



**Coimisiún na hÉireann um Chearta
an Duine agus Comhionannas**

Irish Human Rights and Equality Commission

**Establishing a
Monitoring Framework
in Ireland for the United
Nations Convention on
the Rights of Persons
with Disabilities**

The Centre for Disability
Law and Policy
School of Law & Institute
for Lifecourse and Society
NUI Galway



NUI Galway

**CENTRE for DISABILITY
LAW & POLICY**



**Coimisiún na hÉireann um Chearta an Duine
agus Comhionannas
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Foreword

This year, 2016, marks a decade since the United Nations Convention on the Rights of Persons with Disabilities was adopted by the United Nations General Assembly in New York. The Convention marked a significant shift in the international community's approach to persons with a disability.

While it is a ground-breaking document, the Convention is, in its own way, remarkably simple. It does not draw up or confer any new human rights. What it does is mark out in clear, unambiguous terms that the rights of persons with disabilities are human rights. It makes plain that our body of international human rights norms applies equally to persons with disabilities. Ireland signed the Convention in March 2007, and has committed to its ratification in 2016, as outlined in the Department of Justice and Equality's recently-published *Roadmap to Ratification*.

The Convention adopts a modern, forward-looking model of disability, recognising persons with disabilities as primary stakeholders, active participants and equal partners in State action around disability. This principle is prominent in Article 33 of the Convention, which makes clear that the domestic oversight and independent monitoring of the Convention's implementation must involve the direct participation of persons with disabilities.

Given that Article 33 of the UN Convention on the Rights of Persons with Disabilities specifically requires the inclusion of a Paris Principles compliant institution in the State's monitoring framework, ratification of the treaty will create a significant and challenging

new area of work for the Irish Human Rights and Equality Commission. Not least of these challenges will be the obligation placed on us, as with all parties, to ensure the active participation of persons with disabilities within the newly established Article 33 framework.

The Irish Human Rights and Equality Commission is committed to working with the state and with civil society over the course of 2016 to ensure that the mechanisms put in place under Article 33 meet the standards set out by the Convention, elaborated upon since 2007 by the UN Committee on the Rights of Persons with Disabilities. This study, carried out on behalf of the Commission by the Centre for Disability Law and Policy in NUI Galway, I hope, will form a useful contribution to this process, and allow us to benefit from the experiences of other countries in meeting this challenge.

Emily Logan

Chief Commissioner,
Irish Human Rights and Equality Commission



Glossary

Disabled people's organisations (DPOs) – organisations governed, run and controlled directly by persons with disabilities, which also have a majority of persons with disabilities among their membership. The UN Convention on the Rights of Persons with Disabilities (CRPD) has provided a definition of DPOs which is explained in detail in Chapter 4 of the report.

Civil society organisations – this term is used throughout the report to refer to non-governmental organisations and other bodies, including research organisations, service providers, family organisations and other stakeholders outside of government or state bodies who have a role to play in monitoring the CRPD. DPOs are part of civil society too, but throughout this report, the term civil society organisations in general refers to organisations that do not meet the CRPD definition of a DPO.

Global Alliance of National Human Rights Institutions – the international association of NHRIs, which promotes, strengthens, and certifies NHRIs. (Until March 2016, it was known as the 'ICC', the International Coordinating Committee of National Human Rights Institutions.)

National independent monitoring framework – a framework required by Article 33(2) of the CRPD, which promotes, protects, and monitors the implementation of the Convention, working independently of government.

National human rights institutions – State bodies with a mandate to protect and

promote human rights. They are funded by the state, but operate and function independently from government.

Persons with disabilities – according to the CRPD, persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. In this report we use the terms 'persons with disabilities' and 'people with disabilities' interchangeably. This is partly because the term 'people with disabilities' is more frequently used in Ireland. We consider that people who do not identify as having impairments but who are perceived by others to have impairments, and experience discrimination or face barriers as a result of those perceived impairments, fall within the CRPD conceptualisation of persons with disabilities. This includes for example people who have experience of the mental health system.

List of Abbreviations

CERMI:	Spanish Committee of Representatives of Persons with Disabilities
CRPD:	United Nations Convention on the Rights of Persons with Disabilities
DFI:	Disability Federation of Ireland
DPAC:	Disabled People's Advisory Committee (Malta)
DPOs:	Disabled People's Organisations
DRPI:	Disability Rights Promotion International
EDF:	European Disability Forum
ENIL:	European Network of Independent Living
GANHRI:	Global Alliance of National Human Rights Institutions
HSE:	Health Service Executive (Ireland)
ICC:	International Coordinating Committee of National Human Rights Institutions, the name used by GANHRI until March 2016
NCBI:	National Council for the Blind of Ireland
NDA:	National Disability Authority (Ireland)
NGO:	Non-governmental Organisation
NHRI:	National Human Rights Institution
OHCHR:	Office of the High Commissioner for Human Rights
REE:	Recovery Experts by Experience (Ireland)
UKDPC:	UK Disabled People's Council
UKIM:	UK Independent Mechanism
WFD:	World Federation of the Deaf

Executive Summary

The UN Convention on the Rights of Persons with Disabilities (CRPD) contains an important innovation in Article 33, which requires states to establish national mechanisms to implement, to coordinate and to monitor progress in achieving the aims of the Convention. It is the first UN human rights treaty to contain a requirement for the establishment of a monitoring mechanism in the text of the treaty itself, as opposed to in an additional Optional Protocol. This has been described as a key innovation with the potential to transform the 'majestic generalities' of the Convention into concrete reform at the domestic level.¹ Central to the inclusion of this innovation in Article 33 was the concerted effort of people with disabilities, their representative organisations, and National Human Rights Institutions (NHRIs) in the negotiation of the Convention.²

Article 33 CRPD identifies four key elements that ensure a state complies with Article 33:

- a 'focal point', located within government,
- where necessary, a 'coordination mechanism', also located within government,
- a 'framework' to promote, protect and monitor implementation that contains an 'independent mechanism', and
- a high level of participation by civil society.

The focal point oversees the process of the implementation of the CRPD. Appointing a focal point ensures that someone in government is always focused on the implementation process. The second mechanism coordinates action on implementation across all government departments and statutory bodies. The third element, the framework, is the main focus of this report. The CRPD requires that a framework be established to promote, protect, and monitor the implementation of the CRPD, and, importantly, that this framework contain at least one 'mechanism' that is independent of government. The fourth element that is needed is the involvement and participation of people with disabilities and organisations representing them in the monitoring of the CRPD.

The independent monitoring mechanisms in six countries – Germany, the UK, Spain, Sweden, Malta and New Zealand – and the assessment of the UN Committee on the CRPD are examined to identify the main options available to Ireland and the strengths and shortcomings of those options. The six countries were selected because they are sufficiently similar to Ireland to be useful

1 Gerard Quinn, 'Resisting the "Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in: Quinn & Arnardóttir (eds.) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (2009) at 217.

2 For more on the negotiation process, see Rosemary Kayess and Philip French 'Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8(1) Human Rights Law Review 1.

comparators while also providing sufficient diversity in their approach to enable key principles to be identified. It is clear from the assessment by the UN Committee on the CRPD that the inclusion of a national human rights institution like the Irish Human Rights and Equality Commission goes a significant way to enabling a state to meet its obligations under the CRPD. However, the UN Committee has criticised the designation of a national human rights institution as the independent mechanism if that body is not also provided with the resources it needs to undertake that role.

The text of the CRPD itself and the concluding observations of the UN Committee when it has examined countries show that the involvement and full participation of people with disabilities and civil society are essential if a state is to comply with its obligations under the CRPD. Characteristics of systems for the inclusion and participation of people with disabilities that were found by the UN Committee to be important include formal mechanisms for engagement and, ideally, a permanent role for civil society in the monitoring framework. States which established permanent bodies within the monitoring mechanism to represent persons with disabilities, such as Malta and New Zealand, are particularly important examples to consider for the Irish context.

The UN Committee on the CRPD has placed particular importance on the characteristics of disabled persons organisations (DPOs) that participate in the implementation and monitoring of the Convention. The standard it identifies as necessary are that at least half

the membership of a DPO are people with disabilities, and the DPO must be governed, led and directed by persons with disabilities. A particular challenge in Ireland is that many of the organisations that are led by and represent people with disabilities lack the resources they would need to fully participate in the implementation of Article 33 of the Convention. A second significant challenge is that although there are some organisations in Ireland that meet the criteria established by the UN Committee on the CRPD, these organisations do not exist across the full range of disabilities in Ireland.

Three options for developing a monitoring framework are identified and assessed in light of both the findings of the UN Committee on the CRPD and the existing structures of both civil society and public bodies in Ireland with remits that could come within the scope of the Convention. The model identified by the researchers as most suitable for the designation as Ireland's framework containing an independent mechanism is the Irish Human Rights and Equality Commission with an advisory committee, appointed in a transparent way and consisting of a diverse group of people with lived experience of disability. The development of whatever framework the State does adopt will present Ireland with the opportunity to demonstrate leadership and innovative thinking in its processes for involving disabled peoples' organisations, individuals with disabilities and broader civil society.

Introduction

The purpose of this report is to explore the establishment of a national independent monitoring framework in Ireland ‘to promote, protect and monitor’ the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, or the Convention), as provided for in Article 33 of the Convention. Ireland signed the CRPD in 2007, and the government has indicated that it intends to ratify the CRPD once the necessary legislative reforms have taken place to ensure Ireland’s conformity with the principles of the Convention. The purpose of the report is to inform the Irish Human Rights and Equality Commission in anticipation of this, by providing some illustrative examples of promising practices from comparative countries and considering how these examples might be adapted to fit within the Irish political, legal and social context.

Approach to the Research

As described in more detail in Chapter 1 of this report, Article 33 requires the establishment of a focal point within government to oversee implementation of the Convention, and a monitoring framework (containing one or more independent mechanisms) to review compliance with the Convention. In the *Roadmap to Ratification*, the Irish government proposes that the Equality Division in the Department of Justice and Equality will be designated as the focal point and that the Irish Human Rights and Equality Commission (the Commission) and the National Disability Authority would form the monitoring framework under Article 33. The *Roadmap* further states that ‘provision will be made

in the amending legislation for formal consultation with all relevant stakeholders.’³

However, for the purpose of this report, we have not confined our research to the Roadmap’s proposal. We have taken a step back from this proposal and review the emerging commentary from the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) on the approaches of various states which have established monitoring frameworks under Article 33 and which the CRPD Committee has examined to date (Chapter 1). In Chapter 1 we also consider academic commentary and the views of civil society, particularly disabled people’s organisations (DPOs), on the monitoring frameworks which have been established to date under Article 33. We have chosen to focus in detail on six comparative jurisdictions which have established monitoring frameworks of interest and relevance to the Irish context – Germany, Malta, New Zealand, Spain, Sweden and the UK. The selection of these six comparators and criteria for analysing their approaches are discussed in more detail in Chapter 2. In Chapter 3, we examine in more detail the role of civil society and disabled people’s organisations, in particular in the monitoring processes in each of these six states, along

3 Department of Justice and Equality, *Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities* (Dublin: October 2015), available at <<http://www.justice.ie/en/JELR/Roadmap%20to%20Ratification%20of%20CRPD.pdf/Files/Roadmap%20to%20Ratification%20of%20CRPD.pdf>> (last accessed 30 March 2016).

2

with other illustrative examples from around the world of interest to the Irish context. Finally, in Chapter 4, we explore the existing domestic players in civil society in Ireland who could be involved in the implementation of Article 33, with a view to providing options to consider as Ireland prepares to ratify the CRPD.

Research Methodology

This research was commissioned by the Irish Human Rights and Equality Commission (the Commission) and conducted by Dr Meredith Raley, Jennifer Kline and Dr Eilíonóir Flynn at the Centre for Disability Law and Policy, NUI Galway, between January and March 2016. As the research was completed in a short timeframe, it has been primarily conducted using desk-based methods, with some additional information provided on the operation of existing Article 33 frameworks in the comparative study through key stakeholders drawn from the international contacts of the Centre for Disability Law and Policy.

The input of Commission staff and key stakeholders into the report and the provision of several opportunities to feedback on its progress has been vitally important to the research process. Given the nature of the study, and in keeping with the spirit of the CRPD, a small advisory group composed of representatives from groups of persons with disabilities was established for the research. The role of the advisory group was to guide the research process by reviewing and approving the terms of reference, ensuring that data is gathered from the most relevant

sources, reviewing the initial findings and feeding back to the research team, and reviewing and feeding back on the draft report.

Five organisations were invited to send representatives to the advisory group: the National Platform of Self Advocates (representing people with intellectual disabilities), Recovery Experts by Experience (representing people with experience of mental health issues), the National Council for the Blind of Ireland, the Irish Deaf Society and the Disability Federation of Ireland. Four of these five organisations responded to the request and sent representatives to the advisory group meetings.⁴ The advisory group met twice during the research process to review draft chapters and provide insights on the research for the final report. Terms of reference for the advisory group are appended to the report and the research team wishes to acknowledge the valuable input and feedback of the advisory group in developing the final report.

4 The representatives who attended the advisory group meetings were: Sarah Jane Lavin, National Platform of Self Advocates; Fiona Walsh, Recovery Experts by Experience; Eddie Redmond, Irish Deaf Society; and Joanne McCarthy/Joan O'Connor, Disability Federation of Ireland. Commission staff members Walter Jayawardene and Ruth Gallagher also attended the meetings. Emily Logan, Chief Commissioner, attended the first meeting and Frank Conaty, Commission Member, reviewed drafts and provided feedback to the research team.

The aim of this initial report is therefore to critically examine the significant body of existing literature on the implementation of Article 33, and to provide an interpretive analysis that is applicable to the Irish context. This research aims to ensure that Ireland can benefit from the experiences of those states that have already established a monitoring framework, and enable Ireland to apply best practice when preparing its own framework to monitor the implementation of the CRPD. While the views of the advisory group have been immensely valuable for the preparation of this report, it is important to emphasise that a further and more extensive State-led participatory process to elicit the views of people with disabilities will be required in the designation of any monitoring framework under Article 33. Depending on the timeline for Ireland's ratification, and new knowledge which may subsequently emerge from the CRPD Committee and from states currently implementing Article 33, further comparative research may also be required to inform Ireland's approach to this issue. Finally, in order to ensure compliance with the spirit and purpose of the CRPD, it is vital to ensure the active participation of people with disabilities and their representative organisations in developing Ireland's monitoring framework under Article 33.

Chapter 1: Scope of Article 33

1.1 Introduction

The creation of a national monitoring framework is an important step in the implementation of the CRPD. The monitoring framework, however, is only one part of a larger framework designed to guide and monitor the implementation process as set out in Article 33. This chapter examines Article 33 as a whole, with a special focus on the monitoring requirements, to give a better idea of what the article contains and requires, and some idea on how states can address this article. Further evaluation of the monitoring requirement of Article 33, and how to best address the need for monitoring in the Irish context, is in chapters below.

Before discussing the monitoring mechanism in depth, it is worth looking at Article 33 as a whole in order to understand how the parts work together and how the monitoring mechanism fits into the larger framework. The article has three subsections, and contains four elements that make up the Article 33 framework. It reads as follows:⁵

- 1** *States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.*
- 2** *States Parties shall, in accordance with their legal and administrative systems, maintain,*

strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

- 3** *Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.*

The framework required by Article 33 has four parts. The first part is a focal point, located within government, which is tasked with overseeing the implementation process. The second part is a coordination mechanism, also located within government, which ensures that government action on the Convention is properly organised, with no conflicts arising through shared areas of responsibility. The third part is outside of government, and is an independent monitoring framework. In defining the word 'independent', the article makes reference to the Paris Principles, which guide the creation and independence of National Human Rights Institutions (NHRIs).⁶ Article 33 does not, however, state directly that the independent mechanism must be an NHRI. The fourth part of the framework is civil

⁵ United Nations Convention on the Rights of Persons with Disabilities, at Article 33.

⁶ The reference is the following phrase that is to be found in the second sentence of Article 33.2: 'the principles relating to the status and functioning of national institutions for protection and promotion of human rights'.

society. Article 33.3 requires that people with disabilities and their organisations be involved in all parts of the monitoring process.

While this report focuses on the status of the Article 33 framework as a whole, and the monitoring mechanism in particular, it is important to note that to create and operate a good monitoring framework, considerations beyond the monitoring structure must be dealt with. These considerations include the power and resources to effectively carry out its functions and hold duty-bearers to account, and the participation of civil society, not just on paper but in practice. In designating a focal point, a coordination mechanism and a monitoring mechanism, all states, including Ireland, must consider the powers and resources required to make the best use of these Article 33 mechanisms, and design the structure of the mechanism and the processes it uses accordingly. Relatively little is known about how the Article 33 mechanisms that have been designated to date in the states that have ratified the CRPD are functioning in practice or about how the powers they have to fulfil their roles are being used. Since the CRPD is the most recent UN human rights convention to be adopted, it is very early to develop any comprehensive analysis of the existing Article 33 mechanisms.⁷ Further in-depth research

would be required to fill this gap in the existing literature, and such work is beyond the scope of the present report. However, in this report, we focus on some promising examples of relevance and interest to the Irish context, and consider what lessons might be learned from the implementation of Article 33 to date in designating an independent mechanism for Ireland.

1.2 Focal Point

The first part of the monitoring and implementation framework of Article 33 is the focal point within government. According to Article 33.1, 'State Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention'. The purpose of a focal point, according to Gauthier de Beco and Alexander Hoefmans, is twofold.⁸ First, it ensures that there is a place within government that always has the rights of

Committee or civil society organisations have critiqued the mechanism, or unless the mechanism has been the subject of academic commentary, we have no knowledge of how they are operating in practice.

⁷ Some information is available on the 34 states which have reported to the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) at the time of writing, but this is in general limited to the bodies that have been designated as Article 33 mechanisms. Unless the CRPD

⁸ Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco, (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 23 (2013).

people with disabilities on its agenda. For this reason, the focal point must be highly placed, and influential enough to compel government action. In addition to this, the designation of a focal point centralises the implementation process.⁹ In order to leave room for all types of governmental organisation, the treaty does not provide any specific guidance on where the focal point should be located, or how many focal points should exist. Since the treaty was drafted, the UN Office of the High Commissioner for Human Rights (OHCHR) has studied the issue and put forward some recommendations,¹⁰ while acknowledging that different governments will have different needs. For states that wish to appoint multiple focal points, the OHCHR recommends placing them within each ministry, to address the fact that full implementation of the Convention will require action by most ministries or departments of government. **Multiple focal points can have several benefits. The nature**

of the Convention and the rights it lays out are such that, in most governments, several ministries or departments are likely to be involved in the implementation process.¹¹

A single overarching focal point also has benefits, as it ensures that there is general oversight of government action. In this case, the OHCHR discourages the use of the ministry of health, as this would promote a medical model of disability. Instead, it recommends the ministry of justice.¹² Using the ministry of justice has further advantages. First, it is consistent with the social model of disability. Civil society and DPOs, pushing for a shift from the medical to the social model, have criticised the use of ministries such as those concerned with health, welfare or labour as focal points.¹³ As a matter of internal

9 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco, (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 23 (2013).

10 Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities*, U.N.Doc. A/HRC/13/29 (22 December 2009).

11 Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities*, U.N.Doc. A/HRC/13/29 (22 December 2009).

