PARENTS OF VISION IMPAIRED (NZ) INC
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Providing a community to support parents of children with vision impairments

12 September 2025

Whaikaha – Ministry of Disabled people
New Zealand Disability Strategy

Via email to: disabilitystrategy@whaikaha.govt.nz

Tēnā koe,

Please find attached a submission from Parents of Vision Impaired NZ on the *New Zealand Disability Strategy*.

Ngā mihi,

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ABOUT PARENTS OF VISION IMPAIRED NZ

Parents of Vision Impaired NZ (PVI) is a registered charity which supports parents who have blind, low vision, or vision-impaired children. There is no cost to enrol, and we provide a supportive community for parents who are overcoming challenges every day. We offer parents advice, information, and opportunities to meet other parents. We publish a quarterly newsletter (eVision) and have a members-only Facebook page for families and whānau to share information and to network. PVI also runs an annual conference which allows parents and whānau to get together face to face for a longer time to talk, listen and learn in a social setting. PVI takes an active part in the disability sector through making sure that the voice of visually impaired children and their parents is heard in consultations with government, schools, local councils, and other organisations.

OUR APPROACH

PVI takes a whole of life approach with the understanding that disabled children and whānau should have a say about outcomes that affect them. In doing so, we draw on key components of the following:

New Zealand Bill of Rights Act (1990). This Act states that everyone has the right to be free from discrimination from government and state officials, including with regards to education and on the grounds of disability.

Aotearoa New Zealand is a signatory to several United Nations conventions. As such, governments are required to undertake all appropriate legislative, administrative, and other measures for the implementation of the rights as recognized in the following relevant conventions:

- **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD.**
- **United Nations Convention on the Rights of the Child (UNCRC).**
- **United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)**

NZ Disability Strategy (2016-2026) is the Government's primary vehicle for implementing the UNCRPD and includes the NZ Disability Action Plan.

Enabling Good Lives Principles. These were developed in conjunction with disabled people and families. EGL is a foundation and framework to guide positive change for disabled people, families, communities and governance structures.

The **eight principles** are:

- *Self-determination:* Disabled people are in control of their lives.
- *Beginning early*: Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- *Person-centred:* Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
- *Ordinary life outcomes:* Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
- *Mainstream first:* Disabled people are supported to access mainstream services before specialist disability services.

- *Mana enhancing:* The abilities and contributions of disabled people and their families are recognised and respected.
- *Easy to use:* Disabled people have supports that are simple to use and flexible.
- *Relationship building:* Supports build and strengthen relationships between disabled people, their whānau and community.

SUMMARY OF OUR SUBMISSION

DISABILITY STRATEGY – CONDENSED FEEDBACK SUMMARY

Key Gaps Across All Sectors

1. **Exclusion of Complex and High Needs Individuals**
    - Actions largely target mild/moderate or single-area disabilities.
    - Intellectual disabilities, non-verbal children, and multi-disability individuals consistently absent.
2. **Lack of Funding, Enforcement, and Accountability**
    - Most action points are aspirational or guidance-based.
    - No mandatory measures, enforceable obligations, or timelines for implementation.
    - Consultation feedback is not linked to tangible outcomes.
3. **Insufficient Integration Across Sectors**
    - Education, employment, and health actions are siloed.
    - Limited linkage between school, post-school transitions, and workforce participation.
    - Digital infrastructure gaps undermine implementation (e.g., health accessibility records, learning support coordination).
4. **Disconnected from Lived Experience**
    - Parents and whānau report strategy appears “outsider-written” or AI-generated.
    - Whānau and child voices largely absent in design and execution.
5. **Structural Barriers Ignored**
    - BOTs, employers, housing providers, and health institutions lack accountability.
    - Ableism, stigma, and service inflexibility remain unaddressed.
    - Māori and Kaupapa Māori contexts underrepresented, especially in education and health.

SECTOR-SPECIFIC RECOMMENDATIONS

Education

- Mandatory, funded professional development for teachers, TAs, and BOTs.
- Include complex and high needs learners in all programs.
- Embed transition planning from school to tertiary education and employment.
- Ensure accountability for inclusive practice, particularly for ORS-funded children.

Employment

- Include complex, intellectual, and multi-disability individuals in all employment actions.
- Address systemic barriers, ableism, and employer accountability.
- Link initiatives to education and school-to-work transitions.
- Implement measurable outcomes and monitoring for all disability types.

Health

- Embed whānau and child voice throughout health services.
- Fund accessible, inclusive health services and digital infrastructure.
- Include all disability types, including intellectual and complex needs, in workforce planning.
- Support disabled people in frontline, professional, and leadership roles, not only peer support.
- Ensure accountability and monitoring of health system improvements.

Housing

- Fund and enforce accessible new builds and home modifications.
- Cover all disability types, including intellectual and complex needs.
- Separate housing provision from disability service delivery where appropriate.
- Embed monitoring and accountability for housing providers.
- Prioritize disabled people and whānau needs over bureaucratic rules.

Overall: Parents and whānau report a consistent lack of practical, funded, enforceable actions across sectors. The disability strategy currently risks being aspirational "vibes" without real-world impact, especially for high needs and complex disability populations. Immediate attention to accountability, cross-sector integration, and lived experience inclusion is essential.

DISABILITY STRATEGY FEEDBACK (SUMMARY)

Sector	Key Gaps / Issues	Recommendations
Education	- Focus on mild/moderate disabilities; complex/high needs children absent - Teacher training insufficiently mandatory, ongoing, or targeted - BOTs not held accountable for inclusion - Transition to tertiary education/employment missing	- Fund mandatory, on-the-job professional development for teachers, TAs, and BOTs - Include complex/high needs learners in all programs - Embed transition planning from school to work and tertiary education - Ensure school accountability for inclusive practices
Employment	- Focus on physically disabled, single-area disabilities - Intellectual and complex disabilities excluded - Overemphasis on awareness campaigns; systemic barriers ignored - No accountability for employers	- Include all disability types, including complex/intellectual needs - Address systemic ableism and barriers - Link employment initiatives to education and transition programs - Implement measurable outcomes and monitoring - Support meaningful career progression, not just entry-level roles
Health	- Whānau and child voices largely absent - Digital infrastructure gaps (NHI, accessibility needs) impede action - Frontline roles for disabled people under-supported; focus on peer support roles - Intellectual and complex disabilities ignored	- Embed whānau and child voice in all health actions - Fund accessible, inclusive services and digital infrastructure - Include all disability types in workforce planning - Support frontline, professional, and leadership roles - Implement monitoring and accountability mechanisms
Housing	- Generic actions; no funding for new builds or modifications - Intellectual and complex needs absent - Slow, inflexible processes (e.g., Kāinga Ora) - No separation between housing provision and disability services	- Fund and enforce accessible housing and modifications - Include all disability types - Separate housing provision from service delivery where needed - Embed monitoring and accountability - Prioritize disabled people and whānau needs over bureaucratic rules

Justice	- Complex/high needs, intellectual, and non-verbal disabled people largely absent - Workforce lacks mandatory disability competence, Deaf competence, trauma-informed and supported decision-making training - Frameworks aspirational, under-resourced, unclear timelines - Lived experience and whānau input not consistently included	- Include all disability types in justice actions - Mandate workforce training in disability competence, Deaf competence, trauma-informed and supported decision-making - Fund, resource, and enforce safeguarding frameworks - Embed lived experience and whānau input throughout policy, design, and monitoring - Implement culturally safe approaches for Māori and whānau

Cross-Sector Observations

- Complex, high needs, and intellectually disabled individuals are consistently excluded.
- Actions are aspirational, lacking funding, enforcement, and accountability.
- Consultation perceived as disconnected from lived experience; AI/writing concerns reported.
- Parents report frustration with repetitive, non-impactful consultation processes.
- Cross-sector integration (education → employment → health → housing) is weak.

VISION AND PRINCIPLES AND CROSS-CUTTING THEMES

The **proposed vision** is: New Zealand is an accessible and equitable society for disabled people and their whānau – a place where disabled people thrive, lead and participate in all aspects of life.

Principles are the key values, ideas and commitments that underpin this strategy. The principles will help make sure the strategy reflects the things that are important to disabled people.

Seven **principles** have been proposed for the strategy. These are summarised below.

- Accessibility: Fundamental to participation and inclusion. Accessible environments and services benefit everyone, not just disabled people.
- Choice and control: Recognises that disabled people are experts in their own lives, and have the same right to self-determination as everyone else.
- Equity, cultural inclusion and intersectionality: Acknowledges that disabled individuals have their own unique identities, and belong to diverse whānau, communities, and cultures.
- Human rights: Anchor the strategy to international human rights frameworks, including the United Nations Convention on the Rights of Persons with Disabilities, the United Nations Declaration on the Rights of Indigenous Peoples, the United Nations Convention on the Rights of the Child, and the Universal Declaration of Human Rights.
- Participation and inclusion: Recognizes disabled people's right to be active members of their communities and cultures in all aspects of life.
- Respect and dignity: Emphasizes that everyone deserves to be treated with respect, and acknowledges that societal attitudes can be a significant barrier for disabled people.
- The Treaty of Waitangi | Te Tiriti o Waitangi: Establishes the relationship between Māori and the Crown, recognising the unique position of Māori as tāngata whenua, and ensuring partnership, participation and protection for tāngata whaikaha Māori.

  On a scale from 1 (not at all important) to 5 (very important) how important is each

FEEDBACK FROM PVI PARENTS AND WHANAU:

OVERALL RESPONSE – EXTREMELY IMPORTANT POINTS

1. **Parents strongly questioned why the EGL (Enabling Good Lives) principles were not used.**
    - EGL principles are already embedded across the disability sector, widely understood, and practical in application.
    - The proposed principles were seen as **wordy, unclear, and confusing** compared to EGL.
2. **The proposed vision and principles feel disjointed, poorly aligned, and disconnected from disabled communities.**
    - Families described them as written by "outsiders" rather than by disabled people or whānau with lived experience.
    - The lack of alignment with existing disability frameworks undermines trust and credibility.
3. **Clarity, simplicity, and alignment are urgently needed.**
    - Parents asked for concise, direct wording that connects with lived experience and with current sector approaches.
    - Without this, the strategy risks being **tokenistic** and duplicative rather than practical and empowering.

PARENT AND WHĀNAU FEEDBACK

- **Unnecessary duplication**: Parents repeatedly asked *"Why reinvent the wheel?"* when the EGL principles are already proven and widely used in practice.
- **Poor readability**: Families found the proposed principles overly wordy and difficult to interpret compared to EGL.
- **Disconnection from community**: Parents felt the vision and principles did not reflect the voices of disabled people and whānau, raising questions about authorship and authenticity.
- **Lack of alignment**: The seven principles did not clearly align with one another, or with the vision, creating further confusion.

DIRECT PARENT QUOTES

- *"Why are we not using the EGL principles?"*
- *"The EGL principles are clear and easy to interpret – unlike these which are wordy, unclear, and confusing."*
- *"We already use the EGL principles in our plans and approach, so why not use the principles we already have?"*
- *"Why are we reinventing the wheel when we already have a set of easily understood principles that work?"*
- *"It sounds like these were written by an outsider – someone who isn't disabled or part of our communities."*
- *"Was this written by AI instead of real people?"*

CORE RECOMMENDATIONS (PRIORITY)

1. **Adopt EGL principles directly** – they are already embedded, clear, trusted, and in everyday use by disabled people, whānau, and providers.
2. **Ensure alignment and authenticity** – principles must reflect the lived experiences of disabled communities, not read like externally drafted or generic statements.
3. **Use clear and concise wording** – simplify language so families and educators can interpret and apply principles in practice.
4. **Demonstrate continuity with existing sector frameworks** – show how the vision and principles build on, rather than duplicate or replace, EGL and related approaches.

Overall, it was felt that, while the vision, principles and cross-cutting themes weren't terrible, they were disjointed, poorly aligned with EGL, and did not seem to have been well thought through.

There was a need for these areas to be clearer, more aligned with existing work in the disability sector, and to be written in more direct and concise manner.

