



FASD-CAN
Fetal Alcohol Spectrum Disorder
Care Action Network

New Zealand Disability Strategy Team
Whaikaha
Emailed to: disabilitystrategy@whaikaha.govt.nz

28 September 2025

FASD-CAN Submission: Draft New Zealand Disability Strategy

FASD-CAN is making this submission on behalf of people with Fetal Alcohol Spectrum Disorder (FASD) and their families and whānau, to ensure their voices and lived experiences are heard and considered in relation to actions by the government to address the needs of disabled communities. This submission outlines significant concerns regarding the Strategy's vision, principles, and proposed actions, particularly as they relate to neurodisabled people, people with high and complex needs, and the crucial role of their family and whānau.

Our feedback is structured to directly address key omissions and provide clear, actionable recommendations.

1. Overall Critique of the Strategy

This section provides a high-level overview of our fundamental concerns before we respond to specific priority areas.

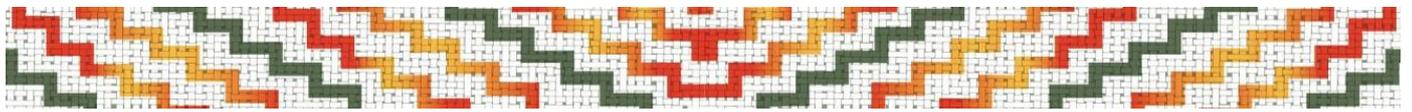
The New Zealand Government Disability Strategy, not a New Zealand Disability Strategy

As constructed and written, this is not an Aotearoa New Zealand Disability Strategy because it has not been written in genuine partnership with the disability community. Rather, it is a New Zealand Government Disability Strategy that fails to address the needs of the entire disability sector. The document's lack of co-design and partnership undermines its legitimacy and limits its ability to reflect the diverse needs and lived experiences of **all disabled people**.

Lack of Māori Voice and Bicultural Representation

The draft Strategy, as a national document, lacks in demonstrating a genuine commitment to bicultural partnership and the principles of Te Tiriti o Waitangi. Where is its strong and authentic Māori voice throughout its vision, principles, and actions. For the Strategy to be truly effective and equitable, it must be co-designed with Māori and reflect the unique aspirations and lived experiences of tangata whaikaha Māori, rather than treating them as a secondary consideration. Furthermore, the absence of bilingualism throughout the document is a significant oversight and





a missed opportunity to be inclusive and honour te reo Māori and to acknowledge our bicultural partnership.

Failure to Give Effect to Human Rights and Indigenous Rights

While the draft Strategy references international and national human rights frameworks, it fails to explicitly and robustly link its proposed actions to these frameworks. The document's references to **Te Tiriti o Waitangi, the UNCRPD, and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)** seem tokenistic. There is no clear indication of how the proposed actions will give effect to Aotearoa New Zealand's obligations under these agreements. This is a failing, as a rights-based approach requires these frameworks to be the foundational principles guiding every single action, rather than being mere footnotes.

Missing Cross-Cutting Theme: "Nothing About Us, Without Us"

The fundamental principle of **"Nothing About Us, Without Us"** is a critical missing cross-cutting theme. It is imperative that disabled people, tangata whaikaha Māori, and their family and whānau are meaningfully involved in all decisions made regarding the proposed actions and their implementation. This is a non-negotiable requirement for an authentic and effective New Zealand Disability Strategy, as a rights-based approach is only made real through genuine partnership and co-design.

Vision, Principles, and Foundational Omissions

The draft Strategy's vision correctly mentions family and whānau, yet their role is largely invisible throughout the document's principles and proposed Actions. This is a fundamental oversight. Family and whānau are not merely supporters; they are essential partners and operators within the disability sector, often providing the majority of care.

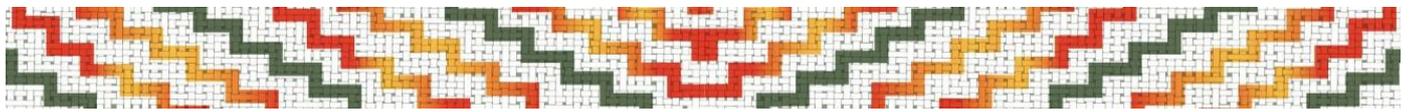
We also note the inconsistent use of "family" and "whānau." These are not interchangeable terms and should be used together as **"family and whānau"** to ensure all communities are represented and respected. The very first question in the document, which asks about the vision's alignment with the values and aspirations of "disabled people etc.," glaringly omits "family and whānau," reinforcing our concern about their marginalisation throughout this document.

Neglect of Neurodisabled People and High-Needs People

The Strategy appears to be almost exclusively focused on advancing the interests and needs of people with physical disabilities. It does not adequately represent or acknowledge the unique challenges faced by **neurodisabled people**, intellectually disabled people, or people with high and complex needs who are cared for in the home.

FASD-CAN does not believe the current vision or plan will lead to any meaningful change for people with **Fetal Alcohol Spectrum Disorder (FASD)** as they are not genuinely represented in this strategy document.





Absence of Enabling Good Lives (EGL) Principles

There is a complete and glaring absence of any reference to the **Enabling Good Lives (EGL) principles** and the urgent need for a nationwide rollout of this framework, as recommended in the recent review of New Zealand's compliance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The EGL principles are a recognised and crucial pathway to empowering disabled people and their families and whānau. Their omission from this Strategy is a major failing.

Ignoring Previous Accessibility Work

There is no reference to the extensive work that has already been undertaken on accessibility. The draft Strategy completely ignores the years of research, consultation, and policy development in this area, which should form a foundational part of this document. This omission suggests a lack of institutional memory and a disconnected approach to genuinely building on existing work.

Dissonance with Other Government Initiatives and Lack of Cohesion

The Strategy demonstrates a significant disconnect between its' stated aspirations and other legislation and consultations currently underway, including the ECE Bill, NCEA changes, Māori rights, the Plain Language Bill, and the Pae Ora (Healthy Futures) Act 2022. There is a need for a clear, cross-government alignment of policy that ensures a cohesive approach to supporting disabled people. The document itself is poorly constructed, a result of the vision and principles being developed independently from the priority area workgroups, and separate work on monitoring measures. This dissonance is evident in the presentation and phraseology, and lack of outcomes and accountability.

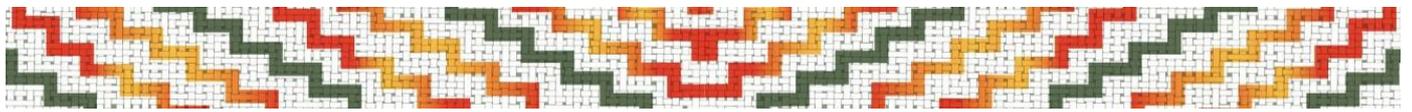
Lack of Link to UNCRPD Recommendations

There is no clear indication how this Strategy links to the government's agreed actions to implement the UNCRPD recommendations. This omission makes it unclear how the proposed actions will contribute to Aotearoa New Zealand fulfilling its international human rights obligations. There should be, at the very least, an appendix that cross-maps the Strategy's actions to the UNCRPD recommendations to ensure accountability and coherence.

Lack of Cohesion and Integration of Cross-Cutting Themes

We find the inclusion of the cross-cutting themes to be ineffectual. While important themes like "Nothing About Us, Without Us" and "a rights-based approach" are crucial, they are not applied across the priority areas. There is no clear representation of how these themes are integrated into the actions for each priority area. This disconnect makes the themes feel superficial and undermines their purpose. To be effective, the Strategy should either have its actions organised by theme or clearly demonstrate how each action reflects and contributes to the overarching themes.





Lack of Measurable Outcomes and Timeframes

The draft Strategy contains no meaningful, measurable outcomes with clear timeframes. This lack of accountability and concrete targets means the Strategy's success cannot be effectively monitored or evaluated.

Detailed Response to Consultation Document Questions

The Consultation document sets out specific questions for submitters in relation to the vision, principles, cross-cutting themes, the five priority action areas identified by the government, and progress measurement. Please refer to Appendix 1 for our detailed response to these questions.

Conclusion

In summary, our submission demonstrates that this draft strategy is flawed. It lacks the cohesion, detail and cross-agency collaboration necessary to address the complex, interconnected needs of neurodisabled people, particularly those with FASD, and their families and whānau. The proposed actions are isolated, insufficient, and, in many cases, are not new commitments but rather existing work programmes are included to give the appearance of progress. Without a genuine focus on breaking down silos and a clear, accountable plan that reflects the lived experience of all disabled people, this strategy will fail to deliver meaningful change.

Please do not hesitate to contact me if we can provide further explanation in support of our submission.

Yours sincerely

Stephanie James-Sadler
Chief Executive Officer
FASD-CAN Incorporated
ceo@fasd-can.org.nz





APPENDIX 1

Detailed Response to Consultation Document Questions

1. Response to Questions on the Draft Vision

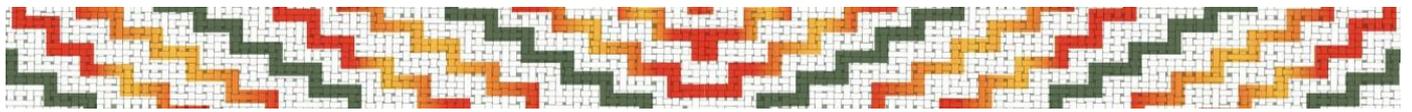
FASD-CAN provides the following detailed responses to the questions posed on the draft Strategy's vision, building on the broader points outlined in our overall critique set out above.

Question 1: How much do you agree with the following statements?

