Re: Consultation on the draft New Zealand Disability Strategy 2026-2030

To: The Ministry of Disabled People – Whaikaha
disabilitystrategy@whaikaha.govt.nz
Date of Submission: 25 September 2025
Submitted by: Rare Disorders NZ
Contact person: Chris Higgins (CE)
Email: Chris@raredisorders.org.nz

Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract. This submission is in response to the consultation on the draft New Zealand Disability Strategy 2026-2030.

Rare Disorders NZ

Rare Disorders New Zealand (RDNZ) is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300,000 New Zealanders with rare disorders and the people who care for them. We help those living with rare disorders to navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

Our vision is for New Zealand/Aotearoa to become a country where people and whānau living with a rare disorder experience best possible health and wellbeing. We seek to achieve this by enabling and empowering people with rare disorders to best benefit from services and therapies available in New Zealand, and by championing their collective voice, advocating for provision of world leading evidence based health, disability, education and other services.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand.

Introduction

This is a submission by Rare Disorders NZ, informed by our support group collective. Attached to this submission is the Whaikaha feedback form which contains themed quotes from our Support Group Leads which were obtained through an online discussion of the draft strategy.

RDNZ welcomes the opportunity to provide feedback on the draft New Zealand Disability Strategy 2025-2030.

Summary

It is pleasing to see in many places throughout the draft Strategy there are signals of a commitment to a more inclusive and responsive system for all disabled people. We hope that for disabled people living with a rare disorder their unique and often complex needs may finally be seen and better supported across systems.

RDNZ notes with concern the absence of the Enabling Good Lives (EGL) principles in the draft strategy. We strongly recommend that these principles be clearly reflected and meaningfully integrated into the strategy.

RDNZ would like to see a more coordinated and whole person approach in this strategy. We need a strategy where the overlap and need for co-ordinated and integrated pathways across the priority areas and government departments is recognised. Rare disorders often touch every aspect of a person and their family's/whanau lives. This includes health, employment and recreation, as well as their access to education, disability, housing and financial support services. Government agencies work in silos, people do not live in them. The Disability Strategy should aim to shift the burden of navigating system gaps away from disabled people and their carers, placing the responsibility instead on government departments and health services to coordinate and deliver integrated support.

Many people living with rare disorders do not fit tick boxes or neatly into categories and fall through the cracks in systems that are not designed with them in mind. RDNZ would like to see more focus on these gaps and grey areas in the strategy. For people with rare disorders, this is particularly apparent in two areas:

- Individuals with both disability and complex health conditions who are poorly served by either the health or disability systems; and
- Disabled people who require supported independence but are left without appropriate services, often feeling "not disabled enough" for some supports and "too disabled" for others.

RDNZ would like to see more focus on disabled people with intellectual and neurodevelopmental disabilities in the strategy. In many instances, this community appears to be overlooked or treated as an afterthought. Many people living with rare disorders and their carers do not feel seen in this strategy as a result. This came through in discussion of all areas of the draft strategy.

RDNZ would also like to see more content in the strategy about Disability Support Services and financial assistance, both for disabled people and their carers. This area is vital for ensuring equity and inclusion. We would like to see this as a priority area, or the priority area of employment reframed to include those unable to earn an income through employment.

Mental health and wellbeing are areas that are relevant across the priorities in the strategy. Disabled people and their carers are overrepresented in mental health statistics and this should be addressed within a disability strategy. Rare Disorders NZ would like to see mental health and well-being recognised as a cross-cutting theme or priority area, or individually in each priority area.

Transitions are another area relevant across the strategy priorities that RDNZ would like to see recognised as a cross-cutting theme or addressed in each priority area. Whether this is the transition between different parts of the education system, into adulthood, into employment, into housing, from paediatric to adult medical services, or from hospital specialists to GP care, transitions need special focus as often they are times of great challenges with little support for disabled people living with rare disorders and their carers and whānau.

To see effective implementation of the strategy, RDNZ recommends assigning responsibility to relevant government departments for the action points throughout the strategy and incorporating accountability measures and how progress will be monitored.

RARE
DISORDERS NZ

Scan for
NZSL name

Whaikaha
Ministry of Disabled People

Feedback Form

The Ministry of Disabled People – Whaikaha is consulting on the draft New Zealand Disability Strategy 2026-2030.

Section 1: About You

Rare Disorders NZ and our Support Group Collective have contributed to the feedback in this form. Comments directly from Support Group Leads are noted in italics.

The rare disorder support groups that were represented in the discussion include the following:

New Zealand Pompe Network
The Angelman Network
Hereditary Hemorrhagic Telangiectasia (HHT)
Unique NZ
Head and Neck Cancer Support Network Trust
CMT NZ - Charcot Marie Tooth Disease Support Network New Zealand
IDFNZ
Fragile X New Zealand
22q Foundation Australia & New Zealand
KiwiCRPS
FACSNZ
TSCNZ
Ehlers-Danlos Syndromes Aotearoa New Zealand
Prader-Willi Syndrome Association NZ
Freidreichs Ataxia Research Association New Zealand
Hirschsrpung's disease support NZ
Ehlers-Danlos Aotearoa New Zealand
Brain Tumour Support Trust NZ
SMA Community

Section 2: Vision and Principles

The strategy will have a vision. This is a statement describing the future that disabled people want to achieve through the strategy.

