Draft New Zealand Disability Strategy

Submission by PWSA(NZ), September 2025

To: New Zealand Disability Strategy Consultation
Whaikaha – Ministry of Disabled People
via: disabilitystrategy@whaikaha.govt.nz
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Section 1: About You

1. Are you giving feedback as:

   ☐ Yourself
   ☐ Someone else
   ☐ A group
   ☒ An organisation

2. What is the name of the group or organisation you are submitting feedback on behalf of?

Prader-Willi Syndrome Association New Zealand Incorporated

3. Do you identify as a disabled person?

   ☒ Yes
   ☒ No

   PWSA(NZ) advocates for people living with PWS (disabled people) AND their families / whānau.

4. Do you identify as tāngata whaikaha Māori?

   ☒ Yes
   ☒ No

   PWS affects people of all ethnicities. PWSA(NZ) supports Māori and non-Māori.

5. If yes to question 3 or 4, what types of impairment or lived experience apply to you?

   ☒ Physical
   ☐ Hearing or auditory
   ☐ Visual
   ☒ Speech
   ☒ Learning, cognitive or neurological
   ☒ Other: health issues that impact daily living, such as hyperphagia

   These are the areas of disability that are characteristic features of PWS.

6. Are you a carer or family member of a disabled person?

   ☒ Yes
   ☐ No

7. What is your age group?

   ☒ Under 15 years
   ☒ 15–29 years
   ☒ 30–44 years
   ☒ 45–64 years
   ☒ 65–74 years
   ☒ 75 years or over

   PWSA(NZ) advocates for people living with PWS of all ages and their families / whānau.

8. What is your gender?

   ☐ Male
   ☐ Female
   ☐ Another gender
   ☒ Prefer not to answer

9. Which ethnic group(s) do you belong to?

   ☒ New Zealand European
   ☒ Māori
   ☐ Samoan
   ☐ Cook Islands Māori
   ☐ Tongan
   ☐ Niuean
   ☒ Chinese
   ☐ Indian
   ☒ Other: Pasifika

   PWS affects people of all ethnicities, but these are the ethnicities of members in our database that we are currently aware of.

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.

10. 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
  ☐ Disagree
  ☐ Neither agree nor disagree
  ☒ Agree
  ☐ Strongly agree

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

  ☐ Strongly disagree
  ☐ Disagree
  ☒ Neither agree nor disagree
  ☐ Agree
  ☐ Strongly agree

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

  ☐ Strongly disagree
  ☒ Disagree
  ☐ Neither agree nor disagree
  ☐ Agree
  ☐ Strongly agree

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

It may not be possible for someone living with PWS to always be able to 'participate in all aspects of life'. The definition of 'aspects of life' is unclear, but as some conventionally viewed aspects of life may not be desired or possible, a vision should recognise that a full life can look different, and that disabled people can participate in "*all aspects of life as they perceive it*".

We also have some reservations regarding the limited word choice to describe society. Accessibility is essential and should be part of a vision for New Zealand society, but this term does tend to have connotations with mainly physical modifications / adaptations, despite its broader meaning. The word 'inclusive' needs to be added after accessible when describing society, "*an accessible, inclusive and equitable society*".

Disabled people sometimes need specialised support, so their right to non-mainstream services and support also needs to be embedded in a vision. This concept goes a bit further than being accessible, inclusive and equitable. The vision could add something like "*a place where disabled people thrive, lead, participate in all aspects of life as they perceive it, and have their rights upheld*".

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

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

Accessibility
Fundamental to participation and inclusion. Accessible environments and services benefit everyone, not just disabled people.

Choice and control
Recognises that disabled people are experts in their own lives, and have the same right to self-determination as everyone else.

Equity, cultural inclusion and intersectionality
Acknowledges that disabled individuals have their own unique identities, and belong to diverse whānau, communities, and cultures.

Human rights
Anchor the strategy to international human rights frameworks, including the United Nations Convention on the Rights of Persons with Disabilities, the United Nations Declaration on the Rights of Indigenous Peoples, the United Nations Convention on the Rights of the Child, and the Universal Declaration of Human Rights.

Participation and inclusion
Recognises disabled people's right to be active members of their communities and cultures in all aspects of life.

Respect and dignity
Emphasises that everyone deserves to be treated with respect, and acknowledges that societal attitudes can be a significant barrier for disabled people.

The Treaty of Waitangi | Te Tiriti o Waitangi
Establishes the relationship between Māori and the Crown, recognising the unique position of Māori as tāngata whenua, and ensuring partnership, participation and protection for tāngata whaikaha Māori.

12. On a scale from 1 (not at all important) to 5 (very important) how important is each of the following **principles**?

