

Disability Sector Engagement: Good Practice Guide

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Achieving equity in transport relies on understanding and resolving inequity. One way to target investment for improved equity is to find the people of greatest basic need of investment and to amplify their voices. However, there is next to no guidance currently available on how to find those people, and how to effectively work with them to reduce historic and systemic inequities.

Disabled people are a group known to experience widespread and serious lack of access to transport, relative to able people. This paper is a good practice guidance document explaining how transport professionals can identify, engage with, and deliver transport that can help disabled people participate in everyday life. It describes why there is a gap in guidance and why that is a problem. It then describes the nature of the disability community. The description explains the differences between disability service providers (such as the Blind Foundation and CCS Disability Action); Disabled Person's organisations (such as the Disabled Persons Assembly); and individuals with lived experience of disability.

Different transport projects and processes have different reasons to engage with stakeholders from the disability community, so the paper will describe the best ways and means to engage with each group, or with individuals. It includes contact details for a wide range of service providers and advocacy groups, and advice for practitioners on how best to engage with them for the good of their transport projects or processes.

The guide also includes a summary and critique of some New Zealand Councils' established "disability reference groups", including a discussion of their value and limitations. It will help all transport professionals to better understand the nature of the disability community in New Zealand, to empower them to find and amplify the voice of those who have most to gain from investment in transport equity.

INTRODUCTION AND PURPOSE

For transport professionals interested in work that improves peoples' wellbeing, it is helpful to look to those people whose wellbeing has the greatest potential for improvement. When it comes to transport, disabled people are most severely limited compared with other people in their everyday lives by infrastructure and systems that prevent them living dignified, independent lives.

This guide has been produced in response to varied understanding amongst transport professionals of what a good transport outcome for disabled people looks like. Transport sector engagement with the disability sector to date has been ad-hoc at best, and frequently absent. One of the reasons that disability sector engagement is not more consistent in transport is that there is no guidance for professionals on how to do engagement well, in different decision-making contexts. Therefore, the purpose of this guide is to describe the disability community in New Zealand; and engagement methods that are likely to result in the best possible outcomes for all people affected by decisions that transport professionals make.

WHY ENGAGE WITH THE DISABILITY SECTOR?

Outcomes for people

Perhaps the most obvious reason to engage with the disability sector is so that transport outcomes benefit all people. Humans vary widely in their physical and mental capabilities, and in their moment to moment abilities to move around and make decisions in transport. Design guidance provides a starting point for best-practice universal design, but compromises are often made that result in a departure from those standards. In addition, some human variations, such as neurodiversity (including autism, for example) and learning disabilities are not explicitly considered in all design guidance. Engaging with people who have lived experience expertise at the margins of human capability is the best way to provide insights that are not otherwise apparent to transport professionals. When planning or designing transport systems and infrastructure, disability sector engagement can help ensure that processes, plans, and infrastructure are designed to be as inclusive as possible, of all people.

The imperative to provide good outcomes for all people is embedded in transport policy at national, regional, and local levels. The most recent Government Policy Statement on Land Transport (Ministry of Transport, 2018) aims to provide “more transport choice (including for people with less or limited access to transport)” (p18) and to ensure that “Public transport is more accessible and affordable, especially for those reliant on it to reach social and economic opportunities (including people with disabilities)” (p28).

Value for money

Just as a safety audit exists to ‘catch’ potential design improvements before sub-optimal design is ‘built in’ to a street, early, comprehensive and effective engagement with the disability sector can prevent costly retrofit. As well as explicit costs to correct infrastructure problems, the costs to individuals of access barriers can be significant. If a new design is not as accessible as it could be, the impact on people who rely on best-practice transport can be that they travel less, to fewer places, with resulting impacts on their education levels, income, mental and physical health, and overall wellbeing. Engagement with the disability sector can give transport professionals confidence that their plans and designs are enabling good lives for everyone.

