
Disability Services Consumer Consortium

Terms of Reference (Revised November 2009)

Background to Consortium

Disability Services (DS) want people with disabilities and their families/whanau to participate in their activities. To determine how best to do this, the then Disability Services Directorate (DSD) held a series of national consumer forums in 2004 and a further series of forums in 2005. The overall consensus from those who attended was that DSD set up a group of consumers to provide advice and input to DS. In September 2005, DS invited a number of national disability consumer organisations to a meeting to discuss the support for setting up this group which was to be called the DS Consumer Consortium, now (Disability Services Consumer Consortium). The attendees at this meeting endorsed the proposal and the initial member organisations were confirmed.

Governing Principles

The consortium is governed by the following principles:

- Activities undertaken by the consortium will be considered in line with:
 - The objectives of the New Zealand Disability Strategy
 - The Treaty of Waitangi
 - UN Convention on the Rights of Persons with Disabilities
 - The NZ Carers Strategy
- Members of the Consortium will:
 - Respect diversity and difference
 - Find commonalities between groups and encourage collaboration
 - Ensure participation and inclusion in meetings
 - Ensure meaningful advice and information is provided to Disability Services

Purpose

The Disability Services Consumer Consortium is a group of people with disabilities and/or family members of people with disabilities that work with Disability Services on an advisory /strategic level in the following areas:

1. Providing input and advice to Disability Services on its annual and forward planning processes, development of policy and services
2. Providing a link for support and communication between Disability Services and the people who receive the services that it funds.

The Role of the Consortium

The Consortium will advise Disability Services on the services and funding it provides to disabled people and their family. These services, which are mainly for people aged 65 and under include:

- Needs assessment and service co-ordination services
- Home based support services
- Environmental support services; funding of equipment and house modifications
- Community residential services
- Respite and carer support
- Disability information and advisory services
- Supported independent living
- Rehabilitation
- Private hospital services
- Assessment and service delivery for people with intellectual disability who have high and complex needs or are subject to a compulsory care order
- Behaviour support services
- Day services (not vocational)
- Child development services
- Cochlear implant services

The main role of the consortium is to provide feedback on Disability Services planning, policy and service development in the above categories from the perspective of how they do, or may, impact on people with disabilities and their families/whanau and caregivers. Advice may be provided around:

- The Health and Disability Services Strategic and Annual Plans
- The agenda and facilitation of the annual national consumer forums
- Strategy development
- Policy development
- The equitable distribution of funding, and the application of any additional funding
- Any possible redistribution of funding
- Prioritising issues

The consortium will also provide a link between disability consumers and Disability Services through:

- Conveying issues to Disability Services
- Providing advice on relative priorities
- Providing input into policy development
- Collecting and providing information on need and service gaps
- Ensuring maximum input into annual consumer forums from a wide sector

- Striving to improve collaboration of information between consumer organizations.
- Considering ways to involve input from people with disabilities and their families across the spectrum and external to the mainstream disability consumer organisations, for example, rural people or those in residential services.

The consortium will not:

- Be a lobby group for any one NGO
- Be a representation of provider organisations

Advice and information provided by the Consortium is not binding on Health and Disability National Services and will largely be informally expressed. However formal recommendations may be made and will be responded to by Health and Disability National Services.

Membership

The consortium will be made up of people with a disability and/or family/whanau of people with a disability. The members will be selected by the agreed consortium member organisations, which must be national disability organisations with:

1. national membership, largely consisting of consumers of Disability Services funded services, AND
2. a mandate to provide information and advice to consumers of Disability Services funded services

The Consumer Consortium will consist of people with a disability and /or families/whanau of people with a disability who have been nominated by the following organisations.

Consumer Consortium Member Organisations	Membership
NZ Down Syndrome Association	One person with disability and one family member
Royal New Zealand Foundation of the Blind	one person with a disability
NZ Association of Blind Citizens	one person with a disability
NZ Hearing Association	one person with a disability
Autism NZ	one person with a disability and one family member
Ngati Kapo NZ	one person with a disability
People First NZ	two people with disabilities at least one to be Maori
Deaf Aotearoa NZ	two people with a disability
Brain Injury Association	two people, one with an acquired brain injury and one family member
Parent to Parent NZ	two family members

Carers NZ	one family member
IHC Advocacy	one family member
CCS Disability Action	one person with a disability and one family member
Cerebral Palsy Society	one person with a disability and one family member
PIASS Trust	Two people with disability
Muscular Dystrophy Association	One person with a disability
Rescare NZ	one family member
Mana Turi	one person with a disability
Deaf Blind Association Inc	One person with disability

Consortium membership is for one term, i.e. two years. Organisations can nominate a person for a second term. However no person should be a member of the consortium for more than two terms, i.e. four years. Consortium members must provide confirmation from their organisation to the consortium administrators, confirming their appointment to the consortium.