- Accessibility
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☐ Important
  ☒ Very important

- Choice and control
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☒ Important
  ☐ Very important
- Equity, cultural inclusion, and intersectionality
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☒ Important
  ☐ Very important
- Human rights
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☐ Important
  ☒ Very important
- Participation and inclusion
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☐ Important
  ☒ Very important
- Respect and dignity
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☐ Important
  ☒ Very important
- The Treaty of Waitangi | Te Tiriti o Waitangi
  ☐ Not at all important
  ☐ Not important
  ☐ Neutral
  ☐ Important
  ☒ Very important

13. Is there anything you would like to add or remove from the list of **principles**?

    Self-determination would be a better way to phrase 'choice and control'. Choice and control are both words which can be misleading or suggestive.

    Equity, cultural inclusion, and intersectionality – Equity is not mentioned in the definition for this principle above, which only focuses on diversity. Equity should be set apart as a separate principle.
    Cultural inclusion and intersectionality are different concepts to equity. The word intersectionality should be removed - not many people would know its meaning.
    A principle could be something like '*Identities and cultural inclusion.*'

14. Do you have any further comments or suggestions on the proposed **principles**?

    It seems very strange that there is no mention of Enabling Good Lives in this draft Disability Strategy and the EGL principles have not been used. It is our understanding that a lot of work, effort (and cost) went into developing and establishing Enabling Good Lives and this appears to have been wasted. It is confusing and disappointing that Whaikaha is 'reinventing the wheel'.
    Clarity is needed on whether there is a temporary pause in the Enabling Good Lives project being rolled out nationwide as promised or whether a decision has been made to terminate the project. The new principles above suggest the latter because otherwise it would have made sense that the draft strategy and EGL are aligned.

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.

15. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the **goal** for education?

    ☒ Agree

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.

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

    ☒ Neither agree nor disagree

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

    Goal – This appears to be a good goal although it can read as if the expectation is solely on the learner to achieve their potential. The goal could be amended to "*….will be supported to achieve their potential…*" which puts the expectation on the system. It should also be recognised that progressing in education may not necessarily relate to progressing in the national curriculum – this could be implied by adding the word meaningful: "*participate and progress in meaningful education*".

    Success – There is a missing emphasis on the rights of disabled learners. For example, the success statement exemplifies 'educators plan for diverse learners to succeed' and 'have high expectations' for them, but there is no emphasis on answerability or verification, i.e. that educators do implement / follow plans, or action the expectation. The next sentence says that "learning support is responsive, timely and effective", but there is no emphasis on the right to receive learning support for pupils with learning disabilities. Easy to navigate is not the same as easy to access. We currently have a system where many intellectually disabled learners are not qualifying for any learning support due to a shortfall of funding for ORS, and for the families of those pupils, this success statement does not provide reassurance that this will change. "Learning support is responsive" touches on support reflecting need but it should be clear that this statement is applicable to ALL disabled learners.

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

18. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with each action?

- **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.

  ☒ Agree

- **Action 2:** Explore new options for targeted and specialised support and provisions to reduce wait times using private providers and non-government organisations (NGOs).

  ☒ Strongly agree

- **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.

  ☒ Neither agree nor disagree

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

  ☒ Strongly agree

- **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.

  ☒ Strongly agree

- **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.

  ☒ Agree

- **Action 7:** Support kaupapa Māori settings, within the existing Education budget, to access the resources, knowledge and capability to deliver high quality kaupapa Māori educational programmes that meet the needs of disabled ākonga (students) in a kaupapa Māori setting.

  ☒ Strongly agree

- **Action 8:** Work with the Ministry of Disabled People - Whaikaha to explore opportunities to identify disabled learners in education data collections.

  ☒ Strongly agree

- **Action 9**: Continue implementation of the Tertiary Education Commission (TEC) mechanism for reviewing provider progress in implementation of disability action plans (which will be integrated into Investment Plans from 2027). The TEC will consult with disabled student representative groups, including the National Disabled Students' Association, on how the mechanism will be implemented.

  ☒ Neither agree nor disagree

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

Action 1 – PWS is a genetic disorder and most children with PWS are usually diagnosed not long after birth. This medical diagnosis alone should ensure that a minimum level of lifelong support is assigned and mapped out. Additional early intervention assessments should then look at how much support the individual child with PWS needs at that time, rather than identify their eligibility for accessing any support at all when ALL pupils with a PWS diagnosis require early intervention support and support at school. If the health and education systems were able to work collaboratively to identify and outline the support needs of pupils with a medical diagnosis like PWS, this would save time, cost and the stress of pointless assessment processes.