12 Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities*, paragraph 27, U.N.Doc. A/HRC/13/29 (22 December 2009).

13 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on

administration, it is not necessary that a focal point be appointed by law, as long as it is given the resources it requires to meet its goals.¹⁴ States should also consider how appointing a particular ministry or other body as a focal point will change the way the body operates, and make any necessary changes to its mandate or funding.¹⁵ It is also important that the focal point be accessible to civil society, so that the participation of DPOs and persons with disabilities can be assured.¹⁶

the Rights of Persons with Disabilities', in Gauthier de Beco (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 24 (2013).

14 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities*, available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> accessed 30 March 2016.

15 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 22 (2013).

16 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities*, available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> accessed 30 March 2016.

1.3 Coordination Mechanism

The second part of the framework identified in Article 33.1 is the coordination mechanism. According to the text of the article, state parties 'shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels'. The first thing to note about the coordination mechanism is that, unlike the other parts of the implementation and monitoring framework, it is optional. If a state feels it does not require a coordination mechanism, it is not compelled to create one. The creation of a coordination mechanism is generally recommended, however, because such a mechanism can help the state ensure that action among ministries is properly coordinated, and no ministry takes isolated action.¹⁷ The OHCHR recommends that whenever a state has appointed more than one focal point, the focal points should form a coordinating committee.¹⁸ In a state with

[cations/Art_33_CRPD_study.pdf](http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf)> accessed 30 March 2016.

17 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities*, available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> accessed 30 March 2016.

18 Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities*, paragraph

more than one focal point, a coordination mechanism can serve several functions distinct from those of the focal points.

According to de Beco and Hoefmans, the coordination mechanism helps the various focal points organise their action, so that it is clear who is responsible for what, what has been done, and what needs to be done. Second, the coordination mechanism can act as a neutral platform, where various factions on issues of policy can meet. To properly serve this function, the coordination mechanism should not be situated in any particular ministry.¹⁹ In a system with several focal points, the coordination mechanism can act as a place where the monitoring mechanism, civil society, and others can communicate with the government on issues of policy. As the coordination mechanism is at the centre of the government's actions on the implementation of the Convention, it can also act a liaison with the international community.²⁰ As the coordination mechanism

and focal point are both located within government, and will work closely together, it is important to keep their functions separate. From the perspective of de Beco and Hoefmans, the focal points are the drivers of policy change within their various areas of competence, while the coordination mechanism ensures smooth communication between the focal points, and acts as a point of communication for actions outside of government.²¹

1.4 Independent Monitoring Framework

Article 33.2 of the CRPD deals with the establishment of an independent monitoring framework. The first part of 33.2 requires that 'States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including

36, U.N.Doc. A/HRC/13/29 (22 December 2009).

19 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 26 (2013).

20 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation

and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 27 (2013).

21 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 29–30 (2013).

one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention.’ This section of Article 33.2 makes clear that a framework that is independent of government must be created to promote, protect, and monitor the Convention. The next part of Article 33.2 clarifies what is meant by independent: ‘When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights’. The principles referred to in Article 33.2 are the Paris Principles,²² originally written to establish the functioning and creation of NHRIs. This requirement raises several questions about the appropriate way to set up a monitoring framework. First, there are the questions raised by using the Paris Principles as the standard for independence. As these principles were originally written to apply to NHRIs, can they apply to other bodies? Or does their use mean that only NHRIs can serve as the independent mechanism?

22 Gauthier de Beco, ‘Article 33(2) of the UN Convention on the Rights of Persons with Disabilities: Another Role for National Human Rights Institutions?’ (2011) 29 *Netherlands Quarterly of Human Rights* 84; Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities*, paragraph 37, U.N.Doc. A/HRC/13/29 (22 December 2009).

In general, the CRPD Committee has held that an NHRI accredited by the Global Alliance of National Human Rights Institutions (GANHRI)²³ fulfils the independence requirement of Article 33.2,²⁴ and where a state already has such a body, appointing it as the monitoring mechanism avoids the need to create a new independent body. Furthermore, it was the work, at least in part, of the NHRIs at the drafting of the Convention that led to the reference to the Paris Principles in the text, and many parties at the drafting clearly had NHRIs in mind when developing the text of Article 33 concerning monitoring mechanisms.²⁵ Therefore, it can be safely assumed that when one exists, the NHRI should at least be a part of the monitoring framework.

23 The GANHRI (formerly the International Coordinating Committee – ICC) is the international coordinating body for NHRIs. Among its responsibilities, it certifies whether or not an NHRI meets the requirements to be considered independent of government.

24 Committee on the Rights of Persons with Disabilities, *Consideration of reports submitted by States parties under article 35 of the Convention, Concluding observations of the Committee on the Rights of Persons with Disabilities, Spain*, paragraph 7, U.N.Doc. CRPD/C/ESP/CO/1 (19 October, 2011).

25 Gerard Quinn, ‘The UN Convention on the Rights of Persons with Disabilities. National Institutions as Key Catalyst of Change’, in: Mexico: Comisión Nacional de los Derechos Humanos (ed.) *National Monitoring Mechanisms of the Convention on the Rights of Persons with Disabilities*, 130, (2008).

Of course, Article 33.2 calls for ‘a framework, including one or more independent mechanisms’, meaning that states may appoint multiple bodies. This raises the question of whether all bodies in the framework must be independent. The wording of the English version of Article 33.2 seems to allow for non-independent bodies, as long as at least one independent body is present. This is also the interpretation of the OHCHR, which states that 33.2 calls for ‘a framework consisting of various entities, amongst which one or more independent mechanisms are included.’²⁶ This interpretation is not universal, however. de Beco and Hoefmans argue that it is ‘against the spirit’ of Article 33.2, and that all bodies within the monitoring framework must be independent.²⁷ This is, however a minority position, with most scholars taking the OHCHR’s view that

only one independent body is required.²⁸ As is demonstrated below in this report, the CRPD Committee has, when faced with frameworks which include non-independent bodies, considered them to be in line with the CRPD, provided one body in the framework is independent.

For European Union member states, there is also the EU’s own monitoring mechanism to consider. The CRPD is the first human rights treaty that the EU has ratified, and like state parties to the Convention, the EU has set up an Article 33 framework, including a monitoring mechanism. In the case of the EU, the monitoring framework was originally made up of five different bodies, each taking on some of the responsibilities of the monitoring framework. These bodies are: the European Parliament, and in particular its Committee on Petitions; the European Ombudsman; the European Commission; the EU Agency for Fundamental Rights; and the European Disability Forum.²⁹ When the EU

26 Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities*, paragraph 38, U.N.Doc. A/HRC/13/29 (22 December 2009).

27 Gauthier de Beco & Alexander Hoefmans, ‘National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities’, in: Gauthier de Beco, (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 38 (2013).

28 Gerard Quinn, ‘The UN Convention on the Rights of Persons with Disabilities. National Institutions as Key Catalyst of Change’, in: Mexico: Comisión Nacional de los Derechos Humanos (ed.) *National Monitoring Mechanisms of the Convention on the Rights of Persons with Disabilities*, 130. (2008); LUIS FERNANDO ASTORGA GATJENS, ‘ANALYSIS OF ARTICLE 33 OF THE UN CONVENTION: THE CRITICAL IMPORTANCE OF NATIONAL IMPLEMENTATION AND MONITORING’, *INTERNATIONAL JOURNAL ON HUMAN RIGHTS*, VOL. 8, 14, 79 (2011).

29 *The protection role of the Committee on Petitions in the context of the implementa-*

was examined by the CRPD Committee, the UN recommended removing the European Commission, from the monitoring framework, as it also serves as the EU's focal point.³⁰ Since this recommendation, the European Commission has removed itself from the framework. The Committee on Petitions is the monitoring body that states are most likely to interact with, as it has the power to investigate complaints about states' violation of rights under the CRPD.

1.5 Involvement of Civil Society

The final part of the implementation and monitoring framework for the CRPD is found in Article 33.3, which requires that 'Civil society, in particular persons with disabilities

and their representative organizations, shall be involved and participate fully in the monitoring process'. This article, on the involvement of civil society in the monitoring process in particular, should be read in conjunction with the broader requirement in Article 4.3, which applies to the entire treaty: 'In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations'.³¹ Both of these articles enshrine the principle of 'nothing about us without us'³² which is a common slogan for the disability rights movement, and was regularly used throughout the negotiation of the CRPD.³³

tion of the UN Convention on the Rights of Persons with Disabilities, (2015), available at <<https://polcms.secure.europarl.europa.eu/cmsdata/upload/493ded5c-c1b9-49c0-8dee-9b3ac9fc3b0f/pe536%20465.pdf>> (accessed 30 March, 2016).

30 *The protection role of the Committee on Petitions in the context of the implementation of the UN Convention on the Rights of Persons with Disabilities*, (2015), available at <<https://polcms.secure.europarl.europa.eu/cmsdata/upload/493ded5c-c1b9-49c0-8dee-9b3ac9fc3b0f/pe536%20465.pdf>> (accessed 30 March, 2016); Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of the European Union* (2015), paragraph 77, available at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/226/55/PDF/G1522655.pdf>>, (accessed 26 April 2016).

31 United Nations Convention on the Rights of Persons with Disabilities, at Article 4.

32 Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' 8 *Human Rights Law Review* 4 (2008).

33 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities*, available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> (last accessed 30 March, 2016).

While states are clearly obligated to include persons with disabilities and DPOs in the monitoring process, the exact form this participation shall take is left unclear. It should be noted, however, that Article 33.3 calls for 'participation', which is a stronger requirement than consultation. It should also be noted that the article requires that people with disabilities be allowed to participate separate from the participation of DPOs, if they so choose.³⁴ In Ireland, this will be particularly important as there are few organisation in Ireland that meet the definition of a DPO that is used by the CRPD Committee and some of those that do may not have the capacity to participate in monitoring (see Chapter 4). If Article 33.3 is read in conjunction with Article 4.3, it also becomes clear that people with disabilities must not only be involved in the monitoring framework of 33.2, but also the focal point and coordination mechanism of 33.1. In addition, state parties to the Convention may have to work on building capacity within civil society to ensure that DPOs have the ability to participate meaningfully in the process of implementation and monitoring.³⁵ In order

for access to the monitoring process to be a meaningful right, people with disabilities will require the resources to make use of this access. This means ensuring that accessibility requirements for various disabilities are taken into account, and that both the Convention and related implementation strategies are made available in forms that all civil society participants can understand.³⁶

1.6 Conclusion

The commentary of academic scholars and the CRPD Committee provides guidance to determine what a best practice Article 33 framework should look like, and some of the actions that framework should take. The focal point should be located at the level of a ministry, in a department where the rights of persons with disabilities are considered holistically as part of a broad human rights, justice or equality agenda, rather than narrowly as a health or social care issue.³⁷ For

[Publications/Art_33_CRPD_study.pdf](#)> (last accessed 30 March, 2016).

34 Mental Disability Advocacy Centre, *Building the Architecture for Change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities*, 15, available at <http://mdac.info/sites/mdac.info/files/Article_33_EN.pdf> (last accessed 30 March, 2016).

35 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities*, available at <<http://europe.ohchr.org/Documents/>

36 Gauthier de Beco & Alexander Hoefmans, 'National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities', in Gauthier de Beco (ed.) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*, 9, 58 (2013).

37 Human Rights Council, *Thematic Study by the Office of the High Commissioner for Human Rights on the Structure and Role of*

most states, this probably means either the ministry of justice or the attorney general. This placement will serve two purposes. First, it complies with the ethos underpinning mainstreaming the rights of people with disabilities,³⁸ treating the implementation of the treaty as a legal issue affecting everyone, rather than a niche issue for a few people. It also conforms to the social model, and does not medicalise the rights of people with disabilities. In Ireland, the Department of Justice and Equality already has an Equality Division³⁹ that may be able to take up the duties of the focal point, as suggested in the *Roadmap to Ratification*. Its location conforms to CRPD Committee and scholarship around the issue, and its staff should be well versed in disability issues in Ireland.

It is more difficult to prescribe the exact form the coordination mechanism should take. While a coordination mechanism is not required, it is clearly helpful, because even

the smallest states will have to coordinate action among various ministries to achieve the goals of Article 33. Therefore, it is best practice to have some kind of coordination mechanism. At the very least, it should be a place for various ministries to meet, to ensure consistent and coordinated action. Ideally, there would be some way for the monitoring mechanism and civil society to access the coordination mechanism, to facilitate their involvement with the implementation process. Ireland has two bodies that may be able to take up the functions of a coordination mechanism. These inter-ministerial bodies are the Senior Officials Group on Disability that coordinates action on the National Disability Inclusion Strategy⁴⁰ and the Inter-Departmental Committee on Human Rights that has a role in guiding the state towards the ratification by Ireland of key international human rights treaties.⁴¹

For the monitoring mechanism in states such as Ireland that have an NHRI, the use of that institution is clearly the best practice. Article 33.2 uses the Paris Principles as the standard for the independent body in the monitoring framework, and the work of NHRIs at the

National Mechanisms for the Implementation and Monitoring of the Convention on the Rights of Persons with Disabilities, U.N.Doc. A/HRC/13/29 (22 December 2009).

38 Luis Fernando Astorga Gatjens, 'Analysis of Article 33 of the UN Convention: The Critical Importance of National Implementation and Monitoring', *International Journal on Human Rights* vol. 8 14, 75 (2011).

39 Department of Justice and Equality, Disability Policy Unit. 'Disability' [web page], available at <<http://www.justice.ie/en/JELR/Pages/WP15000115>> (last accessed 31 March 2016).

40 See: *National Disability Strategy Implementation Plan 2013–2015* <http://www.justice.ie/en/JELR/NDS_ImplementationPlan_FINAL.pdf/Files/NDS_ImplementationPlan_FINAL.pdf> (last accessed 27 April 2016).

41 *National report submitted in accordance with paragraph 5 of the annex to Human Rights Council resolution 16/21: Ireland*, paragraph 169, U.N. Doc. A/HRC/WG.6/25/IRL/1 (9 February 2016).

drafting was a large part of what shaped Article 33.2 of the Convention. Furthermore, it is generally assumed by scholars working on Article 33 that designating an NHRI represents best practice,⁴² and that where an NHRI exists, it should at least form the independent body within a monitoring framework. There remains the question of whether a single or multi body framework represents best practice and that question is addressed in Chapter 4 in further detail with respect to the Irish context.

It is important for the monitoring mechanism to be cognisant of the roles and functions of all parts of the Article 33 framework. One task of the framework is to monitor the progress of the implementation, and without an effective framework, progress will likely be slower and uneven, as has historically been the case with human rights treaties.⁴³ The monitoring mechanism can provide the government with feedback on the creation and running of the focal point and the coordination mechanism, to help ensure that

these bodies are functioning the way that the CRPD intends. Furthermore, the monitoring mechanism must be aware of and promote the involvement of people with disabilities in all stages of the implementation. As this chapter shows, while the participation of people with disabilities in the monitoring process is critical and a high level of involvement is required by the Convention, people with disabilities must also be involved with the focal point and coordination mechanism, and the monitoring mechanism must monitor this involvement to ensure it meets the standards of the CRPD.

42 Gerard Quinn, 'The UN Convention on the Rights of Persons with Disabilities. National Institutions as Key Catalyst of Change', in Mexico: Comisión Nacional de los Derechos Humanos, (ed.) *National Monitoring Mechanisms of the Convention on the Rights of Persons with Disabilities*, 130, (2008).

43 James Crawford, 'The UN Human Rights Treaty System: A System in Crisis?' in: Philip Alston and James Crawford (eds.), *The Future of UN Human Rights Treaty Monitoring*, (2000); Antonio Cassese, *International Law in a Divided World*, 100–1 (1986).

Chapter 2: Existing Article 33 Frameworks

2.1 Introduction

In this chapter, six states that have already designated a monitoring framework under Article 33 are presented, to give some idea of the variety of frameworks that exist, and how the CRPD Committee has responded to the frameworks within these example states. Where they are available, the reactions of civil society have also been included. This chapter also provides an analysis of the various types of framework, what works and what could be improved, to provide further guidance and advice. The six states chosen are Germany, the UK, Spain, Sweden, Malta and New Zealand. This sample was chosen as a diverse mix of states – civil and common law, single and multi-body frameworks – that are similar enough to Ireland to provide guidance in creating Ireland's own monitoring framework, but still diverse enough to provide a variety of experiences. Five of the states are in the EU, while the sixth, New Zealand, is a common law state with a population similar in size to Ireland's. It is also helpful that four of the six states have been reviewed by the CRPD Committee, which means that the Committee's views can be included in the analysis.

2.2 Germany: An NHRI as the Sole Mechanism

Germany is an example of a state that uses a single body, its NHRI, as its entire monitoring framework. For its monitoring mechanism, Germany chose to appoint its NHRI, the German Institute for Human Rights, an 'A status' NHRI.⁴⁴ Within the

Institute, Germany created a separate body to oversee the implementation process. As a previously established NHRI, the Institute had the necessary independence to fulfil the requirements of Article 33.2.⁴⁵ The National CRPD Monitoring Body is made up of four staff members. Its website states that 'currently the National CRPD Monitoring Body does not have a staff member with a more severe disability. However it has had experience with employees with impairments.'⁴⁶ The Monitoring Body hosts consultations with civil society three times a year. Each consultation focuses on one issue that is of concern to the Monitoring Body at that time. Topics the Monitoring Body has focused on include legal capacity, women and girls with disability, and housing.⁴⁷ Over 60 groups are

outline of the difference between them, see <<http://nhri.ohchr.org/EN/AboutUs/ICCAccreditation/Pages/default.aspx>> (last accessed 27 April 2016).

45 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, Germany*, paragraphs 284–290, [U.N.Doc. CRPD/C/DEU/1](http://www.unhcr.org/refugees/4d4d4d4d) (7 May 2013).

46 Deutsches Institut für Menschenrechte, 'CRPD Monitoring Body' [web page], available at <<http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/frequently-asked-questions/>> (last accessed 31 March 2016).

44 The GANHRI accreditation system for NHRIs has three classifications, namely 'A status', 'B status' and 'C status'. For an

47 Deutsches Institut für Menschenrechte, 'CRPD Monitoring Body' [web page] available at <<http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/frequently-asked-questions/>> (last accessed 31 March 2016).

invited to participate in these consultations, including DPOs, service providers, and groups representing family members of those with disabilities.⁴⁸ All groups are invited to all consultations, and there does not appear to be a permanent advisory body of civil society members. Germany's Monitoring Body did submit a shadow report to the CRPD Committee in 2015, but chose not to comment on itself.⁴⁹ The Shadow report submitted by an alliance of German NGOs did not address any aspect of Article 33.⁵⁰ The

report does note, however, that at the time it was submitted, the NGOs in the alliance were unhappy with their level of participation in the implementation of the Convention, and they felt that Germany was not meeting its obligations in this respect.⁵¹

Germany has a formal mechanism for civil society participation in its coordination mechanism, within government,⁵² a body known as the Advisory Council on Inclusion. This Council is responsible for liaising with broader society and representing the coordination mechanism. The Council also has oversight of four specialist committees, made up of various civil society groups who have a

rechte.de/en/crpd-monitoring-body/top-ics/ (last accessed 31 March 2016).

