Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring

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I declare that this thesis is my own work, and that I have acknowledged all results and quotations from the published or unpublished work of other people.
‘Participation and active involvement in the determination of one’s own destiny is the essence of human dignity.’

Mary Robinson

Dedicated to Kara.
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I. Introduction

The UN Convention on the Rights of Persons with Disabilities (hereafter CRPD or the Convention) aims to open up new spaces between the government, human rights system and civil society to involve especially the organisations of persons with disabilities in law and policy-making (Article 4(3) CRPD) and in monitoring its implementation (Article 33). The process of opening up new spaces not only gives room for the disability movement to overcome past exclusion, but also transforms into better correspondence between international and domestic law. The CRPD, as the first human rights treaty of the 21st century, therefore pioneers the provision of an excellent legal framework for governments, non-governmental organisations (NGOs) and the human rights system to better promote human rights norms and create a more just and inclusive society.

The CRPD is seeking to achieve a positive change in the lives of persons with disabilities and empower them to become active rights holders. The disability movement as a new social movement is supported in the text of international law to occupy this new space and become acknowledged partners to decision-makers. States Parties are obliged to open up the space and involve the representative organisations of persons with disabilities at all levels of law development and policy-making procedures. However, the Convention provides a framework for inclusion, the text of the Treaty does not give explicit instructions either to civil society or to States Parties on how to use this opportunity in the best possible way.

The present thesis focuses on the process of change and discusses thoroughly how to make this new space between government and civil society real and meaningful. Only a couple of years after the Convention’s entry into force, it is timely to take an overview on current trends and define potential success in achieving full participation. Although the concept of ‘participation’ is one of the most important leitmotivs in the UN CRPD, it is a great challenge for most States Parties
to ensure the meaningful involvement of persons with disabilities and their representative organisations in policy- and decision-making and monitoring the implementation of the Convention.

The present thesis hypothesises that the participatory provisions of the UN Convention, and the expectations of the disability movement in light of the motto 'Nothing about us without us!', are not yet realised in interactions with governments and National Human Rights Institutions (NHRIs) during implementation and monitoring of the CRPD. On one hand, we presume this is due to lack of commitment and effort from the governments in changing old, exclusionary structures and practices to fully accessible and inclusive ones. On the other hand, there might be other internal and external reasons that prevent the disability movement from meaningful participation. We are particularly interested in the involvement of the most marginalised parts of the disability community, such as persons with intellectual, psychosocial and profound disabilities.

The purpose of the thesis is to offer a novel approach to understanding the participatory provisions of the CRPD as key elements in the process of change and especially in strengthening the meaningful involvement of persons with disabilities. The research objectives of the thesis are therefore twofold:

1. To understand the current level and mode of involvement of persons with disabilities and their representative organisations in law development, policy making and CRPD monitoring process;

2. To identify examples of good practice and the requirements for achieving meaningful participation of persons with disabilities and their representative organisations.

The thesis intends to provide answer to the question based on the empirical research results that: 'What are the conditions and criteria of good practice in achieving meaningful participation of persons with
disabilities and their representative organisations in CRPD monitoring processes? The thesis will build on some promising, grass-roots practices to demonstrate the complexity of shifting from tokenism towards effective involvement of persons with disabilities. It will offer a list of recommendations to governments, to Disabled People’s Organisations (DPOs) and to NHRIs on what is needed to achieve meaningful collaboration in implementing and monitoring the CRPD. The thesis is paying particular attention to the challenges for the disability movement in calling for a new politics of disability to successfully implement the CRPD and achieve full social inclusion for persons with disabilities.

The Literature review in Chapter II provides a thorough overview on the relevant legal and policy implementation scholarship. When assessing the involvement in policy-making, it is essential to understand what constitutes policy processes and in which ways civil society may contribute to the creation and implementation of policies. The insights of Clay and Schaffer and Gubbels regarding the random nature of the policy process and implementation are among the key theories in this regard. Furthermore, Arnstein’s ladder typology on citizen’s participation gives a great theoretical basis to categorize and distinguish different forms of civic participation in policy making and implementation. Its application to the involvement of the representative organisations of persons with disabilities is essential in establishing the difference between non-participation, tokenistic participation and meaningful participation.

The Literature review further discusses the most relevant social movement/new social movement theories to contextualise the disability movement as a new social movement and to describe the commonalities that feature the movement. The commonalities of social/new social movements will be described by largely building on the work of Marx and McAdam and Della Porta and Diani including political and economical perspectives. The criteria on what constitutes the disability movement as a new social movement will be presented
relying on the work of Oliver. Furthermore, collective behavioural, resource mobilisation and citizenship theories are very suitable to describe dynamics that determine the composition and agenda of the movement to date. In light of the European tradition of theorising social movement theories, we are discussing Habermas’ approach in this regard. Beside the social model of disability, recent literature on the conceptualization of the human rights model of disability will be also presented. The concept of fragmentation, its relation to power and the implications on the prospects of participation are the most important references in this section. There is also a brief overview of the history of the disability movement to ensure a better understanding of the broader historical and political circumstances that lead to the evolvement of the movement at national and international level. Oliver’s typology in categorizing disability organisations is the baseline in exploring the forms of advocacy. We also follow his approach when limiting the scope of representative organisations to those that are composed of and led by persons with disabilities. In consideration of the literature review, a dual approach will be taken towards assessing the involvement of persons with disabilities in policy processes. The dual approach will reflect to both the outcomes and the implementation process. This will help to provide a more precise picture of the quality of involvement of the disability movement in line with the provisions of the UN CRPD.

The Methodology chapter (Chapter III) presents in detail the main research questions and study hypothesis, the research objectives and research methodology that were developed for the purposes of the empirical data collection of the present thesis. The ontological standing of the thesis is that disability is a socially constructed phenomenon constituted of those physical, informational and other barriers that prevent persons from full participation. The research realizes that while international human rights law opens up a space between government and the representative organisations of persons with disabilities to participate in policy processes, their involvement
remains in the text of law. It is also recognized that limited data is available on the participation of persons with disabilities in policy processes. Therefore the research seeks to answer the main research question on the criteria of good practices to ensure the meaningful involvement of the representative organisations of persons with disabilities. Furthermore, a number of sub-questions are raised regarding the challenges that Disabled People’s Organisations face in participation and also questions on what are the potential internal difficulties for the disability movement to participate in such processes. How representative organisations indeed ensure representation is another important matter, as well as to explore what is the level of cooperation between different DPOs that form the disability movement? It is very important to explore how the human rights system collaborates with DPOs and what kind of initiatives the government implemented to involve persons with disabilities in law and policy-making processes?

The theories of Habermas and Fraser on considering dialogic/participatory instead of top-down processes in the discussion of new social movements were very influential in developing the research plan. The chapter explains why the area of monitoring was chosen to focus instead of covering all areas of law and policy-making. The chapter further explains that the initial aim was to carry out the research in the spirit of participatory research, but due to the limited capacities, it was finally decided to reach at least a collaborative relationship with the grass-root level in developing the concept and terminology of the research. The research plan is composed of three distinguished phases that are the following: preliminary interviews with leaders of the European disability movement, questionnaires with European DPOs and country studies in Zambia and New Zealand. The preliminary interviews helped to develop the research terminology and the questionnaires with the assistance of the disability movement. The questionnaire was suitable to map the current level of involvement of European DPOs in policy and decision-making processes at the National
level. The case studies aimed to collect data from different actors (government, National Human Rights Institutions, civil society) and provide a more in-depth analysis of the involvement of DPOs in policy processes and monitoring the CRPD in two selected countries: New Zealand and Zambia. Based on Quinn’s suggestions, we consider the monitoring process as a dynamic one and will assess the compliance of established frameworks with the CRPD based on five criteria.

Chapter IV establishes the legal and policy context of the thesis. It discusses how participation of persons with disabilities became one of the overarching principles of the UN CRPD and looks at the exact requirements of the provisions of the CRPD in this regard. The first section discusses the concept of ‘participation’ as it appears in the text of the UN Convention and provides contextual background on the main characteristics and relevant participatory provisions of the UN CRPD, as well as the involvement of Disabled People’s Organisations during the drafting of the Convention. Furthermore, the chapter presents Articles 4(3) and 33 of the CRPD as the two provisions that explicitly require the involvement of persons with disabilities in law and policy-making and monitoring the CRPD. We expand further on the dual approach to assess the implementation of the Convention as introduced earlier in the Literature review as potential tool to narrow the implementation gap between international human rights law and domestic interpretation.

The policy context will include two main parts. First of all, there is an assessment of the remarks of the UN CRPD Committee on the implementation of Articles 4(3) and 33 in the thirteen Concluding Observations already issued. This gives an overview of the current status of the involvement of persons with disabilities, and of the aspects that need to be changed at national level in light of the Committee’s recommendations. The second part will present the data that was gathered in the questionnaires during phase 2 of the empirical data collection.
Chapter V discusses the findings of the empirical research carried out in Zambia and New Zealand. The case studies form an important part of the thesis by presenting the views of members of the disability movement on the current and ideal ways of implementing Articles 4(3) and 33 of the CRPD. The case studies will focus on the involvement of DPOs in law development and policy-making and in monitoring the Convention. In line with the central concept of the thesis, the analysis of the data gathered at these country visits, take the process-oriented approach into account and discuss the fulfilment of the new spaces between government, civil society and the human rights system accordingly.

The discussion and analysis chapter (Chapter VI) provides answers to the main research questions building on the data collected empirically for the purposes of the research. We discuss the main findings of the research by following the main areas of the literature review. In the area of policy implementation the main challenges for persons with disabilities when it comes to participation are the lack of active and effective involvement and the dominance of tokenistic practices instead of meaningful participation. Regarding the internal challenges of the disability movement to participate in policy processes, the issues of fragmentation and representivity will be discussed in detail in that chapter. The disability movement is facing difficulties in representing the different interest and needs of persons with different impairments. Centralized umbrella organisations also face challenges in representing their constituency effectively, when they choose to unify their voice to achieve greater success, but may be leaving the diversity of opinions on the side. The accessibility needs of some persons with disabilities are more complex or unusual than others’, and this needs to be considered during any consultation processes. The research turns attention to the situation of the most marginalised parts of the disability movement and explores in which ways can their voices be

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1 Full copies of the transcripts are available and can be produced if the examiners want to check them.
more heard. The set of criteria on meaningful participation of persons with disabilities is developed on the basis of the case studies in Zambia and New Zealand. This list of criteria hopefully makes a great contribution to academic knowledge in the assessment of the participatory provisions of the CRPD. There are also indicators developed and attached to each criterion to facilitate the evaluation of meaningful participation in the context of policy processes and CRPD monitoring in the future.
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II. Literature review

1. Theories and ideas

This chapter provides a comprehensive review of the ‘state of art’ literature that is most relevant to the thesis. First, the theoretical literature on policy process and implementation will be discussed and then the literature on social movements and new social movement theory. The relevant public policy literature together with academic literature on the evolvement of new social movements forms the theoretical backbone of the thesis. The two disciplines have been chosen to better understand the challenges and complexity for the disability movement as a new social movement to participate in policy and decision-making processes in a meaningful way.

1.1 Policy process and implementation

The expansion of academic literature on policy implementation theories dates back to the 1970s. Authors drew attention to a number of controversial areas in implementation theory, including the rule of law, accountability, and the role of civil servants in the policy process. The present thesis is most concerned with the adaptation of international law in national policy-making and the monitoring of the implementation of those policies. National-level law development becomes relevant in the scope of this study only from the perspective of DPOs’ participation in policy-making.

Policy and implementation are strongly interrelated phenomena. Implementation in general presupposes a prior act of formulating what needs to be done, as an object of the implementation (the ‘policy’).

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2 See: Hill, M. & Hupe, P. (2009), Implementing Public Policy, Sage,
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However, ‘policy’ is a very subjective term and in this chapter we chose to rely on the definition by Hogwood and Gunn:5

Any public policy is subjectively defined by an observer as being such and is usually perceived as comprising a series of patterns of related decisions to which many circumstances and personal, group and organisational influences have contributed.6

Therefore, policies are a set of purposes and methods to solve certain problems or issues appearing in public. Regarding ‘implementation’, the most influential definition is by Mazmanian and Sabatier. According to them, implementation always links to specific policies as a problem-solving mechanism:

The carrying out of basic policy decision, usually incorporated in a statute but which can also take the form of important executive orders or court decisions. Ideally, that decision identifies the problem(s) to be addressed, stipulates the objective(s) to be pursued, and in a variety of ways, ‘structures’ the implementation process.7

Implementation is a very complex process. Putting policies into practice is quite challenging, and a government’s intentions won’t necessarily result in the expected outcomes.8 This is why establishing an effective monitoring mechanism is crucial in following up on implementation. In human rights monitoring, process indicators are very suitable to ensure implementation is going in the right direction, in line with the policies and overarching norms.9

From the practical perspective of how to influence policy-making successfully, there was a tendency to apply a linear policy model and to make a distinction between policy and implementation as considering decision-making a political activity and implementation an

5 Their definition is based on Hill and Hupe’s concept.
8 See also: Pressman & Wildavsky (1980), Hill & Hupe (2009).
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administrative activity. In this model, policy-making was a rational decision-making process with seven distinct steps:

Figure 1: The linear policy model

However, a number of scholars soon realised that the linear model is not realistic. Policy-making is rather a random process, dominated by political, sociocultural and practical circumstances; it is not a strictly estimable procedure. As Clay and Schaffer highlight, ‘the whole life of policy is a chaos of purposes and accidents. It is not at all a matter of the rational implementation of the so-called decisions through selected strategies’. Grindle and Thomas describe policy implementation as an on-going, non-linear process that requires consensus-building, participation of key stakeholders, conflict resolution, compromise, contingency planning, resource mobilisation and adaptation.

As Quinn highlights, international law can bring change by transforming the domestic policy environment. He argues that persuading and socialising State actors, such as senior policy makers, could bring about meaningful change if they become ‘normative

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entrepreneurs’ in their own administration. 13 Therefore, if the organisations of persons with disabilities want to influence the chaotic world of policy-making, they should consider some of the basic needs of policy makers. Gubbels argues that policy makers need evidence that is contextual, timely and policy relevant, seems reasonable, and is addressed in a clear message.14 During negotiations, as Gubbels notes, power comes from information, knowledge, and having positive alternatives to a negotiated settlement.15 However, it is well-known that a high proportion of disability policies fail to meet their objectives (disability is ‘a wicked problem’)16. Gubbels suggests measuring success based not on whether a policy is approved, but on whether the organisations of persons with disabilities can get the policy implemented.17 Some of the potential causes of policy failure could be insufficient knowledge, lack of resources, low capability, low motivation or poor training provided. To resolve these issues, organisations of persons with disabilities must offer locally crafted solutions for new forms of governance based more on collegiate partnership between public and private entities. Gubbels’s insights on the random nature of the policy processes and implementation is one of the key elements in understanding the main barriers in front of the involvement of the organisations of persons with disabilities in policy-making processes.

Based on this part of the literature review, it makes sense to apply a dual approach to assessing the involvement of the organisations of persons with disabilities in line with articles 4(3) and 33 of the UN CRPD towards this thesis. This dual approach would, on one hand, focus on the impact, and on the other hand consider the processes through which the impacts were made, in other words, the process of implementation. Impact is understood mostly as the contribution of

15 Ibid.
16 Ibid.
17 Ibid.
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persons with disabilities and their representative organisations to law development, policy-making and decision-making. It could be any written or less formal input, such as reports, position papers, statements, studies, cost-benefit analysis and so forth.\textsuperscript{18} Processes refer to the methods of operation of the governing bodies and the human rights system in general, as well as to their interaction with disability organisations during policy implementation. The dual approach of impact and process thinking is suitable to ensure that assessment of the implementation of the UN Convention will reflect both functional and structural changes. Furthermore, the dual approach will help in addressing the criteria to successfully implement the participatory provisions of the CRPD in order to create real social changes.

\textit{1.1.1 Arnstein's typology of citizens' participation in policy processes and its application in the disability context}

Arnstein developed the 'ladder typology of citizen participation', arguing that 'participation of the governed in their governance is in theory, the cornerstone of democracy'.\textsuperscript{19} Her statement corroborates that the participation of persons with disabilities is essential in order to achieve a just society and, moreover, real democracy. Arnstein’s typology from 1969 is still a very useful and valid source to understand the different levels of participation and the extent of citizens’ power in determining the planning of policies and programmes. The typology was developed when new social movements\textsuperscript{20} such as the women’s movement and the environmental movement were emerging. Although the first disability rights movement also emerged in the late 1960s and the 1970s, disability movements still have participation at the top of their agenda. This aspiration gained particular traction after the

\textsuperscript{18} The impact approach would quantify how many DPOs’ suggestions made it to the final version of the text of the law or policy document. For instance, percentages could express the successful lobbying of civil society organisations, but in some cases less impact could still result in very important positive changes, or vice versa.


\textsuperscript{20} New social movements will be explained in more detail in the next part of the thesis.
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adoption of the UN CRPD, with explicit obligations in this regard. It is therefore adequate to consider and apply Arnstein’s typology as a relevant source for assessing the participation of the disability movement.

According to Arnstein’s definition, citizens’ participation is the redistribution of power that enables citizens presently excluded from economic and political processes to be deliberately included in the future. Arnstein’s typology (Figure 2) has eight levels that are arranged in a ladder pattern, with each corresponding to the level of citizens’ power in determining the outcome.

The two lowest levels of the ladder are ‘Manipulation’ and ‘Therapy’. They describe non-participation, where those with power only want to educate or cure participants instead of enabling them to have any input. A typical example of manipulation is the establishment of advisory committees or boards, where the aim is to educate members instead of listening to their voices and considering their expertise. Therapy stands

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here as a masked form of citizen complaint mechanism, a channel to express concerns about on-going processes.

The next three categories fall under tokenism in Arnstein’s typology. This means that although ‘Informing’, ‘Consultation’ and ‘Placation’ allow citizens to participate, there is no assurance that their voices will be heard by the power holders. Informing citizens about their rights, options and on-going decision-making is the first important step to legitimise citizens’ participation. 23 When information is provided only at a late stage on fully elaborated plans, people have little opportunity to influence the processes. For instance, the stage of ‘Informing’ does not offer space for bilateral dialogue, but considers citizens only as passive recipients of information. It is tokenistic by failing to support participants in contributing to procedures and by maintaining only superficial forms of consultation.

The upper three categories mark increasing degrees of participation in decision-making. Arnstein distinguishes ‘Partnership’, ‘Delegated Power’ and ‘Citizen Control’ in this regard. When establishing partnership, power is redistributed through negotiations between citizens and power holders. According to Arnstein, at this level some decision-making responsibilities are shared between power holders and citizens, so participation is eventually being realised. ‘Delegated Power’ is a step further and means that citizens are achieving dominant decision-making authority over a particular plan or programme. 24 The last category refers to citizens’ demand to have overall control over government policies and programmes. This would mean that citizens actually take over policy and become owners of the decision-making processes. However, it is important to clarify that delegated power does not mean absolute power in practice in Arnstein’s typology.

Arnstein is critical of her own model, emphasising that in reality groups of both power holders and participants are much more

23 Ibid.
24 Ibid.
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heterogeneous and there are more layers with less sharp distinctions between levels. Others critiqued her model and often regarded it as a means to legitimise rather than formulate policy.\textsuperscript{25} We are convinced that Arnstein's typology could be applied to the disability movement to great extent when assessing the level of involvement in policy- and decision-making. Applying Arnstein’s typology to assessing the participation of DPOs is a very useful tool to differentiate between various forms of non-participation and participation. It also helps to avoid stagnating at the level of tokenism. The aim is to achieve the highest level of citizens’ participation, yet the danger of a civil society group exercising control over the policy process needs to be addressed too.

The work of Frawley and Bigby on the participation of persons with intellectual disabilities in the work of advisory bodies in Australia is another important source to highlight some of the particular challenges that specific parts of disability organisations face when participating in the policy process.\textsuperscript{26} According to them, participation in the political life of a community is one of the main components of full and effective participation.\textsuperscript{27} They focus on issues around tokenism, power relations in forums, representativeness of membership, and provisions of support for better participation. They explain that persons with intellectual disabilities who are formally involved in the work of advisory bodies, despite some easy language text provided, still feel disempowered and face difficulties in understanding the information during these meetings. Concannon and others describe that in these cases ‘persons with intellectual disabilities are present, but not


\textsuperscript{27} We do not intend to consider Australia as a particularly negative example in this regard. The fact that a number of publications are written on the topic shows the visibility of disability as a human rights issue and that there is an on-going public debate on the topic in Australia.
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participating’.  

The support of people with intellectual disabilities in participating in the work of these bodies should include 'access to information, knowledge development, engaging in processes, forming relationships with stakeholders, and skill development'. Frawley and Bigby provided a tentative model of the elements that must be taken into account in supporting meaningful participation in advisory bodies by people with intellectual disability (see below, Figure 3). They also highlight the commitment of power holders to re-conceptualise support and ensure full access to these environments for persons with intellectual disabilities. They further suggest addressing 'both the practical means of supporting participation and the more intangible social and interactional nature of the environment and the dynamic operating therein, so that members with intellectual disability feel confident to participate’.

![Figure 3: Components of meaningful participation]

1.2 New social movements theories

The section provides an overview of the most relevant literature about social movement theories with a special regard to new social movements. When researching the criteria to the meaningful

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30 Ibid., p. 29.
31 Ibid., p. 37.
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participation of the disability movement in policy processes it is necessary to understand the main characteristics of new social movements and the specificities that apply to the organisations of persons with disabilities.

Traditionally, social movements had focused mainly on issues of labour and nations. There are a number of definitions in use to describe social movements. Giddens provides a definition that builds on the desirable social change as a central element in the agenda of social movements:

Social movement is a large grouping of people who have become involved in seeking to accomplish, or to block a process of social change.32

The term 'large grouping of people' indicates that only a considerable number of people could effectively form a movement, influence existing social structures and facilitate real change. Kolb's working definition states:

Social movement is a network of groups and individuals, which on a shared collective identity try to prevent, achieve or persist societal change by means of at least partly non-institutionalized tactics.33

Shared collective identity and a strong intention to facilitate or prevent societal changes are central elements in Kolb’s definition. He also considers a social movement as a network of groups and individuals, thereby referring to some sort of representivity in the process of organising non-institutionalised tactics of actions.

Scholte defines ‘social movements’ as the part of civil society that uses a transformist strategy and aim for a comprehensive change in the social order.34 Similarly, Marx and McAdam define social movements as ‘organised efforts to promote or resist change in society that rely on

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non-institutionalised forms of political action’.\textsuperscript{35} Political aims, voice and empowerment are other key elements in the emergence of new social groups, in particular representing those people who have been silent before.

The abovementioned definitions all regard social movements as:
- Being formed by a group of individuals;
- A group that shares common identity;
- A group that aims to achieve societal changes using non-institutionalised form of actions;
- A group that keeps distance from the government.

As della Porta and Diani emphasise, ‘new social movements’ have emerged since the 1960s and have had different concerns and focus of actions than traditional social movements.\textsuperscript{36} One of the reasons for their emergence was that Marxist ideology no longer provided a satisfying explanation of those conflicts that resulted from social transformations after the Second World War. As opposing class conflicts were the principal components of political cleavages in industrial societies, participants of these new types of conflict were not working-class-related, but were groups like youth, women, environmental activists and other professional groups.\textsuperscript{37} According to Martell, ‘new social movements’ in comparison with older social movements ‘are viewed as being concerned with redefining culture and lifestyle rather than accomplishing overall structural reforms’.\textsuperscript{38}

\subsection*{1.2.1 Early collective behaviour approach: applying Blumer’s theory in the disability context}


\footnotesize{\textsuperscript{36} Della Porta, D. \& Diani, M. (2012), Social Movements, Blackwell Publishing, p. 6.}

\footnotesize{\textsuperscript{37} See: Della Porta \& Diani (2012), p. 6.}

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In this section we will first build on the collective-behaviour explanation of social movements and particularly on the work of Blumer when discussing the disability movement as a new social movement. Later, we will turn to the more appropriate theories that were developed after the late 1960s.

There were certainly other important early theorists, such as Marx or Weber who dealt with social movements from the European tradition’s perspective. Here we focus only the theory of Blumer, as he greatly influenced later theorists of ‘new social movements’.

Most social movement theorists would agree with Blumer in his definition that states:

Social movements can be viewed as collective enterprises to establish a new order of life. They have their inception in a condition of unrest, and derive their motive power on one hand from dissatisfaction with the current form of life, and on the other hand from wishes and hopes for a new scheme or system of living.

Blumer distinguishes three main types of social movements: general, specific and expressive. He explains that general social movements address necessary changes based on how individuals conceptualise themselves. They originate especially from the disjuncture between how people want to see themselves and their actual position. This form of dissatisfaction generates the commitment to make changes in perceptions and towards the desired self-image in society. For persons with disabilities the disjuncture results from the realisation of their unequal position and exclusion from mainstream society and the general experience of being treated as ‘second-class citizens’. Having a


40 While Marx had a positive view of social movements and saw them as a sign of the forthcoming collapse of the capitalist system, Weber considered individual power as an important indicator in the cycle of social movement development. See also: Beckett (2006), pp. 72–73.


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certain type of impairment would not in itself cause a great disjuncture if persons with disabilities were considered as equal citizens.

The intention and commitment to challenge discriminatory patterns in society is a prerequisite to forming a general social movement. Blumer further argues that all movements start as general movements and at this stage they are usually uncoordinated. A social movement can be considered a ‘specific social movement’ once it has a well-defined objective, organised structure, and recognised leadership and membership. Special movements therefore attempt to provide structured forms for the individuals who are determined to make a change. This is the minimum criterion that applies to the disability movement as well.

The ‘we-consciousness’ in Blumer’s theory is another important element in understanding how disabled people’s organisations could play a role in empowering persons with disabilities. The sense of belonging to a group where people face the same struggles is helpful to develop a more positive personal identity. Persons with disabilities could potentially transform longstanding stigmas towards a pride agenda and emphasise that differing from the norms enriches diversity in society. Something similar has already started in countries where persons with psychosocial disabilities organise ‘mad pride’ to reclaim the word ‘mad’ as a badge of honour instead of shame. The mass movement also raises awareness in the general public of the causes and nature of mental health problems. In the disability movement in general, heterogeneity might considerably affect the development of common identity, as people with different impairments can face very different challenges. The centre of gravity of such ‘we-consciousness’ in the spirit of the social model of disability could be the experience of

44 The first mad pride was organised on 18 September 1993 in Toronto, Canada, and people with mental health problems now hold mad prides all over the UK, USA, South Africa, Australia and Ireland. See more at: <http://www.mindfreedom.org/campaign/madpride/madpride-intro> (accessed 8 September 2014).
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pathologisation, the existence of an impairment and systematic exclusion by socially created barriers.

According to Blumer, in the process of social movement development, the role of agitation, the development of *esprit de corps*, and the degree of morale have key importance.\(^{45}\) We now briefly discuss what these elements can mean in the development of the disability movement. As Beckett emphasises on the basis of Blumer’s work, agitation ‘results in the awakening of people and in creating ideas that make for restlessness and dissatisfaction’.\(^{46}\) This is important to generate people’s willingness to take social actions. Nevertheless, people need to become agents of change based on genuine dissatisfaction with their current life circumstances. For persons with disabilities, the agitation must start at the grass-root level based on peer advocacy. If the agitation comes from other interest groups, such as service providers or family members, the disability movement will not develop as a social movement. People without impairment neither share a common identity nor experience marginalisation in the same way as persons with impairment.

In Blumer’s theory, *esprit de corps* determines who is the insider and who is the outsider for the group.\(^{47}\) In-group and out-group relations have an expanded literature in sociology and psychology.\(^{48}\) In this chapter, we will refer only to the positive perception and loyalty towards in-group members and the possible demonisation of out-group members. The emerging group identity often results in turning against those who belong to the out-group.

As the disability movement developed, the motto ‘Nothing about us without us’ became a symbolical tool to mark the border between the in-group (persons with impairments) and the out-group (persons

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without impairments) in the context of decision-making. The in-group defines itself as the legitimate voice of people sharing the same struggles and goals. In contrast, the out-group consists of those who are somehow responsible for the exclusion of persons with disabilities from decision-making that affects their lives. Having said that, in-group members should not develop overall negative feelings towards members of the out-group, but rather aim to find allies among them. Ally-building with members of the out-group is as important as building trust with members of the in-group. In order to achieve social inclusion, a marginalised group should avoid further isolating itself from the out-group. As Quinn notes, isolation ‘makes the formation of effective civil society groups difficult especially in poorer countries’.49

The third element in Blumer’s theory that affects the development of social movements is morale within the movement.50 Morale means that members of the group believe in their goals and have faith that the movement eventually will achieve these goals. It is therefore extremely important for social movements to define their vision and mission as clearly as possible, reflecting the expectations and objectives of members of the in-group. For the disability movement the common goals include combating any forms of discrimination, formal or informal social exclusion and marginalisation, changing negative social attitudes towards persons with disabilities to a more positive one, and removing all barriers that prevent persons with disabilities from participating in society on an equal basis with others. Faith in achieving a more just and inclusive society in light of the social or human rights model of disability is pervasive across the whole disability movement.

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1.2.2 Newer American and European theories to explain new social movements

Although Blumer's collective behaviour theory was somehow applicable to explaining the social movements that emerged in the 1960s, including the disability movement, it imposes a fairly reductionist perspective. It implies that these early theories considered new social movements as just the irrational actions of deviant groups as a result of their social deprivation. A new wave of theories approached new social movements as ‘well-considered responses to legitimate concerns’ about systematic oppression. The common feature of these theories is that they see social movements as ‘well-organised, purposeful, rational action’.51 We will briefly discuss those theories that apply this more dynamic and deliberate assessment of social movements.