We have some concern that with this being the largest education investment listed in the strategy, the focus on early intervention may further the expectation that support needs should lessen as pupils become older. This is not the case in Prader-Willi syndrome where support needs usually increase as pupils head into adolescence and adulthood. That said, early intervention is very important, and this investment is welcome because many services (such as Speech and Language therapy) are lacking, and the level of intervention support provided can also be a postcode lottery.

Action 3 – We know that the Learning Support Coordinator job title is a rephrasing move away from outdated 'special needs' terminology, but many schools already have access to a SENCO, so will existing SENCOs be replaced or just have a name change? The reason for questioning this is because it seems that many existing SENCOs are not specifically trained for the role and are often a member of the senior management team who has the non-teaching time to take on the role. Will the proposed $192.5 million investment for LSCs be sufficient to ensure that all schools have equitable access to a trained and skilled LSC as their primary role or focus?

The proposed investment for ORS ($122.5 million) is significantly less than that proposed for early intervention and LSCs. Considering the ORS scheme has been massively underfunded for many years and that criteria have been made more restrictive as population and demand has increased, we are concerned that this investment will not be enough. It would be more reassuring if the Government were able to provide details of what data was used to calculate this funding increase.
Action 3 aims to make the learning support system easier to navigate, and '*reduce the complexity and accessibility'* of application processes, but this must be a wording error

with '*increase accessibility*' intended? It is not made clear that improving accessibility to the application process includes making the necessary changes to the eligibility criteria to extend access. There are intellectually disabled pupils with Prader-Willi syndrome who have been declined ORS funding because their global support needs do not match a particular criterion, but denying these pupils any learning support funding would be unheard of in other countries with similar education systems. There is consensus agreement by international experts that all pupils with PWS need support at school, yet pupils in New Zealand can still be declined for arbitrary, inconsistent reasons that make no sense. An overhaul of the ORS system has been discussed and promised for many years during successive reviews but is yet to happen. We need a new learning support application system that 1. Can use medical diagnosis for minimum support eligibility, 2. Can evaluate a pupil's global support needs rather than expecting them to fit in the boxes created by the restrictive ORS criteria, 3. Doesn't separate learning and health funding streams as an either/or when pupils can have both (as in PWS), and 4. Ensures that all pupils with a complex disorder like PWS can have access to an I.E.P and behaviour support plan, as well as an appropriate level of funding for support.
In summary, this action point needs to more specifically confirm that an overhaul of ORS eligibility will take place, what new assessment approach will be recommended, and whether the intended investment will cover the shortfall of funding that currently excludes disabled learners who should be receiving learning support. If the Government does not have data on the number of disabled learners and how many are currently missing out on necessary learning support, gathering this data needs to be a priority.

Action 4 - Additional learning support classrooms is a positive action. However, it is not clear whether these are to be extra classrooms where many pupils from the school can access support for some or all the time, or whether they will serve multiple schools, or if they will be attached to a special school as a satellite class? Special schools are not mentioned in the draft strategy, but many have long waitlists for places. These waitlists may be reduced through additional learning support classrooms and improved learning support provision, but there will always be pupils for whom the mainstream environment does not work. The strategy needs to address the problem of waitlists for special schools which is currently adding to our inequitable system. The $90 million budgeted for action 4 is to create 25 new learning support classrooms and 365 property modifications, but 25 new classrooms across Aotearoa is quite a small number and will therefore only provide benefit in some areas.

Action 6 – Accountability needs to be extended to include having systems in place to ensure inclusive and non-discriminatory practice, in addition to reporting on learning and achievement. Under the self-governing schools model, disabled pupils can be too easily stood down and excluded for behaviours that are associated with their disability. PWSA is aware of cases where behavioural incidents have been a result of inappropriate or insufficient support provided by a school, but the Principal and Board have been united in wanting a pupil removed and the Ministry of Education avoid intervening. We need to ensure this cannot happen, perhaps by revising the self-governing model, by ensuring equitable disability sector representation on school boards, and by strengthening complaint processes so that families can more easily challenge discriminatory decisions.

A requirement to report on learning and achievement outcomes for disabled learners also needs to recognise that learning goals may differ to those for non-disabled. Accountability for learning and achievement outcomes of disabled learners needs to have high expectation of progress but understand that progress can be measured in different ways. This might include progress toward individual learning goals through use of I.E.P.s, or progress in social and emotional development. Success is individual growth and wellbeing.

Action 8 – Improving data collection is essential, but this needs to be a system-wide approach because disabled learners often have needs that should be responded to by multiple systems – including education, health, and social systems. We also need to go further than identifying disabled learners in education data collections so that progress can be monitored and compared to non-disabled learners. We also need to collect other data relative to issues experienced by disabled learners, i.e. diagnosis, funding, use of funding, I.E.P review frequency, MoE services accessed, external services accessed, suspensions, attendance, type of schooling etc.

