

Manatū Hauora x Rare Disorders NZ Pae Ora Responsiveness Webinar Summary of input received

Overview

Manatū Hauora | Ministry of Health and Rare Disorders NZ jointly hosted two webinars for people from the rare disorder's community. Objectives for attendees were to:

- learn about the strategies for our future health system and how they can have a say in them;
- share what they want to see changed and what would make the biggest difference to their lives and the lives of their whānau;
- be part of a rare disorders community say on the most important features needed in our future health system.

Summary of Engagement

To allow participants to become comfortable with the Mentimeter mechanism used, we ran through several warm-up questions; 'I have joined this webinar because?', 'Where are you from?', and 'I live in a...'. The answers below are not a true representation of the number of active participants throughout the webinar as some joined late or chose not to answer these questions.



Pae ora: responsiveness to rare disorders in our future health system

Where are you from?...

Webinar One:

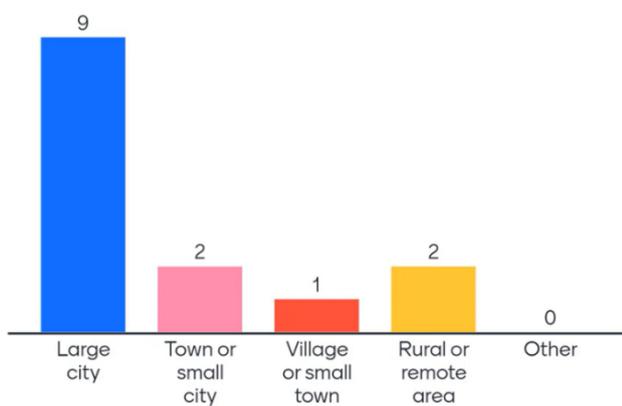


Webinar Two:

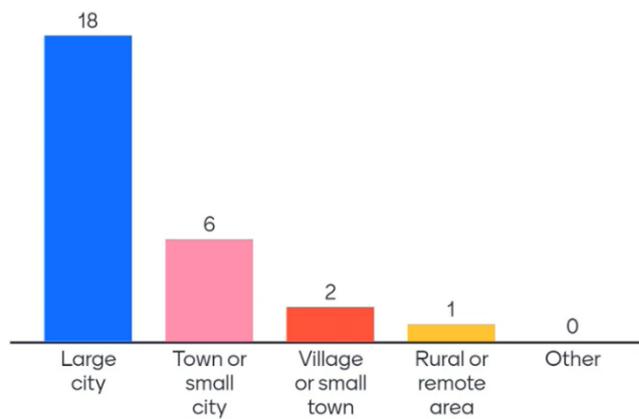


I live in a...

Webinar One:

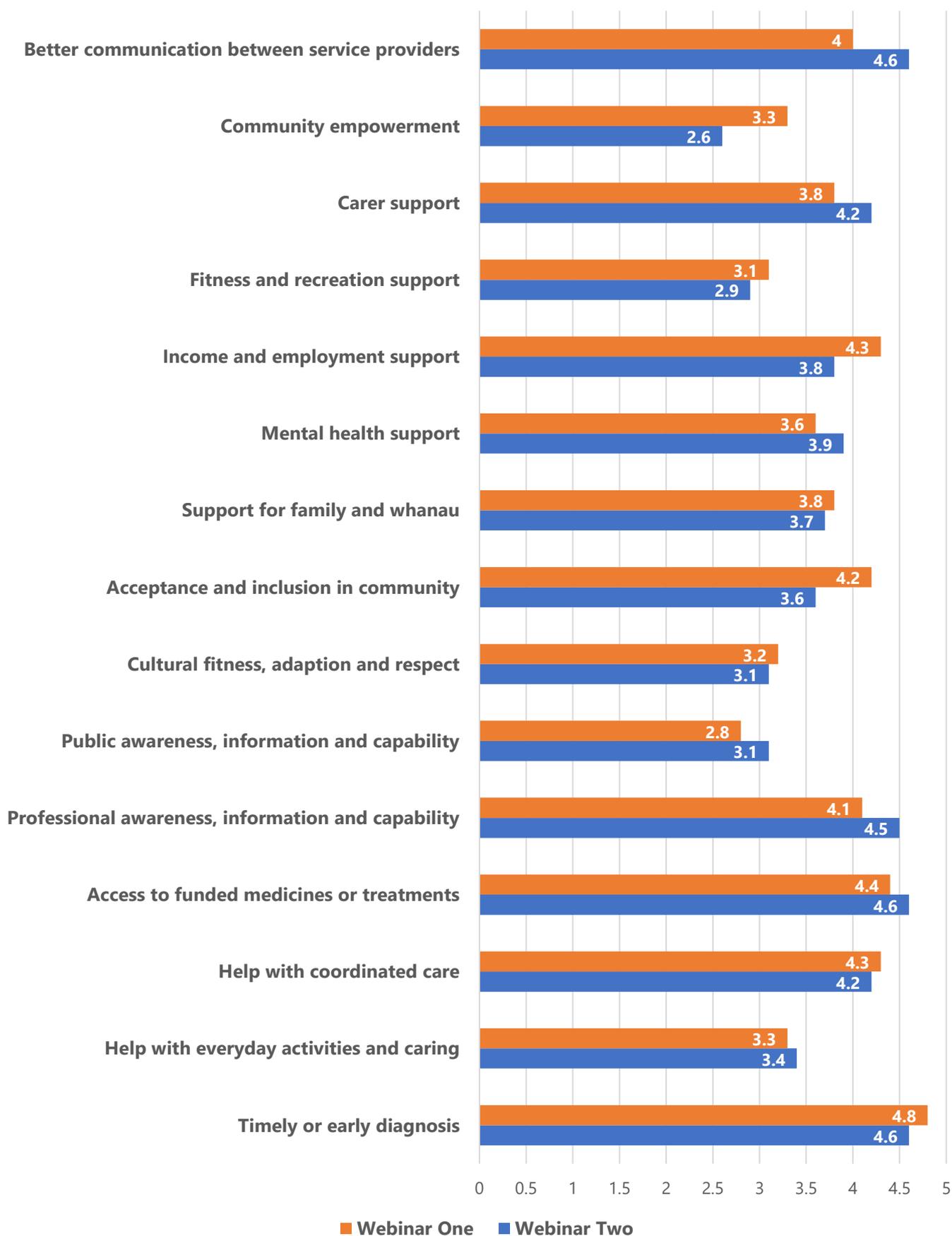


Webinar Two:



Pae ora: responsiveness to rare disorders in our future health system

On a scale of 0 (least important) to 5 (most important), rare disorders could be most improved by?



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Free Text Questions

We received a considerable number of responses, all meaningful and valued, throughout the free text section of the webinar. To ensure all opinions, ideas and voices are being acknowledged we have organised them into overarching themes and exemplifier comments as summarised below.