The **proposed vision** is:

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

On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the following statements about the **vision**?

- The **vision** is clear and easy to understand.

Strongly disagree	6%
Disagree	6%
Neither agree nor disagree	0%
Agree	56%
Strongly agree	33%

The majority agreed or strongly agreed that the vision is clear and easy to understand.

The **vision** aligns with the values and aspirations of disabled people.

Strongly disagree	6%
Disagree	0%
Neither agree nor disagree	6%
Agree	67%
Strongly agree	17%

The majority agreed or strongly agreed that the vision is clear and easy to understand.

- I feel confident the **vision** will lead to meaningful change.

Strongly disagree	0%
Disagree	28%
Neither agree nor disagree	28%
Agree	11%
Strongly agree	17%

The majority disagreed or were neutral that the vision will lead to meaningful change

Do you have any further comments or suggestions about the **vision**?

RDNZ recommends adding appropriately supported to the vision. Currently, the vision is primarily about the disabled person's responsibilities, not how the rest of society and government can support disabled people to achieve these outcomes.

Support Group Lead feedback:

- *Add in "all aspects of life as they perceive it to be"*

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

Seven **principles** have been proposed for the strategy.

Do you have any further comments or suggestions on the proposed **principles**? **(please write your response below)**

Support Group Lead feedback:

- *Surprised EGL was missing*
- *Agree EGL needs to be rolled out as promised.*
- *Does choice and control extend to caregivers?*
- *Accessibility can be interpreted in different ways, the meaning of this could be clearer. Another comment replied: agree, it tends to suggest just physical accessibility. Another comment asked if this is something Sunflower could assist with? or Hapai*

- *Control can be seen as a negative word as a lot of disabled people have had people control them, so can be triggering.*
- *Self-determination would be better than 'control'*
- *what does intersectionality mean? Particularly hard to understand for easy readers*
- *Choice and control can simply be exchanged for self-determination which is all encompassing*

Section 3: Priority Outcome Areas

The strategy has five priority outcome areas: education, employment, health, housing and justice.

Each area has a goal, a description of what success means, a case for change, and a set of proposed actions to which the Government will commit to achieve success for disabled people.

Education

The **goal** for education is:

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

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

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

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

On a scale (strongly disagree) to 5 (strongly agree) how much do you agree with the description of **what success in education means**?

Strongly Disagree	0%
Disagree	11%
Neither disagree nor agree	21%
Agree	53%
Strongly agree	16%

The majority agree with the description of success in education

Do you have any further comments or suggestions on the **goal** or the **description of what success means**?

Support Group Lead feedback:

Education that is meaningful and delivered effectively

- *Suggest that the words meaningful education are included as for the employment definition.*
- *Suggest adding that education and services are delivered effectively.*

Individualised Learning

- *Everyone learns differently so offering tailored options to the person would be more effective to deliver equitable outcomes*
- *I think with education and relating this to UNCRPD, enabling learners to learn in a way that's how they want to learn is important.. providing ways that we can learn is fine, but it comes down to the disabled Person and how they want to learn*
- *Catering learning to the learner's aspirations and personal goals would be valuable for engaging learners improving their sense of belonging in educational settings.*
- *Learning that is suited to the learner.*
- *Consider learning style*

Lifelong Learning

Education should extend beyond school, supporting lifelong learning, including adult vocational services.

- *Life long learning? Learning doesn't stop or is this just the school education system?*
- *Does this include adult vocational services?*
- *People in the KiwiCRPS group have been talking a lot recently about needing support to retrain, having lost their pre-injury vocation. This links with both education and employment..... So perhaps the education section needs something about adult / vocational training.*

Realistic Goals and how success is defined in the real world

- *Having such an aspirational goal is good, but realistically not achievable in 4 years. Inclusive Education Action Group have been trying to do this for years.*
- *This is what good education should mean but not how schools and the government measure 'success' for students*

Collaboration, training, and support

Success depends on effective collaboration between schools, teachers, services, and family/whānau. Teachers need better training and resources to support disabled learners.

- *It also comes down to whether the school-teacher- services can or want to work together.*
- *The schools aren't given the correct training or support to give them the option to take on disabled learners as well. So often they 'give up' because they can't help due to lack of their support too…*
- *Even when there is support e.g. funded TA, hours are misappropriated for other students.*

- *One issue that comes up a lot is that needs are not understand at school governance level. Pupils / families can feel unsupported by the MoE who feel they can't step in.*

Eligibility for support and the 'grey zone' who don't qualify for the support they need (expanded on in feedback on actions 3 and 4)

- *Concerned about how we decide who receives assistance (definition of disability). I agree with the goals, but there are some arbitrary cutoffs*
- *I have concern about how rare disorders fits in because we know that diagnosis takes longer therefore the disabled individual could not have supportive learning opportunities [while undiagnosed].*

Social and emotional well-being is missing

- Success should focus on individual growth and wellbeing, not just academic outcomes.
- *I think social aspect within schools is very important like more adaptable physical education and more inclusive play areas so children feel included and can create friendships and good mental wellbeing*
- *Where is the happiness of the disabled learner considered?*

Alternatives to school

Te Kura and health school are not currently included.