Transition from school – This is a very important area that is missing from the proposed actions. Currently only pupils who receive ORS funding can access transition services. Of those families who have been able to use transition services, some families have not found the model to be particularly useful for their son or daughter due to their lack of understanding of Prader-Willi Syndrome. This understanding is essential to knowing what future environments might be inappropriate, and for 'outside the box' thinking about potential opportunities. Transition support also needs extending during what is often an unsettled and prolonged period of change (delayed social and emotional maturity) and to help prevent disproportionate representation in the justice system.

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.

20. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the **goal**?

☒ Disagree

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.

21. 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**?

    ☒ Disagree

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

Having equal work opportunities should rightly be the expectation for many disabled people, but it is unrealistic for some. The goal and description of success does not address issues faced by people with Prader-Willi syndrome, a disorder characterised by intellectual disability and a complex behavioural profile. The main reason for disagreeing with the goal and description of success for employment is because of the phrasing “equal to non-disabled people”. We agree that people living with PWS have a right to meaningful work opportunities, but describing these as ‘equal to non-disabled’ is confusing – what does this mean? Does it mean an equal number of opportunities and equal access to all types of work? This would not be possible. The controversial right to equal pay already creates barriers to employment opportunities for many people with PWS who may be less productive at work and require more support.

The strategy goal and description of success for employment rightly focuses on accessible and inclusive workplaces, the availability of resources and support, and employer support (a better word than help). However, it also needs to recognise that there can be roles outside the traditional view of employment which can be meaningful, offer dignity and inclusion, whilst also providing some economic benefit. It seems that the goal and description of success focus mainly on equality and not equity. The strategy should reflect that there is not a single life pathway for all, but unfortunately the employment needs of intellectually disabled are not well embodied in the proposed statements.

We would like to see social enterprise schemes included in these statements. The goal to have disability-confident employers recognising and valuing disabled employees and providing accessible, inclusive workplaces is good, but we also need more disability specific employers, such as those that can be provided by social enterprise schemes. This may require more support and encouragement from Government in the same way that employers can be supported to become disability-confident.

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

23. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with each **action**?

- **Action 1:** Work to centralise, and make accessible, information and guidance for disabled people to identify and pursue job pathways matched to their skills and interests.

  ☒ Neither agree nor disagree

- **Action 2:** Review specialist employment supports to improve employment outcomes, in consultation with disabled people.

  ☒ Strongly agree

- **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.

  ☒ Neither agree nor disagree

- **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.

  ☒ Agree

- **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.

  ☒ Strongly agree

- **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.

  ☒ Agree

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

Action 4 – This action point, like action 1, is primarily focused on providing information and guidance. These are admirable goals, but we are uncertain how effective they will be without real 'on the ground' in-person support, and none of the employment actions contain plans for improvement in this area. **Action 2** proposes that specialist employment supports are reviewed, but there is no commitment to act on findings.

Actions 5 and 6 – Workplace inclusion, flexibility and accessibility will be promoted and enabled through partnerships, which will be supported by the awareness campaign in action 6. Promoting these concepts and highlighting the positive impact of employing disabled people to build employer confidence and capability is a positive action, but enabling requires further steps to ensure change, such as offering business incentives. We are living in difficult financial times where many businesses are struggling, so it therefore seems unrealistic to expect change without financial incentive.

Encouraging social enterprise schemes that employ disabled people

Following on from comments on action 5, social enterprises are a good example of what partnerships can achieve. As mentioned earlier on page 12, we would like to see the development of disability focused social enterprise opportunities included in the strategy actions. We understand that work opportunities specifically intended for disabled people may not fit the ethos or ideologies of equal opportunity and ordinary life outcomes, but they have potential to provide much needed work opportunities that are purposeful, socially inclusive, and offer specialised training and skill development. Successful social enterprises might also provide additional resources, support and opportunity for employees, more easily facilitate open communication and peer support, develop insights and expertise, engage in community initiatives and events that promote inclusion and awareness, and collaborate with disability organisations.

There are many different types of disability, which include physical, sensory and intellectual and encompass an extensive range of needs and challenges. The disability strategy needs to recognise the diversity of disabled people and understand that each type of disability presents its own set of barriers that can hinder participation in the workplace. Despite the model of supported employment for individual placement being in place for a long time, employment rates for disabled people remain low, and we know from conversations in the PWS community that paid employment rates are low. Therefore, the strategy needs to extend thinking beyond the traditional view of employment and include an action to encourage social enterprise as a means of creating jobs and enhancing employment participation for groups of disabled people for whom this is needed.

