

## Appendix 1

### Machinery of Government Review

#### Mana, Self-determination and Voice Key Features

##### Overview

We have developed a set of key features, referred to as ‘Mana, Self-determination and Voice’, which will guide how the voice(s) of disabled people should be incorporated into the system design of the Disability Support System Machinery of Government Review (MoG Review). Disabled people include those who have long-term physical, mental, learning or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.<sup>1</sup>

##### Why Mana, Self-determination and Voice?

We have chosen the term Mana, Self-determination and Voice to reflect and embody our key features and what they represent and aim to achieve. Our key features are about giving a voice to disabled people (both as individuals and as a collective) and their whānau. It is also about empowerment and mana and push for real transformational change to allow disabled people to be in control of their lives.

Mana represents the strength, prestige and authority of disabled people. It shows disabled people are valued and respected and are contributing members of society. Self-determination recognises that disabled people are experts in their own lives and should be able to exercise full autonomy. Voice is more than being heard; it is about the ability to exercise decision making and shape the disability support system.

##### What does it mean for the key features to give an “independent voice to disabled people and their whānau”?

**Voice recognises that disabled people are experts in their own lives and have the right to be involved in decisions affecting them. Voice captures both the individual voices and the voices of the collective.**

Voice is about disabled people receiving information and providing comments in a way that can genuinely influence those with governance accountabilities and formal responsibilities within the disability support system. In the context of the MoG Review, voice enables disabled people to be significantly involved throughout the decision-making process when determining what arrangements will be in place.

To ensure disabled people have a genuine voice, the current system needs to be strengthened to provide a platform for disabled people to express their views and personal experiences, and also to identify their own outcomes and live the life they choose. The ability to have a genuine voice builds confidence and trust as well as higher levels of participation and engagement with disabled people.

We recognise voice needs to align with the Enabling Good Lives (EGL) and Whānau Ora principles and vision, which is about disabled people having choice and control of their lives. We note that in July 2018, the International Human Rights Council, in

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<sup>1</sup> Refer to Article 1 of the United Nations Convention on the Rights of Persons with Disabilities

its report regarding the implementation of the United Nations Declaration on the Rights of Indigenous Peoples in Aotearoa recommended “that the government incorporate a Whānau ora approach to its proposed transformation of the disability support system.”<sup>2</sup>

### **The voice of the collective is just as important as the voice of the individual**

Voice is about capturing the voices of disabled people as individuals and as a collective. Individual voice represents the views and experiences of one person with a disability. Collective voice represents the views and experiences of one or more people with disabilities, which could include whānau, families, advocates, networks and communities. The support of whānau, communities and other networks is particularly important to disabled people who may not have the physical, mental or intellectual capability to express their individual voice and therefore rely on the power of the collective voice to express their views.

The voice of the collective helps ensure the diverse communities within the disability sector are heard. This is particularly important from a cultural perspective as the 2013 Disability Survey found that Tāngata Whaikaha (Māori people with disabilities) had a disability rate of 32 percent, compared with 24 percent for Pākehā, 26 percent for Pacific peoples, and 17 percent for Asian. Speaking as a group can give disabled people the confidence to have their voice heard and can help ensure they feel supported by others who understand them. In addition, voice is more than just a physical presence; it can also come in the form of verbal, written and behavioural actions.

### **The collective voice is not one person or a small group representing and speaking on behalf of disabled people.**

Voice recognises that disabled people come from different experiences and circumstances and all have the right to be heard. Therefore, one person’s perspective should not dominate or represent the entire view of a diverse group of people. Having multiple people participate and use their voice also avoids the feeling of tokenism.

### **Voice is not a one-off consultation that happens on an ad hoc basis but is a continuous cycle**

Voice is used to influence how arrangements operate and can be improved over time without fear of negative consequences. This ensures that arrangements respond and adapt to on-going changes. This also builds trust and confidence with government and guides on-going adjustments to ensure arrangements are suitable for disabled people—both now and in the future.

### **Voice is not the same as governance arrangements**

Voice and governance arrangements, while complementary, are distinctively different. Voice does not necessarily hold the authority to make any final decisions. Voice is about influencing the operation of arrangements, to ensure the individual and collective needs of disabled people are met.

