

Building the Architecture for Change:

Guidelines on Article 33 of the UN Convention
on the Rights of Persons with Disabilities



**Article 33
CRPD**

Mental Disability Advocacy Center

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on the Rights of Persons with Disabilities

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Foreword

The UN Convention on the Rights of Persons with Disabilities is a landmark human rights treaty. It obliges State parties to promote, protect and ensure the full and equal enjoyment of all human rights by all persons with disabilities. Equal rights – not just charity, is the message.



Photograph: Terri Potoczna

A number of States have now ratified, or at least signed the Convention and more will follow suit. This makes it urgent to clarify how implementation should be ensured and monitored. Article 33 allows for procedures which are adjusted to the particular legal and administrative system of the country, but requires that the government designate one or more focal points and that it establishes a mechanism for the co-ordination of actions to implement the Convention.

The governments are also required to designate or establish one or more independent mechanisms to promote, protect and monitor the realisation of the treaty. Civil society, in particular representative organisations of persons with disabilities, shall be free to participate fully in the monitoring process.

The implementation of this particular article will affect all of the others. Governments must organise themselves to demonstrate that human rights for persons with disabilities are given priority – and in keeping with the spirit of the Convention. The seriousness of the mechanisms to verify and control the actions taken, and their results, will be decisive. Genuine monitoring will require close involvement of the movement for the equal rights of persons with disabilities and a listening attitude by the authorities.

From what I have seen during my travels to member states of the Council of Europe, a full implementation of the Convention would require dramatic changes. I have, for instance, time after time seen proof of flagrant discrimination against persons with intellectual disabilities and mental health disabilities. They are still stigmatised and marginalised; they are rarely consulted or even listened to; a great number of them continue to be kept in old-style, inhuman institutions; and moves to provide housing and other services in community-based settings have met obstacles and been delayed.

The conditions in some of the so-called “social care homes” are appalling in many countries across Europe. In these segregated institutions very little, if any, habilitation and rehabilitation is provided. Not seldom, persons with intellectual disabilities are mixed up with persons having psychiatric problems and are unnecessarily given sedatives against their will. They are in some cases deprived of their liberty and treated as if they were dangerous. Many are cut off from the outside world. All disabilities carry a stigma, and many people with disabilities have been abandoned by their families through shame and lack of alternatives.

There are certainly many other problems to address as well in the spirit of the UN Convention. For the concrete discussion on implementation and monitoring this present guide will be of paramount importance for both authorities and civil society groups. I recommend it for thorough study.

Thomas Hammarberg
Council of Europe Commissioner for Human Rights
March 2011

Chapter 1. Overview of the Guidelines

This chapter provides a roadmap to the guidelines. It then describes the purpose, including the intended readership, as well as the scope and methods of the guidelines.

1.1. Roadmap

Chapter 1 contains a roadmap to assist the reader in using the guidelines. It also sets out the purpose of the guidelines, their scope, and the methods MDAC employed in developing them.

Chapter 2 presents an overview of the content of Article 33. It lays out some of the reasons Article 33 was included in the Convention on the Rights of Persons with Disabilities (CRPD), and how the provision came about during the Convention negotiations. **Chapter 3** examines States Parties' obligations to ensure meaningful participation of civil society, in particular persons with disabilities and their representative organisations, in implementing and in monitoring implementation of the Convention. MDAC also presents an analysis of Articles 3, 4(3), 29 and 33(3) of the CRPD in this chapter.

Chapter 4 examines States Parties' obligations under Article 33(1) to champion the Convention within government. Article 33(1) requires effective policy coordination, including through the designation of one or more focal points within government for matters relating to implementation of the CRPD and the establishment or designation of a coordination mechanism. **Chapter 5** then examines States Parties' obligations under Article 33(2) to set up a framework of independent mechanisms to promote and protect the rights of persons with disabilities and to monitor implementation of the Convention.

Questions highlighted with this symbol  are listed and explained throughout the text of the guidelines. Altogether, the questions comprise a Checklist, which is intended as a tool for representatives of civil society, including persons with disabilities and their representative organisations, States Parties, parliamentarians and people working for the Article 33 focal points, coordination mechanisms, frameworks and independent bodies, among others, to use in implementing and measuring implementation of Article 33 of the CRPD.

The Checklist is included in **Chapter 6**. A glossary of terminology and list of abbreviations are presented in **Chapter 7**. A list of further resources on Article 33 is included in **Chapter 8**.

1.2. Purpose of the Guidelines

Article 33 of the UN Convention on the Rights of Persons with Disabilities (CRPD) embodies the Convention's architecture for change. The Article sets out governmental coordination, independent monitoring and public participation.

The purpose of these guidelines is to provide a practical tool to:

- a. Guide implementation of Article 33, and
- b. Monitor how Article 33 is being implemented.

MDAC has written the guidelines for the following individuals and groups, whom we have identified as **key audiences**:

1. People with disabilities, their representative organisations and other civil society organisations

Public participation lies at the heart of the CRPD and non-governmental organisations constitute the primary readership of these guidelines. Civil society has an essential role to play in implementing and monitoring implementation of the CRPD. Article 33(3) of the CRPD requires governments to ensure that representatives of civil society, in particular persons with disabilities and their representative organisations, are involved and participate fully in monitoring implementation of CRPD rights. The role of civil society is both a matter of good practice and a legal obligation, as discussed in detail in chapter 3 of these guidelines.

2. People working within government

The guidelines are intended for people working within government who have responsibility for planning or implementing any aspect of the CRPD, disability policy or other policy area that affects the lives of persons with disabilities. This includes people who:

- Work in an Article 33(1) focal point within government that has been designated by the State Party for matters relating to implementation of the CRPD;
- Work in a coordination mechanism within government to facilitate action across and throughout government in order to ensure full and effective implementation of the CRPD;
- Have responsibility for setting up the framework of independent mechanisms set out in Article 33(2), which has a mandate is to promote and protect the rights of people with disabilities and monitor implementation of the CRPD;
- Are employed by the government as consultants for matters relating to CRPD implementation or monitoring.

3. People working in bodies independent from government to protect and promote the rights of people with disabilities, and to monitor the implementation of the CRPD

These guidelines are also intended for people working within the framework and independent mechanisms set out in Article 33(2) of the CRPD with the mandate to promote and protect the rights of persons with disabilities and monitor implementation of the CRPD. As discussed in chapter 5 of these guidelines, such independent mechanisms may include ombudsman offices, national human rights institutions, national human rights commissions, equality bodies and specialist disability agencies.

4. Parliamentarians

Members of Parliament play a key role in securing and monitoring human rights. The CRPD requires States to “adopt all appropriate legislative, administrative and other measures”,¹ and to “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities”.² Furthermore, “parliament, through its oversight function, plays a key role in ensuring respect for the human rights of persons with disabilities”.³ This includes actions such as scrutiny on parliamentary committees, conducting commissions of inquiry, questioning ministers, and scrutiny of executive appointments, state budgets and spending.

5. UN Committee on the Rights of Persons with Disabilities and other international and regional bodies

The guidelines are intended to assist the CRPD monitoring body – the Committee on the Rights of Persons with Disabilities – in developing its guidance on Article 33 which it can provide to States in its concluding observations as a part of the State Reporting procedure (see Articles 34-36 of the CRPD) and by issuing a General Comment on Article 33, should the Committee choose to do so. Focused attention by the Committee on Article 33 will have impact beyond ensuring implementation of a single provision. Effective coordination of policies and an active monitoring mechanism that includes the input of civil society, as required by Article 33, will ensure the necessary conditions are in place on the domestic level for full and effective implementation of the full range rights set out in the CRPD. In addition to use by the Committee on the Rights of Persons with Disabilities, the guidelines are also intended for use by other treaty bodies with a mandate covering people with disabilities: that is, all treaty bodies. The UN Human Rights Council and the UN Special Rapporteurs on Disability, Torture, Health and Education, as well as bodies within regional organisations including the European Union, the Council of Europe, and regional bodies in Africa and the Americas are also encouraged to use refer to these guidelines in their work.

For full disclosure Gábor Gombos, who has been involved in this project from its conception as MDAC’s Senior Advocacy Officer, was elected in September 2010 to be a Member of the UN Committee on the Rights of Persons with Disabilities, serving a two-year term starting 1 January 2011. The Committee has not influenced the development of these guidelines.

1.3. Scope

The Article 33 guidelines focus on the requirements for domestic level structures to implement the UN Convention on the Rights of Persons with Disabilities (CRPD) and to monitor implementation of the Convention. They do not seek to provide an overview of the Convention, nor an account of the international monitoring process involving the UN Committee on the Rights of Persons with Disabilities.

One cannot, of course, read Article 33 in isolation from the rest of the CRPD. The meaning of words contained in Article 33 can be understood only in the context of the Convention as a whole, including its purpose, which is to “to promote, protect

¹ See Art. 4(1)(a) of the CRPD.

² See Art. 4(1)(b) of the CRPD.

³ See “From Exclusion to Equality: Realizing the rights of persons with disabilities. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol”, United Nations, Office of the High Commissioner for Human Rights and the Inter-Parliamentary Union, 2007, pp. 106-107.

and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.⁴

MDAC’s mandate is to focus on the rights of people with intellectual disabilities and people with psycho-social (mental health) disabilities. As alluded to in Commissioner Hammarberg’s Foreword, we have written these guidelines knowing that people with intellectual disabilities and people with psycho-social disabilities are often ignored by policymakers, their views unasked, their needs unaddressed and their rights unfulfilled. Article 33 of the CRPD, however, is intended to implement the Convention, and monitor its implementation, for all people with disabilities, and these guidelines are designed to apply broadly.

1.4. Methods

MDAC submitted a two-year project for funding in February 2009 for the development of guidance on Article 33 of the CRPD. At that time, we, like others, had identified Article 33 for its fantastic potential in implementing the Convention, yet recognised that even in those countries that had signed or ratified the Convention there was little discussion, let alone implementation, of the provision. Article 33 featured only dimly on the United Nations and European Union levels. MDAC had attended meetings on the CRPD at which representatives of States Parties had expressed a need for information on the actual elements of Article 33.

We too were curious to find out how focal points in governments could work. We were worried how national human rights institutions would cope with such a massive mandate in times of financial cutbacks, and wanted to develop some ideas about how they could manage their workload. We were keen to ensure that people with disabilities and other non-governmental organisations (NGOs) were involved in creating mechanisms and in monitoring implementation, in ways similar to how civil society had been instrumental in negotiating the Convention itself. Put simply, we wanted to create a document which would flesh out what Article 33 actually meant.

1.5. Funding

The United Kingdom’s Foreign and Commonwealth Office (FCO) kindly agreed to fund the project, telling us in April 2009 that the two-year project which we had submitted could be on the reserve list for 2009-10. This meant that we might not get the funding at all, or that we might be guaranteed funding in 2010-11 but would have to complete the project in that same financial year. We opted for the guaranteed funding, signed a contract of 112,598.20 GBP, and started the project on 1 April 2010.

The limitation on the funding was from the outset a challenge: we had to implement in one year what we had set out to do in two years. Following the change of UK government in the May 2010 general elections and the austerity measures immediately implemented by the new government, the FCO asked us in June 2010 to submit an assessment of cuts to the project of 10%, 20% and 50% respectively, and froze spending until it had determined the level of cuts. In August 2010, the FCO informed MDAC that the project had been reduced to 100,800 GBP, a cut of 10.7%.

It was understood both by the FCO and MDAC, and the member of the expert advisory group who worked for the UK government (in the Department for Work and Pensions, not the FCO), that MDAC retains complete editorial and operational independence from the funder.

⁴ See Art. 1, CRPD.

1.6. Outreach and Experts

In developing the Article 33 Guidelines and Checklists, MDAC hired Kathryn Vandever as Policy and Advocacy Officer to manage the project. We analysed the publications listed in chapter 8 of the guidelines and reviewed emerging practice as States Parties began to implement Article 33 of the CRPD. MDAC consulted with people with disabilities, disabled people's organisations, disability rights experts, representatives of government, people working in national human rights institutions, public policy experts, parliamentarians and academics. MDAC established an expert advisory group to provide guidance to MDAC throughout the project. MDAC met with members of this group in London in May 2010 and in Budapest in January 2011.

During the Conference of States Parties to the CRPD at UN headquarters in New York on 2-3 September 2010, MDAC had the opportunity to gather input from the participants of the side session, "Ensuring Meaningful Participation of People with Intellectual Disabilities and Psycho-social Disabilities in Implementing Article 33 of the CRPD". MDAC hosted this side session in collaboration with the Office for Disability Issues of the UK government and the Independent Monitoring Committee for the Implementation of the CRPD from Austria. MDAC also had the opportunity to gather input from the participants of the "Work Forum on the Implementation of the UN Convention on the Rights of Persons with Disabilities", in Brussels on 18-19 November 2010; this was hosted by the Belgian Presidency of the Council of the European Union and the European Commission.

In March 2011, coordinators in five European countries conducted interviews and lead focus groups with key individuals from government administration and civil society who reviewed and provided feedback on the final draft version of the guidelines. These people/organisations are Gauthier de Beco (Belgium), Masa Anisic (Croatia), Global Initiative on Psychiatry (Lithuania), League of Human Rights (Czech Republic) and the Resource Centre for People with Mental Disability "Zelda" (Latvia).

A range of international and regional experts from disabled people's organisations, disability rights organisations, government, academia, national human rights institutions and other sectors of society also provided feedback on a draft version of the guidelines at that time. We have done our best to incorporate the advice received. The guidelines cannot, however, reflect the views of all of the people who shared with us their ideas, owing to the diversity of these views, as well as time and page number constraints.

