# Report on the review of disabled people-led monitoring (2017-2018)

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## Executive Summary

### Abbreviations and acronyms

|  |  |
| --- | --- |
| **CCMG** | Convention Coalition Monitoring Group |
| **DPA** | Disabled Person's Assembly |
| **DPO** | Disabled People's Organisation |
| **DPO Coalition** | Disabled People's Organisation Coalition |
| **DRPI** | Disabled Rights Promotion International |
| **HRC** | Human Rights Commission |
| **IMM** | Independent Monitoring Mechanism of the UNCRPD |
| **ODI** | Office for Disability Issues |
| **OTO** | Office of the Ombudsman |
| **UNCRPD** | United Nations Convention on the Rights of Persons with Disabilities |

### UNCRPD Article 33

New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Article 33, one of the Convention’s most innovative aspects, describes how State Parties should implement and monitor the Convention. New Zealand meets its obligations under Article 33(3) by establishing the Convention Coalition Monitoring Group (CCMG) as the third partner in the Independent Monitoring Mechanism (IMM) alongside the Human Rights Commission and Office of the Ombudsman.

### The Convention Coalition Monitoring Group

The CCMG is a governance group made up of representatives from seven Disabled People’s Organisations (DPOs). The CCMG governs the disabled people led component of the IMM.

The CCMG coordinates an ethical mechanism for collecting disabled people’s input to the monitoring of disability rights. The approach comprises qualitative research and monitoring programme which collects data directly from disabled people.

### About this review

This report summarises a review of disabled people led monitoring. The focus of the review was to provide feedback that could be used to strengthen the monitoring in coming years. The review focused on:

* Design, operation, governance and reporting of the disabled people led monitoring
* Relationships between the CCMG and the wider disability sector and government stakeholders
* Opportunities for developing the monitoring in the future.

The review collected information primarily through interviews with CCMG members, monitoring employees, the IMM members and stakeholders across government and the wider disability sector. It also included a review of the documentation of the monitoring in New Zealand and a scan of the literature on international practice in UNCRPD monitoring.

### Review findings

|  |  |  |  |
| --- | --- | --- | --- |
| **Elements of monitoring best practice** | **Strengths of disabled people led monitoring in New Zealand to date** | **Opportunities for strengthening the monitoring in the future** | **Responsibility** |
| **Governance of the monitoring** | | | |
| **Clarity of purpose and direction** | The disabled people led monitoring has a clear mandate and funding from Cabinet, and support from other IMM agencies. | Clarify the functions of the CCMG and the DPO Coalition and how they differ, to strengthen the leadership function of the CCMG. | CCMG/DPO Coalition |
| **Clear scope** | The group members are committed to the success of the project and understand the importance of disabled people led monitoring. | Define the scope of the CCMG to clearly distinguish between operational matters to be managed by monitoring team and governance functions to be managed by the CCMG. | CCMG/DPO Coalition |
| **Provides strategic leadership** | The leadership role of the DPO members and the objectives of the disabled people led monitoring have been established by Cabinet. | Develop a monitoring framework in partnership with disability sector stakeholders that sets out monitoring priorities and appropriate monitoring measures to deliver the objectives. | CCMG/DPO Coalition in consultation with IMM partners and ODI |
| **Has the right people participating** | All DPOs are represented in the group. Some members have governance experience through participation in DPO governance and in the DPO Coalition. The CCMG members were trained by the project lead in the Disability Rights Promotion International methodology. | Further invest in developing the governance skills of CCMG members. Consider including some other perspectives which are currently underrepresented (for example family/whānau of disabled people, youth, some ethnic groups (Pacific people, Asians), new immigrants). People could be included as permanent members or seconded to the group. Include or second research expertise in the group to support the development of a monitoring framework and CCMG technical decision making. | CCMG/DPO Coalition |
| **Efficient and effective** | The chair is committed to the group, well regarded and has a long history with the CCMG. | Support the chair’s role in focusing the group on matters within scope by developing clear terms of reference. | CCMG/DPO Coalition |
| **Clear expectations of members** | Members have a commitment to and passion for disability issues and lived experience of disability. Agendas and meeting minutes are prepared and circulated with material for review in advance of the meetings. The extent to which members can invest time and resource in preparing for meetings varies. | Set clear expectations about preparation for meetings and hold members accountable has the potential to increase meeting productivity. Resource members for meeting preparation time is likely to assist. | CCMG/DPO Coalition |
| **Adequate funding** | CCMG members are paid meeting fees and travel costs are covered.  The budget includes travel costs for meetings. | Fund preparation time and consider whether compensation is adequate, as the preparation time required may vary between members.  Manage the individual members’ travel requirements effectively through the fundholder. | CCMG/DPO Coalition |
| **Accountable and transparent** | Some members routinely report on the CCMG to their DPOs, who consider they are well informed.  Direct communication to wider stakeholder groups through participation in meetings provides responsive communication. | Set clear expectations for members’ responsibilities around consulting and reporting back to their organisations to ensure DPO leaderships and memberships are engaged with the monitoring.  Agree processes for direct communication to wider stakeholder groups to ensure transparency and reflection of consensus views. | CCMG/DPO Coalition |
| **Monitoring management** | | | |
| **Effective and independent fundholding** | ODI took over the role of fundholder and provides administrative support, for the CCMG. No suitable alternative was identified. | Independence of the fundholder from government is viewed by stakeholders as part of the independence of the monitoring as a whole. ODI does not want to be the fundholder and would prefer to administer the fund to the fundholder designated by the CCMG. There are options available to move the fundholder role to another organisation with the required capacity (a new entity, an NGO or another type of organisation). The organisation must have adequate infrastructure to manage the financial aspects of monitoring management. |  |
| **Effective project management team, administration and logistics** | The outgoing national coordinator and project leader have documented the different components of their role, carrying institutional knowledge forward. The current project manager has established some of the needed processes. | Empower the monitoring team to make all operational decisions and report them to the CCMG. Continue to build on the project management foundation that has been established and increase the focus of the CCMG on governance issues, drawing on the expertise of the monitoring team | CCMG/DPO Coalition |
| **Monitoring approach** | | | |
| **Develop a monitoring framework** | The UNCRPD and the DRPI method provide sources of guidance for the structure of the monitoring framework.  There is support from stakeholders to develop a monitoring framework. | There is room to further modify the DRPI method to increase the value of the monitoring. These modifications should be adopted or rejected by the monitoring governance who could draw on expert input to support their decision making.  A first step is to develop a monitoring framework through a process involving expert advice and consultation with stakeholders to focus and strengthen the monitoring with the support of the disability sector. | CCMG/DPO Coalition in consultation with IMM partners, ODI and the wider sector |
| **Building a monitoring team** | The project trained more than 50 monitors in the rights of people with disabilities and how to conduct interviews.  The project team have learned and recorded lessons learned in carrying out the monitoring and all showed dedication and commitment to the project’s success. | Build on the learnings of the project to date in structuring the project team, employing people with the right skills and giving them the mandate to fulfil their roles efficiently. | CCMG/DPO Coalition |
| **Collecting, analysing and reporting data** | In the last three years, the monitoring completed interviews with 176 disabled people, hearing their perspectives and communicating them to government, the disability sector and the UNCRPD Committee. | Developing a monitoring framework will guide sampling, information sought, and reporting priorities. Further adapt the DRPI method to include more perspectives from within the disabled community. Opportunities include incorporating stakeholder consultation, participation of support people, surveys, family/whānau and other group meetings. | CCMG/DPO Coalition |
| **Stakeholder involvement and communication** | Stakeholders support the purpose of the monitoring and are enthusiastic about learning more. | Stakeholders support the purpose of the monitoring and are enthusiastic about learning more.  Stakeholder awareness of the monitoring and engagement with the process could be strengthened by including more opportunities for their participation throughout. | CCMG/DPO Coalition |

### Overview

International comparisons highlight the strengths of New Zealand’s approach to monitoring New Zealand’s progress against the UNCRPD. The monitoring led by the CCMG demonstrates New Zealand’s commitment to disabled people led monitoring of the UNCRPD.

In capturing the voice of disabled people directly, the monitoring has the potential to make an important contribution to the disability sector by reporting directly on what disabled people’s experience of their rights are in New Zealand.

We found strong support for the monitoring throughout the disability sector, including from government stakeholders. Feedback focused on opportunities to strengthen the monitoring through:

* Revisiting and strengthening governance arrangements
* Further developing the structure of the monitoring through consultation and drawing on monitoring expertise to develop a monitoring framework to provide a foundation for the data collection, analysis and reporting
* Refining data collection methods to provide more opportunities for individuals and organisations of different types to participate
* Engaging with stakeholders throughout
* Building on the good work done on reporting to engage a wider audience with the monitoring findings.

## Introduction

### New Zealand and the UNCRPD

New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD or the Convention). The Convention is important as an explicit inclusion of the rights of disabled people in the international human rights framework. It recognises that despite the protections afforded by other international human rights instruments:

*… Persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world.[[1]](#endnote-1)*

The purpose of the Convention is to:

*Promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.[[2]](#endnote-2)*

It is important that the Convention is not seen as something that only benefits disabled people. Meeting New Zealand’s obligations under the Convention benefits the country as a whole.