### **What does voice aim to achieve?**

Voice aims to provide a platform for disabled people and whānau to influence decision-making processes concerning issues relating to them. Government must

<sup>2</sup> <https://www.ohchr.org/EN/Issues/IPeoples/EMRIP/Pages/Session11.aspx>

actively involve disabled people and whānau in the development and implementation of the MoG review.<sup>3</sup>

### **Self-determination for disabled people and whānau**

Disabled people are in control of their lives and should be able to seek support when it is needed. Voice mechanisms celebrate diverse communities living in different circumstances who have a right to be heard. Voice recognises the collective strength and capability of disabled people to achieve better outcomes in different areas of their lives. This enhances the mana of disabled people and acknowledges the valuable contribution that they make to society. It helps enable disabled people to build skills, knowledge and experiences (strengths-based) while maintaining control over their lives to ensure they engage as equal citizens. Voice mechanisms can also enable disabled people to feel connected to people who share similar experiences.

### **Regard to Māori voice**

Disabled Māori and whānau have different attitudes towards disability from other groups and it is important that the Māori voice is heard also. Māori concepts of disability and attitudes towards disability are intertwined with other concepts, beliefs and values such as whanaungatanga, āwhinatanga and manaakitanga and there is a contrast between individualistic Western views of disability and Māori holistic concepts of hauora. Rather than an emphasis on physical, sensory, or intellectual impairments, te ao Māori locates individuals within the whānau, recognizing interdependence, cultural and spiritual determinants. Therefore, specific regard should be given to disabled Māori and their whānau.

### **Voice is person-led**

The voice of disabled people must be the primary contributor to discussions. Enabling disabled people to set their own outcomes and be in control of their lives is crucial to the success of arrangements. It is important that arrangements are in place that enable a self-determined path for disabled people to encompass a whole-of-life approach.

### **Incentive to engage and participate**

Participation requires disabled people to be involved at all levels of the work and development of arrangements. This includes the decision-making, planning, development, delivery and evaluation processes of the arrangements. Voice mechanisms aim to provide stronger incentives for disabled people to participate and engage by helping them realise they have a real opportunity to determine how they want to live their lives. However, it is important to note that disabled people will need to experience this, before they are confident in this change.

## **What causes voice not to work as well as it could?**

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<sup>3</sup> Refer to Article 4(3) of the United Nations Convention on the Rights of Persons with Disabilities

It is important to acknowledge there are factors that could affect the way voice mechanisms work. Below are some of the things that may impact the effectiveness of voice.

### **Power and resource imbalance**

Disabled people do not have the same decision-making power and level of accountability, and resources as government. At times, this makes it hard for them to have their voices heard and needs met. Their mana is often not respected, and neither is their right to self-determination. A partnership between disabled people and government that is built on mutual understanding and respect can help mitigate this risk, as it ensures both parties engage as equals. This helps minimise the power and resource imbalances, as disabled people will be actively involved throughout the entire process.

### **Lack of information sharing**

Lack of information sharing can duplicate time, resources and effort for both government and people with disabilities. It can also result in inconsistent information across government. This risk can be mitigated by ensuring government agencies are open and transparent when dealing with one another and people with disabilities.

Lack of information sharing can occur between people with disabilities, government and service providers. This often occurs because disabled people are not able to access (either physically or through a support network) the required information, which can lead to disengagement and distrust. Without the right information, disabled people are unable to make informed decisions. This risk can be mitigated by ensuring information is disseminated and presented in different modes that are easy for disabled people to access.

### **Lack of shared understanding**

It is important to ensure that disabled people and government have the appropriate skills and cultural competencies to build and maintain productive partnerships. Working towards a common vision will help enable success.

### **Not keeping up with societal or technological changes**

Technological and societal trends can change at a rapid pace. MoG arrangements may not reflect what voice mechanisms are wanting at a certain point in time. Voice mechanisms can help ensure the voice of disabled people provide support for MoG arrangements through maintaining an on-going partnership with government.

### **Misinterpretation and miscommunication**

There is potential for government to misinterpret or misunderstand the voice of disabled people. The issue of misinterpretation and miscommunication can be mitigated by having direct representation of disabled people in the process. This will enable disabled people to work with government to help ensure the understanding of the meaning behind the decisions.

## **The Mana, Self-determination and Voice Key Features**

We have developed a set of key features, referred to as 'mana, self-determination and voice' to ensure disabled people have their voice heard within the MoG arrangements. The term 'mana' represents the strength, prestige and authority of

disabled people and their value as contributing members of society. The term 'self-determination' recognises disabled people are experts in their own lives and should be able to exercise full autonomy. The term 'voice' acknowledges disabled people and their whānau are important and should be heard and incorporated into decisions which affect them.