Resource mobilisation theories can be useful to understand the struggles that groups in an economically deprived situation face when trying to mobilise themselves to pursue their group goals.52 Oberschall and Tilly are two important American theorists in this regard. While Oberschall provides an explanation of what kind of resources can be mobilised by a movement to achieve their goals, Tilly sees the movements as continuously existing networks of individuals that emerge as co-ordinated collective action when it is necessary.53 As Beckett presents Tilly's theory, it is the coexistence of four elements that guarantee social movements will succeed as a political force.54 These elements are: numbers, commitment, unity and worthiness. For such a heterogenic group as persons with disabilities, maintaining unity could be a great challenge. According to Tilly, if one element falls to zero, the movement would lose its standing as a political force.55 He

52 See also: Beckett (2006), p. 76.
53 Tilly therefore rejects Blumer’s notion of social movements as groups that have a career path. See: Beckett (2006), p. 77.
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also emphasises the importance of interacting with powerful actors outside the movement and of building strategic relationships.\textsuperscript{56}

According to Beckett, there are three major approaches to theorise new social movements in the European tradition: by Habermas, Touraine and Melucci.\textsuperscript{57} Habermas ‘sees the role of new social movements as being an essential mechanism for preventing and working against the encroachment of the “lifeworld” by the system’.\textsuperscript{58} Since he considers that the colonisation of the ‘lifeworld’\textsuperscript{59} questions whether modernisation creates more just societies, the role he gives to new social movements in balancing the two systems is crucial. Habermas believed that the crisis of modernity led directly to the emergence of new social movements. The existence of new social movements therefore helps to maintain a less autonomous system and a more accountable ‘lifeworld’.\textsuperscript{60}

Habermas and other theorists started to link the notion of new social movements to citizenship.\textsuperscript{61} Beckett in her book provides an important link between citizenship and social movement theorising. Beckett also explains that Habermas in his later works considers new social movements as existing entities both at the macro (state) and meso-level (civil society).\textsuperscript{62}

\subsection*{1.2.3 Conceptualising the disability movement as a ‘new social movement’}

Based on some current academic literature, we consider the disability movement as a new social movement. Yet, giving a single definition of

\begin{itemize}
\item \textsuperscript{57} Beckett (2006), p. 80.
\item \textsuperscript{58} See: Beckett (2006), Habermas (1987).
\item \textsuperscript{59} According to Habermas, the colonisation of the lifeworld turns workers into consumers and citizens into clients, so new social movements seek to restructure these definitions. See: Habermas, J. (1987), \textit{The Theory of Communicative Action}, Cambridge, Polity Press.
\item \textsuperscript{60} See: Beckett (2006), p. 81.
\item \textsuperscript{61} See: Beckett (2006), p. 81.
\item \textsuperscript{62} See: Beckett (2006), p. 82.
\end{itemize}
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the disability movement is very challenging. It is immediately clear that the movement is composed of a broad range of people. The main cohesive force within the movement is that they are all persons with impairment who are facing socially constructed barriers when participating in society. It is important to note that there is neither a developed agenda nor stable membership at the time of establishment. The movement often takes shape gradually, and the evolution of the vision and mission statements is due to consensus and negotiations. Different segments of the movement might be established with great delay or change completely over time. In the present thesis, building on Oliver's definition, we consider the organisations of persons with disabilities as part of the disability movement.63 The main reason for this is that the organisations that pushed forward the social model of disability were the organisations of persons with disabilities.64 The social model of disability was certainly most influential in seeking to change the exclusion of persons with disabilities. Nonetheless, other organisations working for disabled people are important allies of the movement.

As Callus rightly points out, referring to Beckett's work, the 'concept of movement rests on the assumption that a coherent collectivity of different organisations that work in collaboration with each other towards the same aim exist'.65 However, in reality there is a wide range of organisations with different approaches and compositions. In the 1970s, the leaders of the modern American disability movement believed that an important part of their work was to create a collective identity for persons with disabilities against the previously dominant impairment-specific identity. They wanted to ensure success and effectiveness as a social movement. The desire to pursue a more equal society, where able-bodied and disabled people

63 Oliver (1997).
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enjoy the same rights, led directly to the emergence of the disability movement. What is common to disability organisations is the aim to restore their voice and obtain choice and control over their lives on an equal footing with other citizens in society. Once this is achieved, persons with disabilities will have less in common and the movement could split into smaller units or lead to other new social movements.

Since the 1970s it is believed that social movements are important forces for social change. In light of the definitions, the disability movement as a new social movement must have a strong commitment to achieve social changes. These changes could take various forms, including attitudinal, structural or functional changes. The 'field of social movements grew tremendously in the 1970s and 1980s, but surprisingly studying the outcomes of the movement did not', as Burstein critically points out. Admittedly, there should be more studies focusing on the evaluation of the outcomes of the movements. This thesis offers a small contribution to this field by assessing the ways the disability movement is involved in policy- and decision-making in line with the obligations of the CRPD. It will however be necessary to carry out more comprehensive research on this subject and thus help the disability movement improve its operations and efficiency.

It was probably a fortunate circumstance for those persons with disabilities who first stood up for themselves, that a broad range of new social movements were evolving in parallel, such as the movements of gays and lesbians, black people, women and environmentalists in the 1960s–1980s. According to the two main theorists of the disability movement, Campbell and Oliver, the main difference between new

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67 For instance, Kolb provides a comprehensive analysis on how social movements could affect policy outcomes, and offers six different political mechanisms that can transform the activities of a social movement into policy outcomes. Although he is talking about social movements in general, his remarks on the effective ways of influencing public policy-making could easily be applied to the disability movement as well. See: Kolb (2000).
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social movements and the older ones lies in the scope of their actions and ways of campaigning. Whilst older movements tended to focus on single issues and were led by experts, new movements are dealing with a broad range of issues and use a variety of campaign strategies.

Marx and McAdam define social movements based on whether they bring new political or economic change, whether the changes result in any specific legislation, whether the movement significantly influences public opinion, and whether the movement stimulated the emergence of new organisations.\(^{69}\) Campbell and Oliver added three additional criteria in the context of the disability movement.\(^{70}\) According to them, new social movements must raise consciousness and empower persons with disabilities, internationalise disability issues, and promote disability as a human rights issue effectively. These three criteria serve as a tool to evaluate to what extent the disability movement transfers the theory of the social model of disability in both their internal and external advocacy work.

Summarising the approaches and definitions presented in this chapter, the disability movement is certainly a new social movement as long as it:

- intends to change traditionally dominant discriminatory attitudes and exclusionary politics towards persons with disabilities;
- is committed to strive for the reconceptualisation of disability as a human rights issue in wider society;
- is initiated by people with disabilities themselves who are willing to make their voice heard;
- involves people who have some form of collective identity when they act as a group together.

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\(^{69}\) See: Marx and McAdam (1994).

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1.2.4 Shifting from the medical model to the social model

This subsection will briefly present the social model of disability through its substantive differences from the medical model relying on available literature. The social model of disability is the most important conceptual framework that has been developed during last decades and eventually lead that the United Nations adopted a specific convention on the rights of persons with disabilities.

The traditional medical model regarded disability as an impairment that needs to be treated or at least rehabilitated. By focusing on the lack of physical, sensory, cognitive or mental functioning, the model uses a purely clinical way of describing the individual. Disability is seen as a tragedy and a deviation from normal human functioning. It determines the roots of social exclusion in the impairment, and considers the only solution for achieving social inclusion in ‘fixing’ or ‘curing’ the disabled person. Michael Oliver described ‘the ideological construction of disability through individualization and medicalization, the politics of disablement’.  

During negotiations of the UN CRPD there was consensus among the participants that the medical model should not be reflected in the text of the new Treaty. In fact, previous human rights treaties contained provisions in relation to disabled people only in the light of the medical model. It was very important to overcome those conceptual barriers in international law and reflect current theories.

The social model of disability was developed in the early 1970s by a disability rights organisation in the UK called Union of the Physically

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73 For instance, Article 23 of the Convention on the Rights of the Child (CRC) requires States Parties to ‘recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child’s condition and to the circumstances of the parents or others caring for the child’. See Article 23 CRC. The CRC does not go beyond requiring States Parties to ensure special care facilities, and therefore maintains the social exclusion of children with disabilities.
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Impaired Against Segregation (UPIAS). The definition of the British social model is in a document called ‘Fundamental Principles of Disability’:

It is society, which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called ‘disability’, of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.

The social model was established by persons with physical disabilities, but the model had been applicable to other impairment groups facing similar social oppression. Making such a clear distinction between ‘impairment’ and ‘disability’ was a fundamentally new approach compared to the previously dominant medical model. While impairment reflects a biological condition, disability approaches one’s limitations as a social and not a personal pathology. In other words, impairment is a characteristic long-term attribute of an individual that may or may not be a result of injury, may affect the individual’s appearance in a non-normative way, may affect the functioning of the individual’s body, and may cause pain. Disability is defined as a disadvantage or restriction of activity that is socially constructed and results in exclusion from society of those affected. Instead of defining persons on the basis of their physical, sensory, cognitive or

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78 Ibid.
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psychosocial impairments as objects of care and pity, the social model states that disability is mainly a consequence of environmental barriers. The social model of disability appears in international human rights law, since it is explicitly mentioned in the Preamble of the UN CRPD:

Disability 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.\textsuperscript{79}

The social model implies that if the barriers were removed, persons with disabilities could participate in society like anyone else. It argues that it is not primarily the impairment that creates barriers, but the disabling environment and oppressive social structures.\textsuperscript{80} The model itself focuses very much on society rather than on the individual, and places the barriers that prevent disabled people from participation outside of the individual’s impairment. In the social model, discriminatory attitudes towards persons with disabilities are expected to change mainly by shifting the focus from the impairment to a discussion of common social responsibilities and the need to reform social structures and the built environment and, further than that, the removal of all barriers.\textsuperscript{81}

(a) The critical approach towards the social model of disability

A couple of decades after the initial enthusiasm about the ‘big idea’ of the disability movement, a sort of stagnation occurred instead of progress with a clear agenda or achievements.\textsuperscript{82} The social model of disability had been criticised by a number of scholars for neglecting the personal experience and pain of disabled people that are in fact

\textsuperscript{79} UN CRPD Preamble (e).
\textsuperscript{81} As Tom Shakespeare points out based on the work of Anna Oakley, the redefinition of disability in the social model parallels the feminist movement’s redefinition of women’s experiences in the early 1970s and led to the distinction between sex (the biological difference between men and women) and gender (the socio-cultural distinction between men and women or masculine and feminine. See: Shakespeare (2006), p. 29.
\textsuperscript{82} See: Shakespeare (2006), p. 29.
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important parts of people's identity. The feminist writer Jenny Morris, among others, emphasised that while environmental barriers are crucial parts of a disabling experience, personal experiences such as fear or pain or experiencing one's own body should not be denied. According to Morris, the courage of living with impairment should be acknowledged without any pity or regret. She warns that the distinction between impairment and disability may cover up the impacts of other factors such as destiny on one’s life and would lead to a naïve idealisation of disability.

Shakespeare acknowledges that the social model was crucial in at least two ways: identifying a political strategy of removing barriers, and reconstructing the identity of disabled people themselves in a more powerful way. He argues that defining disability purely as an issue of social oppression and barriers would mean shifting from one extreme – the cultural assumption that disability is a tragedy and equals full dependency – to another. He states that 'even in the most accessible world, there will always be residual disadvantage attached to many impairments'.

(b) A step further: The human rights model of disability

Partly due to the growing criticism of the social model, the paradigm shift eventually moved towards reconceptualising disability as a human rights issue. Drawing on the constraints around the social model, Watson for instance suggested that a new approach would be necessary to incorporate the experiences of disabled people but at the same time

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88 Ibid.
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maintain the political element. The human rights model is a very new concept, developed in the work of Theresia Degener. Contrary to Shakespeare, Degener claims that the manifestation of the social model was the greatest success of the CRPD and international disability politics. The term ‘human rights model of disability’ supposedly appeared for the first time in an article by Degener and Quinn where they stated:

The human rights model focuses on inherent dignity of the human being and subsequently, but only if necessary, on the person’s medical characteristics. It places the individual centre stage in all decisions affecting him/her and, most importantly, locates the main ‘problem’ outside the person and in society.

According to Degener, the UN CRPD indeed goes beyond the social model of disability and codifies the human rights model of disability. The Convention had an enormous influence in many areas and took on a life of its own after coming into force in the human rights domain. Degener provides six arguments to demonstrate the difference between the social model and the human rights model of disability. These arguments have a great impact on the interpretation of social inclusion,

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91 Theresia Degener is a member of the CRPD Committee and was one of the drafters of the UN CRPD as part of the German delegation in the Ad Hoc Committee.
93 Degener (2013), p. 5.
94 For example: accessibility, human rights monitoring, legal capacity discourse, and inclusive education.
96 Firstly, the social model forms the base of the social theory of disability in providing moral principles or values as a foundation of disability politics. In contrast to that, the human rights model is more applicable in light of fundamental rights to reject the common presumption that impairment may hinder human rights capacity. Second, the human rights model includes first- and second-generational rights, while the social model focuses only on anti-discrimination policy reform. Therefore, the human rights model is better in responding to the needs of persons with disabilities. Third, the social model has been criticised for neglecting the pain and the impact of impairment on the quality of life. According to Degener, the human rights model values impairment as part of human diversity. Furthermore, the new model acknowledges identity issues by leaving room for cultural identification. Fifth, the social model is critical of prevention policy, but ‘the human rights model offers a basis for assessment when prevention policy can be claimed as human rights protection for disabled people’. Finally, the human rights model can provide a more specific solution to the social deprivation of disabled people than the social model, which only describes social inequalities. See: Degener (2013), pp. 6–18.
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as well as clarifying that the application of the human rights model is more accurate throughout the discussion on participation.  

Kayess and French further argue that the remarkable influence of the social model during the negotiations of the Convention came from a 'populist conceptualization of the social model as a disability rights manifesto and its tendency towards a radical social constructionist view of disability, rather than from its contemporary expression as a critical theory of disability'. Kayess & French (2008), p. 7. Considering this sort of confusion, presumably it would have been more appropriate to place the human rights model in the conceptual centre of the Convention. However, the human rights model of disability does not enjoy undivided support from all actors of the disability movement. Rachel Hurst for instance argues that the term 'human rights model' is rather confusing and turns human rights inaccurately into an analysis of a relationship instead of considering it as an agreed code to ensure social cohesion. Hurst, R. (2005), 'Disabled People's International: Europe and the Social Model of Disability', in: C. Barnes & G. Mercer, The Social Model of Disability: Europe and the Majority of the World, Leeds: The Disability Press, p. 65.

1.2.5 Fragmentation and its relation to power to assess participation in policy processes

Some scholars wrote extensively about the social and economic elitism of the mainstream disability movement, given the fact that in most places highly educated, well-situated white male activists made the first initiatives. Traditionally, persons with physical or sensory

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97 In this thesis, we will often refer to it as 'social or human rights model of disability', considering Degener's arguments about the human rights model and the dominance of the social model in current literature and in the text of the CRPD.
100 Ibid.
101 Hurst, R. (2010), 'The International Disability Rights Movement'. Public lecture given as part of the 'New Directions in Disability Studies' seminar series, Centre for Disability Studies, University of Leeds, 11 October 2000; Bagenstos (2009).
Theories and ideas

Impairments played a central role in establishing and running the disability movement. At the same time, certain parts of the disability sector were neglected in setting the goals of the movement. This applies mainly to persons with intellectual or psychosocial disabilities, severe or multiple disabilities, profound intellectual disabilities, or deaf blind persons, whose voice is still less heard when forming disability politics. The voices of persons facing multiple discrimination, such as women, children, ethnic and sexual minorities with disabilities were also greatly marginalised. This section gathers the literature that described the disability movement as a fragmented movement and argues that certain segments are not taking equal part in its work.

‘Nothing about us without us’ is probably the most important motto and conceptual source of the political agenda of the international disability movement. However, in current literature the extent of its interpretation is considerably overlooked. The expression was first used in the early 1990s, presumably at an international disability rights conference, before spreading all over the world. Charlton argues that ‘the slogan’s power derives from its location of the source of many types of [disability] and its simultaneous opposition to such oppression in the context of control and voice’.102 Further, he notes that the motto ‘resonates with the philosophy and history of the disability rights movement, a movement that has embarked on a belated mission parallel to other liberation movements’.103 There was a strong influence from the US civil rights movement, that change can never be achieved if others speak for persons with disabilities. Persons with disabilities thus began to proclaim that they know what is best for themselves and for their community. As Charlton describes, ‘Nothing about us without us’ was a militant, revelational claim.104 He provides five reasons why the

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103 Ibid.
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slogan captured the development of disability politics and the expansion of the community and disability culture effectively;\textsuperscript{105}

1. ‘Nothing about us without us’ makes people think about the broad implications of ‘nothing’ in a political-economic and cultural context.

2. The slogan requires persons with disabilities themselves to recognise the need to control and be responsible for their own life in line with the paradigm shift.

3. ‘Nothing about us without us’ is a demand for self-determination and a necessary precedent to liberation.

4. The demand ‘Nothing about us without us’ affirms the principles of the international disability rights movement, which are: independence and integration, empowerment and human rights, and self-help and self-determination.

5. The slogan suggests a fundamental change in the way disability oppression is conceived and resisted just as the disability movement intends to create new attitudes worldwide towards disability.

The slogan ‘Nothing about us without us’ explicitly claims control over all policy and decision-making processes in order to challenge past dependency deriving from powerlessness, institutionalisation, poverty and deprivation. Control is also a central element in Arnstein’s typology when describing participation in contrast to tokenism.\textsuperscript{106} Since the 1970s disability rights activists have criticised non-disabled professionals – such as doctors, therapists, psychiatrists, counsellors, and social workers – who work on disability issues for being paternalistic and oppressive.\textsuperscript{107} However, as Bagenstos points out, the critique of professionalism stood in tension with the practices of

\textsuperscript{105} Charlton (1998), p. 17.


\textsuperscript{107} See: Bagenstos (2009).
Theories and ideas

disability activists who relied on the assistance and endorsement of those professionals who shared their views.108

On the other hand, as Goodley highlights, those key players of advocacy who are pulled into boards of consultation platforms often become key consultants and could eventually lose the political core of their advocacy work.109 This professionalisation in the policy-making field may lead to the unfortunate situation where key activists become key consultants of the governments. Therefore, the balance between being a critical civil advocate and an effective contributor to policy-making should be maintained consciously.

When lobbying in light of the motto ‘Nothing about us without us’ it is important to consider who ‘us’ in fact refers to, and what are the implications of missing some segments that share the same social oppression. Fragmentation means that the disability movement does not operate as a fully inclusive and collaborative organisation: certain groups are excluded or left behind regardless of their willingness to be part of the movement.

The reasons for fragmentation vary considerably. An example from the USA shows that for a long time impairment-specific organisations were common due to the dominance of the identity approach within the disability movement. However, in the USA a number of scholars argued that the division into impairment-specific organisations had an effect on the consciousness of persons with disabilities and resulted in the fragmentation of the disability community.110 The division on one hand ensured to ‘overcome prejudice and discrimination by civil rights legislation’, and on the other hand recognised persons with disabilities as ‘a separate minority group consisting of several subgroups with political identity, pride in the

108 Bagenstos gives examples such as lawyers who brought disability rights cases to court, or psychologists who opposed institutionalisation and forced treatment. See: Bagenstos (2009), p. 22.
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physical or mental characteristics and sense of self-determination and self-identification'.\(^{111}\) For these groups advocacy often builds on a positive identity that reflects their impairment. Yet, it was mainly those groups requiring greater adaptations, complex reasonable accommodation and deep structural changes within the movement who remained excluded. Accessibility offers a relatively straightforward solution to remove the barriers to persons with physical or sensory impairments, especially given the development and expansion of assistive technologies and devices.\(^{112}\) In contrast, the involvement of persons with cognitive or psychosocial disabilities challenges not only governments, the labour market and public policy makers, but the mainstream disability movement as well. It would require significant investments to work together with the most marginalised parts of the movement. Under-resourced DPOs are often not in a position to adapt their working methods to the needs of these groups. Complaints about the discrimination of persons with intellectual disabilities from the disability movement appeared in the British context from as early as the 1980s when people with learning disabilities experienced being approached by other advocates in a very patronising and offensive way.\(^{113}\)

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\(^{112}\) Americans with Disabilities Act of 1990 – ADA – 42 U.S. Code Chapter 126.

2. **Historical developments of the disability movement – structural and functional evolvement**

This section provides a historical overview of the emergence of the disability movement and its operations as a new social movement. This will provide a broad understanding of the constituencies, aims and complexity of the international disability movement.

### 2.1 The history of the international disability movement

According to Traustadóttir, activism by individual persons with disabilities can be traced back to the nineteenth century, but collective mobilisation around disability rights began only in the 1960s and 1970s.\(^{114}\) Regarding the roots of the movement, Charlton argues that ‘the politics and philosophy of the disability rights movement have evolved out of an emerging consciousness of political activists worldwide’.\(^{115}\) There were parallel processes rather than a chronological order, though the first movements certainly influenced further initiatives. As Sabatello notes, a simultaneous boost to the disability rights movement has been the global rise of human rights movements both in the UN and elsewhere.\(^{116}\) The Vienna Declaration and its new understanding of human rights also corresponded well with the demands of disability activists.\(^{117}\)

In some developing or post-conflict countries, the disability movement might be still emerging, and follows very similar patterns to earlier ones. It is now an important aim of international development to

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\(^{117}\) Ibid.
Historical developments of the disability movement – structural and functional evolvement

be inclusive and invest in the capacity building of DPOs by enabling persons with disabilities to mainstream disability and address development goals. Therefore, an external driving force is also present to facilitate the emergence of strong and sustainable disability movements in places where there is a delay in self-mobilisation.

In the following, we discuss the emergence of the first disability rights advocacy groups and present three main disability movements: the independent living movement (California, USA), the People First movement (Oregon, USA), and the British disability movement along with the establishment of Disabled People’s International (Winnipeg, Canada). These movements are important milestones in the history of the international disability movement and influenced other national movements significantly. Nevertheless, it is important to bear in mind that each national or regional disability movement has developed its own ‘flavour’ and characteristics. While the Nordic relational approach focuses on normalisation and the relativity of disability, the North American disability movement is based on a minority group or identity approach to disability.\textsuperscript{118}

\textit{2.1.1 The independent living movement}

The American disability rights movement emerged in the 1930s when members of the League of the Physically Handicapped protested against discrimination by the national and federal relief agencies. Yet the pan-disability movement did not arise until the establishment of the independent living movement.\textsuperscript{119} The independent living movement started in 1967 in the University of California in Berkeley, where Ed Roberts and four other people with physical impairments applied for

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courses.\textsuperscript{120} Due to the nature of their impairments they had to stay in the hospital wing of the university, but were still very much part of the mainstream community. Maybe because of the political climate of the late 1960s, the residents of the hospital began to see their situation in political terms and organised a group called ‘Rolling Quads’.\textsuperscript{121} Their aim was to call on the university to eliminate the architectural barriers that prevented wheelchair users from moving freely around the campus. They also arranged person-centred support services and decided to fight for the establishment of the first centre for independent living (CIL).

As Hurst points out, this was the first time in history when persons with disabilities realised that what they need is not special services, but to change society itself.\textsuperscript{122} The establishment of the CILs included a notion that each individual is different and persons with disabilities are the most knowledgeable experts about their own needs.\textsuperscript{123} The philosophy of the independent living movement explicitly claimed full participation for persons with disabilities in the development of policies and programmes and to be acknowledged as ‘experts by lived experiences’. As Charlton notes, the independent living movement quickly became a driving force behind the broader disability rights movement in the 1970s and 1980s.\textsuperscript{124} In a short time, there were over 140 centres for independent living throughout the USA. This was an incredible success of the independent living movement. CILs were organised along three guiding principles: \textsuperscript{125}

1. They were run and staffed by persons with disabilities themselves.

\textsuperscript{120} Hurst, R. (2010), ‘The International Disability Rights Movement’, text of a public lecture given as part of the ‘New Directions in Disability Studies’ seminar series, Centre for Disability Studies, University of Leeds, 11 October 2000.
\textsuperscript{121} Bagenstos (2009), p. 14.
\textsuperscript{122} Hurst (2010), p. 2.
\textsuperscript{123} Bagenstos (2009), p. 15.
\textsuperscript{124} Charlton (1998), pp. 130–131.
\textsuperscript{125} Hurst (2010).
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2. They had to cover all impairment, including intellectual disabilities, beside physical impairment.

3. Their object must be to achieve social change through changing environmental architectural and cultural barriers.

The UN International Year of Disabled People in 1981 flagged the importance of full participation and equality with special regard to enjoying equal living conditions with other citizens. The independent living movement as a grass-root advocacy initiative could eventually influence the UN’s approach towards persons with disabilities to become a more positive one. The UN started to consider persons with disabilities more and more as a group who need support to become equal citizens and shifted from a rehabilitation-oriented perspective towards a human rights approach.

2.1.2 The emergence of the disability movement in the UK

Literature is relatively limited on the history and development of national disability movements. One of the few exceptionally well-documented examples is the emergence of the British movement and the British Council of Organisations of Disabled People (BCODP).126 The particular relevance of the British movement is that the social model of disability developed in the UK.127 Sabatello argues that the British social model ‘has been pivotal to the disability rights movement’ as it ‘empowered persons with disabilities to mobilize themselves for a social change and enabled them to forcefully challenge repressive societal norms’.128 Although the independent living movement

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126 BCODP was formed in 1981 and its current name is the British Council of Disabled People.
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influenced to some extent activists who founded the British movement, it still had its own characteristics.129

According to Campbell and Oliver, the disability movement as a new social movement in the UK took off in the 1980s through a great expansion of organisations controlled and run by disabled people.130 They also emphasise that persons with disabilities organised themselves long before, on a basis similar to trade unions focusing on employment issues. It all started when people were brought together by locally organised initiatives providing social events and a space to meet. Eventually they started to build so-called disability consciousness and interest in campaigning as a common voice. Campbell and Oliver argue that the impetus for the emergence of the disability movement in the UK was the growing dissatisfaction over financial deprivation, as most disabled people did not share the wealth of other groups.131 Social inequality during the economic boom in the 1960s greatly upset many persons with disabilities, who eventually decided to take control of their lives. They realised that others with impairment faced the same problems, and by joint action they could challenge economic deprivation and increase the quality of their lives.

It is a great challenge to define the point at which a movement can be considered as a movement. Campbell and Oliver consider that the transition from emerging to emergent movement happens when the movement becomes larger, less spontaneous, better organised and led by formal structures instead of ad hoc committees and informal groups.132 In this sense BCODP had many of the characteristics of an emergent movement, yet it does not equal the British movement.133

It is important to note that like the UK, in many countries the disability movement emerged mainly from associations of persons with physical impairment. As Campbell and Oliver argue, the disabling

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133 Ibid.
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barriers to political participation and setting up platforms of advocacy are probably less severe for wheelchair users than for people with other impairments.134 This aspect could be important to understand the reasons for the marginalisation of persons with more severe cognitive or psychosocial disabilities within the international movement.

2.1.3 Disabled People’s International

The establishment of Disabled People’s International (DPI) marks another very important milestone in the history of the international disability movement. According to Rachel Hurst, who was one of the founders of DPI, the organisation started in 1980 in Winnipeg, Canada, at the Rehabilitation International Congress attended by 2000–3000 non-disabled rehabilitation and charity experts.135 Although a few persons with disabilities, such as Ben Lindquist136, were involved in the work of Rehabilitation International (RI), rehabilitation experts dominated the organisation.137 Those persons with disabilities who were involved in the work of RI unsuccessfully tried to get their voices heard in the governing council of the organisation.

At the Winnipeg conference, about 250 disabled people took the opportunity and attended the event from all over the world to express their shared experience of social exclusion and oppression.138 It was very empowering to realise that regardless of their country of origin, they were all facing the same barriers and discrimination. There was also a strong sense of fighting together against dehumanising attitudes that left persons with disabilities for so long as objects of charity, pity or

134 Ibid., p. 96.
136 Lindquist later became special rapporteur for the UN standard rules on the equalisation of opportunities for disabled people, and played an important role in drafting the UN CRPD
138 Ibid.
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care and considered them as consumers of rehabilitation. They wanted to challenge the traditional medical approach and emphasise the inappropriateness of ‘sicknesses’ and ‘diseases’ in the context of disability.  

Persons with disabilities wanted to be recognised as holders of equal citizenship rights, freedom, choices and dignity. They aimed to contest their incarceration and draw attention to the discrimination they encounter in their daily lives. After sharing the commonalities of their oppression and realising the need to organise themselves together for a real change, disabled people ‘decided to go to the council of RI and demand substantial voice in the decisions that were being made’. The leaders of Rehabilitation International refused this, with the result that disabled people left the room, held their own meetings and eventually decided to form their own international organisation. By that point they wanted to put participation and the voice of persons with disabilities as the focus of the agenda instead of social services.

Disabled People’s International was formally established in 1981 in Singapore. From the beginning, it focused on promoting full participation and equalisation of opportunities for persons with disabilities. The Steering Committee of DPI had representatives from all five regions and in their constitution they declared it to be a cross-impairment organisation. As Hurst explains, there were a growing number of national assemblies that wanted to make a great impact on national and international disability politics. Examples of the efficiency and growing importance of DPI could be their involvement in drafting the World Programme of Action Concerning Disabled Persons in 1983, and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

By 1990 the formation of Disabled People’s International paved the way for other national and international organisations to shift...
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towards a more formalised disability movement. DPI still exists and is now present in more than 130 countries worldwide – including developing countries – through its Member National Assemblies.143 Their main goal is to empower persons with disabilities by building capacity in their local organisations, so they can effectively promote full participation.

The birth of DPI in fact emerged through the coincidental combination of various circumstances, such as the idea for persons with disabilities to go to the Rehabilitation International Congress. Also, the conference organisers’ refusal to give more voice to disabled people was the last straw that generated the determination of disabled people to fight against oppression in a more organised form. The establishment of DPI has had a very important impact on the empowerment of persons with disabilities all over the world and in organising the international disability movement in the spirit of the social model.

2.1.4 The People First Movement

People First groups are self-advocacy groups, composed of people with cognitive disabilities, people with learning disabilities, and people with developmental disabilities who want to speak up for themselves. They have a strong vision of improving the lives of their members and empowering persons with intellectual disabilities. The People First Movement started in 1974 during the planning of a self-advocacy conference in Oregon, USA.144 The initial purpose was to organise a convention where people with developmental disabilities could speak for themselves and share ideas, friendship and information.145 The movement emerged properly when someone at the planning meeting started to talk about being often labelled as ‘mentally retarded’ and

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said: ‘I want to be known as a person first!’ As people at the planning meeting shared the same experience of suffering from derogatory attitudes and stigmatisation, they formally established the movement that they called ‘People First’. Along similar lines, the expression ‘Label jars, not people!’ is often used in the movement to mark a rejection of professional labelling of people with disabilities. The initial aim of the People First movement was to ‘seek freedom from institutionalisation and the constant control of institution staff’.