Financial barriers

Addressing financial barriers to obtaining employment are missing from this section of the strategy. Here are two examples of financial barriers:

Adults with intellectual disability and complex support needs who live in a residential support service group home.

Adults in residential support settings are reliant on a weekly personal allowance (currently $82.46) after payment has been made to their support service provider. This is expected to cover toiletries, any additional drinks or snacks, haircuts, any clothing needs, personal

phone connection, their own weekly activity costs, and it is advisable that some funds are saved for things like unexpected medical costs.
Transport and the number of activities that are offered and covered by the residential support service can vary and is often dependent on funding and staffing. Support staff ratios at a residential group home can also vary between 1:2 and 1:4 on average. It is generally recognised that unless adults living in a residential disability support home in New Zealand have their income supplemented by family / whānau, they are living at poverty level. Their financial and funding situation creates many barriers to being able to obtain paid employment, including their ability to look for work, whether there would be funding and staffing available to support them with travel to their workplace, and whether they would be able to receive sufficient support whilst at work.

<u>Adults with intellectual disability and complex support needs who live with family / whānau</u>
Constant supervision may be required for safety reasons in PWS, which often means a family member has given up their job to fulfill a full-time caregiver role. Any funding that the person with PWS receives from WINZ and IF will be used toward basic living costs, to pay part-time support workers for time and travel, and often for the costs of activities and/or attendance at vocational services. As paid work opportunities are limited, the person living with PWS may be engaged in voluntary work or setting up their own micro-enterprise project – all of which incurs cost. There is often insufficient funding to cover the additional costs of searching for paid work opportunities, arranging the necessary preparation, support and training for work, support with travel to the place of work, and any support needed whilst at work. Families often supplement funding if they can, which can have additional impact on the family / whānau.

In addition to addressing the financial barriers for disabled people, the strategy should consider where families / whānau fit into employment actions. We understand this is a disability strategy and not a carers strategy but the financial barriers that affect access to employment for people living with PWS are interrelated with carer issues.

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.

25. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the **goal**?

    ☒ Disagree

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.

26. 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**?

    ☒ Disagree

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

    Goal – This statement is rather lofty and insubstantial. With the current status of our public healthcare system, it is very difficult for anyone to "achieve the highest possible standard of health and wellbeing." There are many treatments funded overseas which are not yet funded in New Zealand, we have shortages of expertise, doctors, nurses and other allied health professionals, and there are long waitlists to see specialists. If the goal is referring to the highest standard that it is possible to achieve in New Zealand, the goal should indicate how this will be achieved by referencing that disabled people will be able to access *equitable* healthcare so that they can achieve….
    If equity is not added to the goal, it suggests that it is only the quality (standard) of healthcare that needs to improve and not that systemic change is also needed.

    We would also like to see the goal include a holistic, multidisciplinary approach to health and wellbeing. This is especially important for improving the health outcomes of disabled people who have complex health and wellness needs.

    We believe rare disorders should also be recognised in the goal or summary of success, as this is a significant group within the disabled community who often have complex health needs that require specific actions to address their unmet needs.

    Finally, the IHC report 'From Data to Dignity' revealed that people with intellectual disabilities are dying approximately 20 years earlier in New Zealand, so urgently addressing this shocking and extremely sad statistic should be prioritised in the goal.
    The following statement in the goal seems a little out of place: "They will decide what this means for themselves and their whānau." This might be an ideal, but it is confusing why this has key priority status in a goal that should primarily be aimed at improving the health, wellness, and mortality rates of disabled people. Furthermore, not all disabled people will have knowledge or understanding of what "the highest possible standard of health and wellbeing" could look like and not all disabled people will be able to decide what this means for themselves and their whānau.

Success – Tāngata whaikaha Māori are singled out as a group to be understood as part of a collective who can involve whānau in their health in the ways they want. Rare disorders could also be mentioned in a similar way due to whānau often being an expert in their family member's disorder when expertise is lacking in the health system. Intellectually disabled people should also be identified as a collective for whom we should measure success, particularly considering they are a group that probably experience New Zealand's highest early mortality rates.

Success in health also needs to add the following underlined text "*Accessibility, equity and inclusion are embedded throughout the health system, supported by* <u>*multidisciplinary approaches to health and wellness for disabled people, and*</u> *by a skilled and responsive workforce*." We are aware of studies that confirm improved outcomes for patients living with PWS receiving multidisciplinary care, and similar studies probably exist for other disorders / disabilities. In the long-term, a multidisciplinary approach also reduces costs for the health system. We currently have siloed departments and systems which are exhausting and overwhelming to manage for patients / whānau and result in wasted time and poor outcomes. It is very disappointing that there is a lack of emphasis on holistic care and access to diverse services in the description of what success in health means. (Ideally there would also be more cohesion between health, education and social systems.)