- *How does home schooling fit in?*

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

❖ Do you have any further comments or suggestions on the proposed **actions**?

Action 1: Invest $266 million to expand early intervention services to support the identification of learning support needs early in a child's life and reduce wait times for assessments and services.

- *I wonder how those who struggle with the barriers associated with getting a formal diagnosis, as is with many rare disorders, access equal early intervention services?*

Action 2. Explore new options for targeted and specialised support and provisions to reduce wait times using private providers and NGOs.

- *I see that point 2 is saying that private providers can reduce wait times, who pays for this? Also a post code lottery*
- *Re: NGO's...it's almost a charter school debate*
- *Just regarding adding more classrooms and things, we don't have to stick with the SENCO model. We can do things differently, and I have pushed our local school here to open up through a provider who has a different model. It's not SENCO-based, and it's not MOE-run. Now, we had to do that ourselves, but I feel like if we push things to be a little bit different, we can have more choices. So, you then have the choice between the model that suits you or not, you know? Our son's ORS is being used by the private provider. They're setting up a hub classroom, they're a specialist teaching outlet, that's all they do, they're child-centered. They bring in speech therapists, they bring in occupational therapists, they bring in everything MOE says we're getting that we're not getting.*

Action 3. Make improvements to the learning support system so it is easier to navigate for educators, families and learners through: funding all schools with Year 1-8 students for a Learning Support Coordinator; and by reducing the complexity and accessibility of the application process.

- *Issues around eligibility are so key but not really addressed here, simplifying the application process does not mean simplifying access to services*
- *From experience the level of expertise of the senco plays a big part in inclusivity and connection*
- *Would be great if the support that is called full time actually was fulltime instead of 20hrs TA support for a child who attends 30hrs but needs one on one support.*
- *Better options for children who don't fit a specific criteria for ORS and aren't entitled but need more hours funded. especially when physical safety is a concern*
- *We've had lots of reviews of learning support in recent years, including the highest needs review, but the promised review of ORS hasn't happened. This may come under point 3, but not specifically mentioned.*
- *Also what happens to those who live rurally and do not have the skill set required for the individual?*
- *Very had to determine what disabled is.. if they don't have an official diagnosis, the teachers often don't think the child are 'bad enough' to receive review.. what are we doing in the grey zone? are the doctors able to input into needs in education ? (very upvoted comment)*
- *ORS is unavailable for our 22q kids, unless their behaviour is a problem, a child who is hearing, speech impaired, 3 learning needs and adhd, does not qualify for any support in school. unless he started acting out.*
- *A lot of focus seems to be more bad behaviour based for support than the children whom sit and fall under the radar.*
- *I would like to see resources targeting primary and secondary education, as we know a lot of disabled learners lack the support they need to complete secondary education. Having a greater emphasis on supporting younger learners would better retain learners throughout all levels of education, and improve the statistics regarding student withdrawals.*
- *It needs to be mandated that pupils with different learning needs have an IEP. Currently this is only officially in place if a pupil has ORS. We need more flexibility in the assessment of different*

learning needs that require additional support. With PWS [Prader-Willi Syndrome] for example, some pupils receive ORS and some can only access SHHNF. But all pupils with PWS have health needs and learning needs. There needs to be assessment of global needs.

- *Our SENCO looks after 3 schools in our district, and every time I raised an issue with her, 'I'm so busy, I'm so busy', and now [my son] does not attend school anymore, and he's only attended school two weeks this year. I feel like we are going to have SENCOs that are stretched to the brink, and how do we apply the workforce to this so that SENCOs are held to an expectation that they deliver on what they can promise, and that it is inclusive. Like, we live in a rural area, and from National's announcement recently, there's going to be one school out of 22 schools that will get a new SENCO. So how does that work compared to Christchurch, which has a huge, vast amount of students, but we have quite a lot of Intellectually and physically disabled children in our area.*

Action 4. Invest funding in additional learning support classrooms to provide choice for parents.

- *Add more classrooms including alternative models to SENCO and MOE classrooms? More choice should mean different models to choose from too.*

Action 5. Work with the Ministry of Disabled People - Whaikaha to develop improvements in teacher training and guidance that support teachers to meet the needs of disabled students.

- *Teachers need support learning more in depth knowledge of the specific disability they are faced so they can better adapt their learning plan for that child.*
- *For a start, there is almost no training in teacher training that prepares teachers to teach those with additional needs.*
- *nonverbal children struggle all the way through due to lack of teacher training and resources.*

Action 6. Work with the Ministry of Disabled People - Whaikaha to explore opportunities to improve accountability for schools though reporting on learning and achievement outcomes for disabled learners.

- *A real lack of acknowledgement of intellectual disability and students that were falling under Level 1 [of the curriculum] because at the moment, data isn't collected by schools on students that are sitting below there, and so for learning disabled students, intellectually disabled students there's no mandate for schools, as you know, to collect data, and record progress, and there's no accountability, so I just didn't see anything, around the action points particularly that was going to address that.*

Areas identified as missing from the actions.

- **Transition**- *need to also address transition from school.*
- **Alternatives to traditional schooling** - *Home school and health school not included.*
- **Attendance** - *Schools have to report days the child is away from school sick - how is this being fairer for those sick due to their disability?*
- **Equity** - *These actions do not mention the importance of equity (across a range of domains, including geographic location).*
- **Emotional and social well-being –** *Where is the consideration of mental health and happiness?*

Employment

The **goal** for employment is:

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

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

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

- On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the description of **what success in employment means**?