The people listed here have not endorsed the guidelines, although we hope they will use the guidelines in their work. They have provided input into this project on a voluntary basis and in their own capacity, which may not represent the views of the institution for which they work. Our gratitude goes to the following people for their insight, enthusiasm and humour:

- Janina Arsenjeva, European Disability Forum
- Michael Bach, Executive Vice-President, Canadian Association for Community Living, Toronto, Canada and MDAC Board Member
- Peter Bartlett, Nottinghamshire Healthcare NHS Trust Professor of Mental Health Law, University of Nottingham, UK and MDAC Board Member
- Gauthier de Beco, Associate Researcher at the University of Louvain, Belgium
- Jerome Bickenbach, Professor, Department of Health Sciences and Health Policy, University of Lucerne and SPF, Nottwil, Switzerland, Swiss Paraplegic Research (SPF), Nottwil, Switzerland
- Felicity Callard, Senior Research Fellow, Service User Research Enterprise, Institute of Psychiatry, King's College London and MDAC Board Member
- Colin Harper, Manager, Disability Action's Centre on Human Rights for People with Disabilities, Northern Ireland, UK

- Judith Klein, Director, Open Society Mental Health Initiative, Open Society Foundations
- Camille Latimier, Human Rights Officer, Inclusion Europe, Prague, Czech Republic
- Anna Lawson, Senior Lecturer in Law, University of Leeds, UK and MDAC Board Member
- Rachel Murray, Professor of Law, University of Bristol, UK
- Mary Nettle, Self employed as a Mental Health User Consultant, Former Chair, European Network of (ex-) Users and Survivors of Psychiatry
- Matthew Pringle, Programme Officer for Europe and Central Asia, Association for the Prevention of Torture, Geneva, Switzerland
- Gerard Quinn, Professor of Law and Director of the Centre for Disability Law and Policy, Faculty of Law, National University of Ireland, Galway, Republic of Ireland
- Debra Shulkes, European Network of (ex-) Users and Survivors of Psychiatry
- Marianne Schulze, Chairperson, Independent Monitoring Committee for the Implementation of the CRPD from Austria
- Michael Stein, Executive Director, Harvard Law School Project on Disability and Cabell Professor of Law, William & Mary Law School
- Rachel Stevens, Director, Empower All, Ireland
- Lisa Waddington, European Disability Forum Chair in European Disability Law, Maastricht University
- James Wolfe, Senior Civil Servant, Department of Work and Pensions, UK
- Kutsal Yesilkagit, Associate Professor of Public Administration, School of Governance, Utrecht University, the Netherlands

The project was coordinated and the guidelines edited by Kathryn Vandever. Various parts of these guidelines were written by Kathryn as well as Gábor Gombos and Oliver Lewis. It was proof-read by Felicity Callard. Gauthier de Beco contributed to chapter 5. We thank Thomas Hammarberg for his inspiring Foreword, and his leadership on human rights throughout Europe.

Chapter 2. The CRPD and Article 33

2.1. The Convention

The UN Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty and development tool. It was adopted by the UN General Assembly in 2006 and entered into force in December 2008. Although the rights set out in international human rights treaties that predate the CRPD extend to persons with disabilities, prior to the adoption of the CRPD persons with disabilities remained largely invisible within the international system of human rights promotion and protection.⁵



The preamble to the CRPD states that the Convention seeks to present an “international Convention to promote and protect the rights and dignity of persons with disabilities”.⁶ It brings together civil and political rights with economic, social and cultural rights within one instrument. An unprecedented level of participation of civil society, including persons with disabilities and their representative organisations, participated in the Convention’s negotiations. The civil society grouping became known as the International Disability Caucus, whose slogan was, “Nothing about us without us”.

The CRPD codifies in international law several conceptual shifts towards disability. This includes the social model of disability that recognises disability as the result of the interaction between a person with impairments and various barriers (including attitudinal, environmental and legal) that hinder a person’s full and effective participation in society on an equal basis with others. The CRPD also sets out a human rights approach to disability that recognises people with disabilities not as objects of other people’s treatment, management, care, pity, charity or fear; but as subjects – of human rights, and on an equal basis with others. Much has been written about the CRPD, and these guidelines seek neither to repeat nor summarise these texts, which are provided as resources in chapter 8 of these guidelines.

⁵ See G. Quinn and T. Degener, “Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability”, Office of the High Commissioner for Human Rights (New York and Geneva: United Nations, 2002), available at: <http://www.ohchr.org/Documents/Publications/HRDisabilityen.pdf>.

⁶ CRPD, Preamble para. (y).

2.2. Overview of Article 33

Article 33 of the CRPD says the following:

Article 33 – National Implementation and Monitoring:

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 a 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.

Article 33 addresses the gap between – on the one hand – international human rights standards that exist on paper, which States promise to respect, protect and fulfil, and – on the other hand – the impact of those rights on the lives of people on the domestic level across the globe. This is known as the implementation gap. Factors that contribute to the implementation gap include:

1. A low level of awareness about international human rights standards among people whose rights are affected, their communities and governments.
2. A human rights rhetoric spoken by diplomats and United Nations officials in Geneva and New York that remains far-removed from the lives of the individuals whose rights international treaties seek to guarantee.
3. A lack of independent mechanisms at the domestic level to monitor implementation of human rights standards, to hold States to account for their human rights obligations, and to create a scandal when human rights violations occur.
4. Policies and programmes that are developed and implemented by individual ministries and departments, without coordination and communication across government.
5. The failure to effectively seek the contributions of civil society in the development and implementation of policies and programmes, and the exclusion of civil society within policy discourse in general.

Some of the additional barriers that persons with disabilities have to face in seeking to realise their human rights are:

1. The clash between the legacy values of human rights (universalism, substantive equality, non-discrimination) and the legacy values of how non-disabled people have treated people with disabilities (“best interests”, social protection, formulaic equality).
2. The lack of recognition of disability as a human rights issue at the international human rights level, prior to the CRPD.

3. Disability laws which exclude some people with disabilities (such as those with psycho-social disabilities or mental illnesses), and fail to address the full spectrum of human rights.
4. The invisibility, stigma and discrimination of persons with disabilities throughout societies, including within the political sphere.
5. The low level of awareness of disability, people with disabilities and the rights of people with disabilities, within all levels of society, including families, service providers, governments, national human rights institutions and human rights organisations.
6. The failure of mainstream politics and policies to take into account the needs and the rights of people with disabilities.

These are long lists and they pose serious challenges in relation to the implementation of the CRPD. Article 33 is the Convention's best attempt to address many of these hurdles, because it sets out roles for domestic level mechanisms to ensure implementation and monitoring of the CRPD.

What does Article 33(1) say?

Article 33(1) encourages States Parties to pursue holistic disability policies in place of governance within distinct ministries or departments. It requires States Parties to designate at least one focal point in government for matters relating to implementation of the Convention and to ensure effective coordination across and throughout sectors and levels of government.

It requires States Parties to give due consideration to the establishment or designation of a coordination mechanism where additional coordination is necessary, which could take the form of a standing committee, annual meeting of cabinet or web-based mechanism. It would be difficult to be a focal point that does not do any coordination, and so we can safely assume that there has to be some formal coordination that happens across government.

Further guidance about implementation of Article 33(1) is provided in chapter 4 of these guidelines.

What does Article 33(2) say?

Article 33(2) requires States Parties to establish or designate a framework within government that includes one or more independent mechanisms to promote and protect the rights of persons with disabilities and monitor implementation of the CRPD. The framework must include at least one robust, adequately-skilled body, which is fully independent from government and meets the requirements of the Paris Principles, a UN General Assembly guidance document for national human rights institutions.⁷

Further guidance about implementation of Article 33(2) is provided in chapter 5 of these guidelines.

What does Article 33(3) say?

Article 33(3) requires States Parties to ensure that civil society, in particular persons with disabilities and their representative organisations, is involved and participates fully in monitoring CRPD implementation. Participation of civil society lies at the centre of the CRPD, which recognises participation as a general principle in Article 3 that runs throughout the Convention, and as a general obligation in Article 4(3). People with disabilities and their representative organisations were a key part

⁷ Principles relating to the Status of National Institutions (The Paris Principles), GA Resolution 48/134, 20 December 1993, available at: <http://www2.ohchr.org/english/law/parisprinciples.htm>.

of negotiating and drafting the Convention, and the resultant text seeks to ensure that a high level of participation is maintained at the domestic level as the Convention is implemented.

Further guidance about implementation of Article 33(3) is provided in chapter 3 of these guidelines.

2.3. Origins of Article 33

This section draws on the official records of the negotiations of the Convention (the *travaux préparatoires*) in order to understand how the final text of Article 33 was reached.

During its 2nd meeting in June 2003, the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities – the body tasked to negotiate what eventually became the CRPD – decided to establish a working group to prepare and present a draft text of a Convention that could provide a basis for negotiations by UN Member States. The working group was mandated to take into account all the previous contributions submitted to the Ad Hoc Committee by States, observers, UN bodies, entities and agencies, regional commissions, other intergovernmental organisations, representatives of civil society, including non-governmental organisations, national disability and human rights institutions and independent experts.

Many of these contributions highlighted the need for the resultant treaty to include mechanisms with responsibility to promote and monitor implementation of the Convention. Most contributions addressed international and national mechanisms together. Owing to limitations in time, it seems that the working group did not consider international monitoring or discuss the draft text in detail. The deliberations took place in a small group, in which an agreement was reached on the following language:

1. States Parties shall designate a focal point within Government for matters relating to the implementation of the present Convention, and give due consideration to the establishment or designation of a coordination mechanism to facilitate related action in different sectors and at different levels.
2. States Parties shall, in accordance with their legal and administrative system, maintain, strengthen, designate or establish at the national level a framework to promote, protect and monitor implementation of the rights recognised in the present Convention.

There was no agreement on the role of national human rights institutions (NHRIs). However, various States proposed that NHRIs perform the following functions:

- Promoting awareness of the provisions of the Convention;
- Monitoring national legislation, policies and programmes to ensure consistency with the Convention;
- Undertaking or facilitating research on the impact of the Convention or of national legislation;
- Developing a system for assessing that impact on persons with disabilities;
- Hearing complaints about failure to observe the Convention.⁸

Lacking a consensus, the working group encouraged the negotiating parties to consider additional proposals in relation to implementation and monitoring mechanisms, including submissions from non-governmental organisations.

⁸ Report of the Working Group, footnote 114, available at: www.un.org/esa/socdev/enable/rights/ahcwgreports25.htm.

The focus of the 4th and 6th meetings of the Ad Hoc Committee was on the domestic monitoring mechanism(s).⁹ There was broad agreement amongst negotiating States that such mechanisms should be independent and should operate in a participatory manner where persons with disabilities are involved. Nevertheless, during the 4th session of the Ad Hoc Committee in August 2004, Canada expressed a concern that was shared by a number of the negotiators, stating “[t]he monitoring approach is a negative one, based on a non-compliance model. Given the importance of progressive implementation Canada wants to see the facilitation of progress, beyond simply monitoring, and that would require a more positive approach to monitoring at the national level. A Canadian national-level reporting framework, including indicators for measuring outcomes of disability policy and legislation, has been developed in cooperation with NGOs [non-governmental organisations]”.¹⁰

Throughout the negotiations several approaches were proposed to realise such facilitation of progress, including the following:

- Focal point(s) within the government: to facilitate coordination across different ministerial departments as well as local, regional or federal authorities as applicable; to ensure or coordinate the collection of data and statistics as required for effective policy programming and evaluation of implementation; to cooperate with civil society and organisations representing persons with disabilities as well as national institutions; to cooperate with the international monitoring mechanism – particularly in connection with periodic reporting, follow-up and implementation of recommendations emanating from the international mechanism; to undertake or coordinate government activities in the area of awareness-raising, educating the general public, training and capacity-building.¹¹
- Action plans for the full, effective and equal enjoyment of the human rights of persons with disabilities, developed in consultation with persons with disabilities and their representative organisations.¹²
- Baseline national reports and national action plans.¹³

Negotiating States at that time felt that in addition to having a domestic monitoring framework, there needed to be supplementary mechanisms to facilitate coordinated implementation. Although there was no consensus on the more prescriptive language, other than the text which became Article 33(1), an understanding of the content and scope of the obligations under this paragraph can be strengthened by considering the proposals on the negotiating table.

With concern to Article 33(2), there was broad support for the establishment of effective and independent domestic monitoring from the very beginning of the negotiation process. However, consensus was not reached on the following:

- The role of NHRIs in the promotion, protection and monitoring, although a quasi-direct reference was made to the Paris Principles;

⁹ Summaries of the 4th and 6th Ad Hoc Committee sessions, 23 August – 3 September 2004 and 1-12 August 2005, available at: <http://www.un.org/disabilities/default.asp?id=1423>.

¹⁰ Daily Summaries of CRPD negotiations, August 23, 2004, available at: <http://www.un.org/esa/socdev/enable/rights/ahc-4sumart25.htm>.

¹¹ See Amnesty International, “Strengthening implementation at the national level”, available at: <http://www.un.org/esa/socdev/enable/rights/documents/ahc6amnestyda25.doc>.

¹² International Disability Caucus: “Draft Article 25 International and National Monitoring and other Aspects of Implementation, 8 August 2005, available at: <http://www.un.org/esa/socdev/enable/rights/documents/ahc6idcda25.doc>.

¹³ National Human Rights Institutions: Draft Text on Monitoring, 10 August 2005, available at: <http://www.un.org/esa/socdev/enable/rights/documents/ahc6nhrda25.doc>.

- The detailed functions of the monitoring framework;
- The relationship between the international and national level monitoring.

The Chair of the Ad Hoc Committee submitted a Discussion text for the 7th Session in January 2006, in which he proposed that the monitoring framework have the following functions:

- Regularly examine the situation of persons with disability with a view to promoting and protecting their human rights;
- Make recommendations to the relevant authorities with the aim of enhancing the enjoyment of persons with disabilities of their rights under this Convention;
- Submit proposals and observations concerning existing or draft legislation;
- Submit proposals and observations concerning existing or draft policies and programmes.¹⁴

These proposals built upon earlier contributions submitted to the Ad Hoc Committee, and also went beyond them. Although no consensus was reached on a prescriptive approach to the functions of the independent framework, the list above can be used as guidance in understanding the obligations under what became Article 33(2). The final text of Article 33 was reached during the last session in August 2006 in informal consultations which took place in corridors and behind closed doors, and there is no formal record of these discussions.