Following that, many self-advocacy groups called themselves People First and organised themselves along the same principles. Such People First groups can be found in Canada, New Zealand, and Germany. According to the West Virginia Developmental Disabilities Council, today the People First movement has grown into an international movement with approximately 17,000 members in 43 countries.

2.2 Forms and strategies of disability advocacy

2.2.1 Conceptualizing disability organisations

The typology of disability organisations devised by Oliver in 1984 and further developed in 1990 makes a clear distinction between organisations for and of disabled persons. Oliver’s distinction between Disabled People’s Organisations (DPOs) and other types of NGOs will form the analytical categories of the present thesis when discussing the participation of the disability movement in policy process.

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DPOs could be defined as a form of NGO that is particular in terms of its composition and leadership: both the membership and the leaders are persons with disabilities themselves. In contrast, in organisations for disabled people it is mainly non-disabled people working for the rights or interest of persons with disabilities. As Drake argues, non-disabled people who want to be involved in the disability rights movement should put their skills and resources at the disposal of disabled people and act on terms set out by them.151

In his developed typology, Oliver has five categories to describe disability organisations:

<table>
<thead>
<tr>
<th>Oliver’s typology of disability organisations</th>
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<tbody>
<tr>
<td>Type 1</td>
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<td>Type 2</td>
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<td>Type 3</td>
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<td>Type 4</td>
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<td>Type 5</td>
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The categories are based on the approach that each type of organisation employs.152 Type 1 covers the earliest established organisations that work in partnership with the government. The second type, Economic/Parliamentarian, initially described organisations that focused on ensuring adequate income for persons with disabilities. Type 3, Consumerist/Self-help, are organisations that intend to help improving the lives of their members who are disabled people themselves. Type 4 includes those organisations that are fully controlled by persons with disabilities and have a strong human rights

152 Callus (2013), p. 3.
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advocacy focus in their lobbying activities. Callus notes, referring to Oliver, that populist or activist organisations are often antagonistic to the partnership approach with governments. Oliver created a new category in the developed version of his typology and put umbrella organisations under Type 5.

The Partnership/Patronage and Economic/Parliamentarian categories cover organisations ‘for’ persons with disabilities, while Consumer/Self-help, Populist/Activist and Umbrella/Coordinating organisations are organisations ‘of’ persons with disabilities (DPOs). According to the terminology introduced by Oliver, partnership organisations are mainly run by various people including professionals, volunteers, parents, or even some persons with disabilities.

In the developed version of his typology, Oliver clearly remarks that he considers only the organisations of disabled people – commonly called DPOs – as part of the disability movement, and not the other two categories.

As the available literature notes, in many countries the disability sector is still dominated by non-disabled people and there is a myriad of other organisations than DPOs advocating for the rights of persons with disabilities. In the following, we provide a very brief overview of these types of civil society groups relying on relevant literature. Human rights organisations carry out important work to promote and protect human rights that are addressed in international law, *inter alia* the treaties of the UN. They systematically identify and challenge States for generating a wide range of human rights abuses through their political actions. As Stammers highlights, the main goal of human rights organisations is to combat human rights violations and improve the human rights situation worldwide. They can operate at international level or focus on national issues. Most human rights organisations

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155 See more, for example, in Callus’s (2013) analysis of the Maltese disability sector.
157 Ibid.
158 For example, Amnesty International or Human Rights Watch.
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have a general focus and work on a broad range of human rights issues. Thus, disability is only one of their areas of interest. Human rights organisations usually have great experience in independently addressing human rights abuses to the government and to the wider public, holding abusers accountable or developing strategies to stop human rights violations effectively.\footnote{Stammers (2009).}

Service providers in the disability context cover a broad variety of organisations. According to the UK Equality and Human Rights Commission, a ‘service provider is any organisation that provides goods, facilities or services to the public, whether paid for or free, no matter how large or small the organisation is’.\footnote{See more: <http://www.equalityhumanrights.com/advice-and-guidance/before-the-equality-act/guidance-for-service-providers-pre-october-2010/what-is-a-service-provider/> (accessed 14 April 2014).} According to a major philanthropy providing grants to disability organisations in Ireland, ‘service provision is a term used to describe a wide range of activities, including the provision of assistive devices, rehabilitation services, occupational therapy and health services’.\footnote{See: Disability Rights Fund, at: <http://www.disabilityrightsfund.org/> (accessed 28 August 2014).} The form and amount of services and support depend on a number of factors, such as: the individual’s personal needs; the type of impairment; the socio-economic background; the development of the area where the person lives; and the degree of support received directly from the family or community. As Hurst underlines, those involved in service provision see the social model of disability as a threat.\footnote{Hurst, R. (2005), ‘Disabled People’s International: Europe and the Social Model of Disability’, in: C. Barnes & G. Mercer, The Social Model of Disability: Europe and the Majority of the World, Leeds: The Disability Press, p. 65.}

Some service providers fear that the more independently persons with disabilities live in the community, the more opportunities they have to choose forms of informal support instead of professional ones. Without any structural changes in the forms of support they offer, service providers could face economic loss and significant decrease in profit. Therefore, service
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providers can be seen neither as impartial stakeholders nor as true promoters of disability rights.

Parents of children with disabilities were among the first advocates for persons with disabilities, even if at that time they strongly represented the charity model. Some scholars acknowledge that impairment and a disabling environment affect not only the person with a disability, but the family as a whole.

Umbrella organisations are the fifth category in Oliver’s developed typology, with an approach of co-ordinating the work of different disability organisations. Organisations often seek a joint form of representation and create ‘umbrella’ structures. As Meyers notes, the two largest global DPO networks claim to be the voice of persons with disabilities: the International Disability Alliance describes itself as ‘the most authoritative representative voice of persons with disabilities’, and Disabled People’s International uses the motto ‘A Voice of our Own’. As Scholte points out, membership organisations offer few opportunities to their constituents to participate in the actual work of the association beyond paying membership fees and attending general assemblies.

### 2.2.2 Organisational forms of advocacy

This section will briefly discuss what advocacy means and what are the main features of self-advocacy. According to Williams and Schoultz, advocacy is ‘speaking or acting on behalf of oneself or another person or an issue with self-sacrificing vigour and vehemence’. In Parsons’ definition, ‘advocacy means speaking up for the rights of people who

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166 Scholte (2002).
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are being treated unfairly'. 168 Grey and Jackson argue that ‘advocacy by and for people with learning disabilities is based on the belief that we are all citizens with the same rights, responsibilities and potential for growth, and there is a need to combat the exclusion and discrimination experienced by some members of our society through enabling them to access their human and legal rights’. 169 In light of the motto ‘Nothing about us without us’, self-determination and the empowerment of marginalised people lies in the heart of advocacy. According to Atkinson, the broad process of advocacy should reflect four main principles: empowerment, autonomy, inclusion and citizenship. 170 Keenan and Keogh notes that there are about 17 different types of advocacy, but the most important distinctions are between legal and social advocacy, and between individual and systematic advocacy. 171 In this chapter we focus on self-advocacy, but other forms, including citizen advocacy 172 and group advocacy, 173 are also important.

Self-advocacy is the process by which people are empowered to speak up for themselves. 174 The core components of self-advocacy enable the individual to express thoughts and feelings with assertiveness if necessary, to make choices and decisions, and to make a change based on knowledge about rights and duties. According to Inclusion Europe, an important principle of self-advocacy is that persons with intellectual disabilities must have the possibility to be involved in all decisions that concern their lives, as far as they are able

172 Citizen advocacy is a partnership between two people, the client at risk of social exclusion and the independent advocate. See: Hindle, H. (1993), 'Citizen advocacy', Australian Disability Review, (2), pp. 29–34.
173 Group advocacy is a form of self-advocacy where a group of people with a common cause act collectively to reach their shared goal. See Keenan and Keogh, p. 28.
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to understand the consequences. As Carey and others noted, the inclusion of persons with intellectual disabilities in participatory forums is a relatively new phenomenon.

Self-advocacy groups operate along some important common principles. First of all, they are independent from services and controlled by persons with learning difficulties. Securing funding without any strings attached is a guarantee of sustainable operations. Furthermore, self-advocacy groups should be shaped by persons with disabilities regardless of any outside expectations. The group should build on the strengths of the group members and give time and space for each to develop. In order to empower members, the support of experienced disabled or non-disabled people is necessary to enable self-advocacy. The most important aim of self-advocacy groups is to be taken seriously by decision-makers and service providers as the authentic voice of persons with intellectual disabilities. As Keenan and Keogh noted, the outcomes and impact of self-advocacy ideally occur at both the individual and systematic level. This means self-advocacy groups on the one hand influence legislative and policy changes, but on the other hand contribute to improving the individual’s communication skills and confidence. This can be a positive outcome regardless of the extent of systematic achievements.

2.2.3 The concept of tokenism in academic literature

As in the work of Frawley and Bigby, tokenism was one of the central elements in describing the challenges that persons with intellectual disabilities face when participating in advisory bodies, we will now

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178 Ibid.
179 Ibid.
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discuss the concept of tokenism more in detail. The concept of ‘tokenism’ has been used widely in academic literature and particularly in women’s studies to explain difficulties women face as they enter traditionally male-occupied positions. \(^{180}\) Zimmer discusses the emergence of the concept of tokenism, building on the work of Laws and Kantner among others. According to Laws, the token is a person meeting all requirements to enter a certain group, but who still holds a marginalised status due to the lack of those auxiliary characteristics (race, sex, able body, etc.) that are expected from someone enjoying full recognition in the group. \(^{181}\) It means that the token has formal entrance but does not fully participate in the group, as there is no real intention from the ‘insiders’ to include them. \(^{182}\) As Zimmer notes, in sociological literature the term ‘token’ often refers to persons who are admitted or hired in a group exactly because of their difference from other members as proof that the group does not discriminate against anyone. \(^{183}\) This is merely to cover and rephrase on-going exclusion in a more politically correct way. Arnstein highlights that there is a critical difference between the ‘empty ritual of participation’ and having the real power to affect the outcome of processes. \(^{184}\) Without an effect, participation remains a frustrating process for the powerless and maintains the status quo between power holders and powerless where power holders would claim that they consider the views of the marginalised group.


\(^{182}\) Ibid.

\(^{183}\) Ibid.

Main research questions or study hypothesis

III. Methodology and ethical issues

3. Main research questions or study hypothesis

The UN Convention on the Rights of Persons with Disabilities had been adopted with the notion that it will bring real change in the lives of persons with disabilities. The CRPD does not create new rights, but manifests that universal human rights must apply to this particularly marginalized group. Persons with disabilities in theory did have the same rights as anyone else, but in practice had been treated as second-class citizens and facing social exclusion, oppression and serious human rights violations. The text of the CRPD strives to overcome those socially constructed barriers that prevented persons with disabilities from participation. The CRPD further wants to achieve a positive change in the lives of persons with disabilities, so they can enjoy their human rights on an equal basis with others. The CRPD was written with the strong influence of the social model of disability to overcome the presently standing barriers. The social model sees disability as a social construction and a result of longstanding barriers facing people with impairments. According to this approach, social inclusion can be achieved through the removal of all social barriers instead of changing or ‘fixing’ the individual. While the social model of disability was developed in the UK as early as the 1970s, in many parts of the world persons with disabilities are still seen as objects of pity and charity and are defined on the basis of their impairment. This happens regardless of the formal ratification of the Treaty and the obligation on the States Parties to introduce the provisions of the CRPD in their national legislation. Following the aim of the drafters of the CRPD, the paradigm shift, from the medical to the social model of disability is expected to pervade at all international, national and local levels of decision-making and change significantly the attitude of the general public as well. Though the social model has been criticised by a number of authors, it
Main research questions or study hypothesis

still provides the conceptual gravity of the CRPD and current disability politics.¹⁸⁵

This research in line with the most current international legal developments considers disability as a socially constructed barrier that prevents the individual with impairment from participating in the society. From the ontological point of view, this presents an important conceptual shift from considering disability as a medical condition and making a clear distinction between impairment and disability. The reconceptualization of disability as a human rights issue further led in the text of the CRPD to opening up new spaces between the state and disabled persons’ organisations. In parallel to this process, another space is to be opened up between disability organisations and the human rights system, through which persons with disabilities can act as active, rights holder citizens enforcing their human rights. However, the Convention provides a theoretical framework for inclusion, it does not include specific guidance on how to ensure active inclusion at all levels of policy and decision-making processes, and in monitoring the CRPD.

Eight years after the CRPD has entered into force, it is timely to take a look at what has been done at the national level to give voice back to persons with disabilities at important high-level decision-making processes. States Parties would need to exchange knowledge and information about how to implement the complex provisions of the CRPD and to develop indicators and benchmarks to assess the implementation process. Ensuring the meaningful involvement of the disability movement at important policy and decision-making processes is indeed a complex requirement under the CRPD. Considering these important points, the thesis aims to answer the following central research question:

‘What are the conditions and criteria of good practice in achieving meaningful participation of persons with

¹⁸⁵ See Preamble (e), Article 1 of the CRPD.
Main research questions or study hypothesis

**disabilities and their representative organisations in CRPD monitoring processes?**

Some research has looked at Article 33 of the CRPD from the legal point of view in the context of examinations of States Parties’ performance on implementing the provisions of the UN CRPD. Following the participatory provisions of the CRPD, this research wants to answer this question by largely building on input received from persons with disabilities themselves. The meaningful participation of persons with disabilities cannot be defined without considering what persons with disabilities understand by meaningful involvement. For that reason, the research methodology builds strongly on the application of socio-legal research methods instead of applying a human rights principle or purely legal research perspective. Socio-legal research and scholarship has its theoretical and methodological base in the social sciences. It seeks to understand law as a social phenomenon. It is distinguished from other traditions of legal scholarship and research as its methodology is predominantly empirical and social-theoretical rather than doctrinal. This approach also serves to improve the methodological deficit in human rights scholarship as described by Coomans and others. According to Coomans and others, human rights research encompasses a broad range of topics and approaches, including the content of human rights standards, the effectiveness of international and domestic enforcement mechanisms, States’ degree of compliance with human rights standards, and many more.

This research gives a voice, through qualitative questionnaires and interviews, to actors from different levels (government, monitoring framework, civil society) involved in the implementation process and in the triangular framework under Article 33 of the Convention. Building

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186 See de Beco, Hoefmans, Waddington etc.
Main research questions or study hypothesis

on their input, the research developed a set of criteria for meaningful participation. The set of criteria was developed by summarizing what persons with disabilities answered to the questions on how they define meaningful involvement and what they find as the key prerequisites to achieve meaningful participation in policy processes and in monitoring the CRPD. Based on the overview of the current situation and the set of criteria for meaningful involvement, practical recommendations have been developed to the government, the human rights system and civil society. These recommendations stand as important findings of the research and will be presented in Chapter VII. Conclusion.

Furthermore, the research is seeking to answer a number of sub-questions that arose while reviewing the literature and planning the methodology of the study. First of all, the research is also interested in the challenges of meaningful participation for persons with different disabilities within and vis-à-vis representative organisations. We are wondering if all parts of the disability movement can take part equally in policy processes and in the monitoring framework or are there certain segments or groups that are left out from the mainstream movement? In other words, we are seeking answer to the question how do the representative organisations of persons with disabilities ensure that they represent their constituencies and how do the member organisations evaluate their representation at the higher levels? We assume that persons with different impairments may face different barriers when it comes to making their voice heard within the representative organisations that include persons with all kinds of disabilities. Thus, it would be important to explore which groups and what kind of barriers they face within the disability movement. Furthermore, we would like to understand better what is the relationship between disabled persons’ organisations in the countries that are part of the empirical data collection, and how do they cooperate with each other in advocating for the implementation of the CRPD? How do internal politics within the disability movement
Main research questions or study hypothesis

determine the participation of certain groups in policy and decision-making processes?

In line with Article 33 of the CRPD, during the monitoring process, the National Human Rights Institutions as independent mechanisms should collaborate with the representative organisations of persons with disabilities. Our knowledge is very limited about the relationship between the human rights system and DPOs, thus it would be necessary to gain more information about current practices and challenges. How do Human Rights Commissions and Equality Bodies collaborate with DPOs during monitoring the CRPD? What helps to establish a good working relationship?

From the Concluding Observations of the CRPD Committee, we can read out the lack of full involvement of the organisations of persons with disabilities in policy processes and in monitoring the CRPD. However, we would like to see if there were any efforts by the government to start creating frameworks for involving the representative organisations of persons with disabilities. How do DPOs evaluate the government’s actions to involve them in any of these processes? While the situation might not fulfil the requirements of the Convention yet, promising practices should be addressed to serve as examples for other States Parties.
Research objectives

4. Research objectives

The overall purpose of the thesis is to offer a novel approach to understanding the participatory provisions of the CRPD as key elements in the process of change and especially in strengthening the meaningful involvement of persons with disabilities. The research objectives of the thesis are therefore twofold:

1. To understand the current level and mode of involvement of persons with disabilities and their representative organisations in law development, policy making and CRPD monitoring process;

2. To identify examples of good practice and the requirements for achieving meaningful participation of persons with disabilities and their representative organisations.

First of all, there is little data available on how persons with disabilities are involved in policy processes and in monitoring the CRPD in their countries. While the Concluding Observations of the UN CRPD Committee on the reports of the States Parties about the implementation of the Convention provides sufficient information on the structure of the monitoring framework, we are lacking data on matters that are more difficult to measure by means of quantitative data. The research therefore aims to expand knowledge on how the organisations of persons with disabilities are involved in policy and monitoring processes by collecting the combination of quantitative (see Phase 2: Questionnaires) and qualitative (Phase 3: interviews) data.

Following that decision, data was collected from representatives of the national organisations of persons with disabilities and other relevant stakeholders involved in the implementation and monitoring of the CRPD. The objective of the research was not to provide a fully comprehensive picture about how things are, but to have a first glimpse about how disability activists feel about their involvement and through which criteria would they define meaningful involvement. Thus the
Research objectives

research will contribute to new academic knowledge by highlighting some of the challenges for DPOs in participating in the monitoring of the CRPD and by setting up criteria that identify meaningful participation of the disability movement. Further studies will be necessary to carry out interviews with all relevant actors, and explore the involvement of the diverse disability community in a more comparable way. This research will describe the current situation in some countries, discuss some challenges for participation and the set-up necessary prerequisites to achieve the meaningful participation of DPOs in policy processes.

In summary, this research aims to define meaningful participation and its criteria by building on the input of the organisations of persons with disabilities. It is the purpose of the research to share and show the diverse opinion of the disability movement including some contradicting opinions.
Research plan

5. Research plan

In the development of the research plan, Habermas’ and Nancy Fraser’s normative theory were very influential in realizing that dialogic/participatory processes are better to focus on than top-down legal or policy processes. As it was described earlier, Habermas considers new social movements as important contributors to maintain more accountable and just society. The disability movement as a new social movement is to play this role along with other new social movements. That role can be achieved through implementing the participatory provisions of the UN CRPD that open up a space between the state and the representative organisations of people with disabilities. On one hand DPOs are expected to develop partnerships with various governmental departments to participate in policy- and decision-making processes. On the other hand, DPOs should remain their critical voice as civil society. While striving for this status quo, the disability movement must overcome a number of challenges that currently prevent their full and meaningful participation in policy processes.

From a theoretical human rights perspective, Article 4(3) and the issue of participation of persons with disabilities in policy making could be framed as a core element of the notion of social justice as advocated by Fraser. When assessing the current trajectory of contemporary knowledge societies, Fraser highlights three problems that threaten social justice in these societies: displacement, reification, and misframing. In this section we will refer only to displacement as the most relevant problem for our discussion. In knowledge societies the centre of gravity shifted from redistribution to recognition when addressing political claims. The struggle for recognition actually

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190 Ibid.
Research plan

drove many of the new social movements in recent decades to claim international human rights. Fraser argues that the struggles for recognition enrich redistribution struggles instead of displacing them, and she provides a conceptual strategy for defusing this risk. According to her, participation is a single normative principle that could encompass justified claims for redistribution and recognition if at least two conditions are satisfied: first, the distribution of material must ensure independence and voice ('objective'), and second, institutionalised patterns must express equal opportunities for all participants for achieving social esteem ('intersubjective'). Therefore, the striving for recognition and equal participation of persons with disabilities is contributing greatly to improving social justice in knowledge societies.

5.1 Development of the research plan – principles and limitations

Although the implementation of Article 33 was initially the centre of gravity of the research, Article 4(3) and the fundamental requirements for the government to actively involve organisations of persons with disabilities in law- and policy-making eventually became another important point of reference. It occurred as a result of realising that the government, as the focal point for CRPD implementation under Article 33(1), also has obligations under Article 4(3) of the CRPD to collaborate with civil society more broadly. It is necessary then to consider these two provisions together and approach participation through a more complex framework of assessment. Yet in the process of identifying indicators that could measure meaningful participation, it seemed sufficient to choose a smaller area to focus on. Therefore, the developed interviews and questionnaires focus mainly on monitoring the implementation of the CRPD instead of considering all areas of law

191 Ibid.
192 Ibid.
Research plan

development, policy-making and decision-making. On one hand, it would have been beyond the capacity of this research project to gather comparable data on the involvement in law and policy processes and this covers a broad range of areas. On the other hand, the preliminary interviews showed that in cases where the government showed commitment in establishing a CRPD compliant, well-functioning monitoring framework, it is also willing to involve in policy processes the voice of persons with disabilities.

5.1.1 Challenges in applying participatory research methods

The research methodology initially aimed to involve some elements of participatory research. The main reason was to resolve the paradox of carrying out research on the participation of the disability movement but excluding them from participating in the project itself. It was also a clear intention from the very beginning to answer the central question of the present thesis by building on the direct input from persons with disabilities.

While not explicitly, the strong participatory nature of the CRPD would suggest involvement of the voice of persons with disabilities in research that aims to define success factors for their meaningful participation. As Walmsley and Johnson point out, research practices and academic disciplines are affected by social changes. It is also believed that research methods would similarly affect or even stimulate social changes. A more inclusive and progressive research method, therefore, could help to combat exclusionary patterns and stigmas and contribute effectively to the creation of a more equitable society.

Similar to emancipatory and action research, participatory research is an inclusive approach that challenges the location of power

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193 It is beyond the scope of this thesis to provide indicators on this complex area. In-depth analysis of all areas that fall under law development, policy-making and decision-making in the context of civil society involvement should be subject to future research.
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in the research process. In contrast to traditional research methodology, participatory research is carried out by locals and builds on first-hand knowledge as the basis for research and planning. Participatory research has a ‘bottom-up approach’ and prioritises points suggested by the grass-root-level participants in the project. Applying Biggs’ typology to the current research project, the initial aim was to reach at least ‘collaborative’ participation: working with persons with disabilities on a project that was initiated by the researcher. The final stage of the typology would require a collegiate relation between the researcher and local people. Yet, in reality, it already presents a challenge to fulfil the lower levels of the typology.

It was realised at very early stages of the research that, as a result of initiation through an academic proposal, the research project does not fulfil the criteria to become a truly participative one. The aim then was to reach at least the collaborative level by involving leaders of the European disability movement in forming the main questions, the terminology and the direction of the research. When effective involvement in policy-making is described in later sections, the analysis is primarily based on what disability movement representatives shared with the researcher in the qualitative interviews. The aim is to avoid drawing conclusions from the researcher’s own remarks and to take as a baseline the first-hand experiences of persons with disabilities themselves when defining the set of criteria for effective involvement.

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196 Biggs defines four models of participation: the *contractual* mode means that people are contracted to participate in the research; the *consultative* method is when participants are asked for their opinion and consulted by the researcher; in *collaborative* participation researchers and local people work together on projects initiated by the researcher; and in *collegiate* relation the researcher and local people work together as colleagues with different skills in a process of mutual learning. Participatory research is theoretically situated at the latter stage, but has rarely been achieved. See: Biggs, S. (1989), ‘Resource-poor participation in research: A synthesis of experiences from nine national agricultural research systems’, OFCOR Comparative Study Paper 3, International Service for National Agricultural Research, The Hague.
197 The research proposal was initiated by the investors of the DREAM (Disability Rights Expanding Accessible Markets) EU FP7 Marie Curie Research project under the title: ‘Monitoring: European & National Monitoring of the UN CRPD’.
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5.2 Empirical data collection

5.2.1 Phase 1: Preliminary interviews with leaders of the disability movement

As it was mentioned above, acknowledging the importance of involving persons with disabilities as ‘experts by lived experience’, the core research questions were developed with the help and expertise of some members of the European disability movement through qualitative interviews. The interviews were conducted in Copenhagen in March 2012 during the Board meeting of the European Disability Forum. Altogether five interviews have been conducted with interviewees representing the following countries:

- Ireland
- Denmark
- Slovenia
- Italy
- Germany/Russia

The interviewees were selected on the basis of expressing their interest in talking to the researcher during the 2 days-long event. A day before the Board meeting started, during the CRPD Working Group meeting, members of the Working Group were informed about the research and the opportunity to take part in the preliminary interviews. The researcher then approached the five people who expressed interest and arranged the interviews in times that suited them during the meeting in coffee or lunch breaks. Four out of the five people were leaders of the National association of the organisations of persons with disabilities in their own countries. The fifth interviewee was involved closely with an international organisation advocating for the rights of people with hard of hearing. The length of the interviews was between 15 and 45

198 The interviewee was originally from Russia and living in Germany, so her perspective somehow reflects to both countries.
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minutes. There were no specific inclusion and exclusion criteria at this stage of the data collection as the purpose was to get a first glimpse on the topic and develop further the wording of the research. The only inclusion criterion was to talk to people who are representatives of the EDF Board and therefore have a great overview of the disability movement in the country they represent. Unfortunately, there was no time to carry out more interviews due to the busy schedule of the meeting.

The interviews had three main purposes:

1. Getting an idea about the most urgent problems with participation at national and European level;
2. Getting feedback from the disability movement on the draft questionnaire that aimed to reach more members of the disability movement;
3. Developing the wording and concept of the research as adequately and inclusively as possible.

During these interviews, the researcher took detailed notes that were further typed down and saved on the laptop of the researcher. The interviews are randomly coded. These interviews, reassuringly, fulfil the criteria of the collaborative model by allowing some members of the disability movement to form the direction of the research. The knowledge and expertise of the interviewees from this preliminary phase of the research on how Article 33 CRPD could be successfully implemented turned the researcher's attention to important problems, such as

- accessibility in participation;
- the fragmentation of the disability movement;
- the dilemma between centralisation and representation;

\[^{199}P11, P12...\]

\[^{200}\text{This mostly affects persons with multiple and profound disabilities, persons with intellectual and psychosocial disabilities, and people who are hard of hearing.}\]
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- the dominance of tokenistic participatory practices instead of meaningful participation at national level.\footnote{These problems will be discussed in later sections of the thesis.}

All of these aspects formed the core part of the research and have been thoroughly discussed with later interviewees. The preliminary interviews confirmed the researcher's initial idea of distinguishing between the process of involvement and the outcomes in order to assess precisely the quality of participation. Furthermore, the interviews helped the researcher to be more comfortable at further interviews and ask the right and more precise questions based on these initial considerations. For instance, in the interview NZ_1, one of the respondents mentioned that people representing different impairment groups 'just go to the government with their individual little agendas', the researcher was able to further ask if the respondent considers the disability movement a rather fragmented movement? This was possible due to the awareness on the issue of fragmentation as it appeared in half of the preliminary interviews. Participants of the group interview then further expanded on the history of the movement in New Zealand and the main reasons for its fragmentation.

The five interviewees were supportive towards the draft questionnaire that was later sent to the membership of the European Disability Forum during Phase 2 of the empirical data collection.

\section*{5.2.2 Phase 2: Questionnaires}

(a) Design of the questionnaire

After conducting the preliminary interviews with some leaders of the European Disability movement, a questionnaire was developed for
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distribution among European Disabled Persons Organisations. The aim with the questionnaires was twofold:

1. To explore the current level of involvement in policy and monitoring processes;
2. To gather evidence and suggestions of ideal modes of participation.

To achieve these aims, the questionnaire was divided into two main parts:

1. 'Current situation';
2. 'Ideal situation: how civil society should be involved'.

It began with a brief explanation in plain language about the research project. This served the purpose that persons with any kind of impairments, including persons with intellectual disabilities could understand what this questionnaire is about. However, the questions were not drafted in an easy-to-read format, the researcher aimed to use the simplest language as possible. The questionnaire did not promise anonymity to the respondents and it asked for the name of the organisation and the name and details of the contact person who filled out the questionnaire for further potential contacts. The questionnaire included 28 open-ended questions, each requiring a rather deliberate response. There were three types of questions:

a) Questions that gathered detailed information on the forms of involvement of persons with disabilities at different processes (e.g. Q11: Is your organisation involved in policy-making regarding the implementation of the CRPD? Through which channels is it happening?; Q13: Is your organisation involved in monitoring the UN CRPD? What does it mean in practice? etc.);

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202 See Annex 1.
203 See Appendices 1.
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b) Questions that asked about the quality of participation (e.g. Q9: Are the focal point(s) and coordination mechanism accessible for the organisations of persons with disabilities?; Q17: In your country what are the main achievements of disabled people’s organisations through Article 33 so far?; Q18: Could you provide practical examples to illustrate the input they made? etc.);

c) Questions that asked about steps respondents considered were necessary achieve meaningful participation (e.g. Q4: What are the prerequisites of effective and active involvement of civil society in policy-making... decision-making... and in monitoring the CRPD?; Q5: How should the State guarantee representativeness of civil society members? etc.)

There was no pre-testing, but the researcher consulted on the design of the questionnaire with the staff of the Secretariat of the European Disability Forum.

(b) Data collection

The questionnaire was sent out twice to all member organisations of the European Disability Forum in the monthly newsletter between 29 June and 31 July 2012. The European Disability Forum is the umbrella organisation that represents 80 million disabled persons across Europe.204 The national councils of disability organisations, as members of the EDF, were also asked by email to distribute the questionnaire to their local branches. Furthermore, the questionnaire was transferred to an online questionnaire, and by providing an easier format it was expected to attain additional responses.205 The online questionnaire was posted on two main online locations until 31 July 2012: the

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websites of the EDF and the DREAM project, however, the number of completed questionnaires did not increase through the online tool.

