

Critical Issues and Challenges in Current Disability Support Services:

A Consumer Perspective

Addressed to the Review Panel of Disability Support Services consisting of
Sir Maarten Wever, Leanne Spice, and Reverend Murray Edridge.

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Compiled by:

- ADHD New Zealand
- ANZMES (The Associated New Zealand Myalgic Encephalomyelitis Society)
- Autism New Zealand
- Complex Chronic Illness Support
- Carers Alliance
- Ehlers-Danlos Syndromes New Zealand
- Epilepsy New Zealand
- FACS-NZ (Foetal Anti-Convulsant Syndrome New Zealand)
- FASD-CAN Incorporated Aotearoa (Fetal Alcohol Spectrum Disorder - Care Action Network)
- Rare Disorders NZ
- Stroke Foundation of New Zealand
- Tourettes Association of New Zealand.

Report

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Overview

This joint submission addresses the review panel of Disability Support Services: Sir Maarten Wevers, Leanne Spice, and Reverend Murray Edridge. The submission represents a collective effort by organisation leads who were members of the internal Whaikaha DSS Eligibility Review Advisory Group. Despite the value of the Advisory Group as a direct voice for consumers unrepresented in the current system, its discontinuation has prompted this joint submission. The organisations, all fitting the New Zealand government and UN definition of 'disability,' but not meeting Whaikaha service eligibility criteria, highlight significant concerns regarding the identification, coding, tracking, and funding of disability conditions in New Zealand. This document emphasises the urgent need for consumer inclusion in the review process to ensure equitable and inclusive disability support services.

This submission advocates for critical changes in Disability Support Services (DSS) eligibility criteria and processes in New Zealand based on direct consumer voice.

Key issues highlighted include:

- **Consumer Inclusion:** The discontinuation of the Advisory Group, which served as a direct voice for consumers, has left a gap in representation. This submission stresses the importance of including consumer voices in the review process to ensure equitable and inclusive support services.
- **Eligibility Criteria:** Current DSS eligibility criteria exclude many conditions that meet the New Zealand government and UN definitions of disability. The disabilities represented in this submission are not adequately coded, tracked, or funded, leading to insufficient support.
- **Inconsistent Criteria and Service Access:** The submission points out the "postcode lottery" effect, where access to services varies significantly by region. This inconsistency highlights the need for integrated support systems across different regions to provide equitable care.
- **Systematic Barriers:** High health literacy and the ability to communicate effectively with health professionals is required to access services, which is a significant barrier for those with cognitive impairments or complex needs.
- **Equity in Support:** The current system fails to provide equitable support based on presenting needs, often waiting for a formal diagnosis. There are also notable inequities between paediatric and adult services.
- **Lack of Integration:** The submission criticises the lack of integration across government agencies, leading to fragmented care and additional stress for individuals with disabilities.
- **Funding Issues:** Current funding mechanisms are inadequate to meet the growing needs of the population requiring disability support. There has been years of under-investment in disability support funding. The submission emphasises that funding needs to be tied

to the level of inflation, and a considerably higher level of government funding is required to meet the needs, given that 25% of people in New Zealand identify as disabled. It also highlights the broader implications and costs of inaction, advocating for a holistic approach to support.

- **Early Intervention:** There is a need for strategies to implement early identification and intervention for individuals at risk of developing disabilities or worsening symptoms. Early and consistent management can prevent the progression to more severe disabilities and improve long-term outcomes.

Introduction

‘Nothing about us without us’

The Enabling Good Lives (EGL) principles, agreed by the Ministerial Committee on Disability in 2012, was created with the intention of having one principles-based system across all government agencies to guide future changes in the disability support system. The policy aimed to empower disabled people and their families, but it was established without their direct input, leading to criteria that do not accurately reflect our needs.

The review has been prompted by budget concerns at Whaikaha for currently recognised conditions receiving these services. However, it is essential for the government and the review panel to acknowledge the broader disability landscape in New Zealand as there is far more disability that goes unrecognised and unsupported. Thousands of individuals who should be entitled to services are not receiving the necessary support. The government is insufficiently identifying, coding and tracking these conditions represented by our organisations, resulting in insufficient funding for Whaikaha. This lack of early identification and proper coding has resulted in inadequate identification of disability support needs in Aotearoa New Zealand, and their funding and service capacity and provision. This submission highlights the urgency and critical need to include the consumer voice in the review process of Disability Support Services to address collective needs, focusing on equity and inclusion.

Our Organisations and Condition Prevalence in Aotearoa New Zealand:

- **ADHD New Zealand:** ADHD New Zealand estimates that around 280,000 people in New Zealand have ADHD, affecting approximately 2.4% of children aged 2-14 years. It is underdiagnosed in adults due to diagnostic criteria initially developed for children.
- **ANZMES (The Associated New Zealand Myalgic Encephalomyelitis Society) and Complex Chronic Illness Support:** There are approximately 25,000 - 45,000 people living

with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and potentially over 400,000 when considering those who meet the criteria of long COVID induced ME/CFS.