Success should also be measured by how well the health needs of disabled people with rare disorders are being met. Health needs will differ according to disability, but we know that in a complex disorder like PWS, there is a need for specific standards of care because standard health guidelines can be inappropriate in some health areas. Patients with rare disorders also have difficulty with being able to access medical expertise, so system change is needed that allows knowledge and expertise to be more centralised and accessible to all, with diagnosis identifiers and care standards also attached to patient records. An example of a success statement could be "*….skilled and responsive workforce.* <u>*Expertise is centralised, developed and shared resulting in improved health outcomes for disabled people with rare disorders.*</u> *Disabled people are included a*t...."

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

28. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with each action?

- **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.

☒ Strongly agree

- **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.

  ☒ Neither agree nor disagree

- **Action 3:** Create opportunities to build disabled people's skills and knowledge to take up health system roles.

  Government agencies will create opportunities to build the capability and capacity of disabled people to carry out health system roles. These roles will include health system design, consultation, monitoring, leadership, advisory and governance roles.

  ☒ Agree

- **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.

  ☒ Strongly agree

- **Action 5**: Implement systems to enable disabled people to record their accessibility needs against their National Health Index.

  Recording people's accessibility needs will mean these needs can easily be shared with health providers. Disabled people will not have to repeat their accessibility needs each time they engage with health services, and health providers will be better placed to plan and meet those needs.

  Work to progress this action should be guided by disability community expectations and data sovereignty.

  ☒ Agree

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

Positives - The proposed actions we are most keen to see implemented are the review and improvement of policies and practices, especially including information, service design and delivery (**action 1**), disabled people (OR PRIMARY CARERS WHEN APPROPRIATE) being involved in health system consultation and design (**action 3**), and data identifiers being used to improve health outcomes (**action 4**).
The embedding of disability responsiveness and lived experience into workforce training and professional development is positive, but not a priority (**action 2**).

Additional comments
Action 4 – We need to go further than identifying people as 'disabled' in national health data to significantly improve health outcomes. As mentioned previously, people with intellectual disabilities appear to have New Zealand's highest premature mortality rates, and PWSA knows of several cases where people living with PWS have died prematurely due to poor care or lack of clinical expertise. This urgently needs to be addressed and one of the ways we can do this is by capturing more specific data on intellectual disabilities and diagnoses (such as PWS). Patient registries could be developed, and if it were easier, these could be combined with registries being established in Australia as many of our professional medical organisations are already combined. (Pooling data might also make sense if there were only a small number of patients with a rare disorder.) Patient registry information could then be reviewed by groups of specialists (Centres of Expertise / Excellence) to inform healthcare practice and training needs.

An essential way to use data systems to improve health outcomes is by including diagnosis identifiers on patient records with an attached standard of care document that could also contain red flag alerts. Identifiers, care standards and red flag alerts need to be accessible on patient health records that GPs and specialists can view nationally.

Negatives

There are several key priorities missing from the planned actions:

Multidisciplinary clinics – We have already mentioned the need for multidisciplinary clinics above on page 17. Some PWS clinics exist in paediatric care but there are none for adult patients living with PWS. Healthcare and support needs become greater as people living with PWS get older, and the transition from paediatric (reasonable) to adult services (poor) is very poorly timed with the period of greatest risk which unfortunately often results in irreversible health deterioration occurring at this time. Multidisciplinary clinics could be linked to a Centre of Excellence / Reference Centre. Large clinics that see a greater number of patients can also assist with the development of expertise.

Mental health – This is a startling and alarming omission from the strategy. Much like the health system, the mental health system in New Zealand is known to be in crisis. However, it is our experience that accessing mental health support is probably far more difficult for people living with PWS, and this is likely to be the same for other intellectual disability and rare disorder groups. Sometimes people are declined mental health support because they are told that their paediatrician or other doctor would be best placed to help (despite not having psychiatric expertise), or they find that when they can access the mental health system, there is a lack of knowledge or understanding about PWS, its atypical presentation and the differences in recommended treatment options. Some patients manage to get a referral to a dual diagnosis or intellectual disability team but there are very long wait lists for these services.