Strongly disagree	0%
Disagree	16%
Neither agree nor disagree	32%
Agree	42%
Strongly agree	11%

The majority agree or are neutral about the description of what success in employment means.

- Do you have any further comments or suggestions on the **goal** or the **description of what success means**?

Suggested changes to wording

- *change the word 'help' [in the description of success] to support or train as it's a measurable action*
- *Would love to see the importance of disabled people having long-term and secure employment highlighted.*

Need for societal change

- *We need social climate/attitude to shift but societal change takes longer than four years. And difficult to achieve with 3 years of government*

- *Systemic barriers ignored*
- *UNCRPD speaks to reasonable accommodation. The education in employment is coming from the govt down showing how great all communities are and actually giving support for all types of disabilities in employment. Neuro diverse as an example often sit quietly, but if it was an inclusive environment supports would all be available from the get go for everyone. The drive for this needs to come from the top down.*

Many don’t feel seen or included in this section

- *I feel that this strategy isn’t a one fits all model, particularly [for] us outliers*
- *Angelman community is not reflected in this employment section, at all. Where do the 'social enterprise' ideas sit?*
- *I feel this doesn't cover those with ID well. My son would need a support person alongside him. He wouldn't be able to do a lot of things on his own.*
- *a very generalised statement that doesn't really mean anything*

A wider view of employment is needed

- *Need to recognise other roles outside of employment that lead to social inclusion and valued roles in community also. (many upvotes)*
- *I find it easier in my head to think about capability than disability. EG. My daughter has disabilities but is capable of working part time in a supported environment.*
- *I keep coming back to social enterprise as a really health means of providing meaningful employment. Would really like more government support for this.*

Support for and inclusion of carers

- *what about the carers???*
- *Alot of the employment options are funded and supported by already exhausted caregivers (many upvotes)*
- *Agree - Parents and whanau largely ignored across the strategy*
- *Agree, need to see how the strategy lines up with the carers strategy*

- *This is person centred, not whanau or carer circle centred. in the same way that the health system became patient centred but cut out whanau.*
- *We fought a lot to get the word whanau in there and as we all know the whole issue always falls around the female caregivers being stuck… we can't go back to our full-time jobs when we are caring full-time for our child with a disability. So where do we fit into something like employment? Where's the flexibility and… this all talks about disabled people. It says nothing about their families and the effect that them, my [adult son] doesn't go along to work every day and earn his own money properly, so I have to supplement his… everything, all his expenses, even his vocational service now, he has to pay a daily fee on top of the MSD funding. everything is expensive, and I have to help support him financially, while not all being able to go and work full-time myself. That word, intersectionality, actually, I really like it, because this cuts through all of that. And I think the way when this is summarised, one to six points, it's very much a singular perspective, and it's not looking at the intersectional aspects of disability and the effects it has on the whanau.*

Equity rather than equality

- Some feedback was around ensuring that disabled people get paid the same amount as other staff. This was countered by- *I feel this would block [my adult child] from employment because she is slower and needs more input.* Another comment-
  I agree, this is also why many people with intellectual disabilities can only find voluntary work opportunities. There was a suggestion of tax credits for the disabled worker.

Lack of collaboration between employment and disability support services/other government financial support.

- *There are funding issues if someone needs a support person to be with them at work. Employment support services and disability support services need to be able to work collaboratively.*
- *MSD can sometimes also be quite rude intimidating and unempathetic in these circumstances*

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

Do you have any further comments or suggestions on the proposed **actions**?

Action 3: Work with disabled people, employers and employer networks to develop mentorship programmes connecting disabled people with successful disabled professionals or employers to provide guidance and support in navigating their careers.

- *Mentorship programmes.. I worry this might lead into NASC systems or funding streams using it as a 'do this or less funding' etc.. we've seen it happen before in other sectors*

Action 4: Partner with disabled people and support providers to create a centralised, accessible repository of practical information and resources for employers and employer networks so they can support disabled people throughout the employment lifecycle and to share knowledge and success stories.

- *4. & 6. Not sure how much change can be achieved by providing information to employers. They need real support and what this means needs to be specified*
- *I also think there is going to need to be a big shift for a lot of employers/businesses to engage disabled people. It will take a long time to change those perspectives.*

Action 5: Partner with disabled people, employers and employer networks to improve accessibility and inclusion in employment lifecycles for disabled people. This includes promoting and enabling the design of jobs and workplaces to support:

- inclusion of disabled people
- flexible working arrangements and reasonable accommodations
- assessing the accessibility of workplaces.

- *Covid has shown that flexibility is available, we should be using that as an example of what's possible*

Action 6: Implement a targeted, ongoing awareness campaign publicising guidance and resources for employers and employees on accessibility and inclusion, relevant data and reports, and highlighting the positive impact disabled people have had on workplaces. This action will support employment action 4.