¹⁴ Discussion Text proposed by the Chair on Monitoring, 7th session, 16 Jan – 3 Feb 2006, available at: <http://www.un.org/esa/socdev/enable/rights/ahc7discussmonit.htm>.

Chapter 3. Civil Society Participation – Article 33(3)

Previous sections have provided an overview of Article 33, the problems of implementation it seeks to address, and the history of how the text was developed. This chapter examines the notion of civil society participation, examining the requirements of Article 33(3) and placing it within the wider context of the UN Convention on the Rights of Persons with Disabilities (CRPD).

3.1. Participation as the Lifeblood of the Convention



Meaningful participation of civil society, in particular of persons with disabilities and their representative organisations, lies at the heart of the CRPD. Indeed, participation in society is seen as the goal of the CRPD, the preamble noting that “persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”,¹⁵ and that a promotion of human rights and participation “will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty”.¹⁶ The treaty recognises participation as: a general principle that runs throughout the Convention, a general obligation that States Parties need to ensure in interpreting and implementing CRPD rights, and a set of rights to and within political life,

public life, cultural life, recreation, leisure and sport.¹⁷ Article 33(3) of the CRPD places an additional obligation on States Parties to ensure that civil society, in particular persons with disabilities and their representative organisations, are involved and participate fully throughout the processes of monitoring implementation of the CRPD.¹⁸

This chapter of the guidelines seeks to strengthen the understanding of governments on how they can “closely consult with and actively involve” persons with disabilities and their representative organisations in matters relating to implementation of the CRPD, including monitoring. The chapter seeks to strengthen civil society’s understanding of their rights to participation and their ability to hold States Parties to account for their corresponding obligations. It further seeks to assist the UN Committee on the Rights of Persons with Disabilities to monitor implementation of Article 33, including the extent to which governments are ensuring civil society involvement.

¹⁵ CRPD, Preamble para. (k).

¹⁶ CRPD, Preamble para. (m).

¹⁷ CRPD, Articles 3, 4(3), 29, 30 and 33(3).

¹⁸ CRPD, Art. 33(3).

3.1.1. Participation as Principle

Article 3 of the CRPD sets out the general principles of the Convention. These include the principle of “full and effective participation and inclusion in society”.¹⁹ The principles set out in Article 3 can be thought of as the CRPD’s value system, or a lens through which all of the rights and obligations in the CRPD need be interpreted, internalised and implemented.²⁰

3.1.2. Participation as General Obligation

Article 4(3) of the CRPD sets out:

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.

This provision therefore requires States Parties to closely consult with and actively involve persons with disabilities through their representative organisations throughout the policy cycle, including in agenda-setting, planning and implementing the policies, and programmes and services that affect the lives of persons with disabilities. This provision is supported by a statement of fact listed in the preamble to the Convention, “that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”.²¹ Article 33(3) completes the policy cycle by ensuring that civil society is involved in monitoring the implementation of the Convention. Figure 1, below, sets out this policy cycle.

Figure 1: Policy Cycle



¹⁹ CRPD, Art. 3.

²⁰ The full text of Article 3 of the CRPD reads: The principles of the present Convention shall be: (a) Respect for inherent dignity, individual autonomy including freedom to make one’s own choices, and independence of persons; (b) Non-discrimination; (c) Full and effective participation and inclusion in society; (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (e) Equality of opportunity; (f) Accessibility; (g) Equality between men and women; (h) Respect for the evolving capacities of children with disabilities to preserve their identities.

²¹ CRPD, Preamble para. (o).

3.1.3. Participation in Monitoring

Article 33(3) of the CRPD sets out:

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

Article 33(3) requires that civil society “shall” (a word which means “must”, and leaves no doubt as to the level of obligation) be “involved and participate fully in the monitoring process”. States Parties must ensure full participation, a much stronger obligation than mere consultation. Article 33(3) allows people with disabilities, separately from disability organisations, to participate. An independent monitoring mechanism established under Article 33(2) could, for example, hire an expert with a disability who is not a member of an organisation that represents persons with disabilities (such as a disabled people’s organisation).

Article 33(3) will be touched on in chapter 5, alongside an examination of Article 33(2), the provision which sets out States Parties’ obligations to maintain, strengthen, designate or establish a framework to promote, protect and monitor implementation of the CRPD.

3.1.4. Right to Participate in Political and Public Life

Article 29 of the CRPD speaks directly to involvement of people with disabilities in civil society to “effectively and fully participate in the conduct of public affairs without discrimination and on an equal basis with others, and encourage their participation in public affairs”.²² It sets out the right to vote and stand for election on an equal basis with others. And beyond that, it ensures that people have opportunities to be part of political parties and non-governmental organisations:

Article 29 – Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

- a. To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
 - i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
 - ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
 - iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice.

²² CRPD, Art. 29(b).

- b. To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
 - i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
 - ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Article 29 is directly linked to Articles 33(3) and 4(3), as it establishes the emblematic right for adults to vote, a prerequisite to citizenship. The right to vote, and to participate in public life, is currently in many countries denied to people with disabilities who are deprived or restricted of legal capacity. This is an area that requires urgent legal reform; it is addressed in Article 12 of the CRPD. States must ensure that people denied the right to vote are not denied the opportunity to participate in CRPD implementation and monitoring.

3.2. How to Ensure Meaningful Participation

Article 29, read together with Articles 4(3) and 33(3) of the CRPD, can be interpreted as requiring States Parties to be proactive in ensuring that persons with disabilities and their representative organisations are provided with the capability and opportunity to participate in civil and political life on an equal basis with others.

Policies and programmes that are designed through the participation of individuals and groups they seek to serve are more likely to:

1. Reflect real needs;
2. Result in effective implementation;
3. Have ownership by the community.

Although there has been significant progress in recent years in involving civil society in a number of policy areas – such as the environment, transport, local education, and healthcare – people with disabilities are consistently excluded from having a voice in the development and implementation of the policies and programmes that affect their lives. Where consultation does occur, it is frequently with medical professionals and service providers in place of persons with disabilities, whose views are regularly dismissed as irrelevant, irrational or incompetent.

Promoting participation of people with disabilities throughout the policy cycle sends a powerful message to the wider society about what it means for all people to be “born free and equal in dignity and rights”.²³ People with disabilities experience stigma and social exclusion, along with other environmental and societal barriers that put them at risk of experiencing violations of their human rights.

Governments can challenge the exclusionary effects of the stigma, discrimination and invalidation which people with disabilities experience by:

²³ Universal Declaration of Human Rights, Art. 1.

1. Recognising that persons with disabilities are experts in relation to their own lives;
2. Responding to their interests when initiating reform, and;
3. Proactively seeking their counsel when defining an agenda for reform.

Meaningful participation requires structure, and cannot be fully realised through *ad hoc* methods. Participation requires governments to ensure transparency in implementing the Convention. It requires that information is made available to people in formats that are accessible to them. It requires processes are in place to involve persons with disabilities and their representative organisations in determining who participates, when they participate, and how they participate. It requires that mechanisms of participation are made available in accessible and multiple formats, and that reasonable accommodation is made available where it is necessary. Frequently, it also requires capacity building and financial resources. These are now explored in more detail.

Meaningful participation requires that the terms of representation are agreed upon through an open and transparent process that involves persons with disabilities and their representative organisations. A process needs to be in place to address two crucial issues:

1. **Ensuring adequate representation.** Which people and organisations should participate on behalf of civil society in matters relating to implementation of the CRPD?
2. **Ensuring a good process.** At what points will participation take place throughout the development, implementation, monitoring and evaluation of matters relating to implementation of the Convention? What methods and mechanisms will be developed to ensure that the participation is meaningful?

3.2.1. Ensuring Adequate Representation

The participation of civil society in matters relating to implementation of the CRPD needs to represent a full range of disability sectors, as well as other representatives of civil society, including NGOs and academia, that seek to promote, protect or monitor implementation of the Convention. Civil society is wide and encompasses a broad range of actors.

The CRPD in Articles 4(3) and 33(3) of the CRPD is clear that persons with disabilities and their representative organisations must be given an opportunity to be included in policy development and monitoring. They can provide valuable advice on human rights violations and ways of implementing the CRPD. People with disabilities are not a homogeneous group, and nor are their representative organisations. Government needs to understand the differences so that it can include diverse organisations holding different opinions. Choosing which people with disabilities and which organisations should be involved in monitoring is difficult, and the choice can have an impact on organisations as much as it can have an impact on the monitoring.

The International Disability Alliance (the global grouping of disability umbrella groups) suggests that the term “representative organisations” refers to organisations that “can legitimately claim to represent a given constituency of persons with disabilities, preferably those with a membership structure that directly governs the organization or elects the governing body of the organization, and if such a body does not exist, another organization whose credibility with the constituency is demonstrated in a public consultation, and that maintains a mechanism for accountability to that constituency”.²⁴ The Alliance suggests

²⁴ International Disability Alliance, “Contribution to the Office of the United Nations High Commissioner for Human Rights’ thematic study to enhance awareness on the structure and role of national mechanisms for the implementation and monitoring of the Convention on the Rights of Persons with Disabilities”, Geneva, September 2009.

that implementing the CRPD will result in strengthening national umbrella coalitions/federations comprising organisations representing particular constituencies of persons with disabilities. It also points out that priority in consultation should lie with organisations of persons with disabilities that are most representative of various constituencies by having a good presence throughout the country.

National umbrella organisations play a central role, but they should not be the only organisations to be included in monitoring. In many countries at present there are few disabled people's organisations, no organisations of people with psycho-social disabilities (mental health service user organisations), and no self-advocacy groups of people with intellectual disabilities. Many disability groups have limited visibility within society and in the disability sector itself due to stigma, the exclusion of these groups from domestic disability laws, as well as the deprivation of legal capacity, which results in a denial of freedom of association. States need to recognise this and reach out to traditionally marginalised disability groups in ensuring civil society participation.

States Parties need to ensure that they do not set the bar too high for participation on the monitoring mechanisms. While the national human rights institutions may have many employees who are lawyers and sociologists with master's degrees in disability studies, people with disabilities may have been excluded from educational opportunities. Participation should be open to those with practical experience of human rights on the ground, and those with experience advocating for people's rights.

Family and carer organisations and organisations for people with psycho-social and intellectual disabilities are important stakeholders and can play an important role in representing the views of families and carers. None of these people can ever replace the voices of people with disabilities. Parents' organisations and self-advocacy organisations should be encouraged to work together to provide a representative voice for people with intellectual disabilities.

Processes also need to be in place to evaluate whether an organisation genuinely and legitimately represents the persons with disabilities in whose name they claim to speak. Sometimes, service providers, including professional medical, nursing and social care staff, claim to be advocating for their patients/clients, and although they may do this in good faith, it is a practice to be avoided.

The rights of children with disabilities are of concern to many people, and it is parents' organisations which often speak for children with disabilities. The CRPD encourages us all to meet children with disabilities and seek their views directly. Article 7(3) of the CRPD sets out that:

States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Further, Article 3(h) of the CRPD calls for the States to have "[r]espect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities." It is important for this to be taken into account when inviting children to participate in the monitoring functions.

3.2.2. Ensuing a Good Process

Early and continuous involvement

Persons with disabilities should be involved at the stage of planning to ensure that the methods of participation are substantial and meaningful. It is not effective to consult with people after a decision has been made – this is not participation, but

asking for authorisation. Situations and contexts often change, and so in a policy process, States Parties need to review who is being consulted, and actively involve emerging legitimate organisations.

Accessibility

Meaningful participation requires that States Parties ensure that information about matters relating to the CRPD is made available and accessible to civil society, including persons with disabilities and their representative organisations, in the formats they need. This includes information about the location, structure and mandate of the Article 33 mechanisms, as well as information about how individuals and organisations can participate in monitoring processes prescribed in Articles 33(2) and 33(3) of the CRPD.

A simple internet search should, for example, provide this information. States Parties should be proactive in ensuring information is made available to civil society, which is likely to include maintaining a database of all relevant organisations, regularly disseminating information to these organisations, and asking them to inform their membership about the opportunities to participate.

Multiple Forms of Involvement

In order for participation to be meaningful, multiple formats for participation need to be available. If participation occurs only through meetings, people who are unable to travel to the meeting or who are not confident speaking in public places or before large groups may be excluded. There is a range of ways that participation can happen, including through face-to-face meetings, focus groups, telephone interviews and the internet.

Reasonable Accommodation

For participation to be as effective as possible, reasonable accommodation in events, activities and processes needs to be provided. Article 2 of the CRPD defines reasonable accommodation as:

necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Merely inviting people with disabilities to participate is often insufficient, as they may experience various barriers to participating, such as physical, communicational, attitudinal, or legal. Regular breaks in meetings, well-structured agendas, easy to understand and plain text communications and sign language interpretation are important examples of reasonable accommodations that may have particular relevance for persons with disabilities. States should ask people with disabilities what sorts of adjustments they may need to equalize their participation upwards such that it can take place on an equal basis with others.

Enable Capacity-Building

States Parties have duties under Article 29 of the CRPD to ensure that representative organisations of persons with disabilities (including disabled people's organisations) exist, and that such organisations are provided with the organisational capacity, knowledge and expertise to participate in civil society and political life on an equal basis with others. Organisational capacity, knowledge and expertise means:

1. Skills to participate in monitoring activities;
2. Skills to engage in policy formation and implementation;
3. The confidence and skills to participate in meetings and challenge exclusion;
4. Knowledge about human rights, including the CRPD;
5. Knowledge about how to exercise those rights;

6. Knowledge about who the key people are with respect to domestic implementation of the CRPD;
7. An understanding of the relevant policy issues and how policy is formed.

Capacity can be built in a number of different ways, including through seminars, conferences, books and online resources. These should be in formats accessible to the persons whose capacity is being strengthened. Capacity-building should be available to family and other types of organisations, as well as to persons with disabilities and their representative organisations.

All capacity-building activities require some level of funding, but they may not require a lot. If States have the responsibility to ensure effective participation of people with disabilities and their representative organisations, there is a strong case that they have the responsibility to finance the capacity-building that is a pre-requisite to participation.

State funding poses a real risk to an organisation's actual and/or perceived independence, as well as its advocacy effectiveness. For this reason, it is probably not a good idea for governmental agencies to carry out capacity-building activities for non-governmental organisations.