Legal imperative

New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disability (CRPD). The CRPD has several requirements related to transport, summarised in Article 9 which states that government organisations “shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation... ..and to other facilities and services open or provided to the public... ..These measures... ..shall include the identification and elimination of obstacles and barriers to accessibility.” (United Nations, 2019)

DISABILITY SECTOR ENGAGEMENT METHODS

There are many different ways that government can engage with the disability sector. The methods described here are recommended based on research with disabled people themselves, disabled persons' organisations, disability service providers, and council staff who engage with disability advisory groups.

The first step: Building relationships

It is most useful for people who are frequently involved in community engagement for transport, and/or in projects that impact the ways people move around their local communities (particularly the pedestrian and public transport networks) to meet and build relationships with the local disability community over time. The depth and breadth of disability sector groups varies a lot around New Zealand, so it is helpful for local professionals to have a good understanding of who in the disability sector has, first, ready networks of disabled people they can contact; and second, an interest in transport issues. Trusted long-term relationships between transport professionals and leaders in the disability community mean that connections can be called upon where necessary, without time-consuming background explanations of what the engagement process might involve, and to what end.

The issue of payment

Where people are invited to contribute expertise to government process that *does not benefit them directly*, it is appropriate to pay those people for their time. The New Zealand State Services Commission provides detailed guidance on how much people ought to be paid (State Services Commission, 2019). Deciding whether and how much to pay people who engage in transport processes is not black and white. In general however, if the process or project will benefit a person directly – they are an affected person because the street where they live is going to be upgraded, for example – then engagement as part of best-practice information sharing or participatory design process would not typically be paid.

However, where disabled people are invited as part of a reference group, advisory group, or interview panel, their input is not benefitting them directly. They are providing expertise that the transport profession would not otherwise have access to, for the benefit of a programme, process or project that is not directly affecting their personal journeys. In those situations, it is appropriate to pay disabled people for their time, just as other specialist consultants would be paid.

In-person engagement with disabled people

Proactive in-person engagement with people who have lived experience of disability provides important perspectives for local built environment or transport operations changes. Disabled peoples' perspectives can be sought generally, as part of community consultation; and specifically, through approaching local disability advocacy and service provider organisations.

When there is a local programme of works that will affect how people move around, and/or the safety of travel, disabled people who live in the local area can help to prioritise improvements because they have first-hand insights into the most challenging locations, particularly within the pedestrian network. Disabled people can also highlight low-cost improvements that could be included in the works (such as kerb cut replacements), which could have a significant positive impact on inclusive travel choices for everyone.

A Community Street Review (CSR) (Gascoigne & Burdett, 2018; NZ Transport Agency, 2010) is a useful way to involve the perspectives of local people, including those with disability. Local disabled people can be recruited as part of generic recruitment methods, by including in the advertisement that "We welcome participation from people with disabilities to volunteer". Although participants in a Community Street Review are not usually paid, it would be appropriate for necessary support people (such as a sign language interpreter, or a carer who usually accompanies a disabled person) to be invited and paid for their time, if it is outside of their usual duties.

An advantage of engaging with disabled people as individuals is that they are not limited by the perspectives of a service provider, or specific advocacy group. Humans are complex, and talking face to face with a local person about the challenges they face using transport can be both enlightening to a transport professional, and practically very helpful to target the most urgent, but often low-cost, barriers (both in the built environment, and within processes) that need removing.

Engagement with disabled persons' organisations and disability service providers

Disabled Persons' Organisations (DPOs: see **Appendix**) are groups comprised of disabled people themselves. They provide support and advocacy for people with different specific impairments. DPOs operate differently from one another, and their presence in different parts of New Zealand varies. The Disabled Persons' Assembly (DPA) is one of the largest DPOs, and is a pan-disability group that invites membership from anyone who identifies with disability. DPOs, including the DPA, have useful and extensive networks and can reach disabled people when their individual perspectives are invited, for example to be part of an invited panel seeking lived experience of disability; or to advertise local opportunities for general community consultation, that disabled people might not otherwise find out about. DPOs may or may not have paid staff.

Disability service providers (see **Appendix**) are groups and agencies that provide support, advocacy, information, and education services for people with different specific impairments. They are not typically or necessarily staffed by disabled people. Service providers, such as CCS Disability Action and the Blind Foundation, are often central sources of information about the local disability community. They typically have paid staff, some of whom will have specialist interest in transport, or in a specific aspect of transport related to the needs of the people they support.