In total 12 questionnaires were received, 11 from national disability organisations, and 1 questionnaire from a European level organisation. The European level organisation filled out the questionnaire partially, and one of the countries sent information by email in a format of a longer text instead of filling out the specific questions. Answers were received from the following countries:

- Denmark
- Malta
- Sweden
- Austria
- Italy
- Finland
- Luxembourg
- Iceland
- Cyprus
- Belgium
- Germany

The number of the questionnaires received (12) was below expectation, however it gave enough information for the policy chapter of this thesis to explore the various forms and channels through which persons with disabilities are involved in policy making and in monitoring the CRPD. Yet, it is difficult to estimate the response rate, as we do not know the exact number of organisations that the questionnaire indeed reached. We could estimate that the secretariats of the 29 national councils that are full national members of EDF all received the questionnaire. The fact that 11 of them have sent replies means that the response rate among them was 37.9%. However EDF has a very complex membership including 25 full European NGO members (among them the response rate was 4%), 14 European ordinary NGO members, 47 associate members, and 5 observer members. Similarly, we did not receive any
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answers from member organisations of EDF’s National Councils, which can mean two things: they either did not receive the questionnaire from the secretariat of the national organisation, or they did not have the capacity to reply. The following chart shows the response rate by the type of EDF membership:

![Chart showing response rate by EDF membership type](image)

**Figure 4: Response rate for questionnaires**

Initially a larger set of data was to be collected at EU level for the purposes of the research. Although this sample provides enough information for the purposes of this thesis, collecting more data would be necessary in the future. This phase of the research showed that in future data collection that targets DPOs, it is important to avoid making questionnaires too long. Some respondents mentioned that its length made it challenging to answer all questions. The reason behind making such a complex questionnaire was the determination to gain an in-depth understanding of the current level of involvement in the work of the Article 33 monitoring framework. Detailed questions were necessary to obtain comparable data on the actual and ideal forms of participation. We believe this area is often overlooked in disability research. Yet some respondents left full blocks empty in the
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questionnaire, which greatly undermines comparability. The results we present in this chapter give some ideas about the challenges and good practices at national level when participating in law and policy development programmes in line with Article 4(3), and in the monitoring framework in line with Article 33 of the CRPD.

5.2.3 Phase 3: Country studies

(c) Planning the field trips: choosing destinations and preparations for interviews

As part of the research project, three major field trips were organised to collect data and get a comprehensive picture of the implementation of Article 33 of the CRPD, especially of the involvement of persons with disabilities in policy- and decision-making. The country visits aimed to collect information in places that are considered to have promising practices in terms of the implementation of Article 33 of the CRPD in both structural and functional manner. Since the Concluding Observations by the CRPD Committee can only evaluate the structure of the established monitoring mechanisms, but lacks the capacity to observe the functioning of the framework, this research wanted to provide data on this important aspect as well. Based on the available academic literature, and mainly the work of Quinn, we approached implementation and monitoring the CRPD as a dynamic processes in which the functioning of the frameworks is as important as their established structure. In order to develop a set of criteria of good practice it was necessary to analyse countries with a monitoring framework that fulfil at least four of the following five criteria:\footnote{206 OHCHR (2009), 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, A/HRC/13/29 22, available at: <http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf> (accessed: 19 July 2013).}
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1. Paris Principles compliant independent mechanism included in the monitoring framework;
2. Ability to carry out promotion, protection and monitoring under Article 33 CRPD;
3. Involvement of the organisations of persons with disabilities in monitoring the CRPD;
4. Formal designation of the monitoring framework;
5. Financial allocations.

In the preliminary phases of the research, many academics and stakeholders were approached to suggest places that they considered to have promising practices in relation to the participation of disability organisations and people with disabilities in monitoring implementation of the CRPD. Many factors played a role in the final decision. It was necessary to have a contact person in the selected countries, as the organisation of such a field trip requires comprehensive local knowledge and an extensive professional network with the governing bodies, actors in the human rights field, and civil society, particularly the disability movement. The success of the field trips therefore greatly relied on the contact persons’ disposition and willingness to support the project. Another important aspect was to involve countries that have already ratified the Convention – they therefore have a legal obligation to comply with the provisions of the international treaty, and sooner or later will be going through the international monitoring process with the UN CRPD Committee. It was preferred to choose countries where English was the official language or one of the official languages in order to have easy access to persons with disabilities during the qualitative interviews. The researcher wanted to conduct interviews with members of the disability movement, including persons with intellectual disabilities; therefore it was necessary that the researcher and the interviewees have a common language to speak. While it is possible to do interpretation during
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interviews, the researcher was convinced that it would have a negative impact on the substance of the interviews.

The three countries initially selected were Australia, New Zealand and Zambia. Since the need for financial investments was often mentioned in the preliminary interviews as a barrier to ensuring civil society participation, beyond the already mentioned aspects, it was a deliberate choice that Zambia, as a developing country, would take part in the research. 207 Australia and New Zealand were considered as places that pioneered the implementation of Article 33 from the initial stages of the research, so it made sense to organise field trips to both countries due to their geographical proximity to each other. Other possible targets for field trips were Canada, Mexico, Denmark or Austria. Since previous research – carried out mainly by Gauthier de Beco – discussed the implementation of Article 33 in European countries, even if the methodology used in the present thesis significantly differs, it was decided to focus on places where information was very limited on the actual functioning of the monitoring frameworks. Mexico was finally excluded, as there was no convincing proof that there is a mechanism established to monitor the CRPD with the involvement of DPOs and the researcher faced some difficulties in finding a reliable contact person. In Canada, the selected contact person could not confirm Canada is a site of promising practice in the research at the end.

During the country visits, however it turned out that Australia does not fulfil enough criteria of selection to be defined as a promising practice country for the purposes of this thesis. This observation was also confirmed by the CRPD Committee, which made negative remarks on the implementation of Article 33 CRPD just couple of months after the study visit in the country. The Committee expressed its concern about the structure of the monitoring framework, and highlighted the lack of adequate participation of persons with disabilities:

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‘57. The Committee is concerned that Australia lacks a participatory and responsive structure for implementing and monitoring the Convention in line with article 33 thereof.

58. The Committee recommends that the State party immediately set up a monitoring system that is fully in line with the provisions of article 33 of the Convention.’

Despite of some very promising initiatives happening in the country, the consideration of Australia as a promising practice became unsuitable. The following table summarizes the inclusion/exclusion criteria for the country examples, based on the framework we adopted to assess the compliance with Article 33 CRPD:

<table>
<thead>
<tr>
<th></th>
<th>New-Zealand</th>
<th>Australia</th>
<th>Zambia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paris Principles compliant independent element</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Promotion, protection, monitoring</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Involvement of DPOs</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
</tr>
<tr>
<td>Formal establishment</td>
<td>✓</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Financial resources</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Table 2: Inclusion/Exclusion criteria for good practices

During the preparation for the field trip, a one-page long work plan was distributed among DPOs in the target countries. The work plan explained the purposes of the research and the aim of the field trip. This short note gave sufficient information to disability activists about the research, so they could decide whether they want to participate and share their knowledge. For instance, the following information was given to interested potential interviewees in Zambia about the country study:

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208 CO Australia, para. 57–58.
209 See more details about these criteria in the next chapter.
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In the last couple of months I have been in touch with the Zambia Federation of Disability Organisations and they provided me information on the work of the Independent Monitoring Unit. I find Zambian initiatives relating to civil society involvement very interesting, so my purpose is to get more familiar with disability issues in Zambia. During my field trip, I would like to meet with different actors of policy–and decision-making including government representatives, representatives from the Human Rights Commission, and Civil society (especially advocates from DPOs) who can share their experiences about monitoring of the CRPD and their involvement in the whole process. I would like to see what are the different approaches they do have and how they find the current situation. A long-term impact of conducting those interviews during the field trip could be to collect various factors that ensure successful involvement of persons with disabilities in monitoring activities (e.g. effective capacity building, grass-root initiatives etc.)

In total over 35 interviews were conducted between March 2012 and April 2013 for the purposes of the research in Zambia, New Zealand and Australia. In the following we describe the two field trips and how the data was processed.

(d) The field trips to Zambia and New Zealand

During the field trips two types of qualitative interviews have been conducted: individual interviews and group interviews. The researcher’s primary aim was to conduct individual interviews with representatives of DPOs and other important stakeholders who are involved in the monitoring of the CRPD. However, group interviews were carried out mostly for logistical reasons. It was often easier for the contact person to mobilise a number of key activists working for the same national federation before or after their weekly meeting. Another reason for group interview was when more people from the same organisation wanted to share their views on the matter. In Zambia, two group interviews took place with Opportunities Zambia and the Zambia Law and Development Commission. In New Zealand, four group interviews took place with the Board members of the Association of Blind Citizens Auckland Branch, with the UNCRPD shadow-reporting

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210 See Annex II.
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group (Auckland branch), People First New Zealand, and the IHC New Zealand.

Interviews always started with the introduction of the researcher and the research project and the clarification on the basic ethical principles. Respondents were told that their anonymity is respected by means of not revealing their names or associational affiliation. Respondents were asked if they agree with being recorded, by explaining that the researcher only uses the recordings when making the transcripts, but does not publish them under any circumstances. The interviews lasted between 30 minutes and 1h 30 minutes depending on the type of the interview. Group interviews with several respondents were the ones that lasted longer.

Regardless of the type of the interview, the following interview guide was used to cover the same key issues:

1. Which organisation do you represent?
2. What is the structure and function of your organisation?
3. Where is your funding coming from
4. Do you play a role in monitoring the UN CRPD? If yes, what is this role?
5. How do you evaluate the current monitoring activities? What has happened so far?
6. How do you find the collaboration between the Human Rights Commission/Ombudsman and your organisation?
7. How do you evaluate the level of involvement of persons with disabilities in New Zealand in policy and decision-making processes?
8. What are the gaps?
9. What do you think, what are the key factors of effective involvement?
10. How far we can take the ‘Nothing about us without us!’ principle?
11. What would be necessary to improve effectiveness of the involvement and to improve the collaboration?

Figure 5: Interview guide for country visits.

These questions were developed with the view to provide sufficient information to answer the main research questions in line with the objectives of the research. After Question 11, the interviewees had been asked if they want to say anything else. This gave them opportunity to share any additional thoughts or relevant information about the
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participation of the organisations of persons with disabilities in their countries.

During the interviews accessibility was provided on an ad hoc basis responding to the accessibility needs of the interviewees. Those respondents who were deaf used their own sign language interpreters during the interviewees. For respondents with visual impairment the project description and the questions were sent by email beforehand upon request. When interviewing a group of self-advocates in New Zealand, the group interview took a more informal form, by sitting in circle and ensuring that people feel comfortable during the interview. The researcher paid attention to ensure that people understood well the questions and were given enough time to formulate their answers.

New Zealand

The field trip in New Zealand took place from 2–9 April 2013 in Auckland and Wellington. Altogether seven interviews were conducted in New Zealand, four of which were group interviews. The contact person provided significant help in putting together the schedule and arranging important meetings with high-level state actors in the disability field and a meeting with the Maori disability community. During the field trip, the researcher attended a disability fair, where different DPOs and service providers exhibited their work. It was a great opportunity to talk informally to a large number of people.

The organisations that participated in the empirical research in New Zealand are:

- Auckland Disability Law;
- People First New Zealand, Auckland branch;
- Association of Blind Citizens Auckland Branch (ABC);
- UNCRPD shadow reporting group (Auckland branch);
- Disability Community Development and Partnerships;
- Te Roopu Waiora Trust;
- Disabled Persons Assembly, NZ;
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- Deaf Aotearoa;
- Ministry of Social Development, Office for Disability Issues;
- IHC New Zealand;
- Human Rights Commission, Disability Rights Commission;
- Deafradio.

**Zambia**

In Zambia, 9 qualitative interviews were conducted with representatives of 10 disability organisations from 9–20 July 2012 in Lusaka. Two of them were group interviews with two people. This is a difference compared to the data collection in New Zealand, where some interviews had six or seven participants that in Zambia mostly one-to-one interviews were conducted.\(^{211}\) The researcher was based in the office of the Zambia Federation of the Disabled, from where she could go to meet in the offices of the interviewees together with the contact person. Staying in the main office of the national disability organisation, gave an excellent insight to their work and every day challenges of the umbrella disability organisation.

The following organisations participated in the empirical research in Zambia:

- Zambia Federation of the Disabled (ZAFOD);
- Zambia Agency for Persons with Disabilities (ZAPD);
- Zambia Law and Development Commission (ZLDC);
- Sight Savers International (SSI);
- Opportunity Zambia (OZ);
- Zambia National Library and Cultural Centre for the Blind (ZNLCCB);
- Zambia National Federation of the Blind (ZANFOB);
- Mental Health Users Network of Zambia (MHUNZA);

\(^{211}\) More precise information will be provided later in the ‘Findings’ chapter.
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- Zambia Association of Parents of Children with Disabilities (ZAPCD);
- Zambian National Association of the Deaf (ZNAD);
- a freelance disability rights consultant.

Interviews on the field trips were also conducted with people involved in the work of the Article 33 CRPD framework – including representatives of the focal point for CRPD implementation in the government and people from the independent monitoring framework. These interviews, together with the experiences of the disability advocates, aim to draw a more precise picture of the monitoring work carried out in the countries and of the operations of the designated Article 33 mechanism. This data is unique in its own right by looking beyond the structure of the established framework and analysing its actual functioning, as well as mapping the satisfaction of all stakeholders involved. Interviewees were asked to provide feedback and suggestions on how to improve the monitoring work and the collaboration between members of the framework.

(e) Steps of collecting and retrieving the data for analysis

Interviews were recorded with an Olympus VN-4100PC voice recorder unless the interviewee refused permission for recording and preferred that the interviewer only took notes. Respondents were always asked prior to the interview if it was acceptable to be recorded. It was explained to them that the audio will not be used in any public domain, or shared with anyone, but will solely help the work of the researcher in retrieving and analysing the data. It happened only in one case that the person did not want to be recorded. In this case only detailed notes had been made during the interview. The voice recordings were then stored in a specific folder on the private laptop of the candidate. Keeping a safety copy was necessary in order to ensure the data is available during the writing of the present thesis. No one else had
access to the folder, but the candidate. The voice recordings will be deleted once the University approves the PhD thesis. The data was then interpreted by the use of mechanical means and typed in Word files. Since the research did not include any narrative analysis, but only content analysis, it was not indispensable to use specific software for analysing the data. By making mechanical transcripts, the researcher had a great overview of the interviews and this formed an important part of preparing for writing the chapter on the findings of the country examples. The transcripts are coded randomly in the following way:

- NZ for New Zealand: NZ1, NZ2, NZ3 ...
- Z for Zambia: Z1, Z2, Z3, ...

These files are stored together with the voice recordings, but in separate folders on the laptop of the researcher. Full copies of the transcripts are available and can be produced if the examiners of the thesis want to check them.

During the interviews, the researcher also took detailed notes, which were later useful when the quality of the audiotape was not satisfactory. When interviewing people with hearing impairment, detailed notes were also the primary way of recording the information. Unfortunately, voice recordings of group interviews that had been conducted in New Zealand are sometimes difficult to understand. It was essential to have detailed notes available to retrieve the data. In some instances, due to cultural or language specificities (e.g. Maori words), it was difficult to understand some names, words or expressions. However, these challenges did not hinder the analysis of the data. The notes have never been digitalized and are stored in a paper folder to which only the researcher has access. These notes will be destroyed once the PhD examiners of the National University of Ireland, Galway, approve the thesis.

In addition to the conducted interviews, the contact persons in the target countries often shared important details informally on the way to meetings, after the interviews etc. This information could not be
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recorded or systematically noted, but after the meetings the researcher made short notes to retain the most important elements of what was shared by the contact person. This additional information helped greatly in further understanding the local context. However, the subjective opinion of the contact person never resulted in questioning the validity of the answers of the interviewees, but added an additional viewpoint to understand the local complexities.

Finally, during the field trips, interviewees made references to a number of legislations and policy documents that are important in relation to the implementation of Article 33 of the CRPD. Where it was possible, the researcher tried to get a copy of these documents or wrote down the links to electronic copy of these documents. This table shows the different information that was gathered during the field trips and the way in which they were processed.

<table>
<thead>
<tr>
<th></th>
<th>Interviews recorded with a voice recorder</th>
<th>Transcripts were made and stored electronically</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Detailed notes made during the interviews</td>
<td>Stored in notebooks</td>
</tr>
<tr>
<td>3</td>
<td>Informally shared local insights</td>
<td>Partially noted down and stored in a folder</td>
</tr>
<tr>
<td>4</td>
<td>Relevant legal and policy documents</td>
<td>Printed and stored electronically and in a folder if the document was received on paper</td>
</tr>
</tbody>
</table>

Table 3: Information collected during the field trips and ways of processing

The process of coding and annotating the transcripts in order to analyse content started with printing out the transcripts and reading them through carefully. Then, following the adopted frame for analysing compliance with the CRPD\textsuperscript{212}, all information was extracted from the interviews that referred to the five criteria of implementing Article 33 and grouped accordingly:

\textsuperscript{212} See in the next chapter.
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1. Structure of the Article 33 framework
   • Formal designation?
   • Composition?

2. Activities of the independent mechanism
   • Promotion, protection, monitoring?
   • Financial allocations?

3. Independence of the monitoring framework
   • Paris Principles compliant element involved?

4. Implementation of Article 4(3) CRPD
   • Current involvement in policy-making?
   • Current involvement in law-making?

5. Strengths and challenges for the framework
   • Achievements? Involvement of DPOs?
   • Collaboration with stakeholders? etc.

6. Criteria for meaningful participation
   • ??
   • ??

Figure 6: Criteria for processing data

For identifying the strengths and challenges of the Article 33 monitoring framework, as well as for the criteria for meaningful participation, it was necessary to find common patterns in the transcripts. According to the working definition, pattern is any input or idea that appears at least in two different interviews. All these patterns were marked with different colours of sticky notes and then summarized during the writing process. As we explained earlier, the criteria for meaningful participation is developed as a summary of the ideas shared by the interviewees answering Question 9: ‘What do you think, what are the key factors of effective involvement?’.

(f) Challenges and limitations

One of the challenges was to organise the field trips from Europe and ensure from distance to getting in touch with relevant actors from civil society and in particular the disability movement. In order to ensure that the research will reach out a great number of interviewees, a contact person was selected in each country to help in finding potential interviewees and arranging the necessary logistics of the field trip. The
contact persons helped to schedule meetings with DPOs, government representatives and staff of the National Human Rights Institutions. Each contact person played a crucial role in choosing the respondents, and organising the meetings. This obviously causes some limitations in the scope of the study as a few potentially relevant interviewees might have been omitted from participating in the study. However, all contact persons were chosen after careful consideration of their central role in domestic disability issues. The contact person in Zambia has been working at that time, as legal officer for the national umbrella organisation of persons with disabilities and in her/his role was to be responsible for advocating for the implementation of the CRPD in the country. By playing a central role in the monitoring mechanism, this organisation was well connected with the government and by its umbrella structure knew well the different DPOs too. In New Zealand, the contact person also represented an organisation that took part in the civil society formation to monitor the CRPD and provided free legal service on the CRPD supported by government funding. The various roles that these people played in the process of implementing the Convention was essential to arrange meetings with different stakeholders.

More interviews could have been conducted by reaching a broader group of advocates, but the case studies still represent well the opinion of some important advocates and leaders of the disability movement in Zambia and New Zealand. As it was mentioned earlier, in some cases, group interviews had been conducted. Group interviews have advantages and disadvantages. On one hand, it may discourage participants from articulating their opinion if it varies from the views of the majority at the table. On the other hand, it can be very stimulating to reflect jointly on issues and difficulties in an open discussion.

As in any qualitative piece of research, there is no possibility to verify respondents’ answers, especially on very intangible issues such as the government’s willingness to involve persons with disabilities in policy-making. We will present some contradictions between the
opinions of disability activists and government representatives when it arose during the interviews. It is not possible to identify who is right on these matters, but in fact the aim is to highlight the complexity of the issues that governments and civil society have to deal with in implementing the CRPD. The case studies are also great examples of the heterogeneity of disability movements and the diversity of opinions of members of the DPOs.

We reserve the possibility that the local situation could have changed in any direction since then, so our statements refer mainly to the situation at the time of the visits in 2012 and 2013. Nevertheless, respondents have obviously subjective views on the operation of the monitoring frameworks and on their involvement in policy processes. The thesis does not claim that it covers the views of the disability movement as such, but only the parts that took part in the empirical data collection. Furthermore, it is beyond the scope of this thesis to provide indicators on this complex area. In-depth analysis of all areas that fall under law development, policy-making and decision-making in the context of civil society involvement should be subject to future research.

5.3 Ethical issues

Although, the research has not been through formal ethics review, significant efforts were made in order to ensure ethical principles were respected throughout the empirical data collection and during processing of the data that has been gathered.

First of all, participation in the empirical data collection of the research always happened on a voluntary basis. Participants received written information about the research project and the aim of the field trip. This allowed them to make an informed decision whether to participate or not in the research project. The researcher always expressed gratitude towards the participants of the research for their
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time to share their valuable knowledge. The meetings always tried to conform to the availability and schedule of the interviewees.

Anonymity of participants has been protected rigorously, and the data is handled with high confidentiality. By anonymity we mean that the information received has been processed and used separately from any of the personal information that would allow participants to be identified. All the manuscripts have a special code that indicates only the field trip where the interview was conducted and does not refer to the interviewee. At the same time, there are some participants who understand that it is not possible to guarantee anonymity as a result of their particular position in a participating organisation.\(^{213}\) The organisation (DPO, human rights institution or government) where the respondent works needs to be mentioned in the Findings and Discussion sections in order to give context to the interviews. These respondents were informed of this during the qualitative interviews and agreed to participate even so.

Despite the commitment to carry out the entire research in the spirit of collaborative research, such methodology requires more resources than were available. It is also important to note that in order to achieve stronger collaboration and engagement with local representatives, a form of remuneration should be provided to research participants. A few respondents or potential interviewees made a valid point on the necessity of compensation or honorarium. The project had nothing to offer in return for the time and commitment of the participants except the promise to share the research results that would hopefully be useful for the disability movement and all other stakeholders. Especially in times of economic crisis and recession, civil society representatives have to prioritise how they use their limited resources, and this should be respected by a research project. We know that no research should exploit participants in the interest of the researcher. This research aims to have a positive impact on establishing

\(^{213}\) For example, the Human Rights Commissioner.
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sustainable processes that involve persons with disabilities in policy processes.

The findings of the research have been presented at a number of international conferences and summer schools. The results of the questionnaires with members of the European Disability Forum were already presented in May 2014, at the Annual General Assembly of EDF during the European Conference in Zagreb, Croatia. Preliminary results of the Zambian field trip had been shared in New Zealand and Australia. The complete research results shared directly with the participants of the research after publication.

In the following section, we will indicate the main ethical considerations at different phases of the research and what was done to ensure compliance with basic principles of ethical research, with special regard to confidentiality, anonymity, informed consent, or management of data.

(a) Phase 1 – Preliminary interviews

In Phase 1, the researcher had to respect the very tight time schedule that the people who agreed to give an interview had. Interviewees attended a business meeting in Copenhagen and the interview meant an

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214 E.g. at the CDLP NUIG 5th and 6th International Disability Summer School, Galway (Title: ‘Article 33 - Innovation from around the world’) (2013-2014); Presentation at the Nordic Network on Disability Research conference, Turku, Finland (Title: ‘Nothing about CRPD monitoring without us! – case study on the involvement of the disability movement in policy-making in Zambia’) (May 2013); Presentation at the Pacific Rim International Conference on Disability and Diversity, Hawai’i (Title: ‘Nothing about CRPD monitoring without us! – case study on the involvement of the disability movement in policy-making in Zambia’) (April 2013).

215 Presentation at the European Disability Forum’s European Conference in Zagreb, Croatia (Title: ‘Good practices and challenges in implementing Article 4(3) and 33 of the UN CRPD’) (May 2014).


217 Lunchtime seminar at: Australian Human Rights Centre, Sydney (Title: ‘Nothing about CRPD monitoring without us! - case study on Article 33 CRPD implementation in Zambia’) (March 2013).
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unexpected additional item on their agenda. It was promised to the interviewees that their anonymity is protected throughout the research. The interviews took place in a quiet room or corner of the corridor, chosen by the interviewees. The interviewees were informed that the main role of these interviews is to give an idea to the researcher about important issues vis-à-vis the participation of the disability movement in policy processes and monitoring the CRPD. They were also informed about their role in verifying the draft questionnaire and the proposed research terminology. They were ensured that the detailed notes of what they tell the researcher will be treated with high confidentiality.

(b) Phase 2 - questionnaires

In Phase 2, the questionnaires included a short summary about the purpose of the study and an explanation on how respondents contribute to the research project by filling out the questionnaire. Anonymity was not promised to the respondents and their name and contact detail was asked for further potential contact. All respondents agreed to provide this data on the questionnaires. However, the information they provided in the questionnaire is still treated in a confidential manner, so it will not be published, but only used in the policy assessment part of the present thesis. The data was managed with high confidentiality and not shown to anyone.

(c) Phase 3 – country visits

In Phase 3, during organising the country visits, a number of ethical challenges had occurred. First of all, the research aimed to have a big sample to provide better analysis of the situation on the ground. Contact persons were asked to arrange interviews with as many relevant actors as possible, with special regard to representatives of the
disability movement. This meant that the contact person had to spend longer time with finding potential respondents, arranging interviews with them and organise the meeting and their logistics for the researcher. From the ethical point of view, this took significant time off for the contact persons and the interviewees from their advocacy work. While the researcher is fully aware that a research should not be too demanding of participants, we believed that the central research questions – that are crucial in ensuring the effective implementation of the CRPD – could only be answered by reaching out a great number of stakeholders. This research was implemented on a basis of awareness and recognition of the valuable time and resources that contact persons and interviewees invested in participating in the research.

In the beginning of the interviews, all respondents were informed about the basic ethical principles of the research, namely that anonymity is guaranteed them throughout the research project and that the voice recordings, interview transcripts and detailed notes will be confidentially treated.
IV. Legal and policy context

6. Legal context: Set-up of the UN CRPD

In 2001, Mexico put forward a proposal to the UN General Assembly to start elaborating a ‘comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities’. The exact reasons behind Mexico’s proposal are still somewhat unclear: presumably a combination of several fortuitous factors, including the willingness to achieve diplomatic success.

The General Assembly called for the establishment of an Ad Hoc Committee (AHC) open to the participation of all Member States and observers of the UN. The Resolution also invited other stakeholders, such as intergovernmental and non-governmental organisations, relevant human rights treaty bodies, and the Special Rapporteur on Disability, to make contributions to the work of the Ad Hoc Committee. The AHC met twice a year until August 2006. The final text of the Convention was adopted on 13 December 2006 by the General Assembly, along with the Optional Protocol that enables individual complaints to the Committee to be set up under the Convention. On 30 March 2007, the UN CRPD and its Optional Protocol were opened for signatures at the UN Headquarters in New York, with the participation of about 800 NGO representatives in the room.

As de Beco points out, considering the sensitivity and complexity of some of the issues, the negotiation and adoption of the CRPD in a little more than two years was an exceptional achievement in UN history. The fact that the CRPD, right after entering into force, received more signatures than any other human rights treaty shows the States’ clear commitment to acknowledging the importance of

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promoting disability rights and removing barriers that prevent persons with disabilities from participating in society. Commitment does not automatically result in change, but it creates an important space for accountability. The Convention and its Optional Protocol entered into force on 3 May 2008 after receiving a sufficient number of ratifications. As Theresia Degener points out, the CRPD, ‘like any other UN treaty, is a visionary law designed to transform society into a more just society and these visions cannot be achieved overnight’.

One of the main purposes of the first UN Treaty of the 21st century was to clarify and tailor existing international human rights law in the specific context of disability. The UN CRPD does not create any new law, but provides a new framework of reference in disability. As Gerard Quinn highlights, the application of the legacy values of human rights theory and law – such as dignity, autonomy, and equality of opportunity – in the disability context is what makes the CRPD revolutionary and not these principles as such. The transformation of the human rights principles to the disability context aims to change social attitudes towards persons with disabilities by no longer considering them as objects of care, charity or pity, but as subjects of human rights on an equal basis with others. The manifestation of this

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221 See n.1 on CRPD entry into force.
224 With the provision on accessibility, the Convention was close to creating a new right, but this would have been against the initial intention of the drafters. Therefore, Article 9 does not include the right to accessibility, but gives a list of the barriers to be removed in order to ensure the independent living and full participation of persons with disabilities in society.
Legal context: Set-up of the UN CRPD

paradigm shift in the text of international law is one of the most important achievements of the CRPD.

Therefore there are two main ways of looking at the CRPD. As an international human rights treaty, it has a normative context and serves as a traditional tool for lawyers in enforcing Treaty provisions. The importance of developing good law should not be underestimated; however, the elegant words of a treaty do not guarantee that the law will automatically bring a positive change to people’s lives.\(^{226}\) The language of the law does not always provide clear answers to acute problems or a basis for straightforward interpretation.\(^{227}\) However, international human rights treaties provide a very important normative framework and gather the formal commitment of States to recognise the principles of human rights law. In theory, ratification expresses the strong willingness of States to implement the obligations of the Treaty and to promote the rights of the group protected under the Convention. As Quinn emphasises, the main challenge for the Convention is to ensure its effective implementation in all States Parties and this can be best achieved through persuasion and socialisation at domestic level.\(^{228}\) He warns that without socialising states to adapt the new ideas, there is no guarantee that the new values\(^{229}\) will be internalised and operationalised.\(^{230}\) Considering that international law rarely has an effect that somehow coerces States Parties to do what they would

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\(^{226}\) One of the most frequently referred court cases of the last couple of years in the context of disability is *Kiss v. Hungary*. The European Court of Human Rights in Strasbourg issued a landmark judgment in 2010 on the case, holding that there was a violation of Article 3 of Protocol No. 1 of the European Convention on Human Rights. This was the first time the Court referred to the UN CRPD. However, despite the positive judgment and the long-term impact of the case law, there has not been any major change in Hungary in abolishing the guardianship regime. The rights of the applicant are still violated regardless of the Court’s decision or the obligations that Hungary has under the CRPD. This is a very obvious example of the gap between international law and the lived reality of persons with disabilities.