States Parties may also need to remove legal barriers, such as (as noted above) the deprivation or restriction of legal capacity that prevents some persons with disabilities from participating in public organisations and civic life.

States Parties should not assume that all organisations have the same capacity to participate in activities in relation to implementation of the CRPD, including the monitoring activities prescribed in Articles 33(2) and 33(3). Some organisations (such as newly-formed organisations or organisations representing disability groups that have historically been marginalised within society) may need additional forms of capacity-building to be able to participate meaningfully alongside representatives of other disability groups. This is often the situation for organisations of persons with psycho-social disabilities (users and survivors of psychiatry) and organisations of persons with intellectual disabilities (self-advocates). Both types of organisations have been excluded from social discourse in most countries.

Chapter 4. Championing the Convention within Government – Article 33(1)

Article 33(1) of the CRPD sets out the following:

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.

As noted in chapter 2, above, Article 33(1) seeks to ensure effective coordination across and throughout government for matters relating to implementation of the CRPD. It seeks to put a stop to the way in which laws, policies and programmes are developed and implemented by individual ministries and departments without coordination or communication. It seeks a joined-up approach to governance.

This chapter outlines the function of a focal point. It then addresses the number and location of the focal point(s) and the additional mechanism for coordination across government.

4.1. Function of the Focal Point(s)

Legislation, policies and programmes that affect the lives of persons with disabilities are often developed within individual ministries or departments, without ensuring coordination with other ministries or departments. This can result in gaps in policies and programmes for persons with disabilities, a lack of coordination in funding, and incompatible or even conflicting priorities across government. Article 33(1) seeks to ensure that this does not happen, and that, instead, disability policy is holistic.

In order to assist in Article 33(1) implementation, MDAC has developed the following list of functions of the focal point(s):

1. Serve as the CRPD contact point for government and civil society;
2. Spearhead the CRPD and its values across and throughout government;
3. Ensure coordination within government;
4. Secure civil society involvement;
5. Conduct a baseline analysis at the time of CRPD ratification;
6. Publish a national CRPD implementation plan;
7. Collate data and statistics;
8. Liaise with domestic and international human rights mechanisms.

Each of these functions is explained below.

4.1.1. Serve as the CRPD Contact Point

States Parties need to designate at least one focal point in government to serve as the central contact point for information relating to the CRPD. The focal point serves as the CRPD hub for:

- Governmental ministries and departments;
- Local and regional governments;
- Persons with disabilities and their representative organisations;
- Other representatives of civil society seeking to promote, protect or monitor implementation of the Convention;
- Bodies in the Article 33(2) monitoring mechanism, as well as other national human rights institutions and inspectorate bodies;
- International organisations and bodies such as:
 - The Conference of States Parties to the CRPD;
 - The UN Committee on the Rights of Persons with Disabilities;
 - Other UN treaty bodies such as the Human Rights Committee and the Committee on Economic, Social and Cultural Rights;
 - UN Special Rapporteurs, including the post-holders on Disability, Torture, Right to Health, Right to Education;
 - Bodies within the European Union such as the EU Disability High Level Group, and various Directorates General;
 - Bodies within the Council of Europe such as the European Committee for the Prevention of Torture or Inhuman and Degrading Treatment or Punishment, and the Commissioner for Human Rights.



Information about where in government the focal point(s) is located and how to contact the focal point(s) needs to be made available. A simple internet search should arrive at the information easily. States Parties should also proactively communicate this information to the bodies listed above.

The focal point(s) will also likely be the contact point for any activities involving international cooperation under Article 32(1)b of the CRPD, which sets out the obligation on States Parties to ensure they are “[f]acilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices”.



Question 1: Has one or more focal point in government been formally designated by the State Party as the contact point for matters relating to implementation of the CRPD? Has a coordination mechanism been established to facilitate coordination across and throughout government? Has this been communicated to civil society?

4.1.2. Spearhead the CRPD and its Values throughout Government

The focal point(s) needs to spearhead the CRPD and its values across sectors and throughout levels of government. As explained in chapter 2 of these guidelines, the value system of the CRPD is rooted in the principles set out in Article 3 of the Convention. These principles include respect for the inherent dignity, individual autonomy and independence of persons;

non-discrimination; full and effective participation and inclusion in society; equality of opportunity; accessibility; gender equality; and acceptance of persons with disabilities as part of human diversity and humanity.²⁵

Activities to spearhead the CRPD and its values could include developing “awareness-raising programmes regarding persons with disabilities and the rights of persons with disabilities”,²⁶ such as programmes designed for representatives of government and organisations responsible for service delivery. States Parties need to ensure that the focal point(s) has sufficient political leadership to drive a process of change, distribute and mobilise leadership throughout government, motivate colleagues, push ministerial boundaries, challenge the status quo, gather resources and garner support both within and outside government.

These activities are closely related to the activities necessary for implementation of Article 8 of the CRPD, which sets out States Parties’ obligations for awareness-raising about persons with disabilities and the CRPD. They are also related to the activities that the Article 33(2) framework needs to carry out to promote CRPD rights (see chapter 5, below, for a discussion on the Article 33(2) framework), and there needs to be a discussion on the division of labour between the bodies about who does what. Ultimately, however, the focal point(s), as the State Party, bears the responsibility for carrying these activities out.



Question 2: What actions is the focal point(s) carrying out to raise awareness throughout society about the CRPD?

4.1.3. Ensure Coordination within Government

As noted in chapter 2 of these guidelines, disability policy is often developed in a specific ministry or department within the context of that ministry’s/department’s particular policy goals, and without further coordination across government. Article 33(1) of the CRPD seeks to move governments away from this approach and towards joined-up government, in order to implement the CRPD as effectively as possible.²⁷ In practice, this requires the focal point(s) to carry out the following:²⁸

1. **Coordinate disability legislation, policies, programmes and services.** This requires setting up effective channels for communication, and convening regular progress review meetings that bring together representatives from across government departments/ministries. It means ensuring that relevant ministries/departments share priorities, ideas and concerns, so that holistic legislation, policies and programmes can be adopted and services for people with disabilities can meet the needs of people with disabilities as effectively as possible. It may require civil servants working within the focal point(s) to travel across the country to domestic coordination meetings.
2. **Mainstream disability issues across all governmental policies and programmes.** Article 4(1)(c) of the CRPD requires States Parties “to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes”. The focal point should thereby ensure that all governmental ministries/departments take into account the rights of persons with disabilities in all policy and programmes (even non-disability

²⁵ CRPD, Art. 3.

²⁶ CRPD, Art. 8(2)(d).

²⁷ Article 4(1)(b) of the CRPD sets out a general obligation on States Parties “To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities”.

²⁸ Adapted from J. Newman, “Joined-up government: the politics of partnership”, chapter 6 of *Modernising Governance: New Labour, policy and society* (London: Sage, 2001).

policy and programmes). Coordinated action should not be restricted to disability policies and programmes but to all actions, for example, changing the tax system, allocating development aid spending, writing poverty reduction strategies, planning urban spaces, and so on.

3. **Facilitate information exchange.** The focal point should share promising practice across sectors and throughout levels of government in order to develop innovative approaches to CRPD implementation. This will involve bringing in various civil society organisations as well as the private sector, to share ideas and good practices, for example in ensuring that there are accessible support services available to people with disabilities,²⁹ or that staff working with people with disabilities are trained using the latest information.³⁰
4. **Ensure funding for the disability sector.** Securing adequate financial resources for the disability sector is a role which the focal point could play. This could be achieved, for example, by quantifying the needs of persons with disabilities, ensuring that ministries contribute to providing the funding, and developing partnerships which can deliver on providing appropriate services. Such partnerships could, depending on the local circumstances, involve State bodies, quasi-State agencies, private companies, and non-profit organisations. Similarly, the focal point could examine how it might be possible to reduce unnecessary costs that can result from overlapping policies and programmes.



Question 3: What is the State Party doing to ensure effective coordination across and throughout government for matters relating to implementation of the CRPD?

4.1.4. Ensure Civil Society Involvement

Chapter 3 of the guidelines, above, sets out why and how civil society, in particular persons with disabilities and their representative organisations, should be involved at all stages of the policy cycle. The focal point should be responsible for ensuring meaningful participation of persons with disabilities. People who work in the focal point – as the lead civil servant or group of civil servants – need to ensure that people with disabilities through their representative organisations are closely consulted and actively involved in the development and implementation of any law or policy which affects them.³¹

The focal point could play a vital role in securing funding for capacity-building activities for civil society to enable persons with disabilities, their representative organisations and other civil society actors to participate fully in all matters related to the CRPD. This may include training on the CRPD as well as on organisational development to strengthen the voice of civil society (for capacity-building of NGOs, see chapter 3, above).

The focal point needs to have the confidence of other civil servants to approach them in order to discuss the implications of the Convention on the policies and programmes for which they are responsible. These discussions should be as open and transparent as possible, but from time to time it may be necessary for internal government discussion to remain confidential to allow a (safe) space for policy debate.

²⁹ See CRPD, Art. 4(1)(e).

³⁰ See CRPD, Art. 4(1)(i).

³¹ See CRPD Art. 4(3), which requires that: “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 and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”



Question 4: How does the focal point closely consult with and actively involve persons with disabilities in matters relating to implementation of the CRPD?

4.1.5. Conduct a Baseline Analysis at the Time of CRPD Ratification

The focal points should ensure that a baseline analysis is developed at the time of ratification. This analysis should set out the extent to which domestic law, policy, and practice complies with the CRPD – from Article 1 to Article 33 – at the time of ratification.

A baseline analysis is not an explicit requirement of the CRPD. Such an initiative was formally proposed during the negotiation of the CRPD by the national human rights institutions, but a requirement for this was not included within the final text of the Convention.³² This notwithstanding, a baseline analysis is implied by the CRPD, particularly as States Parties will have difficulty complying with Convention obligations without going through this process.

According to Article 35(1) of the CRPD, States Parties need to submit to the UN Committee on the Rights of Persons with Disabilities “a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned”.³³ It will be impossible for a State Party to submit a report on progress made within the two years since ratifying the Convention if there is no baseline analysis. It is not adequate in Convention terms, therefore, for a State Party to rely on the Article 35(1) State report as the first analysis of its compliance with the Convention.

The case for a baseline analysis upon ratification is particularly compelling when considering how the State, civil society and the UN mechanisms will assess implementation of economic, social and cultural rights, which are intended to be realised progressively.³⁴ It will not be possible to determine whether progress has been made over two (or four) years if no data exist on what the situation was at the start of that period.

States Parties should ensure the baseline analysis is made available and accessible to civil society, in particular persons with disabilities and their representative organisations and any other individual or organisation participating in the monitoring process described in chapter 5 of the guidelines, below. They should also ensure that civil society is involved in drafting it.



Question 5: Was a baseline analysis conducted at the time of CRPD ratification? Was it developed with the involvement of civil society, including persons with disabilities and their representative organisations, and was it made available to them?

4.1.6. Publish a National CRPD Implementation Plan

The focal point needs to ensure that a national disability action plan is developed following ratification of the Convention. The national CRPD implementation plan should: set out the government’s priorities in implementing the CRPD, contain SMART (Specific, Measurable, Achievable, Relevant and Time-Bound) objectives to measure progress, and indicate which areas of government are responsible for delivering each action the plan sets out. The CRPD implementation plan also needs

³² National Human Rights Institutions: Draft Text on Monitoring, 10 August 2005.

³³ CRPD, Art. 35(1).

³⁴ CRPD, Art. 4(2).

to indicate the measures by which civil society, including persons with disabilities and their representative organisations, will participate in implementing the plan. As discussed above in chapter 3 of the guidelines, Article 4(3) of the CRPD requires civil society participation in the implementation of the CRPD. The implementation plan itself should be produced in partnership with representatives of civil society.

Such a plan should cover every aspect of what the government does and should not be limited to disability-specific policies and programmes. The national CRPD implementation plan should be properly resourced and monitored. It would be advisable for States Parties to develop a two-year plan immediately following ratification, so that the timeline corresponds with the deadline for State reporting to the UN Committee on the Rights of Persons with Disabilities, two years following ratification.³⁵



Question 6: Has an implementation plan for the CRPD been developed? Was it developed with the involvement of civil society, including persons with disabilities and their representative organisations, and was it made available to them?

4.1.7. Collate Data and Statistics

Article 31 of the CRPD places an obligation on States Parties to “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [CRPD]”.³⁶ Article 31 also requires that the data are disaggregated to assess implementation of the Convention and identify and address the specific barriers faced by persons with disabilities.³⁷

Data include both statistical information and qualitative information about the lived experiences of persons with disabilities. A combination of both types of data is critical to the formulation of evidence-based legislation, plans and policies, as well as for their implementation and evaluation. Data are also necessary to measure progress against the national CRPD implementation plan (see Focal Point Function 6, above).

States Parties need to ensure that the data are disseminated and made available to the public, including to the Article 33(2) monitoring mechanism (see chapter 5 of the guidelines, below) and civil society, in particular persons with disabilities and their representative organisations and any other individual or organisation participating in monitoring as required by Article 33(3) (see chapter 3 of the guidelines, above).

Article 31 needs to be read in conjunction with Article 33, and in particular with Article 33(2). As explained below, in chapter 5 of the guidelines, Article 33(2) requires States Parties to set up a framework that includes independent mechanisms and has a mandate that includes monitoring implementation of the CRPD. The mechanisms within the Article 33(2) framework, which are intended for the monitoring of CRPD implementation, need to satisfy basic research methodology criteria for creating an evidence base for monitoring.

If one draws from the experiences of national level monitoring in other rights-based contexts, such as that of the Millennium Development Goals and the UN International Covenant on Economic, Social and Cultural Rights (ICESCR), it is clear that the basic components that comprise an evidence base for monitoring are:

³⁵ CRPD, Art. 35.

³⁶ CRPD, Art. 31(1).

³⁷ CRPD, Art. 31(2).