48 Deutsches Institut für Menschenrechte, 'CRPD Monitoring Body' [web page] available at <<http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/civil-society-consultations/#c12658>> (last accessed 31 March 2016).

49 National Monitoring Body for the UN Convention on the Rights of Persons with Disabilities, German Institute for Human Rights, *Parallel Report to the UN Committee on the Rights of Persons with Disabilities*, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNHS%2f-DEU%2f19761&Lang=en> (last accessed 31 March 2016).

50 BRK-Allianz (eds.) *For Independent Living, Equal Rights, Accessibility and Inclusion!: First Civil Society Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities in Germany* (2013) available at <http://tbinternet.ohchr.org/_layouts/

treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2f-DEU%2f16323&Lang=en> (last accessed 31 March 2016).

51 BRK-Allianz (eds.) *For Independent Living, Equal Rights, Accessibility and Inclusion!: First Civil Society Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities in Germany* (2013) available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2f-DEU%2f16323&Lang=en> (last accessed 31 March 2016).

52 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, Germany*, paragraphs 284–290, U.N.Doc. CRPD/C/DEU/1 (7 May 2013).

stake in the implementation process. These committees are made up of representatives from trade unions, churches, charities, research, and other organisations. The committees deal with four themes: (1) health, long-term care, prevention, rehabilitation; (2) freedom and protection rights, women, partnership, family and bioethics; (3) work and education; (4) mobility, construction, housing, leisure, social participation, information and communication.⁵³ Finally, the Council acts as a meeting place for civil society, the focal point, and the monitoring mechanism. Most of the members of the Advisory Council are people with disabilities, with most other members being representatives of focal points or other state bodies involved in implementation.⁵⁴ In Germany, the Federal Ministry of Labour and Social Affairs has been named as the federal focal point, with focal points also established at the *Land* (state) level.⁵⁵

In its list of issues, the CRPD Committee did not address Germany's choice of monitoring mechanism, showing concern only for coordination of the framework in a federal system.⁵⁶ However, in its concluding observations, the Committee noted its concern that Germany had not provided its monitoring mechanism with enough resources to fulfil its goals, and recommended that Germany strengthen the capacity of the monitoring mechanism and ensure that it would have adequate resources.⁵⁷

The example of Germany shows that it is possible to create a single body mechanism that it acceptable to the committee, provided it is properly resourced. Germany also demonstrates that it is not necessary to have a formal civil society mechanism within the monitoring framework for the framework to be accepted by the Committee. This may in part be because civil society was included quite clearly on the government side of the

53 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, Germany*, paragraphs 284–290, U.N.Doc. CRPD/C/DEU/1 (7 May 2013).

54 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, Germany*, paragraphs 284–290, U.N.Doc. CRPD/C/DEU/1 (7 May 2013).

55 Committee on the Rights of Persons with Disabilities, *Implementation of the Conven-*

tion on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, Germany, paragraphs 284–290, U.N.Doc. CRPD/C/DEU/1 (7 May 2013).

56 Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of Germany*, paragraph 25, U.N.Doc. CRPD/C/DEU/Q/1 (12 May 2014).

57 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Germany*, paragraphs 61–62, U.N.Doc. CRPD/C/DEU/CO/1 (13 May 2015).

Article 33 framework. Civil society itself, however, was apparently dissatisfied with this arrangement (see Chapter 3). Another aspect of the German framework worth noting is that the monitoring mechanism apparently chose which organisations to invite to the consultation meetings, which could raise questions about the openness of these meetings and the ability of individuals to participate separately from DPOs in the process. As is discussed further in Chapter 4, this sort of framework would be possible in Ireland, as Ireland has a well-established NHRI. However, solely arranging consultations through organisations, rather than allowing individuals to participate separately, may not be the best way to ensure broad civil society participation.

2.3 Malta: Single-body Framework with a New DPO

Malta submitted its state report in 2014, but has not yet been examined by the CRPD Committee.⁵⁸ It designated the National Commission for Persons with Disability (KNPD) as the sole monitoring mechanism under Article 33. The KNPD is a statutory body established under the Equal Opportunity

(Persons with Disability) Act 2000.⁵⁹ It has a legislative duty to raise awareness about the capabilities and contributions of persons with disability and combat prejudices or harmful behaviour stemming from stereotypes. The 2000 Act also empowers the KNPD to investigate complaints it receives about breach of rights arising from discrimination, as well as to promote, protect and monitor the implementation of the CRPD. At the time of writing, Malta does not have an NHRI accredited under the Paris Principles, although a Bill to create a Human Rights and Equality Commission is currently being prepared for parliament.⁶⁰

The KNPD, Malta's independent mechanism, created the Disabled People's Advisory Committee (DPAC) to fulfil the civil society requirement of Article 33.⁶¹ The DPAC's

58 Committee on the Rights of Persons with Disabilities, *Initial reports of States parties due in 2014: Malta*, U.N.Doc CRPD/C/MLT/1, available at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/258/66/PDF/G1525866.pdf?OpenElement>> (last accessed 20 April, 2016).

59 Chapter 413, Equal Opportunities for Persons with Disability Act 2000; available at: <<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8879&l=1>> (last accessed 8 April 2016).

60 Ministry for Social Dialogue, Consumer Affairs and Civil Liberties, 'Towards a Robust Human Rights and Equality Framework: Public Consultation' [web page], available at: <<http://socialdialogue.gov.mt/en/PublicConsultations/MSDC/Pages/Consultations/HumanRights.aspx>> (last accessed 22 April 2016).

61 Kummissjoni Nazzjonali Persuni B'Dizabilita, *UNCRPD Disabled People's Advisory Committee Terms of Reference* (2013) available at

role is defined as assisting the independent mechanism in monitoring and working with the independent mechanism on any other disability related matters. The DPAC is made up of 12 members, 10 of whom are people with various different disabilities⁶² and two members who are parents of children with disabilities.⁶³ Members were selected through an application process that sought to ensure diversity among applicants. The call for applications was sent to existing DPOs and made public.⁶⁴ The focal point for Malta

is within the Parliamentary Secretariat for Rights of Persons with Disability and Active Aging, and, while no official coordination mechanism has been created, the focal point has representatives in all ministries.⁶⁵

As Malta is not yet scheduled for examination, no shadow reports have been submitted to the CRPD Committee. However, since Malta has not included an NHRI in its monitoring framework, it is likely to be criticised by the CRPD Committee for this reason. Unlike Spain, where the civil society body in the framework, CERMI, does not have the powers to investigate or receive complaints, the KNPD is established as a statutory body and does have these powers. The efforts underway to establish a Human Rights and Equality Commission in Malta may have progressed further by the time Malta is examined by the CRPD Committee, and based on the trend in concluding observations to date, it is likely that the Committee will ask the government to consider jointly designating this new Commission along with the KNPD as the monitoring framework for Article 33. However, from an Irish perspective what is interesting about Malta's

<<http://www.knpd.org/pubs/pdf/DPAC%20TOR%2020130226.pdf>> (last accessed 15 March 2016).

62 Committee composition is described as: '1. Person with mobility impairment. 2. Person with hearing impairment. 3. Person with visual impairment 4. Person with intellectual impairment. 5. Person with mental health issues. 6. Person with specific learning difficulties. 7. Person with epilepsy. 8. Person with chronic illness. 9. Person with multiple impairments. 10. Person with hidden impairments. 11. Parent or guardian of a disabled child living at the same address. 12. Parent or guardian of a disabled person with complex dependency needs, living at the same address.'

63 Kummissjoni Nazzjonali Persuni B'Dizabilita, *UNCRPD Disabled People's Advisory Committee Terms of Reference* (2013) available at <<http://www.knpd.org/pubs/pdf/DPAC%20TOR%2020130226.pdf>>.

64 National Commission of Persons with Disabilities, *KNPD Work Report 2013*, 7;

available at <<http://www.knpd.org/pubs/pdf/KNPD%20AR%202013%20EN.pdf>> (last accessed 15 March 2016).

65 Committee on the Rights of Persons with Disabilities, *Initial reports of States parties due in 2014: Malta*, U.N.Doc CRPD/C/MLT/1, available at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/258/66/PDF/G1525866.pdf?OpenElement>> (last accessed 20 April, 2016).

approach is the establishment of a new group composed of people with disabilities and their family members as part of the monitoring framework. The response of Maltese civil society to this new body and its relevance in the Irish context is discussed in further detail in Chapters 3 and 4,

2.4 UK: Multiple NHRIs and Equality Bodies

In the UK, the choice of monitoring mechanism reflects the presence in the UK of devolved regional governments. The UK has designated the three human rights commissions and an equality body: the Equality and Human Rights Commission (England and Wales), the Northern Ireland Human Rights Commission, the Equality Commission for Northern Ireland, and the Scottish Human Rights Commission. Apart from the Equality Commission for Northern Ireland, which is not an NHRI, all of these are 'A status' NHRIs.⁶⁶ According to the state report to the CRPD Committee, the government has provided additional funding to the various commissions to cover their awareness-raising work with civil society.⁶⁷

These four bodies are designated as the United Kingdom Independent Mechanism (UKIM).⁶⁸ The UKIM published a report on the progress of the implementation process in 2014, in anticipation of the UK's examination before the Committee. In this report, the UKIM addresses its own existence, and notes that '[t]here is no framework beyond UKIM to link key stakeholders, such as the regulatory bodies for key public services, to better promote, protect and monitor CRPD implementation.'⁶⁹ The report mentions UKIM's work with people with disabilities, but no details are provided. The UK has not yet gone before the CRPD Committee, but is expected to be examined in 2017.

Some civil society groups have produced and released shadow reports. Disability Action, a disability advocacy organisation, prepared

paragraphs 348–364, [U.N.Doc. CRPD/C/GBR/1](#) (3 July 2013) available at <http://tbin-ternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2F-C%2FGBR%2F1&Lang=en> (last accessed 29 April 2016).

66 'Directory of Institutions – Europe' [web page] <<http://nhri.ohchr.org/EN/Contact/NHRIs/Pages/Europe.aspx>> (last accessed 27 April 2016).

67 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, United Kingdom of Great Britain and Northern Ireland*,

68 Scottish Human Rights Commission, *UN CRPD Report*, available at <<http://www.scottishhumanrights.com/news/latestnews/uncrpdreportdec2014>> (last accessed 31 March 2016).

69 Scottish Human Rights Commission, *UN CRPD Report*, available at <<http://www.scottishhumanrights.com/application/resources/documents/MonitoringtheImplementationoftheUNCPRD.pdf>> accessed 30 March 2016.

a draft shadow report, dated December 2015, which focuses on the Convention in Northern Ireland.⁷⁰ The report found that one barrier to participation was a low awareness of the CRPD among people with disabilities. The report blamed this low awareness, in part, on the lack of resources given to the monitoring framework, which was then unable to carry out an awareness campaign.⁷¹ Within Northern Ireland, the monitoring framework has engaged with civil society through seminars, conferences and other events, but no formal mechanism for engagement exists.⁷²

70 Centre on Human Rights for People with Disabilities, *Draft Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland*, available at <<http://www.disabilityaction.org/centre-on-human-rights/shadowreport/>> (last accessed 31 March 2016).

71 Centre on Human Rights for People with Disabilities, *Draft Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland*, available at <<http://www.disabilityaction.org/centre-on-human-rights/shadowreport/>> (last accessed 31 March 2016).

72 Centre on Human Rights for People with Disabilities, *Draft Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland*, available at <<http://www.disabilityaction.org/centre-on-human-rights/shadowreport/>> (last accessed 31 March 2016), available at <<http://www.disabilityaction.org/centre-on->

The UK has yet to be examined by the CRPD Committee, therefore, the reaction of the committee to the UK framework is unknown. The use of 'A status' NHRIs is in line with other frameworks that the CRPD Committee has commented positively on, and the Committee has also approved other mechanisms where equality bodies are involved. However, civil society has clearly identified problems with both the funding of the monitoring framework and its engagement with civil society. From the shadow report, there appears to be no formal mechanism for engagement, and little outreach to make people aware of their rights, including the right to participate in the monitoring process. Judging by the CRPD Committee's reaction to other states' frameworks, these aspects might be open to critique.

In the UK, the Office for Disability Issues (ODI) was chosen as the main focal point. In addition, each of the devolved governments chose a separate focal point, although the state report does not give any details on these separate focal points.⁷³ The UK did not create a coordination mechanism. This kind of monitoring framework does not

[human-rights/shadowreport/](http://www.disabilityaction.org/centre-on-human-rights/shadowreport/)> (last accessed 31 March 2016).

73 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, United Kingdom of Great Britain and Northern Ireland*, paragraphs 348–364, U.N.Doc. CRPD/C/GBR/1 (3 July 2013).

seem appropriate for Ireland, since Ireland does not have multiple NHRIs, or separate equality and human rights bodies. It does, however, show some of the limitations of appointing only NHRIs and equality bodies in a framework, as this does not always provide clear mechanisms for broader civil society engagement with the mechanism. Although the UK has not yet been examined by the CRPD Committee, based on the Concluding Observations to date, it seems likely that the Committee would request more information on the extent to which civil society is actively involved in the monitoring framework.

2.5 Spain: NHRI Jointly Designated with NGO

Spain was the first European state to be examined by the CRPD Committee, in the spring of 2011. Initially, Spain appointed only the NGO, the Spanish Committee of Representatives of Persons with Disabilities (CERMI), as the independent body to monitor the Convention.⁷⁴ According to its website, CERMI is an umbrella organisation of DPOs, NGOs and 'specialized organisations committed to disability issues'. It includes

over 6,000 organisations in total.⁷⁵ Spain later announced that in addition to CERMI, the Ombudsman, an 'A status' NHRI, would also be a part of the monitoring framework, as the Ombudsman could receive and act on complaints.⁷⁶ In its concluding observations, the CRPD Committee commends Spain for establishing a monitoring mechanism in compliance with Article 33.2, and lists no areas of concern in regards to Article 33, from which one can conclude that a monitoring mechanism made up of an NHRI and a disability focused NGO is acceptable to the Committee.⁷⁷ Spain's coordination

74 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention: Spain*, paragraph 252–253, U.N.Doc. CRPD/C/ESP/1 (05 October, 2010), available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2f1&Lang=en> (last accessed 29 April 2016).

75 'What is CERMI' [Web page] available at <<http://www.cermi.es/en-US/QueesCERMI/Pages/Inicio.aspx>> (last accessed, 29 April 2016).

76 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, List of issues to be taken up in connection with the consideration of the initial report of Spain (CRPD/C/ESP/1), concerning article 1 to 33 of the Convention on the Rights of Persons with Disabilities*, paragraphs 158–165, U.N.Doc. CRPD/C/ESP/Q/1/Add.1 (27 July, 2011).

77 Committee on the Rights of Persons with Disabilities, *Consideration of reports submitted by States parties under article 35 of the Convention, Concluding observations of the Committee on the Rights of Persons with Disabilities, Spain*, paragraph 7, U.N.Doc CRPD/C/ESP/CO/1 (19 October, 2011) available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2f>

mechanism and focal point is the National Disability Council, which is a consultative body composed of both members of the various ministries in government and 16 representatives from DPOs.⁷⁸

In 2011, CERMI prepared a report in the wake of Spain's examination by the CRPD Committee, based on the UN's concluding observations, and its own observations of rights violations.⁷⁹ While CERMI does reference its own role as the monitoring mechanism in Spain, it does not offer a critique of Spain's implementation of Article 33 in the report.⁸⁰ Spain presents an interesting example of how Article 33 bodies, including the focal point, coordination mechanism and monitoring framework, can actively involve civil society.

[CO%2f1&Lang=en](#)> (last accessed, 29 April 2016).

78 EBU, 'Information for Countries: Spain' [web page] available at <<http://www.euroblind.org/convention/article-33--national-implementation-and-monitoring/nr/2224>> (last accessed 31 March 2016).

79 CERMI, *Human Rights and Disability, Spain Report 2011*, available at <http://www.conven-ciondiscapacidad.es/Informes_new/III%20%20INFORME%20DDHH%202011%20eng.pdf> (last accessed 31 March 2016).

80 CERMI, *Human Rights and Disability, Spain Report 2011*, available at <http://www.conven-ciondiscapacidad.es/Informes_new/III%20%20INFORME%20DDHH%202011%20eng.pdf> (last accessed 31 March 2016).

Spain was the first state examined by the CRPD Committee to have a formal, permanent civil society body as part of its monitoring framework. There are clear advantages to this method of including civil society in the monitoring process. Spain was commended by the CRPD Committee, and no complaints from civil society about the monitoring mechanism were uncovered during research for this report. For states like Spain, that have an existing, well-regarded and cross-disability NGO, this kind of framework could be an attractive option. For Ireland, which lacks a single umbrella group for all DPOs and NGOs working on disability issues, and where much of the work of disability rights activism is done by individuals, the idea of a permanent civil society body in the monitoring framework would probably require the development of a new organisation.

2.6 Sweden: NHRI Jointly Designated with Statutory Disability Body

Sweden also created a two-body monitoring framework, although with some important differences. According to Sweden's state report, for its monitoring framework the government of Sweden decided that the Equality Ombudsman should be the main body in the framework, but that Handisam – the government agency for disability policy coordination – should also have responsibilities, such as training and providing information.⁸¹ Sweden's Equality Ombudsman

81 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in*

is a 'B status' NHRI according to the GANHRI.⁸² Handisam is an agency within the Ministry of Health and Social Affairs, established in 2006 to implement the national disability strategy. This body is similar in structure and functions to the National Disability Authority in Ireland.

In its list of issues in response to the state report, issued in the autumn of 2014, the CRPD Committee asked Sweden to clarify the powers and independence of the monitoring mechanism.⁸³ The CRPD Committee also requested more information, including what resources the framework had been given to do its work, and how Sweden was ensuring the 'meaningful involvement' of persons with disabilities. In this list of issues, when commenting on Sweden's Article 33 framework as a whole, the committee was also concerned about multiple discrimination, and asked how Sweden will ensure that the 'disability perspective' is taken into account across all human rights treaties that

Sweden has ratified.⁸⁴ This question, which was not asked of Spain, one of the earliest states examined, could suggest that the CRPD Committee has been broadening its concerns and the functions that it believes are necessary for the monitoring mechanism. It could also be a reflection of the issues raised in shadow reports from various civil society groups in Sweden. In Sweden's reply, the state noted that the Paris Principles had been taken into account in the mandate of the Equality Ombudsman, and that the mandate of the Ombudsman was to deal with discrimination claims in any area of community life, including disability. The Ombudsman also works to raise awareness of discrimination laws and government action in the area of non-discrimination.⁸⁵

Civil society organisations also responded to the List of Issues. The Swedish Federation for Human Rights for Persons with Disabilities, an umbrella group of disability rights organisations, responded to the List of Issues by stating that Sweden had not created an independent mechanism. This response did not mention Handisam, but did state that in its opinion, the Equality Ombudsman was not independent enough to qualify as an

accordance with article 35 of the Convention, Sweden, paragraphs 350–353, U.N.Doc. CRPD/C/Swe/1.

82 'Directory of Institutions – Europe' [web page] <<http://nhri.ohchr.org/EN/Contact/NHRIs/Pages/Europe.aspx>> (last accessed 27 April 2016).

83 Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of Sweden, adopted by the Committee at its tenth session*, paragraph 46, U.N.Doc. CRPD/C/SWE/Q/1.