It is recommended that Disabled persons' organisations (DPOs) and service providers are called upon as useful connecting organisations to link transport professionals with local disabled people. Getting to know local and national DPO and service provider representatives is also a useful way to find individuals with specific interest and technical expertise concerning different aspects of transport. Such individuals might be invited to be paid members of reference groups or steering committees, for research or transport guidance projects related to disability, or where inclusive access is an important consideration. Engaging with DPOs and disability service providers can be useful to understand specific technical/design issues as they relate to people with specific needs, such as the provision of tactile ground Surface Indicators (TGSIs) for people with vision impairment.

Disability reference and advisory groups

Many councils in New Zealand, as well as Auckland Transport, host disability reference groups of different forms. Typically, the groups have 3-8 members and they meet regularly to discuss transport accessibility issues as they arise, and to provide feedback on capital projects.

The most important point to note about disability reference and advisory groups are that:

- Members should be paid. Their expertise is being invited to the benefit of council processes and projects, just like the specialist advice of any consultant.
- Reference and advisory groups are helpful but *not sufficient* to inform accessibility components of all transport investment. Their time and expertise is limited, so councils ought to challenge themselves to consider other ways to deliver more inclusive outcomes – through in-person engagement with local disabled people, as described above, for example;
- The process of membership of reference and advisory groups should be made explicit, so that the local disability community understands the purpose of the group, and how its members are recruited.
- Councils should consider refreshing group membership over time, including broadening member expertise to a range of impairments. Delivering inclusive environments involves broadening our understanding of who we are, and are not, providing for, so inviting fresh perspectives can be a useful step towards inclusion.
- Succession planning for advisory groups should be part of refreshing group membership.

Understanding the language of professional transport decision-making takes time for any professional, let alone an invited member of the disability community. Increasing the number and diversity of people within the disability community who understand transport language and processes can only be helpful for community and for the transport industry.

RECOMMENDED PRACTICE FOR TRANSPORT

It is recommended that transport professionals get to know their local disability community. The most useful first step is to contact and meet with local members of DPOs, disability service providers, and advocacy groups, so that trusted connections can be built. It is also recommended that professionals look beyond their local advisory group to find people whose voices are not typically heard. There is currently little published guidance on transport needs of people who have learning disabilities; neurodiversity such as autism; and complex challenges such as physical or sensory disability combined with anxiety or depression.

Many transport professionals may not be familiar with engaging with people with disability, and therefore might be reluctant to reach out because they do not know or understand how such engagement might impact their projects, or indeed their mindsets. Talking with local people and creating a culture where the widest range of people are included in decision-making is the best step towards breaking down any 'professional anxiety' about the challenges that such conversations might invite.

Specifically in terms of engagement for specific processes, it is recommended that:

- **In-person engagement with disabled people** is sought for projects affecting local disabled people directly, through proactive sharing of community consultation and engagement notices with local DPOs and service providers;
- **Engagement with DPOs and Service Providers** is regular, both as a mechanism to find and recruit local disabled people for different engagement exercises; and as a source of specific expertise on technical design details, to inform research, technical standards, and industry guidance;
- **Council disability advisory groups** are supported; group members are paid for their time; the membership process is made transparent, with opportunities for new membership considered regularly; the group's mandate is clear and consistent, with the kinds of projects they advise on made explicit; and that processes are co-designed with advisory groups to promote inclusive access throughout council activities, particularly for projects that are not reviewed by the advisory group.

A flowchart summarising how to decide on the nature of engagement with the disability sector for different transport projects is shown in **Figure 1**.

CONCLUSIONS

Equity of access to transport means that even the most marginalised people can participate. Engagement between the transport and disability sectors is the most effective way to improve transport accessibility, ultimately making transport work better for everyone. The guidance describes different ways that transport professionals can proactively seek and engage with disabled people, and the organisations that represent and support those people. The more that we develop trusted and effective relationships between people working in transport and disabled people, the easier it will be to develop truly inclusive transport infrastructure and systems.