- **The proposed vision is clear and easy to understand.** FASD-CAN disagrees. While the vision appears superficially clear, it lacks the specificity and depth to be truly meaningful. It does not represent appropriately the needs and aspirations of all disabled people, particularly neurodisabled people and those with high and complex needs. However, we are delighted at the acknowledgement of “whānau” in the wording of the vision but reiterate this should be “family and whānau”.
- **The vision aligns with the values and aspirations of disabled people.** FASD-CAN disagrees. As outlined in this submission, the vision and the subsequent proposed actions are largely focused on advancing the needs of people with physical disabilities. They do not reflect the values, lived experiences, and aspirations of neurodisabled people, intellectually disabled people, or people with high and complex needs.
- **I feel confident that the vision will lead to meaningful change.** FASD-CAN strongly disagrees. We do not believe the current vision or the plan will lead to any meaningful change for people with Fetal Alcohol Spectrum Disorder (FASD) as they are not genuinely represented in this document. While a vision should be aspirational, it is only meaningful if it is grounded in reality and connected to a clear, actionable plan. In this case, the vision not supported by concrete, measurable actions and timeframes. It becomes a statement of what the government *hopes* will happen, rather than a plan for making it happen. The vagueness of the actions proposed throughout the Strategy, coupled with the lack of accountability and timeframes, means the vision will likely remain only an aspirational statement without tangible impact.

There is a crucial disconnect between the aspirational language of the vision and the reality of systemic barriers.

- **"Thrive":** “Thriving” is not something a disabled person can simply decide to do. It's an outcome that is directly dependent on the removal of **systemic barriers** and the provision of **adequate support**. When a strategy talks about thriving without addressing issues like housing instability, healthcare shortages, and inaccessible education, the word is



questionable. It shifts the responsibility from the government and society to the individual, which is a major strategic flaw.

- **"Lead"**: This point is particularly important for neurodiverse people. A vision of "leadership" reflects a neurotypical standard of success that may not align with everyone's aspirations. Many people with FASD, for example, may prioritise different goals, such as personal security, stable relationships, or community contribution in ways that don't involve formal leadership. A truly inclusive vision would celebrate diverse ways of living a good life, not just a single, aspirational model.
- **"Participate in all aspects of life"**: This is an empty promise when the strategy fails to address the foundational issues of **stigma and systemic barriers**. You cannot have genuine participation when people are being misunderstood, judged, or excluded. The plan does not have concrete actions to actively dismantle the stigma that acts as a barrier in every single priority area—from education to justice.

A plan that fails to address stigma and systemic barriers is not a plan for a "good life" for all disabled people. It's a plan for maintaining the status quo. What do true disability rights and inclusion look like for all disabled people?

Question 2: Do you have any further comments or suggestions on the proposed vision and how well it reflects the needs, aspirations, and rights of disabled people in New Zealand?

1. A Vision Centred on Enabling Good Lives: A vision that reflects the needs, aspirations, and rights of all disabled people must be firmly rooted in the principles of Enabling Good Lives (EGL). We propose the following alternative vision, which we believe more accurately reflects these principles:

"An Aotearoa New Zealand where disabled people and their family and whānau are empowered to live a life of their choosing, with genuine choice and control over the supports they need to live a good life and fully participate in all aspects of life important to them."

2. The Critical Role of Family and Whānau: The vision's acknowledgement of whānau is a positive first step, but it is not enough. The vision must explicitly recognise the crucial and often invisible role of family and whānau as essential partners. The inconsistent and marginal mention of family and whānau throughout the rest of the document undermines the vision itself. The term "family and whānau" should be used consistently and intentionally throughout the entire Strategy.

3. Inclusion of "Nothing About Us, Without Us": A vision for disabled people must be co-designed and implemented with them. The fundamental principle of "Nothing About Us, Without Us" must be a core, cross-cutting theme of this Strategy, ensuring that disabled





people and their family and whānau are involved in all decisions regarding how the vision is realised.

4. Explicit Focus on Neurodisabled People: The vision and its implementation must be inclusive of all disabled people. It currently fails to reflect the unique needs of neurodisabled people, intellectually disabled people, and those with high and complex needs who require tailored support and a focus on living a good life in their own communities and homes.

2. Response to Questions on the Possible Principles

Our view is that the principles of this Strategy must include the Enabling Good Lives (EGL) principles. There is no need to reinvent the wheel or dismiss the voice of disabled people who were instrumental in developing these principles. Furthermore, these principles, and the entire Strategy, must consistently include and value the role of family and whānau throughout.

Question 1: How important is each of the following principles? FASD-CAN views all of the possible principles as fundamentally important. However, we consider any principle related to "dignity" or "respect" to be of the utmost importance. Without these as the foundational guiding values, all other principles and actions will be ineffective.

Question 2: Is there anything you would want to add or remove from the list of principles for the strategy?

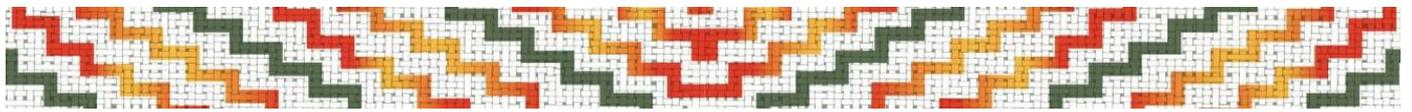
- **Add:** We strongly recommend adding the principles of Enabling Good Lives (EGL), including **tinō rangatiratanga** (self-determination), **manaakitanga** (support and care), **whanaungatanga** (relationships and connections), and **kotahitanga** (collective action). These are more than just principles; they are an operational framework that has proven to be effective for disabled people.
- **Add:** The principle of "Nothing About Us, Without Us" is an absolute requirement that must be explicitly stated as a cross-cutting theme.
- **Add:** An explicit principle recognising the role of **family and whānau** as key partners and operators in the disability sector. Their invaluable contribution must be acknowledged and supported in the principles and throughout the document.

Question 3: Do you have any further comments or suggestions on the proposed principles?

We are concerned that the principles do not adequately reflect the needs and aspirations of neurodiverse and intellectually disabled people. They appear to be heavily focused on people with physical disabilities. The principles must be universal and applicable to all disabled people in Aotearoa New Zealand and must consistently include and value the role of family and whānau.

3. Submission on the Cross-cutting Themes





FASD-CAN has reviewed the proposed cross-cutting themes of Accessibility, Data, and Workforce and our feedback is largely related to how these themes must apply to neurodisabled people and their family and whānau.

Accessibility: The discussion document correctly identifies a broad range of accessibility issues, including physical access, access to services, and access to information. However, for people with FASD and other neurodisabled people, accessibility must be understood in a more holistic sense. This must include **neuro-inclusive design** in all environments (from schools to housing to workplaces), **low-arousal communication**, and accessible, easy-to-understand information. This broader understanding must also encompass systemic accessibility, ensuring people have unhindered access to essential systems and services like housing, employment, and justice. Without this broader definition, the Strategy will fail to address the core barriers faced by our community, particularly in the priority areas of education, housing, and employment.

Data: We agree with the need for better, more consistent, and more detailed data. However, the Strategy must go further than simply recommending general data collection. It is critical that any data collection efforts are designed to provide a more detailed understanding of the diverse experiences of different disabled communities, including neurodisability. This requires data that can be broken down by specific disability types to inform tailored solutions. Without this level of detail, the data will remain insufficient to address the systemic inequities faced by neurodisabled people.

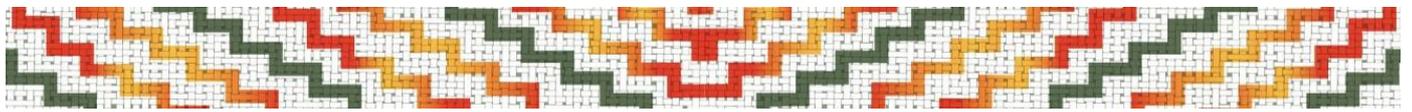
Workforce: We support the recommendation that the government workforce—across education, health, and justice—requires a much better understanding of disability. For our community, this means a deep understanding of neurodisability, and the specific challenges associated with FASD. The workforce must be trained in brain-based, trauma-informed and low-arousal approaches, and move beyond making assumptions about a person's ability. It is also essential to increase the number of disabled people and family and whānau with lived experience working in these areas to inform and lead or support service delivery.

"Nothing About Us, Without Us": This is a critical cross-cutting theme that is entirely missing from the document. The Strategy must explicitly commit to the principle that disabled people and their family and whānau must be involved in all decisions made regarding the proposed actions and their implementation. As it is, it is a document created **for** disabled people rather than **with** them. As such it lacks the authenticity and accountability required to lead to meaningful change. As currently put together and written this seems like a New Zealand Government work plan not a true Aotearoa New Zealand Disability Strategy.

4. Response to Priority Area: Education

We find the Education priority section of this Strategy disappointing given its importance to the educational challenges experienced by disabled ākongā.





Question 1: How much do you agree with the goal for education?

The goal as stated 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."

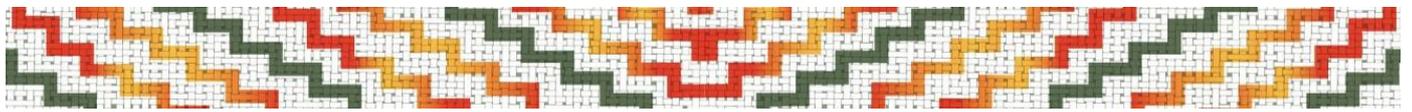
FASD-CAN has a low level of agreement with the proposed goal for education. While the language is aspirational, it is open to interpretation. As such, it is not specific enough to create meaningful change for neurodisabled learners. The goal fails to acknowledge the unique and complex challenges faced by learners with conditions like FASD, who require highly individualised, flexible, and trauma-informed approaches to education. Without more clarity in the use of terminology and specificity, the goal is unlikely to lead to any tangible improvement in outcomes.