### Implementation of Article 33 in New Zealand

Article 33, one of the Convention’s most innovative aspects, describes how State Parties should implement and monitor the Convention. Its three parts require States:

1. Designate a focal point for matters relating to the implementation of the Convention and consideration of a coordinating mechanism
2. Establish a framework including an independent mechanism to promote, protect and monitor the implementation of the Convention
3. Ensure the participation of disabled people and their representative organisations in monitoring the implementation of the Convention.

The requirement for the participation of disabled people in monitoring the implementation of the Convention reflects the participation of disabled people in drafting the Convention.

*Against this background, the active and informed participation of persons with disabilities in the implementation and monitoring of the CRPD is not only consistent with the Treaty, but it is also a requisite of a human rights-based approach.*

The importance of the Convention and the Independent Monitoring Mechanism (IMM) are recognised in Government’s response to the UNCRPD Committee’s concluding recommendations.

New Zealand meets its obligations under Article 33 by:

* Identifying the Office for Disability Issues (ODI) as the focal point to lead a whole-of-government approach to implementing the Convention
* Designating the Ministerial Committee on Disability Issues as the coordinating mechanism for implementation within government
* Designating the IMM consisting of the Human Rights Commission (HRC), the Office of the Ombudsman (OTO) and the Convention Coalition Monitoring Group (CCMG).

### This review

The objective of this review was to review the effectiveness and efficiency of the ‘disabled people led monitoring of their rights’ initiative and to provide recommendations to inform future arrangements. It focused on:

* How effective has the disabled people led monitoring initiative been?
* How efficient have been the arrangements for the disabled people led monitoring initiative?
* In particular, the review examined the:

Methodology used to undertake the disabled people led monitoring

Governance and coordination mechanisms

Contracting arrangements

The interrelationship between the CCMG and other IMM partners

Awareness of the disabled people led monitoring initiative

* Design, operation, governance and reporting of the disabled people led monitoring
* Relationships between the CCMG and the wider disability sector and government stakeholders
* Opportunities for further developing monitoring in the future.

The review collected information through interviews and document review. Interviews were completed with:

|  |  |
| --- | --- |
| **Interview participant group** | **Number completed**  **(with number of people)** |
| CCMG – workshop | 1 (3) |
| DPO Coalition – workshop | 1 (8) |
| CCMG member organisations – individual interviews | 3 |
| Monitoring team members | 3 |
| Monitoring monitors | 5 |
| Disability sector stakeholders | 6 |
| Government stakeholders/report end users | 4 |
| UNCRPD Committee member | 1 |

The project also included a review of the documentation of the monitoring in New Zealand and a scan of the literature on international practice in UNCRPD monitoring. The scan of international practice included Australia, Austria, the United Kingdom and Canada.

## Inclusion of the Convention Coalition Monitoring Group as part of the IMM

In New Zealand, consistent with the requirements of Article 33, disabled people play an essential role in the monitoring the UNCRPD through the CCMG as part of the IMM.

### Factors promoting the success of the CCMG

In the view of the Country Rapporteur for the 2014 country review, New Zealand’s IMM is in a strong position compared to many other countries. The 2014 concluding observations of the UNCRPD Committee commended New Zealand for its implementation of an IMM.

Strengths of the New Zealand IMM related to the CCMG include:

* Clear mandate and funding for the CCMG in the 2010 Cabinet Paper
* Support for disabled people led monitoring from the other IMM agencies (HRC and OTO), the wider disability sector and government
* A process for monitoring the experiences of disabled people through primary data collection.

These factors create a setting for the CCMG to successfully participate in the IMM.

### Designation of the CCMG

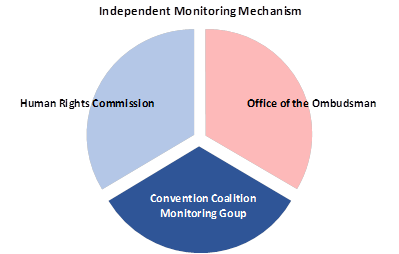
In 2010, the CCMG was formed as a governance-level steering group made up of six DPOs, which were governed by disabled people in line with the expectations of Article 33 of the Convention.

The six DPOs represent New Zealand’s civil society:

* Association of Blind Citizens of New Zealand Incorporated
* Deaf Aotearoa New Zealand Incorporated
* Disabled Person’s Assembly New Zealand Incorporated
* The committee representing mental health consumers known as Nga Hau E Wha
* Ngāti Kāpo O Aotearoa Incorporated
* People First New Zealand Incorporated – Ngā Tāngata Tuatahi.

There are now seven DPOs represented in the CCMG following the addition of Balance NZ (representing mental health consumers) and Deafblind NZ Incorporated in 2012 and the withdrawal of Nga Hau E Wha in 2015. The CCMG governs in the disabled people led component of the IMM and is the third IMM partner alongside the HRC and OTO (Figure 1).

**Diagram description** - Figure 1 below is a pie chart titled 'Figure 1. Structure of the IMM in New Zealand'. with three equal sized segments. The diagram is headed 'Independent Monitoring Mechanism' and the three segments are: Human Rights Commssion (coloured light blue), the Office of the Ombudsman (coloured light salmon pink) and Convention Coalition Monitoring Group (dark blue colour with white text).



The objective of the CCMG is to coordinate an ethical mechanism for disabled people’s input to the monitoring of disability rights as spelled out in the Convention.

The Convention Coalition provides an ethical mechanism for disabled peoples’ input into the monitoring of disability rights as spelled out in the Convention and aims to ensure a sustainable process for this input in the future.

The CCMG conducts a qualitative research and monitoring programme including the collection of evidence directly from disabled people:

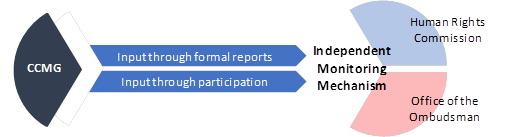
*The Convention Coalition will lead disabled peoples’ work on monitoring the rights of disabled people. It is committed to ensuring that the Treaty of Waitangi is upheld and reflected in its activities. It also recognises the importance of its work in sharing its monitoring work with the regional and global disability communities.*

The DPOs described the vision of the CCMG in a memorandum of understanding signed by all:

*DPOs unite to act at a high level to ensure there is leadership by disabled people to oversee the implementation of the UNCRPD (and other disability rights treaties) within New Zealand.*

The CCMG informs the IMM through formal monitoring reports and through participation in quarterly IMM meetings and more regular IMM working group meetings (Figure 2).

**Diagram description** - Figure 2 below is a linear style graphic titled ' Figure 2. Channels for CCMG input into the IMM.' Figure 2 progresses on from Figure 1 (above) The CCMG wedge (dark-blue coloured) has been pulled back from the chart. Flowing on from the CCMG wedge are two mid-blue arrows titled ' Input through formal reports' and 'Input through participation'. The arrows point to the other two remaining pie chart wedges: 'Human Rights Commission' (pale blue coloured) and Office of the Ombudsman (pale pink coloured).



**Figure 2. Channels for CCMG input into the IMM**

Formal reports on monitoring findings are reviewed and supported by the CCMG members. While the IMM has engaged with the reports, it has relied more on information provided by the CCMG through participation in working group meetings and full IMM meetings.

Informing the IMM through participation in meetings means the CCMG can be an active participant in the IMM, and be responsive and direct in addressing IMM questions. However, input through participation depends on either all members attending the group, or the subset of the members who attend representing the views of the CCMG and the monitoring as a whole.

## Governance of the monitoring project

Effective governance is fundamental to the success of an organisation or programme. The characteristics of effective governance are described in a number of resources across different sectors in New Zealand and overseas.

We have drawn on these references to collate a list of characteristics (sections 4.1 – 4.6 below) relevant to the CCMG that provide a framework to consider the effectiveness of the governance of the monitoring.

### Characteristics of effective governance for monitoring projects

Effective governance includes the following characteristics:

* Clarity about its purpose and direction

Transparent function distinct from other groups

Clear scope for the group (described in terms of reference or similar)

* Provides strategic leadership

Develops policies and activities that are consistent with its scope and purpose

Maintains a focus on learning and improving - actively monitors and reviews its effectiveness

* Has the right people on board for its responsibilities

Membership represents the diverse community of disabled people

Membership includes governance expertise

Membership includes monitoring and research expertise

* Is run effectively and efficiently and makes group meetings count

Clear expectations of members in preparing for meetings, participating in meetings and communicating meeting activity

Adequate funding for members’ participation

Adequate secretariat support for members

* Is accountable and transparent.

### Effective governance has a clear purpose and direction

#### Clear scope

|  |  |
| --- | --- |
| CCMG strengths | The group members are committed to the success of the monitoring and understand the importance of disabled people led monitoring. |
| Opportunities for development | Defining the scope of the CCMG to clearly distinguish between operational matters to be managed by the monitoring team and governance functions to be managed by the CCMG. |

Clearly defining the scope of the governance group improves its efficiency as members’ time is focused where they can add most value. The scope of governance groups is usually defined and documented in clear terms of reference. The memorandum of understanding between the DPOs in establishing the CCMG goes some way towards this but could be strengthened with greater detail.