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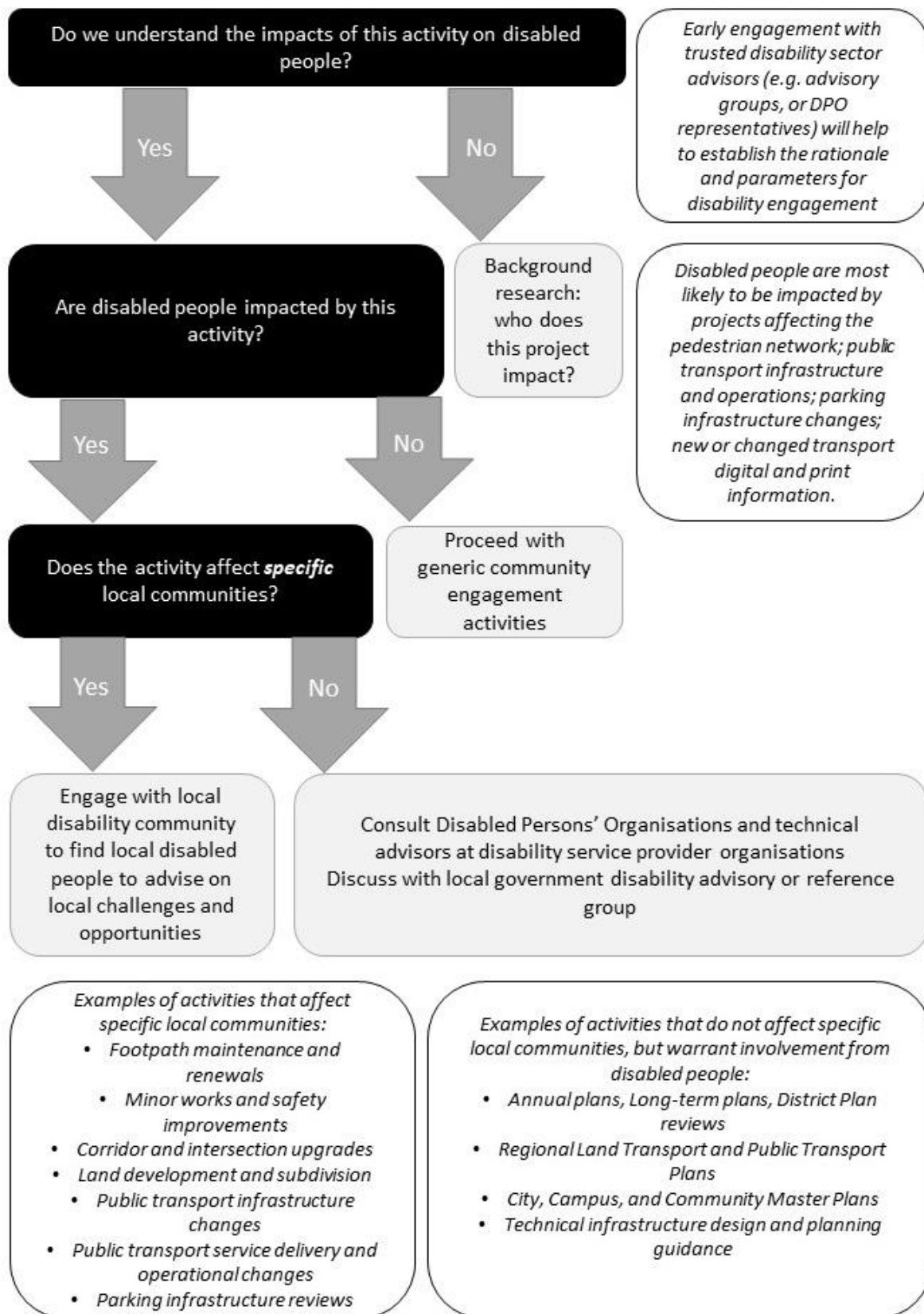


Figure 1 Flowchart to consider and select engagement methods with the disability sector for transport activities