- *Running a campaign isn't enough.. it needs to be continuous.. maybe give businesses perks to continue to work towards being a fully accessible environment, auditing them to make sure they do their job properly.*
- *our experience is that employers are incredibly reluctant to spend the time and money in a tight financial environment to take on people like my daughter.*
- *It has also shown when disabled people are honest about their disability they can end up not getting the job. (many upvotes)*
- *Employment : reference check questions around health I think breaches human rights*

Health

The **goal** for health is:

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

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

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

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

On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the description of **what success in heath means**?

Strongly disagree	0%
Disagree	24%
Neither agree nor disagree	12%
Agree	53%
Strongly agree	12%

Majority agree but a significant subset disagree with the definition.

Do you have any further comments or suggestions on the **goal** or the **description of what success means**?

Suggested changes to wording

- *Tangata whaikaha generally. Not just Māori*
- *Success in health means no discrimination, diagnostic over shadowing, no more treatment injuries due to a lack of treatment. This statement is nice fluff but how does it translate to real life outcomes?*

Recognition of health and accessibility needs of disabled people and that these differ based on the individual, family, and the disability

- *Timeliness of healthcare is an important determinant of health success for the CRPS group.*
- *Intellectual and complex disabilities ignored. Whānau and child voices largely absent.*
- *Definition of disabled (some conditions are invisible but have a huge impact). Also genetic testing to get a formal diagnosis*

- *What accessibility means to one isn't necessarily how everyone sees it e.g. pictures how to explain a procedure.*
- *The IHC study that revealed people with ID are dying approx. 20 years earlier in NZ needs to be addressed through this strategy. Regular specialist health checks...multidisciplinary clinics...understanding different communication styles etc (many upvotes)*
- *I would like to see rare disorders mentioned in health success summary.*
- *Include newborn screening to earlier detect disability causing conditions (in the rare community). By finding out early, we are better equipped to deal with future problems, and it gives more of an opportunity to live better lives.*

Need for holistic and coordinated care

- *Wrap around services for quicker better outcomes,*
- *Disappointing that there is a lack emphasis on holistic care and access to such diverse services (many upvotes)*
- *Co-ordinated care is very much needed (many upvotes)*
- *the siloed systems are exhausting and add to the overwhelm (many upvotes)*
- *People shouldn't have to navigate through multiple systems (both within health and with regards to health/education/disability/employment services)*
- *so many wasted appoinments because arthur didnt talk to martha!*
- *We need whakawhanaungatanga*

Recognition of the state of New Zealand's health system

- *We have a health system that is in crisis and our healthcare professionals are overwhelmed and short staffed, this means that more harm is going to occur.*
- *funding and how long it takes for NZ to access life saving treatments many other countries have*
- *GPs and other medical staff still lack a lot of knowledge for Rare disorder s*
- *How can we get more expert care in the regions? response: by centralising knowledge. Response: Would be great if we could access surgery in a timely matter by using other DHBS that aren't overwhelmed if we can travel our selves, eg 1 cleft team in south*

island. Response: Yes, I think decentralising was well intended (keep whanau together) but has had really negative impact with each area trying to provide everything.

In the draft New Zealand Disability Strategy there are **5 proposed health actions** to reach the goal.

Do you have any further comments or suggestions on the proposed **actions**?

Action 1: Review and improve policies and practices, so the health journey is equitable, accessible and inclusive. This review will include all interactions with the health system, covering communication, information, technology, decision-making, service design and delivery, and the built environment.

Self-determination should be a key consideration of the review. This includes making tools for self-determination and supported decision-making standard practice in health care – especially for people with different communication, cognitive or psychosocial needs.

- *While I like that my son can participate in making decisions about his own healthcare. With his ID he wouldn't be able to make a lot of decisions on his own - so I still believe in those instances having family as part of the collective in the decision is important.*
- *I have talked before about the grey area.. when we get funding for health based situation vs funding for disability.. when do we get funding for disability and health.. we need to capture this grey area and create a pathway for this as well*
- *Those with Intellectual impairment will more likely access through proxy, not advocate for themselves directly*
- *Technology: Disabled people travel a lot for medical care. How about national sharing of medical records so we don't have to do this out of region*

- *Making our health system accessible also means up dating the travel assistance figures so that families are not burdened by most of the cost of travel they can't access at home.*
- *UNCRPD speaks to people being allowed to choose their health care provider, so this speaks to things like distance, quality, and how people should be able to access this equally*

Action 2: Build health workforce capability to deliver services that are inclusive, culturally safe, and easy to navigate.

Building workforce capability includes increasing the proportion of disabled people across the health and disability workforce, through recruitment and workplace policies, inclusive and accessible work environments, and career development. It also includes embedding disability responsiveness and lived experience into health workforce training and ongoing professional development.

- *Need more health care providers and more people trained.. govt aren't funding more medical professionals to come through and this needs a massive focus. If we can train from the beginning, it will be a much stronger system for all kiwis*

- **Action 4:** Identify disabled people in national health data. Identifying disabled people in data will make them more visible in the health system. It will enable better monitoring of population health outcomes and patient experiences.