*The CCMG were named by government and it makes sense but their role has never really been defined. (IMM stakeholder)*

The governance function for the monitoring is best focused on:

* Leading the development of the monitoring framework and reporting
* Decisions on who to employ in the monitoring team and monitoring the team’s performance
* Communicating with their DPOs and the wider sector about the monitoring.

Decisions relating to other operational matters fall outside the scope of a governance group. They can be managed by the monitoring team and reported to the governance group.

Maintaining a focus on governance instead of operational issues has been described by group members and other stakeholders as a challenge for the group that has impacted its leadership and strategic direction setting of the monitoring. At times, a focus on operational decisions has resulted in delays in making the decisions which have impacted the monitoring team’s ability to work efficiently.

The monitoring team leader was spoken of very highly by CCMG members, other monitoring team members and stakeholders in the wider disability sector. The CCMG was described as functioning more effectively in recent times with a strong project leader in place to effectively manage the project management matters. Maintaining an effective project leader should be prioritised for the success of the monitoring.

### Effective governance has a transparent function

|  |  |
| --- | --- |
| Strengths for the CCMG | The disabled people led monitoring has a clear mandate and funding from Cabinet, and support from other IMM agencies. |
| Opportunities for development | Clarify the functions of the CCMG and the DPO Coalition, and how they differ, to strengthen the leadership function of the CCMG. |

The DPO Coalition, whose function is not related to the CCMG, was established in 2012.

*Suppose – what’s very unusual is that the Convention Coalition actually was set up before the DPO Coalition which is the governance group. A bit like the cart before the horse. (DPO)*

The two groups have different purposes:

* **DPO Coalition:** Work with government to develop and implement the Disability Action Plan (DAP) in partnership with government.
* **CCMG:** Govern the disabled people led monitoring component of the UNCRPD IMM.

The same DPOs participate in both groups (with small differences as the groups evolve over time). All DPOs are represented in the DPO Coalition by two people holding senior governance and management positions (for example, a president and a chief executive). The group has included a facilitator to strengthen its function while it has developed.

Some DPOs use the same representative for the DPO Coalition and the CCMG while others use a different representative for each. Where DPOs are not represented by the same people in both groups, the leadership can be distanced from the activity of the CCMG and have less awareness of its operation. Members who represent their DPOs on both groups face an increased demand on their capacity, which they often have difficulty meeting.

At times the boundaries in the functions of each group have blurred. For example:

* Some monitoring ssues have been carried from the CCMG to the DPO Coalition meetings for decisions

*This has raised confusion. Sometimes people, if they have felt perhaps annoyed by a decision the DPOs made in the context of the CCMG, they would have an attempt to bring up their frustration at the Coalition. (stakeholder)*

* Some government agencies have made requests for input from the CCMG on issues outside the scope of the monitoring.

Lack of clarity about the scope of the two groups is evident amongst monitoring stakeholders.

*The two organisations creates confusion for the people involved and the people looking in. People often confuse them. And it’s often the same organisations and people in both. (stakeholder)*

There is an opportunity to revisit the governance structure to provide clarity and increase its effectiveness.

*Both have to be there but it’s always been who does the CCMG report to. It should report to the organisations. There has to be clear terms of reference. (DPO)*

Options include:

* Absorbing the function of the CCMG into the DPO Coalition would provide clarity about governance and has the potential to reduce workload and lead to a more efficient and effective governance structure. However, some stakeholders are concerned about the potential conflict of interest between the CCMG’s monitoring function and the DPO Coalition’s implementation role. Potential conflicts of interest are not unusual in sector governance groups and may be managed by open acknowledgement of its existence and transparency in how potential conflicts are managed.

*DPO Coalition could absorb the role of the CCMG. We all have different views on how that might work but the DPO Coalition would be the people who govern that umbrella organisation and make the real decisions about things. (DPO)*

* Disbanding the CCMG and establishing a new legal entity in its place. The new legal entity could be governed by the DPO Coalition and could be the fundholder for the monitoring. This would strengthen independence from government by taking the fundholder back from ODI, who has held the role temporarily and reluctantly. This approach would require the support of all DPOs and resources to establish.
* Maintaining the existence of two groups but formalising the requirements of the role of DPO representatives (discussed below).

*Overall, the CCMG adds a lot of value to the work of government. It’s a mechanism to ensure that government is accountable and that the DPOs and disabled people across NZ are well represented. That they are part of the decision-making process. (government stakeholder)*

### Effective governance provides strategic leadership

|  |  |
| --- | --- |
| Strengths for the CCMG | The leadership role of the DPO members and the objectives of the disabled people led monitoring have been established by Cabinet. |
| Opportunities for development | Develop a monitoring framework in partnership with disability sector stakeholders that sets out monitoring priorities and appropriate monitoring measures to deliver the objectives. |

A governance group’s most important role is setting the long-term direction for the and planning the strategies to achieve the organisation’s goals. This involves:

* Developing policies and activities that are consistent with its scope and purpose
* Maintaining a focus on learning and improving through active review of effectiveness.

*The governance of the monitoring – if it’s run properly the governance should not be costly. They should be monitoring the process of the [project lead] and ensuring they are following the process. (stakeholder)*

The CCMG’s objectives were established at its formation: to coordinate an ethical mechanism for disabled peoples’ input to monitoring of disability rights. The role of the CCMG as a governance group is determining how the objectives will be achieved and overseeing implementation.

Development of a monitoring framework through a process involving consultation with the sector and expert input will enable the CCMG to build support across the sector and will provide structure for the monitoring. The development of a monitoring framework is further discussed in section 6.2.

**International context for governance structures**

Where the governing body has set clear strategic direction that aligns with the UNCRPD, with supporting action plans that include ownership and timeframes – and where the governing body takes responsibility for ensuring these are monitored against specific indicators – we can assume that these governing bodies are at least minimally effective. Internationally, only New Zealand and Australia seem to meet these criteria for effectiveness.

### Effective governance has the right people on board for its responsibilities

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| Strengths for the CCMG | All DPOs are represented in the group.  Some members have governance experience through participation in DPO governance and in the DPO Coalition.  The CCMG members were trained by the project lead in the Disability Rights Promotion International methodology. |
| Opportunities for development | Further invest in developing the governance skills of CCMG members.  The group could include some other perspectives which are currently underrepresented (for example family/whānau of disabled people, youth, some ethnic groups (Pacific people, Asians), new immigrants). People could be included as permanent members or seconded to the group.  Include or second research expertise in the group to support the development of a monitoring framework and CCMG technical decision making. |

DPOs nominate members holding various positions to represent their organisation in the CCMG. The memorandum of understanding states:

*Each organisation’s Board will appoint a disabled representative to participate in meetings and planning on its behalf. It may also arrange to appoint a replacement representative to attend when the appointed representative is unavailable.*

DPO representatives are asked to put aside their personal views and represent their organisations in discussions of difficult decisions about a challenging project. This challenge is not unique to the CCMG. The former Chair of the UNCRPD Committee described similar challenges in the UNCRPD Committee itself. Members had to be reminded to leave aside descriptions of their own lived experiences of disability or issues related to their own disabilities to focus on the agenda of the group.

In governing the monitoring, group members need to collectively have:

* Lived experience of disability: The UNCRPD requires the CCMG’s component of the IMM to be led by disabled people.
* Governance skills and experience: Effective functioning of the monitoring requires skilled governance.
* Monitoring and research expertise: Members make sometimes technical decisions in guiding the monitoring. Technical expertise is essential in developing a monitoring framework. Decisions should be informed by the input of appropriate monitoring and research expertise.

*The big thing is they should have the ability to put into the research. That’s a mechanism to ensure the right people are recruited and the research is done appropriately. (DPO)*

The DPOs have been limited in the amount of resource they can invest in the development of their representatives’ governance skills. Stakeholders frequently commented that DPOs were under-resourced and in high demand from various advisory and steering groups across government and the disability sector. Members with governance experience are likely to be over committed or working at capacity.

The DPOs may not currently have monitoring, research and governance expertise available or spare capacity for those with this experience. Expertise in these areas could be provided by project team members or an external expert. If this option is adopted, a core principle of their engagement should be creating as many opportunities as possible to build the capability of the DPO members over time.

**International context regarding monitoring governance funding**

International approaches in establishing independent monitoring mechanisms vary in their alignment to the Paris Principles of independence and civil society participation.

**Australia:** has designated the Australian Human Rights Commission, an independent statutory body, as the organisation responsible for monitoring how Australia is doing in meeting its obligations under the UNCRPD and what improvements can be made. The Australian Government has funded the establishment of the Australian Cross Disability Alliance which includes broad representation of the disability community. One stakeholder interviewed however considered the organisation of the DPOs in New Zealand to be strong by comparison.

**Austria:** Has an independent Monitoring Committee responsible for the implementation of the UNCRPD. Members of the IMC are appointed by the Minister for Social Affairs. Under the Act, all members of the Committee are independent and not bound by any directives or orders. Members include representatives of DPOs, a human rights NGO, international development NGO and an academic.