- **Autism New Zealand:** Approximately 93,000 people in New Zealand are on the autism spectrum, translating to about 1 in 54 people.
- **Carers Alliance:** Carers NZ is a national not-for-profit supporting a network of approximately 490,000 individual family carers and supporting organisations.
- **Ehlers-Danlos Syndromes New Zealand:** These conditions, affecting all ages, genders, and races, represent a complex chronic disability. Though EDS is likely present in 1 in 500 people, it is currently diagnosed in only 1 in 5,000 due to inadequate training, knowledge, and coding issues in New Zealand.
- **Epilepsy New Zealand:** Epilepsy is a condition that affects 1 in 100 people, approximately 50,000 New Zealanders. 70% of people living with epilepsy gain good control on anti-seizure medication however, 30% will not get control and this has long lasting effects.
- **FACS-NZ (Foetal Anti-Convulsant Syndrome New Zealand):** The exact prevalence is unknown due to the complexity of diagnosis and underreporting. However, the condition is recognised to be a significant risk for children exposed to anti-seizure medicines during pregnancy.
- **FASD-CAN Incorporated Aotearoa (Fetal Alcohol Spectrum Disorder - Care Action Network):** Te Whatu Ora estimates that between 3 - 5% of people born each year may be affected by the effects of prenatal alcohol exposure. This implies that around 1800 - 3000 babies, approximately 8 babies per day, may be born annually with FASD.
- **Rare Disorders NZ:** Approximately 300,000 New Zealanders, 6% of the population, live with a rare disorder, with half of these individuals being children. Rare disorders, which have a prevalence of 1 in 2,000, encompass over 7,000 distinct conditions, each with varying levels of support needs.
- **Stroke Foundation of New Zealand:** An estimated 89,000 are currently living with the effects of their stroke. 10,000 people are expected to have a stroke this year. The number is rising with Māori, Pacific, and Asian peoples having strokes early and more severely than other ethnicities.
- **Tourettes Association of New Zealand (TANZ):** Tourette Syndrome affects approximately 1 in 100 school-aged children in New Zealand. Up to 85% of individuals with this disability experience co-occurring conditions such as ADHD, OCD, anxiety, and mood disorders.

Recognition as a Disability

These chronic, disabling conditions often operate in a 'grey' area where they meet the New Zealand government and United Nations (UN) definitions of 'disability,' yet fail to qualify for Disability Support Services (DSS) eligibility. This discrepancy stems from insufficient coding, tracking, identification and a general lack of awareness and skill set among healthcare providers regarding disability conditions in New Zealand.

Disability encompasses physical disability or impairment, physical illness, psychiatric illness, intellectual or psychological disability or impairment, any other loss or abnormality of psychological, physiological, or anatomical structure or function, reliance on a guide dog, wheelchair, or other remedial means, and the presence in the body of organisms capable of causing illness.¹

The DSS eligibility criteria should be inclusive of a diverse range of conditions that meet this definition and are globally recognised as disabilities. For the majority of the organisations represented by this joint submission, our conditions and disorders align. One of the major obstacles we face is the lack of professional understanding, diagnostic capacity, and capabilities. Requiring a diagnosis to access support further exacerbates this issue. To ensure that individuals with these and other disabilities receive the necessary support, it is imperative that the DSS eligibility criteria is reviewed and revised.

See Appendix [section 1](#) for more detail.

Tracking and Coding

The absence of identification and routine coding in primary and secondary healthcare, coupled with the lack of tracking and reporting, complicates the assessment of individuals requiring Whaikaha services. Without proper identification, coding and tracking mechanisms, it becomes challenging to identify and support those who need disability services. Furthermore, if there is coding present, it is not always used due to lack of awareness of there being a code.

See Appendix [section 2](#) for more detail.

Functional Capacity and Severity of Conditions

The system is not working for many with the disabilities and conditions represented in this submission. For instance, many exist on a spectrum from mild to very severe. Some individuals with these disabilities and conditions may require support with feeding, bathing, toileting, may be bedbound, or housebound. Despite their significant needs, they are excluded from DSS, which should recognise these conditions as disabilities. Furthermore, the eligibility criteria need to be revised so that individuals with certain conditions are not automatically excluded from DSS simply because of diagnosis or because they have chosen not to pursue a claim from another government agency ie. ACC.

See Appendix [section 3](#) for more detail.

¹ [Definition of disability - Map \(workandincome.govt.nz\)](http://workandincome.govt.nz)

Early Intervention to Improve Outcomes

Strategies need to be implemented for early identification and intervention for individuals at risk of developing disabilities or symptoms becoming more severe. This proactive approach can significantly improve long-term outcomes and reduce the severity of disabilities. For instance, investing in prevention measures can mitigate the high incidence and associated economic costs of various conditions. Additionally, early and consistent management can prevent the progression to more severe disability. Research also shows that diagnosis as early as possible enables functionality-based approaches and individualised support plans to be put in place leading to better life outcomes.

Our recommendations would be to develop integrated care pathways that streamline access to early intervention services across different health and disability sectors. This approach would ensure that individuals receive timely support without facing delays due to complex bureaucratic processes.

See *Appendix [section 4](#)* for more detail.

Funding Availability

'The cost of doing nothing'

The current funding mechanisms for DSS are inadequate to meet the growing needs of the population requiring disability support. The government is inadequately identifying, coding and tracking these conditions, resulting in a lack of awareness of their full scope. Consequently, they are not allocating appropriate funding to Whaikaha to accommodate all individuals in Aotearoa who meet the definition and have varying needs for access.