- *Data is pinnacle.. how else do we know what disability is. Very hard to quantify disability as not everyone sees themselves as disabled. If people need more help they should be able to get more help regardless of their disabled status*
- *Yes, data is absolutely essential. But we also need information / useful data attached to patient health records which is vital for rare disorders.*
- *I think points 4 and 5 are the priority*

Other areas identified for potential actions or inclusion

- *I wonder if including people with disability in the design of health services would be an important point to put as an action (I know this concept is addressed elsewhere, but it's quite key so might belong here too?)*
- *Health : connections with others in similar situations with lived experiences .. and international health advice*
- *Nothing mentioned about improving recognition and access to assessment/diagnosis*
- *Centre of expertise!*

Housing

The **goal** for housing is:

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

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

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

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

On a scale (strongly disagree) to 5 (strongly agree) how much do you agree with the description of what success in housing means?

Strongly disagree	0%
Disagree	12%
Neither agree nor disagree	24%
Agree	53%
Strongly agree	12%

The majority agree with the definition of success.

Do you have any further comments or suggestions on the **goal** or the **description of success**?

Comments

- *Again, housing is something EGL is already addressing. Are we trying to reinvent the wheel?*
- *this sounds like the focus is on the building - not on the systems around accessing homes*

Affordability and funding

- *housing costs due to needing specific modifications and being unable to work is a big barrier- for both disabled people and their carers*
- *Most of our community hit a road block the second we can't access NASC, so we can't get alterations or help in our homes to help them at home. Some often having to move to poorer areas to afford to live, but then can't get to medical appts*
- *there is no mention of safety in the planning and design ?*
- *Again this is lovely in principle but how will it translate to the real world when we don't have enough housing.*
- *still no separation between housing provision and disability services which is often an issue and barrier for choice and control*
- *Having government departments trying to pass the buck… I'm in a KO house that was semi-wheelchair accessible before I moved in. But the laundry is in an internal garage that has two steps down.*

Enable do not count a laundry as a necessity, so they wouldn't pay for a ramp. KO would let me have a ramp, but they wouldn't pay for it, so everyone passes the buck to somebody else to try… I was shocked that Enable don't see a laundry as essential for someone with a neuromuscular condition. People that are in semi-accessible houses [they are battling to get full accessibility while] different departments try to pass the buck.

- *Nelson IHC had 2 houses that they couldn't find people for as the funding cuts meant families couldn't afford for them to move into these homes*
- *this doesn't address the expenses involved*
- *and the perception of what disabled people 'deserve'*
- *how do you make these visions a reality, where's the money coming from? When you're talking about housing, for me, it's more about the money. Where's the money coming from? And then you get the staff and the providers involved, and they've got to have a room to sleep over. You know, it just adds and adds and adds, and they struggle with their budgets, so it's, for me, it's a big financial Giant. It sounds beautiful, the way it's written, and build more nice flat homes with ramps or whatever, but actually, it's how this all comes together with the funding models we've got around housing, especially for the adults.*

Supported independence

- *Focus seems very much on physical accessibility, there's a lack of acknowledgement that many people with disabilities require support from people (many upvotes)*
- *a lot of our, kids that, of course, then become adults, need supported independence. They don't need residential, but they can't be alone. They need that supported independence. That's how I like to positively frame it. But there isn't housing options out there for them. And so, like, I'm hoping that for this sort of strategy, it would*

incorporate designs that aren't already out on the market. Ones that, through consultation, there would be more variety, You know,

- *available to people.*
- *Many adults with Prader-Willi remain living at home because there isn't the option of specialist residential support (only minimal options in Auckland).*
- *Does not seem to acknowledge or address the housing needs of people who have intellectual or neuro disabilities (many upvotes)*
- *and flatting brings it's own dynamics to manage*
- *It doesn't address the needs of complex needs and/or intellectually disabled*
- *In an ideal world a setting like a home in a community that you can access support , social events but still have some independence, hate to say it but like where my nana lives in Mosgiel (many upvotes)*
- *I think it's kind of a matter of the social discourse around housing as well. So what [another group lead] called supported independence. we don't talk much about that. We talk about other things, and when we do build new residences, residential care….that doesn't come anywhere close to suiting supported independence. So, I think that, what the public understands to be amazing, you know, is having a new residence built, and so maybe it's just… it's how we talk about it publicly that influences the choices that are there. So because we lump disability all together, so then we just think, okay, so we've just built another purpose-built home, amazing, everybody's got their own bedroom, but that's not what a lot of us are after. So, I think it is just also what makes it through the media and into the public's mind about what we need. Everyone asks me whether my child can go to a residence, and there is no residence that is suitable for her, or in which she would be happy and fulfilled, so in the public's mind, I think it's like, well, aren't there homes for people like your children? So that supported independence thing is… and people are very surprised that we can…*

but most of us are creating those situations, on our own with huge financial strain.

- *On that note [of supported independence], we don't even like talking about residential homes. One of our families purchased a house that was close to being accessible, and we invited Spectrum Care, and four of our guys are basically flatting there together. They all knew each other from school. But it's been a very expensive exercise, and that kind of thing isn't even described in this strategy.*

Location and community

- Not clear if supply of accessible housing includes allowing people to stay in homes that need adaption for their needs
- Also considering where housing is built. Is it near public transport, parks, shops that can be accessed easily? It's not just about how the house is built.
- housing strategies also need to promote community inclusion

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

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

Action 3: Identify possible barriers to increasing supply of accessible houses in the private market and investigate opportunities to remove those barriers. Understanding barriers to the supply of accessible housing will help target potential interventions to improve supply.