There is also a Disability Ombudsman who is independent and not bound by government instructions. However, the UN Committee for Country Review noted:

*“The monitoring committee does not have its own budget and appears to lack the independence required by the principles relating to the status and functioning of national institutions for protection and promotion of human rights (the Paris Principles).”*

**The United Kingdom:** has designated three National Human Rights Institutions to monitor implementation of the UNCRPD. These are the Equality and Human Rights Commission, the Scottish Human Rights Commission, and the Northern Ireland Human Rights Commission. The rules governing the composition, mandate and working methods follow the Paris Principles of independence and civil participation. The NHRI bodies ensure participation through legislation such as the Equality Act 2006 (UK). This Act establishes the Disability Committee which is a statutory decision-making committee, of which at least half of the members must be disabled people and the chair must be (or have been) a disabled person.

**Canada:** The Continuing Committee of Officials on Human Rights has the responsibility for the monitoring of the CRPD. The Canadian government determined that it could meet the monitoring functions in respect of the Convention through existing mechanisms. The Canadian Human Right Commission disagreed with this position in its 2016 report. However, a Parallel Report produced by the Coalition of Canadian Disabled Persons Organisation noted Canada had not designated an independent mechanism to promote, protect and monitor the implementation of the Convention. While the Canadian HRD has the legislative basis to act as the monitoring body it lacks the resources to do so, and is also limited by a narrowly focused federal mandate.

### Effective governance represents the diversity of the disability community

One product of the DPO Coalition was the establishment of formal criteria organisations are required to meet to qualify as DPOs. It is expected that CCMG member organisations will meet the DPO criteria although some currently do not.

All the DPOs who meet the DPO Coalition’s criteria for holding DPO status are represented in the CCMG. The memorandum of understanding includes a statement allowing other DPOs to be added to the group. The only barrier to entry identified by the CCMG is organisations meeting the DPO requirements.

*Additional eligible DPOs may be invited to become a member of this Convention Coalition.*

Stakeholders reported some perspectives are underrepresented in the CCMG members.

*I’m sure other DPOs have said there is voices missing. It wasn’t meant to be an exclusive club. It shouldn’t always be these particular groups. One of the key components in looking at who should be on it, similar to the DPOs, is they need to have a national perspective. (DPO)*

Suggestions for strengthening the representativeness of the group included:

* Maintaining a focus on Māori perspectives, identified as a priority

*The UN reports coming back focus a lot on Māori disabled and we keep pushing it but I believe there needs to be more targeted research around it. (DPO)*

* Other ethnic groups – the perspectives of Pacific peoples, Asian peoples and new immigrants to New Zealand

*I would suggest that from our discussions organisationally that we’re probably not getting into the depth of some of the communities, our Māori and Pacific communities, not getting to those people. (stakeholder)*

* Family/whānau perspective – parents or other family/whānau of people with disabilities who were unable to participate themselves

*A monitoring committee, particularly when we’re dealing with issues of disabled children, should include parents. It would also make sense to have on someone who could show necessary expertise in research. (Former UNCRPD chair)*

* Youth – young people with disabilities are an important group, as recognised by the focus on youth in one of the CCMG reports

*Someone should be on the monitoring thing talking about us. They are a small but very vulnerable population. I just felt the views of our young people hadn’t been taken on board. (stakeholder)*

* Older people – older people represent a large portion of the population who identify as disabled but who may not be connected to DPOs particularly where disabilities were acquired later in life.

CCMG members pointed out organisations could not be invited to join the group where they did not yet exist.

*The DPOs can’t be held responsible for the DPOs that can’t exist. It’s responsibility of DPOs to form other DPOs. But when it comes to monitoring there is perhaps an obligation to make sure more perspectives are at the table to govern the monitoring process. (stakeholder)*

There are opportunities to include these other perspectives in the monitoring by seconding individuals, and/or including consultation and data collection in the method even if there is not a DPO able to represent them at the governance level.

**International context of representing the diversity of the disabled community**

Countries reviewed as part of this study have a mandate to include people with lived experience at the governance table for monitoring implementation of the UNCRPD. Australia, Austria, the United Kingdom and New Zealand have applied this principle in practice. There are different approaches. Some countries include people with disabilities in their capacities as employees or representatives of agencies, while others include DPOs, who are also often represented by people with disabilities.

Australia and New Zealand have also included representation from the indigenous communities. However, there are opportunities for improving engagement with indigenous people with disabilities and current models could be seen as tokenistic or placatory in practice, with indigenous models for addressing issues related to their disabled communities applied sporadically.

This is in part due to historical policy and practices, but may also result from capability of the representative to engage effectively at the governance table. This capability is not limited to indigenous people but is the case often when the need to fill the mandate at the table for a person with particular life experience overrides the need to ensure that all people at the governance table have the right skills, knowledge and experience to operate at a governance level. Where this is missing, there is often little or no funding/ resources available to provide appropriate training to address the capability gap.

A particular gap that was seen across all countries and governing bodies was effective and appropriate representation from the mental health and learning disability communities. New Zealand’s CCMG includes representation from DPOs focused on mental health and learning disabilities which is a strength of the monitoring.

### Effective governance is efficient

Part of effective governance is ensuring all issues are dealt with efficiently within the limited time available for CCMG meetings. The following factors contribute to using governance time efficiently and effectively:

* Effective chairing
* Clear expectations of members in preparing for meetings and participating in meetings
* Adequate funding for members’ participation
* Adequate secretariat support for members.

**The role of the chair**

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| --- | --- |
| Strengths | The chair is committed to the group, well regarded and has a long history with the CCMG. |
| Opportunities for development | Support the chair’s role in focusing the group on matters within scope by developing clear terms of reference. |

The role of the chair is to keep the group focused on the scope of the group and to hold members accountable to the standards agreed in the terms of reference.

*A lot depends on the nous of the chair who… You need to spend a lot of time talking through these issues. The chair should do deep listening and say what do we really want to tell the government. (former UNCRPD chair)*

*Effectiveness of a monitoring committee will depend on the standing of its chair and how well it dialogues with members of the committee. Everyone has their own barrows to push. (former UNCRPD chair)*

The role has been particularly challenging to date because there are no clear terms of reference. Stakeholder and CCMG members spoke highly of the current chair’s commitment to the monitoring.

The chair also has had an important role contributing to the IMM through participation in meetings and other communications. Communication through participation has most often been provided through the chair, who has also chaired some IMM meetings. Some other CCMG members have also participated, but to a much lesser degree.

*The CCMG Chair has played a very active part of the IMM. She has been to every meeting since she started. She critically read documents. Comes to the internal working group as well. Comes to all meetings and played a part. (Stakeholder)*

**Clear expectations of members**

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| --- | --- |
| Strengths | Members have a commitment to and passion for disability issues and lived experience of disability.  Agendas and meeting minutes are prepared and circulated with material for review in advance of the meetings. The extent to which members can invest time and resource in preparing for meetings varies. |
| Opportunities for development | Setting clear expectations about preparation for meetings and holding members accountable has the potential to increase meeting productivity.  Resourcing members for meeting preparation time is likely to assist. |

Materials are circulated with meeting agendas at least two weeks in advance to allow members time to review them and prepare to discuss them. However, there is variation in the time members invest in preparation. When members have not prepared, meeting time is used for summarising material instead of consensus building and decision making, hindering the group’s effectiveness and efficiency.

Once at meetings, members are expected to represent their DPOs’ perspectives, as distinct from their personal perspectives. The group benefits from the depth of knowledge and experience of the members, but discussions must be strictly limited to the group’s scope. The chair has a role in enforcing these limitations but the members should self-manage as much as possible.

*People with disabilities will think about their own disability. You need a balance – people with lived experience of disability, parents, experts. A lot in the disability community say there is no substitute for lived experience. (former UNCRPD chair)*

Adequate funding

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| Strengths | CCMG members are paid meeting fees and travel costs are covered.  The monitoring budget includes travel costs for meetings. |
| Opportunities for development | Fund preparation time and consider whether compensation is adequate, as the preparation time required may vary between members.  Manage the individual members’ travel requirements effectively through the fundholder. |

Stakeholders provided consistent feedback that the DPOs are under resourced to meet the demand placed on their members, particularly those in leadership roles. There is a growing recognition of the need for input from disabled people in steering and advisory groups across government to contribute towards co-design of services and research and evaluation.

Members must sometimes prioritise in choosing which meetings to attend. For example, some members of the CCMG who would like to actively participate in IMM meetings are not always able to attend due to other demands for their time.

While meeting costs have been covered, limited funding has been allocated to the development of expertise. It is important that any changes in the allocation of resources contributes to building the capacity of the DPOs and their CCMG representatives.

One stakeholder commented on the challenges in asking some DPO representatives to participate as equals in meetings with senior public servants without sufficient investment in training and development.