There is a significant cost to New Zealand for not supporting these conditions. It is crucial to understand the 'whole of life' benefit. Instead of focusing solely on the expense of providing services, the government should consider the broader implications and costs of inaction. This includes the importance of a social and wellbeing approach, with wraparound services to support individuals holistically.

Limited funding restricts the number of individuals who can be assisted and the extent of support they receive. Many individuals face long waiting times for assessments and services. This delay can exacerbate their conditions and increase the overall cost of care in the long run. Here is an idea of what some of these conditions cost the NZ economy based on existing statistics from NZ and overseas.

- It is estimated that at least 25,000 people live with ME/CFS. Furthermore, up to 50% of all long COVID cases are expected to meet the diagnostic criteria for ME/CFS, potentially increasing this number to over 400,000. Due to the lack of routine coding in primary and secondary care, and the absence of tracking and reporting, the exact numbers are uncertain. However, based on 2017 data, the estimated cost per person living with ME/CFS is at least \$45,000. This translates to a total cost of \$1.125 billion for the 25,000 people living with ME/CFS. If the number of people living with ME/CFS and long COVID has risen to 400,000, the total cost would escalate to \$18 billion. Given the passage of time and inflation, these costs are likely to have increased, further emphasising the financial burden of this condition.
- Strokes cost the NZ economy around \$1.1 billion annually, a figure expected to rise to \$1.7 billion by 2038, highlighting the urgent need for adequate funding to support preventative measures and rehabilitation. Up to 90% of strokes are avoidable or delayable so investment in prevention would reap significant system savings.
- The June 2024 NZIER report estimated alcohol-related harm in 2023 (based on the increased risk of morbidity and mortality) to be \$4.8 billion due to FASD. This was more than all the other associated alcohol harms combined.
- Ehlers-Danlos Syndromes NZ estimates that there is an economical impact for an individual seeking a diagnosis based on own translation of data and calculations in an American study² equating to \$1,909,500,000 of lost productivity by individuals of working age. \$2,149,500,000 of lost productivity for caregivers, family, and support. Morally a lack of diagnosis means there is lack of proactive care for individuals.
- The average lifetime cost to ACC of a single FACS claim is estimated at \$7 million. A single severe claim is estimated to cost ACC between \$5 million and \$25 million, which is an indication of the impact on the person.³

Cost-effectiveness in funding disability support services requires comprehensive data collection to ensure proper allocation of resources. A potential solution includes implementing a GP tick box to indicate additional support needs. Cost-effectiveness must consider the systemic costs avoided, such as reduced hospital time, adverse outcomes arising from involvement in the justice system, mental health system, homelessness, and unemployment, and decreased reliance on educational systems for medical equipment. Early investments should not only target children but also focus on adults and the evolving needs of individuals over their lifetime. Additionally, the financial impact on family and whānau health and disability should be factored into funding decisions to provide a holistic approach to support.

Continuous medical training is also necessary, and medical professionals need to connect with the community to understand consumer needs genuinely. Unfortunately, they often lack the time,

² PMLiVE (2014). The distressing impact of rare diseases. Retrieved from: [The distressing impact of rare diseases - PMLiVE](#)

³ [ACC7971-Supporting-Treatment-Safety-2021.pdf](#)

funding, or capacity to do so. Therefore, New Zealand needs more healthcare staff, including nurse specialists and a centre of diagnostic medicine, to ensure better care and understanding of complex conditions.

Issues with current DSS

Inconsistent Criteria and Postcode Lottery

The DSS eligibility criteria are inconsistent throughout the country resulting in what is referred to as a “postcode lottery” for health care. There is an issue of regional disparities in service provision, emphasising the need for integrated support systems across different regions. Needs Assessment and Service Coordination (NASCs) often work differently in various areas, which can lead to inconsistent access to services depending on where a person lives. This "postcode lottery" effect means that individuals in some regions may receive better or more comprehensive support than those in others.

Systematic Barriers

A major issue facing people with disabilities when accessing services is the reliance on high health literacy and the ability to effectively communicate needs to health professionals. The current system is overly complicated, often requiring extensive documentation and high health literacy, making it particularly challenging for those with complex needs, such as cognitive impairments associated with these disabilities and conditions.

Additionally, NASC providers, who are responsible for needs assessment and coordination, often lack the expertise to fully understand these complex conditions. This results in assessments that do not accurately capture the fluctuating nature of these medical issues.

See Appendix [section 5](#) for more detail.

Equity

Equity in obtaining diagnoses and accessing DSS is crucial for all these disabilities and conditions. Disability support needs to be provided based on presenting needs rather than waiting for a formal diagnosis. However, service conflicts often arise, with agencies like WINZ and NASCs sometimes rejecting healthcare professionals recommendations due to a lack of knowledge. Additionally, there are notable inequities between paediatric and adult services, exacerbated by some GPs' false beliefs that certain disabilities disappear with age.

See Appendix [section 6](#) for more detail.