It is important to note that communication is an underpinning value for all the key features—good communication will help ensure arrangements are built on a strong foundation. The key features are:

- Ensure arrangements, which include engaged decision making and clear communications, are transparent, accountable and timely;
- Explore the use of existing machinery of government arrangements as part of the development of a new approach;
- Enable voice to be heard through multiple channels;
- Enable capability building for disabled people and their whānau;
- Partnership between disabled people and government is built on trust, mutual respect and a shared purpose.
- Ensure there is proactive engagement with disabled people and whānau throughout the process;
- Voice mechanisms are independent and an integral part of machinery of government; and
- Make certain that arrangements are collectively responsible to hear, respond and adapt to the voices of all.

The eight key features are set out in detail below.

### **One: Ensure arrangements, which include engaged decision making and clear communications, are transparent, accountable and timely**

Transparency involves openly communicating with disabled people and whānau in a timely manner. This means disabled people and whānau are actively involved in the process and understand what is going on throughout all stages of development. This includes respecting the mana of disabled people and ensuring they have access to the required information to make informed decisions and also sharing that information as early as possible. This is key to ensuring disabled people have confidence in government to deliver MoG arrangements that meet their needs. Transparency will require both parties to keep each other advised of what is happening in a timely manner.

New MoG arrangements must also be accountable to people with disabilities, and to the public.<sup>4</sup> Accountability requires government agencies to listen to the voices of disabled people and to justify the reasoning behind their decisions and actions. It involves accepting responsibility and being answerable for actions. Accountability and transparency provided in a timely manner can help strengthen the partnership between government and disabled people and build trust. Accountability can be described in two levels:

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<sup>4</sup> The government must be accountable to the public as it is a good public management principle. This does not mean that disabled people are accountable to the public also.

- government level—where government is held accountable to disabled people and the public for their decisions and actions.
- ground level—where providers and services are held accountable to disabled people and government for their decisions and actions.

## **Two: Explore the use of existing machinery of government arrangements as part of the development of a new approach**

Exploring the use of existing machinery of government arrangements can mitigate the risk of duplicating resources, time and effort. This will ensure government agencies and disabled people have considered all possible current machinery of government arrangements before developing a new approach. Building on current arrangements will require co-ordination between disabled people and government—focusing on outcomes and maximising progress from available resources. This will also strengthen the case to seek a new approach should the use of existing arrangements prove to be inadequate to deliver for people with disabilities.

Voice mechanisms can help disabled people share their experiences with current arrangements. This will indicate what types of arrangements work and how arrangements that do not work as well could be improved. Thus, MoG arrangements can be developed on the failures and successes of existing resources. Exploring the use of current arrangements does not mean that new arrangements will not be considered. Rather, it means that arrangements that are currently working can be further developed, and arrangements that are not working can be improved or replaced.

*Example of key feature two in action: The Health and Disability Commissioner*

The purpose of the Health and Disability Commissioner (HDC) is to advocate for, promote, and protect the rights of health and disability service consumers in New Zealand. To help do so, the system provides a process that resolves complaints in a timely, fair and effective way. Voice mechanisms can help indicate what issues exist within the current arrangements (e.g. timely feedback issues with the HDC) and ensure these issues are addressed.

## **Three: Enable voice to be heard through multiple channels**

Disabled people must be able to access arrangements that provide a range of support to give them self-determination and help them live the life they want. This can be done by developing and promoting meaningful dialogue using various channels of communication. People must have the autonomy to choose what arrangement is best tailored to their individual needs. Examples of multiple channels include:

- face to face engagement;
- online platforms;
- in-store service centres; and
- call centres.

These channels of communication must be mindful of the person's specific circumstances, whether that be physical, visual, intellectual, verbal or financial. These channels of communication must also be mindful of the person's whanau or support network, particularly disabled people from Māori and Pacific backgrounds or children and young people. The mana of disabled people and their whānau must also be preserved.

Having multiple channels will help ensure that information is presented and delivered in a way that suits all disabled people from all diverse backgrounds and circumstances. Whether this is face-to-face or online, arrangements must ensure they are tailored to the needs of people with disabilities. By doing this, disabled people can express their voice freely and be comfortable to do so without feeling restricted or constrained. This will hopefully help give disabled people who do not usually have their voice heard, the confidence and incentive to engage with government.