### Effective governance is accountable and transparent

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| Strengths | Some members routinely report on the CCMG to their DPOs, who consider they are well informed.  Direct communication to wider stakeholder groups through participation in meetings provides responsive communication about the monitoring. |
| Opportunities for development | Set clear expectations for members’ responsibilities around consulting and reporting back to their organisations to ensure DPO leaderships and memberships are engaged with the monitoring.  Agree processes for direct communication to wider stakeholder groups to ensure transparency and reflection of consensus views. |

CCMG members participate in the governance group as representatives of their organisations, not as individuals. The memorandum of understanding states:

*Members … will be well connected with their communities.*

This requires CCMG members to:

* Report back to their organisations from CCMG meetings to their memberships
* Consult with their DPOs to ensure their CCMG contributions effectively represent their membership.

There is variation in how well members communicate with their organisations in both reporting back and seeking input. Where communication is minimal, there is a risk that members no longer represent the views of their DPOs and DPOs become disengaged with the monitoring they are tasked with governing.

Communication through participation relies on the chair representing the views of the CCMG member organisations and the monitoring findings. This information has been received by the IMM on the understanding that it represents the views of all CCMG members and the monitoring. IMM members have noted however that some issues raised by CCMG organisations in separate meetings have not been represented in IMM meetings.

*One thing that strikes me as odd is that the DPOs we have experience dealing with and working with and who have worked on the strategy and action plan, there seems to be a disconnect between them and the rest of the IMM. (government stakeholder)*

Establishing a transparent process for informing the IMM outside formal reports would strengthen the CCMG’s ability to best represent the monitoring findings. It would also increase the confidence of the IMM and wider disability sector that the information provided represents the findings of the monitoring rather than the personal views of the members involved. The process could include:

* Involving the research team in responding to requests
* Feeding back to CCMG members on the information provided in IMM meetings. CCMG members must be responsible for subsequent reporting back to their organisations).

These communication requirements could be strengthened by formalising them in the governance group’s terms of reference.

## Operational management of the monitoring project

This is the 'operational management of the monitoring' section of the report on the review of disabled people led monitoring, completed in 2017-18.

### Fundholding

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| Strengths | ODI took over the role of fundholder and provides administrative support, for the CCMG. |
| Opportunities for development | Independence of the fundholder from government is viewed by stakeholders as part of the independence of the monitoring as a whole.  There are options available to move the fundholder role to another organisation with the required capacity (a new entity, an NGO or another type of organisation). The organisation must have adequate infrastructure to manage the financial aspects of project management. |

The monitoring fundholder manages the finances, including paying the people involved in the monitoring, managing payments for expenses, tracking expenditure and meeting reporting requirements to government and the CCMG.

Fundholding is a project management function, not a governance function. While the fundholder reports to the governance group, most decisions do not need the approval of the governance group once a monitoring plan is agreed.

As the party responsible for paying monitoring employees and expenses, the fundholder must have the expertise and capacity to:

* **Demonstrate the monitoring’s independence:** The fundholder role has the potential to influence the monitoring.
* **Track finances:** The fundholder should track and report on the budget to the CCMG to provide assurance monitoring funds are used efficiently and transparently. The fundholder also reports to ODI to fulfil contractual requirements.
* **Be accountable to governance:** The fundholder must account to the CCMG, including providing accurate reports and responding to requests for information about expenditure.
* **Manage contractual relationships with the project team:** The monitoring employed/contracted many people as monitors (more than 50 since 2010). The fundholder must meet their obligations as an employer, including supporting monitors in responding to Work and Income and Inland Revenue requests.
* **Provide means for employees to pay expenses:** The monitoring involved a large number of expenses (for example for taxis and flights). At times expenses were paid on employee’s own credit cards and not reimbursed for some time. The fundholder should quickly process and pay invoices or provide employees with the ability to pay expenses directly from monitoring funds.

The Disabled Person’s Assembly (DPA), one of the CCMG member DPOs, was established as the monitoring fundholder under a contract with ODI. This role is also recorded in the CCMG memorandum of understanding.

*The Convention Coalition appoints DPA (NZ) Inc as the administrative fundholder on its behalf. Expenditure of funds will be consistent with the agreed budget and the [CCMG]’s oversight. Provision of reports by the fundholder will be as directed by the CCMG.*

In 2015 ODI reluctantly took on the fundholder functions of providing administrative support for the monitoring from DPA. ODI’s role includes contracting the monitors and monitoring team members and managing their invoices and payments.

Having a government agency providing the fundholder functions creates a potential risk of perceived undue influence on the monitoring. Under the Paris Principles, referred to in Article 33(2) of the Convention, the monitoring should have:

*Adequate funding and not be subject to financial control that might affect independence.*

There is no suggestion that this risk has been realised in New Zealand. ODI took on the fundholder functions as a necessity. New Zealand ensures independence through Cabinet directive, and provision of transparent and accountable funding for the CCMG. However, most stakeholders would feel more comfortable if the role sat outside government. Stakeholders suggested a range of options for reassigning the fundholder role (all have implications for governance structures as well):

* **An entity created for the monitoring:** As noted above, the DPO Coalition could govern a legal entity which in turn could be the monitoring fundholder. The greatest risk is that of capacity, though this could be mitigated through including the fundholder responsibilities in the role of one of the employees.

*We had talked about at some stage setting up an umbrella entity that would be very clear. The Chairs/CEOs could govern it. (stakeholder)*

* **One of the DPOs:** Some of the DPOs have the capacity to meet the demands of the fundholder role. However, selecting a single DPO creates risk to the unity of the CCMG and creates another resource demand.
* **Another NGO (disability service provider or other):** Some service providers in the disability sector manage high value contracts with government and have the infrastructure to fulfil the fundholder role. However, there is a clear distinction between DPOs and service providers in New Zealand. Including service providers in such an important role in the monitoring may conflict with the principle of ‘by disabled people, for disabled people’.
* **Another organisation:** There are many other organisations who undertake contract work for government on a regular basis (from universities to private finance, accounting, policy or research companies), are independent from government and have the necessary capability. They could hold the contract but be governed by the CCMG.

### Project management team, administration and logistics

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| Strengths | The outgoing national coordinator and project leader have documented the different components of their role, carrying institutional knowledge forward.  The current project manager has established some of the needed processes. |
| Opportunities for development | Empower the monitoring team to make all operational decisions and report them to the CCMG.  Continue to build on the project management foundation that has been established and increase the focus of the CCMG on governance issues, drawing on the expertise of the project team. |

There are aspects of the monitoring that need to be actively managed to ensure the monitoring functions effectively and efficiently. As noted in section 4.1, these operational activities fall outside the scope of the governance group and should be managed by the monitoring team. They have been well documented by the current monitoring team which should enable planning to improve their management in the future. They include:

* Paying for and approving expenses
* Arranging travel for governance group meetings, monitors, etc
* Arranging bookings for training sessions
* Recruiting monitors
* Ethics applications
* Managing electronic and physical data.

The monitoring team should report activity in these areas to the governance group. Reports should be reviewed outside meetings. They should not use meeting time, unless a problem for the monitoring arises.

The project leader role was very important in managing the monitoring.

*[Project lead] did a lot of great work. There was clarity when she was there and she was independently selected by the Coalition. She was able to get a really good handle on it. Project plan, budget, monitoring how that’s going. The last two years worked better (DPO)*

The broad role included:

* Managing the relationships within the monitoring team and between the monitoring team and the CCMG
* Tracking progress through regular reports from the researcher and project coordinator
* Being the focal point for communication
* Presenting issues requiring CCMG decisions to the group
* Coordinating CCMG meetings
* Working on monitoring reporting.

CCMG members and other stakeholders spoke very highly of the project leader and the improvement after the project leader was in place.

Once in place the national coordinator managed the data collection, including scheduling interviews and reporting on progress. The role involved managing issues with logistics (for example, managing expenses and coordinating multiple people and their travel arrangements for interviews).

The project leader was the main representative of the monitoring team in CCMG meetings. The national coordinator did not communicate with the CCMG directly but through the project leader. At times, there were long waits for decisions from the CCMG on operational matters which could have been resolved by the monitoring team.

The monitoring could be strengthened by ensuring the project management team are empowered to make operational decisions.

## Approach to monitoring data collection and reporting

This is the 'approach to monitoring data collection and reporting section of the report' section from the report on the review of disabled people led monitoring, completed in 2017-18.

* Monitoring definition, objectives and scope (addressed in section 4)
* Developing a monitoring framework
* Stakeholder involvement and communication
* Collecting, analysing and reporting data
* Using monitoring data for management action and decision making.

The monitoring adheres to the DRPI method for UNCRPD monitoring, though only one of the three elements of the DRPI framework was implemented after the first year of monitoring (monitoring individual experiences through interviews with disabled people). The other elements (studying legislative frameworks and media analysis) are not included in the CCMG approach.

### Developing a monitoring framework

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| Strengths | The UNCRPD and the DRPI method provide sources of guidance for the structure of the monitoring framework.  There is support from stakeholders to develop a monitoring framework. |
| Opportunities for development | There is room to further modify the DRPI method to increase the value of the monitoring. These modifications should be adopted or rejected by the monitoring governance who could draw on expert input to support their decision making.  A first step is to develop a monitoring framework through a process involving expert advice and consultation with stakeholders to focus and strengthen the monitoring with the support of the disability sector. |

New Zealand has implemented a monitoring framework under Article 33. The 2010 Cabinet Paper which established the CCMG referred to a monitoring framework for the CCMG’s monitoring. The UNCRPD provides some structure for the monitoring and its reporting, as does the DRPI method.