It is essential that mental health is specifically addressed in the health section of this strategy because there are likely to be higher rates of mental health problems experienced by disabled people, and this is certainly the case in Prader-Willi syndrome. Disabled people require specialised psychiatric care from knowledgeable clinicians. Approaching mental wellness as part of a multidisciplinary, holistic approach to healthcare for disabled people is also essential. Mental health can be very closely interrelated to how well other aspects of a disabled person's life are going, such as being engaged in meaningful opportunities, whether a person feels supported or valued, and the level of stress they are having to manage.

Rare disorders and disability – This should be an action point, as mentioned on pages 16 and 17.

Improving life expectancy for intellectually disabled people – This could be a separate action point and needs to be a key priority. As mentioned above (pages 16 and 17), the statistics in IHC's report 'From Data to Dignity' are alarming and New Zealand must urgently set a target to improve this data. One of the reasons for intellectually disabled people dying prematurely and being overly reliant on emergency and hospital care is the lack of targeted systematic health screening.

One way to address this issue is by introducing a health check programme for people with intellectual disabilities. As an example, CHAP has been introduced for this purpose in Australia:
https://www.health.gov.au/resources/collections/comprehensive-health-assessment-program-chap-annual-health-assessment-for-people-with-intellectual-disability

Housing

The **goal** for housing is:

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

30. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the **goal**?

☒ Neither agree nor disagree

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.

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

☒ Neither agree nor disagree

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

These statements only appear to refer to housing availability and accessibility, but do not acknowledge that many people with disabilities also require support from people.
The quality and availability of residential support services should be included in measures of success. Whilst not explicitly stated, these statements and the 6 actions below suggest the strategy is focused on housing accessibility for physically disabled and do not appear to address the housing needs of people who have intellectual disabilities.

The housing actions are quite ambitious, and it is difficult to see how all disabled people "will have a range of suitable housing options so they can choose where they live" without addressing funding issues. Adults living with PWS are reliant on NASC funding and the residential support services available to them. Any accommodation offered is usually part of a home and support package from a residential service. Therefore, there is little choice in where a person with PWS lives because their funding / income is also not enough to find their own accommodation and buy-in the necessary amount of support (as in CiCL).

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

33. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with each action?

- **Action 1**: Develop, consult on, and make publicly available, clear definitions of accessible homes, describing the key features of different levels of accessibility (for example, from basic universal design through to fully accessible).
  Clear definitions of accessible homes can support the development of voluntary guidelines for accessibility for residential dwellings (housing action 6).

  ☒ Agree

- **Action 2**: Improve data matching between disabled people and social housing properties with accessible features that meet their needs and ensure disabled people and their whānau are prioritised to accessible properties. Data matching will both identify disabled people's housing needs and social housing that meets those needs.

  ☒ Agree

- **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.

  ☒ Agree

- **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.

  ☒ Agree

- **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.

  ☒ Strongly agree

- **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.

  ☒ Agree

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

The 6 housing actions will all work toward increasing housing quality, suitability, accessibility, availability and prioritisation of need, but they do not address the housing needs of people who have intellectual disabilities.

Action 1 – Australia has a similar system of accessible homes definitions as part of the NDIS in which design standards are met and key accessible features are described. Specialist Disability Accommodation (SDA) can be applied for as part of a person's support plan. People living with PWS usually need homes defined as robust, and with some secure features.

Action 3 – This action identifies barriers to increasing accessible houses in the private market and investigates opportunities to remove them. It would be good to see some focus on diagnosis specific purpose-built housing. There are good examples of purpose-built homes for PWS in Australia, Denmark, USA etc. These are often built for food security, in ideal calm locations away from food sources / shops but still connected to the community, and they allow for the feeling of having your own apartment within a small complex with some communal areas. Building purpose-built homes might require partnership between government, property investors/managers, and with specialised residential support providers. In Australia it is usual for disability property manager companies to work with disabled people in finding or building a suitable home, and to also work with support provider agencies, i.e. Property Specialists Australia (PSA) and SDA Management Australia.

Develop specialised residential support services –The waitlists for a placement with a residential support service can be very long, and this is not helpful if a family has reached crisis point. However, many adults living with PWS also continue to live with family / whānau because there are no suitable PWS specialised options in the region where they live. An international study has shown that health, wellness and behavioural outcomes are improved for adults living with PWS if their support service is specialised in PWS. Currently New Zealand only has one PWS specific home which accommodates four residents. PWSA(NZ) is very keen to see more PWS specific residential care options across the country and has previously submitted a detailed proposal on this subject to DSS, but increasing the availability of specialised support services has not been mentioned in this strategy.