For example, disabled people already have the right to attend school enshrined in legislation. The problem is more systemic. The current learning support system in education is “broken” and is not working for disabled ākonga, who are often ultimately excluded from mainstream education. All reports point to this undeniable fact. So where is the vision and goal for systemic change that would make a difference for disabled people?

- **"High Expectations":** We are also concerned about the vision’s statement inclusion of the phrase "high expectations". This is problematic because it fails to acknowledge that success for learners with conditions like FASD is not solely about academic outcomes. Without a focus on flexible, neuro-inclusive, and trauma-informed practices, and a focus on education’s contribution to a good and meaningful life, this term is potentially harmful, placing an expectation on the student and their family and whānau that may not accord with their own vision and goals for themselves.
- **The Problem with Undefined "Potential":** The phrase "achieve their potential" is a generic aspiration that places a burden of performance on learners without defining who sets the expectation or how it will be met. We submit that for learners with conditions like FASD, success is not a singular academic outcome but is also about their wellbeing, a sense of belonging, and their ability to participate in their own way. It is very disconnected from the "lived reality of families and whānau." Without a flexible framework, the idea of "potential" can be a one-size-fits-all expectation that fails to acknowledge the unique and complex needs of neurodisabled learners.

A meaningful definition of "potential" would be grounded in the Enabling Good Lives (EGL) principles, empowering disabled people and their families and whānau to have genuine choice and control over their lives and supports. This would allow them to define their own version of success and "potential," rather than having it determined by a generic government or education system goal.





- **The Inclusive Education gap:** The goal's language is also fundamentally flawed in its assertion that "all learners – including disabled learners –..." will achieve their potential. This phrasing is not only unnecessary but also undermines the core tenets of inclusive education theory. By explicitly singling out disabled learners as a subgroup, the document creates a false dichotomy, suggesting they are somehow separate from "all learners." A truly inclusive and rights-based goal would recognise that disabled learners are, by definition, part of the whole and should be afforded the same opportunities and expectations without being categorised as an addendum. The use of this language exposes a disconnect between the document's aspirations and genuine inclusive practice, making the goal feel disingenuous rather than empowering.

Question 2: How much do you agree with the description of what success in education means?

We have a very low level of agreement with the description of what success means. While some points are positive, they are framed in a way that is inadequate for neurodisability. For example, focusing on "high expectations" (b) without acknowledging the need for different and flexible ways of meeting those expectations can be harmful. The descriptions are too generic and do not reflect the lived reality of families and whānau who are struggling to get even get basic support for their child in mainstream education settings.

As another example, one of the success statements is: "Work with the Ministry of Disabled People - Whaikaha to explore opportunities to identify disabled learners in education data collections." But to what effect? And the success statement for this is:

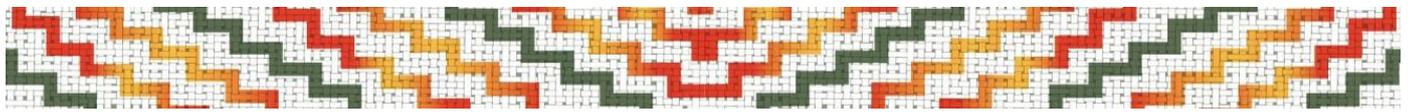
Success area this progresses:

(g) data is gathered to support understanding the progress of disabled learners

Flawed Data Collection: The success statement about data collection (g) is also critically flawed. It focuses on gathering data to "support understanding the progress of disabled learners." This is insufficient. What's equally important is capturing the lived and living experience of disabled people and their families and whānau within the education system, including attendance issues and barriers, and situations involving stand-downs, seclusion, exclusion and expulsion – all common lived experiences of FASD and other neurodiverse ākonga because their needs are not being met.

Furthermore, it is not just about the **progress** of disabled learners (noting many neurodiverse people have hidden disabilities that don't manifest until they get older), we would argue what is equally important is capturing data on the lived and living experience of disabled people and their family and whānau in our education system.





Generic and Inadequate Language: The entire description of success is too generic. It doesn't reflect the daily realities faced by families and whānau. True success for these learners includes well-being, a sense of belonging, and the ability to participate in their own way, not just meeting a pre-defined standard.

In short, the description of success is fundamentally disconnected from the lived experience of FASD ākongā and their families and whānau.

Question 3: Do you have any further comments or suggestions on the goal for education, or the description of what success means?

The goal and description of success set out good aspirations but are fundamentally flawed by their lack of reference to the **Enabling Good Lives (EGL) principles** and the lived and living experience. The final document must incorporate these principles, which are grounded in the lived experience of disabled people and their family and whānau. A meaningful goal for education must include:

- **Neuro-inclusive education** with a focus on flexible, trauma-informed, and low-arousal practices.
- **Addressing systemic barriers** to inclusion so that disabled ākongā can have a stable education experience which is a key protective factor for positive life outcomes.
- **Family and whānau as key partners** in planning for and supporting their child's education.
- **A focus on wellbeing** and life-long learning outcomes, not just academic achievement.
- **Concrete actions with clear accountability and timeframes**, rather than vague statements about "working with" or "reviewing" existing programmes.

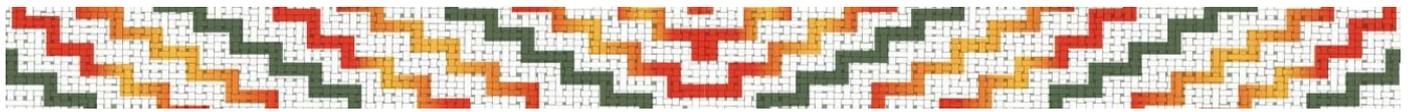
Education Actions

Question 1: How much do you agree with each action?

FASD-CAN has a **very low level of agreement** with the proposed actions. While the intentions behind many of the actions are positive, they fail to provide the meaningful change required for neurodisabled learners and their family and whānau. Actions 1-4 and 9 are a particular point of concern. These are not genuine, new actions. They are simply a restatement of the government's pre-determined budget announcements. Including these in a consultation document and asking if we agree with them is disingenuous as the decisions have already been made. This undermines the entire process. Furthermore, the effectiveness of these funding injections is yet to be proven in meeting the complex and high-needs requirements of the FASD community.

A Confusing Definition of "Learning Support": The term "learning support" has also been used as a synonym for "disability," but they are not the same thing at all. There are many people who may need learning support who are not disabled and would not see themselves as disabled. While many disabled people require learning support, the term is much broader. It can apply to anyone





facing a barrier to learning, whether that barrier is temporary, situational, or due to a specific learning difference that might not be considered a formal disability.

The **Ongoing Resourcing Scheme (ORS)** is a specific funding mechanism for a small subset of students with very high-level needs. By using "learning support" to refer to a wider group of people, the document risks conflating the two and obscuring the fact that many neurodisabled people and people with high and complex needs do not meet the stringent criteria for ORS funding yet still require significant and targeted support. This point supports our argument that the document fails to truly represent and address the full spectrum of disability.

Vague and Non-Committal Language: Actions 5, 6, 8, and 9 use vague, non-committal language such as "work with," "explore opportunities," and "continue implementation." This language lacks accountability and concrete timeframes, making these actions meaningless. They represent a continuation of the status quo rather than a commitment to tangible and transformative change.

TEC: We also note that the sole goal for TEC just seems out of place and "thrown in". More importantly it is already something that is required and being done. So why include it and consult on it?

Question 2: Do you have any further comments or suggestions on the proposed actions?

The proposed actions in the draft Strategy are a missed opportunity to enact real, systemic change. They are insufficient and fail to address the core inequities faced by neurodisabled students and their families and whānau. In essence, the system needs to move from a reliance on the "goodwill" of individual school boards to a robust, rights-based framework with clear, non-negotiable obligations and accountability mechanisms. This would ensure that every disabled student receives the support they need, regardless of which school they attend.

To genuinely support our learners, we strongly suggest the following:

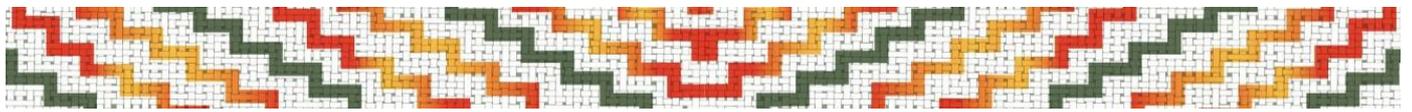
Direct Accountability for Schools

- **Lack of MOE Accountability:** MOE must be given the legislative authority to take action against schools who fail to comply with sections 33 and 34 of the Education and Training Act 2020 (check s 127 of the Act too). And to require schools to continue enrolments where there is every reason to do so. Lack of resources and "we can't meet your needs" withdrawals must be addressed.

The 2023 Household Disability Survey found that 51% of disabled people in school (around 48,000 people) had an unmet need for support or accommodations at school. While many (67%) rated their school's responsiveness to their needs highly, a significant portion of disabled students experienced bullying (62%), or had to change schools due to their health or disability (16%).

- **Number of disabled ākonga (students):**





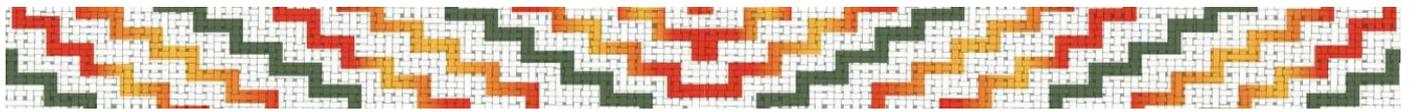
- In total, the 2023 survey estimated that 1 in 6 people in New Zealand were disabled, totalling 851,000 people.
- Of these, 98,000 were children (aged 0-14) and 753,000 were adults (aged 15+).
- Disabled students in the age group of 15-44 years had a disability rate of 12%.