\(^{227}\) Ibid.


\(^{229}\) As Quinn emphasises, the Convention includes old values in their novel application to disability.

Legal context: Set-up of the UN CRPD

otherwise not do, the ratification of the CRPD does not yet guarantee the empowerment and social inclusion of persons with disabilities.\(^{231}\) The internalisation must happen through the participation of persons with disabilities, to ensure that their longstanding exclusion ends effectively and that society gradually changes to a more equal and inclusive one. Thus, the main question is how to accelerate this process of internalising the values of the Convention, and how to configure the implementation and monitoring provision of the Convention at its best.\(^{232}\)

6.1 The impact of ‘participation’ in the text and evolvement of the UN CRPD

There are two important aspects of ‘participation’ in regard to the UN CRPD. First, the Convention was drafted in a participatory way, involving organisations of persons with disabilities. Second, participation is a leitmotiv throughout the whole Treaty. This subsection will give a brief overview of the two aspects in order to better understand the significance of ‘participation’ in the text of the Convention.

6.1.1 Participation in drafting the CRPD

The UN CRPD has a number of innovative features, one of which is its strong participatory nature by authorising accredited non-governmental organisations (NGOs) to attend initially all public meetings and later also informal and closed meetings.\(^{233}\) The General Assembly invited NGOs to make contributions to the work of the Ad Hoc

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\(^{232}\) As Gerard Quinn mentions, it does not refer to the role of treaty bodies in making a change, because being an 'exogenous force' they would rarely achieve that. See: Quinn (2009b), p. 219.

\(^{233}\) The term 'non-governmental organisation' was first used by the UN in 1945 to specify the role of consultants that were not representing national governments.
Legal context: Set-up of the UN CRPD

Committee as early as the first session of the Committee in 2002.\textsuperscript{234} At the second session, the Ad Hoc Committee decided to establish a Working Group composed of 27 governments and 12 NGOs with the aim of preparing and presenting the draft text of a Convention. The Resolution of the second session of the Ad Hoc Committee particularly stresses ‘the importance of the active participation of non-governmental organizations in the work of the Ad Hoc Committee and the important contribution of non-governmental organizations to the promotion of human rights and fundamental freedoms of persons with disabilities’.\textsuperscript{235} By January 2004, the Working Group had prepared the draft text of the Convention\textsuperscript{236} that served as a basis for negotiations among the Member States.\textsuperscript{237} Persons with disabilities were therefore directly involved in developing the concept and text of the Treaty.

A broad coalition of international, regional and national-level DPOs and allied NGOs formed the International Disability Caucus (IDC), which developed into the strongest civil society voice during the negotiations.\textsuperscript{238} The International Disability Alliance (IDA) played an instrumental role in establishing the Caucus.\textsuperscript{239} The involvement of NGOs in the drafting of the Convention was a remarkable

\textsuperscript{234} Resolution adopted by the General Assembly, A/RES/56/168.
\textsuperscript{235} Resolution adopted by the General Assembly A/RES/57/229, para. 2.
\textsuperscript{236} The text is often referred to as ‘Working text’ or ‘Chair’s text’.
\textsuperscript{237} See more about the negotiations in the UN archive of the CRPD at: <http://www.un.org/disabilities/default.asp?id=1423> (accessed 9 January 2013).
\textsuperscript{238} Members of the International Disability Caucus: Australian Federation of Disability Organisations; Bizchut, The Israel Human Rights Center for People with Disabilities; Canadian Association for Community Living; Center for International Rehabilitation; Council for Canadians with Disabilities; Danish Organisation of disabled people; Disability Australia Ltd.; Disabled Peoples International; European Disability Forum; Forum of people with disabilities; Forum for Human Rights of people with disabilities – Costa Rica; Fiji Disabled People’s Association; Handicap International; Inclusion International; Inter-American Institute on Disability; International Disability Convention Solidarity in Korea; Japan Disability Forum; Landmine Survivors Network; Lebanese Council of Disabled People (LCPD); National Disability Party; National Association of Community Legal Centres; National Disability Council of Netherlands; People with Disability Australia Incorporated; People Who; Rehab Group; Rehabilitation International; Support Coalition International; World Blind Union; World Federation of the Deaf; World Federation of the Deafblind; World Network of Users and Survivors of Psychiatry; World Union for Progressive Judaism.
\textsuperscript{239} The International Disability Alliance (IDA) was established in 1999 as a network of global and, since 2007, regional organisations of persons with disabilities (DPOs) and their families. See more about the work of IDA at: <http://www.internationaldisabilityalliance.org/en> (accessed 14 October 2014).
acknowledgment of the disability movement as first-hand experts and potential stakeholders in any political discussions affecting the lives of disabled people. This symbolic gesture will hopefully advance in the future and serve as an example to follow at international, national and local law- and policy-making levels. Although in other fields, such as environmental protection, the UN co-operated over a longer period with the non-governmental sector in implementing programmes, the collaboration with DPOs started just around the negotiation of the CRPD. The experiences of other movements have been a useful source for the disability movement in achieving a greater voice in the international human rights arena and in liaison with the Treaty Bodies. Yet, the adoption of the CRPD marks only the beginning of a long process to empower the disability movement to fight effectively for the realisation of human rights from an equally acknowledged and respected position as members of society.

6.1.2 ‘Participation’ in the text of the CRPD

‘Participation’ stands as a leitmotiv throughout the whole Treaty, guaranteeing inclusion at all levels of policy- and decision-making. The Convention aims to achieve participation by eliminating discrimination and removing various types of barriers (legislative, environmental, attitudinal) as mentioned in Article 5 of the CRPD. Nothing, indeed, shows the conceptual relevance of ‘participation’ better than the more than 30 explicit mentions in the text of the Convention.

Paragraph (o) of the Preamble to the CRPD emphasises that persons with disabilities should be actively involved in decision-making, policies and programmes, including those directly concerning

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242 Article 5 of the CRPD.
Legal context: Set-up of the UN CRPD

them. Moreover, Article 4(3) of the CRPD ‘General obligations’ requires involving persons with disabilities in all policy- and decision-making concerning their lives. According to Article 33(3) of the CRPD, civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring of the Convention.

A number of other thematic articles put a particular focus on the participation of persons with disabilities: Preamble (m) and (y); Article 3(c) – general principle on full and effective participation and inclusion in society; Article 9 – provide accessibility to ensure participation in all aspects of life; Article 19 – right to be included in the community; Article 24(1)(c) – right to education to enable full participation of persons with disabilities in society; Article 24 (3) – full and equal participation in education; Article 26 (1) – habilitation and rehabilitation to ensure participation in all aspects of life; Article 29 – participation in political and public life; Article 30 – participation in cultural life, recreation, leisure and sport; Article 32 (1)(a) – involving persons with disabilities in international co-operation; Article 34(4) – participation in the work of the Committee on the Rights of Persons with Disabilities.

6.2 Articles 4(3) and 33 as operationalising the participation of persons with disabilities

This section will discuss the provisions of Articles 4(3) and 33 of the CRPD on requiring States Parties to involve persons with disabilities in law- and policy-making and in monitoring the implementation of the Convention. This will help to understand better the legal provisions and framework under which the meaningful participation of persons with disabilities should be guaranteed in the State Parties of the UN CRPD.
Legal context: Set-up of the UN CRPD

6.2.1 Article 4(3) of the UN CRPD: involvement in law and policy-making

Article 4(3) of the General Obligations of the CRPD states:

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.243

Article 4(3) includes an innovative provision that opens up the space between the government and civil society by requiring States Parties to actively involve and consult closely with persons with disabilities through their representative organisations in the development and implementation of law and policies. Furthermore, Article 4(3) requires the involvement of persons with disabilities in decision-making processes that concern issues relating to their lives. This space did not formally exist before, as governing bodies were not required by international law to meaningfully involve persons with disabilities at all levels of governance.

Article 4(3) is a very important measure to compensate for the past exclusion of persons with disabilities in a quite revolutionary and challenging way to most State Parties. Yet the Convention does not give instructions on how to establish a partnership between the disability movement and the governing bodies. ‘Active involvement’ implies that persons with disabilities – including children with disabilities – are regularly present during policy-making. The term also refers to the commitment of the government to regularly involve disability organisations in high-level meetings and negotiations from the planning stages of any decision-making or policy-making process. Other prerequisites, such as the creation of new, accessible working methods, are indispensable.

Article 4(3) explicitly calls on States Parties to involve persons with disabilities and their representative organisations in the development and implementation of legislation. That would essentially

243 UN CRPD Article 4(3).
Legal context: Set-up of the UN CRPD

include all legislation that affects the lives of persons with disabilities in any way. This is a very complex provision, not only because it brings a previously marginalised group to the space where rules and norms are created, but also because effective participation requires the knowledge and ability to draft laws. Only those privileged in society to undertake tertiary education in law could obtain such knowledge.

According to Gemmill and Bamidele-Izu, the role of civil society in governance can be described in five key areas: 244

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Table 4: The role of civil society in governance

Gemmill and Bamidele-Izu contend that existing structures do not enable civil society in general to perform the aforementioned roles effectively. 245 Drafters of the CRPD intentionally incorporated a legal obligation on States Parties to ensure the active and critical role of the disability movement in governance. We chose these five categories to form the framework for assessing in the following chapters the involvement in law and policy-making processes, as they cover all satisfyingly the different areas where civil society groups can influence policy-making and its implementation. Therefore, the framework is suitable for the assessment of how organisations of persons with disabilities participate in policy- and decision-making processes.

Legal context: Set-up of the UN CRPD

(a) Example to the involving disability organisations in law development: the drafting of the Americans with Disabilities Act (ADA)

Samuel Bagenstos found that the Americans with Disabilities Act (ADA) raises interesting questions about how a social movement could affect the development of new law.\(^{246}\) The ADA was adopted in 1990 and since then has been the most influential legal instrument on disability, even affecting the drafting of the UN CRPD. The ADA is a civil rights law that prohibits discrimination on the basis of disability. Important concepts of the UN CRPD such as reasonable accommodation and accessibility are rooted in the ADA. The disability rights movement in the USA participated actively in drafting the ADA, so it can be a good example for any national disability movement to assess the crucial elements of successful involvement in law development.

Disability rights activists in the USA were influenced by the British social model of disability, and clearly ‘characterized the environmental barriers that attach disadvantage to impairments as a form of discrimination’.\(^{247}\) Although the American disability rights movement had many internal tensions and disagreements, a key point of agreement was that there is a strong need to move towards civil rights and away from welfare programmes as a response to disability.\(^{248}\) Activists on both the political left and right could find arguments for supporting such an approach.\(^{249}\) The welfare system was considered a prime example of when superficial pity or sympathy in fact ‘conceals a deeper sense of discomfort and resistance that has perpetuated the segregation and inequality of persons with disabilities’.\(^{250}\) The common


\(^{248}\) See Bagenstos (2009), p. 23.

\(^{249}\) As Bagenstos explains, from the left, people argued that welfare programmes are usually symbolical acts of governments to ‘buy off’ people instead of making fundamental changes to social relations and strive for equality and integration. From the right, activists argued that the welfare model promoted cultural dependency and eliminates individual initiatives. See: Bagenstos (2009), pp. 23–24.

achievement of the on-going grass-root protests and advocacy was to redefine and gain independence for all persons with disabilities.\footnote{According to disability rights activists such as Judy Heumann, ‘independence is the ability of people to make their own choices concerning how to live their lives, what service to receive, and how and where to receive them’.}

The economic cuts to welfare during the Reagan era were a fortunate circumstance for disability advocacy in arguing that persons with disabilities do not want to rely on this funding, but rather aim to work and earn their own money for living.\footnote{Nevertheless, the disability movement in the USA at that time was mainly composed of persons with physical and sensory impairments. Therefore, it was the voices of people who could actually work and live independently with relatively limited support that were primarily represented. Persons with severe intellectual or multiple disabilities were not considered as potential sufferers of the consequences of such conservative politics at that time.} Since the establishment of the independent living movement, persons with disabilities have raised awareness all over the United States of the exclusion of persons with disabilities and challenged societal barriers effectively. As Mayerson highlights, the ADA succeeded due to the tireless and persistent lobbying of the American disability rights movement.\footnote{Mayerson, A. (1992), ‘The History of the ADA: A Movement Perspective’, available at: <http://dredf.org/news/publications/the-history-of-the-ada/> (accessed 22 September 2014).}

Similarly to other civil rights movements, disability activists protested against injustice and discrimination for a long time before the ADA was adopted, by marching through streets, sitting in federal buildings and obstructing the movement of inaccessible buses.\footnote{Ibid.} It all started in small, ad hoc activities and eventually grew to the adoption of an enforcing legal instrument.

As Mayerson and others highlight, ‘from a legal perspective, a profound and historic shift in disability policy occurred in 1973 with the passage of Section 504 of the 1973 Rehabilitation Act’.\footnote{Ibid.} The Section explicitly banned discrimination on the basis of disability.\footnote{Ibid.}

For the first time in history, exclusion from the school system and unemployment of persons with disabilities were seen not as direct and

\footnote{The Section was modelled after previous laws which banned discrimination by federal fund recipients based on race, ethnic origin and sex.}
Legal context: Set-up of the UN CRPD

rational consequences of their impairment, but as a form of discrimination. It is unequivocal that without the advocacy and awareness-raising campaign of the disability movement, decision-makers would not have realised that. Due to the enactment of Section 504, similarly to the case of racial minorities and women, Congress acknowledged that legislation was necessary to eradicate discriminatory practices and policies.

Participation in legislation has an implication on educating the legal system on the rights of persons with disabilities and in particular on the interpretation of Section 504. In the USA, the need for litigation at the Supreme Court level was already realised in the late 1970s after the negative decision on *Southeastern Community College v. Davis*.257 As part of strategic litigation at the Court, in a later case, two NGOs with the support of 63 national and local organisations filed an *amicus curiae* brief to educate the Court on discriminatory employment policies258 and to demonstrate the great number of Americans with disabilities who support those organisations.259 The positive decision in that case and the on-going collaboration between disability activists and lawyers on Section 504 cases in the Supreme Court continued throughout the 1970s and 1980s. By building up strategic partnerships with legal experts and other important allies, and as a direct consequence of a number of legislative victories, the disability movement in fact fought for and secured the passage of the ADA.260 It is important to emphasise that during these years the disability movement gained acknowledgment for its skills, expertise and organisational skills even among members of Congress.

The involvement of persons with disabilities in the creation of the ADA happened through a number of formal and informal channels. The long-term and efficacious activism of persons with disabilities raised

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257 *Southeastern Community College v. Davis*, 442 U.S.397.
260 See also: Mayerson (1992).
Legal context: Set-up of the UN CRPD

awareness of the discrimination they suffered, and created space for a piece of legislation to be written at the highest state level. The ADA was supported not only by disability rights activists – regardless of their political preferences – but by politicians too. Bagenstos notes that the ADA, interestingly, was supported by both sides of the political spectrum, including those conservatives who at that time advocated for retrenchment on civil rights in the area of race discrimination.261 Bagenstos argues that ‘the disability rights movement had radical goals, but it used a rhetoric that seemed to have authentic appeal to conservatives’.262

6.2.2 Article 33 of the UN CRPD: involvement in monitoring the CRPD

In this section, first, we overview briefly the structural significance of involving a comprehensive monitoring provision in the CRPD, then each of the three paragraphs of Article 33 will be outlined from the perspective of the participation of persons with disabilities in the second innovative space created by the Convention. Article 33 of the CRPD, on national implementation and monitoring, complements and further expands the scope of the new space opened up between civil society and the government in Article 4(3) of the CRPD.

(a) The process of developing an inclusive monitoring system under Article 33 CRPD

Article 33 creates a new space between national human rights institutions and the organisations of persons with disabilities. This is arguably the most comprehensive provision on national-level implementation and monitoring ever included in an international human rights treaty.263 The only partially comparable example could be

262 Ibid.
Legal context: Set-up of the UN CRPD

Article 3 of the Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), which requires States Parties to designate or maintain a ‘national preventive mechanism’ (NPM). Nevertheless, Article 16(3) of the CRPD also requires that independent authorities should monitor all facilities and programmes designed to serve persons with disabilities in order to prevent all forms of violence, exploitation or abuse.

The reason behind the inclusion of Article 33, and such an explicit and binding provision affecting national implementation, was to give appropriate answer to the criticism of the UN regime and the inability of previous treaties to generate real change in people’s lives. A provision on monitoring was supported by a wide range of stakeholders from the early stages of negotiations of the CRPD. There were in fact high expectations of creating a new form of monitoring mechanism and imposing compliance at national level, in contrast to previous treaties. States had a strong willingness to learn from past mistakes and establish an innovative system. The article on monitoring was discussed at the fourth, sixth and seventh sessions of the Ad Hoc Committee (AHC).

Members of the AHC collectively supported the idea of establishing a monitoring mechanism, and most of them were inclined to have a dual system: monitoring at national and

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264 OPCAT requires that the NPM shall be independent, given due consideration to the Paris Principles relating to the status of national institutions for the promotion and protection of human rights, established within a year after entry into force or ratification of the Optional Protocol, and provided with necessary resources for the functioning. OPCAT, Article 3.

265 However, as Schulze points out, this provision is not directly linked to Article 33, leaving open all possibilities including establishment of a link to the NPM if the country ratified both the OPCAT and the CRPD. See: Schulze, M. (2014), ‘Monitoring the Convention’s Implementation’, in: M. Sabatello & M. Schulze (eds.) (2014), Human Rights and Disability Advocacy, Pennsylvania Studies in Human Rights, p. 218.

266 As a minimum standard, Brazil suggested that the monitoring mechanism of the CRPD should at least not be less effective than other Treaties.

267 The monitoring system of the core human rights treaties focuses on a written report submitted to the relevant UN Committee of experts. This group of experts invites States Parties to a ‘dialogue’ to raise further questions on the information provided in the report.

268 Initially numbered as Article 25.

international levels. Although States Parties at the time of ratification accepted their duty in implementing Treaty provisions, the complex implications of Article 33 for the domestic public administration system were probably underestimated.

At the fourth session, Mexico particularly ‘called for a specific article on both national and international monitoring mechanisms that takes into account existing mechanisms and involves civil society in deliberations’. It was a very important momentum to guarantee the involvement of organisations of persons with disabilities in developing the monitoring mechanism that would enforce the fulfilment of their human rights. Yet it seemed for a while that the issue of monitoring the new Treaty would be delayed due to on-going debate over the treaty reform process in the UN.

The Office of the High Commissioner for Human Rights (OHCHR) was asked to prepare an expert paper by the seventh session of the Ad Hoc Committee, focusing on possible improvements of the existing monitoring mechanism for the draft CRPD. The expert paper recommended, among other points, including a provision similar to the national preventive mechanism in Article 17 of the OPCAT, with explicit reference to the Paris Principle to ensure effective monitoring through independence. The paper also recommended the express mention of

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270 There were in fact more debates about international monitoring, specifically whether to create a new Treaty body or whether existing ones could fulfil the overlapping functions of international monitoring. Many States suggested somehow harmonising or linking the work of the two levels, e.g. Serbia and Montenegro, Mali, Costa Rica, and China.


272 Some countries were not sure if a separate Treaty body for the CRPD should be established before the Treaty Body Reform takes place. Others argued that the reform process will take too long, so the new Treaty should go ahead in creating its own mechanism. Many of the discussions considered the possibility of creating a unified Treaty body that would carry out the international monitoring of all UN treaties.

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persons with disabilities to play a role in the monitoring mechanism.\textsuperscript{274} The Paper furthermore indicated five key purposes that are necessary in order to achieve the objectives of monitoring.\textsuperscript{275}

From the beginning of the negotiations, there was a consensus that civil society, in particular persons with disabilities and their representative organisations, must be included in the monitoring mechanism. There were also States that wanted to give an ultimate role to NGOs in carrying out the monitoring.\textsuperscript{276}

During the fourth session, National Human Rights Institutions (NHRIs) stressed their important role in guiding monitoring bodies.\textsuperscript{277} NHRIs submitted a comprehensive proposal on monitoring at the sixth session of the AHC.\textsuperscript{278} The document included a section on establishing a ‘National Monitoring Body’ and requested explicit reference to the principles relating to the status and functioning of NHRIs.\textsuperscript{279}

The final text of Article 33 was adopted during the seventh session, incorporating the recommendations of the OHCHR expert paper. The three paragraphs of Article 33 will be explained in the following sections.

\textsuperscript{274} OHCHR, Expert paper on existing monitoring mechanisms, possible relevant improvements and possible innovations in monitoring mechanisms for a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities (2006), A/AC.265/2006/CRP.4, para. 77.

\textsuperscript{275} The first purpose is to carry out a proper diagnosis and understanding of the existing human rights situation by developing benchmarks or goals that can be assessed periodically. The second purpose is to assist States Parties in establishing effective evaluation and setting priorities. The third purpose is to establish partnership between States and rights holders, thereby creating occasions where governments can present the reasoning behind their polices and demonstrate their achievement in a transparent way. Rights holders who are affected by those laws and policies could contribute to the formulation of more effective laws. The fourth purpose is to create opportunities for capacity-building and awareness-raising to help all relevant duty-bearers, such as policy-makers, judges and lawyers, employers, teachers, social workers, and parents, to understand the content of the norms and human rights implications of their respective roles. The fifth purpose is to protect the victims of human rights violations by providing various forms of remedy. See: OHCHR Expert paper on existing monitoring mechanisms, section 2.

\textsuperscript{276} For example, Senegal at the sixth session of the Ad Hoc Committee.

\textsuperscript{277} See: Afternoon session, 23 August 2004.


As Quinn points out, the triangulation in Article 33 requires a balance of power and functions between the government, the NHRI, and civil society. The government is deemed to be responsible for ensuring and promoting the full realisation of human rights and fundamental freedoms of all persons with disabilities in line with the General Obligations of the Convention. Therefore, in line with Article 33(1) they must coordinate the implementation of the Convention across and within different departments. The second paragraph of Article 33 requires the establishment of a framework to promote, protect and monitor implementation with the involvement of the National Human Rights Institution. The third paragraph requires that organisations of persons with disabilities must be also involved in the work of the monitoring framework. Quinn argues that the triangulation of Article 33 is the engine room of the Convention that will bring the social model of disability right to power.

Article 33(1) CRPD

According to Article 33(1) of the CRPD, States Parties shall appoint one or more focal points within government for matters relating to implementation of the Convention. Focal points are therefore an

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281 Article 4(3) CRPD.
283 Countries can choose, depending on the structure of the State, to designate one focal point in the most relevant ministry for disability matters, or several focal points (sub-focal points) in different departments. Sub-focal points are often designated in federal states where responsibilities are shared between various layers of the government. See: ‘Final report of the work forum on the implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)’, organised
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issue of internal public administration and have to be formally designated.\textsuperscript{284} Gatjens provides a non-exhaustive list of requirements for the focal point.\textsuperscript{285} He highlights that, amongst other characteristics, the designated entity should be close to the central authority that issues policies and mandate to influence other government departments. Unless the government has an in-depth understanding of the paradigm shift addressed in the CRPD, neither the Ministry of Health nor the Ministry of Social Affairs would be appointed as Article 33(1) bodies. Public policy makers in health and social affairs would likely approach disability from the traditional perspective of charity. In contrast, the focal point for implementation of the CRPD must recognise the human rights of persons with disabilities and take appropriate steps to change national legislation in a holistic manner. The focal point is better placed in Ministries that have not dealt with disability in a traditionally degrading way, but could transform the social model in policy-making. The Ministry of Justice seems a better choice to introduce the rights-based approach to disability.\textsuperscript{286} Despite that rationale, most States Parties designated the Ministry of Health\textsuperscript{287} or a Ministry dealing with Social Affairs, Labour, Social Protection or a fusion of these fields.\textsuperscript{288}

Even if the focal point remains with a designated Health or Social Affairs department, it is very important that the staff of the designated entity gain a comprehensive knowledge of the social or human rights model of disability. This would ensure they incorporate the main principles of the Convention in their policy-making activities. Adequate

\textsuperscript{*} by the Belgian Presidency of the Council of the European Union and the European Commission, Brussels (2010).
\textsuperscript{286} For example, Ecuador designated the Ministry of Justice and Human Rights, and Australia designated the Attorney General.
\textsuperscript{287} In Sweden the Ministry of Health and Social Affairs is designated as focal point. In Italy the Ministry of Labour, Health and Social Policies is designated as focal point.
\textsuperscript{288} For example, the Czech Republic, Bulgaria, Estonia, Denmark, and Austria.
resources and some engaged staff members are necessary for the focal point to effectively and continuously perform its duties in implementing the CRPD. The requirements of Article 4(3) provide the framework for engagement between state officials and representatives of the disability movement at the early stages of policy development. The State should involve persons with disabilities in the development of national action plans, providing clear benchmarks and target goals.

It is not an obligation, but Article 33(1) also mentions the establishment of a co-ordination mechanism, which aims to facilitate co-operation between different layers and sectors of public administration. It is very important in order to avoid adopting isolated measures in different governmental departments.

The focal point or co-ordination mechanism could further set up advisory boards or councils to include civil society, in particular disability organisations, in their work. As de Beco and Hoefmans define, councils are a ‘privileged consortium of DPOs and other non-State actors as well as ministerial representatives towards which government is committed to regularly consult, inform and provide feedback following the consultation’. Advisory boards could be one of the channels to involve persons with disabilities in line with Article 4(3), but the hierarchy, role and place of control of these committees should transfer from a consultative relation towards a partnership between the government and civil society.

**Article 33(2) CRPD**

The second paragraph of Article 33 of the CRPD requires states parties to:

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[M]aintain, strengthen, designate or establish within the state party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, states parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.290

According to the Convention, therefore, a framework shall be designated including one or more independent elements in order to ensure the accountability of States and guarantee the impartial monitoring of their performance in implementing their Treaty obligations. The thematic study published by the OHCHR identifies three criteria for an Article 33(2) framework:291

a) The framework must include one or more independent mechanisms taking into account the Paris Principles.

b) The framework should be able to carry out all the three distinguished functions: promotion, protection and monitoring of the implementation of the Convention.

c) Persons with disabilities and their representative organisations shall be involved, and participate fully in the monitoring framework (in line with Article 33(3) CRPD).

a) Paris Principles’ compliant independent element

The explicit mention of the Paris Principles in the text of Article 33(2) of the CRPD applies to States that have an established NHRI to give a role as independent element to this organisation(s) in monitoring the CRPD. NHRIs are established in principle to assure States’ compliance

290 Article 33(2) CRPD.
with their international legal obligations\textsuperscript{292} and to serve as the bridge between international norms and local implementation.\textsuperscript{293} In UN parlance, NHRIs are broadly defined as bodies ‘established by a government under the constitution, or by law or decree, the functions of which are specifically designed in terms of the promotion\textsuperscript{294} and protection\textsuperscript{295} of human rights’.\textsuperscript{296} NHRIs are at the intersection of the State and civil society, and have a mandate to either create or signal major political changes.\textsuperscript{297} In order to make a real impact on States’ compliance with their human rights obligations, NHRIs must have formal independence, sufficient resources and close relations with civil society.\textsuperscript{298} Independence is guaranteed through the funding provisions in the Paris Principles that enable NHRIs to have their own staff and premises and carry out their activities without any financial control by the government.\textsuperscript{299}

There are different approaches to conceptualising NHRIs,\textsuperscript{300} the most common views, in line with the accreditation process of the


\textsuperscript{293} Cardenas (2012).

\textsuperscript{294} Promoting this function of the NHRI aims to increase awareness of human rights norms by education or legitimising human rights.

\textsuperscript{295} Protection requires more assertive focus and the remedying of human rights violations by investigating abuses, processing complaints and confronting rights violators.


\textsuperscript{298} Cardenas (2012), p. 41.

\textsuperscript{299} Paris Principles: ‘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.’

\textsuperscript{300} Currently six types of NHRIs exist in the world: human rights commissions; human rights ombudsman institutions; hybrid institutions; consultative and advisory bodies; institutes and centres; and multiple institutions.
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International Coordinating Committee (ICC),\textsuperscript{301} still only consider national human rights commissions\textsuperscript{302} and human rights ombudsman institutions\textsuperscript{303} as NHRIs.\textsuperscript{304}

The UN Paris Principles provide the benchmarks for NHRIs to be accredited and define the level at which they can participate.\textsuperscript{305} The Paris Principles include sections on the competences and responsibilities of NHRIs, the composition and guarantees of independence and pluralism, the methods of operation, and finally additional principles on the status of commissions with quasi-jurisdictional competence.\textsuperscript{306} Regarding the collaboration between NHRIs and persons with disabilities in line with Article 33 of the CRPD, it is important to note that the Paris Principles require that the election or appointment of members of the NHRI must guarantee the pluralistic representation of social forces, including NGOs,\textsuperscript{307} universities, NGOs, universities, and institutions.

\textsuperscript{301} The ICC keeps a record on the population data of NHRIs and carries out accreditation based on a three-level system: ‘A’ status institutions demonstrate compliance with the Paris Principles, which implies voting right and full participation in the international and regional work and meetings of national institutions. ‘B’ status institutions do not fully comply with the Paris Principles, so they can only participate as observers in the work of national human rights institutions. ‘C’ status institutions do not comply with the Paris Principles, so they do not have any rights or privileges with the ICC. More information on the work of the International Coordinating Committee (ICC) is available at: <http://nhri.ohchr.org/EN/AboutUs/Pages/RolesTypesNHRIs.aspx> (accessed 22 August 2013).


\textsuperscript{303} Ombudsman offices are established by law and mainly tasked with impartially monitoring maladministration and unfairness on the basis of public complaints received.

\textsuperscript{304} Reif (2012), p. 73.

\textsuperscript{305} The Principles were devised in 1991 at a workshop that was organised by the UN Centre for Human Rights. See: ’Principles relating to the Status of National Human Rights Institutions’, UNGA Res. 48/134, UN Doc.A/RES/48/134 (1993), Art. 1.

\textsuperscript{306} As Carver highlights, four of these competences explicitly relate to the harmonisation of international human rights standards to domestic law. See: Carver, R. (2010), ’A New Answer to an Old Question: National Human Rights Institutions and the Domestication of International Human Rights Law’, Human Rights Law Review, 10, p. 11.