Specific comments from parents:

- Why are we not using the EGL principles?
- The EGL principles are clear and easy to interpret - unlike these which are wordy, unclear, and confusing
- We already use the EGL principles in our plans and approach [with DSS], so why not use the principles we already have?

- Why are we re-inventing the wheel when we already have a set of easily understood principles that work [referring to EGL]?
- It sounds like these 3 areas were written by an ‘outsider’ – someone who isn’t disabled or part of our communities.
- They don’t align [with each other].
- Was this written by AI instead of by real people?

PRIORITY OUTCOME AREA: EDUCATION

The **goal** for education is:

Every learner is supported to attend, participate and progress in education. There is a high expectation that all learners – including disabled learners – will achieve their potential in the education setting of their choice.

Summary of **what success in education means:**

Educators plan for diverse learners to succeed. The education system has high expectations for all disabled learners, focusing on their strengths and aspirations. Learning support is responsive, timely and effective, easy to navigate, and delivered by a skilled workforce. Early intervention happens at the right time and is effective.

Kaupapa Māori education settings have access to the right resources delivered by a capable workforce. Data is gathered to support and understand the progress of learners. Tertiary education providers are supported to implement disability action plans, with progress monitored.

FEEDBACK FROM PVI PARENTS AND WHANAU:

OVERALL RESPONSE – EXTREMELY IMPORTANT POINTS

1. **Parents supported the goal in principle, but found it disconnected from the actual action points.**
    - The aspirational language is positive, but the supporting actions do not reflect or enable this goal.
2. **The use of "diverse learners" was strongly criticised.**
    - Parents stressed: *our children are diverse, but disability itself is the barrier*.
    - Framing this as "diversity" risks minimising the systemic discrimination and barriers disabled children face.
3. **The strategy fails to include children with complex needs.**
    - Parents were clear: the focus is largely on mild to moderate disabilities, while those with high and complex needs are absent.
    - This omission was seen as a fundamental flaw that undermines the credibility of the goal.

PARENT AND WHĀNAU FEEDBACK

- **Supportive but sceptical**: Parents liked the vision of high expectations, early intervention, and skilled support, but could not see how this would translate into practice under the proposed actions.
- **Language matters**: The term "diverse learners" was described as vague and misleading; disability is not simply "diversity," it is a source of exclusion when not properly supported.
- **Exclusion of complex needs**: Parents were deeply concerned that children with significant disabilities and high support requirements were invisible in the strategy.

DIRECT PARENT QUOTES

- *"The goal is fine, but it doesn't connect to the action points at all."*

- *"Our children are diverse, yes – but it is disability that is the barrier, not their diversity."*
- *"Where are our children with complex needs in this strategy? Their realities are entirely absent."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Explicitly connect actions to the education goal** – ensure that the aspirational language is backed by practical, measurable commitments.
2. **Replace vague "diverse learners" framing with explicit reference to disability** – centre disability as the barrier that must be addressed through rights-based, inclusive practice.
3. **Include learners with complex needs explicitly** – ensure the strategy recognises and responds to their realities, not just those with mild/moderate disabilities.
4. **Demonstrate accountability** – set out how high expectations, timely interventions, and skilled workforce development will be delivered in practice.

The goal was considered to be appropriate and supported. However, it seemed to be disconnected from the action points and the focus in the action points. There was concern around what was meant by *diverse learners*. Our children are diverse yes, but it is disability that is the barrier, not their diversity.

Overall, the focus of this outcome area is on children with mild/moderate disabilities. **Where are our children with complex needs in this strategy?** Their realities are entirely absent from this strategy.

EDUCATION ACTIONS

In the draft New Zealand Disability Strategy there are **9 proposed education actions**.

ACTION 1: INVEST $266 MILLION TO EXPAND EARLY INTERVENTION SERVICES TO SUPPORT THE IDENTIFICATION OF LEARNING SUPPORT NEEDS EARLY IN A CHILD'S LIFE AND REDUCE WAIT TIMES FOR ASSESSMENTS AND SERVICES.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **This action is already decided and announced.**
    - Parents felt that consultation here is tokenistic, as the funding commitment has already been made.
2. **What matters now is delivery, not re-announcement.**
    - Parents stressed that the critical issue is *how the investment will be implemented*, monitored, and evaluated – not whether it should happen.
3. **Parents expect real reductions in wait times.**
    - Success must be measured by actual impact on families (e.g., faster assessments, earlier support), not just budget headlines.

PARENT AND WHĀNAU FEEDBACK

- Parents expressed frustration that consultation on this action feels redundant since the decision has already been taken.

- They want to see practical, transparent detail on how the $266m will be spent, and how it will be ensured that services actually reach families who need them most.
- Accountability and measurement are key – parents want clear benchmarks for reduced wait times and improved access.

DIRECT PARENT QUOTES (EXAMPLES)

- *“This has already been announced by the Minister – so why ask us now?”*
- *“We don’t need another announcement, we need to see results – shorter waitlists, earlier support.”*

CORE RECOMMENDATIONS (PRIORITY)

1. **Clarify implementation details** – where will the funding go, who will deliver, and how will families access services?
2. **Set measurable targets** for reduced wait times and early support, and report progress publicly.
3. **Ensure equity of access** across regions so that no family is disadvantaged by postcode.
4. **Maintain ongoing parent and whānau input** into monitoring delivery – feedback must shape how services roll out.

This action has already been announced by the Minister, so further feedback is pointless.

ACTION 2: EXPLORE NEW OPTIONS FOR TARGETED AND SPECIALISED SUPPORT AND PROVISIONS TO REDUCE WAIT TIMES USING PRIVATE PROVIDERS AND NON-GOVERNMENT ORGANISATIONS (NGOS).

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Parents found this action confusing, vague, and disconnected from reality.**
    - Families strongly felt it was written by people with little understanding of what parents face in the current system.
2. **Parents are already using private providers – the issue is inadequate funding, not lack of options.**
    - The overwhelming message was: *“We already use private providers – just fund the ones we have properly!”*
    - Without meaningful funding, simply “exploring new options” will not reduce wait times.
3. **Parents are deeply concerned this action signals outsourcing and privatisation at the expense of quality.**
    - Strong fear that services will be contracted out to **cheaper, lower-quality providers** rather than improving existing supports.
    - Concern that this will further fragment the system, creating *more providers to deal with, more bouncing around, and worse experiences.*

PARENT AND WHĀNAU FEEDBACK

- **Confusion and scepticism**: Families could not tell whether this meant expanding current services, creating new services, or cutting costs by outsourcing.
- **Wait times remain unaddressed**: Parents asked how this would actually improve delays when existing services already have waitlists of 2–3 years (e.g., Mana Whaikaha).
- **Privatisation fears**: Parents worried this would funnel more money into private profit instead of resourcing proven providers and community supports.
- **Fragmentation and duplication**: Families already feel bounced around between multiple providers. This action risks worsening that problem by adding more layers.

DIRECT PARENT QUOTES

- *"We already use private providers for services – just fund the ones we have properly!"*
- *"Are we expanding current services? Or just trying to have cheaper services?"*
- *"At Mana Whaikaha there was/is a 2–3 year wait for a connector – how will this action make a difference?"*
- *"Will we just get worse services that are outsourced to cheap providers who are awful to deal with?"*
- *"We get bounced around already from pillar to post – how will this action make this better? It sounds like it will make it worse."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Fund existing services properly** – strengthen capacity of current providers rather than creating more fragmented or outsourced services.
2. **Be transparent about intent** – clearly state whether this action is about expansion, privatisation, or cost-cutting. Families need certainty.
3. **Address wait times directly** – show how proposed changes will reduce actual waiting periods, with specific targets and timelines.
4. **Avoid fragmentation** – ensure families are not forced to deal with more providers and more complexity; design support that is simple, accessible, and family-centred

Overall, parents were confused by this action and unclear as to what it meant. It was felt that this action was written by people who are deeply disconnected from the realities faced by parents in the current system.

Specific comments from parents:

- We already use private providers for services – just fund the ones we have properly!
- Are we expanding current services? Or just trying to have cheaper services?
- What is wrong with the current providers? Is there more funding?
- At mana whaikaha there was/is a 2-3year wait for a connector – how will this action make a difference to wait times?
- Does this mean more money for private profit?
- Does this mean *new* services? Or *less* funding for existing services?
- Will we just get *worse* services that are outsourced to cheap providers who are awful to deal with?

- We already have to see multiple providers when we have a complex child. Can we just have something that works for us, not have to see more and more and more ‘targeted’ supports?
- We get bounced around already from pillar to post when seeking support – how will this action make this better? It sounds like it will make it worse?

ACTION 3: MAKE IMPROVEMENTS TO THE LEARNING SUPPORT SYSTEM SO IT IS EASIER TO NAVIGATE FOR EDUCATORS, FAMILIES AND LEARNERS THROUGH: FUNDING ALL SCHOOLS WITH YEAR 1-8 STUDENTS FOR A LEARNING SUPPORT COORDINATOR; AND BY REDUCING THE COMPLEXITY AND ACCESSIBILITY OF THE APPLICATION PROCESS.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Funding Learning Support Coordinators (LSCs) in all Year 1–8 schools is welcomed and supported.**
    - Parents agreed this is a positive step, particularly for students with mild or moderate learning needs.
2. **The rest of the action point is vague, overly wordy, and disconnected from reality.**
    - Parents were clear: the proposal lacks substance and clarity.
    - Families could not see how this action would change actual practice for children, particularly those with **ORS funding**.
3. **ORS-funded children and their families are largely left out of this action.**
    - Parents strongly questioned what the proposed improvements mean in practice for ORS-funded students.
    - This is seen as a critical omission that undermines the usefulness of the action.

PARENT AND WHĀNAU FEEDBACK

- **Unclear language**: The action was described as *“too many words”* and *“meaningless”* because it does not define what will change on the ground.
- **Disconnect with ORS**: Parents repeatedly asked: *“What does this mean for ORS children?”* and noted the absence of clear links to ORS processes and supports.
- **Duplication of roles**: Parents questioned why LSCs are needed when the Ministry of Education already has **Special Education Advisors** whose role is to help families navigate the system. The concern is that if these advisors are not effective, **the problem is one of accountability, not a lack of roles.**
- **No clear outcomes**: Parents wanted to know what success would look like, what learning support areas were covered, and what outcome measures would be used.

DIRECT PARENT QUOTES

- *“Too many words here makes this action meaningless.”*
- *“What does this action point mean for ORS funded children?”*

- *"Isn't it the role of MOE Special Education Advisors to help with navigation? Are they not doing their job here?"*
- *"What are the outcome measures? What areas of learning support are meant?"*
- *"This is very vague and unclear."*
- *"Is this more AI writing?"*

CORE RECOMMENDATIONS (PRIORITY)

1. **Clarify the purpose and scope of LSCs** – specify how their role differs from existing MOE Special Education Advisors, and how they will interact with ORS processes.
2. **Explicitly include ORS-funded students** – state clearly what improvements will mean for families navigating the ORS system, which is one of the most complex areas of learning support.
3. **Set measurable outcomes** – define what "reducing complexity" means, with benchmarks to assess whether navigation has improved for families.
4. **Simplify and strengthen communication** – cut vague or wordy language; use precise, plain terms that show families how this action will change their experience.

Parents agreed that funding LSC's for all Year 1-8 students was a positive step.

However, other than this, the action point was viewed as unclear, wordy, and disconnected from reality. It was not clear what these words meant in practice for ORS funding and associated practice.

Specific comments from parents:

- Too many words here makes this action meaningless
- LSC is for moderate (non-ORS) needs, which is positive for mild/moderate learning needs. It is less helpful for us, but we are still supportive!
- What does this action point mean for ORS funded children?
- What is the role of the MOE special education advisor then? Isn't their role to support system navigation? Are they not doing their job here?
- How does this link in with ORS?
- What are the outcome measures?
- What areas of learning support are meant here?
- This is very vague and unclear
- Is this more AI writing?

