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Visual description: A purple Whaikaha logo with a QR scan for the NZSL name.

Aide-mémoire

Date:	8 April 2025
For:	Hon Louise Upston, Minister for Disability Issues
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Disability Strategy Working Groups introductory session on 11 April 2025

Meeting details

Time and date: Friday 11 April 2025, 3:15 - 3:45pm.

Location: Online via Teams at this link: [Join the meeting now](#)

Teams meeting ID: 482 046 982 786 Passcode: oB2zm9US

Primary contact(s)

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Purpose

To provide talking points and background information for your attendance at the first meeting of the Working Groups for the refresh of the New Zealand Disability Strategy (Disability Strategy) on Friday 11 April 2025.

Advice

The Working Group meeting on 11 April starts at 10am with a mihi whakatau. The Ministry will provide an overview about the approach to refresh the Disability Strategy, as agreed by Cabinet on 11 March 2025 [SOU-25-MIN-0017 refers].

You will attend online between 3.15 – 3.45pm. Suggested talking points are attached to support your attendance, focused on setting the scene and outlining your expectations for Working Groups (Appendix 1).

Appendix 2 provides background on disability community and sector/industry Working Group members and chairs. Each Group includes three disability community representatives, two sector experts, and government officials.

Next steps

The Ministry will provide you with regular updates on the Working Groups' progress.

You have agreed to reconvene the Ministerial Disability Leadership Group in late May 2025. This will be an opportunity to update Ministers on progress through the Working Groups, and to test early thinking.

End

Author: Amber Coyle, Principal Policy Analyst, Policy and Insights

Responsible manager: Helen Walter, Group Manager Policy

Appendix 1 - Talking points for 11 April Disability Strategy Working Group meeting

- Welcome, everybody. I'm delighted to have the opportunity to speak with you as you start your role as Working Groups for the refresh of the Disability Strategy.
- I hope you have all had a successful first day together, and you are feeling motivated for the work in the coming months.
- We all know how important it is that we do more, and try different approaches, to improve the lives and uphold the rights of disabled people.
- 1 in 6 New Zealanders are disabled and continue to face many barriers to participating in society. Refreshing the Disability Strategy is an exciting opportunity to identify the most important actions over the next five years that will help improve their outcomes.
- These Working Groups represent a novel approach, bringing disabled people, industry or sector experts and government officials together to develop proposed actions in the five key focus areas for the new Strategy - education, employment, health, housing and justice.
- It has been fantastic to receive so much interest from disabled people, tāngata whaikaha Māori and whānau, and the broader disability community, to be part of these Working Groups.
- We are very fortunate to have your expertise, knowledge, lived experience and leadership over the course of this year. The people in this room are here because you are well placed to identify opportunities and bring new ideas to the table, and I look forward to seeing your advice and proposals.
- As you will be aware, we are taking a different approach to the refresh of the Disability Strategy in some other ways:
 - The Strategy will run for a shorter period of five years, focused on well defined, tangible, and deliverable actions which will drive change for disabled people.
 - Your role as Working Groups, is to develop proposed actions against the five key outcome areas, and associated measures to assess progress.
- The Ministry of Disabled People – Whaikaha is also working with groups representing disabled people, tāngata whaikaha Māori, and whānau to refresh the overarching vision and principles for the Strategy. These will guide the work of central and local government, the private sector and the disability community to support fair access to services and full participation for disabled people.
- It is critical that we make progress for disabled people, tāngata whaikaha Māori, and whānau in the five outcome areas for the new Strategy - education, employment, health, housing and justice. Disabled people have much poorer outcomes and continue to face barriers in all of these areas.

- These five outcome areas are also important for our progressive realisation of the United Nations Convention on the Rights of Persons with Disabilities. They are also key areas of focus for the Government, including our Government Targets, meaning there's work and thinking happening in these areas that we can build on.
- We are looking for proposed actions in each outcome area that are clearly defined and measurable, achievable within five years, and well prioritised so we focus on the most important areas of improvement for disabled people.
- I lead the Ministerial Disability Leadership Group, which will oversee the development of the new Disability Strategy. This Ministerial Group includes the Ministers responsible for the five outcome areas, and will approve the draft Disability Strategy which will go out for public consultation later this year.
- Decisions on the Disability Strategy will be made by me and my Ministerial colleagues, and Cabinet will agree the final Disability Strategy, following consultation, at the end of the year.
- Once again, thank you being part of these Working Groups. You have a challenging task ahead of you to develop the proposed actions against each outcome area in a short space of time. I look forward to talking with you further and seeing the final outputs of each Group.