\textsuperscript{307} Those that are responsible for human rights and efforts to combat racial discrimination, trade unions, concerned social and professional organisations, for
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government departments, Parliament, and trends in philosophical or religious thought.308 NGOs therefore are supposed to play a role in the membership of NHRIIs and directly influence their work in promoting and protecting human rights. Since NHRIIs deal with a broad range of human rights issues, and the methods of selecting partner NGOs is not well defined, organisations of persons with disabilities might be easily neglected.

Nevertheless, the section on ‘Methods of Operations’ in the Paris Principles particularly calls on NHRIIs to develop relations with non-governmental organisations with special regard to ‘physically and mentally disabled persons’.309

b) Three distinct functions: promotion, protection, monitoring

Article 33(2) of the CRPD makes a clear distinction between three dimensions – promotion, protection and monitoring – where tasks need to be carried out in the implementation of the CRPD. The Thematic study of the OHCHR provides the list of activities under these tasks.310

Promotion includes a wide range of activities, such as scrutiny of draft legislation to ensure compliance with the obligations under the Convention, or scrutiny of existing legislation, regulations and practices. Promotion of the CRPD should also happen through various awareness-raising campaigns, public events, research, and human rights education of the wider public as well as targeted audiences. Promotion aims to increase awareness of disability rights that could directly eliminate prejudice against persons with disabilities.311

example, associations of lawyers, doctors, journalists and eminent scientists (Paris Principles).
308 Paris Principles.
311 State Parties of the CRPD also have obligations under Article 8 of the CRPD to raise awareness throughout society of the rights and dignity of disabled people, fostering at all levels of education and through the media the abilities and contributions of disabled people to society, and combating prejudices and harmful practices towards them.
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De Beco and Hoefmans argue that promotion in fact does not require the same level of independence as the other two functions, protection and monitoring. They suggest that promotional tasks should be shared between various actors outside the monitoring framework and potential non-independent elements within the framework, such as organisations of persons with disabilities.\(^{312}\)

The function of ‘protection’ requires a lot more independence than promotion, as it is undertaken against State authorities.\(^{313}\) Protection covers investigation and examination of individual and group complaints, litigation, conducting of enquiries, issuance of reports, and filing \emph{amicus curiae} briefs. Protection should ensure that human rights violations are stopped and legal remedy is made.\(^{314}\) Protection requires legal expertise and a specific mandate to represent someone in court or to deal with complaints with quasi-judicial power. For instance, \emph{amicus curiae} briefs provide the court with additional useful information on a case that requires legal knowledge in terms of substance and form of legal submissions. Protection is an extremely important tool for human rights advocacy in order to bring human rights violations before the court and have an increasing number of legally binding decisions that could form the base of case law when enforcing CRPD implementation. Mostly, equality bodies and Ombudsmen carry out the functions of protection. These bodies do not necessarily have a human rights mandate, but could be easily involved in the Article 33(2) framework.

Monitoring aims to assess the implementation and adaptations of the provisions of the CRPD at domestic level.\(^{315}\) Monitoring includes the collection of data and information on human rights violations\(^{316}\) and the

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\(^{312}\) De Beco & Hoefmans (2013), p. 46.
\(^{313}\) Ibid., p. 47.
\(^{314}\) See also: Ibid.
\(^{316}\) Article 31 of the CRPD also requires States to collect data and statistics to ensure an accurate assessment of the situation of persons with disabilities.
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development of indicators and benchmarks to measure progress.\textsuperscript{317} Monitoring also involves visiting places where violation often occurs, and contributing to State Reports to the UN Committee. Monitoring helps to alert States about human rights situations and violations and to develop measures that can prevent further violations.\textsuperscript{318} In line with the recommendations of international DPOs, monitoring should have a ‘twin-track approach’. That is, on one hand disability should be mainstreamed in all policies and programmes, and on the other hand disability-specific programmes must be developed to implement specific obligations of the CRPD.\textsuperscript{319} As de Beco and Hoefmans suggest, considering that monitoring potentially involves criticism of State authorities, it should be exercised independently with great distance from the State.\textsuperscript{320}

c) Involvement of persons with disabilities (Article 33(3))

According to Article 33(3) of the CRPD, civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process. The word ‘shall’ leaves no doubt about the binding nature of this provision. This third element of the triangulation makes Article 33 truly innovative, by involving in the monitoring process the voice of civil society and in particular persons with disabilities. The NHRI is still required to fulfil the role of the independent mechanism in the framework, but the activities are enriched by the collaboration with civil society. Thus, Article 33 even goes beyond providing detailed arrangements on the implementation and monitoring of the Convention to the governing bodies and the public administration machinery. It requires new forms


\textsuperscript{318} See: De Beco & Hoefmans (2013).


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of collaboration between NHRIs and the organisations representing the disability movement. The provision on formal collaboration with the human rights system creates the second new space for the disability movement to become agents of change and tackle oppressive practices. The demands of Article 33 on independent monitoring symbolise a new stage in the relationship between disability groups and mainstream human rights organisations, which has been strained in the past.321

DPOs that carry out monitoring with the independent mechanism must have great understanding of the provisions of the CRPD and of the principles of human rights monitoring in general. De Beco notes that even financial help might not result immediately in equal capacity to deliberate, due to long-term exclusion and inequalities.322 According to the OHCHR, capacity building of DPOs indeed forms part of and complements the monitoring work.323

As the UN guideline highlights, monitoring of human rights of disabled people must have a cross-disability and cross-society focus and, for instance, involve among the monitors disabled people from all genders, socio-economic backgrounds, types of disabilities,324 age groups, and ethnic groups.325 Schulze highlights that the obligation on national monitoring requiring the active participation of civil society sets a new standard and challenges monitoring at national level in general.326

Besides the abovementioned requirements, there are two additional criteria that should be considered when designating an Article 33(2) CRPD framework. Although these are not explicitly required in the text

321 Quinn (2009b).
325 Ibid.
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of the Convention, both are important to ensure the effective operation of the monitoring framework.

d) Formal designation

The monitoring framework should be formally designated by the government to acknowledge and legitimise its future operations. A formal designation would guarantee that the governing body takes into consideration the critical observations of the framework during implementation. A formal designation would also help to avoid any future confusion over the composition of the framework and to clarify the exact roles member organisations should play.

e) Financial resources to the framework

Systematic monitoring is a great workload, and actors involved in the framework must dedicate significant resources to fulfil their roles. Ideally, therefore, funding is provided for the framework to carry out the tasks under promoting, protecting and monitoring the implementation of the CRPD. It is important to emphasise that the continuous monitoring of CRPD implementation covers a broad range of areas including employment, education, accessibility, political participation, culture, and health, and involves different actions such as assessing legal reforms, litigation, developing indicators, collecting data and writing reports or analysis. The generous annual budget that the National CRPD Monitoring Body in Germany receives from the Federal Ministry of Labour and Social Affairs illustrates well the extent of the necessary resources.\textsuperscript{327} In countries with a worse economic situation, it will present a great challenge to invest that much money in monitoring disability rights and to allocate funding for solving the discovered inequalities with effective and sustainable programmes. The task to

\textsuperscript{327} The German Institute for Human Rights receives about €430,000 per annum to carry out tasks under promoting, protecting and monitoring the implementation of the CRPD. More information is available at: <http://www.institut-fuer-menschenrechte.de/en/monitoring-body.html> (accessed 9 September 2013).
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establish a sustainable and independent framework must not be neglected on the base of financial concerns. Nevertheless, the NHRIs that serve as an independent mechanism to the CRPD will not be able to reallocate funding to this activity from other areas of work, so their budget guaranteed by law must be increased sufficiently to cover the mandate under the CRPD.

Therefore the following framework will be applied in later sections of the thesis to assess whether states parties are compliant with the requirements of the CRPD on the monitoring mechanism:

![Diagram showing 5 criteria to assess the compliance with Article 33 CRPD](image)

**Figure 7**: 5 criteria to assess the compliance with Article 33 CRPD

6.3 The shift to processes thinking – plugging the gap between international and domestic law

As Goodman and Jinks emphasise, ratification is not the ‘magic’ moment of human rights norms, but it is a point in the broader process of
Legal context: Set-up of the UN CRPD

It has long been well known that a considerable gap remains between the aspirations of the international human rights regime, and actual achievements. Stammers refers to a deep crisis in the legitimacy of human rights and the continuing dismissal of human rights and human rights activism. This section provides a link between the implementation gap in international human rights law and the CRPD, and interprets the provisions in Articles 4(3) and 33 of the CRPD as potential tools to narrow this gap in the context of disability. The section expands on the dual approach of impact and process thinking to ensure that assessment of the implementation of the UN Convention will reflect both functional and structural changes.

The Office of the High Commissioner for Human Rights has launched several initiatives to ensure the effective future implementation of UN treaties in the States Parties. Nevertheless, the UN intends to build a much stronger international monitoring system. Narrowing this gap and improving the transformation of treaty obligations into practice are still among the main challenges for international legal and policy actors.

The following table summarises the provisions of the CRPD on the participation of civil society in the two newly opened spaces: in liaison with the government during law, policy-making and decision-making processes, and in relation to the Article 33 monitoring framework. Article 4(3) includes the voice of persons with disabilities in transforming the obligations of international law into domestic legislation, programmes and policies. Article 33 ensures that the voice of persons with disabilities is heard also during the monitoring process of the Convention. The CRPD therefore envisages a dual role for organisations of persons with disabilities in the process of change and in checking the reality at domestic level.

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<th>Guarantees for civil society</th>
<th>Affected other party</th>
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<tr>
<td><strong>Article 4(3) CRPD</strong></td>
<td>Voice in the process of change</td>
<td>Government</td>
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<tr>
<td><strong>Article 33(3) CRPD</strong></td>
<td>Voice in reality check</td>
<td>NHRI</td>
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Table 5: Dual model on the participatory provisions of the CRPD and their affects

Both Article 4(3) and 33 of the CRPD include important provisions to narrow the implementation gap and to stimulate change in the operations of States and the human rights regime. Through these guarantees, the Convention aligns with the domestic level and could become a real instrument for persons with disabilities. The organisations of persons with disabilities are expected to use the participatory provisions for advocacy purposes, as the provisions entitle them to act as a channel between policy-makers and the human rights regime in enforcing Treaty provisions. Furthermore, the CRPD will likely have a future impact on the implementation of other human rights treaties. As Quinn argues, the implementation and monitoring regime introduced by the disability Convention has the potential ‘to trigger real political change where it matters most – within States Parties themselves’.331

According to Goodman, Jinks and Woods, the implementation gap cannot be narrowed or closed with the tools of traditional legal and policy analysis.332 They suggest mainstreaming human rights as a subject of interdisciplinary research including politics, economics, sociology, communications, and psychology to understand the behavioural and organisational patterns of the regimes under observation.333 That is the main reason why this thesis takes an interdisciplinary approach when exploring the criteria of good practice in achieving meaningful participation of persons with disabilities and their representative organisations.

333 Ibid.
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Along with human rights academics, public policy literature discuss the great dissatisfaction with how ineffective are policies and government initiatives in addressing and solving social problems. Scholars have called this gap the ‘missing link’ in describing the insufficiency of policy formation and policy outcomes. The implementation gap cannot therefore be restricted to international law, but should be understood as a general problem in the domestic policy process. It raises questions over whether the failure to implement human rights law lies in domestic policy implementation structures, or in the lack of effective provisions on implementation in the text of international law. Gaps could probably be found at both levels, and improvements should be carried out as parallel processes in national policy cycles and in international human rights law development. Despite their legally binding nature, international human rights treaties still have a weak enforcing power. Having said that, Article 33 of the CRPD is potentially a very important tool to improve the implementation and monitoring of international human rights provisions, and to provide a solid reference to governments to strengthen their domestic policy processes effectively. With the incorporation of such detailed provision, the CRPD has great potential to overcome past weaknesses of other UN treaties by providing more detailed guidance on implementation. Drafters of the CRPD could succeed in seeing the Convention move beyond representing solely a normative framework to offer innovations for national monitoring.  

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335 As Quinn notes, drafters of the CRPD reverted to a quite typical international monitoring model, but managed to create an innovative national monitoring mechanism. See: Quinn (2009b), p. 225.
Policy context

7. Policy context

This section will focus on the implementation of the legal provisions of the CRPD in national law and policies. First, we provide some examples on how States parties implement the five main requirements by presenting the data that was collected during phase 2 of the empirical research for this purposes. This will give us a first glimpse to understand the current situation in some EU Member States and describe challenges around implementing Article 4(3) and 33 of the CRPD. Then we will discuss and evaluate the comments and recommendations of the UN Committee on Article 4(3) and then 33 of the CRPD.

7.1 Policy implementation assessment from the grass-root level – implementing Article 4(3) and 33 in some EU Member States

In the following sections, we give a brief overview on how the organisations of persons with disabilities are currently included in policy and decision-making processes. We will apply the 5 categories of Gemmill and Bamidele-Izu as the framework for assessing the various roles that civil society organisations can play in governance. Due to anonymity reasons, the civil society organisations that provided the information would not be named, but only the country of their origin will be mentioned. All the responding organisations were the secretariats of national associations of organisations of persons with disabilities, thus the views reflects better the opinion of the disability movement as such, if a single NGO was responding to the questionnaire.
Policy context

7.1.1 Article 4(3) CRPD

(a) Information collection and dissemination

In Denmark, at local level, all municipalities are obliged to establish disability councils, and Disabled People’s Organisation Denmark (DPOD) has the right to delegate members to these councils, who regularly provide the Council with data and information of the situation of persons with disabilities.336

In Sweden the Swedish Disability Federation (HSO)337 and the Swedish Federation Human Rights for Persons with Disabilities, delegate representatives to the government disability forum led by the Minister for Children and Elderly.338 This advisory forum meets a few times a year to gather information for policy-making, but it does not directly affect decision-making.339

(b) Policy development consultation

In Denmark there is no mechanism of formal representation in decision-making, but the disability movement is engaged in drafting almost all kinds of policies affecting persons with disabilities. They are not involved in the preparatory phases of legal review, but can participate from very early stages to discuss issues relevant to the lives of persons with disabilities. In Denmark the political system is quite open, and legislators consider the organisations of persons with disabilities as collaborative partners. DPOD mentioned the following channels through which they are involved in the legislative process to

336 DPOD was established in 1934 as a national umbrella organisation of 32 national democratic organisations of persons with disabilities. It is a member of the EDF. See more about DPOD at: <http://www.disability.dk/> (accessed 7 November 2014).
337 The Swedish Disability Federation represents 39 disability NGOs and is a member organisation of the EDF. See more about them at: <http://www.handikappforbunden.se/> (accessed 10 November 2014).
338 HSO delegates eight representatives and Equally Unique delegates two.
339 The Advisory body is chaired by the minister responsible for disability policy, and includes state secretaries from the Ministries of Social Affairs (3), Employment (2), Enterprise (2), Education (2), Justice (1) and Culture (1).
implement the CRPD: informal contacts, formal contacts, meetings with civil servants, meetings with ministers, meetings with members of Parliament, writing bilateral letters, and using the mass media.

In **Finland**, VANE works closely with the Finnish Ministry of Social Affairs and Health. The Finnish Disability Forum[^340] and the Centre for Human Rights of Persons with Disabilities (VIKE[^341]) also represent persons with disabilities in policy- and decision-making.

In **Malta**, the Malta Federation of the Organisations of Persons with Disabilities (MFOPD) gets no opportunity to participate in policy- and decision-making. It has repeatedly expressed its interest in becoming a member of the Civil Society Committee of the Malta Council for Economic and Social Development Act or the National Commission Persons with Disabilities, which is the advisory board for the government on disability issues in policy-making. MFOPD was refused permission to take part in these organisations, and receives no funding from the State to maintain its operations as the representative organisation of persons with disabilities.

In **Sweden**, HSO has raised the issue of the role of disability NGOs in governance several times with decision-makers. The government acknowledged that disability organisations were not provided with the opportunity to influence the development of the National Disability Policy Strategy 2011–2016, and was excluded from assessing its implementation as well.

In **Austria**, the Austrian National Council of Disability Associations (ÖAR) represents persons with disabilities in policy- and decision-making, but the umbrella organisation does not include all Austrian DPOs[^342]. The focal point for implementation of the CRPD is the

[^340]: This is an umbrella organisation of persons with disabilities that represents 320,000 disabled people through its 28 member organisations. The Finnish Disability Forum is a member of the EDF.
[^341]: VIKE is a non-profit non-governmental expert body which promotes the human rights of persons with disabilities.
[^342]: The Österreichische Arbeitsgemeinschaft für Rehabilitation (ÖAR) is the umbrella organisation of the Austrian Disability Associations and comprises 78 member organisations representing 40,000 persons with disabilities. ÖAR is a member of the EDF. See more at: <http://www.oear.or.at/> (accessed 10 November 2014).
Policy context

Federal Ministry of Social Affairs, Labour and Consumer Protection (BMASK), which consult DPOs on a regular basis. ÖAR is represented in most committees as an observer, and its participation is merely consultative instead of co-operative. When it comes to developing legislation, ÖAR is systematically involved in preparing and reforming legislation. For instance, ÖAR was strongly involved in preparing the Federal Disability Equality Act and the National Action Plan on Disability. Furthermore, it has to be informed and consulted at the preparatory stage by all ministries, and makes statements on new legislation. Before issuing a statement, ÖAR contacts its member organisations in order to reach a consensual opinion. This ensures that ÖAR’s statements are supported by 78 member organisations and hence can be considered representative.

The Centre National d’Information et de Rencontre du Handicap from Luxembourg emphasised that decision-makers and especially high-level administrations are not used to having a ‘dialogue’ with any users, and that they need to learn that dialogue will become a growing and unavoidable prerequisite for correct decision-making.

In Cyprus, the Cyprus Confederation of Organisations of Disabled Persons (KYSOA) is representing persons with disabilities in policy-making processes and they are also member of the advisory body under the Ministry of Labour. Their involvement is considered fairly tokenistic as most of the time the conclusion is in line with what the ministry initially and proposed and could not be challenged by other stakeholders.

In Germany, the umbrella organisation of persons with disabilities are involved through hearings, where they can address their opinion and claims, however the opinions are not always considered in the final outcomes.
Policy context

(c) Policy implementation

In Finland the National Council on Disability (VANE) is the co-operative organisation for authorities that closely follows decision-making, gives statements, and promotes the real implementation of the human rights of persons with disabilities.

The Organisation of Disabled People in Iceland is involved in most committees that deal with issues of disabled people in ministries and other public agencies. It feels that its views are taken into consideration, but implementation does not always follow the best interests of persons with disabilities. The Organisation of Disabled People in Iceland is part of the workgroup to review the protection of the rights of persons with disabilities and propose to the Ministry of Welfare the preferred focal point and co-ordination mechanism under Article 33(1), the composition of the independent mechanism under Article 33(2), and how DPOs shall participate in the monitoring process.

(d) Assessment and monitoring

In Denmark, it was highlighted as one of the most positive aspects that members of the Parliament often contact DPOD for advice on disability-related matters, which is a good sign of being acknowledged as experts in monitoring the implementation of laws and policies.

As the Finnish Association of People with Physical Disabilities emphasised, a great way to increase the openness of State actors towards DPOs is to hold training for them based on the experience of disabled people, and to publish toolkits on the implementation of the CRPD.

(e) Advocacy for justice

From Cyprus, the European Social Forum Cyprus (ECFC) mentioned a number of internal problems in the disability movement in Cyprus. They complain to the government about not being invited to
Policy context

discussions before decisions are made, but they try to achieve meaningful involvement though mass media and other channels. A representative organisation of persons with psychosocial disabilities mentioned the lack of their involvement in policy- and decision-making and the inaccessibility of the work of the focal point and the coordination mechanism in their country.

In Luxembourg, disability organisations also emphasised that many persons with disabilities are not yet ready to contribute efficiently to improving services and environments to make them more user-centred and accessible. Since most DPOs work on a voluntary basis, there is a lack of human resources that the government should know and realize while trying to involve disability organisation. Representivity could be improved if the government was investing in the capacity building of DPOs.

7.1.2 Article 33 CRPD

(a) Paris Principles’ compliant independent element

In Austria the state established the Independent Monitoring Committee as a new body for monitoring the implementation of the Convention under Article 33, and four of its seven members are representatives of DPOs. Although the body is not compliant with the Paris Principles, it operates with the effective involvement of persons with disabilities. ÖAR was consulted by BMASK on planning the establishment of the Independent Monitoring Committee, and assignments of the members of the Committee are in line with ÖAR’s recommendations.

(b) Involvement of persons with disabilities

Denmark is probably one of the good examples of maintaining close collaboration between the NHRI and the organisations of persons with disabilities. In compliance with the Paris Principles, DPOD is represented on the board of the Danish Institute for Human Rights,
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which is appointed as independent mechanism to the CRPD. Moreover, five out of the eighteen members of the Article 33 framework are from DPOD. They meet once or twice a year with the focal point, which is the Ministry of Social Affairs, to discuss the issues. DPOD evaluates it as a great achievement that they have an established structure, which can be effective if it has qualified staff and sufficient resources.  

In Sweden, the Swedish Disability Federation is not represented in the independent mechanism under Article 33 of the CRPD. HSO therefore criticised the government for not involving DPOs when it prepared proposals for monitoring. However, the structure of the monitoring mechanism was not finalised at the time of data collection. The Ministry of Social Affairs as focal point has also been criticised for not involving DPOs in its activities on CRPD implementation as well as the Swedish Agency for Disability Policy Coordination as the coordination mechanism. The biggest problem in Sweden is that involvement happens mostly on an ad hoc basis and DPOs are not given stable funding to play a meaningful role in promoting and monitoring CRPD implementation.

In Italy, the National Observatory on the Conditions of Persons with Disabilities is assigned to promote and monitor the implementation of the CRPD as well as to collect data and prepare the report for the UN CRPD Committee. In this Observatory, 14 of the 40 members are associations representing persons with disabilities.

According to ESFC, the Cyprus Confederation of Organisations for Disabled People (KYSOA) is involved in policy-making and in the Article 33(2) monitoring mechanism, but it does not include all relevant NGOs.  

343 For instance, DPOD received approximately €120,000 from the state to finance the shadow report drafted by civil society to the UN CRPD Committee.
344 The Cyprus Confederation of Organisations for Disabled People (KYSOA) is a member of the EDF, so we consider with great concern the remarks of the European Social Forum on the lack of their legitimacy to represent persons with disabilities. ECFC claims that KYSOA receives €300,000 per year, which undermines its independence. See more about KYSOA at: <http://www.kysoa.org.cy/kysoa/page.php?pageID=3> (accessed 10 November 2014).
Policy context

In Austria, ÖAR seeks more central involvement in the operations of the Committee.

(c) Formal designation

Since Finland has not yet ratified the CRPD, there is no Article 33 monitoring framework established. However, VANE, VIKE and the Finnish Disability Forum are involved in the ratification group for the CRPD since 2011 along with representatives of different ministries. The group is writing legislative proposals on how to integrate the Convention into Finnish legislation. With regard to Article 33, DPOs aim to persuade States to create a new type of commissioner on disability who will independently monitor the implementation of the Convention.

In Cyprus, the monitoring mechanism was designated without any broad discussions with civil society.

The Belgian umbrella organisation of persons with disabilities addressed the complex situation in federal states when establishing the focal point(s) and the independent monitoring body of the CRPD. In Belgium the Centre for Equal Opportunities and Opposition to Racism has been appointed as the independent mechanism under Article 33(2) CRPD.

(d) Financial resources to the framework

In Denmark, Disabled People's Organisation Denmark has received approximately €120 000 from the government to cover the costs of coordinating and drafting the Alternative report of civil society for the review of Denmark in front of the CRPD Committee. This generous allocation of funding allowed the umbrella DPO to carry out the additional workload of drafting a comprehensive and systematic report on the implementation of the Convention.

345 According to the Finnish government and Finland's Disability Policy Programme (2010–2015), the UN CRPD will be part of Finnish legislation by 2016.
Policy context

In Austria, ÖAR criticises the lack of budget for the Monitoring Committee.

7.1.3 Input from European umbrella DPOs on the criteria to be effectively involved in policy and monitoring processes

In this section, we provide summaries from the questionnaires on matters that the umbrella organisations marked as necessary conditions to improve their involvement to policy and decision-making processes. The remarks made here will be later applied in setting up the criteria of meaningful involvement for the organisations of persons with disabilities.

Disabled People’s Organisation Denmark highlighted that in the ideal case, the State recognises and accepts the opinions of persons with disabilities and provides DPOs with education, financial support, transparent and accessible communication and information. Education should focus on democracy and techniques to improve representativeness of DPOs. There should be transparency in the choice of organisations involved and in the process by which candidates are nominated. DPOD defines necessary knowledge, sufficient resources, adequate complaint procedures and advisory services as prerequisites of active and effective involvement of civil society.

The Finnish DPO argued that it is very important to include DPOs in the political and legislative processes from the very beginning, as according to the UN CRPD Committee hearings at the end of the processes are already too late. It also suggested that persons with disabilities should be more involved in administration as experts at every level in order to mainstream disability. Furthermore, voting rights in the co-ordination group of in-home services for the Finnish Disability Forum would be necessary to ensure their formal influence on decision-making. In order to achieve effectiveness in policy-making, adequate resources and volunteers are also necessary. Persons with disabilities can best influence decision-making through good contacts and networks to politicians. Nominating persons with disabilities to the
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independent monitoring framework as experts and workers in the advisory board is an absolute prerequisite to ensure the active voice of DPOs during monitoring of the Convention.

According to the Maltese experience, effective involvement should happen throughout the whole process and by giving voice to all stakeholders concerned. It is unsustainable for the umbrella organisation of persons with disabilities to get no funding or invitation from the government to be consulted on disability matters. The government-funded National Commission Persons with Disabilities should keep MFOPD informed on the on-going processes at national and European level and further develop collaboration.

The Swedish Disability Forum argued that involving DPOs before decisions are made is a key element of civil society involvement. DPOs should then participate in the whole process when planning, introducing and monitoring the implementation of the CRPD. Furthermore, representatives of DPOs should receive financial compensation and collaborate with the independent monitoring mechanism. The Swedish Disability Forum highlighted the importance of developing indicators (structural, process and outcome indicators) that could monitor the implementation of the Convention. Other factors that were mentioned include education and competence building (both for DPOs and the public), transparent communication, allowing DPOs to set the agenda, and filling leading positions in public administration with representatives of the disability movement. When involving representatives of the disability movement in decision-making, the State must make sure they have the mandate and competence to make decisions on behalf of the disability community. Nevertheless, involvement should be a standard procedure on a regular basis with continuous evaluation.

As ÖAR highlighted, in Austria it would be necessary for the government to start considering disability as a crosscutting issue and not merely as a social issue. As many NGOs as possible should be involved proactively in political processes. According to the ÖAR,
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transparency and traceability, equal opportunities and shared responsibilities are key factors of effective participation. Consultations must provide time for every group to express itself, there must be room for discussion to take into account the diverse opinions, and the 'know-how' of NGOs should be remunerated by the decision-makers. Capacity building, empowerment, education and financial independence are key factors in achieving sustainability in the involvement.

As the DPO from Luxembourg noted, it is important to select priorities and to make sure that disabled people are actually able to follow and participate in the processes.

An organisation representing persons with psychosocial disabilities suggested that the State should define a per-head figure for the advocates who participate in the implementation and monitoring of the CRPD.

7.2 Perspectives of the UN Committee on the implementation of Articles 4(3) and 33 of the CRPD

The Concluding Observations (CO) issued by the UN Committee formally close a chapter of the reporting cycle. They include immediate feedback to States Parties on their on-going implementation, articulating the most important concerns about human rights violations. The Concluding Observations also include recommendations to States Parties on how to improve implementation, and emphasise those obligations under the treaty that aim to tackle current human rights violations. The Concluding Observations are adopted in a closed meeting of the Committee, but are later made publicly available to any interested department, organisation or individual.346

346 Concluding Observations of the CRPD Committee always follow a similar structure: beginning with the 'Introduction', then highlighting the 'Positive aspects' of the implementation, followed by the main substantive part focusing on 'Principal areas of concerns and recommendations', and finally explaining some technical details on the follow-up and dissemination of the Concluding Observations.
Policy context

Despite the fact that States Parties are requested to follow up the concerns of the Committee, the Concluding Observations are soft laws and barely have enforcing effect on governments. Concluding Observations should function as a catalyst of change in implementing international human rights provisions in a more effective and treaty-compliant way.

At the time of writing the thesis, the CRPD Committee has issued thirteen Concluding Observations in consideration of the State Reports of the following States: Tunisia, Spain, Peru, Argentina, China, Hungary, Paraguay, Austria, Australia, El Salvador, Sweden, Costa Rica and Azerbaijan.

7.2.1 Observations of the CRPD Committee on implementing Article 4(3) CRPD

This section will focus on the implementation of Article 4(3) of the CRPD and present the recommendations of the CRPD Committee in this regard. The issue of involvement in the development of law, policies and programmes is very complex, and we do not expect the Committee to provide very detailed recommendations on how to achieve it. However, it is important to see what kind of efforts States Parties made to step beyond diplomatic gesture and strike for an inclusive society by ensuring the full participation of persons with disabilities.

Tunisia was the first State to go through the reporting process to the CRPD Committee. In the Concluding Observations on the State Report of Tunisia, the Committee recommended that the State Party support and encourage the creation and capacity-building of the representative organisations of persons with disabilities. These organisations shall be involved in the design and implementation of

347 The Chapter was drafted in August 2014.
349 Concluding Observations of the Committee on the Rights of Persons with Disabilities, Tunisia, CRPD/C/TUN/CO/1.
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policies and programmes in line with Article 4(3) of the CRPD. The Committee particularly urged Tunisia to involve the voices of disabled people in the Constitutional Council during the drafting of the new Constitution.

With regard to Spain, the Committee expressed its regret that no information is available on the meaningful participation of persons with disabilities ‘at the regional level in designing and evaluating the implementation of legislation, policy and decision-making processes and on the participation of children with disabilities at all levels’. The Committee therefore recommended that Spain take specific measures that ensure the active participation of the representative organisations of persons with disabilities.