ACTION 4: INVEST FUNDING IN ADDITIONAL LEARNING SUPPORT CLASSROOMS TO PROVIDE CHOICE FOR PARENTS.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Parents are deeply concerned that "choice" may simply perpetuate segregation and exclusion.**

   - While additional learning support classrooms sound positive, the language of "choice" is unclear and parents fear it could mask **continued discriminatory and exclusionary practices.**
   - Parents want clarity: does "choice" mean genuine flexibility and inclusion, or just more satellite classrooms that isolate disabled children?
2. **Inclusion must be the default expectation, not optional.**
   - Parents stressed that additional classrooms are only valuable if they support **inclusive practice, integration, and dignity.**
   - Without systemic monitoring and enforcement of inclusive practices, this action risks becoming a vehicle for exclusion.

PARENT AND WHĀNAU FEEDBACK

- **Supportive but skeptical**: Parents support investment, but are highly critical of the vague promise of "choice."
- **Lived experience of exclusion**: Families shared strong examples of stigma and segregation, including:
   - ORS-funded children being required to wear **hi-vis vests** at playtime.
   - Disabled children being made to leave school early.
   - Schools treating additional units as a way to separate rather than integrate.
- **Missed opportunity**: Parents were disappointed that the action does not explicitly tie funding to **inclusive outcomes** or accountability mechanisms.

SPECIFIC CONCERNS

- **Ambiguity of "choice"**:
   - Parents asked: *Does this mean fewer zoning restrictions, integrated specialist classrooms, or more segregated units?*
   - Without a clear definition, "choice" feels like a **lottery** where families' experiences depend entirely on the culture of the school they are zoned into.
- **Risk of segregation**: Parents worry this action could **reinforce existing patterns of exclusion** under the guise of offering options.
- **Inconsistent school practice**: Some schools model excellent inclusive practice with integrated classrooms, while others are actively discriminatory. There is no mechanism in this action to ensure best practice is replicated.

DIRECT PARENT QUOTES

- *"The idea is good – but what does 'choice' actually mean?"*
- *"Is this just segregation of special needs and disabled children?"*
- *"Some schools do inclusion really well, others stigmatise our kids with hi-vis jackets – how will this fix that?"*
- *"Most choices now are just a lottery depending on your zoning. Is this just more of the same?"*
- *"Need to have inclusion as expected practice and a way of monitoring and enforcing this – not just 'choice'."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Define "choice" clearly and explicitly** – families need certainty about whether this means more integrated specialist classrooms, zoning flexibility, or segregated units.
2. **Tie funding to inclusion outcomes** – require schools to demonstrate that additional classrooms are used to promote dignity, belonging, and equitable participation.
3. **Introduce monitoring and accountability** – ensure Boards of Trustees and school leadership cannot use additional classrooms to sideline disabled children.
4. **Make inclusion mandatory and enforceable** – no school should be allowed to enforce discriminatory practices (such as hi-vis jackets or early leaving) under the guise of "choice."

Overall, parents were supportive of additional learning support classrooms. However, they were unsure what was really meant by 'choice' and were skeptical that 'choice' would provide the type of inclusive and supportive practice needed for our children. Parents shared stories of exclusion and poor practice, and were concerned that this action point would just perpetuate existing segregation and exclusion of disabled children.

Specific comments from parents:

- The idea is good!
- What does 'choice for parents' mean? Less zoning?
- Who are they focusing on here? Do they mean more satellite classrooms? Or...? What do they mean?
- Some schools do inclusion and support really well and have integrated units which work amazingly. But other schools are more segregated and exclusory. How will this support the former rather than the latter?
- It's great to have our kids attending mainstream schools with as specialist class, is this what this means?
- Is this just segregation of special needs and disabled children?
- Some schools really struggle to provide inclusion. The school we are zoned for makes all the ORS funded kids wear hi-vis jackets at playtime and makes them all finish early. That is not inclusion – that is stigma and marginalizing. Need to have inclusion as expected practice and to have a way of monitoring and enforcing this – not just 'choice'.
- What do they mean by 'choice'? Is it, you can have option a or option b, or does this mean you can choose what works and the school has to come to the party?
- Most choices at present are just a lottery. If you're lucky you are zoned with a supportive, inclusive school. If you're unlucky, you get a school that insists on early leaving and stigmatizing hi-vis jackets. Is this just more of the same?

ACTION 5: WORK WITH THE MINISTRY OF DISABLED PEOPLE - WHAIKAHA TO DEVELOP IMPROVEMENTS IN TEACHER TRAINING AND GUIDANCE THAT SUPPORT TEACHERS TO MEET THE NEEDS OF DISABLED STUDENTS.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **The biggest gap is not teacher training, but Boards of Trustees (BOTs).**

  - Parents were clear: **BOTs' lack of understanding and refusal to meet their obligations is the number one barrier to inclusion.**
  - This action misses a critical opportunity to make **mandatory training and accountability for BOTs** a central requirement.
  - Without BOT-level change, schools will continue to fail disabled children, regardless of teacher training.

2. **Teacher training must be ongoing, mandatory, and tied to the presence of disabled students in classrooms.**
   - Baseline training in initial teacher education is useful, but **not enough.**
   - Parents stressed: **on-the-job training and professional development (PD) must be provided at the time it is needed**—when teachers are teaching disabled children.
   - There is currently **no requirement** for this, and this omission undermines inclusion.

PARENT AND WHĀNAU FEEDBACK

- **Supportive but critical**: Parents support baseline disability awareness training for teachers, but strongly criticised this action as **too narrow and disconnected from real challenges.**
- **Severe gaps identified**: Parents felt this action was *"severely ignorant of the issues faced by children and families"* because it ignores ongoing PD, BOT accountability, and broader disability needs beyond vision impairment.
- **Missed opportunity**: Parents expressed disappointment that BOT obligations were overlooked. This is seen as a **core failure** of the action point.

SPECIFIC CONCERNS

- **BOTs are the main issue**: They frequently fail to uphold disabled students' rights and refuse to ensure school leadership implements inclusive practices.
- **Teacher PD is limited and inconsistent**:
  - No mandatory requirement for teachers with disabled students in their classes to undertake PD.
  - PD is not adequately funded, and release time is a major barrier.
  - Teachers need refreshers and targeted PD linked to the specific disabilities of children they teach.
- **Support for TAs is missing**: Teacher aides also require funded training and support.
- **Systemic culture change**: Without addressing school leadership and culture (BOTs and principals), training teachers alone will not deliver inclusive education.

DIRECT PARENT QUOTES

- *"The issue is BOTs not understanding their obligations."*
- *"On-the-job training needs to be mandatory once you have a disabled child in class."*
- *"This is great for new teachers, but what about the teachers we already have?"*
- *"Changing school culture requires leadership—if you are not changing BOTs, you are just setting new teachers up to fail."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Mandatory training and accountability for BOTs** on their obligations to disabled students – this is the most urgent gap.
2. **Mandatory, funded on-the-job PD for teachers and TAs** when they have disabled students in their class.
3. **Ongoing PD beyond initial teacher training**, with refreshers available and linked to the actual needs of students present.
4. **Inclusion principles and rights of the child** must be explicitly embedded across training for teachers, TAs, BOTs, and leadership.

Overall, parents were supportive of this action. Providing a baseline understanding during teacher training was well received and supported.

However, it was felt that this action point was **severely ignorant** of the issues faced by children and families of school age.

Our parents noted that teachers are well supported by BLENNZ who offer teacher training and professional development 'on the job' in a timely manner. There were concerns raised that there is no action point to provide ongoing professional development for teachers, at the point where it is needed. There is no requirement for teachers to undertake professional development if they have disabled children in their classroom, and limited options when they do. Parents noted that while BLENNZ does a great job of ongoing support and training, this does not extend to complex care or areas outside of vision, and that there is a need for ongoing professional development for all areas related to disability.

Parents also noted that, despite teachers being well supported with regards to classroom interventions for our blind and low vision children, barriers were still experienced as a result of ignorance, stereotyping, and a failure of BOT's to understand their obligations to disabled children.

There was disappointment expressed that this was a missed opportunity to give BOT's direct instruction and mandatory training regarding their responsibilities and obligations to ensure an inclusive education for every child. BOT's are the main cause of issues for our parents, and their refusal to ensure that school leadership implements appropriate mechanisms and practices that uphold our children's rights.

Specific comments from parents:

- The issue is BOTs not understanding their obligations
- Teacher training is always helpful but it needs to be targeted on the job
- When you have disabled children in your class you need training then too
- Good to have something in teacher training
- IKT site has resources but what is needed in is in person training
- The is great BUT what about BOTs?
- Where is the training and accountability for BOTs?
- Teachers need PD but don't have the teacher release time – what is being done here?
- On the job training needs to be mandatory once you have a disabled child in class
- What about funded professional development once you leave teachers college?

- TA’s need funded training and support too
- Will this be a mandatory module at teachers college? It needs to be mandatory as otherwise is pointless.
- Disability is such a wide topic, good to have baseline training but need more specific training on the job
- How do you capture the huge diversity of disability in training?
- Would be just as/more useful to have targeted PD once you are teaching, that is related the needs of the children in your class
- A broad understanding of disability is useful as a base or cornerstone, so this action point is really good for that.
- Teachers need ongoing support and PD – our kids (blind/low vision) really benefit from ongoing support and professional development, other disabled kids need this too
- When you have a disabled kid in your class you will need a refresher – who will provide this?
- This is great for new teachers, but what about the teachers we already have? How will they improve if no funded or mandatory training?
- Changing school culture requires leadership. If you are not changing school culture and school leadership (e.g. BOTs) then you are just setting new teachers up to fail.
- This needs to include the principles of inclusion and the rights of the child to education
- Training should have different levels, starting with the core basics.

ACTION 6: WORK WITH THE MINISTRY OF DISABLED PEOPLE - WHAIKAHA TO EXPLORE OPPORTUNITIES TO IMPROVE ACCOUNTABILITY FOR SCHOOLS THOUGH REPORTING ON LEARNING AND ACHIEVEMENT OUTCOMES FOR DISABLED LEARNERS.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Parents supported this action in principle, but saw major gaps in design and accountability.**
    - Support for stronger reporting was clear, but parents stressed this must move beyond *exploration* to *mandated practice*.
2. **Need for compulsory, standardised reporting.**
    - Parents were firm that reporting on disabled learners must be consistent across schools and compulsory, not voluntary.
3. **Connection to ORS students and post-school outcomes is essential.**
    - Parents were concerned that the action does not address ORS-funded students explicitly.
    - They also stressed that reporting should not stop at school outcomes, but must link to longer-term pathways such as employment, training, and community inclusion.
4. **Clarity is needed around duplication with Action #8.**
    - Parents were confused about how this action differs from Action #8 and wanted this clarified.

PARENT AND WHĀNAU FEEDBACK

- **Positive but cautious**: Parents liked the focus on improving accountability but felt the proposal lacked teeth without mandatory standards.
- **Accountability gap**: They questioned where the Education Review Office (ERO) fits in, and whether schools will actually be held accountable.
- **Specificity required**: Inclusion must be explicitly framed as *disabled inclusion* rather than a generic notion of diversity.
- **Future focus missing**: Parents want reporting to include data that tracks progress toward post-school outcomes, not just in-school achievement.

DIRECT PARENT QUOTES

- *"Good to improve reporting, but this should be compulsory, not optional."*
- *"Where is ERO in this?"*
- *"Isn't this just the same as Action #8?"*
- *"We need better data and realistic outcomes – what exactly will be included in this reporting?"*
- *"How is this linked to ORS funding and to employment or training pathways?"*

CORE RECOMMENDATIONS (PRIORITY)

1. **Make reporting mandatory and standardised** across all schools – no voluntary approaches.
2. **Ensure explicit inclusion of ORS-funded students** so those with the highest needs are not left out.
3. **Integrate post-school outcomes** into reporting frameworks to show how education prepares disabled learners for life after school.
4. **Clarify overlaps with Action #8** to avoid duplication or confusion.
5. **Bring in ERO accountability** so that reporting is independently reviewed and enforced.
6. **Be specific about disabled learners** – avoid broad, diluted language about "inclusion."