What makes you feel or be well and healthy?
<p>Support</p> <p>Support was a common theme throughout the webinar. It is clear from the responses that support can be incorporated in many ways:</p> <p>“As a parent to a child with Angelman Syndrome, sleep is essential but also difficult as the syndrome comes with a sleep disorder. Regular overnight respite is essential for our family caregivers”</p> <p>“Support from health providers; being believed rather than being told ‘it’s all in your head’.”</p> <p>“Wait times for support are too long. I’m a single mum, I work full-time, and I have no additional family support. We have been waiting two years for behaviour and sleep support. I’m burnt out.”</p>
<p>Wellbeing</p> <p>Wellbeing enhancing actions can make us feel well and healthy, many responses reflected this:</p> <p>“Being able to have a good sleep, feeling valued and being in nature.”</p> <p>“Keeping fit to maintain my independence so I can live a good life.”</p> <p>“Balance between areas of my life. What use is having support to work/being employed if that work destroys my ability to have a social life?”</p> <p>“Healthy doesn’t feel possible, but I feel better when I have hope.”</p>
<p>Medicines, Treatment & Diagnosis</p> <p>Medicines, treatments and diagnosis are all ongoing themes that people with rare disorders endure a constant struggle with, however when accessed can be one of the only things that bring a sense of feeling well and healthy:</p> <p>“Having access to life changing medications.”</p> <p>“Access to targeted treatments and interventions.”</p> <p>“Access to pain medicine, physiotherapy, strength and conditioning, and talk therapy.”</p> <p>“Access to funding for modern medicine.”</p>
<p>Health Care Accessibility</p> <p>Easy access to aspects of the health care system is essential for those who experience the effects of a rare disorder. This was a standout theme across all questions asked throughout the webinar:</p> <p>“Access to multi-disciplinary medical care.”</p> <p>“Access to specialists and General Practitioners that understand rare disorders”</p> <p>“Access to mobility equipment that is useable.”</p> <p>“Not having to push a system to work for my son’s need’s; health needs, his future mental health and schooling.”</p>

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Communication and Listening

Ensuring that people are being listened to and receiving effective forms of communication is an essential aspect to health:

“Good communication from my doctors.”

“As a consumer – a team that listens and puts my health goals first in order to be successful.”

“When I am listened to as a mother of a child with a rare disorder. We do know what’s best for our child and putting them at the centre as well as whānau means we can all be on the same page.”

Culturally Appropriate Care and Support

Ensuring that there is culturally appropriate care and support available is key for Manatū Hauora, the Pae Ora health strategies will reflect this and the need for this to be addressed is acknowledged:

“Culturally appropriate support that involves the whole whānau, our needs as a collective and acknowledging whakapapa as a key part of rare wellbeing.”

What change/s I most want to see in the health system is?

Health Care Accessibility

“A reduction to wait times to see specialists and a pathway to international expertise for disorders that are very rarely treated in New Zealand.”

“Better access to GPs, 15-minute appointments are outdated and disadvantage those with chronic and rare disorders.”

“Access to clinicians who can help me live as best I can even though there is no cure for my condition.”

“Open mindedness from clinicians when someone presents with atypical symptoms and a willingness to keep investigating rather than blaming symptoms on mental health issues – I’m sick of symptom dismissal.”

Support

“The removal of a ‘one size fits all’ approach to those with rare disorders.”

“I don’t want to have to fight for everything, rather than having to prove myself every year I should just be and feel supported by the system.”

“More ‘wrap around’ support systems.”

“Psychological support for children with rare intellectual disabilities.”

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Coordinated Care

Coordinated and integrated pathways of care create a cohesive health care system, many participants communicated the need for this:

"A clear and coordinated pathway of care for my son with a rare disorder – for wherever he is in the country."

"To have a coordinated approach to dealing with rare disorders from diagnosis to treatment options."

"Coordination of care, access to expertise, and access to support regardless of age, wealth, race or location."

"Specialists from different disciplines, working together to provide coordinated care. My illness covers many different areas of medicine, meaning I am currently on multiple waiting lists."

Research and Education

A greater prevalence of research and education focusing on rare disorders within the health system would make a significant impact to the lives of those affected:

"Increased research and development regarding rare disorders."

"Access to clinical trials in New Zealand."

"Increased access to reasonable training in accordance with the UNCRPD."

"Increased education and training opportunities for health professionals."

Data and Information Systems

Updated systems to capture data and information of rare disorder patients would create transparency across the system:

"Accurate reporting of data and surveillance."

"One place for all patient records and information to be stored as accessed across the health system."

"Coding systems that are the same across the board."

"A register kept for Angelman Syndrome, regular Angelman clinics with experts and collated information."

"Collection of data to better inform care and supports, improve access to expertise/sharing of information for all – too many inconsistencies."

Recognition and Inclusivity

Feeling recognised and included within the health system is important within society and for our health needs and goals:

"Increased understanding and inclusivity about hidden disabilities."