Lack of Integration

Lack of integration across agencies (the silo effect) is a big problem that needs to be addressed by the government. This issue is also felt by medical professionals, as they want to understand a consumer, but do not have access to vital medical notes, reports, and considerations. This often leads to further trauma for a consumer, as new medical professionals may not 'believe' their conditions, attempt to invalidate previous diagnoses, or issue treatment plans that may be harmful. The absence of a cohesive system exacerbates the difficulties faced by individuals with complex medical needs, leading to inconsistent care and additional stress for both consumers and healthcare providers.

Considerations for the Review of DSS Eligibility

Disability Definition

New Zealand should apply the United Nations definition (to which we are a signatory under the UNCRPD) of disability when considering eligibility for DSS.

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1).⁴

We would also like to emphasise that the New Zealand government’s own definition fits all these conditions and disabilities represented in this submission, yet the eligibility criteria does not.

*A disability is an impairment – physical, intellectual or sensory – that lasts for more than 6 months and limits your ability to carry out day-to-day activities. This can include psychiatric illness.*⁵

Functionality-Based Approach and Individualised Support Plans

We need to shift from a strictly criteria-based assessment to a functionality or symptoms-based approach that considers the functional capacity and severity of conditions on a spectrum. Disabilities can fluctuate in severity and impact, requiring flexible and adaptive support mechanisms. Many of these conditions and disabilities exist on a spectrum from mild to very severe, and support should be tailored to the individual's current functional capacity.

⁴ [Article 1 - Purpose | Division for Inclusive Social Development \(DISD\) \(un.org\)](#)

⁵ [Human Rights Act 1993 No 82 \(as at 01 December 2022\). Public Act 21 Prohibited grounds of discrimination – New Zealand Legislation](#)

To achieve this, we recommend developing individualised support plans that are responsive to the changing needs of individuals with disabilities. These plans should be regularly reviewed and adjusted to reflect the current level of need, ensuring that support remains appropriate and effective. Furthermore, they should be flexible enough to be expanded again when additional support needs occur. This is particularly relevant for conditions like FACS and ME/CFS and Rare Disorders, where symptoms can vary significantly over time.

It's important to consider many of these conditions and disabilities can impact individuals systemically and often come with hundreds of comorbidities. A multidisciplinary approach to care is essential for better outcomes. However, as highlighted, the lack of communication between private, public, and allied health systems, as well as the inadequate coding systems, makes it challenging to obtain a comprehensive view of an individual's healthcare journey.

Simplifying Application and Assessment Process

We recommend simplifying the application and assessment processes to make them more accessible and equitable for individuals with varying levels of cognitive and physical abilities. This should include support from GPs in completing applications or assisting patients/consumers throughout the process. The current system's complexity is a significant barrier, particularly for those with cognitive impairments or severe fatigue seen in these conditions and disabilities. A more user-friendly approach would ensure that all individuals receive the necessary support they need.

Improve NASCs Processes

The processes within Needs Assessment and Service Coordination (NASCs) and WINZ Disability Allowance must be improved to allow individuals to express their needs without having to present the worst-case scenario. Current services lack trust and often conflict, leading to frustration and wasted resources. Requiring repetitive medical certificates and evidence for permanent conditions is burdensome and unnecessary. Instead, the system should facilitate a more positive and realistic expression of needs, focusing on enabling individuals to achieve their goals and potential without causing additional emotional or psychological distress. Additionally, there is a need for medical professionals, including occupational therapists (OTs), to assist in decision-making. Their involvement would help create a more compassionate and effective support system, ensuring that individuals receive the appropriate support without unnecessary delays or complications. By incorporating the expertise of medical professionals, the system can reduce the administrative burden on individuals and promote a more efficient and supportive environment. Such improvements would ensure a more compassionate and effective support system, fostering trust and better outcomes for those requiring assistance.

Enhanced Support for Needs Assessments

Healthcare professionals need to have dedicated support in the form of medical staff, such as nurse specialists, to assist with needs assessments. This collaboration would enhance the accuracy and comprehensiveness of these evaluations, ensuring that the varied and complex needs of individuals requiring disability support services are adequately identified and addressed.

Regional Integration and Catch Net for Unmet Needs

Regional Integration:

There is a necessity for regional integration of services to support individuals who move across different regions. DSS must be consistent and equitable, ensuring that everyone receives the same level of care regardless of where they live. This approach would help mitigate the "postcode lottery" effect by providing a more reliable and standardised level of care for all individuals in need. To achieve this, services need to be regionally integrated, guaranteeing equitable access and support across all locations and ensuring that no one falls through the cracks due to regional inconsistencies.

Catch Net:

The current disability support system often leaves individuals who do not fit government service criteria without the necessary support. For instance, individuals with fluctuating symptoms, or complex conditions or disabilities might not meet the stringent criteria for existing services. Many people with these conditions and disabilities fall through the cracks, often relying on family for care if they are fortunate. Those without such support can live in a constant state of unwellness, struggling with daily tasks and functions.

There is an existing silo effect where government agencies do not communicate effectively, maintain separate files, and yet have overlapping individuals with these conditions and disabilities. This lack of inter-agency communication and a shared system contributes to many individuals falling through the cracks. There needs to be a realistic way of showing where all these conditions fit. For instance, recognising that some conditions i.e. Parkinson's fit into the 'Healthy Aging' group within Te Whatu Ora, however many of these conditions can occur in an individual at any age i.e. strokes, chronic illness and rare disorders. Moreover, if individuals meet the disability definition, they should be entitled to Whaikaha's support, and we need to ensure that other systems like Te Whatu Ora Long Term Conditions are effectively serving people who have these conditions or disabilities. For example, we've seen individuals with ME/CFS often get

denied NASC assessments if they are under 65 and not bedridden, leading to significant gaps in care.