Overall, parents were supportive of this action point. There was some confusion regarding how this is different to action #8. Parents also wanted this linked to post-school outcomes. There was also concern that this action was not linked with ORS-funded students.

Specific comments from parents:

- Where is ERO in this?
- Good to improve reporting
- No standardized formula – this is not in every report but it should be
- This in not compulsory to report on – but it should be
- Be good to have this mandatory
- Inclusion is not always about disability – need to be specific that this is about disabled inclusion
- We need better data and reporting
- Realistic outcomes are needed
- Isn't this just the same as Action #8??
- What are the links to employment and training?

- What would be included in this reporting?
- How is this linked to ORS funding?

ACTION 7: SUPPORT KAUPAPA MĀORI SETTINGS, WITHIN THE EXISTING EDUCATION BUDGET, TO ACCESS THE RESOURCES, KNOWLEDGE AND CAPABILITY TO DELIVER HIGH QUALITY KAUPAPA MĀORI EDUCATIONAL PROGRAMMES THAT MEET THE NEEDS OF DISABLED ĀKONGA (STUDENTS) IN A KAUPAPA MĀORI SETTING.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Support for Kaupapa Māori settings is important, but current gaps are severe.**
    - Parents noted that services for disabled ākonga are not KM-focused, and in many cases there are no staff able to deliver in te reo Māori. This is a critical equity gap that must be addressed.
2. **Mainstream services must also be accountable and responsive to Māori.**
    - Parents stressed that the action focuses only on KM settings and misses the needs of Māori disabled students in mainstream education.
3. **This action risks being symbolic unless real investment and system change are made.**
    - Parents were concerned that relying on "within the existing budget" means no real shift, and therefore little improvement in practice.
4. **Disabled Māori perspectives and concepts must guide this work.**
    - The concept of *tāngata whaikaha* is not yet well developed or embedded across the education sector. This action must centre Māori worldviews and leadership, not retrofit mainstream approaches.

PARENT AND WHĀNAU FEEDBACK

- Parents were supportive in principle but skeptical that this action would achieve more than symbolic support unless backed by genuine investment.
- They highlighted the absence of specialist KM disability services, lack of reo Māori capability in providers like BLENNZ, and the general poor state of KM education support.
- They emphasised that KM schools need greater autonomy but also strong support from the Ministry of Education (MOE) to provide effective specialist resources.
- Parents saw a *missed opportunity* in failing to require mainstream disability services to upskill and be responsive to Māori.

DIRECT PARENT QUOTES

- *"BLENNZ have very limited staff (none?) who can speak te reo Māori – how will this gap be addressed?"*
- *"This is good, BUT services for disabled children are not KM focused – you're lucky if there is even one staff member who speaks te reo."*
- *"What about Māori students in mainstream settings? Are their needs not important too?"*
- *"This is a missed opportunity to insist that mainstream disability services are responsive to Māori."*

- *"The concept of tāngata whaikaha needs developing – KM perspectives are different to mainstream."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Invest in reo Māori capability** across all specialist services, including BLENNZ and RTVs.
2. **Require mainstream disability services to upskill** and respond effectively to Māori disabled learners and whānau.
3. **Ensure Māori disabled learners in mainstream settings are not overlooked** – their needs must be explicitly included in the strategy.
4. **Develop and embed tāngata whaikaha frameworks** so Māori worldviews guide education support.
5. **Move beyond "within existing budget"** – dedicated resourcing is essential to make change real.
6. **Strengthen MOE responsibility and accountability** to ensure KM schools and services are properly supported, while protecting KM school autonomy.

Specific comments from parents:

- Depends on how this is done
- BLENNZ have very limited staff (none?) who can speak te reo Māori, yet their RTV's are the ones providing specialist support to KM settings. How will this gap be addressed?
- What is the requirement for mainstream settings and services here?
- There is no push for mainstream to upskill
- This is a missed opportunity to insist that mainstream disability services are responsive to Māori
- What about Māori students in mainstream settings? Are their needs not important too?
- This is good BUT services for disabled children are not KM focused – you are lucky if there is even one staff member who speaks te reo Māori, and there are extremely limited KM services
- Education in general poorly supports KM settings
- Where are the KM disability services?
- Perspectives in KM are different to mainstream. How is this supported here?
- Māori has different ideas regarding disability – the concept of tāngata whaikaha needs developing
- The responsibility is on MOE to provide support
- KM schools need autonomy

ACTION 8: WORK WITH THE MINISTRY OF DISABLED PEOPLE - WHAIKAHA TO EXPLORE OPPORTUNITIES TO IDENTIFY DISABLED LEARNERS IN EDUCATION DATA COLLECTIONS.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Confusion and duplication with Action 6.**

  - Parents repeatedly asked how Action 8 differs from Action 6. Both appear to be about reporting and accountability. Without clarity, this feels like duplication and creates skepticism that the strategy is padded with filler rather than meaningful actions.
2. **Risk of harmful or inappropriate data collection.**
   - Parents raised strong concern about how disabled learners would be "identified." There is fear of deficit-based, stigmatizing, or crude tools being imposed (e.g., Washington Group Short Set administered by teachers).
3. **No clear explanation of purpose or safeguards.**
   - Parents want to know: Why is this data being collected? How will it be used? Who has access? Without transparency, families are worried this could lead to registries of disabled children that risk privacy, stigma, or misuse.
4. **ECE learners and early years missing.**
   - Parents noted that early childhood education is not referenced here, despite early identification and intervention being critical.

PARENT AND WHĀNAU FEEDBACK

- Parents found the wording vague, repetitive, and lacking purpose.
- Concerns centred on duplication with Action 6, and unease about the ethics and implications of "identification" in education datasets.
- Families fear a **registry-like approach** that could reinforce exclusion rather than inclusion.

DIRECT PARENT QUOTES

- *"Isn't this just the same as #6?"*
- *"Where is ECE in all this?"*
- *"What are the parameters for identifying disabled children? Will teachers be administering the Washington Short Set?!"*
- *"Not keen on a registry for disabled children."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Clarify how Action 8 differs from Action 6** – or merge them into a single clear, well-defined action.
2. **Be transparent about purpose and safeguards** – families must know how data will be used, by whom, and with what protections.
3. **Avoid deficit-based labelling tools** (such as the Washington Short Set) being imposed in schools or ECE.
4. **Include ECE explicitly** – early years are critical for support and cannot be excluded.
5. **Ensure co-design with disabled people and whānau** on how data is collected and reported, to avoid stigma and misuse.

Specific feedback from parents:

- Isn't this just the same as 6?
- How is this different to #6?
- These are different words but surely the meaning is the same as #6?
- Where is ECE in all this?

- What are the parameters for identifying disabled children? Will teachers be administering the Washington Short set?!
- How will we be identified?
- Not keen on a registry for disabled children

ACTION 9: CONTINUE IMPLEMENTATION OF THE TERTIARY EDUCATION COMMISSION (TEC) MECHANISM FOR REVIEWING PROVIDER PROGRESS IN IMPLEMENTATION OF DISABILITY ACTION PLANS (WHICH WILL BE INTEGRATED INTO INVESTMENT PLANS FROM 2027). THE TEC WILL CONSULT WITH DISABLED STUDENT REPRESENTATIVE GROUPS, INCLUDING THE NATIONAL DISABLED STUDENTS' ASSOCIATION, ON HOW THE MECHANISM WILL BE IMPLEMENTED.

FEEDBACK FROM PVI PARENTS AND WHANAU:

KEY POINTS

1. **This action is already underway.**
   - Parents questioned why consultation is being sought on something that is already in progress and agreed. It feels redundant to include this as a "new action" in the strategy.
2. **Positive momentum and student input recognised.**
   - Parents welcomed the ongoing work and especially the involvement of disabled student representative groups in implementation. This is a strength and should continue.
3. **Clarity needed on why this action is here.**
   - Parents felt that if the work is already happening, the action point could be reframed as a progress update rather than feedback. Otherwise, it risks undermining the credibility of the strategy by presenting ongoing activity as "new."

PARENT AND WHĀNAU FEEDBACK

- Supportive of student involvement and recognition of the work already happening.
- Frustrated that their feedback is being requested on a process already well underway.
- Suggested reframing to show alignment with the strategy rather than as a separate action.

DIRECT PARENT QUOTES (EXAMPLES)

- *"Already in progress."*
- *"Nice to have momentum."*
- *"Great that there is student input."*
- *"Fabulous that there is an agreement to progress this work."*
- *"This is already happening, so why are we being asked for feedback?"*

CORE RECOMMENDATIONS

1. **Reframe this as a progress update** rather than a new action.
2. **Be transparent** about how this aligns with the wider disability strategy – and avoid duplication or rebranding of existing work.
3. **Continue to embed disabled student voice** as central to implementation and monitoring.

Specific feedback from parents:

- Already in progress
- Nice to have momentum
- Great that there is student input
- Fabulous that there is an agreement to progress this work
- This is already happening, so why are we being asked for feedback?

GENERAL FEEDBACK FROM PVI PARENTS AND WHANAU:

OVERALL FEEDBACK

1. **Major gaps in social inclusion and tertiary experiences.**
    - Parents highlighted that the action points focus almost exclusively on academic or formal learning outcomes, ignoring the social aspects of education, such as campus life, day trips, sporting participation, and extracurricular engagement.
2. **Transition from school is absent.**
    - Parents repeatedly emphasised that moving from school to post-school pathways is a "major pain point."
    - There is no clear plan for disabled children after school, including post-secondary education, vocational training, or employment preparation.
3. **Complex care and high needs students are excluded.**
    - Children with complex needs, high needs ORS students, non-verbal children, and those with intellectual disabilities are largely absent from the strategy.
    - Parents noted that funding structures (e.g., "choose one key area for ORS support") leave complex children without adequate support, as schools often will not share resources unless mandated.
4. **Adult learning and lifelong education are missing.**
    - The strategy neglects disabled adults who require ongoing education or training, leaving a critical gap for lifelong learning opportunities.
5. **Lack of meaningful consultation with parents, whānau, and children.**
    - Parents felt the strategy was drafted without sufficient input from disabled children, young people, or their families.
    - There is extremely limited child voice reflected in the action points.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- *"There is nothing in here about social inclusion."*
- *"Transition from school is a major pain point – there is nothing in this strategy that addresses this."*
- *"What happens after school?"*
- *"Complex care children are excluded from all these areas – what is the plan for us?"*
- *"Adult learning programs for disabled adults are absent."*
- *"Intellectually disabled are excluded from this action plan."*
- *"Non-verbal children are ignored in all of these action points."*
- *"Where was the input from parents? It seems like this was written without input from children, parents, or whānau."*
- *"It isn't clear if this strategy includes very high needs ORS children and associated funding."*

- *"The requirement to choose one key area for ORS support means our complex kids miss out and their other needs get ignored as they are not funded."*

CORE RECOMMENDATIONS (PRIORITY)

1. **Include social inclusion as a central pillar** of the education strategy, covering participation in extracurricular activities, sports, trips, and community life.
2. **Develop explicit transition planning** from school to post-school pathways, including tertiary education, vocational training, employment, and adult learning opportunities.
3. **Ensure inclusion of complex care, high needs ORS, non-verbal, and intellectually disabled learners** – their needs must be clearly addressed in funding, planning, and service delivery.
4. **Integrate lifelong learning for disabled adults** into the strategy to ensure ongoing education and skills development beyond compulsory schooling.
5. **Strengthen co-design and child/parent voice** – involve disabled children, young people, and their families directly in drafting, implementing, and monitoring actions.
6. **Address funding gaps for complex children** – revise mechanisms that currently limit access to multiple areas of support to prevent inequity and exclusion.