- **National targets.** A concrete description of the scope of a CRPD right and the necessary qualitative and quantitative parameters for its full and effective implementation. National targets specify details about the precise social commitment that the right creates.
- **Indicators.** The statistical variables that identify measureable change over time, in particular from an established baseline (described above). Indicators often follow automatically from the wording of a target.
- **Data.** Article 31 mandates the capture of valid and reliable data relevant to the indicator that has been selected to put into operation the right in terms of national targets. In this regard, it should be noted that Article 31 of the CRPD requires States to collect data that enable them to formulate and implement CRPD-consistent policies, and that this data must be “disaggregated” for disability. For example, this means that data on employment rates under Article 27 must use “disability”, gender”, or “age” as a demographic or statistically independent variable so that a comparison can be made between overall employment rates and rates for persons with disabilities.

The focal point(s), in order to successfully collate data and statistics, should consider providing funding for research and reports, including reports which can be used for a baseline report (see Focal Point Function 5, above) and State reports under Article 35 of the CRPD (see Focal Point Function 6, above).



Question 7: How is the State Party collecting appropriate information, including statistical and research data? How has this information been made available and accessible to representatives of government and civil society, in particular persons with disabilities and their representative organisations?

4.1.8. Liaise with Domestic and International Human Rights Mechanisms

The focal point should carry out any domestic reporting that is required and engage in substantive discussions with bodies established to monitor the State Party’s progress in implementing the Convention. These activities may include: preparing reports for national or regional parliaments on the implementation of the CRPD,³⁸ reporting on or giving evidence to parliamentary committees concerned with aspects of CRPD implementation, reporting to the independent mechanism established under Article 33(2) (see chapter 5 of the guidelines, below), and/or publishing a publicly-available annual report. The nature and regularity of domestic reporting will, of course, differ across jurisdictions.

A formal procedure should be put in place to ensure coordination of timely submissions of State Reports to the UN Committee on the Rights of Persons with Disabilities in accordance with Article 35. As noted above, States need to submit such a report within two years of entry into force. With the exception of the first twenty States which ratified, this generally means two years after the date of ratification by a State, unless there was subsequent domestic legislation which brought the Convention into force.

State Parties must submit a comprehensive report on measures taken to implement the Convention and progress made. Following the submission of an initial comprehensive report, States Parties must submit reports at least every four years and upon request of the Committee.³⁹ The overall focal point will need to take action to ensure State reports to the Committee

³⁸ This includes, for the European Union, reports to the European Parliament.

³⁹ CRPD, Art. 35(2).

are written, as the Convention suggests, in a manner that demonstrates “an open and transparent process”,⁴⁰ and that involves people with disabilities.⁴¹

States also have an obligation under Article 36(4) to “make their reports widely available in their own countries”, which means that the State report needs to be made public, in accessible formats and in all national languages, and disseminated to relevant stakeholders including civil society, including persons with disabilities and their representative organisations, and any other non-State actors, NGOs or individuals seeking to promote, protect or monitor implementation of the Convention. The provision further specifies that States need to “facilitate access to the suggestions and general recommendations relating to these reports”, which are written by the UN Committee on the Rights of Persons with Disabilities. This means that States must make available the Committee’s findings, which may be critical of the government. The government nevertheless has a duty to make the concluding recommendations widely available, and this means translating them (from an official UN language) into the national languages of the relevant State.

It should be noted that the focal point needs to be aware of the work of the UN charter bodies⁴² and treaty bodies.⁴³ Their General Comments, State-specific concluding observations, and case-specific findings on individual communications may be relevant for people with disabilities.

The focal point may need to travel across the country in order to carry out research for such domestic reporting. Funding needs to be secured to allow focal point staff to travel internationally, including to the annual Conference of States Parties to the CRPD at the UN headquarters in New York.

The focal point’s responsibility for coordinating reporting should also include responsibility for ensuring that governmental ministries/departments receive the resultant reports from the domestic or international mechanisms, and that recommendations contained in such reports are considered appropriately and acted upon. This includes acting on recommendations by the 33(2) framework (see chapter 5 of the guidelines, below). The focal point should ensure that recommendations contained in the concluding observations of the UN Committee on the Rights of Persons with Disabilities are acted upon so that further recourse to the United Nations level becomes unnecessary.

Focal point(s) in EU Member States have additional responsibilities. The EU acceded to the CRPD in December 2010. A code of conduct sets out internal arrangements for implementation by and representation of the EU in relation to the CRPD.⁴⁴ This includes provision for the European Commission “to convene, on its own initiative or at the request of a

⁴⁰ CRPD, Art, 35(4).

⁴¹ CRPD, Art. 35(4) sets out a recommendation to States “to give due consideration” in developing the State reports to the provision set out in Article 4(3), which provides for the State obligation to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations”. More on civil society participation can be found in chapter 3 of these guidelines.

⁴² Such UN charter bodies include the Human Rights Council (of note are its Universal Periodic Review procedure and its Special Procedures).

⁴³ Such UN treaty bodies include the Human Rights Committee (CCPR), Committee on Economic, Social and Cultural Rights (CESCR), Committee on the Elimination of Racial Discrimination (CERD), Committee on the Elimination of Discrimination against Women (CEDAW), Committee against Torture (CAT) & Optional Protocol to the Convention against Torture (OPCAT) – Subcommittee on Prevention of Torture (SPT), Committee on the Rights of the Child (CRC), Committee on Migrant Workers (CMW), and the Committee on the Rights of Persons with Disabilities (CRPD). More details are available at: <http://www.ohchr.org>.

⁴⁴ “Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities” (2010/C 340/08).

Member State's focal point, a coordination meeting with the focal points of the Member States".⁴⁵ A focal point within an EU Member State must be prepared to send information to the European Commission on preparing the EU report, and must send the Commission its State report in advance on a confidential basis.⁴⁶ In addition, the civil servant responsible for the focal point will need to travel quarterly to Brussels to participate in the EU Disability High Level Group and other European Union meetings and conferences.



Question 8: How does the focal point(s) maintain an effective dialogue with the UN Committee on the Rights of Persons with Disabilities and other international treaty monitoring bodies?



Question 9: What is the focal point doing to ensure that persons with disabilities and their representative organisations are participating in the CRPD Committee reporting process?

4.2. Form of the Focal Point(s)

The previous section of this chapter examined the functions of the focal point(s); this section looks at its form (structure). Similarly, we advise States to ensure that form (structure) follows function in their thinking about Article 33(1): the ultimate test of Article 33(1) implementation is not location, but rather effectiveness.

States Parties need to designate at least one focal point in government for matters relating to implementation of the Convention either prior to or immediately following ratification, in order to ensure that government activity is joined up for matters relating to implementation of the CRPD and that the functions listed above can be realised. The CRPD allows States Parties flexibility in deciding the number and placement of the focal point(s), requiring they do so "in accordance with their system of organization".⁴⁷ As discussed below, Article 33(1) also requires States Parties to consider setting up an additional mechanism in government for coordination across and throughout sectors and levels, as necessary.

4.2.1. Number of Focal Points(s)

In accordance with Article 33(1) of the CRPD, States Parties are required to designate at least **one focal point** in government for matters related to implementation of the CRPD. The designation of one such focal point may be the decision of a State Party with a centralised system of organisation, where disability competency lies largely within one department or ministry. In such a situation a State Party could designate a senior civil servant as its focal point.

Alternatively, States Parties may designate **more than one focal point** horizontally across departments/ministries on the national level and vertically throughout regional and sub-regional levels of government. Most, if not all sectors and levels of government have a role in ensuring the full and effective implementation of the CRPD. The "Thematic study by the Office of the United Nations High Commissioner for Human Rights on the structure and role of national mechanisms for implementation and monitoring of the Convention on the Rights of Persons with Disabilities" has recommended States Parties "appoint focal points at the level of each or most governmental departments/ministries".⁴⁸ If more than one focal

⁴⁵ Code of Conduct, *ibid*, para. 11(d).

⁴⁶ Code of Conduct, *ibid*, para. 12(d).

⁴⁷ CRPD, Art. 33(1).

⁴⁸ OHCHR, Thematic study on the structure and role of national mechanisms for the implementation and monitoring of the Convention on the Rights of Persons with Disabilities, 22 December 2009, A/HRC/13/29, para 24.

point is designated, a **lead focal point** with responsibility for oversight and coordination of the other focal points should be designated to ensure coordination.

4.2.2. Essential Elements of a Focal Point(s)






States Parties should seek to ensure that wherever the focal point is located, there is adequate staffing; that the staff has disability rights competence, embraces the social model of disability, and, in the case of the lead focal point, authority to coordinate policy across and throughout government; and that the focal points have the resources to carry out the functions listed in section 4.1 of these guidelines.

The essential elements of a focal point are:

1. **Adequate number of staff (all focal points).** There needs to be sufficient quantity of staff dedicated to carrying out all of the necessary functions as listed in section 4.1 of these guidelines.
2. **Disability rights competence (all focal points).** Members of staff working in the focal points need to have a thorough understanding of:
 - CRPD principles, States Parties obligations, rights and mechanisms
 - A rights-based approach to disability
 - A social model of disability, which recognises disability as the result of an interaction between a person with impairments and barriers in society
 - The linkages between human rights and various disabilities (including mental health, an area which is frequently left out of disability rights discourse).

There are now various online courses, summer schools, journal articles and books through which staff can strengthen their understanding of the CRPD and the obligations on governments to implement the Convention. Training should be carried out by persons with disabilities and their representative organisations.
3. **Authority to coordinate policy across government (lead focal point).** In order to coordinate implementation actions, the lead focal point must have the authority to ensure action is taken horizontally and vertically.
 - At the central governmental level, the focal point needs to liaise with ministries and departments responsible for developing policies and introducing laws relating to (for example) children, education, employment, healthcare, housing, transportation, recreation and sport, enterprise, social welfare, foreign affairs, justice, labour and finance, among many other policy areas.
 - At regional and local levels of government, implementation of the CRPD requires the involvement of government representatives responsible for the organisation, provision, and allocation of resources for services, including for education, employment, healthcare, housing, transportation, recreation and sport and enterprise, among other policy areas.
 - At both central and local government level, the focal point needs the authority to convene meetings with, obtain information from, and instruct colleagues to take action. If the focal point lacks such authority – if, for example, the civil servant responsible for the focal point is not senior enough to summon colleagues from other ministries to attend meetings, or if the lead focal point does not have the mandate to demand other ministries to contribute to the State Party's report – then the government should formally designate a "coordination mechanism", and this designation should be done in writing and the information should be publicly available.
4. **Adequate funding (all focal points).** The focal point(s) must have adequate funding to carry out the functions listed in section 4.1 of these guidelines. The adequacy of funding will depend on context and needs to be assessed locally.

States Parties should designate the focal point within a ministry which has both the capacity to live and embody the values of the CRPD, and the authority to coordinate action across government. There may be a tension between capacity and authority, and as so much depends on context, MDAC cannot provide hard guidance. States Parties should consider designating the lead focal point at a high level in government, such as in the prime minister's office or cabinet office. Another option is to establish an office for persons with disabilities within the office of the president, office of the prime minister or cabinet office. Another option is to establish a minister for disability, to be accompanied by administrative department or office.⁴⁹ There may be a trade-off between authority and competence, but the ultimate test is whether the focal point is able to do its job properly and whether it has the support of civil society organisations in doing so.

-  **Question 10:** Where in government has the lead focal point been designated? Where have any additional focal points been designated?
-  **Question 11:** Does the lead focal point have the authority to coordinate action to implement the CRPD at national, regional and local levels?
-  **Question 12:** How many people (full-time equivalent) have been designated to work in focal point(s)? To what extent is this number adequate?
-  **Question 13:** What capacity building is provided to people who are working within the focal point(s) to ensure they have a comprehensive understanding of the CRPD and its value system, and domestic disability laws and policies? Has training for the focal point staff been carried out by people with disabilities?
-  **Question 14:** What financial resources have been allocated to the focal point(s) for implementation of the CRPD? Is the focal point(s) able to carry out its mandate with this funding?

4.2.3. Existing Focal Point

Some governments have an existing focal point(s) for disability issues, some of which resulted from the implementation of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (hereinafter "Standard Rules").⁵⁰ The Standard Rules comprise a non-binding UN General Assembly Resolution, which was adopted by all UN Members in

⁴⁹ See G. Beco and A. Hoefmans, The UN Convention on the Rights of Persons with Disabilities: an Integral and Integrated Approach to the Implementation of Disability Rights – Background Document, study commissioned by the Belgian Federal Public Service Social Security (2011).

⁵⁰ Standard Rules on Equalization of Opportunities for Persons with Disabilities, UN General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993, A/RES/48/96:

Rule 17 – Coordination of work

States are responsible for the establishment and strengthening of national coordinating committees similar bodies, to serve as a national focal point on disability matters.

- The national coordinating committee or similar bodies should be permanent and based on legal as well as appropriate administrative regulation.
- A combination of representatives of private and public organizations is most likely to achieve an intersectoral and multidisciplinary composition. Representatives could be drawn from concerned government ministries, organizations of persons with disabilities and non-governmental organizations.
- Organizations of persons with disabilities should have considerable influence in the national coordinating committee in order to ensure proper feedback of their concerns.
- The national coordinating committee should be provided with sufficient autonomy and resources to fulfil its responsibilities in relation to its decision-making capacities. It should report to the highest governmental level.

1993 at the conclusion of the “Decade of Disabled Persons”. Unlike the CRPD, the Standard Rules are not legally binding on States, but they do represent a shared political commitment by States to work toward the equalisation of opportunities for persons with disabilities through implementation of 22 rules set out in four chapters: preconditions for equal participation, target areas for equal participation, implementation and monitoring mechanism. The Standard Rules also established the post of a UN Special Rapporteur on Disability, who is responsible for monitoring their implementation.⁵¹

As noted, the CRPD is a binding instrument in international law. If a State Party designates an existing disability focal point (including any focal points designated in accordance with implementation of the Standard Rules) for matters relating to implementation of the CRPD, the State Party will need to ensure the focal point has the additional knowledge, capacity and resources to carry out its mandate. States Parties will need to:

1. Revise the mandate of the focal point to reflect its responsibilities under Article 33(1) of the CRPD;
2. Ensure additional financial resources are available, as necessary, for the focal point to implement any additional activities;
3. Increase human capacity and providing training for staff on CRPD provisions.