"Greater recognition of the unique challenges for people living with a rare disorder – we all have different needs."

"Stop treating people with rare disorders as interesting 'edge cases', instead centre their needs to their treatment plan."

"Recognition that 'getting back to work' is not the main health goal."

"Co-design."

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Guidance, Direction and Legislation

Changes to guidelines, regulations and legislation to ensure that the impacts of rare disorders is being addressed was a standout opinion from participants:

"A National Framework for rare disorders that means the pathways of care are not fragmented where people fall through the cracks."

"A change to MSD and IRD legislation so spouses can be recognised as dependants."

"Have a rare disorder strategy."

Funding

Increased funding would create an overall positive impact for those with rare disorders. More funding could alleviate many issues around access:

"Increased funding for medication and treatments."

"Funding that considers long-term progressive conditions, not just short bursts but available for the length of the condition needs."

"Funding for medicinal marijuana – opioids shouldn't be the only option."

"Increased funding for the rare disorders community through organisations such as RDNZ."

Communication and Listening

"Better communication between health providers."

"Actually, listening to the needs of patients and RDNZ."

"Health professionals preparing themselves (reading patient notes) before appointments, so no time is wasted repeating myself."

Culturally Appropriate and Supportive Care

"More Māori support systems."

"The use of Māori knowledge in support of a rare approach."

"Whānau are treated with culturally appropriate care, inclusive of a collaborative approach with respect of whānau knowledge."

"If we get it right for Māori first, everyone will benefit."

Medicines, Treatment and Diagnosis

"Access to new medicines that have been through clinical trials and have the ability to help our girl lead a life better than previously thought possible."

"Access to world class medications."

The most important change for people with rare disorders is?

Recognition and Inclusivity

"We want to be visible within the strategy and planning so we know our needs are being addressed."

"Tick boxes that people with rare disorders can tick so we feel included."

"Having more processes like this set up so we have a voice. Seeing change come out of these processes and feeling validated for our efforts."

"Recognition of the complexities that people and families affected by rare disorders are often faced with."

Medicines, Treatment and Diagnosis

"Access to treatment, waitlists are between 6-12 months because the health system is so under resourced, they can't cope."

"Access to early diagnosis and genetic testing."

"Being treated early, it's too late for me, but the next generation. When there is a genetic certainty about a disorder, lets treat people before they're sick."

"Access to modern medicines – on par with other OECD countries."

Health Care Accessibility

"Access. Access to GPs, specialists, allied health providers. I currently have to wait weeks to see a GP, many months to see a specialist, and I can never access allied health."

"Access to specialists beyond my home region/national area."

"Children having access to physiotherapists, speech therapists and paediatricians in school."

"Clinics for Angelman Syndrome means being treated by specialists who are familiar with the disorder. Collaboration with overseas specialists would also help save families from needing to be the expert all the time."

Support

"Having our health providers lobby for us rather than putting up roadblocks."

"Right now, I feel like I'm on my own fighting an enormous monster. Being supported, believed and getting meaningful treatment could change this."

"Ensuring family carers are adequately supported so they can maintain emotional bonds with their children."

"Financial support for parents as usually mothers have to give up working to care for their children, it's not easy."

Guidance, Direction and Legislation

"Our own strategy! We must be recognised so all the important changes can be made."

"Access to provide care to sector via ACC legislative change."

"A rare strategy with co-design."

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Research and Education

"Medical professionals often don't know or understand rare disorders. We need more upskilling and education."

"Research within our own community to see how what impacts our cultural needs."

"Improvements to ongoing compulsory education for practitioners in order to grow system capacity for rare disorders."

"Publicly funded research rather than reliance on the profit motives of pharmaceutical companies."

Coordinated Care

"Personalised and coordinated care, not having to rely on care pathways which often don't exist or are woefully insufficient."

"A system where someone with behavioural challenges isn't being set up to fail due to lack of coordinated care."

Data and Surveillance Collection

"Recording information about rare disorders so we know the true extent of the issue – we can only use overseas statistics at the moment which means we're guessing how it applies to New Zealand."