Appendix 2 – Background on Working Group members

Health working group

Sector Rep and Chair: Dr Josephine Herman is a public health physician and general practitioner who holds a PhD in epidemiology from the University of Auckland. In 2023, she received the Pasifika Medical Association Life Member Award for her contribution to Pacific Health.

Dr Herman was appointed as the Secretary (Director General) of Health for the Cook Islands Ministry of Health in June 2018 and helped lead the national emergency health response to COVID-19. She was appointed Director of Pacific Health at Waitemata District Health Board in 2021.

In 2024, she was appointed Chief Clinical Advisor for Pacific Health, with the Pacific Health Directorate, Public health Agency, Manatū Hauora Ministry of Health.

Community Rep: Mark Benjamin QSM has ongoing personal involvement with the health system as he has a degenerative spinal condition that requires chronic pain management.

Based in Riwaka Nelson, Mark has been involved in multiple disability leadership and advisory groups. Participation in research and evaluation processes over many years means that Mark has heard thousands of personal stories of how society, public services and disability services create barriers to disabled New Zealanders having a good life.

Mark's involvement with the National Enabling Good Lives group and the Insights Alliance keeps him informed on the tensions and issues disabled people face in gaining fair access to the health system.

Community Rep: Dr Sally Britnell is a registered nurse with extensive clinical experience in emergency care and infection control. Having witnessed the inequities disabled people face in getting healthcare her PhD, in computing and mathematics, focused on how digital innovation can improve outcomes for marginalised populations.

As a Senior Lecturer and Senior Research Fellow at Auckland University of Technology, Sally integrates digital health and informatics into nursing education and teaches in health across disciplines. Her research and supervision span health practice, digital health, computer science, accessibility and workforce development.

Sally is Deafblind and has held leadership and advisory roles with Health Informatics New Zealand, Blind Low Vision NZ, the Deafblind Association of NZ, the W3C Mobile Accessibility Task Force and St John.

Sector Rep: Dr Tristram Ingham (Ngāti Kahungunu, Ngāti Porou) KSO ONZM is an Associate Professor at the University of Otago. Tristram is a medical epidemiologist with expertise in addressing health inequities, especially within Māori health, long-term conditions, disability rights, and healthcare governance. He is also a board member of the Te Tāhu Hauora Health Quality & Safety Commission and Chairperson of the Foundation for Quality and Research New Zealand and Te Ao Mārama Aotearoa.

Tristram has muscular dystrophy and is a well-known leader in the disability community. His commitment and advocacy for equality of opportunity and fair access to quality services for tāngata whaikaha Māori is valued by many and has achieved progress for all disabled people in Aotearoa New Zealand.

Community Rep: Tainafi Lefono is from Auckland and has lived experience of disability and professional experience as a physiotherapist and clinical advisor.

Tainafi's work has included professional roles at ACC, Enable NZ, and in the public health sector assessing rehabilitation needs and advocating for appropriate support. Tainafi has contributed to research on disability and healthcare including a Health Research Council-funded study on the information needs of Pasifika individuals with spinal cord injuries. This research strengthened his understanding of how disability, culture, and healthcare intersect, ensuring policies reflect diverse community needs.

Government officials: Officials from the Ministry of Health and Health New Zealand will also be on the Health Working Group.

Education Working Group

Community Rep and Chair: Grant Cleland ONZM has worked in the health, disability, education and employment sectors for over 30 years at governance, senior leadership and practitioner levels. Based in Christchurch he brings lived experience of disability from birth and uses a wheelchair.

Grant has worked extensively in the vocational and tertiary education sector with the development and implementation of Disability Action Plans and was also on the NZQA board. Grant has a thorough understanding of the issues that disabled tamariki, rangatahi and other learners face in our education system and the systemic issues that need to be resolved. He was the project lead for the drafting of the *Kia Orite Toolkit, TEC 2020: A framework to assist tertiary and vocational providers to create and implement Disability Action Plans*. He also wrote the Te Pūkenga report, *Te Rito: Insights of the experiences of Disabled Ākonga (Learners) in vocational education*. He has also provided strategic advice and support to tertiary and vocational providers on the implementation of their disability action plans.

Grant was Chief Executive of Workbridge for over nine years.

Sector Rep: Dr Barbara Disley ONZM is the former Chief Executive of Emerge Aotearoa. She has extensive leadership and management experience leading large teams within the education and mental health sectors.