➤ **Experiences in education:**

- **Unmet Needs:** 51% of disabled people in school education reported an unmet need for support or accommodations.
- **Positive Experiences:** 67% of disabled people in school education felt that their school was responsive to their specific needs.
- **Difficulties:** Many disabled students faced challenges:
 - 62% experienced bullying at school.
 - 24% were unable to attend school due to their health.
 - 16% had to change schools because of their health or disability.
 - 12% were unable to attend school due to inadequate support.
- **Specific Issues:** A significant number also reported difficulty enrolling in a suitable school (7%) or being stood down or removed from school (12%).
- **The Problem with Boards of Trustees:** The current system with Boards of Trustees is set up to materially disadvantage disabled people. From a lived experience perspective, Board members are often parents of children who attend the same school, which can create a fierce protective reaction in decision-making that may not benefit all disabled students. Additionally, Boards of Trustees are often comprised of well-intentioned volunteers who lack the specific training, knowledge, and experience to understand and meet the complex needs of neurodisabled learners. This often results in families and whānau having to engage in a constant and exhausting battle for resources and appropriate accommodations for their children. As families and whānau are already feeling vulnerable and overwhelmed by their caregiving roles, this adversarial relationship with the very people who are meant to support their child's education creates an immense and unfair burden. Boards of Trustees often act as gatekeepers to resources, and their focus on budget and compliance can overshadow the individual human needs of the students they are meant to serve.

Centralised Accountability and Standards





The current system's reliance on the discretion of local boards of trustees creates inconsistency and inequity. The Ministry of Education (MOE) must move from a model of local autonomy to one of centralised accountability and mandated standards.

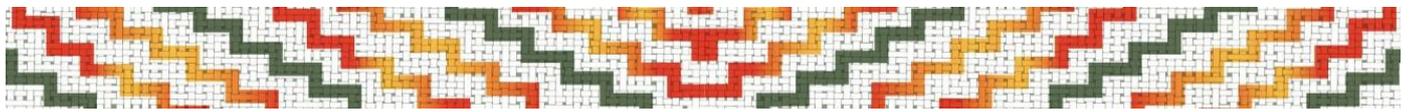
- **Centralised Funding and Resourcing** (other than ORS): Funding for a disabled student's support should be held centrally and tied directly to the student's individual learning plan, ensuring resources follow the student regardless of the school they attend.
- **Mandatory, Verifiable Standards:** MOE must mandate and enforce non-negotiable standards for inclusive education. Boards of trustees would be audited against these standards, which would cover professional development, resource provision, and the implementation of Universal Design for Learning (UDL) principles.
- **Strengthened Accountability:** A clear and easily accessible pathway is needed for families and whānau to hold schools accountable. This should include an independent advocate or complaints service with the power to compel compliance and provide alternative placements. The MOE must be given the legislative authority to take action against schools that fail to comply with the Education and Training Act 2020 and to address informal "we can't meet your needs" withdrawals.

Addressing Exclusionary Practices and Data

The data actions proposed in the draft Strategy are insufficient because they fail to capture the reality of exclusionary practices. True success requires a new approach to data collection that reflects the lived experience of disabled ākonga.

- **Capture Lived Experience Data**
 - **Attendance Data:** We need a data action that captures the real lived experience of disabled ākonga in terms of attendance and seclusion, stand-downs, exclusion, and expulsion (SSEE). Many families and whānau of disabled ākonga experience being asked by the school to immediately come and pick up their child/tamariki due to incidents or accidents, and yet they have already been marked as in attendance. This gives a false view of attendance by disabled ākonga and gives a skewed perspective of the systemic issues facing disabled ākonga and their families and whānau. Often schools say they don't have enough resourcing to have the tamariki or rangatahi there for the full school day. This means the child or young person only attends school part time and families and whānau wonder if true attendance is recorded. Plus the burden this puts on families and whānau to work around what schools declare about school participation and attendance, especially if both parents are engaged in paid work.
 - **SSEE Data:** Likewise, with SSEE situations, meaningful data is not recorded about these situations, so we don't know what to do to address the issue. Moreover, neurodiverse tamariki and rangatahi are being required to agree to conditions so they





can come back to school, often these conditions are impossible to meet or guarantee due to the needs of that child or young person. Finally, many schools put pressure on parents and caregivers to withdraw their child/tamariki by saying the child's needs can't be met here, or your child's needs would best be met in a specialist school, or they threaten they are going to have to take action to expulse that child/tamariki so the parent or caregiver withdraw them first because they don't want that on their education record and they don't want their child/tamariki at a school that does not accept them or want them. This is the reality of "inclusive education" in Aotearoa New Zealand that needs to be captured.

- **Exposing Informal Exclusions:** We must capture data on the reality of informal exclusionary practices, such as when schools pressure parents to withdraw their child by claiming they cannot meet their needs or threatening official expulsion. This is the reality of "inclusive education" in Aotearoa New Zealand that needs to be exposed and addressed.

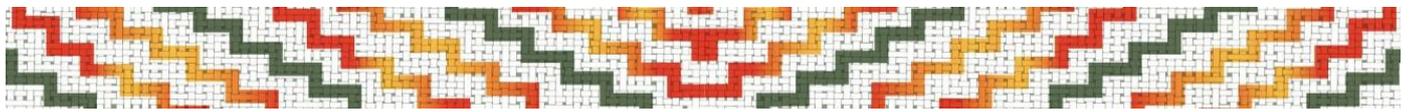
Mandating Professional Development and Practice

- **Initial Teacher Education (ITE):** ITE training must be required to explicitly include teaching about inclusive education theory and practice, and Universal Design for Learning, so that the needs of all ākonga can be met. This training must be in place as soon as possible, and no later than teacher training intake commencing January 2027.
- **Universal Design for Learning:** All teachers employed by the government should be required to start implementing UDL in their classrooms, showing significant progress in its roll out in their settings after three years. A fund to support training of UDL must be implemented to ensure its implementation.
- **Neuro-Inclusive Training:** Mandatory, funded professional development for all educators and support staff on neuro-inclusive design, **trauma-informed practice**, and the specific learning profiles of neurodisabled students is essential.
- **Disability Action Plans:** All government-funded schools and kura must be required to develop and implement a disability action plan by 30 June 2026 and this must be done in consultation with the diverse range of disabled ākonga at their school, and their family and whānau. Boards of Trustees should receive specific training on the rights of disabled ākonga to an inclusive education as part of their on-boarding, and Board's will be held account for implementation of the plan through annual reporting and ERO reviews.

Empowering Family and Whānau

- **Dedicated Support:** The Strategy must provide dedicated, funded support coordinators to act as navigators for family and whānau within the education system. These coordinators would assist with accessing resources, navigating Individual Education Plans (IEPs), and ensuring the rights of the student are upheld.





- **Removal of Red Tape:** The process for securing a formal diagnosis and support plan is a major barrier and places a huge administrative burden on families. This needs to be streamlined into a single, cross-agency process that includes education, health, and disability services from an early age.

A New Approach to Learning

- The goal of "achieving their potential" is meaningless without genuine flexibility. The Ministry of Education (MOE) must develop and fund genuinely individualised learning pathways that are co-designed with the student and their family and whānau, based on the principles of **Enabling Good Lives (EGL)**. This would move beyond rigid, one-size-fits-all curricula to a system that truly meets the diverse needs of all learners.

General Comments

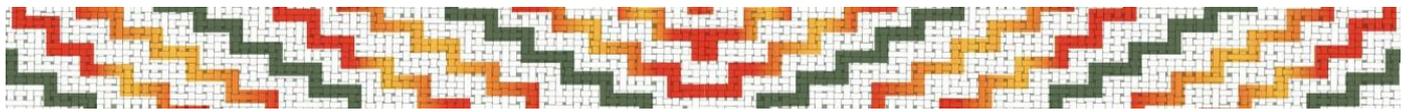
- **Embed the Enabling Good Lives (EGL) principles** into every single action. These principles should guide all efforts to support disabled learners.
- **Replace vague language** with clear, measurable actions and concrete timeframes. Instead of "work with," provide specific deliverables and dates.
- **Prioritise neuro-inclusive, trauma-informed practice.** The actions must explicitly address the needs of neurodisabled learners, including professional development for educators on these topics.
- **Involve families and whānau** in the design and delivery of all actions. The principle of "Nothing About Us, Without Us" must be a fundamental guide.
- **Broaden the definition of "success"** beyond academic qualifications to include wellbeing, participation, and a sense of belonging for all learners, particularly those who face significant barriers.
- **Link to Cross-cutting themes:** There must be actions that directly relate to each of the cross-cutting themes.

5. Response to Priority Area: Employment

Question 1. How much do you agree with the goal for employment?

FASD-CAN does not agree with the proposed goal for employment, as it fails to adequately address the realities for neurodisabled people, particularly those with FASD. The framework is focused on fitting neurodisabled people into an existing, neurotypical employment model rather than adapting the model to support diverse neurotypes. In this regard, as with elsewhere in the





strategy, it will only potentially help physically disabled people find employment, not people with intellectual or neurodisabled people.