84 Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of Sweden, adopted by the Committee at its tenth session*, paragraph 46, U.N.Doc. CRPD/C/SWE/Q/1.

85 Committee on the Rights of Persons with Disabilities, *Replies of Sweden to the list of issues*, paragraphs 192–195, U.N.Doc. CRPD/C/SWE/Q/1/Add.1.

independent mechanism.⁸⁶ However, the Swedish Disability Federation also responded to the list of issues, and noted that, in its view, Sweden does not have an NHRI of the type described in Article 33. It also criticised the government decision to designate the monitoring framework via a ministerial letter, instead of a parliamentary bill, which would have involved parliamentary debate.⁸⁷ This is notable as it is the only example of a shadow report (of those that we examined) that comments on and criticises the method by which the monitoring framework was created.

In its conclusions on Sweden's report, the CRPD Committee was not satisfied with the monitoring framework Sweden had created. The CRPD Committee stated that 'the state party has not yet introduced an independent mechanism based on the principle relating to the status of national institutions for the protection and promotion of human

rights (Paris Principles) to monitoring the implementation of the Convention.' The CRPD Committee recommended that Sweden establish an independent monitoring mechanism.⁸⁸

Clearly, some aspect of Sweden's framework was not acceptable to the CRPD Committee. The fact that Sweden's Ombudsman is a 'B status' NHRI, compared to the 'A status' NHRIs of Germany and Spain, may have been a problem. It is entirely possible that the CRPD Committee felt that the Ombudsman was therefore not independent enough to serve as the independent mechanism in a monitoring framework. The fact that Handisam, while given a lesser role of providing information and raising awareness, is a governmental body could also have been a problem. Certainly, as a government body, Handisam could not fulfil the independence requirement of Article 33. It is interesting that civil society, while not satisfied with the framework, chose to focus on the Ombudsman, instead of Handisam. When Handisam was referenced by civil society, it was generally in a neutral matter, referring to the organisation's work.⁸⁹

86 Swedish Equally Unique – The Swedish Federation Human Rights for Persons with Disabilities, *Submission and comments on the Written replies by the government of Sweden to the list of issues CRPD/C/SWE/E/Q1* available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2f-NGO%2fSWE%2f16664&Lang=en> (last accessed 31 March 2016).

87 Swedish Disability Federation, *Replies to the List of Issues*, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2f-NGO%2fSWE%2f16818&Lang=en> (last accessed 31 March 2016).

88 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Sweden*, paragraph 61, U.N.Doc. CRPD/C/SWE/CO/1 (2014).

89 For example, the Swedish Disability Federation refers to a study by Handisam showing that people of non-Swedish background generally take longer to have their disability recognised by government. See Swedish Disability Federation, *To the Committee on the Rights of Persons*

It should also be noted that unlike Spain, Sweden did not provide a permanent role for civil society in the monitoring process. The CRPD Committee did not comment specifically on this in its recommendations under Article 33. However, it did recommend that Sweden make more of an effort to involve civil society in the preparation of future periodic reports.⁹⁰ Ireland could create a framework similar to Sweden's by designating its NHRI and a statutory body such as the National Disability Authority. However, the trend in Concluding Observations from the CRPD Committee, as will be discussed further in the following two examples, suggests that a more formal role for civil society in the monitoring framework would constitute international best practice.

2.7 New Zealand: Multi-body Framework with NHRI and DPOs

New Zealand is an example of a tripartite monitoring framework. The New Zealand Human Rights Commission (an 'A status'

NHRI⁹¹) and the Office of the Ombudsman have both been appointed as part of the monitoring framework. Additional funding has been provided to allow these bodies to take on new responsibilities.⁹² In addition, the New Zealand Convention Coalition, an umbrella group of DPOs that is funded by the New Zealand government, forms the third element of the monitoring framework.⁹³ This umbrella group consists of representatives from six national DPOs: the Association of Blind Citizens of New Zealand Inc; Deaf Aotearoa New Zealand Inc; Disabled Persons Assembly; Ngā Hau E Wha; Ngati Kāpo o Aotearoa Inc; and People First New Zealand Inc – Ngā Tāngata Tuatahi.⁹⁴

with Disabilities: Proposals on questions for the List of issues of Sweden, at page 8, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2fSWE%2f10%2f20822&Lang=en> (last accessed 31 March 2016).

90 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Sweden*, paragraph 64, U.N.Doc. CRPD/C/SWE/CO/1 (2014).

91 'Directory of Institutions – Asia Pacific' [web page] <<http://nhri.ohchr.org/EN/Contact/NHRIs/Pages/Asia-Pacific.aspx>> (last accessed 27 April 2016).

92 *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, New Zealand*, U.N.Doc CRPD/C/NZL/1 paragraphs 267–274 (1 October 2013)..

93 *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention, New Zealand*, U.N.Doc CRPD/C/NZL/1 paragraphs 267–274 (1 October 2013)..

94 New Zealand Human Rights Commission, *Making Disability Rights Real* Available at <<https://www.hrc.co.nz/files/2014/2357/0091/Making-disability->

Within this framework, each body has different responsibilities. The Human Rights Commission has a Commissioner with responsibility for disability rights, and the Commissioner's role is to identify areas where people with disabilities are vulnerable, and advocate for solutions from government, the private sector, and the community.⁹⁵ The role of the Ombudsman within the monitoring framework is to accept, and where appropriate, investigate complaints about the conduct of state agencies concerning violations of the rights of people with disabilities.⁹⁶ The Convention Coalition is designed to ensure that people with disabilities have a role in the monitoring process, and to provide a point for people with disabilities to have direct input into the process.⁹⁷

New Zealand's monitoring framework is not mentioned in the List of Issues from the spring of 2014 that the CRPD Committee put forward in response to the state report.⁹⁸ In the CRPD Committee's concluding observations, the monitoring framework is mentioned only once, as a positive aspect of New Zealand's report, and the CRPD Committee commends New Zealand for establishing an independent monitoring mechanism in accordance with the CRPD.⁹⁹ While several civil society groups,¹⁰⁰ as well as the New

[ty-rights-real.html](https://www.hrc.co.nz/files/2014/2357/0091/Making-disability-rights-real.html)> (last accessed 31 March 2016).

95 New Zealand Human Rights Commission, 'Making Disability Rights Real' [web page] available at <<https://www.hrc.co.nz/files/2014/2357/0091/Making-disability-rights-real.html>> (last accessed 31 March 2016).

96 New Zealand Human Rights Commission, 'Making Disability Rights Real' [web page] available at <<https://www.hrc.co.nz/files/2014/2357/0091/Making-disability-rights-real.html>> (last accessed 31 March 2016).

97 New Zealand Human Rights Commission, 'Making Disability Rights Real' [web page] available at <<https://www.hrc.co.nz/files/2014/2357/0091/Making-disability-rights-real.html>> (last accessed 31 March 2016).

[ty-rights-real.html](https://www.hrc.co.nz/files/2014/2357/0091/Making-disability-rights-real.html)> (last accessed 31 March 2016).

98 Committee on the Rights of Persons with Disabilities, *List of Issues in relation to the Initial Report of New Zealand*, U.N.Doc. CRP-D/C/NZL/Q/1 (2014).

99 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of New Zealand*, paragraph 4, U.N.Doc. CRPD/C/NZL/CO/1 (31 October 2014).

100 Disabled Persons Assembly and others, *New Zealand DPOs submission on the list of issues and questions for the New Zealand Government*, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2fNZL%2f16660&Lang=en> (last accessed 31 March 2016); Acclaim Otago, *The Costs of Paradigm Change: Access to Justice for People with Disabilities Caused by Personal Injury in New Zealand – A Shadow Report to the United Nations Committee on the Convention on the Rights of Persons with Disabilities*, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2fNZL%2f16660&Lang=en> (last accessed 31 March 2016).

Zealand Human Rights Commission,¹⁰¹ submitted reports, none offered criticism of the monitoring framework. According to the New Zealand state report, the Office for Disability Issues (ODI) is the designated focal point for the Convention. For a coordination mechanism, the ODI established the Ministerial Committee on Disability Issues. The membership of this Committee includes senior Ministers, and it is tasked with improving the implementation process.¹⁰²

ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2fNZL%2f17807&Lang=en (last accessed 31 March 2016); Disabled Persons Assembly NZ Inc. and others, *Report to the United Nations Committee on the Rights of Persons with Disabilities on New Zealand's Implementation of the Convention on the Rights of Persons with Disabilities*, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2fNZL%2f18075&Lang=en> (last accessed 31 March 2016).

101 New Zealand Human Rights Commission, *Consideration of New Zealand's initial report under Article 35 of the Convention on the Rights of Persons with Disabilities: Response to List of issues*, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNHS%2fNZL%2f18087&Lang=en> (last accessed 31 March 2016).

102 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities*,

New Zealand offers an example of a larger framework than any of the other states considered in this study. That framework combines New Zealand's existing human rights infrastructure – in the form of the Human Rights Commission and the Ombudsman – with a newly created umbrella group. The fact that New Zealand was able to create an umbrella group that served the narrow purpose of ensuring civil society participation in the monitoring process – may be an encouraging example for Ireland, which lacks a pre-existing umbrella group in disability rights. Neither civil society nor the Committee raised any concerns about the New Zealand framework during the examination, at least none that appeared in the Concluding Observations or shadow reports from autumn 2014. However, it is important to note that New Zealand's Convention Coalition is fairly small, representing only 6 groups, and does not, for instance, include any groups representing people who have experience of mental health issues. It is also important to note that, like the other countries in our study, New Zealand did not set out any explicit route for individuals to participate in the monitoring process outside of the network of DPOs. In many ways, New Zealand is quite similar to Ireland, which makes it a valuable example. However, as is shown in Chapter 4, New Zealand's network of DPOs is more advanced than Ireland's, with more and larger national DPOs, with more stable funding and

Initial reports submitted by States parties in accordance with article 35 of the Convention, New Zealand, paragraphs 267–274, U.N.Doc CRPD/C/NZL/1 (1 October 2013).

experience of contributing to human rights monitoring. For example, representatives from the majority of the DPOs in the New Zealand Coalition were involved in the negotiations on the drafting of the CRPD, whereas for Ireland, only a few individual activists participated in the negotiations. Lacking such a network and experience of human rights monitoring, Ireland may not be able to replicate New Zealand's example of a Convention Coalition, but as is discussed in Chapter 4, other options are available, including through seeking individuals to represent the broad diversity of the disability community in Ireland.

Table 1 at the end of this chapter represents a summary of the findings across all six case studies considered in this chapter against the requirements of the CRPD Committee. In this analysis, New Zealand emerges as the case study which meets all the criteria considered, and appears as a promising practice for further consideration in the Irish context.

2.8 Conclusion

Table 1 summarises the profiles of the frameworks that have been established in the six countries we examined. The six examples offer both good practices that have been accepted by the Committee and by civil society and some notes of caution about practices that are less than ideal. First, having an 'A status' NHRI in the monitoring framework is clearly desirable. The Committee generally accepted all examples in this study that had an 'A status' NHRI without criticism of their form, even in the case of Germany, which had no other bodies involved,

and no formal, permanent role for civil society. Germany was criticised for not providing enough resources,¹⁰³ which indicates that a good choice of framework is not enough; the framework must have the resources to operate effectively. This problem also appears in the UK example, where civil society noted that the monitoring framework is unable to carry out effective awareness raising, which in turn limits its effectiveness.¹⁰⁴

A monitoring framework also must be independent from government, as the Concluding Observations of the Committee make clear.¹⁰⁵ This is most starkly illustrated in the example of Sweden, which used both an NHRI that was not certified as fully independent, and a government agency. With this framework, Sweden was criticised by the Committee, which did not feel that Sweden had been able to create an independent

103 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Germany*, paragraphs 61–62, U.N.Doc. CRPD/C/DEU/CO/1 (13 May 2015).

104 Centre on Human Rights for People with Disabilities, *Draft Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland*, available at <<http://www.disabilityaction.org/centre-on-human-rights/shadowreport/>> (last accessed 31 March 2016).

105 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Sweden*, paragraph 61, U.N.Doc. CRPD/C/SWE/CO/1 (2014).

framework as required by the Committee.¹⁰⁶ While the Committee seems to look for a fully independent, properly resourced framework, civil society has higher demands. In Germany, Sweden, and the UK, where the monitoring framework lacks a permanent, formal role for civil society, civil society is much more likely to criticise the framework in shadow reports, and request a greater role in the process. This is true even in Germany, where civil society does have a formal role in the coordination mechanism under Article 33.

There are also aspects of these frameworks that are not addressed by the Committee or civil society, but deserve further comment here. In none of the states in this study is an explicit method provided for individuals with disabilities to participate in the monitoring process separately from DPOs or umbrella groups. Most states that have civil society participation focus on organisations, such as umbrella groups in the case of Spain and New Zealand, or invited organisations in the case of Germany. While this may meet the current standards of the Committee, it is worth noting that it does not meet the high standard of the CRPD as it is understood by many scholars.¹⁰⁷

Malta was the only state examined for this report which created a body composed of individuals with disabilities in its monitoring framework, rather than relying on existing organisations. One of the dangers of using a group of DPOs as a part of the monitoring framework is that certain segments of the disability community may be left out. In the case of New Zealand, none of the six groups in the Convention Coalition represent people with experience of mental health issues. The creation of a body composed of individuals, similar to Malta's, may serve to avoid the problem of under-representation of various groups. All these factors should be taken into account in the creation of Ireland's monitoring framework under Article 33, and this is discussed in further detail in Chapter 4.

106 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Sweden*, paragraph 61, U.N.Doc. CRPD/C/SWE/CO/1 (2014).

107 See, for example: Mental Disability Advocacy Centre, *Building the Architecture for Change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities*, 15, <http://mdac.info/sites/mdac.info/files/Article_33_EN.pdf> (last accessed 31 March 2016).

Table 1

Summary of the situation with the Article 33 frameworks in the six countries in this study

State	Multi-body Framework	Formal mechanism to consult with civil society	Civil society is a permanent part of the framework	Created a DPO for the framework	'A' status NHRI in Framework
Germany		✓			✓
UK	✓				✓
Spain	✓	✓	✓		✓
Sweden	✓				
Malta		✓	✓	✓	
New Zealand	✓	✓	✓	✓	✓

Chapter 3: How States Support Involvement of People with Disabilities in CRPD Monitoring – A Global Perspective

35

3.1 Introduction

This chapter examines how different states have involved civil society in their Article 33 mechanisms. The chapter starts by exploring how the six states (Germany, Malta, New Zealand, Spain, Sweden and the UK) have involved civil society in implementing the CRPD and in particular how Article 33 mechanisms have involved people with disabilities and DPOs. In addition to these six states, this chapter looks at how other states that may have less well established DPO networks have involved people with disabilities into their Article 33 mechanisms. The chapter also looks at models for the involvement of people with disabilities in CRPD monitoring and concludes with a summary of important considerations in establishing involvement of civil society and DPOs.

3.2 Civil Society Involvement in Germany

3.2.1 DPO and Civil Society Involvement in the State Report

A study of Article 33 implementation in Germany reported that the Federal Ministry for Labour and Social Affairs, which funds the independent mechanism, 'regularly consults with civil society and the German Disability Council in particular.'¹⁰⁸ However, a report

submitted to the CRPD Committee from the BRK-Allianz (an alliance of German NGOs with a focus on the CRPD) indicates dissatisfaction with the inclusion of civil society and people with disabilities. The report states that while DPOs and people with disabilities have been invited to take part in governmental committees and meetings, their participation has not been given equal weight compared with other members of the various committees in question.¹⁰⁹ The report further asserts that the state report submitted by Germany at the time of its examination in the spring of 2014 was compiled without the involvement of people with disabilities or their representative organisations.¹¹⁰ This issue was mentioned by CRPD Committee in the concluding observations for Germany in 2014.¹¹¹

108 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities in Europe*, UN Office of the High Commissioner of Human Rights, Europe Regional Office (2014) 25, available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> (last accessed 15 March 2016).

109 BRK-Allianz, *Submission by the German CRPD Alliance (BRK-Allianz) for the List of Issues on Germany Committee on the Rights of Persons with Disabilities 11th Session, 31 Mar – 11 Apr 2014* (December 2013) 9, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpdc-committee-31-march-2014>> (last accessed 15 March 2016).

110 BRK-Allianz, *Submission by the German CRPD Alliance (BRK-Allianz) for the List of Issues on Germany Committee on the Rights of Persons with Disabilities 11th Session, 31 Mar – 11 Apr 2014* (December 2013) 9, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpdc-committee-31-march-2014>> (last accessed 15 March 2016).

111 Committee on the Rights of Persons with Disabilities, *Concluding Observations on*

3.2.2. DPO and Civil Society Involvement in the Article 33 Mechanism

The BRK-Allianz also praised the independent monitoring body for actively consulting with DPOs and for trying to employ people with disabilities on the staff of the monitoring body.¹¹² In discussing the participation of people with disabilities in relation to Article 4 of the CRPD, the Article 33 national monitoring body suggested that the government needs to adopt an empowerment approach and recommended that self-advocacy groups – especially self-advocacy groups of marginalised groups of people with disabilities – must be ‘strengthened and appropriately equipped’ in order to better facilitate participation.¹¹³

the Rights of Persons with Disabilities-Germany. 13 May 2015, CRPD/C/DEU/CO/1, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en> (last accessed 15 March 2016).

112 BRK Allianz, BRK-Allianz, *Submission by the German CRPD Alliance (BRK-Allianz) for the List of Issues on Germany Committee on the Rights of Persons with Disabilities 11th Session, 31 Mar – 11 Apr 2014*. (December 2013), 28, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpdc-committee-31-march-2014>> (last accessed 15 March 2016).

113 German Institute for Human Rights, *Parallel Report to the UN Committee on the Rights of Persons with Disabilities-in the contexts of the*

3.2.3 DPO and Civil Society Involvement in Shadow Reporting

There were several shadow reports written by civil society groups in Germany including BRK Allianz, which made a series of submissions to the CRPD Committee during the examination of Germany in 2014. However, there was limited participation of civil society in the development of the state report, which led the CRPD Committee to recommend that further efforts should be made in future state reporting to actively involve the representative organisations of persons with disabilities.¹¹⁴

examination of the Initial Report of Germany under Article 35 of the UN Convention on the Rights of Persons with Disabilities (Berlin, March 2015) 10, available at <http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Sonstiges/Parallel_Report_to_the_UN_Committee_on_the_Rights_of_Persons_with_Disabilities_March_2015.pdf> (last accessed 15 March 2016).

114 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Rights of Persons with Disabilities-Germany*, 13 May 2015, CRPD/C/DEU/CO/1, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en> (last accessed 15 March 2016).

3.3 Civil Society Involvement in New Zealand

3.3.1 DPO and Civil Society Involvement in the State Report

In 2013 the government of New Zealand developed principles of engagement with people with disabilities, which defined DPOs in accordance with the CRPD definition and recognised them as the representative organisations of people with disabilities.¹¹⁵

The Ministry of Social Development noted that involvement of DPOs does not preclude the involvement of other disability organisations 'so long as DPOs always have the opportunity to participate.'¹¹⁶

The ministry outlined five principles of engagement:

- '1. Government will engage with DPOs as representatives of disabled people
2. We involve the right people, at the right time, in the right work
3. We value the contribution of each party and make it easy to engage
4. We will be open, honest, transparent and creative in our engagement with each other
5. We jointly learn about how to engage with each other.'¹¹⁷

Despite this involvement, in its Concluding Observations the CRPD Committee asked New Zealand to better involve DPOs in the development of its second periodic report.¹¹⁸

115 Ministry of Social Development of New Zealand, Office for Disability Issues, 'Disability Action Plan 2014-2018, We worked with DPOs to develop the new plan' [web page] available at <<http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan/2014-2018/we-worked-with-dpos-to-develop-the-new-plan.html>> (last accessed 15 March 2016).