Specific feedback from parents:

- The action points don't include social aspect of tertiary education – what about experiences on campus/at school, attendance at day trips, involvement in sporting endeavors?
- There is nothing in here about social inclusion
- What about transition from school – where does this belong?
- Transition from school is a major pain point for parents – there is nothing in this strategy that addresses this
- What happens after school?
- There is not clear plan for disabled children after school
- Complex care children are excluded from all these areas – what is the plan for us?
- Adult learning programs for disabled adults are absent
- Disabled adults need ongoing education too, there is nothing in this plan for our adult 'children'
- Intellectually disabled are excluded from this action plan
- Non-verbal children are ignored in all of these action points.
- Where was the input from parents? It seems like this was written without input from children, parents, or whānau.
- Extremely limited child voice throughout.
- It isn't clear if this strategy includes very high needs ORS children and associated funding.
- The requirement to choose one key area for ORS support means our complex kids miss out and their other needs get ignored as they are not funded. Schools won't share funding if they aren't required to, so if you don't have vision ors, you don't get vision support unless the school agrees to give some funding to blennz.
- There is nothing for very high needs ORS children in this strategy.
- The strategy ignores *intellectual* disability completely

- There are so few programs for disabled adults and for their learning, why was this not considered?
- Where is the transition from school?
- What about NEET kids - how will this change?

EDUCATION ACTIONS SUMMARY – PVI PARENTS AND WHĀNAU FEEDBACK

Education Goal: Every learner is supported to attend, participate, and progress in education, with high expectations that all learners, including disabled learners, achieve their potential.

Key Issues:

- Disconnected from action points; “diverse learners” terminology obscures that disability is the barrier.
- Focus is primarily on mild/moderate disabilities; children with complex or very high needs are largely absent.

Recommendations:

- Ensure explicit inclusion of complex and high needs children.
- Align actions clearly with stated educational outcomes.

ACTION 1: INVEST $266M IN EARLY INTERVENTION SERVICES

Feedback: Already announced by the Minister; no further parent feedback required.

ACTION 2: SUPPORT KAUPAPA MĀORI SETTINGS TO ACCESS RESOURCES

Key Issues:

- Limited BLENNZ staff who speak te reo Māori to support KM settings.
- Mainstream services are not required to upskill; Māori students in mainstream schools overlooked.
- KM perspectives on disability (tāngata whaikaha) are underdeveloped in current strategy.

Recommendations:

- Build capability in KM services while ensuring mainstream services are responsive to Māori learners.
- Include autonomy for KM schools and culturally appropriate disability practices.

ACTION 3: IMPROVE LEARNING SUPPORT SYSTEM NAVIGATION

Key Issues:

- Funding for Learning Support Coordinators (LSCs) is positive but vague.
- Action point unclear for ORS-funded children; lacks connection to existing support systems.

Recommendations:

- Clarify scope, outcomes, and responsibilities for all learners, including ORS-funded children.
- Simplify language and ensure practical guidance.

ACTION 4: INVEST IN ADDITIONAL LEARNING SUPPORT CLASSROOMS

Key Issues:

- “Choice for parents” is vague and may perpetuate segregation.
- Risk of inconsistent quality: some schools inclusive, others still exclusionary.

Recommendations:

- Define inclusion standards and monitoring to ensure classrooms support integration rather than segregation.
- Clarify meaning of “choice” to prevent lottery-style access.

ACTION 5: WORK WITH WHAIKAHA TO IMPROVE TEACHER TRAINING

Key Issues:

- Baseline training good but does not address ongoing professional development, complex care, or all disability types.
- Boards of Trustees (BOTs) are major sources of exclusion; no mandatory training for them.
- BLENNZ support is strong for blind/low vision but gaps exist for other disabilities.

Recommendations:

- Include mandatory, ongoing on-the-job PD for teachers and TAs.
- Provide BOTs with explicit training and accountability for inclusive education.
- Ensure training covers complex needs and diverse disabilities.

ACTION 6: IMPROVE ACCOUNTABILITY THROUGH REPORTING ON LEARNING OUTCOMES

Key Issues:

- Overlaps with Action 8; not linked to ORS-funded students.
- Parents want post-school outcomes included.

Recommendations:

- Make reporting mandatory and standardized.
- Link outcomes to employment and post-school pathways.

ACTION 7: SUPPORT KAUPAPA MĀORI SETTINGS WITH RESOURCES

Key Issues:

- Limited KM-specific disability services and staff who speak te reo Māori.
- Mainstream schools not required to be responsive to Māori learners.

Recommendations:

- Invest in KM-specific services and workforce.
- Ensure Māori learners in mainstream settings are also supported.

ACTION 8: IDENTIFY DISABLED LEARNERS IN EDUCATION DATA

Key Issues:

- Parents confused; seems duplicative of Action 6.
- Concerns about data collection methods, privacy, and use of registries.

Recommendations:

- Clarify purpose and scope; avoid individual-level registries.
- Include ECE and diverse disability types.

ACTION 9: REVIEW TERTIARY PROVIDER DISABILITY ACTION PLAN IMPLEMENTATION

Key Issues:

- Already in progress; parents supportive but questioned need for consultation.
- Social inclusion, transitions from school, and adult learning largely absent.

Recommendations:

- Include social inclusion, transition planning, and ongoing education for adults.
- Ensure complex care and intellectual disability are included.

GENERAL EDUCATION FEEDBACK

- Social inclusion, extracurricular participation, and transition planning missing.
- Very high needs, complex care, non-verbal, and intellectually disabled learners are excluded.
- Parent, child, and whānau voice largely absent.
- ORS funding limitations leave complex needs children under-supported.

PRIORITY OUTCOME AREA: EMPLOYMENT

The **goal** for employment is:

Disabled people will have meaningful career opportunities, equal to non-disabled people, and be valued the same way. Disability-confident employers will recognise disabled people’s talents and will provide accessible and inclusive workplaces throughout the employment lifecycle.

Summary of **what success in employment means**:

Disabled people have meaningful career, employment and self-employment opportunities, equal to non-disabled people. They have the right resources and support, and confidence their employer can help them to thrive at work, whether they are urban or rural, in a workplace or working remotely. Better work outcomes give disabled people more economic security, dignity, self-determination and choice.

In the draft New Zealand Disability Strategy there are **6 proposed employment actions** to reach the goal:

- **Action 1:** Work to centralise, and make accessible, information and guidance for disabled people to identify and pursue job pathways matched to their skills and interests.
- **Action 2:** Review specialist employment supports to improve employment outcomes, in consultation with disabled people.
- **Action 3:** Work with disabled people, employers and employer networks to develop mentorship programmes connecting disabled people with successful disabled professionals or employers to provide guidance and support in navigating their careers.

- **Action 4:** Partner with disabled people and support providers to create a centralised, accessible repository of practical information and resources for employers and employer networks so they can support disabled people throughout the employment lifecycle and to share knowledge and success stories.
- **Action 5:** Partner with disabled people, employers and employer networks to improve accessibility and inclusion in employment lifecycles for disabled people. This includes promoting and enabling the design of jobs and workplaces to support:
  - inclusion of disabled people
  - flexible working arrangements and reasonable accommodations
  - assessing the accessibility of workplaces.
- **Action 6:** Implement a targeted, ongoing awareness campaign publicising guidance and resources for employers and employees on accessibility and inclusion, relevant data and reports, and highlighting the positive impact disabled people have had on workplaces. This action will support employment action 4.

GENERAL FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Action points exclude complex and multiple disabilities.**
    - All six proposed actions are focused on individuals with a single, primarily physical disability.
    - Children and young people with complex needs, intellectual disabilities, or non-verbal disabilities are entirely absent from consideration.
2. **Disconnect from education and school-to-work transition.**
    - Parents highlighted a complete lack of connection to school, tertiary education, or transition planning.
    - Employment actions do not address the pathway from education to meaningful employment for disabled learners.
3. **Barriers are oversimplified.**
    - Actions assume ignorance is the primary barrier. Parents stressed that there are *multiple structural, systemic, and attitudinal barriers* that prevent disabled people from accessing meaningful work.
4. **Lack of accountability for employers.**
    - There is no mechanism to hold employers or networks accountable for ableism, discrimination, or failure to provide reasonable accommodations.
    - Actions risk being symbolic without enforcement measures.
5. **Limited impact for young people with complex needs.**
    - Parents expressed concern that these actions will not improve real-world employment outcomes for their children.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- “These action points are for physically disabled who have only one area of disability.”
- “None of these action points will help our complex kids.”
- “Where are intellectual disabilities in this?”
- “How does this link with school and education?”
- “Zero understanding of the barriers our kids face here.”

- “Assumes that the only issue is ignorance – there are lots more barriers.”
- “Where is the accountability for ableism?”
- “None of these actions will improve employment outcomes for my young person.”

CORE RECOMMENDATIONS (PRIORITY)

1. **Include complex and multiple disabilities** explicitly in employment actions.
2. **Link employment actions to education and transition pathways** to ensure meaningful career opportunities for young people leaving school or tertiary education.
3. **Recognise and address systemic barriers** beyond employer ignorance, including structural, policy, and attitudinal barriers.
4. **Embed accountability mechanisms** for employers, networks, and government agencies to monitor and enforce inclusive practice.
5. **Ensure equity of opportunity** for intellectually disabled, non-verbal, and high-needs learners, not only those with single-area physical disabilities.
6. **Co-design actions with disabled young people and whānau** to ensure actions reflect lived experience and practical barriers.

Specific feedback from parents:

- These action points are for physically disabled who have only one area of disability.
- None of these action points will help our complex kids
- Where are intellectual disabilities in this?
- How does this link with school and education?
- Zero understanding of the barriers our kids face here
- What about complex needs?
- Assumes that the only issue is ignorance – there are lots more barriers
- Where is the accountability for ableism?
- None of these actions will improve employment outcomes for my young person

EMPLOYMENT ACTIONS SUMMARY – PVI PARENTS AND WHĀNAU FEEDBACK

Employment Goal: Disabled people will have meaningful career opportunities equal to non-disabled people, with disability-confident employers providing accessible and inclusive workplaces throughout the employment lifecycle.

Key Issues:

- Focus is primarily on physical disabilities or single-area disabilities.
- Complex needs, intellectual disabilities, and multiple disabilities are not addressed.
- Assumes ignorance is the main barrier, overlooking systemic and structural ableism.
- No accountability mechanisms for discrimination or ableist practices.

Proposed Employment Actions

Action 1: Centralize information and guidance for job pathways. Issues:

- Only helpful for physically disabled individuals with one area of need.
- Does not account for barriers faced by complex or high needs learners transitioning from education.

Action 2: Review specialist employment supports. Issues:

- Lacks connection to the realities of complex or high needs individuals.
- Does not clarify targets, monitoring, or accountability for outcomes.

Action 3: Develop mentorship programmes. Issues:

- Mentorship limited to those with simpler or single-area disabilities.
- Complex needs learners and intellectually disabled individuals excluded from participation.

Action 4: Central repository of employer resources. Issues:

- Focuses on general disability inclusion; lacks recognition of systemic barriers.
- Overlooks connection to school-to-work transitions and complex disability needs.

Action 5: Improve accessibility and inclusion in employment lifecycles. Issues:

- Concentrates on flexible working arrangements and accommodations for simple disabilities only.
- Does not address systemic ableism, structural barriers, or multi-disability challenges.

Action 6: Awareness campaign for accessibility and inclusion. Issues:

- Limited to awareness; does not address structural or policy barriers.
- No measurable outcomes for complex or intellectual disabilities.

General Parent/Whānau Feedback

- None of the actions meaningfully support complex or high needs individuals.
- No integration with education, transition planning, or training pathways.
- Intellectual disability and multi-disability individuals are invisible in this strategy.
- Actions assume ignorance is the sole barrier, ignoring systemic ableism.
- Lack of accountability and enforcement mechanisms undermines potential impact.

Key Recommendations:

1. Include complex, high needs, and intellectually disabled learners in all employment actions.
2. Link employment initiatives to education and school-to-work transition programs.
3. Address systemic barriers, structural ableism, and employer accountability.
4. Include measurable outcomes and monitoring for all disability types.
5. Ensure actions support meaningful career growth, not just basic or tokenistic roles.