The proposed goal is high-level and lacks the specificity needed to be meaningful. Phrases like "meaningful career opportunities" and "thrive in employment" do not reflect the lived experience of people with FASD. The primary challenge for people with FASD is often maintaining stable, supported, and dignified employment. This can be due to significant challenges with executive function, social communication, and regulation, which require highly specialised, long-term support, not just general "disability-confident employers." This section, like others in the Strategy, is a series of positive statements that are disconnected from tangible actions that would lead to real-world change for people with high and complex needs, who might only ever be able to work short part-time hours, or will be unable to engage in paid employment opportunities at all.

Question 2. How much do you agree with the description of what success in employment means?

We submit the success statements in the draft Strategy are also inadequate. They do not address the need for a fundamental shift in employer and community attitudes, nor do they support the development of alternative employment models that value contributions outside of traditional metrics. There is no mention of the critical role of support workers or the need for sustained, individualised support tailored to the unique needs of people with neurodisabilities. The proposed statements fail to acknowledge that for many with FASD, success may not be a linear career path, but rather a dignified, supported, and stable presence in the workforce or community, with a focus on wellbeing and participation.

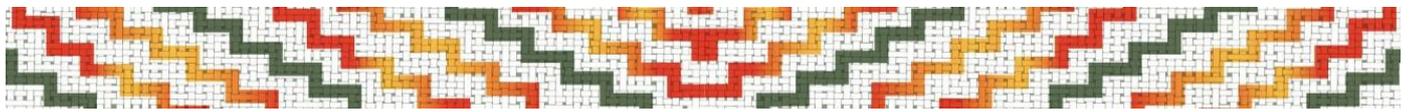
Question 3: Do you have any further comments or suggestions on the goal for employment, or the description of what success means?

To genuinely address the needs of neurodisabled people, particularly those with FASD, the employment goals and success statements must move beyond aspirational, neurotypical language and embrace a framework that supports diverse neurotypes.

The current goal and success statements fail to reflect the lived reality of neurodisabled people, for whom the primary challenge is not a lack of opportunity but a lack of appropriate, sustained support. Phrases like "meaningful careers" and "thriving" are disconnected from the day-to-day challenges faced by people with FASD, such as navigating social cues, managing executive function deficits, and regulating emotions. The existing framework aims to force the neurodisabled into a neurotypical employment model, rather than adapting the model to meet their needs.

To make the employment goals and success statements relevant and actionable, we recommend the following:





- **Prioritise Supported and Stable Employment:** The goal should shift from a focus on "careers" to one that supports **stable, dignified, and supported employment**. Success should be measured not just by job acquisition but by the ability to maintain employment over the long term, with appropriate accommodations and support.
- **Acknowledge and Fund Support Workers:** The critical role of **support workers** in enabling employment must be explicitly recognised and funded. These professionals provide the tailored, long-term support necessary for people with complex needs to succeed. The success statements must reflect the availability and accessibility of these vital services.
- **Develop Alternative Employment Models:** The Strategy must commit to exploring and funding **alternative employment models** that value contributions beyond traditional metrics. This includes flexible work arrangements, part-time opportunities, and roles that are specifically designed to leverage the strengths of neurodiverse individuals.
- **Focus on Attitude and Capacity Building:** Success must be linked to a measurable shift in **employer and community attitudes**. This requires clear actions to build capacity and understanding among employers, moving beyond generic "disability confidence" training to a deeper understanding of neurodiversity and trauma-informed practice.
- **Incorporate Well-being and Participation:** The definition of success should be broadened to include well-being, social participation, and a sense of belonging within the workplace and wider community. For many neurodisabled people, success is not a fast-paced career trajectory but the ability to contribute to society in a safe, supportive, and stable environment.

Without these critical changes, the employment section of the Strategy will remain a series of positive but ultimately meaningless statements that fail to deliver tangible change for the very people it claims to serve.

Employment Actions

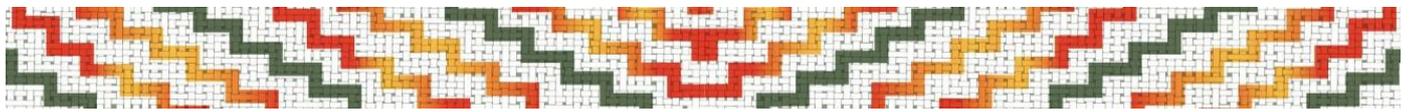
Question 1: How much do you agree with each action?

The proposed employment actions are insufficient and fail to provide the meaningful change required for neurodisabled people and those with high and complex needs.

Critique of Proposed Actions

- **Reliance on "Vibes" and Voluntary Action:** The proposed actions are based on vague, "good vibes" and voluntary cooperation. They are highly unlikely to be effective in creating meaningful new job opportunities unless there is a commitment to robust legislation and enforcement, and new job opportunities are created.





- **The Small Business Reality:** The Strategy fails to acknowledge the reality of Aotearoa New Zealand's business landscape, where a significant majority of employers are small businesses. According to Statistics New Zealand data from 2024, about 17.6% of businesses had five or fewer employees, while the largest proportion of businesses (around 73%) have no paid employees at all. It is extremely unlikely that these small business owners will take on the perceived risk of employing someone with a disability without financial incentive, such as a government grant or subsidy scheme.
- **Failure to Address All Disabilities:** Once again, this part of the strategy only reflects and is aimed to support one part of the disability sector - those without neurodisability or intellectual disability. There is nothing here for neurodiverse or intellectually disabled people, or those who have high and complex care needs.
- **Beyond Traditional Employment:** The focus solely on "paid employment" is symptomatic of a larger problem. It ignores the reality for many disabled people who will never be able to consistently hold down a job in the traditional sense, and it fails to meaningfully address systemic ableism that is a constant barrier to participation. The Strategy must think outside and beyond traditional employment as an option. There needs to be investment in a broader range of meaningful activity, such as social enterprises, that give a sense of worth and value without the pressures of a traditional workplace.
- **A Publicity Campaign:** The actions read like a publicity campaign. They are not going to change the lives of the diverse range of disabled people. Where are the actual, part-time, realistic jobs they can do?
- **Transitions:** A glaring omission in a disability employment strategy is a plan for effective transitions when aging out of education into employment or community activity. This is a critical point in a person's life that requires a clear, funded pathway.
- **Disability Poverty:** The Strategy is also silent on a strategy to address disability poverty other than through employment, which only a small percentage of disabled people will ever achieve. The lack of viable options to full-time employment perpetuates poverty and financial hardship among disabled people.
- **Shifting Responsibility:** The responsibility for these actions seems to sit mainly with disabled people themselves and employers. The Strategy is silent on the government's direct, active responsibility and its role in creating a supportive ecosystem.
- **Missing a Strategy for Family and Whānau:** As with the other priority action areas, there is a complete absence of a strategy for caregivers, family and whānau. There is no action to increase investment in support services so that caregivers can be supported to return to the workforce, nor is there a recognition that their paid or unpaid labour contributes to the economy.





- **Lack of Measurable Actions and Timeframes:** The proposed actions are highly subjective and lack meaningful, measurable outcomes and clear timeframes for implementation. Without these, accountability is impossible.

Question 2: Do you have any further comments or suggestions on the proposed actions?

Our Recommendations:

- The Strategy must commit to a nationwide rollout of the Enabling Good Lives (EGL) framework across the employment sector. This is the only model that will provide the flexible, person-centred support needed.
- The focus should shift from "disability-confident employers" to a system of long-term, individualised funding for support workers who can assist people with neurodisabilities throughout their entire employment lifecycle.
- The government must explore and invest in alternative employment models, such as social enterprises and supported self-employment, that are better suited to the needs and strengths of neurodisabled people.

6. Response to Priority Area: Health

Question 1: How much do you agree with the goal for health?

Once again, while the proposed health goal and success statements are aspirational, they are fundamentally flawed. We therefore have a **very low level of agreement** with the goal as it is currently written. It fails to reflect the lived experience of disabled people, particularly those with high and complex needs and their families and whānau.

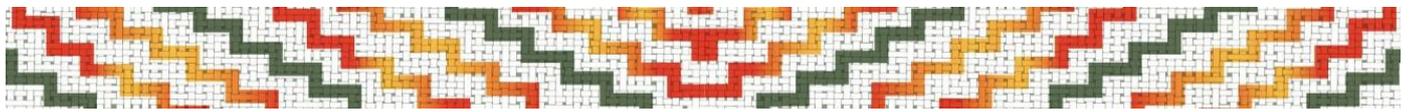
We disagree with the statement that the goal and success descriptions will lead to meaningful change. The language is vague and aspirational, using terms like "thrive" and "enhance quality of life" without providing concrete, measurable actions or timeframes. It perpetuates the disconnect between high-level policy and the urgent, practical needs of disabled people.

Furthermore, the proposed health goals fail to acknowledge the critical, on-the-ground realities of the health system. The health workforce is currently facing severe shortages, which makes the successful implementation of any of these actions unrealistic. Without a clear plan to address the systemic failures and staffing shortfalls, the goals cannot lead to meaningful change.

Question 2: How much do you agree with the description of what success in health means?

We have a **very low level of agreement** with the description of what success in health means. It is disconnected from the practical realities of accessing healthcare for neurodisabled people and their families, leaving them vulnerable.





The proposed success statement on self-determination is a welcome addition, but it is a glaring contradiction to have this principle without an explicit commitment to the **Enabling Good Lives (EGL) principles**. EGL provides the established, person-centred framework that would turn this aspirational goal into a reality. By not including it, the document ignores the extensive work already done by disabled people to define what self-determination truly means in a service delivery context.

Furthermore, the concept of **accessibility in health** is far too narrow. For neurodisabled people and those with cognitive impairments, accessibility is not just about physical access to buildings or transport. It is about **systemic accessibility**:

- **Access to healthcare professionals** who are trained in neurodiversity and understand the complex health needs of people with FASD.
- The provision of health information and communication that is **clear, concise, and easy to understand**.
- **Flexible service delivery models** that account for sensory sensitivities and challenges with executive functioning, making it possible for disabled people to attend appointments and engage with their care.