- *Private market with allowing overseas buyer to buy and build bulk, I don't see this being something govt wants to change*
- *Australia appears to have a good model for building purpose built accommodation for residential services (partnerships between residential support providers and property companies)*

Action 4: Review and explore ways to improve the housing modification system. Addressing inefficiencies in the housing modification system could reduce current problems: inaccessibility of homes, increased costs, and health and safety issues for disabled people, whānau and carers.

- Property modification is very complex and individual
- for their sense of independence its essential for them to be able to access there whole house

Action 5: Gather annual data on the housing-related needs of disabled people and compare this to what is being built in each region, to influence the housing market to build and make available more accessible housing.

Data will increase developers' awareness of the housing-related needs of disabled people and raise the profile of the demand for accessible homes.

- *Keen on #5*
- *5, not just disabled, but new mums and older generations are needing same type of needs, so I think in general data from all types of communities needs*

Action 6: Develop voluntary national guidelines on accessibility for residential dwellings. Guidelines would be based on the definitions for accessible homes in housing action 1 and would set out best practice guidance for how to build accessible homes.

- *For point 6 why voluntary?*

Justice

The **goal** for justice is:

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

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

Disabled children, young people and adults in care are safeguarded from abuse, neglect and violence. Disabled children and young people are supported to avoid the care and protection or youth justice systems.

Disabled people who interact with the youth justice or criminal justice systems have their rights and accessibility needs considered and get support to transition out. Those charged with an offence but unable to stand trial are treated consistently with the New Zealand Bill of Rights Act. Justice sector workforces have the skills to uphold disabled people's rights.

Disabled parents in Family Court will have equitable access to family justice services.

On a scale (strongly disagree) to 5 (strongly agree) how much do you agree with the description of **what success in justice means**?

Strongly disagree	6%
Disagree	12%
Neither agree nor disagree	31%
Agree	50%
Strongly agree	0%

Majority agreed or were neutral about the description of success in Justice

Do you have any further comments or suggestions on the **goal** or the **description of success**?

Clarification sought

- *Definition of 'in care' – in the justice system or in foster care? Etc,* another noted *That needs to made much clearer, most people think of 'in care' as meaning under the care of OT. "Anyone who is in* *compulsory care would be the best way to think about that." Was the response from Whaikaha representative.*

- *Does this include the HDC*
- *Does this include PPPR*

Support to prevent entry and re-entry into the justice system.

- *We didn't discuss mental health in the health section, but the lack of supports here lead to many behavioural / justice issues (many upvotes).* Response comment: *Specially when they aren't classed as need now, always waiting till its past, preventative measures would be great.* Another response comment: *and family carers mental health*
- *This summary doesn't address that people with complex behaviours as a result of their disability / challenging needs are over-represented in the justice system due to the lack of cohesive supports received. [later noted this is covered in action 3, but not in description of success]*
- *Many people with intellectual/neuro disabilities struggle to access rehab/treatment services in prison*

Disabled rights and complaint systems

- *I can't see anything here that speaks to disabled rights by UNCRPD, or speak to any complaints systems?*
- *Does this include protection for disabled people from the justice system itself which can also abuse them, arrest them for behaviour they can't self manage etc. A young autistic child was arrested here, mistaken for another adult person of police interest, sedated multiple times in the hospital before they were formally identified and they realised it was a child*
- *Little about protecting disabled people from crime in this strategy*

In the draft New Zealand Disability Strategy there are **7 proposed justice actions** to reach the goal.

Do you have any further comments or suggestions on the proposed **actions**?

Action 1: Develop and implement a safeguarding framework for disabled people in long-term detention settings (such as prisons and youth justice residences) and Disability Support Services funded residential facilities. The framework will include preventing, reporting, responding, and safely removing disabled people from abusive situations.

- *Regarding to the safeguarding framework and action 1, these systems should be applied not only to residences and DSS facilities, but also when disabled people are under a compulsory treatment act (including hospitalisation under the MHA). As seen in the Abuse in Care Report, both settings open disabled people up to the possibility of abuse, neglect, and violence, and as such safeguarding frameworks/systems should be developed for those in care AND those under treatment acts.*
- *Preventative care, like for carers and consumer.. having people coming in and doing audits to make sure there isn't anything else happening, as there's lots of people who don't know what's wrong, or too scared to say anything. From both ends*

Action 3: Develop a social investment plan for early intervention and support, to reduce the number of disabled children and young people entering the youth justice system.

- *There needs to be cohesive supports from mental health, DSS, etc etc*
- *What do plans cover? What they need is access to help and support (both the disabled person/child) and family/carers to avoid them even entering the youth justice system. Speaking from experience even getting access for help with a child with an ID is extremely difficult.*

- *Relating to question3. early support at school, education, life skills, social skills*

Action 5: Review, as work programmes allow, the effectiveness of current protections for disabled people in family law, including adoption, guardianship and personal property rights, to identify gaps where strengthened provisions or support are needed. Any review should also consider supported decision-making and use of plain language in key justice sector legislation and processes. Consideration should be given to reviewing human rights legislation, as work programmes allow.

- The law commission have been reviewing guardianship / PPPR legislation - report due soon. The IDCCR Act allows people with ID to be discriminated against and would not align with the UNCRPD.