To address this gap, it is crucial to implement a "catch net" for those who fall through the cracks. This catch net should provide reassessment options for individuals who are undiagnosed or have diagnoses that do not meet existing criteria, ensuring that everyone who needs support can access it, regardless of their diagnostic status. By offering reassessment opportunities and flexible criteria, the system can better accommodate these individuals, preventing them from slipping through the support network.

Regional integration and the implementation of a "catch net" approach will enhance equity and inclusivity across DSS. It would also ensure that no one falls through the cracks due to regional inconsistencies or more complex diagnostic status, creating a more inclusive and supportive system for all individuals with disabilities.

Centralised system

We need a centralised system or processes to enable sharing of information to address the lack of integration across agencies. We are already seeing that the current migration of DHB's into regions is already proving a lack of change and sharing of information consistently.

The support services available from Health New Zealand/Te Whatu Ora for people with chronic health conditions and those available from Whaikaha for people with disabilities should be equitable and based on the person's need for support, not whether their disorder is considered a health condition or a disability. This should also include support for family carers as they often need to jump through more hoops to gain access to finance to help fund themselves as a carer. It is essential to recognise that disabilities and health conditions are intertwined, and funding should address both aspects comprehensively - the disability should not be separated from the health condition and only the disability needs be funded.

Mental Health Support

Understanding Whaikaha's role amidst other changing systems is crucial to address the needs of those falling through support gaps. We realise that mental health support is currently under the Ministry of Health, yet mental health can be a disability as well, a comorbidity or result of these conditions and disabilities that can be triggered by a lack of support or medical trauma. The lack of support can lead to mental health and addiction issues; therefore, recommendations for mental health support for disabled people must be considered.

See Appendix [section 7](#) for more detail.

Clarity of Scope

It is important to comprehend the integration issues within the disability system to ensure effective support. While the review cannot directly change Work and Income or the health system, it can provide valuable cross-government advice to address these issues. Understanding the limitations and potential areas for improvement within the scope of Whaikaha's role is essential for comprehensive support. Additionally, the government needs to be more transparent to ensure consumers understand and have clarity on where the support is coming from and where they need to advocate for support.

Convention-Based (EGL/UNCRPD/Te Tiriti)

To ensure accountability in implementing conventions, there is a need for ongoing audits. Ongoing audits by the community and consumers, from a range of medical standpoints, are essential. While Disabled Peoples Organisations (DPOs) are sometimes included in audits, it is crucial to also involve smaller groups/organisations to ensure diverse perspectives are considered and no voices are excluded. This approach will help maintain adherence to the principles of Enabling Good Lives (EGL), the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and Te Tiriti o Waitangi.

Summary

The submission makes the following key recommendations to address the highlighted issues:

- **Revise Eligibility Criteria:** Expand DSS eligibility to include a wider range of conditions that meet the UN and New Zealand definitions of disability, ensuring these conditions are properly coded and tracked.
- **Improve Regional Integration:** Establish integrated support systems across regions to eliminate the "postcode lottery" effect, ensuring equitable access to services for all individuals regardless of location.
- **Simplify Application Processes:** Streamline the application and assessment processes to make them more accessible, especially considering individuals with cognitive impairments or severe fatigue.
- **Enhance NASC Processes:** Improve the processes within Needs Assessment and Service Coordination (NASC) to reduce the administrative burden on individuals and facilitate a more compassionate and effective support system.
- **Increase Funding:** Advocate for increased funding for DSS to adequately support all individuals who meet the definition of disability. Highlight the long-term benefits and cost savings of providing early and consistent support.

- **Early Intervention:** Develop integrated care pathways that streamline access to early intervention services across different health and disability sectors.
- **Centralised System:** Implement a centralised system for sharing information across agencies to ensure cohesive and comprehensive care for individuals with complex needs.
- **Catch Net for Unmet Needs:** Create a "catch net" for individuals who fall through the cracks of the current system, ensuring they receive reassessment and support regardless of their diagnostic status.

Appendix

1. Recognition as a Disability:

- ME/CFS aligns with the disability definitions set by the United Nations, the World Health Organisation, the Human Rights Act 1993, Statistics New Zealand, and the New Zealand government's own criteria. Despite this, ME/CFS does not meet the criteria to access DSS.
- Ehlers-Danlos syndrome is classified as a 'rare' disorder and due to the lack of coding, results in insufficient data and visibility.
- Rare disorders - It takes one in five individuals with a rare disorder over ten years to obtain a diagnosis.⁶ Those who remain undiagnosed must still be able to access support. Furthermore, many rare disorders present with diverse symptoms and needs, making diagnosis-based access to support inappropriate.
- Although epilepsy is considered a health condition it is very disabling for many people. Challenges include social isolation, mental health issues, financial challenges, relationship difficulties and ongoing, recurring health issues.
- Getting a diagnosis for a stroke is fairly straightforward and there are clinical systems in place. However after the event and treatment in hospital, recognition of subsequent disability and adequate support is an issue.