4.2.4. A Coordination Mechanism Outside the Focal Point(s)

As well as designating “one or more focal points within government for matters relating to implementation” of the Convention, Article 33(1) requires States Parties to, “give due consideration to the establishment or designation of a coordination mechanism to facilitate related action in different sectors and at different levels”.⁵² While States Parties are required only to give “due consideration” to setting up a coordination mechanism, MDAC takes the view that it would be difficult for the focal point to carry out the appropriate functions without a coordination mechanism. States Parties need to decide whether to attribute responsibility for coordination to a focal point (a lead focal point, where more than one focal point is designated) or formally establish or designate a coordination mechanism that is distinct from the focal point(s).

The CRPD text offers no guidance regarding the meaning of a “coordination mechanism”. Some suggestions are:

- Monthly committee meetings of senior civil servants from across relevant ministries/departments;
- A governmental working party to analyse each bill or policy recommendation;
- An annual meeting of cabinet to discuss progress and challenges to CRPD implementation;
- A web-based interface for ministries/departments to upload progress to the focal point.

In some States Parties, a coordination mechanism outside the focal point(s) may be better placed to oil the government machine. This is particularly relevant in States where the focal point lacks authority or resources to effectively coordinate across and throughout government. A coordination mechanism outside the focal point could be convened by, for example, the prime minister’s office, which would have the authority and resources to convene the relevant ministries to solicit the required information and order actions to be taken.

If there is a separate mechanism, the government should ensure that civil society, including persons with disabilities and their representative organisations and any other non-State actors, NGOs or individuals seeking to promote, protect or monitor implementation of the Convention are involved in the coordination mechanism.

⁵¹ See the UN Enable website for further information on the Standard Rules: <http://www.un.org/esa/socdev/enable/dissre00.htm>.

⁵² CRPD, Art. 33(1).

In States where there is more than one focal point, States Parties may want to assign the coordination function to the lead focal point rather than establish or designate a separate mechanism for coordination. In order to be effective, the lead focal point will need to be adequately resourced and have significant public policy authority. Where a State Party has designated a single focal point for matters relating to implementation of the CRPD, that focal point would logically assume responsibility for coordination.

The single focal point (where there is only one focal point), the lead focal point (where there are multiple focal points dotted around government) or the coordination mechanism (where one is established or designated) needs to be able to carry out the full range of functions (see section 4.1, above).

Chapter 5. Independent Watchdogs – Article 33(2)

Article 33(2) sets out the following provision:

States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within a 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 give due consideration to the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

This provision provides for the strengthening, maintaining, designation or establishment of a framework which:

- Consists of at least one independent mechanism;
- Has responsibility to promote, protect and monitor implementation of the CRPD; and
- Complies with the principles relating to the status and functioning of national institutions for protection and promotion of human rights (the “Paris Principles”).



5.1. An Interpretation Puzzle

Before examining the background, functions and characteristics of the Article 33(2) bodies, an interpretative problem needs to be resolved that arises from use of the term “including”.⁵³ There is an ambiguity in Article 33(2) with regard to the mechanisms that are included in the framework. If this provision is to be read literally, the framework could be understood to allow for mechanisms that fully comply with the Paris Principles (and therefore are independent and pluralistic) as well as mechanisms that do not fully comply with the Paris Principles (such as those with close links to government).⁵⁴ According to this interpretation, the Article 33(2) mechanism could comprise nine government-run bodies and one independent body.

MDAC does not accept this interpretation, however, and firmly believes that all of the mechanisms that are strengthened, maintained, designated or established to promote, protect and monitor implementation of the Convention ought fully to comply with the Paris Principles. It is essential particularly for bodies that are seeking to protect CRPD rights and monitor implementation of CRPD rights that they remain independent from government: these bodies need to remain impartial,

⁵³ On this interpretative problem, see de Beco, G., ‘Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities. Another Role for National Human Rights Institutions?’, (2011) 29 (1) Netherlands Quarterly of Human Rights.

⁵⁴ See the discussion below in this section of the Guidelines about the Paris Principles, which set out obligations for independence and pluralism.

remain free from undue interference and maintain credibility with the public. It should also be noted that the official translations of the CRPD vary. The Spanish version of the CRPD uses the term “made up of” (“*que constará de*”), which adds some ambiguity. Although there is a need for the framework to bring into its discussions bodies outside of the framework, including those that do not comply with the Paris Principles, MDAC recommends that the Article 33(2) framework be composed solely of bodies which are fully independent.

5.2. Overview of Article 33(2)

As set out above in chapter 2 of the guidelines, Article 33 of the CRPD seeks to address the implementation gap between international human rights law and the realisation by people with disabilities of their rights in practice. Historically, the monitoring of international human rights treaties has been conducted by international bodies which can seem far removed from reality. The CRPD is the first international human rights treaty to place an obligation on States Parties to focus on domestic mechanisms for monitoring, and it does this through the inclusion of Article 33(2).⁵⁵ The provision does not seek to replace international monitoring, however, but rather to complement the work of the UN Committee on the Rights of Persons with Disabilities – whose mandate and functioning are set out in Articles 34, 35, 36 and 37 of the CRPD and in the Optional Protocol.

States Parties are required to submit State reports two years after the CRPD enters into force and thereafter every four years,⁵⁶ which the UN Committee on the Rights of Persons with Disabilities reviews during its sessions.⁵⁷ The Committee monitors the measures taken and progress made by States Parties in realising the rights set out in the CRPD. In addition to this, the Optional Protocol to the CRPD provides an individual complaints procedure and an inquiry procedure.

Article 33(2) seeks to facilitate implementation of the Convention by requiring States Parties to designate domestic bodies with responsibility to foster an environment in which people with disabilities are able to realise their rights as set out in the Convention. The rationale behind this is that domestic bodies are closer to the ground, have greater expertise about what is happening and greater opportunity for follow-up than an international monitoring body. While the UN Committee on the Rights of Persons with Disabilities has an important role, domestic bodies are much better placed to work within a country in order to secure long-term impact.

Article 33(2) requires each State Party, upon ratification, to adapt its internal structures by doing one of four things with respect to a framework of one or more independent mechanisms to promote, protect and monitor implementation of the Convention. A State must:

maintain, or

A State will maintain a framework in the event that there is already a framework which carries out exactly the function which Article 33(2) requires. This may seem unlikely, but a State Party may have designated such a framework on signing the Convention, so there would be no need to do anything differently upon ratification.

strengthen, or

A State will strengthen a framework if there is an existing framework which, perhaps, does not have a sufficiently wide mandate nor enough resources to carry out the Article 33(2) functions.

⁵⁵ Note should be made of the Optional Protocol to the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, which requires States to create “national preventive mechanisms” to visit places of detention. National preventive mechanisms do not have a mandate to monitor the UN Convention against Torture (or the Optional Protocol) as a whole. In contrast, the independent mechanisms within the framework created under Article 33(2) of the CRPD must focus on the entire CRPD.

⁵⁶ CRPD, Art. 35.

⁵⁷ CRPD, Art. 34.

designate, or

A State will designate a framework if the pieces already exist. For example there may be a national human rights institution and some NGOs which together carry out the various functions of the Article 33(2) framework. The State's role in this case is to officially declare or designate these bodies as the framework.

establish a framework. A State will establish a framework where most or all of the functions are not carried out by existing bodies, or where there are no such bodies.

As the State progressively realises the economic, social and cultural rights in the Convention, there is an ongoing obligation on a State to **maintain** the framework by continually resourcing it, and to ensure it continues to exist whatever political, financial or other considerations there may be. The State must also continually **strengthen** the framework and the mechanisms within the framework, so that it improves over time: the framework should be stronger next year than this year.

The ratification of the Convention is the beginning of a process. By requiring States Parties to equip themselves with domestic bodies especially concerned with disability rights, the CRPD helps government to embrace a rights-based approach to disability issues, and it empowers persons with disabilities and their representative organisations to claim their rights under the Convention.

States Parties do not have to wait to ratify the CRPD to set up their Article 33(2) framework. If a State Party identifies the framework and one or more independent mechanisms that will have responsibility for Article 33(2) before ratifying the CRPD, those mechanisms can seek to encourage ratification without reservations or interpretive declarations and advise the government on how to adjust its laws and policies in order to meet the standards provided for by the Convention.

The Article 33(2) framework and the independent mechanisms that are included within it have a collective mandate to "promote, protect and monitor implementation" of the CRPD. States Parties may designate distinct responsibilities to the various mechanisms within the framework, as long as the full mandate is covered by the framework.

In order to discourage government from threatening or altering the existence of NHRIs, the Paris Principles require that NHRIs be established "by a constitutional or legislative text".⁵⁸ Independent mechanisms under Article 33(2) of the CRPD need to be provided for in law. Questions to ask may include the following:

- **Is there a law establishing the Article 33(2) mechanisms?** The law should be in accessible formats and able to be found easily by domestic civil society organisations.
- **How has this law been communicated to the international community?** Where possible, States parties should attach information on the establishment or designation of the independent mechanisms to their ratification instrument. This means that they should reflect on who will be the article 33 (2) bodies as soon as they sign the CRPD.
- **Is the composition, mandate, working methods and budget each stipulated in law?**

In order to help facilitate at a minimum the identity of the independent mechanisms comprising the framework in each State Party, MDAC recommends that the UN Committee on the Rights of Persons with Disabilities develops an internet-based register of frameworks, with contact information and hyperlinks to these frameworks and mechanisms.

⁵⁸ Principle 2, Competence and responsibilities, Paris Principles, Principles relating to the Status of National Institutions (The Paris Principles), GA Resolution 48/134, 20 December 1993, available at: <http://www2.ohchr.org/english/law/parisprinciples.htm>.



Question 15: Has a framework of one or more independent mechanism(s) been established/designated in law by the State Party to promote, protect and monitor implementation of the CRPD?

5.3. Functions of the Framework

We now turn to the functions of the framework, which are to promote, protect and monitor. These three functions have distinctive features and include their own set of activities. The three functions, however, are complementary and even overlap to a certain extent, so that they cannot be considered as categories that can be separated from each other.

Two examples demonstrate the artificiality of separating out the functions.

1. The independent mechanisms within the framework may encourage States Parties to sign and ratify the Optional Protocol to the CRPD: this is a monitoring function. The mechanisms could thereafter distribute material on the complaints procedure under the Optional Protocol: this is promotion. The mechanisms might help persons with disabilities to introduce complaints before the UN Committee on the Rights of Persons with Disabilities and ensure follow-up to the decisions of the Committee by the State Parties: this is protection.
2. The independent mechanisms within the framework may receive a high number of individual complaints on an alleged grave or systemic violation of CRPD: this is protection. They may then decide to carry out a general inquiry into these allegations: this is monitoring. Drawing on the inquiry's recommendations, they may then provide training and information to policymakers on how to prevent abuses in the future: this is promotion.

5.3.1. Promote

The promotion of human rights includes both general awareness-raising activities that seek to sensitise the public, policymakers and other stakeholders about human rights, as well as targeted activities designed to advance effective realisation of a right, set of rights or a human rights instrument for a general or specific audience.

Activities which the framework of independent mechanisms can carry out to **promote** CRPD rights include the following, non-exhaustive list:

1. Provide detailed analyses of the rights and obligations set out in the CRPD to policymakers;
2. Organise training on the CRPD for policymakers, including those working in the focal points;
3. Engage with governmental departments and help them to mainstream the rights of the persons with disabilities into their policies;
4. Provide information on the States Parties' reporting obligations and remind policymakers thereof;
5. Organise training which provides disability-appropriate support on the CRPD for persons with disabilities on how to advance meaningful participation in policy-making, build capacity for self-advocacy and take action to protect their rights;
6. Ensure that education systems integrate disability into human rights education. This includes encouraging schools to disseminate the CRPD in formats and languages, including sign language, accessible to children with disabilities and encouraging law faculties and human rights institutes to include the rights of persons with disabilities in curricula, teaching and research;

7. Ensure training for lawyers and judges to apply the CRPD in order to create legal precedents or clarify or improve legislation;
8. Review and disseminate the jurisprudence (General Comments, statements and decisions) of the UN treaty bodies, including the UN Committee on the Rights of Persons with Disabilities in particular; translate these into an understandable language for policymakers and people with disabilities; and encourage government to implement the recommendation or enforce the judgment, to avoid new recourse to UN treaty bodies;
9. Produce and distribute material on the complaints procedure under the Optional Protocol to the CRPD as well as the complaints procedures under other existing legal instruments; and
10. Organise campaigns and other awareness-raising activities about the CRPD in the media.

Promotional activities are essential for ensuring that the conceptual shifts set out in the CRPD, including the social model of disability and a human rights approach to disability, are understood and effectively internalised throughout society. Other bodies within government, in addition to civil society organisations, need to be involved in the promotional activities. Article 8 of the CRPD, for example, requires States Parties to undertake awareness-raising activities and distribute materials on the CRPD. In contrast to protecting and monitoring, promotional activities can be carried out by various actors, including governmental bodies, and need not be the exclusive role or responsibility of the independent mechanisms within the framework. In order to avoid duplication and ensure consistency in promotion, the framework needs to examine and coordinate the awareness-raising activities it is carrying out, ensure that the disseminated information is accurate and, where necessary, fill in any gaps.



Question 16: What activities are being carried out by mechanisms in the framework to promote the rights of persons with disabilities? How does the framework coordinate with other bodies (including government) that are carrying out promotional and awareness-raising activities?

5.3.2. Protect

The protection of human rights includes activities that aim to uphold human rights through quasi-judicial powers (such as the handling of individual complaints and mediation), activities to provide support to people so that they can claim their rights before domestic courts (such as legal aid and assistance), and the provision of in-depth expertise directly to domestic courts to assist in the proper administration of justice. In this way, protection activities involve assisting people to bring individual complaints before domestic, regional and international bodies or tribunals and encouraging government to remedy human rights problems or violations.