Barbara has held many senior public positions including chair of the first Mental Health Commission and Deputy Secretary Ministry of Education where she was responsible for learning support (formerly known as special education).

Sector Rep: Dr Kiri Fortune (He uri nō Te Āti Awa me Kāi Tahu) has lived experience as the mother of a daughter Te Ahupō who was born with Down Syndrome. Te Ahupō is a raukura (graduate) of kura kaupapa Māori education and speaks te reo Māori as her first language. The whānau journey has been represented in her PhD titled *E kore e piri te uku ki te rino: He huarahi hei tautoko i ngā ākonga hauā i roto i ngā horopaki*

reo Māori. The Pathways Forward in Supporting Māori Learners with Special Needs in Māori Medium Education Settings.

Kiri has experience across all education sectors from kōhanga reo through to tertiary education. Her leadership role as Kaihautū Whakarito for Ngā Kura ā Iwi requires her to lead, develop and execute a strategic plan across 50 kura reo Māori to create change for Uri Whaikaha. She also has broad experience through her contribution and membership on many advisory groups and boards.

Sector Rep: Adjunct Associate Professor Sonja Macfarlane (Ngāti Waewae, Ngāi Tahu) PhD, FRSNZ is an Adjunct Associate Professor in Te Kaupeka Mātauranga Faculty of Education, Te Whare Wānanga o Waitaha Canterbury University. She researches and writes about culturally responsive, evidence-based approaches in education, health, psychology and counselling.

Sonja's work has been published in leading research journals nationally and internationally. She has national awards for her contribution to Māori research and in 2019 was made a Fellow of the New Zealand Psychological Society. Sonja's academic excellence and leadership is founded on her experience as a teacher and resource teacher: learning and behaviour.

Community Rep: Dorothy Taare-Smith (Ngāti Porou) is deeply committed to supporting whānau as they navigate the complexities of the disability sector. She brings extensive experience in special education, advocacy, and system-level transformation, with a strong focus on culturally grounded and inclusive practices.

Dorothy holds postgraduate qualifications in Specialist Teaching (ASD) and has worked as a specialist teacher supporting disabled learners. She is the founder of Taonga Takiwātanga Charitable Trust in Tairāwhiti Gisborne. The Trust partnered with Te Mahau – Te Tāhuhu o te Mātauranga Ministry of Education to deliver marae-based wānanga on takiwātanga (autism from a te Ao Māori perspective) to fostering culturally responsive practice in education.

Dorothy is doing a PhD in Health Studies at Te Herenga Waka – Victoria University of Wellington on how neurodiversity is understood within Te Ao Māori and the implications for clinical practice.

Community Rep: Nikita Van Dijk is completing her Masters in Disability and Inclusion Studies at the University of Waikato. Her lived experience is through living with two rare disorders, chronic illness, neurodivergence and her disabled whānau members.

Nikita has leadership experience in a variety of roles including as the founder of the University of Waikato Disabled Students Association. She is now the Co-President of the National Disabled Students Association.

Nikita's lived experience is complemented by her study, her advocacy for other disabled people, and her experience as the former Youth Ambassador for Ehlers Danlos Syndromes New Zealand, and as a representative for Aotearoa New Zealand at a UNESCO summit on supporting students with rare disorders in education.

Nikita is also a member of the Ministry of Education Te Mahau Advisory Group for Young Persons with Disabilities.

Government officials: Officials from the Ministry of Education will also be on the Education Working Group.

Employment working group

Sector Rep and Chair: Lorraine Toki (Ngāpuhi) has worked in leadership roles supporting hapū and iwi development. Lorraine has a background in community economic development, holds a master's degree in management and is currently the lead advisor to the Iwi Chairs Forum – Pou Tangata. She is an advocate for Māori on many kaupapa involving justice, health, social services, organisational policy development and Te Tiriti o Waitangi.

Community Rep: Jason Boberg is a proud disabled person who draws strength from the disability community he often represents. Through his professional and personal life, he has been dedicated to advocating for disability rights from the grassroots level to the United Nations.

As the co-founder and Director at Activate, a disability- led consultancy, Jason has championed inclusive employment practices, advising businesses, local government, and organisations on removing barriers for disabled people. Jason has been a member of the Disabled Persons Assembly's National Executive Committee and the Auckland Council Disability Advisory Panel. He was a founder of the Sustained Ability Disability and Climate Network and continues to take a leadership role at international conferences and summits for the United Nation's Framework Convention on Climate Change.

