A%2F%2Fmsdgovtnz.sharepoint.com%2Fsites%2Fwhaikaha-ORG-Specialist-Services%2F_vti_bin%2Fwopi.ashx%2Ffiles%2Fd56caa2d91744516a797fcc55f447f4f&wdlor=c7F7259F9-2043-4F65-9459-60C1D105F61B&wdenableroaming=1&mscc=1&hid=929D7F28-218C-4E88-ABB4-FDB19F0FD76E&wdorigin=Outlook-Body&wdhostclicktime=1664744688712&jsapi=1&jsapiver=v1&newsession=1&corrid=3f90eb5c-2e85-4a4e-a128-444c6a2fa5b2&usid=3f90eb5c-2e85-4a4e-a128-444c6a2fa5b2&sftc=1&cac=1&mtf=1&sfp=1&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush&rct=Medium&ctp=LeastProtected#_ftnref1) [Convention on the Rights of Persons with Disabilities (CRPD) | United Nations Enable](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext)

1. 1.1 million New Zealanders identify as disabled. However, DSS is based on eligibility criteria. DSS is currently provided to approximately 43,000 of these disabled people who have a physical, intellectual or sensory disability (or a combination of these) which is likely to continue for at least six months and needs ongoing support to live independently. [↑](#footnote-ref-2)
2. Congregate care includes residential care services and supported living services [↑](#footnote-ref-3)
3. []](https://auc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en%2DNZ&rs=en%2DNZ&wopisrc=https%3A%2F%2Fmsdgovtnz.sharepoint.com%2Fsites%2Fwhaikaha-ORG-Specialist-Services%2F_vti_bin%2Fwopi.ashx%2Ffiles%2Fd56caa2d91744516a797fcc55f447f4f&wdlor=c7F7259F9-2043-4F65-9459-60C1D105F61B&wdenableroaming=1&mscc=1&hid=929D7F28-218C-4E88-ABB4-FDB19F0FD76E&wdorigin=Outlook-Body&wdhostclicktime=1664744688712&jsapi=1&jsapiver=v1&newsession=1&corrid=3f90eb5c-2e85-4a4e-a128-444c6a2fa5b2&usid=3f90eb5c-2e85-4a4e-a128-444c6a2fa5b2&sftc=1&cac=1&mtf=1&sfp=1&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush&rct=Medium&ctp=LeastProtected#_ftnref1) [Convention on the Rights of Persons with Disabilities (CRPD) | United Nations Enable](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext) [↑](#footnote-ref-4)