Finally, while the document correctly includes "**Nothing about us without us**" as a success statement, this principle is too important to be a mere outcome. It must be a foundational principle that guides every action in the Strategy, ensuring disabled people and their families and whānau are at the core of all decision-making.

The document's lack of focus on these vital issues demonstrates that its scope is largely limited to physical disability, leaving people with FASD and other high and complex needs, and their families and whānau vulnerable.

Question 3: Do you have any further comments or suggestions on the goal for health or the description of what success means?

Please consider our submission on the health priority area above.

Health Actions

Question 1: How much do you agree with each action?

We disagree with the proposed health actions. While they are well-intentioned, they are too high-level and lack the specificity and accountability needed to drive meaningful change, particularly for neurodisabled people and their families and whānau. The actions are almost entirely passive ("review," "build," "work with") and do not provide concrete, time-bound commitments.

- **Action 1 (Review and improve policies):** A review is not an action. The health sector has been reviewed multiple times. The current challenge is implementation, not understanding





the issues. Instead of a review, the strategy must mandate the **immediate and nationwide implementation of the Enabling Good Lives (EGL) principles** as the guiding framework for all disability-related health services.

- **Action 2 (Build health workforce capability):** This action is too vague. It must explicitly require mandatory, ongoing, and evidence-based training for all health professionals on **neurodisability and co-occurring mental health conditions**, particularly for FASD, which is frequently misdiagnosed. This training should be a prerequisite for all professional certifications and should not be a "nice-to-have."
- **Actions 4 and 5 (Data):** While the goal of better data is laudable, the actions are insufficient. Simply "identifying disabled people" and recording accessibility needs is not enough. The Strategy must mandate that this data is actively and seamlessly shared between health providers to eliminate the need for disabled people and their families to constantly repeat their medical history and support needs. This will help to reduce a major source of frustration and mental exhaustion.

Question 2: Do you have any further comments or suggestions on the proposed actions?

To make effective progress, the health sector must break down the rigid silos that separate health, disability, education, mental health, and social services. A comprehensive and holistic approach is required, one that funds packages of care that span a disabled person's entire life. The current Disability Support Services (DSS) and mental health systems are inadequate and fail to meet the diverse needs of all disabled people.

Furthermore, a significant omission is the lack of any action to support **family and whānau** in this priority area. There is no mention of support for their health and well-being, particularly in relation to caregiver stress and mental health. Once again, the voice of the child/tamaiti and the family and whānau is missing from these actions. Finally, there is no specific goal to improve and de-silo the crucial transition from paediatric to adult health services, a point of significant vulnerability for disabled people.

Suggestions for the Health Priority Area

The goals for the Health priority area are aspirational, but the proposed actions are far from realistic given the severe health workforce shortages in Aotearoa New Zealand.

- **Siloed Systems:** The current health system operates in rigid silos. To make effective progress, the Strategy must commit to breaking down the silos between health, disability, education, mental health, and social services. It should fund holistic packages of care for disabled people across their entire lifespan.
- **Inadequate Systems:** The inadequacy and limitations of the current Disability Support Services (DSS) and mental health systems are not meeting the needs of all disabled people, particularly those with neurodisabilities and high and complex needs.





- **Lack of Family and Whānau Support:** The proposed actions do not reflect the lived experience of people with FASD and their family and whānau. There is a glaring absence of actions to support the health and wellbeing of families and whānau, particularly in relation to caregiver stress and mental health. The child's voice and the family and whānau voice are missing from the actions.
- **Transition from Paediatrics:** A significant omission is any goal or action to improve and de-silo the critical transition from paediatric to adult health services. This transition is a major challenge for families and must be addressed.

Inadequacies in the Mental Health Area

Of particular concern is the lack of specific and active proposed actions around mental health. The draft strategy does not adequately address the significant mental health challenges faced by neurodisabled people and their families.

For people with neurodisabilities, mental health issues are often directly linked to their disability-related barriers, including communication challenges, sensory sensitivities, and the experience of living in a world not designed for them. The Strategy fails to propose concrete actions to:

- **Ensure training for mental health professionals** to recognise and understand neurodisability and its impact on mental health.
- **Provide accessible and flexible mental health services** that go beyond a "one-size-fits-all" approach and can be tailored to individual needs.
- **Acknowledge the unique mental health burden on family and whānau**, who are often providing intensive, unpaid care without adequate support. This contributes to caregiver burnout and impacts the family unit's overall wellbeing.

The document's vague language and lack of measurable outcomes mean there is no clear plan to improve mental health services for this vulnerable population. There is no commitment to funding, timeframes, or accountability, rendering the mental health section largely ineffective.

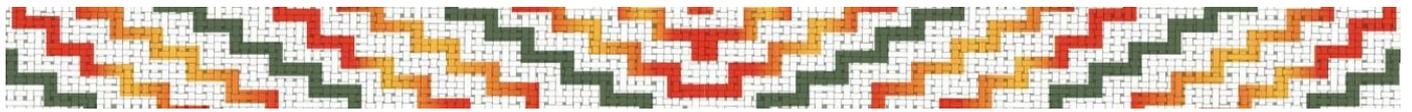
7. Response to Priority Area: Housing

Question 1: How much do you agree with the goal for housing?

The proposed goal for housing is admirable in its aspirations. The focus on providing **choice, security, and supply** is exactly what disabled people and their families and whānau want and need. However, we have significant concerns with the goal's fundamental scope.

The goal is flawed because it fails to genuinely recognise and support the **family and whānau** of disabled people. There are no actions to address the housing needs of families and whānau in supporting disabled people, nor do the goals consider the unique housing needs that arise from the caregiver role. Furthermore, the focus is exclusively on traditional housing models. The





document does not acknowledge the need for significantly increased **supported living options** for people with FASD and other high and complex needs, where a home is a place that provides both housing, security, and integrated, flexible care. Without these vital components, the goal is not truly inclusive.

Question 2. How much do you agree with the description of what success in housing means?

The success statements for housing are **aspirational and detached from the reality** of achieving meaningful change. They read more like a description of an ideal state rather than a concrete plan.

A fundamental omission is the lack of any mention of **mandatory universal design or accessibility standards** for all new housing. Relying on the "housing sector understanding" or "urban design" will not create the required supply of accessible homes. History has shown that voluntary codes do not work, and the only way to meet demand is to legislate and enforce mandatory standards.

Additionally, the document mentions "affordable" homes but completely fails to acknowledge that **poverty** is a significant barrier to housing for many disabled people. Without addressing income inequity, access to housing will remain a pipe dream. Finally, like the other priority areas, the success statements are not tied to specific, measurable actions or timeframes, making it impossible to hold the government accountable for progress.

Question 3: Do you have any further comments or suggestions on the goal for housing or the description of what success means?

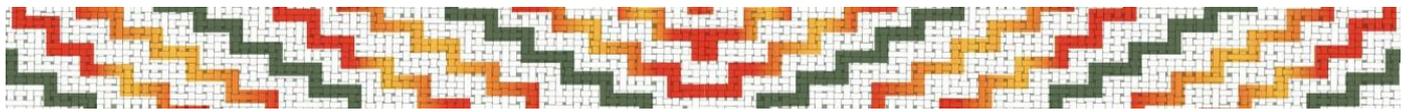
Aspirational Goals, Unclear Actions: The goals of choice, security, and supply are exactly what disabled people and their families need. However, the document lacks a clear pathway to achieve these goals. The statements of "what success means" are not a plan; they are a description of an ideal state. Without specific, legislative actions, these goals are unattainable.

The Unaddressed Issue of Universal Design: A fundamental omission is any mention of mandatory universal design or accessibility standards for all new housing. Relying on the "housing sector understanding" or "urban design" will not create the required supply of accessible homes. History has shown that voluntary codes do not work; the only way to meet demand is to legislate and enforce mandatory standards.

Poverty as a Barrier: The document mentions "affordable" homes, but it fails to acknowledge that poverty is a significant barrier to housing for many disabled people. Without addressing income inequity and providing realistic pathways out of poverty, access to housing, regardless of its design, will remain a pipe dream.

Exclusion of Family and Whānau: The goals once again fail to recognise and support the family and whānau of disabled people. There are no actions to address the housing needs of families with high-needs children, nor do the goals consider the unique housing needs that arise from the caregiver role.





Lack of Supported Living Options: The focus is on traditional housing. The document does not acknowledge the need for supported living options for people with high and complex needs, where a "home" is a place that provides both housing and integrated, flexible care.

No Meaningful Accountability: Like the other priority areas, the goals and success statements are not tied to specific, measurable actions or timeframes, making it impossible to hold the government accountable for progress.

Housing Actions

Question 1: How much do you agree with each action?

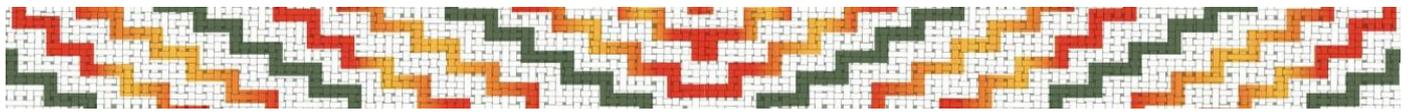
The proposed housing goals are laudable, but once again, they are lacking in actionable detail. The goal of having safe, healthy, and stable housing that meets disability needs is essential for every person, not just disabled people. However, the proposed actions focus almost exclusively on physical accessibility, to which has been applied a very old and narrow definition of "accessibility".