Appendix: List of Disability Sector Organisations

Disabled Persons' Organisations

Association of Blind Citizens of New Zealand

An advocacy organisation for blind and vision impaired people.

www.abcnz.org.nz

Balance NZ

An organisation of people with mental health issues and mood disorders that provides support and advocacy.

www.balance.org.nz

Deaf Aotearoa New Zealand

An organisation that provides information and resources on life for Deaf New Zealanders, Deaf culture and New Zealand Sign Language. Deaf Aotearoa also provides New Zealand Sign Language classes and Deaf awareness training.

www.deaf.org.nz

Deafblind (NZ) Inc

An organisation that provides advocacy and support for Deafblind people in New Zealand.

www.deafblind.org.nz

Disabled Persons Assembly NZ

A national pan-disability organisation. Its website publishes various resources, including on the rights of disabled people.

www.dpa.org.nz

Kāpō Māori Aotearoa New Zealand (Ngāti Kāpō)

An organisation that offers kaupapa Māori-based disability support services with a focus on kāpō Māori and their whānau.

www.kapomaori.com

People First New Zealand Ngā Tangata Tuatahi

A national self-advocacy organisation that is led and directed by people with learning disabilities.

The organisation provides an Easy Read translation service, which involves translating a document into an accessible format. It also provides trained meeting assistants.

www.peoplefirst.org.nz

Disability Service Providers and Advocacy Groups

Altogether Autism

Altogether Autism is a nationwide information and advisory service for people living on the autism spectrum, their families/whānau and the professionals who work with them.

www.altogetherautism.org.nz

Altogether Autism is a service funded by the Ministry of Health. It is provided in partnership by Parent to Parent (see below) and Life Unlimited (a charitable trust whose mission is 'to enhance individual wellbeing by enabling people to live the life they choose').

lifeunlimited.net.nz

Autism NZ

Autism NZ provides support, training, advocacy, resources and information on autism spectrum disorder (ASD) to those with these conditions, their family/whānau, caregivers and professionals.

www.autismnz.org.nz

Blind Foundation

The Blind Foundation provides its members with adaptive skills, technology, resources and support with moving around (including through the use of guide dogs) and accessing information. It also provides services to the wider community, including: web accessibility consultation, accessible format production, built environment advice and awareness training.

www.blindfoundation.org.nz

Brain Injury Association

The Brain Injury Association provides support, education and information services throughout New Zealand to people living with brain injuries.

www.brain-injury.org.nz

Carers New Zealand

Carers New Zealand is the national body supporting family, whānau and aiga carers. It provides information, advice, learning and support for families with health and disability needs.

www.carers.net.nz

CCS Disability Action

CCS Action's purpose is to strengthen communities and provide information, advocacy and support so people with disabilities are included in the life of their family and in their community. It also has 16 branches nationally that provide frontline support and services, create local awareness and education around disability issues.

www.ccsdisabilityaction.org.nz

Cerebral Palsy Society

The Cerebral Palsy Society of New Zealand's purpose is to enhance the lives and wellbeing of people with cerebral palsy (CP). It provides programmes designed to enhance the independence and quality of life of people living with CP and their families, and grants to its members for this purpose.

www.cerebralpalsy.org.nz

Complex Care Group Trust

The Complex Care Group Trust is a support and information network run by and for carers who look after people with complex needs.

It provides up-to-date information and support to carers to help them navigate the many challenges they face and is also responsible for communicating to Ministry of Health, funders and other providers, the needs of this group.

www.complexcaregroup.org.nz/

eCALD

eCALD® is a website that hosts a range of resources to support the NZ health and disability workforce to develop competencies to work and engage with culturally and linguistically diverse (CALD) migrants and refugees from Asian, Middle Eastern, Latin American and African (MELAA) backgrounds. www.ecald.com

Hearing Association

The Hearing Association is a volunteer-based organisation that helps people with any type of hearing problem.