Create more choice in where intellectually disabled people can live – Aside from providing more options for disability specific residential support (as above), if there was easier and more affordable separation of housing and support, disabled people who require full-time support services could have more flexibility and choice in where they live by choosing a house, finding housemates (with assistance), and engaging a support provider separately. This approach is intended by CiCL but is difficult to achieve for people living with PWS due to funding limitations and the need for family to supplement costs and significantly help with the set-up process. How can we make it easier and possible for people who need full-time in-person support to be able to live in a way that provides the opportunity to have their own space if that is what they want or need? (Supported independence but still with vital social and community connection.)

Addressing the housing needs of disabled people with complex and challenging behaviours - When this is not addressed things can go very wrong and result in higher cost intensive support solutions which do not provide an ideal living environment. People living with PWS are over-represented in the justice system for a variety of reasons such as unmet health and mental health needs, lack of education support, lack of opportunities and inclusion, or because their living situation has not been conducive to being able to manage life situations (lack of service provider preparation and poor transition process, staffing issues, housemate issues etc).

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.

35. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with the goal?

☒ Strongly agree

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.

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

☒ Strongly agree

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

No

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

38. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do you agree with each action?

- **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.

  ☒ Strongly agree

- **Action 2**: Establish a cross-agency project to identify and address gaps in data and evidence about disabled people’s experiences of crime, including for disabled people in residential and secure facilities, and experiences of cyberbullying.

  ☒ Agree

- **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.

  ☒ Strongly agree

- **Action 4**: The Law Commission has been asked to undertake a review of the Criminal Procedure (Mentally Impaired Persons) Act 2003 (CPMIP). This review is expected to consider the CPMIP’s relationship to other relevant legislation, such as the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 and Mental Health (Compulsory Assessment and Treatment) Act 1992.

  ☒ Agree

- **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.

  ☒ Neither agree nor disagree

- **Action 6:** Integrate lessons from disability-specific safeguarding approaches into the development of the future state for multi-agency responses to family violence, to strengthen outcomes for disabled people experiencing violence and abuse. This includes supporting workforce capability to ensure a coordinated, safe and disabled-person centred response.

  ☒ Agree

- **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.

  ☒ Neither agree nor disagree

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

Action 1 – We agree with this action. People living with PWS are overrepresented in the justice system and then at risk because RIDSAS placements can be inappropriate, unsafe, and staffed by a rapid turnover of untrained employees. However, it is unclear what solution is being suggested for safely removing people from these situations.

Action 4 – Why is the IDCCR Act not being reviewed - what exactly does reviewing the CPMIP’s relationship to the IDCCR Act mean or involve? The IDCCR Act discriminates against disabled people because they can be sentenced more harshly with much longer court orders or sentences than those received by the general population. It does not sit well with the UNCRPD or reflect the goal statement "Disabled people will be treated fairly and equitably by the justice system."

Action 5 – The Law Commission has already been reviewing legislation around adult decision making and the report is due soon. Therefore, this action seems unnecessary at this time.

Action 7 – It is our understanding that this type of training already takes place (mana and trauma informed practices). However, we agree with plans to make the justice sector more disability competent, but in particular, we would like to see a mandatory requirement for training to take place before supporting disabled people with rare or complex health conditions such as PWS.

Section 4: Overall Comments

40. On a scale from 1 (strongly disagree) to 5 (strongly agree) how much do agree with the following statement?

- The strategy will lead to meaningful change.

☒ Strongly disagree

Apologies for the negativity. Cynicism develops after seeing and contributing to many reviews, reports and consultations over the years, hearing lots of talk but seeing little action. However, there are also some key actions missing from this draft disability strategy which are essential to bring about meaningful change.

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

☒ Yes
☐ No

42. If yes, please write your response below:

Detailed comments have mainly been added in the sections above regarding what else we would like to see in the strategy. Key missing points are also summarised below:

- Holistic, multidisciplinary, wrap-around, collaborative/cohesive approaches to supporting disabled people.
- Diagnosis-based care and support mapped out to ensure minimum education support and standards of healthcare with centralised expertise available.
- Goal to improve mental health provision for disabled people.
- Specific goal to reduce the early mortality of people living with intellectual disabilities.
- More disability specific residential support options (for PWS).
- More choice in where people with intellectual disability and full-time support needs can live with associated funding issues addressed.
- Preventing discrimination and protecting the rights of disabled learners in the education system.
- Increased access to the learning support system so that funding meets need. Funding increase should be diagnosis-based and data-informed.
- Extending transition from school support.
- Encouraging social enterprise schemes to increase employment opportunities.
- Addressing financial barriers to employment.
- Recognition of rare disorders as a significant disability group with complex unmet needs.
- Mandatory disability specific training for support staff before working with someone living with a rare health condition and /or complex behaviour profile. This is essential in PWS to prevent serious illness or loss of life.
- Enabling Good Lives