For people with FASD and other neurodisabled individuals, accessibility extends beyond physical access to include neuro-inclusive design, flexible support systems and housing models, and accessible communication. The Strategy must adopt a broader definition of accessibility to genuinely address the needs of all disabled people in Aotearoa New Zealand.

Question 2: Do you have any further comments or suggestions on the proposed actions?

- **The Ineffectiveness of Voluntary Guidelines:** Housing Action 6 proposes "voluntary national guidelines" for accessibility. This is a fundamentally flawed approach. The private housing market has shown it will not adopt these standards voluntarily. To truly address the housing crisis for disabled people, the government must mandate minimum accessibility features in all new-build homes, with legislation that is monitored and enforced.
- **Neglect of Affordable Home Ownership:** The strategy fails to address home ownership schemes, which are crucial for providing disabled people with long-term housing stability and equitable housing outcomes.
- **Lack of Mixed Housing Investment:** The government needs to invest in or incentivise private developers to create mixed-housing options. We do not want to create isolated communities of disabled people, detached from the wider community. The development of accommodation must also be pet-friendly, as pets often serve as a major source of support for disabled people.



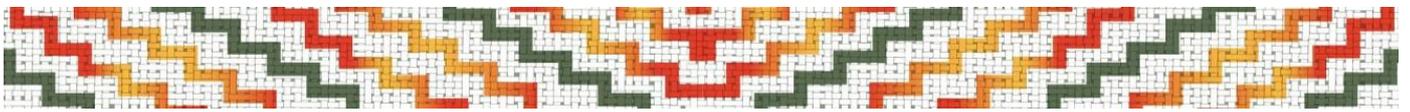


- **Missing UNCRPD Link:** There is no specific reference to the UNCRPD's right to adequate housing included in Article 28, which should be a foundational principle for all housing actions.

We find the proposed housing actions to be inadequate, preferential, and lacking in ambition. They are an uncoordinated set of aspirational statements that will not create the systemic change required to address New Zealand's housing crisis for disabled people.

- **Reliance on Voluntary Measures:** The reliance on "clear definitions" and "voluntary national guidelines" (Actions 1 and 6) is a recurring, ineffective approach. History has consistently shown that voluntary codes for accessible design do not work. The only way to ensure the supply of accessible housing meets demand is through a legislative mandate for universal design in all new builds. This is a fundamental right, and it is also the most cost-effective solution in the long term.
- **Limited Definition of Accessibility:** Furthermore, the understanding of accessibility within these sections appears to be limited to the physical environment. For people with FASD and other neurodisabled people, accessibility extends beyond physical access to include neuro-inclusive design, flexible support systems, and accessible communication. The Strategy must adopt a broader definition of accessibility to genuinely address the needs of all disabled people, particularly in the context of housing and employment. The goal should be that every disabled person has safe, healthy, stable housing that meets their specific needs, including neuro-inclusive design.
- **Home Ownership Omission:** A critical omission is any mention of a home ownership scheme for disabled people. This is what ultimately provides true housing stability, a crucial right outlined in the UNCRPD. The document fails to provide a strategy for building wealth and providing long-term security.
- **Inadequate Focus on Poverty:** The proposed actions do not address the root cause of housing insecurity for many disabled people: poverty. Simply making more houses available, even if they are accessible, does not solve the problem if disabled people cannot afford them. A truly effective strategy would include actions to address income support, benefit levels, and the financial hardship faced by disabled people.
- **Reactive, Not Proactive:** The review of the housing modification system (Action 4) is a reactive approach to a problem that could be largely avoided. Retrofitting homes is expensive, inefficient, and often leads to delays that put disabled people's safety and well-being at risk. A proactive strategy would focus on mandating accessible design from the outset, which is far more cost-effective.
- **Lack of Family and Whānau Support:** There is no action dedicated to supporting the housing needs of families and whānau. The Strategy fails to acknowledge the unique pressures on caregivers who require accessible homes that can accommodate high and





complex needs. The housing crisis also directly contributes to caregiver stress and burnout.

- **Data as a Substitute for Action:** Actions 2, 3, and 5 are focused on data collection and market "influence." While data is important, the government already has more than enough evidence to act. The focus on data gathering feels like a way to avoid taking concrete, politically difficult steps. It is not going to put a single roof over the head of a disabled person.
- **Omission of Supported Living and Mixed Housing:** The actions are designed for a mainstream housing model and do not include any provisions for the creation and funding of supported living models. For many people with neurodisabilities and intellectual disabilities, supported living provides the best opportunity for a life of independence and well-being. Furthermore, the government needs to invest in mixed-housing options or incentivise private companies to do so. This will prevent the creation of segregated communities of disabled people and promote true community inclusion.
- **Pet-Friendly Accommodation:** It is critical that housing options are pet-friendly. For many disabled people, pets are a major source of support, companionship, and emotional regulation, and a lack of pet-friendly housing is a significant barrier.
- **Lack of Measurable Timelines:** Once again, these actions are vague. They lack any specific timeframes or measurable outcomes, making it impossible to hold anyone accountable for their implementation.

We also support the submission on Housing made by Disability Connect on this issue.

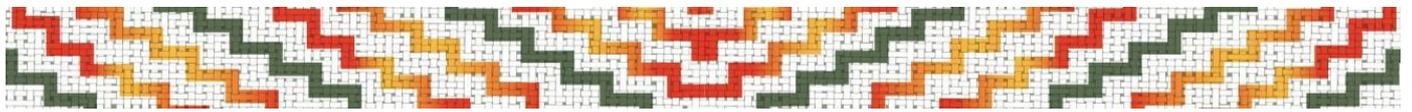
8. Response to Priority Area: Justice

Question 1: How much do you agree with the goal for justice?

We agree, in principle, with the proposed goals for the Justice priority area. They correctly articulate the need for disabled people to be protected and treated equitably. However, like many other sections of this Strategy, we have a **very low level of agreement** with the goal as written because it is vague and fails to provide a clear, actionable plan to address systemic barriers.

- **Vague and General:** The goals use broad and unspecific language such as "treated fairly and equitably" and "have the right supports." For neurodisabled people, and particularly those with FASD, the definition of "fairly and equitably" needs to be highly specific. It must acknowledge that traditional justice processes are inherently inaccessible and traumatising for those with cognitive impairments.
- **Failure to Acknowledge Reality:** The proposed goals are detached from the lived and living experience of neurodisabled people. The high prevalence of neurodisability,





particularly FASD, in New Zealand's prison and youth justice populations is a critical reality that is not reflected in the vagueness of the goals.

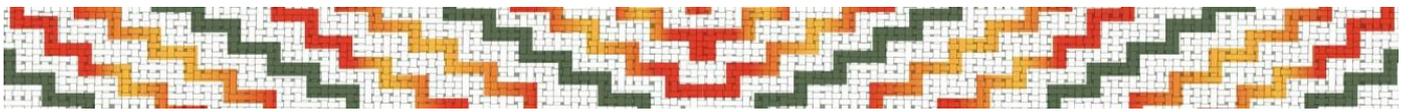
- **Missing UNCRPD Link:** The document fails to explicitly link the justice goals and actions to the rights enshrined in the UNCRPD, particularly those related to access to justice and legal capacity. This omission weakens the strategy's foundation in international human rights law.

Question 2: How much do you agree with the description of what success means?

We have a **very low level of agreement** with the description of what success means in this priority area. While the proposed success statements are admirable in their intent, they read like a theoretical framework rather than a response to the lived experience of neurodisabled people within the justice system. They fail to provide a clear, actionable plan to address systemic barriers.

- **The Missing Lived Experience:** The success statements fail to include actions that directly address the overrepresentation of people with neurodisabilities in the justice system. To be effective, the strategy must acknowledge and respond to this reality.
- **Lack of Family and Whānau Focus:** As with other priority areas, the crucial role of family and whānau is largely absent. Parents and caregivers are often the primary advocates for their disabled children and adults, navigating complex and adversarial systems. The strategy fails to address their need for support, training, and a formal, recognised role within the justice system to assist with decision-making and communication. There is no mention of the child's voice being heard through their family and whānau in these processes.
- **Beyond the "Justice Workforce":** While Action (e) mentions building skills and capabilities, it lacks specific detail. This is not just about general "disability competence" but about providing mandatory, comprehensive training on neurodisabilities, cognitive impairment, and trauma-informed practices for all justice sector staff, from police officers to court officials. Without this, the system will continue to fail this vulnerable population.
- **Omission of Key Transitions:** The success statements lack any meaningful detail on how transitions out of the system and early intervention will be achieved. There is no mention of funded, multi-agency transition plans or the crucial need to break down the silos between the justice, health, and social services. A person leaving the justice system with a neurodisability requires a holistic, long-term package of care, not a disjointed set of services.
- **Prevention is Key:** While early intervention is mentioned, it is not a strong enough focus. The primary goal for a meaningful strategy on neurodisability and justice should be proactive prevention. The strategy needs to invest in early, lifelong supports that reduce the





risk factors for justice system involvement in the first place, rather than waiting until a person is already in the system.

- **Failure to Address the Pipeline:** The justice system does not exist in a vacuum. A significant number of disabled people who interact with it have been failed by the education, health, and social service systems. Without addressing these upstream failures and providing early, lifelong support, the justice system will continue to be a primary point of contact for neurodisabled people. The strategy must commit to a cross-agency, whole-of-life approach to disrupt this pipeline, rather than simply focusing on the justice system in isolation.

Question 3: Do you have any further comments or suggestions on the goal for justice, or the description of what success means?

Please consider our submission on the Justice priority area above.