116 Ministry of Social Development of New Zealand, Office for Disability Issues, 'Disability Action Plan 2014-2018, We worked with DPOs to develop the new plan', [web page] available at <<http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan/2014-2018/we-worked-with-dpos-to-develop-the-new-plan.html>> (last accessed 15 March 2016).

117 Ministry of Social Development of New Zealand, Office for Disability Issues, 'Disability Action Plan 2014-2018, We worked with DPOs to develop the new plan', [web page] available at <<http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan/2014-2018/we-worked-with-dpos-to-develop-the-new-plan.html>> (last accessed 15 March 2016).

118 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Rights of Persons with Disabilities – New Zealand*, 31 October 2015, CRPD/C/NZL/CO/1, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fCO%2f1&Lang=en> (last accessed 15 March 2016).

3.3.2 DPO and Civil Society Involvement in the Article 33 Mechanism

The Government of New Zealand also set up a New Zealand Convention Coalition Monitoring Group (Convention Coalition), which is described as ‘a governance-level steering group by disabled peoples’ organisations’ that is tasked with providing the civil society input into the CRPD monitoring process.¹¹⁹ This Convention Coalition along with the New Zealand Human Rights Commission and the Ombudsman constitute the independent monitoring mechanism. The independent mechanism of New Zealand has issued two annual reports. In its most recent report it recommended that the government change the way it was funding the Convention Coalition to allow for more independence.¹²⁰ The government responded by moving from a year-to-year funding on contract basis to a

three-year contract with a guaranteed level of funding each year.¹²¹

3.3.3 DPO and Civil Society Involvement in Shadow Reporting

The Convention Coalition is government-funded and is made up of members from a diverse group of national disability organisations that represent not only the diversity of types of disabilities but also the ethnic diversity of New Zealand.¹²² As noted in Chapter 2, however, none of the groups represent people with experience of mental health issues. Members of the group are all people with disabilities who have been trained by Disability Rights Promotion International (a collaborative human rights monitoring

119 Ministry of Social Development of New Zealand, Office for Disability Issues, ‘Framework to promote, protect and monitor implementation’ [web page] available at <<http://www.odi.govt.nz/what-we-do/un-convention/framework/index.html>> (last accessed 15 March 2016).

120 Independent Monitoring Mechanism, *Making Disability Rights Real: Second Report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities*, (July 2012 – December 2013) 107, available at <<https://www.hrc.co.nz/files/8014/2357/0686/Making-disability-rights-real-full-report.pdf>> (last accessed 15 March 2016).

121 Independent Monitoring Mechanism, *Making Disability Rights Real: Second Report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities*, (July 2012 – December 2013) 107, available at <<https://www.hrc.co.nz/files/8014/2357/0686/Making-disability-rights-real-full-report.pdf>> (last accessed 15 March 2016).

122 Independent Monitoring Mechanism, *Making Disability Rights Real: Second Report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities*, (July 2012 – December 2013) 107, available at <<https://www.hrc.co.nz/files/8014/2357/0686/Making-disability-rights-real-full-report.pdf>> (last accessed 15 March 2016).

project)¹²³ to interview people with disabilities on how they have experienced their rights in New Zealand.¹²⁴ The Convention Coalition has issued several monitoring reports about the experiences of people with disabilities in New Zealand that relate to the CRPD.¹²⁵ The reports are available in different formats, to make them accessible to different groups. The Convention Coalition in its report to the CRPD Committee in 2014 recommended that the government provide ongoing funding to the Convention Coalition to enable it to fully monitor the Convention and assist the independent mechanism.¹²⁶

123 DRPI is a collaborative project to establish a comprehensive, sustainable international system to monitor human rights of people with disabilities.

124 Independent Monitoring Mechanism, *Making Disability Rights Real: Second Report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities*, (July 2012 – December 2013) 107, available at <<https://www.hrc.co.nz/files/8014/2357/0686/Making-disability-rights-real-full-report.pdf>> (last accessed 15 March 2016).

125 Disabled Persons Assembly New Zealand, 'Convention Coalition Monitoring Group Reports' [web page] Available at <<http://www.dpa.org.nz/resources/sector-resources/the-convention-disability-rights-in-aotearoa-new-zealand>> (last accessed 15 March 2016).

126 Disabled Persons Assembly NZ Inc. and others, *Report to the United Nations Committee*

3.4 Civil Society Involvement in Malta

3.4.1 DPO and Civil Society Involvement in the State Report

Malta's state report notes that it was prepared by the Focal Point Office within the Parliamentary Secretariat for the Rights of Persons with Disability and Active Aging. It was prepared in consultation with other government bodies, and discussions were held with people with disabilities and NGOs in the disability sector.¹²⁷ As Malta has not yet been examined by the CRPD Committee, the reactions of the CRPD Committee to this level of participation are not yet known.

3.4.2 DPO and Civil Society Involvement in the Article 33 Mechanism

As described in Chapter 2, the designated independent mechanism for Malta is solely the National Commission of Persons with Disability (KNPD). The Commission created a new body, the Disabled People's Advisory Committee (DPAC), which consists of 12 individuals with disabilities and family

on the Rights of Persons with Disabilities on New Zealand's Implementation of the Convention on the Rights of Persons with Disabilities, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2fNZL%2f18075&Lang=en> (last accessed 31 March 2016).

127 Committee on the Rights of Persons with Disabilities, *Initial reports of States Parties due in 2014: Malta*, U.N.Doc. CRPD/C/MLT/1 (2014).

members as part of its monitoring framework. The selection process for the DPAC was conducted by the KNPD. The selection committee chose one person to represent each impairment group (and the parent representatives) and a person who would stand in if the first representative was unable to attend the meeting. Members of the DPAC come from a diverse range of backgrounds and experience, and significant efforts were made to accommodate all members. The KNPD is in the process of setting up a separate forum for NGOs that work on disability rights but are not DPOs.¹²⁸

The two groups making up the DPAC – general DPOs and intellectual disability DPOs – meet on average once every two months. The DPAC has been very vocal in its views on the adequacy of existing legislation to assist the inclusion of disabled people in society and has made a number of recommendations regarding current policies that the Government has in place. The Parliamentary Secretary for the Rights of Persons with Disability is informed of advice given and has also attended some meetings in order to explain legislation or take questions from the committee members of both groups. The response from the disability community in Malta to the formation of the DPAC has been positive overall.¹²⁹

128 Email communication from Rhonda Garland, Executive Director of KNPD, submitted to research team on 3 April 2016.

129 Email communication from Rhonda Garland, Executive Director of KNPD, submitted to research team on 3 April 2016.

The DPAC is funded by the KNPD, which receives its budget from the Government. The KNPD provides secretarial support to the DPAC through its CRPD Manager, whose role is to organise the committee meetings (logistics, transport provision, sign language interpreters), to answer queries submitted by the public, and to organise awareness raising conferences on different articles in the CRPD. Members of the committee are not paid, but transport and sign language interpretation are provided for them. In addition, when the DPAC committee was formed, an EU-funded research project was launched to ascertain the current situation of disabled people in Malta in all areas of their lives. The committee members formed part of the steering group for this project and they were paid for each meeting they attended.¹³⁰

This is a particularly interesting example to consider in the Irish context, in light of the fact that there is a small number of organisations that meet the CRPD Committee's definition of a DPO, and many of these do not have significant funding to carry out functions required in the monitoring process. (These issues are discussed in Chapter 4.)

3.4.3 DPO and Civil Society Involvement in Shadow Reporting

The KNPD prepared a shadow report in 2013. While the KNPD does cover the technical details of being appointed as the monitoring mechanism and beginning the creation of the

130 Email communication from Rhonda Garland, Executive Director of KNPD, submitted to research team on 3 April 2016.

DPAC, it does not cover the involvement of civil society in the monitoring process.¹³¹

3.5 Civil Society Involvement in Spain

3.5.1 DPO and Civil Society Involvement in the State Report

The CRPD Committee asked that Spain have more involvement of civil society, particularly DPOs in the creation of its periodic report.¹³²

3.5.2 DPO and Civil Society Involvement in the Article 33 Mechanism

Spain designated CERMI, an umbrella group of organisations of persons with disabilities, as its independent mechanism.¹³³ CERMI

represents people with disabilities and their families and defines its mission as 'articulating and structuring the Spanish disability social movement to develop a representative political action in defence of the rights and interests of persons with disabilities and their families.'¹³⁴ In its report to the CRPD Committee CERMI did not make any comment on the involvement of people with disabilities or DPOs in the monitoring process.¹³⁵

3.5.3 DPO and Civil Society Involvement in Shadow Reporting

In 2007, the United Nations Department of Economic and Social Affairs formed a high-level expert group with the OHCHR, the Government of Spain and Fundación ONCE (a disability NGO in Spain), and held a meeting in Spain to discuss civil society participation and

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- 131 National Commission Persons with Disability, *Working Towards the Implementation of the United Nations Convention on the Rights of Persons with Disabilities*, 37, available at <http://www.knpd.org/wp-content/uploads/2016/04/007-Implementation_UN-CRPD-Report.pdf> (last accessed 25 April 2016).
- 132 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Rights of Person with Disabilities-Spain*, 19 October 2011, CRPD/C/ESP/CO/1, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en> (last accessed 15 March 2016).
- 133 Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the*

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- Rights of Persons with Disabilities in Europe*, UN Office of the High Commissioner of Human Rights, Europe Regional Office (2014) 36, available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> (last accessed 15 March 2016).
- 134 CERMI, 'Statutes' [web page], available at <<http://www.cermi.es/en-US/QueesCERMI/NormasReguladoras/Pages/Estatutos.aspx>> (last accessed 15 March 2016).
- 135 CERMI, *Human Rights and Disability: Alternative Report Spain 2010*, (2010), available at <<http://www.internationaldisabilityalliance.org/en/crpd-reports-0>> (last accessed 15 March 2016).

implementation of the CRPD.¹³⁶ The expert group made several recommendations related to DPO involvement in monitoring, including that civil society should 'Provide capacity to the national DPOs for implementation and monitoring of the CRPD at national level, including capacity on the specific monitoring techniques.'¹³⁷ This shows that Spain had meetings prior to establishing its Article 33 bodies to discuss and envision how civil society, especially DPOs, would fit into the monitoring structure and process.

3.6 Civil Society Involvement in Sweden

3.6.1 DPO and Civil Society Involvement in the State Report

The Swedish Disability Federation (Federation) notes in its report that the Ministry of Health and Social Affairs (Sweden's Article 33 focal point) did not invite civil

society to engage in dialogue about the Government's response to the list of issues, and the Federation noted that this is common practice for the other conventions in Sweden.¹³⁸ The Federation also noted that more needed to be done by the government to include the perspective of individuals with various disabilities.¹³⁹ The CRPD Committee echoed this concern in its concluding observations and asked that Sweden involve people with disabilities, particularly DPOs, in the creation of its periodic report.¹⁴⁰

136 *Making it work – Civil society participation in the implementation of the Convention on the Rights of Persons with Disabilities: Recommendations from the Expert Group to Civil Society*, available at <<https://view.officeapps.live.com/op/view.aspx?src=http://www.un.org/disabilities/documents/reports/egm/madridint.doc>> (last accessed 25 April 2016).

137 *Making it work – Civil society participation in the implementation of the Convention on the Rights of Persons with Disabilities: Recommendations from the Expert Group to Civil Society*, available at <<https://view.officeapps.live.com/op/view.aspx?src=http://www.un.org/disabilities/documents/reports/egm/madridint.doc>> (last accessed 25 April 2016).

138 Swedish Disability Federation (Handikapp Förbunden), *Comments on the written replies by the government of Sweden to the list of issues*, 8, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpdc-committee-31-march-2014>> (last accessed 15 March 2016).

139 Swedish Disability Federation (Handikapp Förbunden), *Comments on the written replies by the government of Sweden to the list of issues*, 31, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpdc-committee-31-march-2014>> (last accessed 15 March 2016).

140 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Rights of Persons with Disabilities-Sweden*, 12, May 2014, CRPD/C/SWE/CO/1, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fSWE%2fCO%2f1&Lang=en> (last accessed 15 March 2016).

3.6.2 DPO and Civil Society Involvement in the Article 33 Mechanism

The Swedish Disability Federation noted that Handisam (the independent monitoring body), arranged a forum with the Swedish Disability Federation, Equally Unique and the Swedish Federation for Human Rights for the national disability strategy.¹⁴¹ There was no information in any report on the level of involvement of civil society in Article 33 mechanisms.

3.6.3 DPO and Civil Society Involvement in Shadow Reporting

Equally Unique, a CRPD-focused organisation made up of six national disability organisations, also developed a shadow report to the CRPD Committee in 2013. Equally Unique's report notes that financial support for DPOs has remained unchanged in Sweden since ratification. In its view, however, there should be an increase in financial support to compensate for the increase in work arising from DPOs' active involvement in the work to implement the Convention.¹⁴²

141 Swedish Disability Federation, *Swedish disability movement's alternative report of the UN Committee on the Rights of Persons with Disabilities* (2011), 11, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2f-CRPD%2fNGO%2f10%2f20823&Lang=en> (last accessed, 29 April 2016).

142 Equally Unique, *Submission on the written replies by the government of Sweden to the list of issues CRPD/C/SWE/E/QI*, (June 2013) 4, available at <<http://www.internationald->

The Swedish Disability Federation was of the opinion that the government was handpicking experts or panels rather than having a democratic and transparent process of involvement of people from the disability movement.¹⁴³

3.7 Civil Society Involvement in the UK

3.7.1 DPO and Civil Society Involvement in the State Report

In the initial report from the United Kingdom to the CRPD Committee the UK in 2011, the government states that it extensively engaged with people with disabilities and their organisations in the preparation of the UK's report.¹⁴⁴ The report notes that government held several meetings with the

isabilityalliance.org/en/article/ida-information-note-11th-session-crpd-committee-31-march-2014> (last accessed 15 March 2016).

143 Swedish Disability Federation (Handikapp Förbunden), *Comments on the written replies by the government of Sweden to the list of issues*, 7, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpd-committee-31-march-2014>> (last accessed 15 March 2016).

144 Committee on the Rights of Persons with Disabilities, *UK Initial Report on the UN Convention on the Rights of Persons with Disabilities*, CRPD/C/GBR/1 (3 July 2013), 58, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?sym-

Disabled People’s Council (UKDPC) as a part of the CRPD working group and Network of Networks Project.¹⁴⁵ Participation in the CRPD working group was by invitation only, and the working group was chaired by a member of UKDPC.¹⁴⁶ Members of the working group were from a variety of disability organisations throughout the United Kingdom which represented diversity not only in impairment but also broader diversity within the disability community, including gender, race and ethnicity.¹⁴⁷

[bolno=CRPD%2fC%2fGBR%2f1&Lang=en>](#) (last accessed 15 March 2016).

145 Committee on the Rights of Persons with Disabilities, *UK Initial Report on the UN Convention on the Rights of Persons with Disabilities*, CRPD/C/GBR/1 (3 July 2013), 58, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2f1&Lang=en> (last accessed 15 March 2016).

146 Committee on the Rights of Persons with Disabilities, *UK Initial Report on the UN Convention on the Rights of Persons with Disabilities*, CRPD/C/GBR/1 (3 July 2013), 75, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2f1&Lang=en> (last accessed 15 March 2016).

147 Committee on the Rights of Persons with Disabilities, *UK Initial Report on the UN Convention on the Rights of Persons with Disabilities*, CRPD/C/GBR/1 (3 July 2013), 76–77, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Down-

The UK made its report available for public comment prior to submitting it to the CRPD Committee and included a summary of the issues raised by the public in the annex. The UK government said it also funded training sessions for the UKDPC to support its work in awareness raising around the CRPD.¹⁴⁸ One civil society group countered that the state’s initial report does not adequately reflect the work of the UKDPC: ‘Neither “involvement” nor “full participation” is apparent in the draft UK report; yet a significant investment of time has been made by disabled people’s organizations in the Working Group as part of the structure established by the UK government to meet this obligation.’¹⁴⁹

[load.aspx?symbolno=CRPD%2fC%2fGBR%2f1&Lang=en>](#) (last accessed 15 March 2016).

148 Committee on the Rights of Persons with Disabilities, *UK Initial Report on the UN Convention on the Rights of Persons with Disabilities*, CRPD/C/GBR/1 (3 July 2013), 76–77, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2f1&Lang=en> (last accessed 15 March 2016).

149 Reclaiming Our Futures Alliance, *ROFA’s Shadow Report – United Nations Convention on the Rights of Persons with Disabilities*, (October 2014) Article 33, available at <<http://www.rofa.org.uk/the-united-nations-convention-on-the-rights-for-disabled-people/>> (last accessed 15 March 2016).

3.7.2 DPO and Civil Society Involvement in the Article 33 Mechanism

In the Equality and Human Rights Commission's report (available in multiple accessible formats), the Commission notes that it actively worked to involve DPOs but states 'the primary responsibility for involvement rests with the UK as the state party.'¹⁵⁰ The Commission also recommended that the CPRD Committee ask the UK what resources the state has provided to ensure that people with disabilities and DPOs are actively involved in the reporting process across the UK.¹⁵¹ A group of civil society organisations noted that the designated independent mechanism, the Equality and Human Rights Commission, experienced serious cuts in funding and staff making it

difficult for the Commission to carry out its duties.¹⁵²

3.7.3 DPO and Civil Society Involvement in Shadow Reporting

Although the UKDPC was heavily mentioned and featured in the initial state report, it seems that the organisation stopped active operations in 2013 and no longer has a strong presence. One group that has formed is the Reclaiming Our Futures Alliance, which published a shadow report in response to the state report.¹⁵³

In 2013, the UKDPC conducted a survey on monitoring implementation of the CRPD. To date this has not been included in any of the official CRPD monitoring reports on the UK or as a separate shadow report.¹⁵⁴ As

150 Equality and Human Rights Commission, *Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities – The UK Independent mechanism list of issues interim report* (December 2014), 36, available at <<http://www.equalityhumanrights.com/about-us/our-work/human-rights/international-framework/un-convention-rights-persons-disabilities>> (last accessed 15 March 2016).

151 Equality and Human Rights Commission, *Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities – The UK Independent mechanism list of issues interim report* (December 2014), 36, available at <<http://www.equalityhumanrights.com/about-us/our-work/human-rights/international-framework/un-convention-rights-persons-disabilities>> (last accessed 15 March 2016).

152 Reclaiming Our Futures Alliance, *ROFA's Shadow Report – United Nations Convention on the Rights of Persons with Disabilities*, (October 2014) Article 33, available at <<http://www.rofa.org.uk/the-united-nations-convention-on-the-rights-for-disabled-people/>> (last accessed 15 March 2016).