Activities which the framework of independent mechanisms can carry out to **protect** CRPD rights include the following, non-exhaustive list:

1. Ensure there is some form of (self-, peer- or lay-) advocacy in community settings and (where they exist) places of detention, such as prisons, psychiatric departments, children's homes and social care institutions;
2. Handle individual complaints on alleged violations of the CRPD reported by persons with disabilities and make recommendations to government to comply with the CRPD;
3. Provide mediation between policymakers and persons with disabilities on the application of the CRPD;
4. Provide assistance to persons with disabilities in domestic courts. This can be done directly by independent mechanisms, such as ombudsman's offices, or by providing financial assistance in cases of strategic importance to set legal precedents by, for instance, allocating funds for the provision of legal expertise or to support legal costs;
5. Lobby government to provide legal aid so that people with disabilities can bring alleged violations of the CRPD in domestic courts. Legal aid should be available to people often missed out in accessing justice: those who have

been deprived of legal capacity, children, people deprived of their liberty or in institutional settings, as well as next of kin of people with disabilities who have died;

6. Take legal action in the name of victims of alleged violations of the CRPD in domestic courts;
7. File *amicus curiae* (friend of the court) briefs or third-party interventions to provide domestic courts with in-depth expertise on the rights and obligations set out in the CRPD and assist courts in their proper administration of justice;
8. Help persons with disabilities to introduce complaints before regional and international bodies and tribunals, including the UN Committee on the Rights of Persons with Disabilities;
9. Act upon issues or individual cases which have been brought to light by domestic as well as regional or international inspection mechanisms. These include the bodies mentioned in Article 16(3) of the CRPD, National Preventive Mechanisms established under the Optional Protocol to the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), the Commissioner for Human Rights of the Council of Europe, the UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (SPT), UN Special Rapporteurs or Working Groups or any other inspection mechanism; and
10. Ensure follow-up to the decisions of the UN Committee on the Rights of Persons with Disabilities following individual complaints based on the Optional Protocol within the States Parties.

States Parties must provide the framework with formal authority so that the independent mechanisms can use their quasi-judicial powers. The independent mechanisms must have the right to receive complaints from any individual and access to necessary information to evaluate the complaints it receives and make recommendations to government.

Responsibility for ensuring protection of CRPD rights, both by taking measures to prevent violations of the Convention and by establishing effective judicial systems to sanction such violations, rests with the State Party.



Question 17: What activities are being carried out by the mechanisms in the framework to protect the rights of persons with disabilities?

5.3.3. Monitor

Monitoring domestic implementation of an international human rights treaty is a way of assessing whether domestic legislation, policy and practice comply with the treaty. It is a way of determining the effectiveness of measures taken by a government in its attempt to implement a treaty. It is a way to hold government to account for its human rights obligations.

Monitoring includes gathering information on implementation (see Article 31 of the CRPD, and see section 4.1.7 of the guidelines, above), pushing for the cessation of human rights violations, and encouraging States Parties to cooperate with international monitoring mechanisms. Monitoring the implementation of the CRPD is an enormous task. Focused, strategic prioritisation is necessary.

Activities which the framework of independent mechanisms can carry out to **monitor** CRPD rights include the following, non-exhaustive list:

1. Develop a strategic monitoring plan. This includes establishing time-framed programmes and identifying key governmental departments responsible for the realisation of the rights set out in the Convention. The strategic monitoring plan might focus on themes (health, education, employment, etc.) or specific groups of persons with disabilities (women with disabilities, minority ethnic groups, rural people, etc.). This plan should take into consideration the government's CRPD implementation plan (see section 4.1 of these guidelines) but the strategic monitoring plan need not be bound by it.
2. Work with colleagues in different countries to establish a set of rights-based indicators and benchmarks to evaluate progressive realisation of the rights set out in CRPD. This should enable the framework to advocate at governmental level to identify areas where more efforts are needed and to point out discrimination between different categories of people with disabilities.
3. Evaluate the compliance of legislation and policies with the CRPD and/or make recommendations for their harmonisation with the CRPD.
4. Monitor practice through carrying out or commissioning research into the lived experience of persons with disabilities.
5. Monitor practice by carrying out field visits to where persons with disabilities live, including community-based services or institutions (see Article 16(3) of the CRPD); or ensuring a link with national inspectorate bodies, including National Preventive Mechanisms established under the Optional Protocol to the UN Convention against Torture.
6. Provide strategic direction to policymakers and parliamentarians.
7. Utilize the judicial system to document violations of the rights of persons with disabilities. Many persons with disabilities face barriers to filing complaints, including as a result of stigma and discrimination, a lack of information about their rights and how to exercise their rights, denial of legal capacity, and denial of reasonable accommodation.
8. Conduct formal investigations and general inquiries on issues of grave or systemic violations of CRPD and make recommendations to government on how these violations can be remedied and future violations prevented.
9. Encourage the government to involve persons with disabilities in the development of laws, policies and programmes (see Article 4(3) of the CRPD).
10. Remind the State party of its obligation to submit on time its State report as provided for by Article 35(2) of the CRPD, and to answer the questions of the UN Committee on the Rights of Persons with Disabilities.
11. Provide training and information to policymakers on the elaboration of the State report.
12. Create a space to allow NGOs to coordinate and elaborate a "shadow report" for the UN Committee on the Rights of Persons with Disabilities, and ensure full coverage in the report by including all categories of persons with disabilities through their representative organisations.
13. Ensure follow-up to the concluding observations of the UN Committee on the Rights of Persons with Disabilities following the submission of the State report.
14. Encourage the government to enhance the protection of persons with disabilities by signing and ratifying the Optional Protocol to the CRPD. Also encourage similar action with respect to existing or future Optional Protocols to treaties.
15. In countries which have ratified the Optional Protocol to the CRPD, alert the UN Committee on the Rights of Persons with Disabilities on areas of "grave or systemic violations" and request the Committee to conduct an inquiry (under Article 6 of the Optional Protocol).
16. Provide relevant and timely information to the full range of UN treaty bodies, UN Special Rapporteurs and Working Groups, European Union bodies, Council of Europe bodies.
17. Participate in the Conference of States Parties (see Article 40 of the CRPD) and encourage the Conference, in collaboration with colleagues in different countries, to discuss implementation issues of regional relevance.

The purpose of monitoring CRPD implementation is to ensure that people benefit from the Convention. Independent mechanisms therefore need to be pluralistic and encourage persons with disabilities and their representative organisations to have a decisive voice in the monitoring process. This is also required by Article 33(3); more detail on these obligations is provided in chapter 3 of the guidelines, above.



Question 18: What activities are the framework and the independent mechanisms carrying out to monitor implementation of the CRPD?



Question 19: How do representatives of civil society, including persons with disabilities and their representative organisations, participate throughout the monitoring process? How is such participation meaningful?

5.4. Form of the Framework

Having looked at the three functions of the framework, this section addresses the different forms that the framework might adopt. We first look at the Paris Principles, as this document is referenced in Article 33(2). Then the section looks at composition and pluralism, civil society involvement, independence, and finally the legal basis of the independent framework.

5.4.1. Paris Principles

Article 33(2) requires States Parties to “take into account the principles relating to the status and functioning of national institutions for the protection and promotion of human rights”. The origins of the Convention (see section 2.3, above) make clear that this wording is code for the “Paris Principles”, which set out basic guidance for the establishment and strengthening of national human rights institutions (NHRIs). An NHRI is a body established by the State Party for implementation of international human rights treaties at the national level. While the specific mandate of NHRIs differs from country to country, their activities may include providing guidance on human rights issues, advising on legislation, conducting inquiries, disseminating materials, receiving individual complaints, launching investigations and intervening in court cases. Examples of NHRIs include human rights institutes and commissions or ombudsman bodies.

The Paris Principles were established by NHRIs at their first international workshop held in Paris and endorsed by both the (then) UN Commission on Human Rights and the UN General Assembly in 1993.⁵⁹ In addition to providing for the composition, competences and working methods of NHRIs, the Paris Principles require that NHRIs be independent from government, be representative of civil society, and have a broad mandate to promote and protect human rights. There is an international ranking system of NHRIs. Those that fully comply with the Paris Principles are granted A-status by the International Coordinating Committee of the NHRIs.⁶⁰ These institutions have voting rights within the ICC and have speaking rights at the UN Human Rights Council.

⁵⁹ Composition and guarantees of independence and pluralism, Principles relating to the Status of National Institutions (The Paris Principles), GA Resolution 48/134, 20 December 1993, <http://www2.ohchr.org/english/law/parisprinciples.htm>.

⁶⁰ See: <http://nhri.net/default.asp?PID=85&DID=0>.

5.4.2. Composition and Pluralism

Article 33(2) of the CRPD applies the Paris Principles, which sets out the requirements for domestic bodies that are established to promote and protect human rights generally, to a framework that includes one or more independent mechanisms with the mandate to promote, protect and monitor the rights of persons with disabilities. In doing so, the Paris Principles require adaptation in the context of the CRPD.⁶¹

The CRPD does not prescribe exactly who or what should comprise the Article 33(2) framework. The use of the terms “as appropriate” allows States Parties the flexibility to determine the number and the type of mechanisms necessary to include in the framework for it to meet its mandate, as long as the framework and the independent mechanisms comply with the Paris Principles. As discussed in further detail below, this means that each of the mechanisms must be independent from government and all of the mechanisms, together, must meet the requirements of pluralism. One of the mechanisms in the framework should be designated as a coordinator. This is important in order to coordinate work, call meetings, avoid duplication and ensure consistency in approach.

While an NHRI that meets the necessary requirements of independence may be included as one of the mechanisms within the framework, States Parties need to be aware that on its own (for example, in the case of a single mechanisms framework) it may not meet the necessary requirements of pluralism. MDAC recommends that States Parties maintain, strengthen, designate or establish other bodies, in addition to an NHRI, to ensure that the full spectrum of the mandate set out in Article 33 (2) is covered by the framework. The following are examples of some of the bodies that may be included in the framework:

- national human rights institutions (NHRIs) – see below;
- ombudsman’s offices;
- equality bodies;
- inspectorates (such as those established under the Optional Protocol to the UN Convention against Torture);
- disabled people’s organisations (organisations comprising persons with disabilities). See section 5.4.3 below;
- disability rights organisations (organisations carrying out advocacy for persons with disabilities);
- disability organisations focusing on children’s rights, women’s rights or other groups that face multiple forms of discrimination;
- human rights organisations;
- trade unions;
- universities and research institutes.

With regard to the first type of body on this list, an NHRI, the Paris Principles require that its composition and the appointment of its members “shall be established in accordance with a procedure which affords all necessary guarantees to ensure the pluralist representation of the social forces (of civilian society) involved in the promotion and protection of human rights”.⁶² According to the Paris Principles, these should include:

⁶¹ G. Beco and A. Hoefmans, UN Convention on the Rights of Persons with Disabilities: An integral and integrated approach to the implementation of disability. Background document prepared for the international conference “Work Forum for the Implementation of the UN Convention on the Rights of Persons with Disabilities” (Brussels: Federal Public Service Social Security, 2010).

⁶² Composition and guarantees of independence and pluralism, Principles relating to the Status of National Institutions (The Paris Principles), GA Resolution 48/134, 20 December 1993, available at: <http://www2.ohchr.org/english/law/parisprinciples.htm>, Principle 1.

- a. "Non-governmental organizations responsible for human rights and efforts to combat racial discrimination, trade unions, concerned social and professional organizations, for example, associations of lawyers, doctors, journalists and eminent scientists;
- b. Trends in philosophical or religious thought;
- c. Universities and qualified experts;
- d. Parliament;
- e. Government departments (if these are included, their representatives should participate in the deliberations only in an advisory capacity)."



Question 20: How is the composition of the Article 33(2) framework pluralistic? How has composition been decided?

5.4.3. Civil Society Involvement

States Parties need to closely consult and actively involve persons with disabilities through their representative organisations in setting up the framework and determining which independent mechanisms should be included in it. Organisations of and for persons with disabilities should also be involved with the regular evaluation of these mechanisms.

Readers are encouraged to turn back and read chapter 3 of the guidelines, which deal with Article 33(3) of the CRPD in detail. That provision ensures that civil society, in particular persons with disabilities and their representative organisations, participate throughout the monitoring process. Effective participation in monitoring requires multiplicity of forms of engagement and should, among others:

- Include persons with disabilities as commissioners or board members of the Article 33(2) body;
- Ensure that the monitoring function under Article 33(2) comprises an independent mechanism (such as an NHRI), as well as some named organisations of persons with disabilities, and broader civil society (organisations of persons of minority ethnic groups, women's organisations and so on);
- Involve such persons with disabilities in the evaluation of policies, programmes and laws;
- Investigate promptly any law or policy not developed in close consultation and active involvement of persons with disabilities, contrary to Article 4(3) of the CRPD;
- Ensure data are available to enable meaningful participation in monitoring; and
- Include people with disabilities as monitors to, for example, closed facilities under Article 16(3) of the CRPD.

5.4.4. Independence

As noted above, MDAC believes that the entire framework needs to be compliant with the Paris Principles. This means that each of the mechanisms in the framework should be independent. This does not preclude creating a space for discussions between civil society and government, for instance through the focal points. However, the framework needs to be driven solely by actors that are fully independent and pluralistic.

The independent mechanisms must be financially independent to avoid any threat to their functioning as a result of their action. According to the Paris Principles, an NHRI:

shall have an infrastructure which is suited to the smooth conduct of its activities, in particular adequate funding. The purpose of this funding should be to enable it to have its own staff and premises, in order to be independent of the Government and not be subject to financial control which might affect its independence.⁶³

Questions to ascertain independence may include the following. Some of these questions relate more to NHRIs, than, for example, to disability organisations, and we have indicated this as appropriate. This list is not exhaustive.