There is an opportunity to strengthen the monitoring by developing a formal framework to guide the disabled people led component of the monitoring. The framework should include:

* **Questions the monitoring will address:** The questions the monitoring will seek to ask to monitor New Zealand’s progress against each of the rights included in the Convention
* **Priorities:** Establishes priority areas for monitoring to focus data collection and reporting which change over time. This does not equate to establishing a hierarchy of outcomes but acknowledges the breadth of the Convention.
* **Indicators and measures:** Describing what success and failure may look like for each monitoring question. Drawing on the indicators used for other pieces of work may be a useful starting point (such as the Outcomes Framework for the Disability Strategy). Some indicators and measures may be aspirational.
* **Data sources:** Which data sources will inform reporting on each of the questions and how the data will be collected.

A formal monitoring framework would provide a structure for further adapting the DRPI data collection approach to New Zealand’s needs, prioritising topics, communicating the monitoring approach to stakeholders and determining report topics.

*Setting the monitoring agenda should be done in a genuinely targeted way that should clearly involve the DPOs around priorities for measurement. Once that agenda is agreed, the DPOs should stand back and wait for the results. (stakeholder)*

Developing a monitoring framework requires specialist skills. Government agencies invest significant resources in developing and maintaining monitoring frameworks for their work. The governance group, drawing on monitoring and research expertise, would lead the development of the monitoring framework.

The development process should involve broad and systematic consultation with stakeholders within the disability sector (including disabled people) and within government. There is an opportunity to align the work of the full IMM and the CCMG through the development of a shared framework. Developing a framework was part of the IMM agenda but the task has not yet been resourced.

**International context for national alignment of UNCRPD monitoring**

**New Zealand:** The New Zealand Disability Strategy 2016 - 2026 (the Strategy) was developed by the Office for Disability Issues in consultation with other government agencies and the disability sector. More than 1,130 people attended workshops and there were approximately 770 submissions from individuals and organisations submitted online. The DPOs played an important role in its development. The Strategy will guide the work of government agencies on disability issues from 2016 to 2026.

The Strategy is supported by an Outcomes Framework and a Disability Action Plan. The Outcomes Framework will outline how progress against the Strategy will be monitored.

It is currently being developed (2017). The Outcomes Framework will specify targets and indicators, where the information will come from, how often it will be collected, who is responsible for collecting it, and where proxies are needed and how information gaps will be addressed.

The Disability Action Plan will be the primary vehicle for implementation of the Strategy. The Disability Action Plan presents priorities for action that advance implementation of the Strategy and the UNCRPD. These priorities emphasise actions requiring government agencies to work together, as well as with disability sector organisations and others. . These plans also include success indicators and refer to use of an evidence base for measuring progress.

The Strategy, Disability Action Plan, Outcomes Framework and UNCRPD monitoring frameworks provide structure and accountability for work to improve the wellbeing of disabled people in New Zealand. Together, they put New Zealand in a strong position, along with Australia, in comparison to the other countries reviewed during this study.

**Australia:** Each focus area in the National Disabilities Strategy (2010-2020) aligns with priority areas under the UNCRPD and contains clear outcomes. The Australian National Disability Strategy includes trend data indicators against each of the focus areas. These are reported against every two years.

**Austria:** The Council of Europe Disability Strategy sets out a number of cross-cutting themes that align to the UNCRPD, and sets priority areas for Europe as a region. The intention is that the Council of Europe Disability Strategy Committee will work with government representatives to form implementation plans relevant to each nation. This is currently a work in progress.

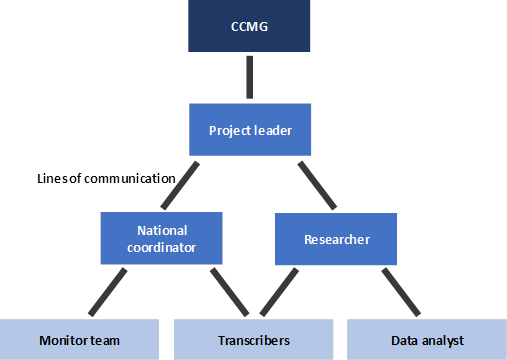
**The United Kingdom:** There is a lack of clear indicators, measures and monitoring framework to guide the monitoring of implementation of the UNCRPD across the UK. Monitoring appears to be disparate and lacks a comprehensive framework and plan for ensuring the desired outcomes are being met, as intended by the UNCRPD. There are some robust reports available on specific topic areas, but these do not seem to link to a coordinated and planned monitoring approach.

**Canada:** A number of Canadian disability bodies (national and state-based) have developed strategies but there is no over-arching federal strategy that provides national direction for addressing disability matters. The Canadian Human Rights Commission and the Canadian Civil Society Parallel Report Group provide progress reports against the requirements of the UNCRPD and its articles. The Group is the closest parallel to the CCMG in New Zealand. It was a temporary coalition of sixteen DPOs with government funding.

### The monitoring team

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| Strengths | The monitoring trained more than 50 monitors in the rights of people with disabilities and how to conduct interviews.  The monitoring team have learned and recorded lessons learned in carrying out the monitoring and all showed dedication and commitment to the monitoring’s success. |
| Opportunities | Build on the learnings to date in structuring the monitoring team, employing people with the right skills and giving them the mandate to fulfil their roles efficiently, including separating out operational and governance decisions. |

Diagram description - The monitoring team described in the diagram below includes tier 1: the CCMG core monitoring team, tier 2: a project leader, tier 3: a national coordinator and a researcher) and tier 4: monitors, transcribers and a data analyst (Figure 3). The diagram represents the lines of communication flowing between the various tiers and roles in a hierarchical fashion.



**Figure 3. Monitoring team. Lines represent lines of communication.**

**Project leader:** The project leader played a role in data collection and reporting though her focus was on project management and communication.

**National coordinator:** The national coordinator prepared the monitor material including interview guides, policies and procedures, tracking documents, communications, etc). The national coordinator managed the work of the monitors, including arranging interviews and seeking initial consent for participation. Initially these functions were managed by multiple local coordinators but the role was combined into one national coordinator, which benefited the monitoring by condensing institutional knowledge and simplifying communication.

The role extended longer than planned and was challenged by difficulties obtaining contacts from the DPOs to begin the snowball approach used to sample people to interview.

Researcher: The researcher led data analysis and reporting, bringing expertise in analysis of qualitative data and commitment to the purpose of the monitoring. The researcher managed the analysis of transcribed interview notes and analysed them in NVIVO to inform reporting. The researcher was not included in CCMG meetings and had limited control over decision making and oversight. The researcher noted in the end of study ethics review (unpublished):

*Future research may wish to address the role of the researcher regarding research responsibility, the training of contractors who are in roles of responsibility regarding research practices, the targeting of disabled people with a research background for key roles, and a review of operational and governance factors that may have impacted on adverse events.*

The researcher was supported through two of the last three years by a data analyst who coded the transcribed interview data. The researcher drafted reports for input from the project lead.

*What I did was come up with drafts. Impossible not to write a draft when you’re writing up the analysis. Then the project lead restructured it but the analysis remained the same. (researcher)*

The efficiency of all roles was limited by issues including:

* Lack of continuity and handover following changes in the monitoring team roles
* Sometimes long delays waiting for decisions on operational or methodological issues from the CCMG
* Research decisions made by the CCMG with limited input from the researcher
* Long delays in receiving samples of interview participants from the CCMG
* Slow payments of invoices both for time and expenses, resulting in some monitors accumulating debt to Work and Income and Inland Revenue due to having difficulty in reporting their income
* Long gaps between monitor training and beginning interviews due to delays in identifying interview participants
* Unavailability of essential interview equipment (for example, recorders) due to delays in purchasing additional equipment
* Challenges with scheduling interview travel times.

The monitoring could be strengthened by addressing these difficulties through separating governance and operational functions, as discussed in section 4. However, some challenges such as the monitoring’s variable demand for time and materials will remain and will need to be managed on an ongoing basis. Development of a monitoring framework is likely to help plan and manage time and resource requirements.

**Monitors:** The monitors interviewed disabled people. They were trained in the DRPI method. There is growing evidence in the literature about the advantages of peer interviewers in establishing rapport and collecting robust information from disabled people.

The monitors generally worked relatively small number of hours sometimes spread over long periods of time. Some monitors were given additional responsibilities in managing interview scheduling and logistics as local coordinators.

Monitors spoke very highly of the training provided by the monitoring team and of benefiting from increased understanding of the UNCRPD and disability rights.

*I enjoyed the workshopping type part, talking about the questions and how you would open up the person you were interviewing, how to ask open-ended questions. That was really awesome. You don’t really get that kind of training anywhere else. Everyone was able to be involved in that. It was a very participatory type process. We were very excited and looking forward to the work. (monitor)*

Building the understanding of human rights in the disability community through training monitors was seen by many stakeholders as a valuable secondary benefit of the monitoring.