153 Reclaiming Our Futures Alliance, *ROFA's Shadow Report – United Nations Convention on the Rights of Persons with Disabilities*, (October 2014), available at <<http://www.rofa.org.uk/the-united-nations-convention-on-the-rights-for-disabled-people/>> (last accessed 15 March 2016).

154 UK Disabled Peoples Council, *Survey: UN Convention and Disabled Peoples Rights in the UK* (09/04/2013), available at <<http://www.ukdpc.net/site/news-archive/202-ukdpc->

is discussed in Chapter 2, since the UK has not yet been scheduled for review by the CRPD Committee, it is likely that many DPOs and civil society organisations are not yet undertaking the preparation of their shadow reports in order to ensure that the reports submitted to the CRPD Committee will be as up to date as possible. It is also important to note that DPOs in the UK have been active in using the CRPD in domestic reform processes in other ways, for example requesting the CRPD Committee to investigate grave human rights violations caused by the ‘work capability assessment’ processes introduced as part of austerity cuts to the UK welfare system and their impact on people with disabilities, including on their right to life.¹⁵⁵

3.8 Other Examples of Civil Society Involvement in Article 33 Mechanisms

While it is useful to examine the six example states and their involvement of people with disabilities and civil society, the disability civil society landscapes of Spain, Malta, the United Kingdom, New Zealand, Sweden and Germany are not fully analogous to the landscape that currently exists in Ireland. While some

states in our sample (New Zealand and Malta) created new bodies to ensure involvement of people with disabilities, and some in the sample (New Zealand and Spain) drew from robust and existing DPO organisations and networks in the formation of their monitoring frameworks, it is important to note that states outside our sample, which may have weaker DPO networks and organisations, have created or supported new bodies to ensure the participation of people with disabilities. The following paragraphs provide short notes on three such states.

3.8.1 Rwanda

Rwanda ratified the Convention in 2008. In 2011 Rwanda created the National Council of Persons with disabilities, which is composed of ‘all persons with disabilities’,¹⁵⁶ and is designated as an Article 33 focal point. It receives government funding but is designated an independent body with financial and administrative autonomy. The National Council is charged with many duties, including monitoring laws that protect persons with disabilities and consulting and collaborating with foreign institutions that have similar duties.

[survey-un-convention-and-disabled-peoples-rights-in-the-uk-posted-090413](#)> (last accessed 15 March 2016).

155 Disabled People Against Cuts, *So DPAC triggered the UNCRPD inquiry but what does it really mean?* (8 September 2015), available at <<http://dpac.uk.net/2015/09/so-dpac-triggered-the-uncrpd-inquiry-but-what-does-it-really-mean/>> (last accessed 15 March 2016).

156 Law No. 03/2011 of 10/02/2011 Determining the Responsibilities, Organization and Functioning of the National Council of Persons with Disabilities, available at <<http://www.ilo.org/dyn/natlex/docs/SERIAL/93163/108817/F-678858339/RWA-93163.pdf>> (last accessed 15 March 2016).

3.8.2 Algeria

Algeria instituted a Council of People with Disabilities in 2014 (the executive order that provided for such a body was issued in 2006). The council is made up of 47 members that are a mix of ministry department representatives, organisations, disability services, and people with disabilities.¹⁵⁷ The council is a consultative body that is charged with studying the situation of persons with disabilities and advising the government. The council is also involved in Article 33 duties as a consultative body to the focal point.¹⁵⁸ In addition to this council, a platform of NGOs on the implementation of the CRPD was established in 2010. This platform included both DPOs and other disability organisations.¹⁵⁹

157 Ilhem Terki, 'Journée nationale des handicapés- la double injustice' *L'Expression* (15 March 2014), available at <<http://www.lexpressiondz.com/actualite/191201-la-double-injustice.html>> (last accessed 15 March 2016).

158 Comité des droits des personnes handicapées, *Rapport initial de Algérie*, CRPD/C/DZA/1 (2 November 2015), available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDZA%2f1&Lang=en> (last accessed 15 March 2016).

159 Paula Pinto *et al*, *L'inclusion sociale des personnes en situation de handicap dans la wilaya*, Document satellite Collection Recherche et Études Ds/RE|14, (November 2014), available at <<http://drpi.research.yorku.ca/>

3.8.3 Cyprus

Post ratification, Cyprus created a Pancyprrian Council for Persons with Disabilities that is composed of four representatives of from DPOs and has designated the Council as the coordination mechanism.¹⁶⁰ The Department for Social Inclusion of Persons with Disabilities provides the administrative support for the Pancyprrian Council.¹⁶¹ Outside the Article 33 mechanisms Cyprus already requires that the government consult with the Confederation of Organisations (an umbrella body made up of nine DPOs) on decisions that directly or indirectly impact on people with disabilities.¹⁶²

<wp-content/uploads/2015/01/rapport-al-g%C3%A9rie-WEB.pdf>>

160 Fundamental Rights Agency, *DPO involvement – Indicators on political participation of persons with disabilities*, (2014), 56, available at <https://fra.europa.eu/sites/default/files/fra-2014-right-political-participation-persons-disabilities_en.pdf> (last accessed 15 March 2016).

161 Cyprus Ministry for Labour, Welfare and Social Inclusion, 'Department for Social Inclusion of Persons with Disabilities' [web page], available at <<http://www.mlsi.gov.cy/mlsi/mlsi.nsf/All/E289FD9CBCFBDACEC-2257784002933B1?OpenDocument&highlight=pancyprrian%20disability%20council>> (last accessed 15 March 2016).

162 Fundamental Rights Agency of the EU, *The Right to political participation for persons with disabilities: human rights indicators*, (2014), available at <<https://fra.europa.eu/sites/default/files/fra-2014-right-political-par>

3.9 Other models of DPO Involvement

Disability Rights Promotion International (DRPI), an organisation based in York University in Canada, which is working to create an international system to monitor the rights of persons with disabilities, has offered a model for monitoring the rights of people with disabilities.¹⁶³ The organisation first started using its frameworks and tools in 2002, prior to the adoption of the CRPD, to ensure that people with disabilities were represented in the monitoring of other human rights treaties.¹⁶⁴ Since the entry into force of the CRPD, DRPI has refined its monitoring tools and expanded its methodologies to contribute to shadow reporting efforts and other opportunities for human rights monitoring for persons with disabilities. DRPI divides monitoring into three broad areas: **monitoring systems (legislative frameworks and case law); monitoring experiences of individuals; and monitoring media (societal**

attitudes).¹⁶⁵ DRPI holds that looking in these three areas creates a holistic monitoring framework that provides a fuller picture of the situation of people with disabilities.

The organisation's model requires participation and inclusion of people with disabilities in the lead role of monitoring. As stated in their training manual, 'The structure, organization and design of DRPI monitoring projects is grounded in, and based on, partnerships and the involvement of disabled people's organizations (DPOs) and people with disabilities.'¹⁶⁶ DRPI also promotes the use of human rights principles in their monitoring efforts. DRPI has five general human rights principles it abides by in monitoring¹⁶⁷:

[ticipation-persons-disabilities_en.pdf](#)> (last accessed 15 March 2016).

163 Disability Rights Promotion International, 'Disability Rights Monitoring' [web page] available at <<http://drpi.research.yorku.ca/disability-rights-monitoring/>> (last accessed 20 April 2016).

164 Disability Rights Promotion International, *Phase I Report – Opportunities, Methodologies, and Training Resources for Disability Rights Monitoring*, (October 2003), available at <http://drpi.research.yorku.ca/wp-content/uploads/2015/01/DRPI_Phase_I_Report.pdf> (last accessed 15 March 2016).

165 Disability Rights Promotion International 'Disability Rights Monitoring' [web page], available at <<http://drpi.research.yorku.ca/disability-rights-monitoring/>> (last accessed 15 March 2016).

166 Disability Rights Promotion International, *A Guide to Disability Rights Monitoring-Participant Version Country Training*, (November 2014) 24, available at <<http://drpi.research.yorku.ca/drpi-resources/drpi-regional-training-manual-a-guide-to-disability-rights-monitoring/>> (last accessed 15 March 2016).

167 Disability Rights Promotion International, *A Guide to Disability Rights Monitoring-Participant Version Country Training*, (November 2014), 25, available at <<http://drpi.research.yorku.ca/drpi-resources/drpi-regional-training-manual-a-guide-to-disability-rights-monitoring/>> (last accessed 15 March 2016).

- 1 Dignity
- 2 Autonomy
- 3 Participation, Inclusion and Accessibility
- 4 Non Discrimination and Equality
- 5 Respect for Difference

Through training and projects, DRPI has produced a range of monitoring reports of disability rights around the world.¹⁶⁸ New Zealand uses the DRPI model and has availed of its training for the Convention Coalition. Bosnia and Herzegovina also followed DRPI's model in the development of its shadow report to the CRPD Committee.¹⁶⁹ As is mentioned in Chapter 1, the process of how the monitoring framework fulfils its role under Article 33 is as important as its structure, and regard should be had in the designation of a framework in Ireland to the processes that will be used in its work and how these processes will facilitate the active involvement of people with disabilities.

[ty-rights-monitoring/](#)> (last accessed 15 March 2016).

168 Disability Rights Monitoring, 'DRPI Resources' [web page] available at <<http://drpi.research.yorku.ca/drpi-resources/>> (last accessed 20 April 2016).

169 MyRight, *Alternative report on the implementation on the implementation of the United Nations Convention on the Rights of Persons with Disabilities in Bosnia and Herzegovina* (Bosnia and Herzegovina 2014). Available at <<http://drpi.research.yorku.ca/wp-content/uploads/2015/01/Bosnia-Holistic-Report.-pdf.pdf>> (last accessed 15 March 2016).

3.10 Conclusion – Considerations for Involvement of Civil Society and DPOs in Article 33 Monitoring

3.10.1 Funding

As shown by the comments by civil society in Sweden and the example of New Zealand, funding of DPOs to support and encourage participation of people with disabilities in the monitoring of the Convention is hugely important. This is likely to be especially important in Ireland given that many of the disability organisations that are DPOs under the CRPD are small, and may not have the current capacity or resources to undertake CRPD monitoring duties without receiving funding and support from government.

3.10.2 Selection Processes

The sample of six states shows a mix of approaches to designating independent mechanisms and monitoring frameworks under Article 33. Some states appoint existing members of DPOs or civil society as part of their monitoring frameworks to ensure participation and involvement of people with disabilities (Spain, New Zealand) while others engaged in a transparent process of determining participation of individual representatives in the monitoring (Malta). It is important to note here that some states (Germany and Sweden) have been criticised by civil society for the lack of transparency in selection processes for the inclusion of people with disabilities and DPOs in monitoring the CRPD.¹⁷⁰

170 Swedish Disability Federation (Handikapp Förbunden), *Comments on the written replies*

3.10.3 Inclusion

The CRPD Committee has consistently informed states in its concluding observations that civil society, and in particular people with disabilities and DPOs, must be involved in Article 33 duties, including the development of the state report submitted to the CRPD Committee and the ongoing work of monitoring frameworks.¹⁷¹ The issue of exclusion from aspects of monitoring is also a common theme in shadow reports. This highlights the importance of the inclusion of people with disabilities in all parts of the monitoring process and the need to make sure DPOs and individuals with disabilities are included.

by the government of Sweden to the list of issues, 7, available at <<http://www.internationaldisabilityalliance.org/en/article/ida-information-note-11th-session-crpdc-committee-31-march-2014>> (last accessed 15 March 2016).

171 For example, Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Rights of Persons with Disabilities – Germany*, 13 May 2015, CRPD/C/DEU/CO/1, available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en> (last accessed 15 March 2016).

Chapter 4: The Irish Context: Civil Society and Representative Organisations of Persons with Disabilities

4.1 Introduction

As is set out in Chapter 1, Article 33.3 CRPD states that ‘civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process’. In its concluding observations, the CRPD Committee has often noted the importance of involving and need to involve organisations of people with disabilities in their monitoring duties.¹⁷² For the purposes of this analysis, a distinction must be drawn between ‘civil society’ and the more specific term ‘disabled peoples’ organisations’ (DPOs). The CRPD Committee has defined DPOs as ‘those comprising a majority of persons with disabilities – at least half their membership

– and governed, led and directed by persons with disabilities.’¹⁷³ While few national organisations in Ireland meet this exact definition, this chapter identifies a selection of organisations that probably do. There are many active organisations working on disability issues in Ireland who, although they are not DPOs under the CRPD’s definition, will also play an important role in monitoring. A selection of these organisations is also identified in this chapter, including disability advocacy organisations within civil society, statutory bodies, existing inspection and monitoring structures, and research organisations.

4.2 Methodology

This chapter aims to provide illustrative examples of some of the major national disability organisations, statutory bodies, and disability monitoring and inspection frameworks in Ireland in order to identify organisations that could be involved in any monitoring framework established in Ireland. Organisations that are national in scope and

172 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Turkmenistan*, CPRD/C/TKM/CO/1 (13 May 2015); Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of the Dominican Republic*, CPRD/C/DOM/CO/1 (8 May 2015); Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Peru*, CPRD/C/PER/CO/1 (16 May 2012); Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of China*, CPRD/C/CHN/CO/1 (15 October 2012); Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Hungary*, CPRD/C/HUN/CO/1 (22 October 2012); Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Argentina*, (CPRD/C/ARG/CO/1 (22 October 2012).

173 Committee on the Rights of Persons with Disabilities, *Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee*, CPRD/C/11/2 (April 2014) paragraph 3, Annex II in: *Report of the Committee on the Rights of Persons with Disabilities on its eleventh session (31 March–11 April 2014)* available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CPRD%2F-C%2F11%2F2&Lang=en> (last accessed 20 April 2016).

reach that include advocacy or research as part of their work were selected for inclusion. Where a large disability umbrella organisation exists, the umbrella organisation is included but not generally the organisations that fall under the umbrella body. This report attempts to identify the organisations whose ethos and membership closely align with or fit the definition of DPOs set out by the CRPD Committee. This information was gathered by the research team from organisation websites, from third-party organisations such as European or international NGOs, and from academic sources. There are many disability organisations in Ireland that are not listed here. Their omission does not mean that they are not a valuable part of the disability civil society landscape in Ireland nor does it mean that they should be excluded from contributing to future CRPD monitoring efforts.

4.3 Discussion

4.3.1 Defining DPOs under the CRPD and the Importance of Involvement of People with Disabilities

In the CRPD, the participation of people with disabilities is enshrined in Article 4.3. The unofficial motto of the Convention was 'nothing about us without us'.¹⁷⁴ This principle was put into practice throughout the drafting: people with disabilities and their

representative organisations were included in the negotiation of the Convention.¹⁷⁵

The inclusion of DPOs and people with disabilities in the drafting of the Convention has been seen as the first step in a continuing partnership between the Convention and the people it protects.¹⁷⁶ From the outset of the drafting of the Convention there was general support for the involvement of people with disabilities and their representative organisations in 'all levels of the monitoring process'.¹⁷⁷ As previous chapters have shown, the CRPD Committee continues to take the participation of people with disabilities seriously, particularly through DPOs. For this

174 Rosemary Kayess and Phillip French, 'Out of Darkness and into Light? Introducing the Convention on the Rights of Persons with Disabilities', *Human Rights Law Review*, 8(1) 1–34.

175 Janet E. Lord, 'The U.N. Disability Convention-Creating Opportunities for Participation' *Business Law Today*, 23 (May/June 2010).

176 Rosemary Kayess and Phillip French, 'Out of Darkness and into Light? Introducing the Convention on the Rights of Persons with Disabilities', *Human Rights Law Review*, 8(1) 1–34.

177 *Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Sixth Session* paragraph 159 (17 August 2005) U.N. Doc. No. A/60/266, available at <<http://www.un.org/esa/socdev/enable/rights/ahc6reporte.htm>> (last accessed 4 February 2016).

discussion, we rely on the definition of DPOs used by the CRPD Committee, given above.¹⁷⁸ Some disability organisations in Ireland represent multiple parties (for example, family members and people with disabilities) or both represent people and provide services to them. The CRPD is quite clear that under the Convention it is the person with the disability that is the rights holder. Even when the Convention mentions the family, its focus is on ensuring people with disabilities have the right to a family life, rather than on the rights of family members of people with disabilities.¹⁷⁹ In the context of monitoring, hybrid organisations such as these are unlikely to be considered DPOs using the CRPD Committee's definition, unless people with disabilities form the majority of their membership and direct and control the organisation

Ireland does not currently have a DPO that represents all people with disabilities (including people with experience of mental health issues), known as a 'cross-disability' DPO. There have been two attempts in the past 30 years to create a national DPO for all people with disabilities, People with Disabilities in Ireland (2000–2011)¹⁸⁰ and the Forum of People with Disabilities (1996–2000). The Irish government financially supported both organisations. Since 2011 there has been no state-funded national DPO that represents all people with disabilities in Ireland.¹⁸¹ This lack of an umbrella organisation could prove to be a challenge when it comes to creating a monitoring framework, as some states, such as Spain, have relied on existing national umbrella organisations to ensure the participation of people with disabilities.

Therefore, it is important to look at the different groups of people that make up people with disabilities to ensure that all people with disabilities are adequately

178 Committee on the Rights of Persons with Disabilities, *Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee*, CRPD/C/11/2 (April 2014) paragraph 3, Annex II in: *Report of the Committee on the Rights of Persons with Disabilities on its eleventh session (31 March–11 April 2014)* available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2F-C%2F11%2F2&Lang=en> (last accessed 20 April 2016).

179 Rosemary Kayess and Phillip French, 'Out of Darkness and into Light? Introducing the Convention on the Rights of Persons with Disabilities', *Human Rights Law Review*, 8(1) 1–34.

180 Kathleen Lynch, 'Equality as Rhetoric: The Careless State of Ireland'. Paper delivered at the *MacGill Summer School 2013*, available at <<http://www.macgillsummerschool.com/equality-as-rhetoric-the-careless-state-of-ireland/>> (last accessed 4 February 2016).

181 In 2012 in the wake of the closure of People with Disabilities in Ireland a National Council of People with Disabilities was formed but it does not seem to be very active and seems to only have offices in the west of Ireland. 'National Council for Disabilities Ireland' [web page], available at <<http://galway.ncpd.ie/index.htm>> (last accessed 6 February 2016).

represented.¹⁸² As stated above, Ireland's disability civil society organisations are generally grouped around disability identity. The report attempts to include the groups that cover the majority of people with disabilities by looking at organisations that represent people with physical disabilities, sensory disabilities, intellectual disabilities, autism and experience of mental health issues. We do not include organisations that are based around a medical diagnosis such as the Post Polio Support Group or Muscular Dystrophy Ireland where such groups would also be represented by a broader, larger DPO or another national organisation, or where the organisation does not appear currently active in monitoring, research or advocacy.

4.4 Mapping: Disabled People's Organisations under the CRPD

As stated above, the CRPD defines DPO as organisations 'comprising a majority of persons with disabilities – at least half their membership – and governed, led and directed by persons with disabilities'. The following organisations as examined through their mission statements, membership and leadership are DPOs under the CRPD

182 The Convention on the Rights of Persons with Disabilities conceptualises 'persons with disabilities' in Article 1 as including 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder the full and effective participation in society on an equal basis with others.' This definition draws on the social model of disability, which posits that disability occurs when society creates barriers that specifically hinder people with impairments.

definition that work at the national level in Ireland.