Justice Actions

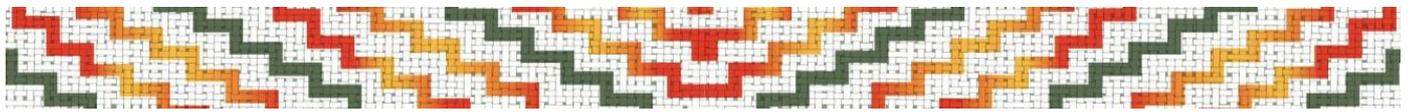
Question 1: How much do you agree with each action?

We find the proposed justice actions to be an uncoordinated set of aspirational statements that will not create the systemic change required to address the overrepresentation and mistreatment of neurodisabled people in Aotearoa New Zealand's justice system.

The government's focus in these actions appears to be heavily skewed towards addressing disabled people as victims of crime and abuse, a focus undoubtedly influenced by the abuse in care report. While this is a critical issue, it is not the full picture of the lived experience of all disabled people. The proposed actions fail to address other common interactions with the justice system, such as being accused of a crime, or having proceedings in the Family Court, Tenancy Tribunal, or other justice settings. The actions are insufficiently defined and non-committal, with no accountability or meaningful measurement.

- **Inappropriate Inclusion of Pre-Existing Work:** We note with concern that Justice Action 4, the Law Commission's review of the Criminal Procedure (Mentally Impaired Persons) Act 2003, is not a new commitment but a pre-existing work programme. Its inclusion as an 'action' within this Strategy is therefore disingenuous.
- **Vague Language:** The actions rely on vague commitments such as "develop," "review," "explore," and "integrate lessons." These are not strong, actionable commitments. They lack clear timeframes and accountability measures, creating a significant risk of no real change.
- **Omission of Key Interactions:** The actions fail to address key issues for disabled people interacting with the justice system, such as:

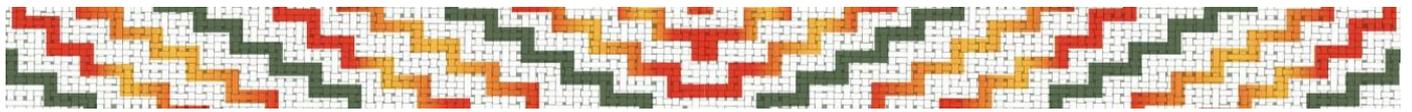




- Protecting disabled people who are witnesses and may be perceived as "unreliable."
 - Acknowledging disability as a mitigating circumstance during sentencing.
 - Developing effective neurodisability-based rehabilitation programmes to address recidivism within the Corrections and Youth Justice systems.
- **Workforce Competence (Action 7):** While the goal of increasing workforce competence is important, the action lacks specific detail. This is not just about general "disability competence" but about providing mandatory, comprehensive training on neurodisabilities, cognitive impairment, and trauma-informed practices for all justice sector staff, from police officers to court officials. Without this, the system will continue to fail this vulnerable population.
 - **Early Intervention (Action 3):** A "social investment plan" is too weak. The focus should be on proactive, lifelong, holistic supports that prevent justice system involvement in the first place, rather than waiting until a person is already in the system. The government needs to break down the silos between health, education, and social services to address the root causes of offending.
 - **Supported Decision-Making:** While Action 5 mentions "considering" supported decision-making, this is not a strong enough commitment. The UNCRPD calls for the immediate and full recognition of legal capacity and supported decision-making. "Considering" a review is an insufficient action.
 - **Data as a Substitute for Action:** The focus on data collection (Action 2) is a common strategy to delay concrete, politically difficult steps. The government already has enough evidence to act. While better data is important, it should not be an excuse to avoid immediate, effective action.
 - **Omission of Key Transitions:** The actions fail to provide a clear, funded plan for people with neurodisabilities transitioning out of the justice system. A person leaving detention requires a holistic, long-term package of care that involves multiple agencies, not a disjointed set of services. This is a critical area that requires a formal, multi-agency approach.
 - **Protection for Family and Whānau:** The actions fail to include any provisions for the protection of family and whānau, particularly from the pressures and responsibilities of caregiving, which can be an issue in terms of **Child and Adolescent Violence to Parents (CAPVA)**.

Question 2: Do you have any further comments or suggestions on the proposed actions?





We find the proposed justice actions to be an uncoordinated set of aspirational statements that will not create the systemic change required to address the overrepresentation, misunderstanding and mistreatment of neurodisabled people in Aotearoa New Zealand's justice system.

The government's focus in these actions appears to be heavily skewed towards addressing disabled people as victims of crime and abuse, a focus undoubtedly influenced by the government's commitment to address issues arising from the Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions report. While this is a critical issue, it is not the full picture of the lived experience of all disabled people. The proposed actions fail to address other common interactions with the justice system, such as being accused of a crime, or having proceedings in the Family Court, Tenancy Tribunal, or other justice settings. The actions are **insufficiently defined and non-committal**, with no accountability or meaningful measurement.

- **Inappropriate Inclusion of Pre-Existing Work:** We note with concern that Justice Action 4, the Law Commission's review of the Criminal Procedure (Mentally Impaired Persons) Act 2003, is not a new commitment but a pre-existing work program. Its inclusion as an 'action' within this Strategy is therefore disingenuous and undermines the document's credibility, but again highlights this is Government strategy document not a New Zealand Disability Strategy.
- **Omission of Key Interactions:** The actions fail to address key issues for disabled people interacting with the justice system, such as:
 - Protecting disabled people who are witnesses and may be perceived as "unreliable."
 - Acknowledging disability as a mitigating circumstance during sentencing.
 - Developing effective neurodisability-based rehabilitation programmes to address recidivism within the Corrections and Youth Justice systems.
 - Ensuring protections for family and whānau in terms of **Child and Adolescent Violence to Parents (CAPVA):** The Strategy fails to address the significant and disproportionate issue of violence and abuse that can be committed by disabled children and young people against their parents, caregivers, and family and whānau members. This is a critical safety issue for families and whānau with neurodisabled children, yet it is completely absent from the proposed actions, reinforcing the narrow focus on disabled people solely as victims.

A meaningful strategy must acknowledge and fund a comprehensive, cross-agency response that addresses the need for immediate physical support and protection for families, while recognising that the violence is often a symptom of the neurodisability rather than an intentional, criminal act. This response should be focused on therapeutic and restorative approaches rather than criminalisation.





- **Supported Decision-Making:** While Action 5 mentions "considering" supported decision-making, this is not a strong enough commitment. The UNCRPD calls for the immediate and full recognition of legal capacity and supported decision-making. "Considering" a review is an insufficient action.

9. How we will measure progress

Question 1: How much do you agree with the following statements?

- The strategy reflects what matters most to disabled people and their whānau?
- I feel confident that the strategy will lead to meaningful change.

We have a **very low level of agreement** with both statements. Our position is that the strategy, in its current form, neither reflects what matters most to disabled people and their families and whānau, nor will it lead to meaningful change for our FASD community.

- **The strategy reflects what matters most to disabled people and their whānau.** The strategy fails to consistently acknowledge the central role of family and whānau as a primary support system and advocate. Furthermore, it largely reflects a neurotypical, deficit-based model that does not align with the needs and aspirations of neurodisabled people, intellectually disabled people, or those with high and complex needs. We are told to fit into an existing system rather than seeing the system adapt to us.
- **I feel confident that the strategy will lead to meaningful change.** We have little confidence that this strategy will lead to meaningful change. As highlighted in our submissions, the document's vague and aspirational language, combined without concrete, measurable actions and timeframes, makes genuine accountability impossible. It is a collection of high-level goals and needs a clear plan for implementation. The absence of a cross-agency, whole-of-life approach means the strategy will not address the systemic failures that create a "pipeline" of neurodisabled people who are failed by one system only to encounter the next.

Question 2: Is there anything else you would like to see in the strategy?

Yes. To be effective, the strategy must be fundamentally rewritten to embed the **Enabling Good Lives (EGL) principles** as its foundation. We want to see a vision for Aotearoa New Zealand that is genuinely rights-based and focused on empowering disabled people and their family and whānau.

Specifically, we would like to see:

- **Centralised Accountability:** A shift away from local autonomy to mandatory, verifiable standards and funding that follows the person, not the service provider. This would end the "postcode lottery" for support.





- **A Focus on Prevention:** The strategy must address the upstream failures in the health, education, and social service systems that disproportionately impact neurodisabled people. We need to see proactive, lifelong support that reduces the risk factors for engagement with the justice system and other services.
- **Mandatory, Neuro-Inclusive Training:** Comprehensive training on neurodisability, cognitive impairment, and trauma-informed practices for all professionals in the health, education, and justice sectors.
- **Data that Captures Lived Experience:** A commitment to collecting data that goes beyond generic metrics to capture the real-world, lived experience of disabled people and their families. This is essential for truly understanding and addressing systemic inequities.

Question 3: Do you have any further comments or suggestions on this strategy?

Our central comment is that this strategy is a missed opportunity. While it is well-intentioned, it fails to provide a clear, actionable plan to address the systemic barriers faced by disabled people.

The document's proposed method of measuring progress relies on government agencies reporting on their own actions and a dashboard of indicators. This approach is insufficient. True progress cannot be measured solely by whether an action was taken, but by the tangible impact on the lives of disabled people. Without a clear mechanism to hold agencies accountable to real-world outcomes, the proposed framework for measuring progress will not be effective.

To lead to genuine change, the strategy must:

1. **Commit to a whole-of-life, cross-agency approach** that breaks down silos between services.
2. **Adopt a rights-based framework** with a focus on EGL, "Nothing about us, without us" and a genuine Māori voice.
3. **Provide clear, non-negotiable obligations** for agencies, backed by legislative authority and independent oversight.

Without these fundamental changes, the strategy will remain an aspirational document with little chance of making a meaningful difference.