*I’d really like to be involved again. The biggest benefit I had, especially for people who are blind and deaf. I know my disability, but their disability, wow, I didn’t even think of that! (monitor)*

Completing interviews was often very rewarding work and monitors spoke of their commitment to the work.

*The one on one stuff was amazing. The training was excellent. The support throughout for us in Auckland, you always worked in pairs. The project head who gathered reports from us was great. The DRPI stuff was great. (monitor)*

However, the sparse and unreliable hours along with the paperwork necessary in managing contracting work and reporting income created challenges for some monitors.

Some monitors invested considerable time in reporting their availability and on logistics to conduct interviews. The monitoring aspires to give as wide a group as possible the opportunity to participate as monitors. However, the cost involved in some arrangements can be substantial. More restrictive requirements in selection of monitors would streamline the process and reduce the overhead costs of transport and support time required. The advantages and disadvantages of such an option would need to be considered by the CCMG.

### The data collection approach

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| **Strengths** | The monitoring completed interviews with 176 disabled people in the last three years, hearing their perspectives and communicating them to government, the disability sector and the UNCRPD Committee. |
| **Opportunities** | Further adapt the DRPI method to include more perspectives from within the disabled community.  Development of a monitoring framework (discussed in section 6.2) will guide the development of appropriate sampling approaches, data collection tools and reporting priorities.  Opportunities include incorporating stakeholder consultation, participation of support people, use of surveys, family/whānau and other group meetings and other sampling approaches. |

#### Data collection method

The core components of the DRPI approach used for data collection were:

* Qualitative interviews with people with disabilities using open-ended and semi-structured interview questions focused on negative experiences identified by the participant
* Conducting interviews using monitors who are themselves people with disabilities
* Founded on the human rights principles (dignity, autonomy, participation, inclusion and accessibility, non-discrimination and equality, respect for difference).

The monitoring completed 176 interviews under the most recent three-year contract. While this did not reach the target of 300 interviews (100 per year) it still gave many disabled people a chance to have their views heard and communicated. Interviews were conducted by two monitors, or one monitor and the national coordinator (with few exceptions) using the DRPI interview guide.

*Right now, I think the reports are going to give the wider perspective of the disability community than the feedback from one or two individuals at the meetings. That’s the benefit of the interview process to gather the information. (Stakeholder)*

The DRPI approach should be considered to provide a starting point for adaptation to the New Zealand context and priorities. There is room to further modify the DRPI method to increase the value of the monitoring.

*DRPI is a system in place. Where the monitoring mechanism could do better is more community focus groups. Not everyone wants to be interviewed for a couple of hours but they could learn a lot about what people say through group meetings. I might think education is accessible till I go to a meeting and learn that other people have had it better or that I could have expressed my needs better. (stakeholder)*

Opportunities include:

* Revisit data collection tools to increase their focus on issues important to New Zealand, for example cultural wellbeing. Changes should be based on a monitoring framework supported by monitoring stakeholders.
* Include other methods of data collection, for example written or online questionnaires, family/whānau focus groups or other group meetings. New Zealand’s disabled community includes great diversity in both disability and culture. There is no one-size-fits-all data collection approach. Including different methods increases likelihood that people will be able to participate in a way that suits them.

*I think it’s easy to send things out online – but sometimes you shouldn’t underestimate the power and peer support and almost educational opportunity of getting people together. (stakeholder)*

*Transcribed interview recordings resulted in thousands of pages of interview transcripts, which were coded in NVIVO using the DRPI coding scheme.*

#### Sampling approach

The DRPI method uses a snowball method to identify and engage interview participants. The monitoring team sought an initial list of interview participants from the DPOs through the CCMG representatives. Monitors would then grow the sample by asking participants at the end of their interviews to suggest names of two friends who might be interested in being interviewed.

The sampling method posed challenges for the monitoring because there were sometimes long delays in receiving contact details for interview participants to start the snowball rolling from the DPOs. Interview participants were sometimes unwilling to suggest other people to be interviewed.

*One other issue – in finishing the interview we were required to ask whether the person knew two other people. As monitors, we would then give those names to the coordinator. Often they did not put two names forward. (monitor)*

There was little support for the effectiveness of the snowballing approach amongst the monitoring team, stakeholders or monitors.

Development of a monitoring framework and agreement about measures would provide more clarity on who should be interviewed and why. Options include drawing a sample from government administrative data, using social media and local publications to call for participants and utilising the monitors’ networks. Some people, especially those least able to participate, may need to be reached through personal connections. This is particularly important for people disengaged from DPOs, or who are hard to reach for other reasons. Stakeholders identified these challenges as impacting Māori and Pacific participation in the monitoring.

*I think there are the usual suspects. The disabled people who are always invited to contribute and have a voice who are well known. That’s great. But the area we find much harder to connect to is the people who don’t have a voice. People living in residential facilities, that sort of thing. There’s a large section who aren’t being asked to contribute. Who aren’t finding ways to contribute. I think that’s a real issue. I don’t know how to connect those people in to the community. Would love to be able to do that. Those are the people who most at risk, who aren’t connected through other people. (stakeholder)*

Using additional methods to sample interview participants could increase the efficiency of data collection while reducing the monitoring team’s reliance on contact details from DPO members.

*The people we got, … it felt like we could have got so much more stronger and harder information if we just changed the process a little. When I first started we all have huge networks and we couldn’t use any of them. It was frustrating. (monitor)*

*The other thing was especially the European side of the people we interviewed, they had homes, they were selling homes and buying others. You don’t get Māori in those situations. We missed that type of questioning. We missed out on a lot. Up here it’s word of mouth that gets you in the door. (monitor)*

#### Challenges in data collection materials and logistics

Data collection was a challenging process, primarily managed by the national coordinator. Challenges encountered are summarised below.

|  |  |
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| **Challenge** | **Details and potential mitigations** |
| **Monitor support** | |
| Monitor requirements for individualised materials | Monitors need high quality tools and materials to carry out their jobs effectively. Monitors had requirements for the format of paper material (paper colour, font size, etc) to enable them to manage.  Adequate resourcing is required for the time required to individualise materials to meet the needs of individual monitors. |
| Not enough and difficult to use recorders | Unfortunately, monitors encountered challenges with digital recorders. They were a source of frustration for the monitors. They proved difficult to use and some interview recordings were lost. Requests for purchasing new recorders went unapproved for an extended period during the transition in fundholders.  *"We only had two dictaphones between four monitors. There was a time when two of us turned up to an interview and there was no dictaphone."* (monitor) |
| Inconsistent monitor and interview participant availability | Monitors were asked to make themselves available over an extended period of time following their training due to challenges identifying and recruiting interview participants. Adopting new approaches to sampling could address this issue by condensing interview scheduling into a shorter period of time.  *"This is where the problem is. It took a year before anything began. We weren’t very happy about it. We were told it was coming but it didn’t come. A lot of us lost the motivation. We lost a few people who wanted to do the work. We ended up with four of us who did the work for three months. We weren’t happy with it. We were expecting we would get lots of interviews. We didn’t."* (Monitor) |
| Professional supervision and de-briefing for monitors | Some interviews involved hearing very difficult stories, including some of abuse. Supervision was available through the national site coordinator but some monitors may have benefited from the availability of external supervision to debrief and manage the effects of difficult interviews. |
| Delays in payment | Some monitors reported long waits for payment for their work.  *"Being involved in that level was great. The payment didn’t work out very well. Many people had to wait months and months for payment. Didn’t matter too much to me but there were people there not in employment… If that’s to continue, that group training followed by one on one interviews, there needs to be a really robust financial system."* (monitor) |
| **Logistics** | |
| Complex transport arrangements | Transport was a substantial cost for the monitoring. Interviews sometimes involved taxis for multiple people (two monitors, support people, interview participants, their support people, etc) over long distances.  "Three of us didn’t have car licences and couldn’t drive. So the logistics of getting paperwork and so on was horrendous. There was a massive amount of paper shuffling while the lead monitor had to manage turning over corners and stuff like that." (monitor)  Arranging the logistics of travel consumed much national coordinator time and allowance for this should be included in planning. The national coordinator reported:  "Approximately 10% of interviews took about 75% of the National Site Coordinator time due to the complexity in coordination." |
| Remote management | The national coordinator managed the interview process. The coordinator’s location in Wellington made coordination more difficult at times when local knowledge could have eased some of the logistical challenges. Some monitors were given extra responsibilities to use their local knowledge to facilitate the interview process. |
| Data transmission and storage | The monitoring team used various tools for data transmission and storage. Processes were reviewed and approved by the Health and Disability Ethics Committee but in some cases were not followed. Future work should explore the best options available for securely and reliably transferring recordings and other data between monitors and other monitoring team members to prevent data loss and ensure confidentiality. |
| **Ethics** | |
| Managing disclosures | Processes were in place to manage disclosures during interviews and were approved in the ethics process. However, monitors were not aware how their reports were followed up when they raised concerns.  *"It is difficult if their stories are harrowing. The injustices they felt, feeling that emotion, it’s strong and skilful work. What I do believe is that the way any disabled people was given the opportunity to engage was really good."* (monitor) |
| Ethical decisions around consent and support people | The interviews involved sometimes difficult decisions around the capability of participants to consent, or whether support people (family/whānau, friends or staff members) should be allowed to assist the interview process. Some scenarios were covered by the ethics application but others were negotiated on a case by case basis.  Experiences to date could inform the development of detailed processes (including case stories/scenarios) for managing these situations. Consent can be a difficult issue but it is important to err on the side of giving people the opportunity to participate given the purpose of the monitoring. |

Stakeholder involvement and communication

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| **Strengths** | Stakeholders support the purpose of the monitoring and are enthusiastic about learning more. |
| **Opportunities** | Stakeholder awareness of the monitoring and engagement with the process could be strengthened by including more opportunities for their participation throughout the monitoring. |

The monitoring aims to include all disabled people in New Zealand. The monitoring must therefore engage the diversity of the disability sector throughout the monitoring process. The term ‘diversity’ here is used to represent different genders, ages, types of disability, ethnic groups, means of communication and any characteristics seen across people who are considered part of the disability sector.