#### **Four: Enable capability building for disabled people and their whānau**

Voice mechanisms help build the capability of disabled people and enable them to have self-determination and more control of their lives. Disabled people can use voice mechanisms to have their say and speak about their experiences. It is important to recognise that disabled people have skills, knowledge and experiences that contribute to their own resilience. Voice can provide disabled people a platform to become more self-managing. By determining how they want to live, disabled people build their capabilities and can take control of their lives. This gives disabled people the confidence to know they are the primary contributors and stewards in their lives.

#### **Five: Partnership between disabled people and government is built on trust, mutual respect and a shared purpose**

Partnership involves government working with disabled people to develop arrangements that enable disabled people to access the best possible life opportunities and services available to them. Having a partnership between disabled people and government ensures both parties can engage as equals based on a common understanding that is built on mutual respect and trust. This emphasises the need for co-design, co-decision and collaboration throughout all stages of the process.

##### *Example of key feature five in action: The DPO Coalition*

Article 4(3) of the United Nations Convention on the Rights of Persons with Disabilities (the Convention), promotes the active involvement of government agencies with Disabled people's Organisations (DPO's). DPO's recognise that disabled people need to have the opportunity to be involved in decisions that affect them. The DPO Coalition is a group of DPO's that meet and think about how disabled people can work collaboratively with government to implement the Convention. The DPO Coalition have a partnership with the Government to ensure the voices (both individual and collective) of disabled people are actively incorporated into decision affecting them.

#### **Six: Ensure there is proactive engagement with disabled people and whānau throughout the process**

It is important that government proactively engages with disabled people throughout the process. In practice, this would look like government approaching disabled people from diverse experiences and circumstances as early as possible to keep them informed of progress over time, rather than disabled people waiting to be approached or being completely disengaged from the process. This helps ensure the partnership between disabled people and government is transparent and timely, and built on mutual respect and trust.

## **Seven: Voice mechanisms are independent and an integral part of machinery of government**

Voice mechanisms should be independent to ensure it can influence arrangements without fear of being managed or controlled. Disabled people will quickly lose faith if voice mechanisms are not perceived as being independent without fear of consequences. However, it is important to note that arrangements will not be completely autonomous from government, as there are other aspects such as funding and resourcing that needs to be considered. Independent mechanisms which are incorporated as an integral part of machinery of government will help ensure the voices of disabled people are heard and protected.

## **Eight: Make certain that arrangements are collectively responsible to hear, respond and adapt to the voices of all**

Disabled people come from diverse backgrounds and circumstances and live in varied communities. New arrangements must reach those who are usually disengaged in the process and ensure their voices are heard. Disabled people and whānau should be able to easily access the resources and help they need as their lives and circumstances change.

Collective responsibility ensures disabled people can easily access the necessary services and support and information available that enables them to make empowering decisions. Taking a collective approach will enable arrangements to be more responsive to the needs and goals of people with disabilities. Having collective responsibility will help ensure there is better information sharing and improved consistency—both across government and with disabled people.

It is important that new MoG arrangements adapt to the voice of disabled people and are responsive to what is said. Disabled people do not want to waste their time by having to repeat themselves. New arrangements must adapt to the changing needs of people with disabilities—giving them the confidence that their voices are heard and valued. Having arrangements that respond to the voice of disabled people will also increase its credibility.

New arrangements must actively listen, respond and justify decisions. Justification is extremely important as disabled people need to know what has happened and why it has happened. Decision-making processes should be explained clearly and in a timely manner to people with disabilities—giving them the opportunity to review the decision and be able to challenge and test that decision.

### *Example of key feature eight in action: The cross-agency family violence and sexual violence joint venture*

In 2018, Cabinet agreed to a cross-agency arrangement to take collective responsibility for reducing family violence and sexual violence. The approach involved a group of Chief Executives (the Board) taking collective responsibility for the response. Chief Executives are accountable for their department's contributions to the joint venture. The Board reports to the lead Minister, who is supported by a Ministerial Group. The lead Minister and the Ministerial Group develop and coordinate advice to the Social Wellbeing Committee. The Social Wellbeing Committee is also collectively and individually responsible for the contributions of their portfolios and departments to the shared goals of the joint venture.