Members may be accompanied to the consortium by a paid support person where required. It is expected that the organisations who nominate the person/people to bring consumer perspectives will support those individuals to help them be familiar with and confident in providing information and advice to a government agency (i.e. at strategic/planning level).

Duties and Responsibilities of Members

Members of the Consumer Consortium should have a commitment to work for the greater good of the group and the people they represent. It is expected that they will make every effort to attend Consortium meetings and perform their functions in good faith and honesty.

Where members believe they have a conflict of interest on a subject they will declare that conflict of interest and not take part in the discussion or activity.

Members must ensure they have mechanisms to provide perspectives from the population of people with disabilities and/or their families/whanau that they are representing via their organisation. There will need to be a clearly described mechanism for communication between the individuals who are members of the consortium and the 'population' of disabled people and/or family/whanau of people with disabilities they are conveying a 'voice' for, including cultural perspectives and values.

Members must have the ability to attend meetings, communicate with their peers and so bring a breadth of perspectives (that is, not speak individually), become familiar with and confident in discussing strategic, macro planning and prioritisation, and avoid focusing on an individual circumstance.

Duties and Responsibilities of Disability Services

Designated representatives of Disability Services will be members of the consortium to help ensure a collaborative approach and relationship development. Working together will also help ensure that information and advice provided aligns with Disability Services planning cycle and mechanisms of decision making.

Disability Services will ensure that consortium members are issued with relevant background material for each meeting, and an outline of discussion topics from guest speakers in accessible format a month before each meeting. Every endeavour will be made to provide information in accessible formats. Disability Services will ensure that minutes of meetings are issued within two weeks of the meeting and will respond to any formal representation from the consortium. The meeting minutes will first of all be sent as a draft, allowing two weeks for feedback before being confirmed as FINAL. The consortium administrators will prepare a summary of the minutes to assist members. Consortium members can distribute the minutes, or the summary, once they are agreed as accurate and so marked FINAL.

Disability Services will provide the contact details of a key person who will represent the Health and Disability National Services Directorate in the organisation of the Consumer Consortium. .

Duration of the Consortium

The role and purpose of the Consumer Consortium will be reviewed regularly. The consortium will have the ability to add or remove members.

Confidentiality

It is understood that any information disclosed for advice or raised for discussion in any form by either party is strictly confidential and will not be disclosed to any person or persons outside of the group without the prior permission and consent of both parties.

Administrative Support

Disability Services is responsible for meeting any secretarial or administrative costs for the Consortium. The administration of meetings will be provided on behalf of Disability Services by the New Zealand Federation of Disability Information Centres. The Federation will provide a constant key contact person for enquiries and to make arrangements for the meetings.

Meetings

It is intended that the Consortium will meet at least twice yearly, usually in the months of October/November and March/April to coincide with Disability Services' annual planning cycle. Meetings will be held in the most cost effective main city, as determined by the consortium administrators. Meetings will be facilitated by Consortium Members.

Consortium members may ask the Disability Services' key contact person to place items on the agenda. Such requests should be made at least 4 weeks prior to a consortium. Every effort will be made to respond to members requests.

Consortium members are responsible for the gathering of views, concerns and feedback from their organisations, when this is requested by Disability Services, as preparation for forthcoming consortium discussions.

Consortium Meetings are generally to be of two days duration. Care should be taken to ensure that the agenda allows for sufficient discussion time of topics presented. Additional breaks to those advised in the agenda are at the discretion of individual consortium members; however the meeting will proceed as advised on the agenda.

Members of the Consortium will throughout the year, be invited to form part of, or advise who could become a member of, advisory groups or panels for Disability Services work activities.

Fees and Expenses

Members will be paid a fee of \$200 per day (including GST) when attending consortium meetings. Fees may be reviewed from time to time by Disability Services but will remain consistent with the Cabinet Fees Framework guidelines. Fees are regarded as income by Work and Income. Withholding tax will be deducted.

Support people will also be paid for their time at the usual rate.

Additional time of one day per consortium will also be paid to each member and/or support person. This time is for preparation prior to meetings and for time after meetings to prepare reports for member organisations. Additional support requirements to this will need to be arranged with the NZ Federation of Disability Information Centres.

Travel and accommodation plus any special needs assistance costs will be paid for and arranged by NZ Federation of Disability Information Centres on behalf of Disability Services.