2. Tracking and Coding:

- The lack of data regarding rare disorders in New Zealand is not only a challenge to estimating prevalence, but also for improving diagnosis, treatment and research. Business and Economic Research Limited (BERL) Rare Disorders insights report.⁷
- This is true for nearly every disorder and disability in Aotearoa. Data is required for good decision-making.

3. Functional Capacity and Severity of Conditions:

- Only the very severe cases, which account for about 2-5% of all people with ME/CFS, typically qualify for NASC as "very high needs." Even those who meet the criteria have inadequate support, for example a 22-year-old who requires feeding, toileting, and bathing was granted 22 hours per week of care but, due a staff shortage, received only 11 hours in reality. Those in the moderate and severe categories, who account for approximately 60-75% of all people with ME/CFS and are often bedbound or housebound, do not fit the NASC criteria under the DHBs / Te Whatu Ora's LTC-CHC.

⁶ Rare Disorders NZ (2024). Impact of Living with a Rare Disorder. Retrieved from: [RDNZ | Impact of Living with a Rare Disorder \(raredisorders.org.nz\)](https://www.raredisorders.org.nz/)

⁷ [Rare Disorders Insights Report \(berl.co.nz\)](https://www.berl.co.nz/)

- The eligibility criteria needs to change as FACS see individuals excluded from DSS because they have chosen not to pursue ACC claims, when they should only be excluded if they have an accepted ACC claim.

4. Early Intervention to Improve Outcomes:

- Investing in prevention measures for strokes such as diagnosing and treating high blood pressure, could mitigate the high incidence and associated economic costs, which are projected to rise significantly by 2038. Programmes such as early vocational rehab in stroke services and person centred self directed interventions such as Taking Charge After Stroke can significantly improve survivors' recovery and quality of life.
- Research also shows that diagnosis as early as possible enables FASD-informed approaches and supports to be put in place leading to better life outcomes.
- Early intervention is particularly crucial for conditions like ME/CFS, where early and consistent management can prevent the progression to more severe disability.

5. Systematic Barriers

- Many individuals reach out to Complex Chronic Illness Support in crisis, having previously lacked sufficient support. CCI Support have seen a notable rise in mental health challenges among their clients, prompting them to expand from one counsellor to six, with more awaiting assistance. Individuals are coming to them with much higher mental health needs, with more on the waitlist, as people wake to a day where they can't even manage to meet their basic human needs.

6. Equity:

- Research indicates the significant benefits of diagnosing FASD for affected individuals, their families, and professionals working with them. Despite benefits for FASD and other conditions, limited diagnostic resources in New Zealand mean that less than 5% of individuals with FASD receive a diagnosis.

7. Mental Health Support:

- Complex Chronic Illness see the escalation in suicide and self-harm risks, emphasising the urgency of work needed in this space, as individuals struggle to meet even their most basic needs. They've seen an increase of suicide and self-harm risk as they no longer wish to live lives many of us couldn't even imagine.
- People with FASD face significant and unmet mental health and addiction issues compared to the general public. Various studies revealed that 90% of people with FASD have co-occurring mental health diagnoses, compared to 20% in the general population, with depression (45%-50%) and anxiety (20%-40%) being the most common comorbid conditions. Substance use rates are five times higher among individuals with FASD, with

35% developing an alcohol or drug use disorder. One-third of people with FASD experience suicidal ideation, with rates critically higher than the general population (25.9% vs. 3%-12%). Suicidal ideation also occurs at much younger ages among those with FASD, and adolescents with FASD require medical assistance for suicide attempts at rates 5.5 times higher than their peers. Victimization by peers, which is common in the FASD population, increases the risk of suicide. A 2019 study showed that people with FASD have significantly higher Adverse Childhood Experience (ACE) scores, averaging 3.4 ACEs per person, with almost half (46%) experiencing four or more ACEs and 13% experiencing six or more. Higher ACE scores are associated with increased rates of comorbid neurodevelopmental disorders. Additionally, rates of psychiatric disorders such as psychotic and personality disorders, conduct and oppositional defiance disorders, depression, anxiety, and substance use are higher in the FASD population compared to the general population.

- People with epilepsy often face depression and anxiety, leading to difficulties in gaining or retaining employment. Many are on the Job Seekers allowance, despite its inappropriateness, and experience discrimination from employers. MSD's pressure to find work can heighten anxiety, increasing the risk of seizures.
- Around half of all stroke survivors experience significant depression or anxiety in the first year following their stroke. It is also common to experience both depression and anxiety at the same time. There is a significant gap in psychological support for people after stroke or support for carers/families.

Our Organisations: Key Insights and Issues:

ADHD New Zealand:

- ADHD New Zealand: is the largest and longest-standing non-profit organisation dedicated to supporting those living with ADHD in New Zealand. Formed in 1979, their mission is to provide practical information and support, connect people and organisations, and inspire members through learning events and shared stories.
- We emphasise evidence-based treatment, ongoing support, and appropriate accommodations to help those with ADHD thrive.
- Key issues include the need for better awareness and understanding of ADHD, the provision of adequate support services, and addressing the stigma associated with the condition.