In the Peruvian report, the Committee acknowledged some positive developments (e.g., the establishment of the Permanent Multi-Sectoral Commission and the National Council for the Integration of Persons with Disability), but regretted the lack of meaningful participation of persons with disabilities, in particular when it comes to children and women with disabilities. The Committee therefore suggested to the State Party to take measures to ensure the active participation of all persons with disabilities in planning, implementing and monitoring public decision-making processes.

In the Concluding Observations of Argentina, the Committee recommends that the State take effective steps to ensure the active involvement of persons with disabilities in planning, implementing, monitoring and evaluating the strategy to implement the human rights model of disability across the country.

With regard to Hungary, the Committee emphasised ‘the insufficient participation of persons with disabilities and their representative organisations in the review and design of disability-

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350 Concluding Observations of the Committee on the Rights of Persons with Disabilities, Spain, CRPD/C/ESP/CO/1.
351 Concluding Observations of the Committee on the Rights of Persons with Disabilities, Peru, CRPD/C/PER/CO/1.
352 Concluding Observations on the initial report of Argentina as approved by the Committee at its eighth session, CRPD/C/ARG/CO/1.
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related legislation and policies, as well as in other policy and decision-making processes, in line with their obligation under Article 4(3) of the Convention’. Furthermore, the Committee regretted that the representative organisations of persons with disabilities did not participate in constructive dialogue with the Committee. The Committee therefore recommended that the State Party take measures and involve persons with disabilities in those processes, ‘giving them reasonable and realistic timelines for providing their views, and providing them with adequate funding in order to enable them to fulfil their role under Article 4(3) of the CRPD’.

In the Concluding Observation on the State Report of China, the Committee noted with regret that the organisations of persons with disabilities outside of the China Disabled Persons’ Federation are not involved in the implementation of the Convention. The Committee therefore urged China to introduce a ‘comprehensive and inclusive national plan of action, which includes full participation of all representatives of persons with disabilities’.

With regard to Paraguay, the CRPD Committee expressed its concern that the State Party has not established consultative mechanisms with the organisations of persons with disabilities when developing law and policies. The Committee urged Paraguay to establish such participatory mechanisms for persons with any kind of impairment.

In the Austrian report, the CRPD Committee recognises the difficulties coming from the federal structure of the country, but still recommends the development of policies and legislation at both federal and regional level with the ‘real and genuine participation by persons

353 Concluding Observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session, CRPD/C/HUN/CO/1.
354 Concluding Observations on the initial report of China, adopted by the Committee at its eighth session, CRPD/C/CHN/CO/1.
355 Concluding Observations on the initial report of Paraguay, adopted by the Committee at its ninth session, CRPD/C/PRY/CO/1.
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with disabilities through their representative organisations in line with Article 4(3) of the CRPD'.

The Concluding Observations on El Salvador include a serious concern about the lack of consultation with organisations of persons with disabilities in the design of laws and policies. The Committee calls for the development of a process that ensures broad participation.

Regarding Australia, the Committee regretted that 'there are not enough mechanisms for consultation and engagement between Government and persons with disabilities and their organisations in all matters of policy development and legislative reform relating to the Convention'. The Committee therefore called on the State Party to establish such mechanisms in partnership with persons with disabilities. The Committee was also concerned about the fact that the organisations of persons with psychosocial disabilities, and Aboriginal and Torres Strait Islander people, do not receive sufficient funding from the government for their operations.

The Concluding Observations on the State Report of Sweden do not include a concern or recommendation in relation to the implementation of Article 4(3) of the CRPD. Although the issue is not mentioned in the section on positive aspects, we presume that the Committee has not seen a major problem in this regard.

In the case of Costa Rica, the CRPD Committee expressed its concern that the State Party has not established ‘permanent mechanisms for consulting organisations of persons with disabilities in accordance with Article 4(3) of the CRPD’. The Committee recommended that the State Party establish such mechanisms ‘respecting the autonomy and taking into account the diversity of

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356 Concluding Observations on the initial report of Austria, adopted by the Committee at its tenth session, CRPD/C/AUT/CO/1.
357 Concluding Observations on the initial report of El Salvador, adopted by the Committee at its tenth session, CRPD/C/SLV/CO/1.
358 Concluding Observations on the initial report of Australia, adopted by the Committee at its tenth session, CRPD/C/AUS/CO/1.
359 Concluding Observations on the initial report of Sweden, adopted by the Committee at its eleventh session, CRPD/C/SWE/CO/1.
360 Concluding Observations on the initial report of Costa Rica, adopted by the Committee at its eleventh session, CRPD/C/CRI/CO/1.
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persons with disabilities including children and women with disabilities and the country's indigenous population'.

In the Concluding Observations on the first State Report of Azerbaijan, the Committee calls on the State Party to review and harmonise the legislation in order to incorporate the provisions of the CRPD and shift towards a human-rights-based model of disability. In this process the Committee calls on Azerbaijan to ensure the full participation of persons with disabilities and their representative organisations.

7.2.2 Observations of the CRPD Committee on implementing Article 33

Considering that Article 33 demands great structural changes and more progressive monitoring than any other UN Treaty, it has particular relevance whether the Committee uses forceful language to address these changes in the State Parties. At the end of the section we provide a table highlighting three categories of non-compliance that the Committee addressed in the Concluding Observations: lack of independence, lack of civil society involvement, and other remarks.

In Tunisia two specialised institutions are mandated to protect the rights of Persons with Disabilities: the Higher Council for the Social Advancement and Protection of Persons with Disabilities, and the Higher Committee for Human Rights and Fundamental Freedoms. The Committee expressed its concern that the Higher Committee for Human Rights and Fundamental Freedoms does not have independent status, and therefore called on the State Party to ensure compliance with the Paris Principles and establish a dedicated unit on disabilities within this body. The Committee also asked for the participation of persons with disabilities in the work of the Higher Council for the Social Advancement and Protection of Persons with Disabilities.

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361 Concluding Observations on the initial report of Azerbaijan, adopted by the Committee at its eleventh session (31 March–11 April 2014), CRPD/C/AZE/CO/1 para. 9.
362 CO Tunisia, para. 41–42.
Advancement and Protection of Persons with Disabilities, and of the Higher Committee for Human Rights and Fundamental Freedoms, considering the central role this body plays in monitoring the implementation of the CRPD.\textsuperscript{363}

The Committee commended \textbf{Spain} ‘for establishing independent monitoring mechanisms in full compliance with Article 33(2) of the Convention’.\textsuperscript{364} Spain has designated two independent mechanisms to promote, protect and monitor the implementation of the Convention: the Spanish Ombudsman, and the Spanish Committee of Representatives of People with Disabilities (CERMI).\textsuperscript{365} CERMI is the umbrella organisation for the organisations of persons with disabilities in Spain; it raises awareness and protects the rights of disabled people in Spain, drafts proposals to improve the legislation of the government, and occasionally represents disabled people in court.\textsuperscript{366}

The Concluding Observations do not refer to it, but implementation of Article 33 in Spain shows a potential way the Committee can have a direct impact on domestic law. Initially, Spain designated only CERMI as the independent mechanism under Article 33(2), assuming it would fulfil the requirements under Article 33(3) as well. The Committee asked Spain in the List of Issues to report on whether CERMI is compliant with the Paris Principles.\textsuperscript{367} CERMI as an umbrella DPO is clearly not compliant with the Principles, so Spain decided to include the Ombudsman in the monitoring framework by adapting the Royal Decree just before the Concluding Observations were issued. This is a great example of the State’s willingness to comply with obligations in cases that require only a formal act to achieve that. Obviously, the formal involvement of the independent element does not

\textsuperscript{363} Ibid.
\textsuperscript{364} CO Spain, para. 6.
\textsuperscript{365} Royal Decree No 1276/2011.
\textsuperscript{366} CERMI was established in 1997 by the National Disability Council and represents over 5500 organisations. Source: <http://www.cermi.es/en-US/QuessCERMI/Pages/Inicio.aspx> (accessed 21 February 2014).
\textsuperscript{367} List of Issues to be taken up in connection with the consideration of the initial report of Spain (CRPD/C/ESP/1), concerning Articles 1 to 33 of the Convention on the Rights of Persons with Disabilities, CRPD/C/ESP/Q/1.
guarantee that the framework will succeed in practice, but it does establish a framework with the potential to become a solid base for independent and inclusive monitoring. The Committee indeed commended Spain in the Concluding Observations for realising the need to establish a CRPD-compliant structure.

In the Concluding Observation on the Peruvian State Report, the Committee expressed its concern about the lack of clarity on the exact functions and divisions of responsibilities of the Multi-Sectoral Permanent Commission and the National Council for the Integration of Persons with Disabilities (CONADIS) under Article 33.68 CONADIS as a government body is not compliant with the Paris Principles, and it was quite confusing which role it actually fulfils under Article 33. The Committee specifically recommended the State Party to designate a Paris-Principles-compliant monitoring framework as a matter of priority with the full participation of persons with disabilities and their representative organisations.69

In Argentina, the National Advisory Commission on the Integration of Persons with Disabilities (CONADIS) is tasked to arrange implementation of the Convention in Argentina and co-ordinate matters relating to the implementation at all levels. The Committee noted with great concern that CONADIS does not have a sufficiently high institutional rank to carry out its duties as a focal point and co-ordination mechanism. Moreover, the National Disability Observatory that is tasked to be the Article 33(2) body and oversee implementation is a subsidiary body of CONADIS – violating the provisions under Article 33(2) and the Paris Principles.70 The Committee urged ‘the State Party to designate an independent national oversight mechanism71 that is in

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68 CONADIS (El Consejo Nacional para la Integración de la Persona con Discapacidad) is established under the Ministry of Women and Vulnerable People. Source: <http://conadisperu.gob.pe/> (accessed 23 February 2014).

69 CO Peru, para. 48–49.

70 CO Argentina, para. 51–52.

71 Interestingly, the language of this Concluding Observation refers to an ‘oversight mechanism’ instead of the commonly applied ‘monitoring mechanism’. However, the two expressions clearly mean the same thing and the difference is probably linguistically trivial.
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full compliance with the Paris Principles and to provide guarantees for the full participation of persons with disabilities’ and their representative organisations.372

The Concluding Observations on the initial report of China include sections also on Hong Kong and Macao due to the complexity of the political situation. In the case of China, the Committee expressed its great concern towards the overall absence of independent bodies and organisations of persons with disabilities systematically involved in the implementation of the Convention.373 The Committee was not able to identify a body designated as the independent monitoring mechanism in China under Article 33(2) of the CRPD. Since the China Disabled Persons’ Federation is the only official representative of persons with disabilities, the Committee strongly recommended that the State Party should allow other NGOs besides the China Disabled Persons’ Federation ‘to represent the interest of disabled people and be involved in the monitoring process’.374

The Committee further recommended the establishment of a Paris-Principles-compliant independent national monitoring mechanism. The language the Committee used in the recommendations on Article 33 in the Chinese report is the strongest so far amongst the Concluding Observations. The complete absence of an independent monitoring mechanism and independent civil society is presumably the greatest challenge the Committee has had to face in addressing the implementation of Article 33. Considering the political system in China and the currently reigning regime, the Concluding Observations of the CRPD Committee seem to be a weak tool to achieve significant structural changes at the national level. However, every opportunity matters that highlights at international level the lack of civilian voices in China and emphasises the importance of involving persons with disabilities at all levels of society. The Committee also noted the lack of an Article 33(2) mechanism in Hong Kong, and recommended the

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372 CO Argentina.
373 CO China, para. 49–50.
374 Ibid.
establishment of an independent mechanism with the participation of persons with disabilities. The Committee did not make a remark on Article 33 implementation in the sections discussing Macao.

Although the Committee acknowledged Hungary's effort to put in place a monitoring mechanism for the implementation of the Convention, it expressed concern that 'the National Disability Council which has been designated as independent monitoring mechanism is not in compliance with the Paris Principles'. The Committee therefore called upon Hungary to establish an independent monitoring mechanism in accordance with the Paris Principles, and to involve civil society and especially the organisations of persons with disabilities.

In Paraguay, the Secretariat for the Human Rights of Persons with Disabilities (SENADIS) has been designated as Article 33(1) body to co-ordinate policy-making on the rights of persons with disabilities, and has also been given the task of monitoring implementation under Article 33(2) of the CRPD. The Committee was concerned that the same body was tasked to carry out both functions, and recommended the State Party to set up an independent monitoring mechanism in compliance with the Paris Principles, to provide the necessary resources for monitoring, and to ensure the permanent involvement of persons with disabilities.

The Concluding Observations on the initial report of Australia contain the shortest recommendations from the Committee on the implementation of Article 33 of the CRPD. The Committee was concerned that 'Australia lacks a participatory and responsive structure for implementing and monitoring the Convention', and therefore called on the State Party to 'immediately set up a monitoring system that is fully in line with the provisions of Article 33 of the Convention'.

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375 CO China, para. 83–84.
376 CO Hungary, para. 51–52.
377 CO Paraguay, para. 75–76.
378 Ibid.
379 CO Australia, para. 57–58.
Policy context

**Austria** was commended by the Committee on being the first State Party to establish a monitoring body under Article 33 at the federal level.\(^{380}\) The Committee noted later in the COs that the Independent Monitoring Committee was created to promote, protect and monitor the implementation of the Convention in fulfilment of the provisions of Article 33(2).\(^{381}\) Austria therefore is the second State after Spain whose solution to implement Article 33 was positively evaluated by the Committee. However, the Committee expressed its concern that the Monitoring Committee does not have its own budget and lacks independence in complying with the Paris Principles. The Committee recommended that the monitoring body should receive a transparent budget and be entitled to administer this budget autonomously. Moreover, independence should be guaranteed in line with the Paris Principles. The Committee’s suggestion is intended to facilitate the sustainability of the Independent Monitoring Committee. The Committee also recommended that the Länder\(^{382}\) establish their own independent mechanisms to further co-ordinate disability policies and practices throughout Austria.\(^{383}\)

In the Concluding Observations on the initial report of **El Salvador**, the Committee concluded that the State Party has not set up a framework to monitor the implementation of the Convention.\(^{384}\) The Committee therefore recommended that El Salvador ‘officially designate mechanisms to monitor the implementation of the Convention involving both civil society and an institution fulfilling the Paris Principles regarding independent human rights institutions’.\(^{385}\)

In the Concluding Observations on the report of **Sweden**, the Committee expressed its concern ‘that the State party has not yet introduced an independent mechanism based on the principles relating

\(^{380}\) CO Austria, para. 5 and 52–54.

\(^{381}\) Ibid.

\(^{382}\) Austria is a federal republic, made of nine States (Länder): Burgenland, Carinthia, Lower Austria, Upper Austria, Salzburg, Tyrol, Styria, Vorarlberg, and Vienna.

\(^{383}\) CO Austria, para. 53.

\(^{384}\) CO El Salvador, para. 67–70.

\(^{385}\) Ibid.
Policy context

to the status of national institutions for the protection and promotion of human rights (Paris Principles) to monitor the implementation of the Convention'.\textsuperscript{386} Therefore, the Committee recommended that Sweden establish an independent monitoring mechanism in line with the Paris Principles and designate a ministry other than the Ministry of Health and Social Affairs to carry out co-ordinating tasks during the implementation of the Convention.

With regard to \textbf{Costa Rica}, the Committee expressed its concern that the State Party has designated neither a focal point to oversee the implementation of the Convention, nor an independent monitoring mechanism to fulfil its obligations under Article 33 of the CRPD.\textsuperscript{387} The Committee mentioned that the Ombudsman Office plays only a small role in monitoring the implementation of the Convention. Therefore, the Committee called on Costa Rica to consult closely with the organisations of persons with disabilities, and to designate a focal point and a Paris-Principles-compliant independent mechanism for the implementation and monitoring of the CRPD. The Committee also urged Costa Rica to provide an adequate budget and strengthen the capacity of the monitoring mechanism so that it can effectively carry out its tasks.

In the Concluding Observations on the State Report of \textbf{Azerbaijan}, there is no particular mention of Article 33 and its implementation. However, in the section on ‘Follow-up and dissemination’, the Committee encourages the State Party to involve the organisations of persons with disabilities in the preparation of their periodic report.\textsuperscript{388}

The following table summarises the remarks of the Committee on Article 33 implementation and indicates the main problems mentioned in the Concluding Observations:

\begin{itemize}
\item \textsuperscript{386} CO Sweden.
\item \textsuperscript{387} CO Costa Rica.
\item \textsuperscript{388} CO Azerbaijan.
\end{itemize}
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<table>
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<th>States Parties that went under reporting until February 2014</th>
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<th>Non-Compliance with the provisions of Article 33 of the CRPD</th>
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<td></td>
<td>Lack of independence in line with the Paris Principles</td>
<td>Lack of involvement of civil society</td>
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<tr>
<td>Tunisia</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Spain</td>
<td>X</td>
<td></td>
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<tr>
<td>Peru</td>
<td>X</td>
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<tr>
<td>Argentina</td>
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<tr>
<td>China</td>
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<tr>
<td>Hungary</td>
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<tr>
<td>Paraguay</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Australia</td>
<td></td>
<td>X</td>
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<tr>
<td>Austria</td>
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<tr>
<td>El Salvador</td>
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<td>X</td>
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<tr>
<td>Sweden</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Costa Rica</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Azerbaijan</td>
<td>n.d.*</td>
<td>n.d.</td>
</tr>
</tbody>
</table>

n.d. = no data.

Table 6: Summary of remarks of the CRPD Committee on Article 33 CRPD
7.2.3 The first remarks on implementing of Article 4(3) and 33 of the CRPD

In this section, we provide our views and a short assessment on the recommendations of the CRPD Committee to what extent States Parties have started opening up new spaces for persons with disabilities and their representative organisations. This process is supposed to happen through two main channels: by creating a mechanism for the full participation of persons with disabilities in the development of legislation, policies and programmes, and by the formal establishment of an independent monitoring mechanism that directly involves persons with disabilities. The Concluding Observations, as they address the governments, are not able to evaluate the relationship between the members of the independent monitoring framework and the organisations of persons with disabilities. Therefore, we do not refer to this aspect now, but will discuss it in more detail in part C of the thesis.

It would be too early to draw any conclusions based on just thirteen Concluding Observations, as we do not have reliable information on how other countries implement Articles 4(3) and 33 of the CRPD.\textsuperscript{389} The thirteen countries do not represent all regions equally, as five are American countries (two Central American and three South American)\textsuperscript{390}, five are European,\textsuperscript{391} only one is African,\textsuperscript{392} and two are from the Asia-Pacific region.\textsuperscript{393} Therefore, we emphasise that the section does not generalise to all States Parties, but discusses the ones that have had the first round of reporting with the Committee. At the same time, the Concluding Observations could be a very useful tool for other States to re-consider their domestic solution based on the recommendations of the UN Committee.

\textsuperscript{389} The work of Gauthier de Beco and the OHCHR is a very useful source to describe European improvement in the field of implementing Article 33 of the CRPD. However, comparative analysis is not available from other parts of the world in this regard.
\textsuperscript{390} Paraguay, Peru, El Salvador, Costa Rica, Argentina.
\textsuperscript{391} Hungary, Spain, Sweden, Austria, Azerbaijan.
\textsuperscript{392} Tunisia.
\textsuperscript{393} China, Australia.
Policy context

(a) Article 4(3) CRPD

The CRPD Committee did not particularly commend any of the States Parties for the successful implementation of Article 4(3) of the Convention. Sweden was the only country where the Committee did not make a negative remark on the performance in involving persons with disabilities in the development of legislation and policy. In most cases the Committee expressed its concern that no formal mechanism had been established to ensure the meaningful involvement of persons with disabilities. Further areas of concern involved special groups, such as women, children, or indigenous people and their omission from consultation.

Interestingly, the Committee did not express similar fear with regard to persons with profound intellectual or multiple disabilities. This thesis argues that persons with intellectual or psychosocial disabilities are largely excluded from the mainstream disability movement, and that this has a very negative impact on their participation. Presumably, the Committee did not want to distinguish between different groups of persons with disabilities and refer only to those that face multiple discrimination. What is clear from the Concluding Observations is that the CRPD Committee wants to see formal and permanent mechanisms that ensure the full participation of all persons with disabilities. It is also important to note that the remarks of the Committee focused on persons with disabilities themselves and not on their allies (e.g., families, service providers). This might be an important point of reference in future debates between the disability movement and other interest groups.

In a number of States Parties (Australia, Hungary, Tunisia), the Committee called specifically for budgetary investment through capacity building in order to facilitate the participation of the organisations of persons with disabilities.

394 In the Concluding Observations on Australia, persons with psychosocial disabilities were mentioned in the listing of groups that need additional support to participate.
In summary, the thirteen Concluding Observations that the CRPD Committee has issued so far underpin the hypothesis we made at the beginning of the thesis on the lack of efforts of governments to open up new spaces for civil society as it is envisaged in the Convention. It seems that the process of opening up new spaces has not even started yet in those countries that had the first round of reporting with the Committee. Governments do not involve the organisations of persons with disabilities in the review or development of laws and policies, so persons with disabilities cannot yet influence the decision-making processes that directly affect their lives. The fact that the Committee in most Concluding Observations had to express its concern about the complete lack of such consultative mechanisms shows that persons with disabilities are far from being considered as partners by the governments.

As the Concluding Observations include countries from both the developed and the developing worlds, it can be said that participation is mostly not a financial but an attitudinal issue. Considering the first dozen remarks from the UN, States Parties will hopefully start creating more inclusive spaces for policy-making and change their operations with the clear aim of improving the participation of persons with disabilities. Furthermore, as the Concluding Observations do not provide detailed guidance on the implementation of each provision, it would be necessary to develop General Comment on Article 4 of the CRPD. That could help States Parties to understand the complexity of involving persons with disabilities in law- and policy-making in a meaningful way.

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395 To expand the knowledge and understanding of Treaty provisions, the Committee can formulate General Comments (GC) that assist States Parties in the implementation process by interpreting single Articles. See: Working methods of the Committee on the Rights of Persons with Disabilities, adopted at its fifth session, (2011) CRPD/C/5/4, para. 54–57.
Policy context

(b) Article 33 CRPD

The Concluding Observations show that most States Parties failed to establish a monitoring mechanism that is compliant with the provisions of Article 33. Only Spain and Austria designated such mechanisms that fulfil the structural requirements under Articles 33(2) and 33(3). Notably, the Committee did not make any remarks on the operational work of the framework, but looked only at whether the structure of the framework is compliant with the Convention. Therefore, there are no particular remarks in the COs on the relationship between the organisations that serve as independent mechanism in the monitoring framework and the organisations of persons with disabilities under Article 33(3).

Most States do not have an adequate framework established (Hungary, Peru, etc.) or have not established a framework at all (China, El Salvador, etc.). The Committee in its analyses focused on two main characteristics in the implementation of Article 33:

- Independence in line with the Paris Principles;
- Participation of civil society and the representative organisations of persons with disabilities.

The disappointing results show that the process of change is very complex, and the Treaty body wants to see serious steps from States Parties in ensuring the shift from tokenism towards meaningful participation. The negative remarks of the Committee could motivate States Parties to develop a clear strategy on how to include the voice of the disability movement more effectively in their work. It would also be very useful if the UN CRPD Committee developed a guideline or General Comment in the near future on what is necessary to guarantee the participation of persons with disabilities in public policy and law development. Such a General Comment could give clear guidance on what sort of structural changes are needed to fill the new space in a mutually beneficial way. This would serve as a very helpful tool for
Policy context

States Parties, NHRIs, and organisations of persons with disabilities in interpreting Articles 4(3) and 33 of the CRPD.

Conclusion

In this section we explored the two unique provisions that empower the voices of persons with disabilities in order to ensure they can fully participate in the policy and decision-making processes that affect their lives. Article 4(3) of the CRPD creates a new space between governments and the representative organisations of persons with disabilities by requiring States Parties to closely consult with and actively involve persons with disabilities in the development and implementation of laws and policies that affect their lives. We interpreted the provisions of Article 4(3) as it requires not only active but also effective participation to guarantee that disability organisations make a real impact. We discussed Article 4(3) of the CRPD from the public policy perspective and highlighted the difference between policy-making and policy implementation. There are a number of policy stages through which persons with disabilities could influence policy-making, and in this thesis we chose the 5 categories set-up by Gemmill and Bamidele-Izu to assess the involvement of disability organisations in policy-making processes. Literature suggested that Disabled People’s Organisations develop their capacity to address the right problem to the right civil servant or politician in rhetoric that could gain unanimous support regardless of political orientation. We presented the involvement of the disability movement in the drafting of the ADA as best practice in the meaningful involvement in the development of law.

Article 33 manifests the important mission of the CRPD to renew traditional human rights monitoring and facilitate the successful implementation of international human rights norms at national level. In order to achieve that, Article 33 gives unprecedented roles for NHRIs
Policy context

and civil society to monitor together the obligations of the Treaty. The fulfilment of this new space requires NHRIs and DPOs to establish partnerships and enrich the monitoring activities with their distinctive expertise. Persons with disabilities could contribute with first-hand experience on the violations of the rights of disabled people, while NHRIs can offer their fully independent voice and traditional expertise in monitoring human rights.

The three requirements to implement Article 33 are: involve a Paris-Principles-compliant independent element in the framework; carry out all tasks under promotion, protection and monitoring; and involve the organisations of persons with disabilities in monitoring. Moreover, in order to ensure successful operation it is strongly recommended that governments officially designate the monitoring framework and provide sufficient funding for its operations. We decided to apply these five criteria to assess the involvement in monitoring the CRPD in the country examples of this thesis.

The Concluding Observations on the implementation of Articles 4(3) and 33 of the CRPD show similar patterns in the thirteen States Parties in terms of the lack of effective involvement of persons with disabilities and the lack of governments’ efforts to comply with their international obligations. Based on the recommendations of the CRPD Committee, States Parties must start establishing independent monitoring frameworks in line with the Paris Principles and ensure that the voices of persons with disabilities are involved effectively in all such frameworks and in the development of law, policies and programmes.
V. Findings

This chapter discusses the findings of the empirical research carried out in Zambia and New Zealand. The case studies form an important part of the thesis by presenting the views of members of the disability movement on the current and ideal ways of implementing Articles 4(3) and 33 of the CRPD. The case studies will focus on the involvement of DPOs in law development and policy-making and in monitoring the Convention. In line with the central concept of the thesis, the analysis of the data gathered at these country visits, take the process-oriented approach into account and discuss the fulfilment of the new spaces between government, civil society and the human rights system accordingly.

Nonetheless, the two case studies have different contexts and are relevant for different reasons. The case study on New Zealand will demonstrate a developed country's solution of how to involve disabled people's organisations in the implementation and monitoring of the CRPD. The case study on Zambia shows a developing country that ratified the Convention, and so has to meet the same obligations as developed ones but with a significantly smaller financial sources available. Implementing the economic, social and cultural rights provisions of the CRPD does require financial investment, but involving persons with disabilities in decision-making rather demands a conscious decision and a change of attitudes. As many of the interviewees emphasised, 'participation in principle is not a money issue'. The Zambian case study will raise some important concerns about the sustainability of the implementation process in developing countries and give some encouraging examples to wealthier countries that disability issues can be taken seriously even in places less materially wealthy.

396 For example, accessibility, reasonable accommodation, right to cultural life.
8. Developed World – New Zealand: Taking Process Seriously

New Zealand is an island country, situated in the South-western Pacific Ocean. The population of New Zealand is about 4 601 072. In 1840, representatives of the British Crown and Maori Chiefs signed the Treaty of Waitangi, making New Zealand a British Colony.\textsuperscript{397} According to the Global Competitiveness Report, which looks at factors that affect economic growth, New Zealand is ranked 18 out of 144 countries.\textsuperscript{398} According to the UN Human Development Index 2013 report, New Zealand is ranked 6 out of 187 countries. Social indicators such as life expectancy at birth (about 80.8 years) and the GNI per capita ($24,358) rank New Zealand at the top of the list of very high human development countries.\textsuperscript{399}

New Zealand signed the CRPD on 30 March 2007 and ratified the Convention on 25 September 2008 with no reservations. It has not signed and therefore not yet ratified the Optional Protocol of the Convention. In this section we present how New Zealand implements Articles 4(3) and 33 of the CRPD with special regard to the participation of Disabled People’s Organisations in monitoring the implementation of the CRPD. The interviews with different stakeholders helped to understand the perspectives of the government, the Human Rights Commission and various DPOs on the strengths of the current situation and the challenges ahead. Between 2–9 April 2013, altogether seven interviews were conducted in Auckland and Wellington.\textsuperscript{400} Since four of them were group interviews, in total 26 people have been interviewed. People with different kinds of impairment were represented in the sample: blind people and persons with visual impairment, persons with intellectual disabilities, persons with physical impairment, deaf people.

\textsuperscript{397} King, M. (2001) Nga Iwi O Te Motu, Reed, Auckland, p 35.
\textsuperscript{400} More information about how interviews were conducted, recorded and analysed is available in Chapter III. Methodology.
The following table shows the roles and the dispersion of the respondents:

<table>
<thead>
<tr>
<th>Government</th>
<th>Number of interviewee</th>
<th>Role(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Human Rights Commission</td>
<td>1</td>
<td>Manager</td>
</tr>
<tr>
<td>Disabled Persons Organisations</td>
<td>2</td>
<td>Manager, Senior staff</td>
</tr>
<tr>
<td>Civil society organisation</td>
<td>3</td>
<td>Manager, project coordinator, Advocacy worker</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td></td>
</tr>
</tbody>
</table>

Table 7: Information on people interviewed in New Zealand.