Áiseanna Tacaíochta

Áiseanna Tacaíochta or AT Network is a small organisation led by people with disabilities for a diverse group of people with disabilities.¹⁸³ It was founded in 2010 by a group of four people with disabilities and the network's mission statement is 'To provide leadership and support in Ireland to empower those of us who have disabilities to direct our own lives and enjoy the same equality and freedoms as non-disabled citizens'. The organisation advocates for and facilitates direct payments to people with disabilities in Ireland. 'Direct payments' are a form of individualised funding, allocated directly to the person with a disability, to arrange their own services, in contrast to the existing system of block funding allocated to disability service providers. In addition to this work, it held a first assembly in June of 2015 in Athlone that was intended to create a new disability rights movement in Ireland led by people with disabilities and their allies.¹⁸⁴

As I Am

As I Am is an autism spectrum organisation providing information, advice, and a

183 'Áiseanna Tachíochta' [web page], available at <www.theatnetwork.com/> (last accessed 20 April 2016).

184 Áiseanna Tacaíochta, *First Assembly 2015*, available at <<http://www.theatnetwork.com/news-events/first-assembly-2015/>> (last accessed 11 February 2016).

meeting point.¹⁸⁵ It was founded by a person with autism in 2014. The purpose of the organisation is to educate people about autism, empower people with autism and advocate on behalf of people with autism.¹⁸⁶ It provides support and information both to people with autism and families and friends of people with autism.¹⁸⁷

Centres for Independent Living

The Centres for Independent Living¹⁸⁸ were first established in Dublin in 1992.¹⁸⁹ Their mission states that they are a user-led organisation that is committed to achieving

equality for people with disabilities.¹⁹⁰ The Centres operate in 23 locations throughout the Republic of Ireland. The Centres are the lead member of the European Network of Independent Living (ENIL). ENIL describes itself as 'a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living.'¹⁹¹

Irish Deaf Society

According to its website, Irish Deaf Society is the largest Deaf-led organisation in Ireland and also works with the hard of hearing community.¹⁹² Its board is entirely made up of members of the Deaf community of Ireland and its mission statement revolves around the promotion of rights of and equality for Deaf people in Ireland. The organisation was founded by a group of Deaf people in 1981 and currently represents 5,000 Deaf and hard of hearing people in Ireland.¹⁹³ It is

185 AslAm' [web site], available at <www.asiam.ie/> (last accessed 20 April 2016).

186 Adam Harris, 'AslAm Launch: Adam's Speech (1 April 2014)' [web page], available at <<https://www.asiam.ie/asiam-launch-adams-speech>> (last accessed 11 February 2016).

187 Adam Harris, 'AslAm Launch: Adam's Speech (1 April 2014)' [web page], available at <<https://www.asiam.ie/asiam-launch-adams-speech>> (last accessed 11 February 2016).

188 Centre for Independent Living [web page], available at <www.dublincil.org> (last accessed 20 April 2016).

189 Dublin Centre for Independent Living, 'About us' [web page], available at <<http://www.dublincil.org/introduction.asp>> (last accessed 6 February 2016).

190 Dublin Centre for Independent Living, 'About us' [web page], available at <<http://www.dublincil.org/introduction.asp>> (last accessed 6 February 2016).

191 European Network for Independent Living, 'About ENIL' [web page], available at <<http://www.enil.eu/about-enil/>> (last accessed 6 February 2015).

192 'Irish Deaf Society' [web site], available at <www.irishdeafsociety.ie/> (last accessed 20 April 2016)

193 Irish Deaf Society, 'Press Information' [web page], available at <<https://www.irishdeafso->

the Irish member of the World Federation of the Deaf (WFD).¹⁹⁴ WFD is the largest Deaf organisation in the world and the UN recognised spokes-organisation for Deaf people.¹⁹⁵

MindFreedom Ireland

MindFreedom Ireland¹⁹⁶ was started in 2003 as a way to explore and promote alternatives to the psychiatric model of mental health care.¹⁹⁷ People with experience of the mental health system founded the group. The group is linked to both the European Network of Users and Survivors of Psychiatry and the World Network of Users and Survivors of Psychiatry. The organisation describes most of its

ciety.ie/about/press-information/ (last accessed 6 February 2016).

194 World Federation of the Deaf, 'list of members' [web page], available at <<http://wfdeaf.org/membership/ordinary-members/list-of-members?cn-s=&cn-cat=59&cn-pg=1>> (last accessed 5 February 2016).

195 World Federation of the Deaf, 'Who we are' [web page], available at <<http://wfdeaf.org/membership/ordinary-members/list-of-members?cn-s=&cn-cat=59&cn-pg=1>> (last accessed 5 February 2016).

196 'MindFreedom Ireland' [web site], available at <www.mindfreedomireland.com/> (last accessed 20 April 2016).

197 MindFreedom Ireland, 'About MindFreedom Ireland' [web page], available at <<http://www.mindfreedomireland.com/index.php/about>> (last accessed 5 February 2015).

members as users and survivors of psychiatry. It has also supported the development of Hearing Voices Ireland, an emerging Irish DPO for people who hear voices, by sponsoring the organisation's opening conference.¹⁹⁸

National Council of People with Disabilities

The National Council of People with Disabilities was started in 2012 after the government ceased funding People with Disabilities in Ireland.¹⁹⁹ It is made up of former members of that organisation and seems to be largely active in the west of Ireland. (The headquarters are in Clare.)

National Platform of Self Advocates

Founded in 2011 the National Platform of Self Advocates is composed of self-advocates with disabilities (largely people with intellectual disabilities and people with autism).²⁰⁰ All twelve members of its steering committee are people with disabilities.²⁰¹

198 Hearing Voices Ireland, 'About HVI' [web page], available at <<http://www.voicesireland.com/about/>> (last accessed 11 February 2016).

199 'National Council of People with Disabilities' [web site], available at <<http://galway.ncpd.ie>> (last accessed 20 April 2016).

200 'National Platform of Self Advocates' [web site], available at <http://thenationalplatform.ie/>.

201 Inclusion Ireland, 'National Platform committee members voted in' [web page], available

Recovery Experts by Experience

Recovery Experts by Experience is a small group made up of people in Ireland who have personal experience with the mental health system. Members of the group come from all over Ireland. Amnesty International established an Experts by Experience Advisory Group in 2008 as a part of its now concluded mental health campaign in Ireland,²⁰² and members of this group have now gone on to form their own organisation. Amnesty described Recovery Experts by Experience as at the 'forefront of the mental health movement in Ireland.' Members of Recovery Experts by Experience were actively involved in a coalition of over 15 NGOs across disability, mental health and ageing which campaigned for a human-rights compliant Assisted Decision-Making (Capacity) Act 2015.

4.5 Mapping: Civil Society in Ireland

Organisations discussed in this category do not meet the CRPD definition for DPOs, but are nonetheless able and expected to play an important role in the monitoring process. This report lists the larger and more prominent disability organisations in Ireland that have regularly participated in national advocacy or policy discussions around disability. Several

of them are the representative organisation for Ireland in international or European fora. Many of these organisations play a role in policy making and advocacy on a national level on disability issues. It is also important to note that the organisations listed below are only a sample of the civil society groups working on disability issues in Ireland, and this section is not presented as a complete list of organisations.

DeafHear

Deaf Hear was established in 1964 and advocates on behalf of Deaf and hard of hearing people and their families.²⁰³ It is also a major service provider in Ireland for Deaf people and people who are hard of hearing. Only two members of its current board self identify as Deaf or people who are hard of hearing.²⁰⁴

Disability Federation of Ireland (DFI)

DFI is an umbrella body, and the 'national support organisation for voluntary disability organisations in Ireland that provides services to people with disabilities and disabling conditions'.²⁰⁵ It works to enable

at <<http://www.inclusionireland.ie/content/page/national-platform-committee-members-voted>> (last accessed 5 February 2016).

202 Amnesty, 'Mental Health' [web page], available at <<https://www.amnesty.ie/mental-health>> (last accessed 29 April 2016).

203 'DeafHear' [web site], available at <www.deafhear.ie> (last accessed 20 April, 2016).

204 DeafHear, 'Governance' [web page], available at <<https://www.deafhear.ie/DeafHear/aboutUsBoard.html>> (last accessed 11 February 2016).

205 Disability Federation of Ireland [web site], available at <www.disability-federation.ie>

organisations to enable people with disabilities. DFI's current membership is a mix of service providers, voluntary organisations, family organisations, disability organisations and DPOs. It has begun to focus in recent years on ensuring greater representation of people with disabilities through changes made to its articles of association.

Down Syndrome Ireland (DSI)

Although Down Syndrome Ireland defines its mission as mostly support, the organisation has also been involved in advocacy.²⁰⁶

The mission of Down Syndrome Ireland is 'dedicated to being the primary source of information and support to people with Down syndrome, their families and the professional community, working towards an improved quality of life for our members along with a respect and acceptance of people with Down Syndrome as valued members of Irish society.'²⁰⁷

Enable Ireland

Enable Ireland is a large service provider for children and people with disabilities as well

as their families.²⁰⁸ It provides a wide variety of services, including clinical assessment, therapy, education, training, residential, respite, personal assistance and family support services. Enable Ireland aims to promote choice and inclusion through its work and describes its ethos as based on a person centred-approach and the social model of disability. It works in 40 locations in Ireland.²⁰⁹

Inclusion Ireland

Inclusion Ireland is an umbrella group for people with intellectual disabilities, parents and friends of people with intellectual disabilities, service providers, other professional bodies and self-advocacy groups.²¹⁰ In 2014 the organisation had 84 organisational members and 163 individual members. It advocates for the rights of people with intellectual disabilities and their families.²¹¹ Its mission is 'to be the independent champion of people with an

(last accessed 20 April 2016).

206 Down Syndrome Ireland [web site], available at <www.downsyndrome.ie> (last accessed 20 April 2016).

207 Down Syndrome Ireland, 'Our Mission' [web page] available at <<http://www.downsyndrome.ie/about-us-2/our-mission/>>

208 Enable Ireland [web site], available at <www.enableireland.ie> (last accessed 20 April 2016).

209 Enable Ireland, 'About us' [web page], available at <<http://www.enableireland.ie/about>> (last accessed 7 February 2016).

210 Inclusion Ireland [web site], available at <www.inclusionireland.ie> (last accessed 20 April 2016).

211 Inclusion Ireland, *Annual Report 2014*, available at <<http://www.inclusionireland.ie/sites/default/files/attach/basic-page/512/203185-inclusion-ireland-fi>>

intellectual disability and their families whose standing and expertise in intellectual disability is acknowledged and to ensure that people with an intellectual disability have their voices heard, are not isolated or segregated and can lead more independent and healthier lives'.²¹² It is a member of Inclusion International Federation, which is the global organisation of people with intellectual disabilities and their families. According to its mission statement and board composition it is not run and directed by people with disabilities, although self advocates with intellectual disabilities are represented on its Board.

Irish Autism Action

Irish Autism Action an umbrella organisation with 33 member groups and 3,500 individual members.²¹³ It was formed in 2001 and is based in Mullingar, Co. Westmeath.²¹⁴

[nal.compressed.pdf](#)> (last accessed 5 February 2016).

212 Inclusion Ireland, 'About Inclusion Ireland: Who we are and what we do' [web page], available at <<http://www.inclusionireland.ie/content/books/about-inclusion-ireland-who-we-are-and-what-we-do/508/about-inclusion-ireland-who-we>> (last accessed 11 February 2016).

213 Irish Autism Action, 'About IAA' [web page], available at <<http://www.autismireland.ie/about-iaa/>> (last accessed 11 February 2016).

214 Irish Autism Action [web site], available at <www.autismireland.ie> (last accessed 20

Its Members include special autism schools and local support groups as well as individuals. It provides support to people with autism, their families and professionals. It also provides services (counselling, education support helpline, home based support, transition planning, social housing, early detection), as well as carrying out advocacy and awareness-raising activities. Publicly available information about the organisation does not indicate that it is run and directed by people with disabilities.

National Council for the Blind of Ireland (NCBI)

NCBI is the largest organisation for people with visual impairments and people who are blind in Ireland.²¹⁵ NCBI's mission is for people 'who are blind and vision impaired to overcome the barriers that impede their independence and participation in society'. In addition to representing people who are blind and people with visual impairments, a large part of NCBI's work is the provision of services to people who are blind and people with visual impairments. It provides services to 7,000 people a year.²¹⁶ Publicly available information about the organisation does not indicate

April 2016).

215 National Council for the Blind in Ireland [web site], available at <www.ncbi.ie> (last accessed 20 April 2016).

216 NCBI, 'About NCBI' [web page], available at <<https://www.ncbi.ie/about-ncbi/who-we-are-and-what-we-do>> (last accessed 6 February 2016).

that it is run and directed by people with disabilities, but its governance code includes the provision of 'encouraging those who benefit from our organisation in the planning and decision-making of the organisation'. NCBI is the Irish representative to the World Blind Union, which is the recognised international representative organisation for people who are blind and visually impaired.

National Federation of Voluntary Bodies

The National Federation of Voluntary Bodies is the umbrella organisation for voluntary agencies that provide services to people with intellectual disabilities.²¹⁷ Publicly available information about the organisation does not indicate that it is run and directed by people with disabilities. Their mission is 'To provide the leadership and support that will enable voluntary organisations to adapt to a radically changing operating environment, with the ultimate aim of ensuring that the people whom our members support benefit from best quality service according to their needs'.

Not for Profit Business Association²¹⁸

The Not for Profit Business Association is a representative body for large service providers that provide services to people

with physical and sensory disabilities.²¹⁹ It was formed in 1988 and 'represents the business interests of its members as service providers, particularly in view of the need to combine the care ethos of the past with a commercial ethos to deal with current and emerging market forces.'²²⁰ Publicly available information about the organisation does not indicate that it is run and directed by people with disabilities.

Mental Health Reform

Mental Health Reform is an umbrella organisation that 'aims to be the unifying voice that drives progressive reform of mental health supports in Ireland.'²²¹ Its members are a variety of service providers, non-governmental organisations, and medical associations. Publicly available information about the organisation does not indicate that it is run and directed by people with disabilities.

217 National Federation of Voluntary Bodies [web site], available at <www.fedvol.ie> (last accessed 20 April 2016).

218 Not for Profit Business Association [web site], available at <www.notforprofit.ie> (last accessed 20 April 2016).

219 Not for Profit Business Association [web site], available at <www.notforprofit.ie> (last accessed 20 April 2016).

220 Not for Profit Business Association, 'About Us' [web page], available at <<http://www.notforprofit.ie/home/about/>> (last accessed 11 February 2016).

221 Mental Health Reform, 'Vision, Mission and Values' [web page], available at <<https://www.mentalhealthreform.ie/vision-mission-and-values/>> (last accessed 7 February 2016).

4.6 Statutory Disability Bodies

National Disability Authority

The National Disability Authority is the 'independent state body providing expert advice on disability policy and practice to the government and the public sector'.²²² It is largely not run or staffed by people with disabilities but some members of the governing body of the Authority are people with disabilities.²²³

4.7 Existing National Disability Monitoring and Inspection Frameworks

This section lists existing national governmental disability monitoring groups about which information is publicly available, where the group includes civil society in monitoring disability policy.²²⁴ Not listed

are interdepartmental groups on disability that do not include civil society, people with disabilities or DPOs. The list also does not include the broader human rights monitoring mechanisms in Ireland such as the Office of the Ombudsman, the Ombudsman for Children and Irish Human Rights and Equality Commission.

National Disability Strategy Implementation Group: Disability Stakeholders Group

The Disability Stakeholders Group (DSG), established by the Minister of State for Equality,²²⁵ is an integral part of the National Disability Strategy Implementation Group and was first established in 2004. The Disability Stakeholders Group monitors the implementation of the National Disability Strategy at a national level. It is made up of national disability organisations²²⁶, service

222 National Disability Authority [web site], available at <<http://www.nda.ie>> (last accessed 20 April 2016). See also the National Disability Authority Act 1999, available at <<http://www.irishstatutebook.ie/eli/1999/act/14/enacted/en/html>> (last accessed 28 April 2016).

223 Department of Justice and Equality, 'New appointments to the National Disability Authority announced', [press release, (22 September 2014)], available at <<http://www.justice.ie/en/JELR/Pages/PR14000253>> (last accessed 11 February 2016).

224 This section draws heavily from Eilionóir Flynn, *Implementing and Monitoring Ireland's National Disability Strategy: Who, How and When?*, Centre for Disability Law and Policy, NUI Galway (10 December 2010).

225 'Minister Ó Ríordáin announces new membership of the Disability Stakeholders Group', [press release, 10 May 2015], available at <www.justice.ie/en/JELR/Pages/PR15000135> (last accessed 20 April 2016).

226 Representatives from the following service providers and disability organisations are a part of the current DSG: Asperger Syndrome Association, National Federation of Voluntary Bodies, National Council for the Blind of Ireland, Brothers of Charity, Centre for Independent Living, WALK, Disability Federation of Ireland, Not for Profit Business Association, Inclusion Ireland, Mental Health Reform, DeafHear, Irish Association of Supported Employment.

providers, individuals with disabilities and family members of people with disabilities.²²⁷

Sectoral Plan Monitoring Bodies

A number of government departments and state agencies have committees that consult with department officials on annual reviews of sectoral plans. Sectoral plans lay out how the department or agency is implementing the National Disability Strategy. Table 2 lists the departments and agencies whose consultative groups have recent reports or evidence of recent meetings.

227 Department of Justice and Equality, 'Minister Ó Ríordáin announces new membership of the Disability Stakeholders Group', [press release, 10 May 2015], available at <<http://www.justice.ie/en/JELR/Pages/PR15000135>> (last accessed 20 April 2016).

Table 2

Departments and agencies with active consultative bodies which include disability civil society organisations

Department	Committee Name	Civil Society Members
Department of Social Protection	Disability Consultative Forum	Asperger Syndrome Association Brothers of Charity Centres for Independent Living DeafHear Disability Federation of Ireland Inclusion Ireland Irish Association of Supported Employment Mental Health Reform National Council for the Blind of Ireland National Federation of Voluntary Bodies Not for Profit Business Association WALK
Department of Transport, Tourism and Sport	Public Transport Accessibility Committee	DeafHear Disability Federation of Ireland Inclusion Ireland Irish Senior Citizens Parliament Irish Wheelchair Association National Council for the Blind of Ireland National Federation of Voluntary Bodies National Service Users Executive Not for Profit Business Association
National Council of Special Education	National Council for Special Education Consultative Forum	COPE Foundation Down Syndrome Ireland KARE

HSE Working Groups

The HSE has a number of working groups, which include disability organisations and service providers, to monitor the progress towards implementation of a number of policy objectives.²²⁸ A number of these groups were established following the publication in 2012 of a report commissioned by the Department

of Public Expenditure and Reform that made a number of significant recommendations for reforming the implementation of various policies, including the transition of people with disabilities from institutions into the community, and the personalisation of disability services.²²⁹ Table 3 lists these working groups and the civil society organisations that are members of them.

228 Information from this section is taken from the Department of Health, *Value for Money and Policy Review of Disability Services in Ireland HSE Working Groups and Sub Groups 2014–2015*. Available at <<http://health.gov.ie/wp-content/uploads/2014/08/HSE-Working-Groups-and-Subgroups.pdf>> (last accessed 11 February 2016).