Relevant for all organisations of the mechanism, including NHRIs:

1. **Has each mechanism made public its governance structure, aims and objectives and sources of funding?** This is an important step towards transparency. Mechanisms need to put in place systems to ensure that its donors do not assert undue influence on the mechanism's work.
2. **Have the members of each mechanism declared conflicts of interest?** In order to secure their impartiality and maintain the public's trust, the members of the independent mechanisms should inform the framework of any conflicting interests they may have as a result of other mandates. If so, they should make declarations of conflict of interest, which should be uploaded on this framework's website, and abstain from deciding on issues where they hold a conflict of interest.
3. **Does each mechanism have resources to carry out its core functions?** Such functions are detailed in section 5.3 of the guidelines. Without sufficient finance being given by government, the framework will not be able to carry out its functions, and by definition the Convention will not be properly implemented.
4. **Is each mechanism free from outside influence to set its own spending priorities and agenda?** The independent mechanisms within the framework should not be the subject of undue interference by government or State bodies or by other aspects of civil society including, for instance, disability service providers or the pharmaceutical industry.
5. **Can all of the mechanisms hire and fire staff without outside influence?** The independent mechanisms should be able to employ their staff members and determine their own priorities without being subjected to governmental permission or oversight.
6. **Does the budget of the framework include funding for civil society capacity-building?** Resources are necessary to finance capacity-building so that persons with disabilities and their representative organisations – an essential element of independence from government – are able to participate fully in the monitoring process on an equal basis as others (see section 3.2.3 of the guidelines).

Of specific relevance for NHRIs:

7. **Does parliament (not government) determine the budget of the NHRI within the framework?** This is an important emblem of independence, as well as providing structural guarantees of independence.
8. **Are the members of the NHRI appointed and dismissed according to a fair, objective and clear procedure?** It is important to provide a guarantee that members can be elected or re-elected notwithstanding the fact that their views may conflict with those of government. The appointment of members should preferably be done by parliament and not government, with the active involvement of civil society organisations, who should be allowed to appoint some of them or, at least, to participate in the selection procedure.
9. **Is the NHRI's mandate durable through time?** The Paris Principles provide that "to ensure a stable mandate for the members of the national institution, without which there can be no real independence, their

⁶³ Composition and guarantees of independence and pluralism, *ibid.*, Principle 2.

appointment shall be effected by an official act which shall establish the specific duration of the mandate”.⁶⁴ Long term mandates are preferable, because they allow members to address the root causes of problems relating to implementation of the CRPD and because they prevent these members from having their reappointment constantly in mind.

While independence is an essential requirement for all the independent mechanisms within the framework, it applies in a different way according to the functions of these mechanisms. Independence is not required to undertake activities in relation to promoting the CRPD. Promotional activities include awareness-raising activities which are recognised by the CRPD as a State obligation in Article 8 and can be carried out by a wide range of actors, some of which may not be independent in the sense of the Paris Principles. In contrast, independence is essential to protect and monitor implementation of the CRPD, since these functions may and often put governmental action into question.



Question 21: How have the mechanisms in the Article 33(2) framework demonstrated their independence?









⁶⁴ Composition and guarantees of independence and pluralism, *ibid.*, Principle 3.

Chapter 6. Checklist for Effective Implementation of Article 33 of the CRPD






Article 33(1) – establishment

-  **Question 1:** Has one or more focal point in government been formally designated by the State Party as the contact point for matters relating to implementation of the CRPD? Has a coordination mechanism been established to facilitate coordination across and throughout government? Has this been communicated to civil society?


Article 33(1) – functions

-  **Question 2:** What actions is the focal point(s) carrying out to raise awareness throughout society about the CRPD?
-  **Question 3:** What is the State Party doing to ensure effective coordination across and throughout government for matters relating to implementation of the CRPD?
-  **Question 4:** How does the focal point closely consult with and actively involve persons with disabilities in matters relating to implementation of the CRPD?
-  **Question 5:** Was a baseline analysis conducted at the time of CRPD ratification? Was it developed with the involvement of civil society including persons with disabilities and their representative organisations, and was it made available to them?
-  **Question 6:** Has an implementation plan for the CRPD been developed? Was it developed with the involvement of civil society, including persons with disabilities and their representative organisations, and was it made available to them?
-  **Question 7:** How is the State Party collecting appropriate information, including statistical and research data? How has this information been made available and accessible to representatives of government and civil society, in particular persons with disabilities and their representative organisations?
-  **Question 8:** How does the focal point(s) maintain an effective dialogue with the UN Committee on the Rights of Persons with Disabilities and other international treaty monitoring bodies?
-  **Question 9:** What is the focal point doing to ensure that persons with disabilities and their representative organisations are participating in the CRPD Committee reporting process?





Article 33(1) – form and structure

-  **Question 10:** Where in government has the lead focal point been designated? Where have any additional focal points been designated?
-  **Question 11:** Does the lead focal point have the authority to coordinate action to implement the CRPD at national, regional and local levels?
-  **Question 12:** How many people (full-time equivalent) have been designated to work in focal point(s)? To what extent is this number adequate?
-  **Question 13:** What capacity building is provided to people who are working within the focal point(s) to ensure they have a comprehensive understanding of the CRPD and its value system, and domestic disability laws and policies? Has training for the focal point staff been carried out by people with disabilities?
-  **Question 14:** What financial resources have been allocated to the focal point(s) for implementation of the CRPD? Is the focal point(s) able to carry out its mandate with this funding?


Article 33(2) – establishment

-  **Question 15:** Has a framework of one or more independent mechanism(s) been established/designated in law by the State Party to promote, protect and monitor implementation of the CRPD?

Article 33(2) – functions

-  **Question 16:** What activities are being carried out by mechanisms in the framework to promote the rights of persons with disabilities? How does the framework coordinate with other bodies (including government) that are carrying out promotional and awareness-raising activities?
-  **Question 17:** What activities are being carried out by the mechanisms in the framework to protect the rights of persons with disabilities?
-  **Question 18:** What activities are the framework and the independent mechanisms carrying out to monitor implementation of the CRPD?
-  **Question 19:** How do representatives of civil society, including persons with disabilities and their representative organisations, participate throughout the monitoring process? How is such participation meaningful?

Article 33(2) – form and structure

-  **Question 20:** How is the composition of the Article 33(2) framework pluralistic? How has composition been decided?
-  **Question 21:** How have the mechanisms in the Article 33(2) framework demonstrated their independence?

Chapter 7. Glossary of Terminology and List of Abbreviations

Accessibility: Article 9 of the CRPD requires States Parties to take a range of actions to ensure that people with disabilities are able to live independently and participate fully in their communities. This includes developing, disseminating and monitoring implementation of minimum standards and guidelines for accessibility of public services and facilities; providing training on accessibility issues; providing accessible signage and live assistance (guides, readers, interpreters) in public spaces, promoting access for persons with disabilities to new information and communications technologies, and promoting the design, development, production and distribution of accessible information and communications technologies.

Advocacy: Advocacy includes a wide range of actions that individuals or groups can take through speech, writing or actions to influence the formation or implementation of policies and programmes, secure rights, obtain services, or influence the allocation of public resources. Advocacy can take the form of peer, citizen, professional or legal advocacy, and can be conducted on behalf of oneself or others.

Civil Society: Civil society is comprised of civic and social organisations and represents a third sector of society that is distinct from government and the private sector. A healthy civil society forms the basis of a functioning democracy and requires un-coerced collective action for social development and public interest. Civil society participation lies at the centre of the CRPD and civil society participation in monitoring implementation of the CRPD must include persons with disabilities and their representative organisations, as well as any other NGOs or individuals seeking to promote, protect or monitor implementation of the CRPD.

Commissioner for Human Rights, Council of Europe: A person appointed as an independent institution within the Council of Europe, who promotes the awareness of and respect for human rights in the Council of Europe Member States.

Communication: According to Article 2 of the CRPD, which sets out key definitions for the Convention, communication, “includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.” Article 2 also sets out the language, “includes spoken and signed languages and other forms of non spoken languages.”

Coordination Mechanism: Article 33(1) of the CRPD requires States Parties to give due consideration to the establishment of a coordination mechanism within government to facilitate the action horizontally across and vertically throughout government necessary for full and effective implementation of the CRPD. See chapter 4 of these guidelines for a discussion on the Article 33(1) coordination mechanism.

Disability: The preamble to the CRPD describes disability as an “evolving concept” that “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” Article 1 of the CRPD provides further interpretation and sets out that “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.”

Focal Point: Article 33(1) of the CRPD requires States Parties to designate one or more focal points in government for matters relating to implementation of the Convention. See chapter 4 of these guidelines for a discussion on the Article 33(1) focal points.

Framework: Article 33(2) of the CRPD requires States Parties to designate or establish within the State Party a framework including one or more independent mechanisms to promote, protect and monitor implementation of the CRPD. See chapter 5 of these guidelines for a discussion on the Article 33(2) framework.

Independent Mechanism: Article 33(2) of the CRPD requires States Parties to designate or establish within the State Party a framework including one or more independent mechanisms to promote, protect and monitor implementation of the CRPD. See chapter 5 for a discussion on the Article 33(2) framework and the independent mechanisms it includes.

Monitor human rights: Monitoring implementation of an international human rights treaty is a way of assessing whether domestic legislation, policy and practice comply with the obligations set out in a treaty. It is a way of determining the effectiveness of measures taken by a government in its attempt to implement a treaty. It is a way to hold government to account for its human rights obligations. Monitoring includes gathering information on implementation (see Article 31 of the CRPD, and see section 4.1.7 of the guidelines, above), urging human rights violations to be stopped, remedied and prevented. It is also a way to encourage States Parties to cooperate with international monitoring mechanisms.

National Human Rights Institution (NHRI): An organisation established by the State to promote and protect human rights at the domestic level. According to the Paris Principles, an NHRI should be independent from government and be representative of civil society and have a broad mandate to promote and protect human rights. While the specific mandate of NHRIs differs from jurisdiction to jurisdiction, their activities may include providing guidance on human rights issues to government, advising on legislation, conducting inquiries, disseminating materials, dealing with individual complaints, and intervening in court cases.

Office of the High Commissioner for Human Rights (OHCHR): The OHCHR is an office of the United Nations Secretariat, based in Geneva, with a mandate to promote and protect human rights. Within the UN, it carries out human rights research, education, public information, and advocacy activities.

Paris Principles: Article 33(2) requires States Parties to “take into account the principles relating to the status and functioning of national institutions for the protection and promotion of human rights”. These principles, referred to as the “Paris Principles”, set out the basic guidelines for the establishment and strengthening of national human rights institutions (NHRIs). See chapter 5 of these guidelines for a discussion on States Parties’ obligation in relation to Article 33(2).

Persons with intellectual disability: An intellectual disability generally means having greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen. People with this label may have greater difficulty in carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care. While the term ‘intellectual disability’ is technically distinct from other ‘developmental disabilities’ these terms are often used interchangeably.

Persons with psycho-social disability: People with psycho-social disabilities are those who experience mental health issues, and/or who identify as ‘mental health consumers’, ‘psychiatric survivors,’ or ‘mad.’ These are not mutually exclusive groups. The rights of people with psycho-disabilities are covered by the CRPD (see Article 1 of the CRPD).

Promote human rights: The promotion of human rights includes both general awareness-raising activities that seek to sensitise the public, policy-makers and other stakeholders about human rights, as well as targeted activities designed to advance effective realisation of a right, set of rights or a human rights instrument for a general or specific audience.

Protect human rights: A State Party to a human rights treaty has a duty protect human rights. This means that it must protect everyone, including people with disabilities, against abuses by non-state actors, such as businesses, healthcare providers, institutions, or other private organisations or individual people. Protection is set out in Article 33(2) as an activity of the framework. The protection of human rights includes activities that aim to uphold human rights through quasi-judicial powers (such as the handling of individual complaints and mediation), activities to provide support to people so that they can claim their rights before domestic courts (such as legal aid and assistance) and the provision of expertise directly to domestic courts to assist in the proper administration of justice. In this way, protection activities involve assisting people to bring individual complaints before domestic, regional and international bodies or tribunals and encouraging government to remedy human rights problems or violations.

Reasonable accommodation: Article 2 of the CRPD defines reasonable accommodation as the “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”. See chapter 3 of these guidelines for information about reasonable accommodation.

Respect for human rights: The obligation to respect human rights means that States must not interfere with the exercise and enjoyment of the rights of people. They must refrain from any action that violates human rights. They must also eliminate laws, policies and practices that are contrary to human rights.

State Party (plural States Parties): When a state or a regional integration organisation ratifies a covenant, convention or treaty it becomes legally bound to the provisions set out in the instrument and becomes a State Party to that instrument. Within these guidelines, “State Party” refers to a State Party to the CRPD.

Universal Declaration of Human Rights (UDHR): A globally-agreed document that sets out civil and political, as well as economic, social and cultural rights. The UDHR was adopted by the UN General Assembly on 10 December 1948, following the Second World War, and all UN Member States have agreed to uphold it. Although the UDHR was developed as a non-binding instrument, over time some of its provisions have become binding on governments through customary international law.

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules): The Standard Rules were adopted by the UN General Assembly in 1993 and present a moral and political commitment by governments to take action to attain equal rights for persons with disabilities. Its 22 rules cover all aspects of life of people with disabilities and serve as a basis for policy-making and technical and economic cooperation.

List of Abbreviations

CRPD	UN Convention on the Rights of Persons with Disabilities
CRPD Committee	UN Committee on the Rights of Persons with Disabilities
DPO	Disabled people's organisation
ICESCR	International Covenant on Economic, Social and Cultural Rights
MDAC	Mental Disability Advocacy Center
MDGs	Millennium Development Goals
NGO	Non-governmental organisation
NHRI	National human rights institution
OHCHR	Office of the UN High Commissioner of Human Rights
OPCAT	Optional Protocol to the UN Convention against Torture
OP-CRPD	Optional Protocol to the UN Convention on the Rights of Persons with Disabilities

Chapter 8. Further Resources

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Mental Disability Advocacy Center

The Mental Disability Advocacy Center (MDAC) is an international human rights organisation which advances the rights of children and adults with intellectual disabilities and psycho-social disabilities. MDAC uses law to promote equality and social inclusion through strategic litigation, advocacy, research and monitoring and capacity-building.

Our vision is a world of equality – where emotional, mental and learning differences are valued equally; where the inherent autonomy and dignity of each person is fully respected; and where human rights are realised for all persons without discrimination of any form.

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