Local branches offer one-to-one support for members and non-members alike, socially and in the workplace.

www.hearing.org.nz

Hearing Dogs

Hearing Dogs supports and trains hearing dogs for people with hearing problems.

www.hearingdogs.org.nz

IHC New Zealand

IHC New Zealand is a membership-based organisation that supports people with intellectual disabilities to live satisfying lives in the community. IHC provides a range of services, including advocacy and a library related to intellectual disability.

www.ihc.org.nz

iSign

iSign is a nationwide booking organisation providing New Zealand Sign Language interpreters.

www.isign.co.nz

Te Pou o Te Whakaaro Nui

Te Pou o Te Whakaaro Nui is a national centre of evidence-based workforce development for the mental health, addiction and disability sectors.

www.tepou.co.nz

Mental Health Foundation

The Mental Health Foundation provides a range of services and campaigns addressing all aspects of mental health and wellbeing.

It provides free information and training, and advocates for policies and services that support people with experience of mental illness and their families/whānau and friends.

www.mentalhealth.org.nz

Multiple Sclerosis Society of New Zealand Inc

The Multiple Sclerosis (MS) Society of New Zealand is a non-profit organisation that provides on-going support, education and advocacy for people with MS and their support networks. It also aims to educate the general public, employers and health professionals about MS and actively funds key research into the condition.

<https://www.msnz.org.nz>

Muscular Dystrophy Association

The Muscular Dystrophy Association is a New Zealand not-for-profit organisation which provides information and support to people affected by neuromuscular conditions. Its services include a national fieldwork service, as well as specialist information and advice.

www.mda.org.nz

National Foundation for the Deaf

The National Foundation for the Deaf works to promote the rights, interests and welfare of people with hearing loss. It offers support, prevention and advocacy programmes. The Foundation's website publishes various resources.

www.nfd.org.nz

Needs Assessment Service Co-ordination Association

The Needs Assessment Service Co-ordination Association (NASCA) is the national association for managers of NASC organisations. The Ministry of Health contracts these organisations to:

- work with people with disabilities to identify their strengths and support needs
- tell people about available support services
- determine people's eligibility for Ministry of Health-funded support services
- allocate Ministry-funded support services
- help people access other supports.

Support services are then delivered by their respective service providers.

www.nznasca.co.nz

New Zealand Disability Support Network

The New Zealand Disability Support Network is a national association of disability support providers.

www.nzdsn.org.nz

New Zealand Down Syndrome Association

The New Zealand Down Syndrome Association promotes the participation of people with Down syndrome in their community. It provides:

- information, support, education and advocacy services for the Down syndrome community
- support for parents and families/whānau
- information resources and a quarterly journal
- support for regional groups so that they can offer support and services to the Down syndrome community in their area through family events, social groups, guest speakers, individual support and advocacy.

www.nzdsa.org.nz

NZ Federation of Disability Information Centres

The Federation:

- provides generic, impartial and accurate disability information through 23 community-based hubs across NZ.
- employs Information Consultants (20% with lived experience of disability) to assist people to navigate the disability support services sector.
- has expertise in community engagement and facilitating responsiveness in communities.
- is a respectful ally of disabled people, working together to ensure that New Zealand is a fully inclusive and accessible society where everyone has a good life.

www.nzfdic.org.nz

Le Va

Le Va is the national hub for Pasifika mental health and addiction workforce development and coordination for the disability support services sector.

www.leva.co.nz

Parent to Parent

Parent to Parent supports parents of children with a disability, health impairment or health issue by connecting them with trained volunteer support parents who have a child or family member in a similar situation. It also provides training programmes for families and siblings.

www.parent2parent.org.nz

Vaka Tautua

Vaka Tautua is a charitable organisation that aims to help improve the health and wellbeing of Pasifika people in New Zealand. It provides community support for older people, people with a disability and those needing support for mental health.

www.vakatautua.co.nz

Rescare NZ

Rescare NZ is an umbrella organisation for support groups and individuals who support people with an intellectual disability.

www.rescarenz.org.nz

Sign Language Interpreters Association of New Zealand

Sign Language Interpreters Association of New Zealand is a national professional association of sign language interpreters.

www.slianz.org.nz

Weka

Weka is a website providing information on a range of disabilities, resources, support and services.

www.weka.net.nz

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