Action 7: Develop and implement a plan to make the justice sector workforce more disability competent, including in the use of mana and trauma informed practices. This plan would include increasing recruitment and retention of disabled people and should consider mandatory professional standards.

- *Workforce lacks mandatory disability competence, trauma-informed and supported decision-making training*
- *In terms of educating justice workers, it would be important for this to include education regarding those who have episodic conditions or fluctuating needs. An understanding that appropriate accommodations may differ day-to-day and person-to-person is paramount to fair treatment.*
- *[As an OT caregiver], caregivers do a lot of training around trauma, the effects of traumatic upbringing, family violence, all that sort of stuff, but what I noticed personally is there's not a lot of stuff around disability, like FASD and some things like that, so it would be good to see something that forces OT to do a little bit more work*

with some of their kids, you know, within their training regime of disabilities.

- *Disabled people can interact with the justice system as contributors - i.e. jurors or witnesses etc. Courts are not very accommodating and can be exclusionary (many upvotes)*

Areas identified as missing from the actions

- *Complex/high needs, intellectual, and non-verbal disabled people again largely absent*
- *Again, no mention of improving assessment and diagnosis for those who are involved with the criminal justice systems*
- *How do we recognise safety of whanau /caregivers here?*
- *Where does restorative justice fit here?*
- *"Surveys show that the rate of divorce in families with a child with disabilities may be as high as 87%." (no accurate data on this, so it would be interesting to run a NZ survey)*
- *In NZ, solo-parents who become the primary carer of a child with very high and complex needs, aren't legally entitled to receive any support from the other parent,* ***once the child turns 16*** *- not financially, nor in the form of some shared-care with the other parent, for respite breaks. Even though the 16yr old child will receive their own WINZ supported living allowance, the entire responsibility of care is placed on the single primary carer. They are expected to provide 24/7 care on their own, organise all extra support (eg IF paperwork & payments, etc), usually give up their own careers and resort to part-time jobs, lose their kiwisaver perks, their health & wellbeing suffers especially as they age, and often have to subsidise the adult child at times of medical crisis when finances don't stretch. Additional finances and regular monitoring is even necessary when the adult child is moved into a residential setting. It seems unjust and totally inequitable that one parent is permitted to walk away and live free of any responsibility (especially when they have a very lucrative career), when it's their adult child, too.*

Section 4: Overall Comments

On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do agree with the following statement? **(Please select by putting X next to the option that applies, or removing the options that don't apply)**:

- The strategy will lead to meaningful change.

Strongly disagree	12%
Disagree	35%
Neither agree nor disagree	29%
Agree	24%
Strongly agree	0%

The majority disagree or feel neutral

❖ Is there anything else you would like to see in the strategy?

Enabling Good Lives (EGL)

- *Adopt EGL principles directly – they are already embedded, clear, trusted, and in everyday use by disabled people, whānau, and providers (many upvotes)*
- *Rolling out EGL to the rest of the country should be there.*
- *I am appreciative of the work that has gone into the strategy but it is seems really unnecessary when the disability community and their whanau clearly wanted EGL and this was already promised. EGL already covered all of this and we should be pushing the government to reinstate the roll out immediately.*

Grey areas

- *Need to have a more complex/grey area working group at Whaikaha/nz health to help speak for the grey areas in the systems* *that continue to be ignored, but need continued support, and feedback from this area of the sector*

Mental Health

- *Mental health needs a bigger focus across the board*

Carers and whānau

- *Carers and families are overlooked in all areas of this strategy.*
- *Include the voice of parents and whānau*
- *As a primary caregiver. I'd like to see nothing about US without US! (many upvotes)*

Look holistically

- *Siloed systems and lack of coordination are major barriers in all areas.*
- *Everything is quite holistic, and we need to look at things a little bit more widely than split into the separate priority areas, because there is so much overlap, and also that burden that falls on disabled people or their carers in terms of navigating all the different systems.*

Other

- *One big thing seen in our community is some parents are said to be abusing their child due to breaks, dislocations and bruising, and the kid gets removed.. but because they don't have appropriate medical care, or diagnosis of a rare disorder, this situation is not dealt with correctly and causes a lot more trauma for anyone else involved.. family abuse issues needs a multi systemic approach in case their is a medical issue needed for assessment, including the rare disorders. (many upvotes)*

- *Fully reinstate Whaikaha to it's full and intended function so that our community is properly represented in government*
- *Recognise and address the specific barriers and discrimination experienced by individuals with learning and intellectual disability (many upvotes)*
- *support and resources for people with non-accident related disabilities should aspire to equal that of people whose disability is caused by an accident*
- *Improving data collection is vital but how that data is then accessed and used needs to be addressed (many upvotes)*

❖ Any other comments or suggestions?

Action, accountability and financing

- *I guess the challenge is whether the strategy is then operationalised and delivered to achieve the aims, otherwise its just a strategy … and doesn't really mean anything. Its just talk and no action (many upvotes)*
- *This strategy has good bones, but due to societal change there is a concern that the actions won't be achieved so what happens then?*
- *will it all be well financed?....*
- *Cost savings could be made by operating in a more collaborative way across health, education, disability supports etc etc. There would also be long term savings by investing now instead of dealing with the ambulance at the bottom of the cliff. A strategy needs targets addressing the how, and investment.*