229 *Value for Money and Policy Review of Disability Services in Ireland*, available at <<http://health.gov.ie/blog/publications/value-for-money-and-policy-review-of-disability-services-in-ireland/>> (last accessed 20 April 2016).

Table 3

HSE working groups and civil society membership

Work Group Number	Work Group Name	Civil Society Members
Working Group 1	Person-Centered Model of Services & Supports – Strategic Planning	Disability Federation of Ireland Enable Ireland KARE National Federation of Voluntary Bodies St. John of God Services
Working Group 2	Person-Centered Model of Services and Support – Implementation, Oversight & Support	Ability West Cheeverstown Disability Federation of Ireland Daughters of Charity Enable Ireland Inclusion Ireland Prosper Fingal Rehab Group
Working Group 3	People with Disabilities and Community Involvement	Catholic Institute for Deaf People Centers for Independent Living Cope Foundation Disability Federation of Ireland DeafHear Disability Equality Specialist Inclusion Ireland LEAP National Council for the Blind of Ireland National Parents and Siblings Alliance Support Agency

Table 3 Continued

HSE working groups and civil society membership

Work Group Number	Work Group Name	Civil Society Members
Working Group 4	Quality & Standards	Disability Federation of Ireland Dara Residential Services Not For Profit Business Association SOS Kilkenny St. John of God Services Western Care Association
Working Group 5	Management and Information Systems	Brothers of Charity Cope Foundation Disability Federation of Ireland KARE Not for Profit Business Association
Working Group 6	Governance & Service Arrangements	Brothers of Charity Carriglea Cairde Services Disability Federation of Ireland Enable Ireland Kerry Parents & Friends Association Muiriosa Foundation National Federation of Voluntary Bodies Not For Profit Business Association Sisters of Charity of Jesus & Mary St. Michael's House

4.8 National Inspection and Monitoring Structures

In addition to the frameworks within government departments and state agencies to monitor disability policy, a number of public bodies have been established in Ireland with powers to monitor and investigate situations of abuse or residential services where people with disabilities live. These bodies could all potentially play a role in the monitoring of the CRPD, and careful consideration will have to be given to how the Article 33 mechanism, once established, will engage with these bodies. A snapshot of some key investigative and monitoring agencies for the disability community in Ireland is provided below.

Health Information and Quality Authority (HIQA)

HIQA is the independent authority that develops and monitors the *National Standards for Residential Services for Children and Adults with Disabilities*.²³⁰ The standards apply to all residential services (public, private, voluntary bodies, etc.).

Confidential Recipient

In response to the abuse scandals at Áras Attracta,²³¹ the HSE appointed a confidential

recipient for vulnerable persons²³² in December 2014.²³³ The confidential recipient is independent of the HSE and has the authority to advise and assist individuals on the best course of action to raise concerns, to assist with the referral and examination

the Department of Health. Kathleen Lynch TD, 'Written Answers: HSE Investigations' (question no. 531), *Parliamentary Debates: Dáil Éireann*, 16 December 2014, available at <<http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2014121600085?opendocument#WRW00750>> (last accessed 28 April 2016).

²³² Vulnerable Persons are defined with reference to the Safeguarding policy as 'an adult who may be restricted in capacity to guard himself/herself from harm or exploitation. The restriction of capacity may arise as a result of physical, mental, sensory or intellectual impairment. Vulnerability to abuse is influenced by both context (e.g. social or personal circumstances) and individual circumstances'. HSE, 'Confidential Recipient' [web page], available at <<http://www.hse.ie/eng/services/yourhealthservice/feedback/Complaints/ConfidentialRecipient/>> (last accessed 11 February 2016).

²³⁰ HIQA, *National Standards for Residential Services for Children and Adults with Disabilities*, (January 2013), 6, available at <<https://www.hiqa.ie/standards/social/people-with-disabilities>> (last accessed 11 February 2016).

²³¹ For information on the scandal at Áras Attracta, see, for example: Minister of State at

²³³ Aine McMahon, 'HSE defends appointing Leigh Gath as the confidential recipient', *Irish Times*, 17 December 2014, available at <<http://www.irishtimes.com/news/health/hse-defends-appointing-leigh-gath-as-confidential-recipient-1.2040251>> (last accessed 11 February 2016).

of concerns and to ensure the concerns are appropriately handled by the HSE and its funded agencies.²³⁴

National Advocacy Service

The National Advocacy Service provides independent and free advocacy services to people with disabilities who need support in accessing services or lodging complaints about services received.²³⁵ Its mandate is partly based on the Personal Advocacy Service envisaged under the Citizens Information Act 2007. While advocates within the service do not currently have statutory powers to conduct their work, the service is currently working with the Department of Social Protection to introduce legislative powers for advocates within the service.²³⁶

234 HSE, 'Confidential Recipient' [web page], available at <<http://www.hse.ie/eng/services/yourhealthservice/feedback/Complaints/ConfidentialRecipient/>> (last accessed 11 February 2016).

235 Citizens Information Board, 'National Advocacy Service for People with Disabilities' [web page], available at <<http://www.citizensinformationboard.ie/en/services/advocacy/>> (last accessed 11 February 2016).

236 Houses of the Oireachtas Joint Committee on Health and Children, *Report on the Role of Advocacy in Health and Social Care Services in Ireland* (January 2016), available at <<http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2015/JCHC-Report-on-Advocacy.pdf>> (last accessed 31 March 2016).

4.9 Disability Research Centres and Databases

This section lists some relevant disability research centres and databases with key information about people with disabilities in Ireland. These organisations may gather information that could be useful to any future monitoring framework established under Article 33.

Centre for Disability Law and Policy

The Centre for Disability Law and Policy (CDLP) at NUI Galway was founded in 2008.²³⁷ The CDLP focuses on advancing social justice and human rights for persons with disabilities through legislative and policy reform. It is a part of several research networks in Europe and has worked on many domestic and international projects.

Irish Disability Studies Association

This association was founded in 2011 by a group of Irish universities. The association provides a network for disability studies programs and scholars to connect and collaborate across Ireland.

National Intellectual Disability Database

The National Intellectual Disability Database is an annually updated database about people with intellectual disabilities who receive or

237 Centre for Disability Law and Policy [web page], available at <http://www.nuigalway.ie/research/centre_disability_law_policy/> (last accessed 20 April 2016).

need services in Ireland.²³⁸ It was established in 1995 and is managed by the Health Research Board.

National Physical and Sensory Disability Database

The National Physical and Sensory Disability Database was established in 2002 and is managed by the Health Research Board.²³⁹ It measures annually the health and social services used or needed by people with physical and sensory disabilities.

Trinity Centre for People with Intellectual Disabilities

The Trinity Centre for People with Intellectual Disabilities was established in 1998 and promotes the inclusion of people with intellectual disability and their families.²⁴⁰ The Centre both provides a two-year course for people with intellectual disabilities and

conducts and promotes inclusive research projects.

4.10 Conclusion

The CRPD Committee has, in its comments to other states, repeatedly highlighted the special role that DPOs play in ensuring the participation of people with disabilities in the monitoring process. In Ireland, their inclusion is a particular challenge, as there is a lack of well-funded national DPOs and no comprehensive cross-disability DPO. This gap might be partly filled by reaching out to other civil society groups which play a crucial role in advocating for the rights of people with disabilities and are expected to continue to play an important role in the monitoring process. Nevertheless, the existence of these groups does not displace the State's obligation to support the development of a strong DPO community, and to build capacity for DPOs and individuals with disabilities to be actively involved in the monitoring of CRPD.

As is discussed in Chapter 3, the CRPD Committee has asked several countries in the concluding observations to better include DPOs in Article 33 duties. Such an inclusion follows both the spirit of the CRPD's motto of 'nothing about us without us' and the requirements set out in Article 33. As the examples presented in earlier chapters demonstrate, the CRPD Committee is most likely to accept a monitoring framework when the involvement of a wide variety of DPOs and individuals with disabilities is assured through some kind of formal mechanism, such as CERMI in Spain, the Convention Coalition in New Zealand or Malta's Disabled

238 Health Research Board, *National Intellectual Disability Database* [online database], available at <<http://www.hrb.ie/health-information-in-house-research/disability/nidd/>> (last accessed 20 April 2016).

239 Health Research Board, *National Physical and Sensory Disability Database* [online database], available at <www.hrb.ie/health-information-in-house-research/disability/npsdd/> (last accessed 20 April, 2016).

240 Trinity Centre for People with Intellectual Disability [web page], available at <www.tcd.ie/ciid/> (last accessed 20 April, 2016).

Persons' Advisory Committee. The structure of DPOs gives them a unique ability and mandate to ensure that the voices of people with disabilities are heard, in a way that is difficult for other civil society groups to replicate. Ireland will need to ensure that people with disabilities are truly represented in the monitoring framework, even within its challenging domestic context.

Chapter 5: Conclusion and Options for Consideration

From the comparative analysis and exploration of the Irish context in Chapters 1–3, it is clear that a number of options for developing a monitoring framework are worthy of consideration by the State. Three options are considered below. It is also clear from the analysis in those chapters that the Irish Human Rights and Equality Commission, as Ireland’s ‘A status’ NHRI, should play a role in the framework, and is most suited to being designated the independent mechanism within that framework. Therefore, all three options considered include the Commission as a key body in the framework.

The first option involves the designation of a single body as the independent mechanism with responsibility for generating a monitoring framework. The second option is to jointly designate the Irish Human Rights and Equality Commission and another body as the monitoring framework. The particular variant of the second option considered would be to designate the National Disability Authority as the second body within the monitoring framework, along with the IHREC. The third option would be the designation of the IHREC and a new advisory committee composed of persons with disabilities. Based on the experiences outlined in this report, it is highly advisable that the monitoring framework create a designated space for the active involvement of people with disabilities. These options are described in further detail below.

Option 1: Designation of the Irish Human Rights and Equality Commission as a Single-Body Independent Mechanism

Given the approach of the CRPD Committee in its Concluding Observations to date as outlined in Chapter 1, it is clear that single-body monitoring mechanisms that meet the Paris Principles are sufficient to ensure compliance with Article 33.²⁴¹ As is noted in Chapter 2, Germany is an example of a single-body approach, having designated its NHRI, the German Institute of Human Rights, as its independent mechanism under Article 33.²⁴² Since the Irish Human Rights and Equality Commission, like the German Institute, is an ‘A status’ NHRI, it complies with the Paris Principles and would likely be acceptable to the CRPD Committee as the Article 33 mechanism.

This approach of designation has the advantage of simplicity and clarity – providing a single location for coordinating

241 See for example Gauthier de Beco, *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities in Europe* (Brussels: 2012) available at <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> (last accessed 30 March 2016).

242 Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention: Germany*, paragraphs 284–290, U.N.Doc. CRPD/C/DEU/1 (7 May 2013).

all monitoring activity under Article 33, and ensuring that the scope, functions and powers of the mechanism are clear to all stakeholders, as these will be based on the legislation already governing the Commission. However, as is shown in the comparative study, the CRPD Committee has been critical of the designation of single-body mechanisms if this occurs without providing the necessary resources to ensure the mechanism can fulfill its function. Further, without a dedicated process to build capacity in and engage with civil society, particularly DPOs, the validity of the mechanism is likely to be challenged by the CRPD Committee and by the representative organisations of people with disabilities in Ireland. In engaging with DPOs and other civil society organisations the mechanism would have to design a transparent participation process, rather than selecting certain stakeholders who are invited to participate in the monitoring, as such selection processes in other states have been criticised by both civil society and the CRPD Committee.²⁴³ Another challenge to consider is how a single-body mechanism could fulfill on its own all of the expectations of civil society concerning the monitoring of the CRPD. For these reasons, based on the comparative research conducted for this report, this option is not the preferred approach of the research team.

Option 2: Designation of a Multi-Body Mechanism without DPO Engagement

If this option were to be pursued, the Irish Human Rights and Equality Commission would remain the independent mechanism under Article 33, but other bodies could be jointly designated as parts of the monitoring framework. The decision as to which bodies to involve remains open and would require a process of consultation with relevant stakeholders. One option here would be to select the National Disability Authority as the jointly-designated body within the framework. A similar approach was taken in Sweden with the designation of the Swedish Ombudsman and of Handisam, a statutory body which advises government on disability policy.²⁴⁴ However, based on the comparative research for this report, such an approach may risk falling short of the standards set out by the CRPD Committee, including in its recent Concluding Observations on Sweden.²⁴⁵

Where the statutory body within a multi-body mechanism does not meet the definition of a DPO provided by the Committee, and

²⁴³ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Germany*, paragraphs 61–62, U.N.Doc. CRPD/C/DEU/CO/1 (13 May 2015).

²⁴⁴ Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities, Initial reports submitted by States parties in accordance with article 35 of the Convention: Sweden*, paragraphs 350–353, U.N.Doc. CRPD/C/Swe/1.

²⁴⁵ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Sweden*, paragraph 61, U.N.Doc. CRPD/C/SWE/CO/1 (2014).

where no formal mechanism exists to ensure permanent, transparent and comprehensive DPO engagement in the monitoring framework, this approach would probably not represent best international practice. In other states that have ratified the CRPD, a statutory body which advises government on disability policy is more likely to be designated as the focal point or the lead of the coordination mechanism under Article 33 rather than be designated as a body within the monitoring framework. Given the Irish context, it might be more appropriate for a body such as the National Disability Authority to play a greater role in the focal point and coordination mechanism under Article 33, rather than as a part of the independent monitoring mechanism.

Option 3: Designation of a Multi-Body Framework with DPO Engagement

Another interesting approach for Ireland to consider would be the joint designation of the Commission with a DPO, or group of DPOs as the main components of the monitoring framework. This was the approach taken in Spain, New Zealand and Malta as is discussed in Chapters 2 and 3. However, in the Irish context, as discussed in Chapter 4, no single umbrella DPO currently exists that represents the full diversity of all people with disabilities in Ireland. Further, as is discussed in Chapter 4, the national organisations which currently exist and which meet the CRPD Committee's definition of DPO are often small, with limited capability in their current form to carry out the full range of monitoring activities required within the framework.

Therefore, it does not seem feasible for Ireland to designate a group of existing DPOs to form a new umbrella body, as occurred in New Zealand. The approach of Malta, however, which created a new advisory committee of people with disabilities in response to its ratification of the CRPD, is a relevant option to consider in the Irish context. As is discussed in Chapter 2, Malta sought ten people with lived experience of different kinds of disabilities as members of this new committee, as well as two representatives from family members of people with disabilities.²⁴⁶ As part of a transparent appointment process, the call for representatives was distributed to existing DPOs as well as the broader public in Malta. This approach seems well suited to the Irish context, and would allow for new voices and perspectives to emerge, rather than relying on existing DPOs alone. It is especially relevant to ensure that broad representation across the diversity of the disability community in Ireland is ensured.

While umbrella DPOs have been developed in Ireland in the past but have not proved sustainable, the CRPD places a responsibility on the State to build the capabilities of the representative organisations of people with disabilities and to ensure that individuals with disabilities and DPOs fully participate in the monitoring of the Convention at national level. The creation of a new representative

246 See Kummissjoni Nazzjonali Persuni B'Diz-
abilita, *UNCRPD Disabled People's Advisory
Committee Terms of Reference* (2013),
available at <[http://www.knpd.org/pubs/pdf/
DPAC%20TOR%2020130226.pdf](http://www.knpd.org/pubs/pdf/DPAC%20TOR%2020130226.pdf)> (last
accessed 31 March 2016).

and diverse advisory committee, using a transparent process, would build confidence and trust among the disability community, and with the right support in terms of resources and skills development should ensure robust monitoring of the rights contained in the CRPD at grassroots level in Ireland. Such a committee would be well-placed to support the Commission in its role as the independent mechanism by providing up-to-date information on the lived experiences of people with disabilities at grassroots level. New Zealand's success in facilitating the participation of DPOs and people with disabilities in the monitoring can probably in part be attributed to the training and funding provided to their umbrella DPO specifically for CRPD monitoring. In addition to the creation of a new advisory committee of people with disabilities, further mechanisms for the engagement of existing DPOs, of individuals with disabilities and of broader civil society would also need to be put in place to ensure compliance with best international practice in implementing Article 33.

diverse group of people with lived experience of disability. It is clear from the analysis in Chapters 1–3 that the CRPD Committee expects to see a monitoring framework under Article 33 with an NHRI that is compliant with the Paris Principles as the independent mechanism, and the development of a transparent process for regular and active engagement with DPOs and individuals with disabilities. However, there are many options that the State can consider in designating an Article 33 monitoring framework, and there is a diverse range of civil society organisations in the Irish context that can play an active role in the monitoring process. There are challenges to consider for Ireland, given the low number of DPOs with capacity to fully engage in an intensive monitoring process, but there are also opportunities for the State to demonstrate leadership and innovative thinking in its processes for involving DPOs, individuals with disabilities and broader civil society.

Conclusion

Based on the comparative research conducted for this report, Option 3 seems the most appropriate in the Irish context, given the current landscape of DPOs and civil society organisations that advocate on disability rights. In keeping with the spirit and purpose of the CRPD, and in acknowledgment of the current Irish civil society and DPO landscape, the research team's recommendation would be for the Commission to be jointly designated as the monitoring framework with an advisory committee composed of a

Appendix A – IHREC CRPD Framework – Inclusive Advisory Group Proposal

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The research team in the tender document and at the start of the project proposed that an advisory group should be assembled of civil society members to consult with and provide advice to the researchers and the Irish Human Rights and Equality Commission during the creation of this report. The proposal for the creation of that advisory group was as follows.

The advisory group meetings are spaces for the research team from the Centre for Disability Law and Policy to present the results of research and to get feedback from the members of the group. The advisory group meetings are not intended to change the scope and breadth of the research project. The Centre for Disability and Law and Policy will provide a letter or one-page information sheet that will clearly state the purpose and scope of the steering group meeting.

We propose that the Advisory Group for the *Research Project on Establishing on a Monitoring Framework for the CRPD* include members with disabilities who represent the five main groups of people with disabilities (people with psychosocial disabilities, people with visual disabilities, people with intellectual disabilities, people with physical disabilities, and people with hearing disabilities). These members should be drawn from representative disability organisations in Ireland that advocate on behalf of people with disabilities, have members with disabilities and are governed by people with disabilities. We have identified the following groups as groups that fit this criteria: Recovery Experts by Experience (mental health), National Council for the Blind of Ireland, National Platform of Self Advocates (intellectual

disability), Disability Federation of Ireland (as Ireland's representative in the European Disability Forum), and the Irish Deaf Society.

Including members with disabilities from the five main groups of people with disabilities not only would fulfill good research practices for research project on disability but could help develop further good practices that may be of use to an Article 33 monitoring body. Although the scope of this project is already determined, we feel very strongly that, as this research may be used in the creation of the monitoring frameworks of the Convention on the Rights of People with Disabilities, it is important to have people with disabilities included at this very early stage. Including people with disabilities in the steering group will also will increase the likelihood that the research addresses the needs and concerns of people with disabilities and will provide richer feedback.

The Centre for Disability Law and Policy is prepared to create easy-to-read materials and provide support for the member with intellectual disabilities. The CDLP will prepare a summary document (also in easy-to-read format) in advance of the meetings to aid steering group preparation.

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