PRIORITY OUTCOME AREA: HEALTH

The **goal** for health is:

Disabled people will achieve the highest possible standard of health and wellbeing. They will decide what this means for themselves and their whānau.

Summary of **what success in health means**:

The health system enhances quality of life for disabled people. Self-determination means disabled people can make informed choices and have their decisions respected. Tāngata whaikaha Māori are understood as part of a collective and can involve whānau in their health in the ways they want.

Accessibility, equity and inclusion are embedded throughout the health system, supported by a skilled and responsive health workforce. This includes disabled people at every level. Better data is collected and used for system improvement.

FEEDBACK FROM PVI PARENTS AND WHANAU:

Parents were largely supportive of the goals and outcomes

ACTION 1: REVIEW AND IMPROVE POLICIES AND PRACTICES, SO THE HEALTH JOURNEY IS EQUITABLE, ACCESSIBLE AND INCLUSIVE. THIS REVIEW WILL INCLUDE ALL INTERACTIONS WITH THE HEALTH SYSTEM, COVERING COMMUNICATION, INFORMATION, TECHNOLOGY, DECISION-MAKING, SERVICE DESIGN AND DELIVERY, AND THE BUILT ENVIRONMENT.

SELF-DETERMINATION SHOULD BE A KEY CONSIDERATION OF THE REVIEW. THIS INCLUDES MAKING TOOLS FOR SELF-DETERMINATION AND SUPPORTED DECISION-MAKING STANDARD PRACTICE IN HEALTH CARE – ESPECIALLY FOR PEOPLE WITH DIFFERENT COMMUNICATION, COGNITIVE OR PSYCHOSOCIAL NEEDS.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Disabled children and whānau are largely absent.**
    - The action does not explicitly include children with disabilities or the role of parents/whānau in health decision-making.
    - Parents expressed concern that this creates a gap where children may be treated without family support or input.
2. **Child and family voice must be central.**
    - Parents highlighted that excluding whānau could lead to unsafe decisions or failure to understand the child's needs, aspirations, or best interests.
    - Family involvement is critical in all interactions, especially for children with complex needs or no formal advocacy arrangements in place.
3. **Risk of tokenistic or insufficient implementation.**
    - Without clear mechanisms, this action could provide a "get-out" for health providers to avoid challenging or complex situations.
    - Practical tools, training, and accountability are missing.
4. **Accessibility of health information is absent.**
    - Parents stressed that easy-read resources and accessible documentation are essential. Current action points do not address this.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- "Where are disabled children?"
- "Where are the parents of disabled children?"

- “Where is the voice of the child in this action?”
- “This is a red flag – could say that someone with a disability, who turns up at hospital with no family and without a PPPR in place, wants xyz – which may not align with their best interests.”
- “Massive gap in identifying needs and aspirations and what is needed to achieve these.”
- “Whānau need to be involved throughout.”
- “Makes it too easy to exclude parent and whānau support here.”
- “Is this in easy-read format – too many health docs are not available in easy read. Why is having documents in easy read not included as an action point?”

CORE RECOMMENDATIONS (PRIORITY)

1. **Embed child and whānau voice at every stage** of health policy, service design, and delivery.
2. **Explicitly include disabled children** in the scope of the review, with clear mechanisms for parental and whānau involvement.
3. **Develop practical tools for self-determination and supported decision-making** that are accessible and account for cognitive, communication, or psychosocial differences.
4. **Ensure health documentation is universally accessible**, including easy-read formats.
5. **Introduce accountability measures** to prevent tokenistic or superficial implementation.

Specific comments from parents:

- Where are disabled children?
- Where are the parents of disabled children?
- Where is the voice of the child in this action?
- This is a red flag – could say that someone with a disability, who turns up at hospital with no family and without a PPPR in place, wants xyz – which may not align with their best interests
- There is no room for family voice in this action
- Gives an easy (and dangerous!) out to avoid dealing with challenging situations
- Massive gap in identifying needs and aspirations and what is needed to achieve these
- Whaanu need to be involved throughout
- Makes it too easy to exclude parent and whaanau support here
- Whānau voice is absent
- Is this in easy read format – too many health docs are not available in easy read. Why is having documents in easy read not included as an action point?

ACTION 2: BUILD HEALTH WORKFORCE CAPABILITY TO DELIVER SERVICES THAT ARE INCLUSIVE, CULTURALLY SAFE, AND EASY TO NAVIGATE.

BUILDING WORKFORCE CAPABILITY INCLUDES INCREASING THE PROPORTION OF DISABLED PEOPLE ACROSS THE HEALTH AND DISABILITY WORKFORCE, THROUGH RECRUITMENT AND WORKPLACE POLICIES, INCLUSIVE AND ACCESSIBLE WORK ENVIRONMENTS, AND CAREER DEVELOPMENT. IT ALSO INCLUDES EMBEDDING DISABILITY RESPONSIVENESS AND LIVED EXPERIENCE INTO HEALTH WORKFORCE TRAINING AND ONGOING PROFESSIONAL DEVELOPMENT.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Legislative conflicts and implementation uncertainty.**
    - Pae Ora legislation currently under consideration may prevent or conflict with this action.
    - Parents highlighted a lack of clarity about targets, timelines, and mechanisms for delivery.
    - Current hiring freezes in health may make workforce expansion impossible in practice.
2. **Exclusion of complexity and diversity of disabilities.**
    - Action assumes only physical disabilities are relevant.
    - Intellectual disabilities, complex needs, and non-verbal conditions are not addressed.
3. **Absence of whānau voice.**
    - Families are not included in workforce planning, training, or design processes.
    - Parents warned that excluding whānau could compromise care and fail to reflect lived experience.
4. **Risk of tokenism and undue burden on disabled staff.**
    - Without clear supports, disabled staff may be expected to represent all perspectives, creating burnout.
    - No mechanisms to address stigma, support inclusion, or prevent exploitation.
5. **Disconnect from broader systems, including employment.**
    - Workforce capability should align with employment, education, and health transitions.
    - Wrap-around support is required for disabled staff to succeed in their roles.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- “Pae Ora legislation currently in front of the Select Committee strips this action out from health.”
- “These are very high and lofty goals with zero commitment to implementation.”
- “Where is whānau voice in this?”
- “This assumes that the only disabilities are physical impairments.”
- “No responsiveness to intellectual disability in this action.”
- “This could put enormous pressure on one disabled person to be the all and end all in health organizations – this is not great.”
- “How does this align with employment actions?”
- “This is a recipe for burnout.”

CORE RECOMMENDATIONS (PRIORITY)

1. **Clarify implementation, targets, and accountability**, ensuring workforce capability goals are realistic and actionable within current legislative and operational constraints.
2. **Explicitly include all disability types and complex needs**, not just physical impairments.
3. **Embed whānau involvement** in workforce design, training, and service delivery planning.

4. **Develop anti-stigma strategies and wrap-around supports** for disabled staff to prevent tokenism and burnout.
5. **Ensure alignment with education and employment pathways**, creating coherent systems across sectors.
6. **Provide safeguards and supports** so that disabled staff are not expected to bear the entire responsibility for disability responsiveness in health services.

Specific feedback from parents:

- Pae Ora legislation currently in front of the Select Committee strips this action out from health
- What are the % targets here?
- This is fine I guess?
- While there be training for overseas staff?
- Why is this in here when there is legislation in front of Parliament to prevent this?
- These are very high and lofty goals with zero commitment to implementation
- How will this be implemented?
- There is currently a hiring freeze in health, so this runs against what is currently happening in health
- How will disability stigma be addressed? Zero efforts made here
- There are no efforts to reduce stigma in this action
- This action sets disabled people up to fail
- Where is whanau voice in this?
- Whaanau voice is absent
- There is no inclusion of complexity
- This assumes that the only disabilities are physical impairments
- No responsiveness to intellectual disability in this action
- Need wrap around support for health to support employment options
- How does this align with employment actions?
- This is a recipe for burnout
- Where is the support for the disabled person?
- This could end up putting enormous pressure on one disabled person to be the all and end all in health organizations – this is not great.

ACTION 3: CREATE OPPORTUNITIES TO BUILD DISABLED PEOPLE'S SKILLS AND KNOWLEDGE TO TAKE UP HEALTH SYSTEM ROLES.

GOVERNMENT AGENCIES WILL CREATE OPPORTUNITIES TO BUILD THE CAPABILITY AND CAPACITY OF DISABLED PEOPLE TO CARRY OUT HEALTH SYSTEM ROLES. THESE ROLES WILL INCLUDE HEALTH SYSTEM DESIGN, CONSULTATION, MONITORING, LEADERSHIP, ADVISORY AND GOVERNANCE ROLES.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Action restricts opportunities and sets low expectations.**

  - Parents observed that the proposed roles focus primarily on back-office, advisory, or peer support positions, often lower-paid or viewed as “second tier.”
  - Disabled people are largely excluded from professional, clinical, or leadership pathways (e.g., doctors, nurses, physiotherapists, OTs).
  - This conflicts with broader education and employment goals, which aim for meaningful, professional career opportunities.
2. **Exclusion of complexity and diversity of disabilities.**
   - The action appears aimed at disabled adults with single physical impairments.
   - High needs, very high needs, and intellectually disabled individuals are absent from consideration.
   - Complex needs children and young people are not represented.
3. **Implementation and accountability are unclear.**
   - Targets, percentages, timelines, and mechanisms for building capability are unspecified.
   - There is no clarity on integration with existing workforce development or professional pipelines.
4. **Disconnect with systemic issues in health.**
   - Parents noted anti-DEI practices in health may undermine this action.
   - Without addressing stigma, low pay, and structural barriers, this action risks being tokenistic.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- “This assumes disabled people can only be back room support – this is a very low expectation.”
- “The peer support workforce is viewed as second tier in health, with lower pay and limited career growth.”
- “Where are the disabled doctors?”
- “This seems very aimed at disabled adults with only one type of physical impairment.”
- “What about very high needs and high needs kids? Where are they in this?”
- “This action point does nothing to help my child.”
- “How will this be implemented? What % figures are being aimed for here?”

CORE RECOMMENDATIONS (PRIORITY)

1. **Expand role expectations and career pathways** to include professional and clinical positions (e.g., nurses, doctors, allied health professionals), not only peer support or advisory roles.
2. **Include all disability types and levels of complexity**, ensuring opportunities for high needs, very high needs, and intellectually disabled individuals.
3. **Clarify implementation, targets, and accountability** to prevent tokenistic outcomes.
4. **Align with education and employment goals** to ensure consistent career pathways from schooling into professional health roles.
5. **Address systemic barriers**, including stigma, low pay, and anti-DEI practices, to ensure genuine inclusion.
6. **Ensure parental and whānau input** is embedded in role design and workforce planning.

Specific feedback from parents:

- Same concerns as for #2
- What about support to be frontline health persons like nurses and doctors?
- This assumes disabled people can only be back room support – this is a very low expectation and directly opposes what is in education and employment
- The peer support workforce is viewed as second tier in health, with a lower payscale, reduced responsibilities, and not viewed as professional services. This action point does nothing to address this
- This is a horrible action point as it reduces disabled people to peer support and lower paid minor roles. This isn't good enough!
- This action just creates a lower tier of staff with limited opportunities for career growth
- These are just low paid non clinical and non professional roles. We should have higher expectations e.g. physios and OT's
- But Health is currently implementing very anti-DEI actions – which undermines this action
- Where are the disabled doctors?
- Is this a way to give disabled people 'busy work'?
- This action point does nothing to help my child
- What are the % figures being aimed for here?
- How will this be implemented?
- What about very high needs and high needs kids? Where are they in this?
- Where are intellectually disabled people here?
- This seems very aimed at disabled adults with only one type of physical impairment
- What about complex needs, where are they in this action?

ACTION 4: IDENTIFY DISABLED PEOPLE IN NATIONAL HEALTH DATA. IDENTIFYING DISABLED PEOPLE IN DATA WILL MAKE THEM MORE VISIBLE IN THE HEALTH SYSTEM. IT WILL ENABLE BETTER MONITORING OF POPULATION HEALTH OUTCOMES AND PATIENT EXPERIENCES.

FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Serious concerns about privacy and autonomy.**
    - Parents strongly opposed any form of disability registry.
    - Risks identified include misidentification, misuse of data, and potential harm (e.g., automatic DNRs or other discriminatory practices).
    - Questions raised about consent, privacy laws, and who will be responsible for identifying disabled individuals.
2. **Implementation feasibility is unclear.**
    - The action assumes health system capacity that does not currently exist.
    - Digital infrastructure for centralized, reliable data collection has been cancelled by the current government.
    - Parents question whether all patients would be assessed (e.g., Washington Short Set) and how complex or variable disabilities would be captured.

3. **Exclusion and complexity are not addressed.**
    - Children and adults with complex needs, global developmental delays, or multiple disabilities may be misrepresented or excluded.
    - Intellectual disabilities and non-verbal individuals are not specifically considered.
4. **Trust and safety concerns.**
    - Parents noted a lack of confidence in government systems, citing previous actions that undermine trust.
    - Strong opposition to monitoring that could be misused or have harmful consequences.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- "It is good to have data, but how will 'the system' determine who is disabled?"
- "Will everyone be administered the Washington Short Set by a nurse now?"
- "This will require significant digital infrastructure investment – something this government has already cancelled."
- "Is this just a disability registry? No thanks!"
- "Who is going to be identifying people?"
- "Clinical staff already misrepresent ethnicity; will disability be next?"
- "What about privacy laws? How will they be upheld?"
- "This risks poorer outcomes, e.g., automatic DNRs applied."
- "Very against 'monitoring' of disabled people. Do better."

CORE RECOMMENDATIONS (PRIORITY)

1. **Reject the creation of any disability registry** that identifies or labels disabled individuals without consent.
2. **Ensure privacy, consent, and autonomy** are central to any data collection initiative.
3. **Focus on aggregate, anonymized, and voluntary data** to inform system improvements without exposing individuals to risk.
4. **Consider complexity and diversity of disabilities** when designing data initiatives to avoid misrepresentation or exclusion.
5. **Align with infrastructure capacity and legislative context**, ensuring feasibility and protection against misuse.
6. **Embed parental, whānau, and disabled people's input** at all stages of data design, collection, and use.

Parents had serious safety, trust, and privacy concerns. This reflects the poor actions by Health NZ with regards to minority groups. There have been major attacks by current health legislation to erode wellbeing. These legislative gaps do not support these action points.

Specific feedback from parents:

- It is good to have data
- How will "the system" determine who is disabled?
- Will everyone be administered the Washington Short set by a nurse now? Like in corrections?

- How will this work in practice?
- Global Development Delay has a very wide range of outcomes – how will this be differentiated?
- What about complex needs?
- This will require significant digital infrastructure investment – something this government has already cancelled.
- Is this just a disability registry? No thanks!
- Not keen on a disability register
- Who is going to be identifying people?
- Clinical staff already misrepresent ethnicity, will disability be the next for them to misrepresent?
- What about privacy laws? How will they be upheld?
- Will there be an assessment? For everyone? How will this be done?
- NO to a disability registry!!
- This risks poorer outcomes e.g., automatic DNRs applied
- Will the government now be trawling through our health records?
- The current system lacks digital infrastructure and is not centralized. There is a need for major investment in digital support. The current government cancelled the planned upgrades. Does Minister not talk to the Ministry and the disability team?
- There is a major disconnect between this action point and the current actions by Health
- This government is not trustworthy and this risks euthanasia based outcomes
- Very against "monitoring" of disabled people. Do better.

ACTION 5: IMPLEMENT SYSTEMS TO ENABLE DISABLED PEOPLE TO RECORD THEIR ACCESSIBILITY NEEDS AGAINST THEIR NATIONAL HEALTH INDEX.

RECORDING PEOPLE'S ACCESSIBILITY NEEDS WILL MEAN THESE NEEDS CAN EASILY BE SHARED WITH HEALTH PROVIDERS. DISABLED PEOPLE WILL NOT HAVE TO REPEAT THEIR ACCESSIBILITY NEEDS EACH TIME THEY ENGAGE WITH HEALTH SERVICES, AND HEALTH PROVIDERS WILL BE BETTER PLACED TO PLAN AND MEET THOSE NEEDS.

WORK TO PROGRESS THIS ACTION SHOULD BE GUIDED BY DISABILITY COMMUNITY EXPECTATIONS AND DATA SOVEREIGNTY.

GENERAL FEEDBACK FROM PVI PARENTS AND WHANAU:

EXTREMELY IMPORTANT POINTS

1. **Implementation and infrastructure gaps.**
    - Current digital systems cannot support this functionality.
    - Parents stressed the need for investment in digital infrastructure, integration, and ongoing maintenance.
    - Self-management features are required so that disabled people can log, update, and verify their own accessibility needs.
2. **Accessibility and social model considerations.**
    - Parents emphasised a broader social model of disability: the system and providers must take responsibility for accessibility, not just record needs.

  - Issues such as NZSL, AAC support, wheelchair access, and hoists are not addressed in current systems.
  - Recording accessibility needs must not be deficit-oriented or stigmatizing.
3. **Data integrity, governance, and accountability.**
   - Risks of incorrect or outdated data being tagged to an individual.
   - Clear responsibilities are needed for accuracy, updating, and protection of sensitive data.
   - National integration is critical, but there is no clear commitment to investment or standards.
4. **Provider readiness and systemic responsibility.**
   - Health providers must be proactively accessible and prepared; recording needs alone does not ensure accessibility.
   - Parents highlighted that services currently fail to meet accessibility standards, including communication and physical access.

PARENT AND WHĀNAU FEEDBACK – DIRECT QUOTES

- "We still get our hospital appointments in the mail, even though the hospital knows our child is blind – need to change this!"
- "Who will provide support for NSL or AAC users?"
- "Will this be denigratory and deficit-oriented?"
- "Hospitals should have NZSL and AAC available as a matter of course – how will this action point support this?"
- "Where is wheelchair access and hoists in this?"
- "Needs significant investment in digital infrastructure to make this happen."
- "Needs to be nationally integrated – this needs investment. But there is no commitment."
- "Data needs regular updating – who will do this?"
- "Why are health services not built to be accessible for wheelchairs and hoists?"

CORE RECOMMENDATIONS (PRIORITY)

1. **Invest in robust, integrated digital infrastructure** that allows disabled people to record, update, and manage their accessibility needs.
2. **Embed the social model of disability**, ensuring that accessibility is the responsibility of health services, not solely the disabled person.
3. **Provide proactive accessibility measures**, including NZSL, AAC support, wheelchair access, and hoists as standard in all services.
4. **Ensure data accuracy, governance, and accountability**, including clear roles for maintaining and updating accessibility information.
5. **Guarantee national integration**, so accessibility needs are visible across the entire health system.
6. **Align with the Code of Rights and human rights obligations**, embedding non-stigmatizing, inclusive, and respectful practices.
7. **Provide regular review and updates**, ensuring the system evolves with the needs of disabled people.

Specific feedback from parents:

- Idea sound good
- We still get our hospital appointments in the mail, even though the hospital knows our child is blind – need to change this!
- Digital infrastructure is not there to support this
- Need more of a social model of disability
- Providers need to be better prepared as a matter of course
- Why is this not happening already?
- Who will provide support for NSL or for AAC users?
- Will this be denigratory and deficit oriented?
- How will this support providers to non-stigmatizing?
- Where is the social responsibility of the health system and of health providers here?
- The Code of Rights in health is being somewhat addressed here and is getting close fo being addressed
- Hospitals should have NZSL and AAC available as a matter of course – how will this action point support this?
- Why are health providers not accessible to disabled people already? How will this action improve this?
- Where is wheelchair access and hoists in this?
- Great idea to tag to NHI
- Needs significant investment in digital infrastructure to make his happen
- Need to be able to log in ourselves and update as we go
- Needs for access need regular updating – who will do this?
- Risks incorrect data being tagged to disabled person. Who will be responsible for this
- Data needs to be nationally integrated – this needs investment. But there is not commitment to this
- Why are health services not built to be accessible for wheelchairs and hoists?
- Where is the commitment to building accessible services?

HEALTH SUMMARY FEEDBACK

ACTION 1: REVIEW AND IMPROVE POLICIES AND PRACTICES

Goal: Make the health journey equitable, accessible, and inclusive, embedding self-determination and supported decision-making.

Key Issues:

- Absence of disabled children, parents, and whānau voices.
- Lacks practical mechanisms for family involvement.
- Risk of excluding complex or non-verbal patients.

Recommendations:

- Embed child and whānau input throughout.
- Ensure tools for self-determination and supported decision-making are standardized.
- Address gaps in accessible communication and easy-read materials.

ACTION 2: BUILD HEALTH WORKFORCE CAPABILITY

Goal: Create an inclusive, culturally safe, and navigable health workforce, increasing disabled representation and embedding lived experience.

Key Issues:

- Legislative conflicts (e.g., Pae Ora) and current hiring freezes.
- Excludes intellectual disabilities, complex needs, and non-physical impairments.
- Whānau voice absent; risk of burnout or tokenism for disabled staff.

Recommendations:

- Include all disability types and complex needs.
- Clarify targets, timelines, and accountability.
- Align workforce development with education and employment pathways.
- Embed anti-stigma measures and wrap-around support for disabled staff.

ACTION 3: CREATE OPPORTUNITIES FOR DISABLED PEOPLE IN HEALTH ROLES

Goal: Build skills and knowledge for disabled people to take on health system roles, including advisory, governance, and leadership.

Key Issues:

- Focused on back-office or peer support roles, limiting professional and clinical opportunities.
- Excludes high needs, very high needs, and intellectually disabled individuals.
- Implementation mechanisms, targets, and accountability are unclear.

Recommendations:

- Expand career pathways to include clinical and professional roles.
- Include all disability types and levels of complexity.
- Align with broader education and employment goals.
- Address systemic barriers like stigma, low pay, and anti-DEI practices.

ACTION 4: IDENTIFY DISABLED PEOPLE IN NATIONAL HEALTH DATA

Goal: Make disabled people more visible in the health system through data collection to monitor outcomes.

Key Issues:

- Strong opposition to disability registries; privacy, consent, and autonomy concerns.
- Digital infrastructure insufficient; high risk of misidentification or misuse.
- Excludes complex, intellectual, or non-verbal disabilities.

Recommendations:

- Use anonymized, voluntary, and aggregate data only.
- Ensure consent, privacy, and data governance.
- Include all disability types and complexity.
- Align with existing infrastructure capacity and safeguard against misuse.

ACTION 5: RECORD ACCESSIBILITY NEEDS AGAINST NHI

Goal: Enable disabled people to log their accessibility needs once for the health system, improving service delivery.

Key Issues:

- Digital infrastructure inadequate; integration and maintenance unclear.
- Accessibility currently lacking (NZSL, AAC, wheelchair access, hoists).
- Risks of inaccurate or outdated data; unclear responsibility for updating.
- Action alone does not address broader systemic responsibility of providers.

Recommendations:

- Invest in integrated digital systems with self-management capabilities.
- Ensure proactive accessibility measures across all health services.

- Embed the social model of disability and non-stigmatizing practices.
- Define accountability for data accuracy and system-wide implementation.

PRIORITY OUTCOME AREA: HOUSING

The **goal** for housing is:

Disabled people and their whānau will have affordable, healthy, secure and accessible homes that meet their needs.

A summary of **what success in housing means** is:

Disabled people have a range of suitable housing options in the community, so they can choose where they live. They enjoy secure tenure in housing, can move if they want, and do not experience delays accessing housing when leaving hospital inpatient care.

The housing sector meets accessibility needs, and the supply of accessible housing meets demand, with monitoring in place. Urban design and planning create accessible neighbourhoods. Suitable housing improves disabled people's outcomes and protects against harm, neglect, violence and abuse.

In the draft New Zealand Disability Strategy there are **6 proposed housing actions** to reach the goal.