Community Rep: David Corner has lived experience and is an advocate for intellectually disabled people. He is the National Advisor in the IHC Self Advocacy Team.

As an experienced advocate and representative of people with an intellectual disability David has been a valued participant and contributor to groups such as the New Zealand Health and Disability Commissioner Consumer Advisory Group, the Community Connections Board, the Asia-Pacific Inclusion International Council and the Ombudsman Disability Advisory Panel.

David has been awarded Life Membership of People First Aotearoa and Inclusion International.

"I have an intellectual disability and I am passionate and committed to ensuring that other people with an intellectual disability have an ordinary life and can speak up for themselves and have their say and have their voices heard."

Community Rep: Andrew Hall is a wheelchair user with a strong background of working in the health system and of developing vocational rehabilitation and peer support programmes for people with spinal cord injury. Andrew is the father of a disabled 21-year-old and has additional experience of navigating and accessing services for his son. Andrew is also an IT specialist with many years of work in the health system.

Andrew has extensive involvement in organisational governance roles typically in finance and recruitment/human resources subcommittees. He is director of the New

Zealand Rugby Foundation, vice-president of the Australia New Zealand Spinal Cord Society, deputy chair of the Burwood Academy Trust, a founding trustee of the Pacific Disability Support Trust and serves on the Ombudsman's Office Disability Advisory Panel (Te Rōpū Kaiārahi Hauātanga). Andrew is also the National Programme Manager of the New Zealand Spinal Trust.

Sector Rep: Phil O'Reilly ONZM is Managing Director of Iron Duke Partners and prior to that CEO of Business New Zealand for 11 years. Iron Duke Partners is a government relations and public policy advisory firm. Business New Zealand is the country's largest advocacy group for businesses engaging regularly with Government, community groups, Ministers, and MPs.

Phil has acted in a governance or advisory capacity for local and international organisations on issues of trade, sustainability, diversity, pay equity, manufacturing, tertiary education, child poverty and the future of work. Previously, he was a member of the Governing Body of the International Labour Organisation, based in Geneva and the Chair of Business at OECD.

Government officials: Officials from the Ministries of Social Development and Business, Innovation and Employment will also be on the Employment Working Group.

Housing working group

Community rep and Chair: Daniel Clay (Ngāti Whātua) has experienced the challenges and opportunities faced by young disabled people through his 12-year-old daughter who has cerebral palsy and is a wheelchair user. Daniel is on the board of directors of the Cerebral Palsy Society of NZ Inc and is currently President and Chair.

Daniel is Chief Executive of an iwi-owned investment entity which operates in the housing sector partnering with national housing developers and working with organisations such as Kāinga Ora and the Ministry of Housing and Urban Development. Prior to his current role, Daniel was a practising lawyer for 20 years, holding partnership positions with two national law firms for 10 years. His legal specialties included public law, local government, and environmental and planning law.

Sector Rep: Ali Hamlin-Paenga (Te Aitanga ā Mahaki, Ngāti Kahungunu) is Chief Executive of Te Matapihi which is an independent, national body advocating for Māori housing, assisting with policy development, and supporting the sector's growth by providing advice, facilitating collaboration, and sharing resources and information.

Prior to her role as the CEO of Te Matapihi Ali was the Chair of the Te Matapihi board taking on the CEO role to reset the organisation. She was the CEO of Ngāti Kahungunu ki Poneke and Poua ki Raro Community Housing and is also currently the Chair of the Australasian Housing Institute New Zealand branch.

Community Rep: Renata Kotua (Ngāti Toa Rangatira) brings significant experience in governance and leadership roles. As an advocate for disabled people, she provides consultation to client organisations and is training workshop facilitator. Renata works as a disability and inclusion consultant for Mind Matters, a workplace psychology firm. She draws on her lived experience as hine whaikaha Māori navigating the health

system, pursuing an education, facing the many challenges of working and finding suitable accessible accommodation.

Renata has Congenital Cerebral Palsy, which affects her gait, balance, coordination, and ability to walk long distances. She is driven to improve outcomes, combat stereotypes, and shift societal assumptions about what disabled people can achieve.

Renata has a special interest in psychology and in wellbeing from a Te Ao Māori perspective. Her previous and current governance and leadership roles include Vice President of the Cerebral Palsy Society, Disability Advisor for Auckland Council, and trustee positions with Whaikaha and Your Way Kia Roha.

Renata has supported research projects focused on reducing inequity for disabled people, including in the areas of driving, ageing, and reproductive health, collaborating with institutions such as the University of Auckland, The Liggins Institute, the Starship Foundation, Donald Beasley Institute, Te Kupenga Hauora Māori, and the NZ Cerebral Palsy Register.