The importance of sharing the monitoring with the disability community is recognised in the founding memorandum of understanding

*The [CCMG] recognises the importance of sharing its work with the regional and global disability communities.*

There is strong support for the monitoring as a means to promoting disability rights in New Zealand and giving voice to the disabled community. These views were evident in discussions with stakeholders and with the monitors employed to conduct interviews with people with disabilities.

Stakeholders with low awareness of the current approach or who felt excluded from the process were more dissatisfied with the monitoring as a whole. This feeling of dissatisfaction contributed to desire for alternative reporting to the UNCRPD.

*Hopefully next time around there will be a quicker and more in-depth community consultation by whoever is managing the monitoring. (stakeholder)*

The monitoring method adopted limited the involvement of stakeholders. However, modifications to the approach, as suggested by this review, create opportunities to engage with stakeholders through:

* **Development of the monitoring framework:** Include consultation with disability sector stakeholders (including individuals, disability sector organisations, government agencies and IMM agencies) in developing the monitoring framework. Broad participation in the development of the framework will increase support for the monitoring, promote it in the early stages and strengthen the method. The DPOs play an important role in this process representing the views of their membership.
* **Data collection.** Include stakeholder consultation in the data collection phase. Collecting data from organisations beyond the DPO group will strengthen the monitoring by increasing understanding of the approach taken, including a wider range of perspectives and consequently increasing support for monitoring reporting. The data collected through stakeholder interviews could complement interview data and give more people and a wider range of people the chance to participate in the monitoring process.
* **Reporting:** It is difficult for stakeholders to engage with monitoring reports when they are delivered as finished products with no prior opportunity to review and comment. Stakeholders can be engaged through discussion of draft findings and the implications for different groups within the disabled community and identification of any factual issues or contextual information that might help in interpreting qualitative data.

### Using the monitoring data

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| **Strengths** | The reports represent substantial pieces of work and communicate unique data on the experiences of disabled people. |
| **Opportunities** | The reporting process could be refined by aligning it with a monitoring framework.  There are opportunities to increase stakeholder engagement in the reporting process. Involving government stakeholders may increase the influence of the monitoring and build capacity of the CCMG and monitoring team.  Making the reports easy to find and access online may increase their profile in the community. |

#### Formal reporting

The CCMG have published the following reports for the disabled people led monitoring:

* 2016 – The Education and Employment Report (completed but not yet released)
* 2016 – The Health Report (due to be completed by end of November 2016 but not yet published)
* 2015 – Acceptance in Society (standard and large print)
* 2015 – Participation and Poverty (standard and large print)
* 2014 – The story so far (not published online)
* 2013 – Youth monitoring report (available on the DPA website)
* 2013 – Media report (standard and large print)
* 2012 – Disability Rights in Aotearoa NZ (standard, large print and easy read)
* 2010 - Disability Rights in Aotearoa NZ (standard and easy read).

Stakeholders valued the reports as capturing the independent voice of some of New Zealand’s disability community. Some saw the reports as important resources to draw upon in planning and justifying work in their communities.

*For us, the positive thing is the [CCMG] … We have been able to say our reports have been significantly influenced by the voice of disabled people. Whether it can be better is a question but it’s there. (IMM stakeholder)*

Feedback also identified opportunities for strengthening the reports including:

* Demonstrating the soundness of the conclusions by providing a more thorough account of the sampling, data collection and analysis methods
* Bringing the voice of disabled people through more strongly
* Report the research findings in other forms so they are more likely to engage a wider audience

*I don’t know if they reach out wider. I’m in the know, I know where it is and how to find it. But even with the one on one monitoring, that’s when I realised there are people who aren’t in the loop and they are the ones that could use that information. (Stakeholder)*

* Focus on the issues that are either higher priority or more likely to influence change.

Report topics were set in advance and included in monitoring contracts. The former chair of the UNCRPD and New Zealand Country Rapporteur noted New Zealand produced a high number of different reports for the Committee in the last reporting round (2014) relative to its size. For example, the DPOs also produced the shadow report for the Committee in a process separate from the work of the CCMG. He suggested reducing the number of reports in the UNCRPD process could strengthen the influence of the UNCRPD in New Zealand.

*I would encourage disabled groups to put in one report next time. (former UNCRPD chair)*

In future, focusing more intensively on fewer issues, which can be selected in the development of the monitoring framework, may make the reports more useful tools for informing the IMM and influencing change. Increasing the engagement of the sector with the CCMG and the monitoring could contribute to more focussed reporting.

*I would say what are the main issues you would like the committee to think about. What are the things you want to highlight that you want the government to focus on. Selecting the issues to focus on is very difficult. Doesn’t mean you don’t mention other issues but the question is, how do you want to push the dialogue. The issues selected should balance importance and likelihood to change. (former UNCRPD chair)*

Some stakeholders commented the reports did not clearly target an audience.

*They tried to theme them but I’ve read every one of them and I’m not sure who they are for. Who the audience is. They could miss everybody. It’s a difficult one. The audience is wide. They should be reaching disabled people. But they also have an academic, monitoring and Government role. (Stakeholder)*

People who may be expected to use the reports include:

* The other IMM partners in producing the IMM reports
* Government stakeholders
* Disabled people
* The wider disability sector including disability service providers and organisations representing disabled people
* Media and the public.

Different audiences respond to different types of reports. For example, the public and media may engage better with summary level reporting while government stakeholders and the IMM may need more detail. Developing a reporting plan with different products for different audiences mapped to the four-yearly UNCRPD Committee cycle may increase the reach and profile of the monitoring.

Regardless of the format of the reporting, making them easy and intuitive to access online is an important part of making them available to the disability community.

### Working with government

Government agencies are an important part of the disability sector. The monitoring is led by disabled people for disabled people, but meaningful engagement with the entity being monitored, government, can influence change directly rather than through the UNCRPD Committee’s review of New Zealand. Building good relationships with stakeholders within government does not reduce the independence of the process.

Government stakeholders currently have little involvement and in some cases awareness of the monitoring. Government stakeholders reported they wanted to be able to discuss the findings of the reporting before being presented with the final reports. Engaging with government stakeholders throughout the monitoring process increases the likelihood that government will act on the findings of the monitoring. Government may also be able to provide useful information (for example statistics based on administrative data) to inform analysis and reporting.

Building a relationship of trust between the monitoring and government begins with consistent communication from both sides. Stakeholders noted the expertise needed for the CCMG to navigate government processes and represent the findings to high-level meetings.

*The experience of those who attend. There are some represented at the CE level who are comfortable in these situations, but others who don’t have that experience and knowledge of the machinery of government. (DPO)*

Working more closely with government stakeholders through the process could contribute to building the capacity of the CCMG members as well as government stakeholders’ understanding.

*Understanding the nature and the context of the people representing the DPOs, issues with communication or using sign language interpreters or whatever, chuck that into the mix of their individual communication issues. Chuck in that they’re meeting Government. If you don’t have the right people in place, it’s quite a challenge to ensure they’re heard. Completely understandable. (govt stakeholder)*

## Overview

International comparisons highlight the strengths of New Zealand’s approach to monitoring New Zealand’s progress against the UNCRPD. The monitoring led by the CCMG demonstrates New Zealand’s commitment to disabled people led monitoring of the UNCRPD.

In capturing the voice of disabled people directly, the monitoring has the potential to make an important contribution to the disability sector.

We found strong support for the monitoring throughout the disability sector, including from government stakeholders. Feedback focused on opportunities to strengthen the monitoring through:

* Revisiting and strengthening governance arrangements
* Further developing the structure of the monitoring through consultation and drawing on monitoring expertise to develop a monitoring framework to provide a foundation for the data collection, analysis and reporting
* Refining data collection methods to provide more opportunities for individuals and organisations of different types to participate
* Engaging with stakeholders throughout the monitoring
* Building on the good work done on reporting to engage a wider audience with the monitoring findings.

1. United Nations Convention on the Rights of Persons with Disabilities: Preamble. Accessed at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html> [↑](#endnote-ref-1)
2. United Nations Convention on the Rights of Persons with Disabilities: Article 1 – Purpose. Accessed at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html> [↑](#endnote-ref-2)