"Collect rare data so we can identify problems and gaps within the system for rare disorders."

"Better record collection – personal and system access."

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The most important change for carers is?

Support

"Financial support for loss of income or the ability to work for themselves."

"While we waited almost a year to see a genetic health service, I wondered 'where's the support group for those stuck in undiagnosed limbo-land?'"

"Practical support at a regional level. Help with getting my son to eat, toilet training, school support, sleep help. It's just me and I can't keep travelling to get help."

"There is not enough support and understanding in place so I as a carer and not feeling constantly burnt out and feeling like I have to go into battle mode for things that should not be a barrier."

Recognition and Inclusivity

"Greater recognition of the fundamental role that they play."

"More acknowledgment of how crucial this role is to the entire community (keeping people out of hospital, allowing more community engagement)."

"Recognition that it is unrelenting, 24/7 work for the rest of your life."

Funding

"More trust from agencies around funding – we know what we need and should have autonomy."

"Trust and flexibility from funding providers around how carer support is used."

"The funding we get is too restrictive in regional areas, it doesn't work in Taranaki."

Communication and Listening

"Better communication with providers."

"Stop making us repeat ourselves. Why overdo form filling for multiple agencies when there is little change over time."

"Listen to us. I have the lived experience of caring for my child, don't dismiss my concerns."

Education and Training

"Paid carers – need to have an understanding of the condition and how they can support the person to maintain function, independence, fitness and a healthy diet."

"Education for carers."

"Training where appropriate so that carers are better equipped, along with mental health support and respite."

Respite

"Easier access to respite."

"Agencies trusting whānau that we are genuinely needing respite and care support."

"Total change in the model for supported living if you are the spouse and your partner is on SLP you must then pay secondary tax on your job. Respite is ridiculous, 20 days a year?"

"Respite funding is very low and particularly hard to find for high and complex needs children and adults."

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The most important change for health providers is?

Research and Education

"Research instead of assuming there is no access to treatments or medicines because they don't understand my child's disorder."

"Have better understanding of rare disorders and upskilling when needed."

Health Care Accessibility

"I should be able to receive the same level of care no matter where I live in the country."

"If they can't provide expertise, allow us to get it elsewhere, don't just ignore, dismiss or limit access."

"Time. They need more time per patient to be able to listen, acknowledge and research symptoms."

Communication and Listening

"As a contracted information and support provider for a rare disorder, it would be nice to have a medical team of experts we can consult. Each specialist to communicate information within their own area."

"Better communication between specialists."

"Listen to parents and whanau – respect their knowledge about both the rare disorder and their child."

Funding

"More funding. I think most health providers would like to do a better job, but don't have the time and resources."

"Better funding for RDNZ to be able to provide training to health providers."

"Increased funding for rural health providers to offer sleep clinics and eating clinics."

International Collaboration

"There is more data available in Australia and our specialists should be able to access those resources and collaborate."

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The most important change for the wider community is:

Awareness

Greater awareness can create a greater sense of belonging and self-worth:

"Greater awareness and therefore, hopefully compassion, kindness and respect toward those with rare disorders."

"The community must be given the opportunity to have a voice and a real say in what agencies do and how they do it."

"More events, more education, more community awareness."

Recognition and Inclusivity

"Inclusion of rare disorders as a population group."

"Inclusion. Recognition as to how isolating it can feel to have a rare disorder."

"People with Angelman Syndrome are nonverbal but can learn to communicate with a device (AAC). This needs to be recognised more as a language alongside braille and NZSL."

"Being heard, understood and accepted."

"Promote inclusion in all communities and celebrate diversity on all levels."

Accessibility

"Better access to local pools."

"School age sports and activities for children with rare disorders, especially in rural towns."

"Being able to go to the shops and not having to worry if I will be able to get an accessible parking spot."

"Improved employment opportunities and better-quality education."

Support

"Support networks so people don't feel alone."

"Take the pressure off self-advocacy."