ANZMES:

- It is estimated that at least 25,000 people live with ME/CFS. Of all long COVID cases, up to 50% will meet the diagnostic criteria for ME/CFS, . We conservatively increase the number then to around 400,000. But it may be higher, as coding is not routinely used in primary and secondary care and no tracking or reporting is conducted, it is difficult to ascertain accurate prevalence data. This does not mean that all these people require Whaikaha services.
- ME/CFS exists on a spectrum like many conditions, from mild to very severe. The very severe usually require 24/7 care and are entitled to NASC as "very high needs." This accounts for 2-5% of those with ME/CFS, but as mentioned previously, insufficient care is granted to this small proportion.
- However, those in the moderate and severe categories are not deemed severe enough, even though the majority are bedbound or housebound, unable to work or exert energy for simple tasks like housework. They are meant to get NASC through the DHBs / Te Whatu Ora under LTC-CHC but do not fit the criteria. Given that the conditions fit the criteria for disability, it should be included in Whaikaha. Moderate-severe account for approx 60-75% of all people with ME/CFS.

Autism New Zealand:

- Autism NZ supports individuals on the autism spectrum and their families through education, advocacy, and support services.
- We provide training for educators, employers, and healthcare professionals to better understand and accommodate autistic individuals.
- Our services include outreach, diagnostic support, employment transition services, and a resource centre.
- Key issues include increasing public awareness and understanding of autism, providing consistent support services, and addressing systemic barriers to access, particularly for adults seeking diagnosis and support.

Carers Alliance:

- Carers Alliance is a national not-for-profit organisation that supports a network of approximately 490,000 individual family carers and supporting organisations in New Zealand.
- We provide resources, advocacy, and support to improve the well-being and recognition of family carers.
- Our organisation focuses on ensuring carers have access to the necessary information and services to manage their caregiving responsibilities effectively.
- Key issues include better support and recognition of the challenges faced by carers, access to respite care, and advocating for policies that benefit carers.

Complex Chronic Illness Support:

- CCI Support is the largest one:one charitable support service for people with ME/CFS, FM and Long COVID. With 9 paid staff and many volunteers throughout NZ. Our referrals are increasing daily and the need within them is escalating as more people are coming to us in crisis -state, having not been supported well previously. They are coming with much higher mental health needs, we had 1 counsellor and now have 6 and there is more on the waitlist as people wake to a day where they can't even manage to meet their basic human needs. There is an increase of suicide and self-harm risk as they no longer wish to live lives many of us couldn't even imagine. The intensity of management has increased exponentially. All of this could be prevented with adequate basic needs funding and early intervention.

Ehlers-Danlos Syndromes New Zealand:

- Impacting all ages, genders and races, these groups of conditions are a multifaceted chronic disability. There is likely to be 1:500 people with Ehlers-Danlos Syndrome however, they are currently rated 1:5000 due to lack training and knowledge, this along with coding not working properly in New Zealand only exacerbates the issues further, leading to continuing lack of knowledge, delays in diagnoses and treatments and misdiagnoses.
- Because we are classed as 'rare' and that medical professionals do not take us seriously, our coding isn't applied to us, and in turn the data is not there. We are basically invisible in the government's eyes.
- There is a high percentage of our community that rely on others/friends/family to help them out/care for them, and often these people often have the condition themselves, and yet the financial support is not there because our main symptom is 'pain'.
- Our condition can impact us systemically, and often comes with comorbidities. We need a multi disciplinary approach to care for better outcomes, but the private/public/allied health systems and coding systems not talking to each other makes this near impossible to get a true visibility on an individual's health care journey.

- Medical training needs to be continued, and we need medical professionals to connect with the community to have a true understanding of consumer needs, but they don't have time, funding, or capacity to do so. We need more staff in New Zealand, including more nurse specialists and a centre of diagnostic medicine.

Epilepsy New Zealand:

- Epilepsy is a condition that affects 1 in 100 people, approximately 50,000 New Zealanders.
- 70% of people living with epilepsy gain good control on anti seizure medication however 30% will not get control and this has long lasting effects.
- Though epilepsy is considered a health condition it is very disabling for many people. Challenges include social isolation, mental health issues, financial challenges, relationship difficulties and ongoing, recurring health issues.
- Depression, anxiety, memory issues and fatigue are common for people living with epilepsy often resulting in people struggling to gain or retain employment.
- A large number of people with epilepsy are on the Job Seekers allowance which is not appropriate; they often experience discrimination by employers and potential employers. MSD puts pressure on someone to search for work, pressure that can lead to an increase in anxiety which, in turn can lead to an increase in seizures.
- Seizure monitors and alarms can be a valuable tool for some people living with epilepsy however there is no public funding for this important medical equipment which is expensive. This equipment can give a form of virtual respite for caregivers as well as piece of mind.

FACSNZ (Foetal Anti-Convulsant Syndrome New Zealand):

- Foetal Anti-Convulsant Syndrome (FACS) and the relative individual syndromes that come under this heading are recognised as a disability under DSS, as they are recognised as a disability with ACC, and internationally.
- If someone has a diagnosed syndrome/spectrum disorder that is recognised as a disability in New Zealand and/or internationally, that DSS also recognises this disability and provides DSS for the person.
- Remove the wording to determine eligibility “does not have an injury that is likely to meet ACC’s cover and entitlement criteria under the Accident Compensation Act 2001” to state the people would only be ineligible if they already have an accepted ACC claim. Some people choose not to go down the ACC route, or don’t have capacity to go down this route, so they shouldn’t automatically be deemed ineligible for not doing so.