- **Action 1**: Develop, consult on, and make publicly available, clear definitions of accessible homes, describing the key features of different levels of accessibility (for example, from basic universal design through to fully accessible).
  Clear definitions of accessible homes can support the development of voluntary guidelines for accessibility for residential dwellings (housing action 6).
- **Action 2**: Improve data matching between disabled people and social housing properties with accessible features that meet their needs and ensure disabled people and their whānau are prioritised to accessible properties. Data matching will both identify disabled people's housing needs and social housing that meets those needs.
- **Action 3**: Identify possible barriers to increasing supply of accessible houses in the private market and investigate opportunities to remove those barriers. Understanding barriers to the supply of accessible housing will help target potential interventions to improve supply.
- **Action 4**: Review and explore ways to improve the housing modification system. Addressing inefficiencies in the housing modification system could reduce current problems: inaccessibility of homes, increased costs, and health and safety issues for disabled people, whānau and carers.
- **Action 5**: Gather annual data on the housing-related needs of disabled people and compare this to what is being built in each region, to influence the housing market to build and make available more accessible housing.
  Data will increase developers' awareness of the housing-related needs of disabled people and raise the profile of the demand for accessible homes.
- **Action 6**: Develop voluntary national guidelines on accessibility for residential dwellings. Guidelines would be based on the definitions for accessible homes in housing action 1 and would set out best practice guidance for how to build accessible homes.

FEEDBACK FROM PVI PARENTS AND WHANAU:

Housing Goal: Disabled people and their whānau have affordable, healthy, secure, and accessible homes that meet their needs.

Key Issues:

- Strategy is too generic; fails to address intellectual disabilities or complex needs.
- Focuses on guidance and data rather than practical, funded solutions.
- No accountability, enforcement, or funding mechanisms for new builds or modifications.

Proposed Housing Actions
Action 1: Define accessible homes. Issues:

- Clear definitions alone are insufficient without mandatory application or funding.

Action 2: Improve data matching for accessible social housing. Issues:

- Useful concept, but no mechanisms to ensure priority access or timely allocation.

Action 3: Investigate barriers to accessible housing in the private market. Issues:

- Investigation without enforcement or incentives unlikely to change supply.

Action 4: Review and improve housing modification system. Issues:

- Modifications are slow, costly, and inflexible (e.g., Kāinga Ora).
- No funding or accountability included; system prioritizes rules over disabled people's needs.

Action 5: Gather annual data to influence housing market. Issues:

- Raising awareness is insufficient without enforcement, funding, or new builds.
- No consideration for separating housing provision from service delivery (e.g., IHC/IDEA).

Action 6: Develop voluntary national accessibility guidelines. Issues:

- Voluntary guidance alone will not increase actual supply of accessible homes.
- Lacks funding, enforcement, and integration with new builds or modifications.

General Parent/Whānau Feedback

- Housing actions lack funding for both new builds and modifications.
- Enforcement and accountability measures are absent.
- Kāinga Ora and other providers are slow, inflexible, and rules-driven.
- Intellectual disabilities and complex care needs are not included.
- Strategy fails to separate housing provision from disability service delivery.
- Current action points are unlikely to create meaningful change without funding, mandates, or enforcement.

Key Recommendations:

1. Include funded, enforceable measures for new builds and home modifications.
2. Ensure accessible housing provisions cover all disability types, including intellectual and complex needs.

3. Embed accountability, monitoring, and enforcement mechanisms for housing providers.
4. Separate housing provision from service delivery where appropriate.
5. Prioritize disabled people and whānau over bureaucratic rules in housing allocation.

Specific feedback from parents:

- Modifications are slow and costly
- Need to make it easier to request modifications
- Kainga ora is inflexible and slow when ti comes to disability modifications. They need to be more flexible
- Kainga Ora needs to be put the disabled person first, not rules
- There is no funding in these actions for new builds or for modifications!!!
- Need to separate out privders from landlords for disabled adults. This is an easy win but is entirely absent from this strategy
- Intellectual disabilities are absent from this area
- Action points need accountability and enforcement – where is this?
- Housing is too generic.
- We need to build accessible, affordable homes.
- Didn't Kainga Ora cancel a bunch of new builds? That would have provide housing for us? How can you show up with these action points after you've cancelled multiple builds?!
- Need better separation for IHC – accessible housing is too closely intertwined with service delivery (IDEA Services). No mention of this is in any of these action points.
- How will any of these action points be enforced?
- Where is the funding for the new builds?
- Where is the funding for modifications?
- What is the point of these action points if they are not enforceable and/or funded?

PRIORITY OUTCOME AREA: JUSTICE

The **goal** for justice is:

Disabled people's human rights and freedoms will be protected, and their disability rights will be realised. Disabled people will be treated fairly and equitably by the justice system. Justice system policies and practices will embed accessibility, inclusion and lived experience.

For disabled people, success in access to justice means:

a) Disabled people, including disabled children, young people and adults in care, are **safeguarded from abuse, neglect and violence**.
b) The needs of **disabled children and young people are understood and supported early** to avoid them becoming involved in the care and protection or criminal justice systems.
c) For disabled children and young people who interact with the youth justice system, and for adult **disabled people who interact with the criminal justice system, their rights and accessibility needs are consistently considered**, and they have the right supports to transition out of those settings.

d) Disabled people who are charged with an offence but are **unable to stand trial are treated consistently with the New Zealand Bill of Rights Act**.

e) The **justice sector workforce will have the right skills and capabilities to uphold the rights of disabled people**. This includes disability competence, Deaf competence, and an understanding of supported decision-making.

Disabled parents who use the Family Court will have **equitable access to family justice services**.

ACTION POINTS

1. Develop and implement a safeguarding framework for disabled people in long-term detention settings (such as prisons and youth justice residences) and Disability Support Services funded residential facilities. The framework will include preventing, reporting, responding, and safely removing disabled people from abusive situations.
2. Establish a cross-agency project to identify and address gaps in data and evidence about disabled people's experiences of crime, including for disabled people in residential and secure facilities, and experiences of cyberbullying.
3. Develop a social investment plan for early intervention and support, to reduce the number of disabled children and young people entering the youth justice system.
4. The Law Commission has been asked to undertake a review of the Criminal Procedure (Mentally Impaired Persons) Act 2003 (CPMIP). This review is expected to consider the CPMIP's relationship to other relevant legislation, such as the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 and Mental Health (Compulsory Assessment and Treatment) Act 1992.
5. Review, as work programmes allow, the effectiveness of current protections for disabled people in family law, including adoption, guardianship and personal property rights, to identify gaps where strengthened provisions or support are needed. Any review should also consider supported decision-making and use of plain language in key justice sector legislation and processes. Consideration should be given to reviewing human rights legislation, as work programmes allow.
6. Integrate lessons from disability-specific safeguarding approaches into the development of the future state for multi-agency responses to family violence, to strengthen outcomes for disabled people experiencing violence and abuse. This includes supporting workforce capability to ensure a coordinated, safe and disabled-person centred response.
7. Develop and implement a plan to make the justice sector workforce more disability competent, including in the use of mana and trauma informed practices. This plan would include increasing recruitment and retention of disabled people and should consider mandatory professional standards.

PARENTS & WHĀNAU FEEDBACK

Key Gaps / Concerns:

1. **Exclusion of Complex and High Needs Individuals**
   - Current actions may insufficiently consider disabled children and adults with intellectual, non-verbal, or complex disabilities.
   - Parents worry that youth and adults with high support needs may still be underserved in detention, family court, or youth justice settings.
2. **Lack of Enforcement, Accountability, and Funding**

  - Safeguarding frameworks and reviews are largely aspirational; parents seek clear accountability measures, timelines, and resourcing.
  - Cross-agency collaboration needs concrete responsibilities and oversight mechanisms.
3. **Limited Inclusion of Lived Experience**
   - Disabled people, children, and whānau should be directly involved in designing and monitoring justice system policies.
   - Parents are concerned that frameworks may be “outsider-written” without real understanding of lived realities.
4. **Workforce Capability Gaps**
   - While actions address workforce training, parents note that real-world implementation is often weak.
   - There must be mandatory training on disability competence, Deaf competence, trauma-informed care, and supported decision-making.
5. **Systemic Barriers and Cultural Responsiveness**
   - Māori and Kaupapa Māori disabled people require culturally safe justice approaches, including recognition of tikanga, mana, and whānau engagement.
   - Parents are concerned about ableism, stereotyping, and systemic bias affecting disabled people in courts, youth justice, and detention.
6. **Monitoring and Data Concerns**
   - Parents want robust, ongoing monitoring of outcomes for disabled children and adults in all justice interactions.
   - Data collection must be transparent, safeguard privacy, and include disability, intellectual ability, cultural, and intersectional considerations.

Cross-Cutting Observations

- Complex, high needs, and intellectual disabilities are consistently absent or underrepresented.
- Actions risk being aspirational without funding, measurable outcomes, or enforcement mechanisms.
- Whānau and child voices are essential for meaningful design, implementation, and monitoring.
- Culturally safe approaches, especially for Māori and whānau, must be central.
- Alignment with Education, Health, and Employment systems is critical to ensure smooth transitions and comprehensive support.

OVERALL COMMENTS

Key Themes:

1. **Vague and Ineffective Measures**
    - Progress indicators are simplistic, vague, and lack accountability.
    - Unclear what the indicators are actually measuring.
    - No clear timelines, measurable outcomes, or agency accountability.

2. **Language and Authorship Concerns**
    - Strategy language is overly wordy, confusing, and full of “government speak.”
    - Parents perceive the strategy as possibly AI-generated, not written by people with lived experience.
    - Need explicit assurance that real people with disability experience wrote and validated the strategy.

3. **Lack of Meaningful Impact**
    - Parents feel the strategy will make no material difference to their children.
    - Action points do not align with UNCRPD, IMM, or international recommendations.
    - Consultation process is repetitive and disempowering, with no accountability for outcomes.
    - Strategy is perceived as a PR exercise rather than a substantive plan for change.

4. **Comparisons to Existing Frameworks**
    - EGL (Enabling Good Lives) principles are clearer and better understood.
    - UNCRPD has stronger enforcement and teeth than this strategy

5. **Parent Sentiment**
    - Zero confidence that the strategy will lead to meaningful change.
    - Felt it mocks lived experience and realities of disabled children and their whānau.
    - Parents are frustrated with consultation fatigue and lack of government follow-through.

Key Recommendations:

1. Include clear, measurable, and accountable indicators of progress.
2. Ensure timelines and responsibilities are explicit for all actions.
3. Engage real people with lived experience in writing, reviewing, and validating the strategy.
4. Align all actions with UNCRPD and best practice frameworks such as EGL.
5. Move beyond consultation “vibes” to enforceable, funded, and practical commitments.

SPECIFIC FEEDBACK FROM PARENTS:

- The measures of progress are vague and simplistic
- Indicators lack detail and accountability
- It is unclear what the indicators are measuring
- The language throughout is vague and confusing – who wrote this?

- The whole strategy smacks of AI. Where are real people in this?
- It needs to be really clear that AI is not used in writing the strategy, and it needs to be written by real people.
- The strategy is overly wordy. It needs to be clear and direct and simple.
- Nothing in this strategy will make a material difference to me or my child
- Where is the accountability for government agencies in this strategy?
- The UNCRPD has more teeth than this strategy!
- EGL is clearer and better understood that this strategy!!
- There is no teeth, just vibes, in this strategy – what is the point?!
- Vibes don't change anything for our kids
- Action points don't align with the IMM and the UN's recommendations
- Lots of vague 'government speak'
- This strategy doesn't seem to have been written by real people
- Timeline is not specific or accountable
- Having to repeat out story endlessly under the guise of 'consultation' with no accountability to us for any actions is frustrating
- We are sick of 'being consulted' with no action, and no accountability from government departments for action.

There was zero confidence from any of our parents that this strategy would lead to meaningful change. Mostly parents felt that this was a wasted opportunity and made a mockery of their lived experience and realities.

The absence of accountability and clear measurable outcomes meant parents felt this was a PR exercise with no commitment to improving anything meaningful for their child.