Sector Rep: Geoff Penrose has been General Manager of Lifemark since 2014 and is a member of CCS Disability Action's national leadership team. Lifemark was established in 2008 to promote Universal Design principles of adaptability, accessibility, usability, safety and lifetime value in this country.

Prior to Lifemark, Geoff was the Chief Executive of Qualmark New Zealand and was also a business consultant in Europe, Asia and the Pacific. Since 2011, Geoff has volunteered for Global Sustainable Tourism Council's assurance panel. The council is a United Nations initiative to establish and manage sustainable tourism standards across six continents.

Community Rep: Christine Potts is disabled and acknowledges the diversity of lived experience across the disability community. Based in the Bay of Plenty, Christine has experience of the disability sector within government departments such as Enabling Good Lives at the Ministry of Social Development, the Office for Disability Issues, DSS at the Ministry of Health and within non-government organisations such as CCS Disability Action. While Regional Manager for CCS Disability Action in Te Tai Tokerau she established the Whangarei Accessible Housing Trust. In Waikato Christine coordinated Council housing for older people and later managed home support services for older people across Waikato and Bay of Plenty for a community provider.

Government officials: Officials from the Ministry of Business, Innovation and Employment, Ministry of Housing and Urban Development and Kāinga Ora will also be on the Housing Working Group.

Justice working group

Community Rep and Chair: Paul Gibson QSO Paul has lived experience of disability, is the partner of a disabled person and parent of two adult daughters, one of whom is disabled. Paul has been a strong and skilled advocate for disabled people and their rights. He was the Disability Rights Commissioner at the Human Rights Commission for more than five years and was a Commissioner for the Royal

Commission of Inquiry into Abuse in State Care and in the Care of Faith Based Institutions.

Paul has policy analysis skills and a history of involvement in the disability community, including being on the first New Zealand Disability Strategy reference group.

Paul is the Chief Executive of VisAble - a disabled person-led organisation working to strengthen national capabilities across agencies and sectors to prevent and respond to the violence, abuse and neglect affecting disabled people and their whānau.

Community Rep: Tarewa Cowan (Ngāti Kahungunu, Ngāti Porou and Tahitian/Cook Island descent) has worked in the disability sector for almost five years. Based in Auckland, Tarewa grew up around her kaumatua and kuia who were Kāpō (blind) and had other disabilities, and her partner is Kāpo.

Tarewa's work as the co-ordinator/leader of a youth/rangatahi tāngata whaikaha group, as the board secretary of Te Kahui Tumuaki (Kāpō Māori Aotearoa), and in her day-to-day working with rangatahi, pakeke, takatapuhi, and kaumatua in the community, enable her to give voice to the experience of tāngata whaikaha Māori.

Sector Rep: Dr Huhana Hickey (Ngāti Tāhinga, Waikato and Whakatōhea Ngāti Ira) MNZM is an academic, disability rights lawyer and disability advocate. She has multiple sclerosis and was the first openly disabled Housing New Zealand board member and is an unflinching advocate for whānau hauā and all disabled people.

Huhana is a member of the New Zealand Human Rights Review Tribunal and became a member of the New Zealand Order of Merit in 2015 for services to people with disabilities.

Community Rep: Ruth Jones (Ngāti Porou, Rongowhākāta) QSM has been part of the disability sector for more than 30 years. She is a registered social worker with lived experience of disability.

Ruth has held a variety of national governance positions, including chair of the Workbridge Board, member of the Disability Coalition Against Violence, and co-chair of the design group for the redress for Survivors of Abuse in State and Faith-based Care. She is currently a member of the Ministerial Advisory Board for Oranga Tamariki; Te Ao Mārama Aotearoa, the Iwi Māori Partnership Board for the Ngāi Tahu takiwā, Te Tauraki; and is Chair of Disability Leadership Canterbury.

Sector Rep: Professor Ian Lambie ONZM has more than 30 years' experience as a psychologist for children and adolescents. As both a clinical psychologist and academic, he has worked with government departments including the New Zealand Fire Service, Police, Department of Corrections and Oranga Tamariki, as well as community groups.

Ian is Chief Science Advisor for the justice sector, which spans the Ministry of Justice, Police and Department of Corrections, and advises government on ways to improve the justice system.

Government officials: Officials from the Ministry of Justice and New Zealand Police will also be on the Justice Working Group.