FASD-CAN Incorporated Aotearoa (Fetal Alcohol Spectrum Disorder - Care Action Network)

- Te Whatu Ora/Health NZ estimates that between 3 to 5 percent of people born each year in Aotearoa may be affected by the effects of prenatal alcohol exposure each year. This implies that around 1800-3000 babies (approximately 8 babies a day) may be born annually with Fetal Alcohol Spectrum Disorder (FASD) in New Zealand. In addition, the June 2024 NZIER report estimated alcohol-related harm in 2023 (based on the increased

risk of morbidity and mortality) to be \$4.8 billion due to FASD. This was more than all the other associated alcohol harms combined.

- FASD is both a brain and body disorder, and it is a lifelong disability where the brain and body has both structural and functional damage. FASD is an incredibly complex condition and the daily living challenges experienced by people with FASD are individual and unique due to the pattern of alcohol exposure during pregnancy, and other factors such as parental genetics, comorbid drug use, maternal health and wellbeing, and pregnancy environmental factors.
- Research shows FASD is associated with 428 comorbid conditions, and many adverse life outcomes such as disrupted school experiences, trouble with the law, confinement, placement in care, alcohol/drug difficulties, mental health issues, homelessness, social isolation, unemployment, multiple Adverse Childhood Experiences (ACEs). These can only be mitigated by having the right supports in place to support the individual and their family.
- Disability supports should be provided on the basis of both diagnosis and presenting needs because:
 - Research shows that diagnosis as early as possible enables FASD-informed approaches and supports to be put in place leading to better life outcomes. This is true for all disabilities.
 - Research also shows that diagnosis has many positive benefits for the person with FASD, their family/whānau, and the professionals interacting with them.
 - However, because we have limited public FASD diagnostic capability and capacity in New Zealand and currently less than 5% of people with FASD get diagnosed in Aotearoa, we also need to be able to provide disability support on the basis of presenting needs until support can be better targeted after diagnosis.
 - Lack of diagnosis must not delay access to disability support. The needs of caregivers are urgent. An October 2023 survey of FASD caregivers highlighted their clear need and desperation for support, and indicated many child placements were at risk if support was not provided urgently.

Rare Disorders NZ:

- A disorder is considered rare when it affects less than 1 in 2000. Approximately 300,000 New Zealanders have a rare disorder of which approximately 50% are children. There are over 7,000 rare disorders with varying levels of need for support.
- Support should be needs based rather than diagnosis based. Having to have a diagnosis is a barrier to support and for 1/5 people with a rare disorder it took >10 years to get a diagnosis in our last survey.⁸
- Undiagnosed people need to be able to access support. In addition to this, a lot of rare disorders have varying presentations with varying needs, so diagnosis based access to support is not appropriate.

⁸ www.raredisorders.org.nz/about-rare-disorders/impact-of-living-with-a-rare-disorder/

- Many rare disorders are complex and involve multiple body systems. The current model does not manage this well in that it tries to separate the disability from the health condition and only fund the disability needs. People can not be split in half.
- The support services available from Health New Zealand |Te Whatu Ora for people with chronic health conditions and those available from Whaikaha for people with disabilities should be equitable and based on the person's need for support, not whether their disorder is considered a health condition or a disability.
- Many rare disorders have a fluctuating course and needs can increase and decrease rapidly, the current system is not well set up for this.
- Better data is needed to make funding decisions, lack of data collected on rare disorders contributes to this.
- It would be good to see the costs reframed as opportunities for investment with consideration of long term benefits that can be achieved for individuals, whānau and communities through support.

Stroke Foundation of New Zealand:

- Approximately 10,000 people experience a stroke in Aotearoa annually (NZ Health Survey 2022/23.) The NZHS also found that 33,000 people are permanently disabled from stroke (37%).
- In 2022, 37% became 'disabled' because of their stroke (minor impairment excluded) – approximately 1/3 passed away
- An estimated 89,000 are currently living with the effects of their stroke (2.1% prevalence).
- Stroke costs the NZ economy around \$1.1b annually (figures from 2020), and is expected to rise to \$1.7b in 2038
- Stroke is a leading cause of adult disability
- Up to 90% of strokes are avoidable (or at least delayable) – more investment in prevention is needed
- 25% - 30% of stroke occurs in people < 65 – young fit, healthy people have strokes
- Māori and Pasifika experience strokes 10 – 15 years earlier, often during working age which has significant financial and family impacts. –

Tourettes Association of New Zealand (TANZ):

- TANZ supports individuals with Tourette Syndrome and their families. They offer education, advocacy, and resources to improve the lives of those affected by Tourette Syndrome and Tic Disorders.
- TANZ provides support groups, educational materials, and awareness campaigns to increase understanding and acceptance.
- We also promote research into the causes and treatments of Tourette Syndrome.
- Key issues include raising awareness, reducing stigma, and ensuring access to comprehensive support services.