The sample covers a broad range of stakeholders including disability advocates in higher positions as well as project coordinators or social workers working more on the grass-root level. The composition of the sample helps to get a more comprehensive picture of disability politics in the country. As it was mentioned in the Methodology chapter, the interview transcripts are coded like NZ1, NZ2, etc. This table shows the number of participants in each interview to give a better idea about the number of people involved when later making references to these interviews:

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401 Organisations for persons with disabilities (e.g. family organisation).
<table>
<thead>
<tr>
<th>NZ1</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>NZ2</td>
<td>6</td>
</tr>
<tr>
<td>NZ3</td>
<td>1</td>
</tr>
<tr>
<td>NZ4</td>
<td>2</td>
</tr>
<tr>
<td>NZ5</td>
<td>3</td>
</tr>
<tr>
<td>NZ6</td>
<td>2</td>
</tr>
<tr>
<td>NZ7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

*Table 8: Number of participants in interviews in New Zealand.*

### 8.1 Monitoring the implementation of the UN CRPD in New Zealand

Article 35 of the CRPD requires governments to submit a report to the UN Committee on the Rights of Persons with Disabilities on their progress towards implementing the treaty. The first report should be submitted within two years of the Convention coming into force. Since the CRPD entered into force in New Zealand in October 2008, the first report to the CRPD Committee was due to be submitted by October 2010. Technically the Ministry of Social Development finished the report on time, but the CRPD Committee only received it in March 2011. We interviewed someone from the Ministry, who was unsure about how the report got lost on the way. This caused some delays in the examination process. At the time of visiting the country, local disability organisations were organising the work around drafting the shadow report to the UN CRPD Committee. This section builds on the relevant documents that have been reviewed for the purpose of the research (*New Zealand Disability Strategy, Disability Action Plan, background documents available on the website of the Office for Disability Issues, joint report of the Independent Monitoring Mechanism 2012 etc.*) and the interviews that were conducted with high-level member of the

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402 See NZ3.
Developed World – New Zealand: Taking Process Seriously

government’s focal point to implement the CRPD, high-level representative of the NHRI and various civil society representatives. The 2012 report of the Independent Monitoring Mechanism (IMM) is an especially important source of mapping the activities of the framework:

'It is probably a good overview of what we did, who we met with, some of the summaries of the conversations we had. Our timeline was stretched out, but we did two reports at the end of last year; one on family care and one on well-fare changes relating to CRPD articles.' (NZ2)

8.1.1 Article 33 implementation in New Zealand: the structure

The government in New Zealand designated the Office for Disability Issues (ODI) as the focal point on disability issues to oversee the implementation of the Convention under Article 33(1) of the CRPD. In fact, since 2002 the Office has fulfilled the function of a focal point for disability issues in the implementation of the New Zealand Disability Strategy.403 The Strategy sets a coherent direction for disability issues across the government and presents a long-term plan to change New Zealand from a disabling to an inclusive society.404 The Minister for Disability Issues is required to report to the Parliament on the progress of implementing the Disability Strategy. Having designated a Minister for Disability Issues already shows the government’s awareness of taking seriously the challenges persons with disabilities face in society.

The Strategy has been developed in consultation with persons with disabilities and the wider disability sector, reflecting many individual experiences. It is quite remarkable that the Strategy was drafted well before the CRPD in 2001 and yet includes a clear concept of participation. Its main vision is to ensure the full participation of persons with disabilities by guaranteeing that ‘disabled people have a meaningful partnership with Government, communities and support

404 The Strategy includes fifteen Objectives underpinned by detailed Actions. See: Ibid.
Developed World – New Zealand: Taking Process Seriously

agencies, based on respect and equality’.\textsuperscript{405} It is important to note that the Disability Strategy has many conceptual elements that were later included in the text of the Convention. These elements show, that New Zealand realised well before the Convention was adopted the need to involve persons with disabilities in society by removing all barriers in light of the paradigm shift from the medical to the social or human rights model. The Disability Strategy is very important in understanding why New Zealand was considered as a good practice for the implementation of the CRPD and became one of the country examples of this thesis. Furthermore, New Zealand played an active role in drafting the CRPD in New York, and the advisory group took the Strategy with them as a baseline for negotiating certain areas in the UN. They did this with the outstanding support of the government to ensure the Convention would offer new goals to New Zealand as well.\textsuperscript{406} Yet, an advocate representing a Maori disability organisation noted that while New Zealand did a wonderful job in terms of making the CRPD happen, the government advocated against the involvement of an article on indigenous people and that was unfavourable for the Maori people living in New Zealand:

‘So, New Zealand government played quite a significant role in making sure that indigenous people didn’t have a separate article in the Convention, so that’s again cause huge tension between national DPOs and the grass-root and obviously particularly Maori people going: Hang on a minute, you are representing our abuse!’ (NZ2)

As a high-level interviewee from ODI said, the main difference between the Strategy and the CRPD is that the Convention has a lot more detail about what ought to be done, while the Strategy represents a high-level abstract policy document. The government therefore links the two

\textsuperscript{405} Ibid.

\textsuperscript{406} For example, Article 19 on independent living goes beyond what happened in New Zealand on the basis of the Disability Strategy, but the government agreed to push it forward to the right to choose with whom and where to live, even if the person requires support.
documents and tries to implement the Disability Strategy in light of the CRPD.\textsuperscript{407} This shows an exceptionally clear vision of improving the lives of disabled people in New Zealand by maximising the two key instruments through their joint application. In the same time, other respondents representing DPOs criticised the Convention for being a too theoretical legal document and lacking guidance on practical implementation.

The Ministerial Committee on Disability Issues is designated as co-ordination mechanism under Article 33(1) of the Convention. The government established the Committee in 2009 to ‘provide visible leadership and accountability for implementing the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities, and set a coherent direction for disability issues across government’.\textsuperscript{408} The chair of the Committee is the Minister for Disability Issues, and other relevant ministers are also involved in the work of the group.\textsuperscript{409} The government expects that the different agencies will ‘better focus their activity and policy development on what makes a real difference in the life of persons with disabilities’. Through the establishment of such a co-ordination mechanism, the government on one hand intended to facilitate the joint work of different departments, and on the other hand aimed to use the limited resources more efficiently. Among other important tasks, the Ministerial Committee asked the ODI to launch a public consultation on the draft report on the implementation of the CRPD, and to get the opinion of persons with disabilities directly in some key areas.

New Zealand has an Independent Monitoring Mechanism (IMM) developed in accordance with Article 33(2) of the Convention. It comprises three entities: the Human Rights Commission, the

\textsuperscript{407} See interview NZ3.


\textsuperscript{409} Members of the Ministerial Committee on Disability Issues are representing the Ministries of Health, Education, Justice, Transport, Business, Innovation and Employment, Foreign Affairs and Trade, Accident Compensation Corporation (ACC), Housing New Zealand Corporation (HNZC).
Ombudsman, and the Convention Coalition Monitoring Group. The Convention Coalition is a grouping of eight Disabled Persons Organisations operating under the Memorandum of Understanding 31 March 2010. Members of the Convention Coalition are: Disabled Persons Assembly New Zealand (DPA), Blind Citizens New Zealand, People First, Deaf Aotearoa, Ngati Kāpo, Nga Hau E Wha (a network of organisations of people with experience of mental illness), and Balance New Zealand. Four of the eight organisations were represented in the empirical data collection, as well as the Auckland branch of the Convention Coalition’s Shadow Reporting Group. The designation of the monitoring mechanism was formally recognised by a notice of the Minister for Disability Issues in the New Zealand Gazette on 13 October 2011.410

The Government provided funding for the Monitoring Mechanism as part of realising its obligations under the Convention to support independent monitoring of the implementation including the voice of persons with disabilities. The framework was initially provided with three years’ funding starting May 2010. As the ODI representative highlighted, the funding did not create any dependency, as members of the IMM could decide how to use this money during monitoring. An interviewee from a blind organisation said:

'We are fortunate in New Zealand that we have three years funding from government for this collaboration of the activities for the Convention Coalition. There will always be a debate about whether the funding is well spent, whether the collaboration has worked out well, but there are some quiet useful information in the reports, various things that we have done.' (NZ1)

The IMM is expected to submit one report per year to the government. Some interviewees representing DPOs underlined that the funding was not sufficient to carry out a broad range of activities, and this particularly affected the participation of the Convention Coalition, as

the HRC and the Ombudsman had more stable funding for their mandates.

In order to ensure sustainability, the Ombudsman and the Human Rights Commission were, at the time of the visit, in fact seeking additional funding to be able to carry out tasks related to CRPD monitoring in the future. However, the Convention Coalition would certainly need stable funding from the government to keep up the work as part of the framework. ODI mentioned that the Prime Minister promised to secure on-going funding for the DPOs that participate in monitoring the Convention.

Within the Convention Coalition there is little governance among the DPOs, and the government intends to consider each member equally. Disabled People’s Assembly was contracted by the government to be the fund holder for the Convention Coalition for practical reasons, but it was emphasised that by no means do they co-ordinate the Coalition. The Memorandum in fact clarified this flat structure to avoid future tensions among DPOs.

8.1.2 Activities of the Independent Monitoring Mechanism

As mentioned earlier, the Monitoring Mechanism is supposed to provide the government with a report each year on the implementation of the CRPD in New Zealand. At the time of the visit, the Independent Monitoring Committee had already prepared one report on the monitoring activities, published on the website of the Office for Disability Issues.\footnote{Making disability rights real: Annual report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities 1 July 2011 – 30 June 2012’. See: <http://www.hrc.co.nz/wp-content/uploads/2012/12/Making-disability-rights-real-Print.pdf> (27 November 2014).} In terms of the impact that such monitoring reports could make, ODI explained that they try to mainstream findings of the report across the government to facilitate its wide usage by public servants in the drafting of new policies. As we have shown, the report turns the attention of policy-makers to discrepancies between laws and
policies and their implementation, and offers possible solutions directly by Disabled People's Organisations. Even if the government disapproves the recommendations, the monitoring report provides a baseline for developing effective solutions. The Office for Disability Issues therefore plays an important mediating role between the government agencies and members of the Monitoring Mechanism to ensure that the activities and recommendations of the framework will reach the responsible departments effectively.

Another activity of the IMM was to promote the CRPD across the country and hold forums for groups of people with different impairment. According to a blind advocate these days were very useful if the Human Rights Commission and Auckland Disability Law facilitated it:

‘The good thing about that day is that between the Human Rights Commission and Auckland Disability Law there was an intend to have forums, the Human Rights Commission went around the country talking about the Convention and Auckland Disability Law, at the same time was speaking to audiences in Auckland in terms it had to be various meetings, because we chose different topics, such as education or health.’

DPOs welcomed that by these seminars, the Human Rights Commission expanded the knowledge of local advocates on the provisions of the CRPD.

8.1.3 How independent is the New Zealand Article 33 framework?

The Independent Monitoring Mechanism formally includes the Human Rights Commission (HRC) and the Ombudsman Office. The HRC was established in 1977 and currently operates under the Human Rights Act 1993. It is the National Human Rights Institution of New Zealand that holds ‘A’ status accreditation from the International Coordinating

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Committee of National Human Rights Institutions, and is a member of the Asia-Pacific Forum of NHRLs.413 This means that the HRC can convincingly perform the role of the independent element in the framework.414 The HRC has a long-established history of promoting, protecting and monitoring the implementation of other human rights treaties New Zealand ratified earlier.

The Commission is financed through the Ministry of Justice, but enjoys full independence during its operations. There are eight commissioners in the HRC, one of whom is the Disability Rights Commissioner, focusing particularly on promoting the rights of disabled people. It is another clear sign of New Zealand taking the implementation of the Convention seriously, that the current Disability Rights Commissioner was appointed on the day New Zealand ratified the CRPD. The Disability Commissioner has been an advocate and a former president of Disabled People’s Assembly, so he maintains close connections with the disability movement across the country.

The Ombudsman Office was created in 1962 to act as an independent authority between the community and government agencies.415 Under the Ombudsmen Act 1975, the Ombudsman can investigate complaints about the administrative acts of the national and local government agencies. 416 The Ombudsman Office can make independent investigations on its own initiative or based on a complainant. The Ombudsman as the National Preventive Mechanism under the OPCAT carries out a broad range of monitoring activities in places of detention. 417 Besides dealing with complaints, the

414 The Human Rights Commissioner said that the government is getting more involved in the appointment of the Commissioners, which ultimately might compromise their independent status.
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Ombudsman Office provides training and raises awareness to public authorities. Interestingly, a government official considered the Ombudsman Office the most independent body from the government, because the HRC has to report through the Ministry of Justice while being reliant on government funding. In contrast, the Ombudsman Office reports directly to Parliament, which means slightly more independence from the government. According to the Disability Rights Commissioner, most people were happy about the structure of the IMM; only a few organisations were surprised that the Ombudsman Office was involved to such a great extent. This is because the Ombudsman Office traditionally had a more formal relationship with civil society, without any co-operation. After the monitoring framework was established, the Ombudsman Office started shifting from being a complaint-driven body towards a more pro-active body, and gaining the trust of DPOs.

After overviewing the relevant legislations, policies and talking to important government and civil society representatives, we are convinced that the monitoring framework in New Zealand formally fulfils all the five criteria for the Article 33(2) framework that we described earlier in this thesis. First of all, it includes a Paris-Principles-compliant independent element, the Human Rights Commission. Secondly, there is a clear understanding to carry out tasks under promotion, protection and monitoring. Thirdly, the representative organisations of persons with disabilities are formally involved in the framework through the Convention Coalition. Fourthly, the government has formally designated the monitoring framework, so its legitimacy is guaranteed. Fifthly, the government provided additional funding for the members of the framework to carry out the workload that Article 33 requires. Even if it was unsure at the time of the field trip whether the framework will receive more stable funding in the future, the government expressed its willingness to provide support for the

[accessed 27 November 2014].
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operations of the framework. Yet a CRPD-compliant monitoring framework does not guarantee by its structure that it operates in a satisfying way for all stakeholders. Thus we will now taking a closer look on the involvement of person with disabilities in policy processes, and the framework’s operations, building on the qualitative interviews with representatives of DPOs, the Human Rights Commission and the government.

8.2 The implementation of Article 4(3) of the CRPD in New Zealand: Participation in policy- and decision-making

The Disability Advisory Council in New Zealand, comprising thirteen members delegated by DPOs, fulfilled the role of a consultative platform for a long time, even before ratification of the Convention. They often successfully influenced policy making, for instance when the government wanted to merge health and disability politics and DPOs successfully opposed it.

After the ratification of the CRPD, DPOs in New Zealand asked for the government to engage with them in a more formal way. According to the Office for Disability Issues there is a general awareness in the government to consult with persons with disabilities, but capacity building would be necessary for staff members of the departments, to enable them to develop more accessible working practices. The Ministry of Health for instance has many different mechanisms for consultation, but some disability organisations would not find them efficient. It was also highlighted that many DPOs would get involved in complex policy-making on a voluntary basis, making meaningful input very difficult. Some DPOs addressed to the Minister for Disability Issues that if the government seriously intends to involve DPOs in policy-making, additional funding should be available to ensure meaningful participation. As a representative of a blind organisation explained:
Developed World – New Zealand: Taking Process Seriously

'At the National level so far the emphasis has been on monitoring, because New Zealand was preparing to prepare its first report... so the monitoring framework was set-up very quickly.' (NZ1)

The government’s initial reaction about funding DPOs was reserved, referring to the fact that in general they do not fund advocacy or any other interest groups. DPOs then made a clear link between the obligations of the CRPD and the necessity of funding to effectively participate in debates on issues concerning the lives of disabled people.

'We are even turning that into a discussion with government around funding, which is interesting, because the challenge that government has issued so far is... ‘we don’t normally fund advocacy, so why should we fund it for disabled people’s organisations?’ And the answer is “well, because we have got a Convention and the Convention says that we have a right to be at the table when it comes to decisions that impact on our lives and it especially refers to the organisations that represent us.’ (NZ1)

At the time of the field trip, the government was looking at what it actually means to be a DPO, to ensure that only organisations that represent people with disabilities can benefit from such funding. Yet it is a real fear that even if the strongest representative organisations receive support to participate, persons with disabilities who do not belong to any of the big organisations will be likely left out of the consultation.

ABC New Zealand explained the concern over being busy monitoring the CRPD, but the government is making a number of policy changes without involving the organisations of persons with disabilities, including changing the benefits system, housing policies, transport policies and access to legal aid. In these processes DPOs felt that the government did not follow the provisions of the CRPD, and that DPOs lacked the capacity to influence the processes effectively and mainstream disability rights in line with international law. As a blind activist emphasised:
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‘DPOs just don’t have the ability to engage in terms of significant influence into that process over there. So, you are busy with monitoring stuff, while we are here, that actually all the time is changing: so they are changing benefits, they are changing housing policies, they are changing transport policies, they are changing access to legal aid, they are changing the way the call system set-up. All these things are changing over here with no reference to the CRPD and the voice of disabled people is largely lagged behind.’ (NZ2)

Members of the Convention Coalition and the Shadow Report group try to ensure that whenever the government proposes a policy change, it would reflect the provisions of the CRPD.

‘Shadow reporting is actually about saying every stage where the government is planning to change something, we need to comment on it from the respective UN CRPD and every time remind them – and that applies to local government as well, so when the local government puts together a plan we say “Hey, remember CRPD!”’. So, have you consulted it with the disabled people, have you done reply in accessible format, what are the plans about transport – and here what UN CRPD asked and says, here is what we think, we don’t match up to that.’ (NZ2)

8.3 Strengths of the work of the IMM

Due to the close involvement of New Zealand in drafting the CRPD, a DPO representative said that there is

‘probably a higher than average community level of awareness than in some other countries on the rights of persons with disabilities.’ (NZ2)

The establishment of the Independent Monitoring Mechanism had a positive impact on the collaboration of DPOs in general. The platform created opportunities to work together more closely than ever before and address many of the areas where specific DPOs had different perspectives. As a respondent from a blind DPO explained, they have now sessions where:
‘...the blind, the deaf, persons with intellectual impairments are involved and it takes a bit of time that everyone is getting used to each groups, because before the blind people got angry for the communication of the deaf people took too long and persons with intellectual disabilities got lost, so at the end everyone was angry at each other.’ (NZ1)

Establishing the IMM has been considered a great learning process for DPOs representing different impairment groups on how to work together and solve conflicts. During the last couple of years, groups of blind people, deaf people, post-polio groups, users of mental health services, and persons with intellectual disabilities found many similarities in the struggles they are facing in society and gained a better understanding of the differences as well.

It shows quite clearly the strategic thinking of the DPOs in New Zealand that they intended to use the shadow reporting process to raise awareness at national and local level on the implementation gaps instead of waiting for the feedback from the UN. As the Shadow Report Group of DPOs emphasised, the shadow reporting process is

‘much more about trying to engage on a local, regional and national level in the here and now rather than seeking for long-term impacts of the shadow report’. (NZ2)

Since consultation has not been done in the best interest of persons with disabilities in the past, the Monitoring Mechanism tries to mainstream the shift towards collaboration and partnership internally when gathering information for the reports.

### 8.4 Challenges and recommendations

The challenges presented below are drawn from issues that more than one interviewee mentioned and seemed to be somehow re-occurring during the study visit. The decision on thematizing these concerns was up to the decision of the researcher. This was done in a very careful way
to ensure that the challenges presented here cover the areas of main concerns of the interviewees adequately. However, there are certainly other challenges that this thesis is not discussing either because they were not mentioned during the interviews or, as it was only one person referring to it. This is then a non-exhaustive list of some challenges that those DPO representatives, who took part in the research, perceived about the participation in implementing and monitoring the CRPD.

8.4.1 Lack of systematic monitoring

One of the main concerns about the monitoring framework in New Zealand is the lack of systematic activities to promote, protect and monitor the implementation of the CRPD. While most members of the Coalition were satisfied with the established structure, it was highlighted several times that apart from the reports and the organisation of the shadow report group, the Coalition does not carry out systematic work.

'We have not yet evaluated the changes that we have recommended to take place. So we don’t know if the government is listening, but we suspect they probably not. We haven’t yet developed the mechanism to have the input, so the monitoring reports are going in and sometimes they can be quite critical... but there is not yet a mechanism developed or that government actually sit down with disabled people organisations and say what we do.' (NZ1)

Someone else highlighted, that:

'We all go into the government with our own individual little agendas which they don’t really like, but that is the way how it is... but at the same time we would like to see a bit more structure around how that should work, so that it's documented and we actually can see that sort of a plan of attack developing.' (NZ1)
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This might be a result of the limited resources and lack of co-ordination in the framework. Furthermore, some representative organisations of the Convention Coalition stated that the IMM does not meet frequently enough to discuss common work and plan activities in detail under promotion, protection and monitoring.

One of the specific areas where monitoring work faces great challenges is the lack of disaggregated statistics on persons with disabilities. A representative of a DPO explained that he once had to calculate the number of disabled people in Auckland himself for a study, relying on the registers of disability organisations and service providers. The system itself is overregulated and prevents data collection at the national level, for instance in the area of education and the number of children with disabilities in the school system. For that reason, the shadow report of civil society to the CRPD Committee does not aim to provide data or statistics, but to discuss how New Zealand promotes and creates opportunities for implementing the Convention in local communities.

8.4.2 Confusion in the function of the monitoring framework

Some respondents from DPOs highlighted that it is often not clear what is expected from the Independent Monitoring Mechanism. While initially the role was understood more as a reporting group to the UN, some members feel that they in fact report to the government.

‘The confusion is: does the coalition report to the UN or does it report to the government, and I ended up reporting to the government.’ (NZ2)

Respondents also emphasised that the government funding undermines the independence of the monitoring framework. Advocates from ABC New Zealand mentioned the lack of any mechanism at government level to use the recommendations of the monitoring report in the

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418 See NZ1.
development of laws and policies. Without such a follow-up mechanism established, the efforts of the IMM are without effect. Members of the Convention Coalition were not sure during the interviews if the government ever read their recommendations on the changes necessary in New Zealand's legislation. DPOs were also unsure whether the report could be harmonised with their own advocacy agendas. They agreed that the government should ensure the remarks of the IMM reports are considered and reflected in their decision-making processes.

8.4.3 Representivity

On the field trip in New Zealand, a group interview was carried out with members of the Northern Region branch of People First (PF) New Zealand. The People First movement in New Zealand started in the 1980s, and today there are over 30 local groups split into six regions.419 Local members vote directly for regional chairpersons, who form the National Committee. People First New Zealand is formally involved in the work of the Convention Coalition, but members of the Auckland branch did not feel they were really part of it. Despite having established a well-functioning internal democratic structure, advocates from the Northern region suggested contacting the Wellington branch, as they themselves had no information or experience of being involved in any way in the work of the Convention Coalition.

Altogether, the involvement of persons with intellectual disabilities in monitoring the CRPD remains tokenistic, but the effort to include them in, for instance, the Shadow Report working group is a positive aspect. The representative member of People First was acknowledged and listened to in the roundtable discussion by other members. It is a very important learning experience for advocates with other impairments to slow down the pace of the meetings and use more plain language when discussing complex issues there. The self-advocate

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respondent underlined that the situation with regard to the participation of persons with intellectual disabilities improved a lot, but there is still a long way to go to successfully implement the ideas of the Convention for their benefit.420

During the field trip, we did not meet any advocacy groups representing persons with psychosocial disabilities. It seemed that while certain DPOs carry out effective and remarkable advocacy work, some impairment groups are under-represented in forming disability politics in the country. Surprisingly, this applies also to persons with physical impairments. Having said that, DPOs that participated in the research emphasised the need to build a more inclusive disability movement. It was mentioned that when the Disability Strategy was drafted in 2001, persons with mental health problems and the deaf community had tensions with the government in the course of defining their own identity outside of the impairment.

"That is a national process, there is resistance when the New Zealand disability strategy in 2001 was including mental health as a disability type and they would kind of go: "No, not, we are an own, separate thing." And they had the same tension with the deaf community, going: "We are not certain..." So, a constructive relationship I think evolves (...) But they (people with mental health problems) tend to call themselves consumers without them saying what they consume exactly.' (NZ2)

During the interviews, it was argued that the voice of persons with psychosocial disabilities is missing from the movement because their needs of reasonable accommodation and the everyday difficulties in working together with them have not been realised. There are frequent tensions between advocates with mental health problems and other groups. Some advocates with sensory impairments for instance argued that persons with psychosocial disabilities should make their needs clearer in order to be accommodated in a more inclusive way:

420 See NZ7.
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‘What I am going to say it’s going to sound a little bit judgemental, but it’s not meant to be. Often with the impairments where you are in a wheelchair, visibly, obviously, you have got an impairment, mental disability is often even more stigmatized that people find out you have got some. (…) And not only you are invisible, but there is a lot of other factors, just even in the daily capacity sometimes… They then say “I am now stop coming to meetings as a disabled person.” So, I think there are various people who come to some sort of terms with that and there are many people in the society that are so traumatized because of the many neglecting experiences. You have to be responsible for sharing some of your lived experience, because you can’t assume the world around you know to threat you perfectly.’ (NZ2)

Another concern for representivity by members of the Convention Coalition was the difficulties in reaching most persons with disabilities in New Zealand and engaging with them in monitoring the CRPD:

‘One of the biggest challenges we have is there is no way of reaching most disabled people in New Zealand, there is no way reaching most disabled people in Auckland…. So you are not getting the representative experience at all. You might not get a lot of intellectual impairment staff, even though there is three times more people with intellectual impairment than blind people. For certain things you tend to get people in wheelchair, but you are still missing some aspects of the experience purely as a consequence that does not engage with the community.’ (NZ2)

The Convention Coalition is using a snowball methodology to find people who would like to share first-hand experiences of the violation of their rights. People First tries to find potentially interested people in social clubs, where they talk about the activities of People First and try to motivate them to build the movement at grass-root level all over the country. Yet some advocates criticised the Convention Coalition for being a national body that does not really represent persons with disabilities.

Finally, the role of parents’ organisations was mentioned recurrently during the interviews. A blind advocate noted that while parents usually have different interests and views than DPOs, in New
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Zealand the disability movement generally acknowledges that advocacy groups of parents are entitled to express their views on the on-going debates.

“So we didn’t want to say that the parents aren’t entitled to a view, because parents are invited to share their views. But you have to acknowledge where that views come from and the different interest they have…” (NZ2)

Although there is an intention to strengthen the voice of self-advocates through People First, IHC New Zealand, a parent-led organisation, is still indispensable for providing practical support to get people to meetings and inform them about self-advocacy initiatives. This dependency on services maintains the traditional power relation between persons with intellectual disabilities and families during participation. In the views of the DPO members of the Convention Coalition, family organisations, like other service providers, should not consider themselves as advocacy organisations. The reason for much of the tension between DPOs and service providers is that disability activists see that resources are still with the service providers even if they do not have the mandate to carry out advocacy work. At the same time, DPOs are struggling to finance their projects on a day-to-day basis. The representative of People First emphasised the important role of supporters during meetings to ensure the meaningful involvement of persons with cognitive impairments if the person needs help reading the scripts or understanding some guidelines.

8.4.4 The involvement of the Maori disability community

The Maori are the indigenous Polynesian people of New Zealand. According to the 2013 census, 14.9% of the population of the country belong to the Maori community. While most respondents highlighted

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421 See NZ2.
422 New Zealand Census of Population and Dwellings 2013. See:
the wonderful job New Zealand did to create and appreciate the Convention, they also mentioned the country’s role in making sure that indigenous people did not have a separate article in the CRPD. The Maori community considered it as an abuse of their rights and were greatly disappointed not only in the government at that time, but also in national DPOs for maintaining a sort of hierarchy within the disability community. There has been significant tension between the Maori and non-Maori\textsuperscript{423} disability movements in New Zealand on the basis that disability rights are a Western-driven phenomenon and constructed as individual rights. In contrast to the European understanding of human rights linked to individuals, the Pacific indigenous people’s view of rights is connected to the community and the extended family. Therefore, most of the provisions of the Convention that address the rights of an individual with impairment are inapplicable to the Maori community.

One member of the Auckland CRPD Shadow Report group is a Maori advocate, which might help decrease the tension on monitoring local issues.\textsuperscript{424} She personally highlighted that New Zealand should turn the ethnic diversity to its advantage and facilitate discussions on the debated issues. The head of a local Maori DPO highlighted the difference between the Maori and non-Maori disability communities as the non-Maori being organised along impairment groups, whereas for Maori people this would be impossible because of tribal traditions.

Among the Pakeha disability community...they developed organisations or groups of organisations in services that concentrate on a particular impairment. So you have got a big association for deaf people, foundation for the blind people, physical disabilities, dyslexia etc., so they formed their organisations around certain conditions. We haven’t. We can’t. We can’t


\textsuperscript{423} Interviewees of the research referred to New Zealanders with European descent as ‘Pakeha’. Considering that some people would find the term offensive, we will stick to the Maori/non-Maori distinction in this section of the thesis.

\textsuperscript{424} Auckland is the city with the biggest Pacific population in the world.
because we are what we consider a Maori, so our commonality is affected with Maori. And you have got a country, that develop funding and planning and policy based on impairment, then for us working out of it is really difficult, because the funding is targeted other way. So, all of these organisations has fallen in to line to attract their piece of funding for that particular impairment. (...) We have lost quite a bit of funding opportunities, because we maintained that we are a Maori community.’ (NZ6)

This also presents a challenge in securing funding that targets specific impairment groups. Moreover, Maori disabled people face an additional layer of discrimination as a result of their Maori origin that distinguishes them from those ‘Pakeha’ disabled people who can participate if the socially constructed barriers are removed. For Maori people thus there are additional barriers that cannot be removed simply by the implementation of the CRPD.

8.4.5 Fragmentation within the disability movement: regional and impairment-specific issues

Advocates from organisations of blind people called the movement in New Zealand fragmented. However, they noted that the situation improved in the last few years. Respondents representing different DPOs highlighted that there are tensions between different impairment groups. During the field trip, some interviewees with visual impairment expressed their negative feelings about working with advocates who have psychosocial disabilities. They referred to abruptly ended meetings, and complained about the ‘impolite tone and unpredictable behaviour’ that caused difficulties in working together. As an advocate from a blind umbrella organisation emphasised,

‘it will always be a challenge to compromise the conflicting views of different disability groups, but it needs to be done through listening to all opinions and understanding where are they coming from’. (NZ1)
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There are significant tensions within the deaf community between people who want to be proud as deaf by maintaining sign language and deaf culture, and those who would like to be fully included and use cochlear implants to hear again. According to the Disability Rights Commissioner, the tension between impairment groups is less intense than elsewhere, but quite strong between DPOs and NGOs focusing on disability issues.

A number of interviewees mentioned that in New Zealand regional disability groups face very different challenges compared to each other. During the shadow reporting process, Auckland-based DPOs focused more on the community and tried to define necessary changes to improve the situation at that level, while in Wellington, due to the physical proximity to the government, DPOs address more national-level issues.

‘I think Auckland was much more about staff and the community and build upwards on that. Wellington is building upwards towards the government and so the two processes started kind of independently, but we have also had explicit conversations around determining to the Auckland process and say we want to fit your stuff in.’ (NZ2)

Interviewees noted that the two processes started to develop independently of each other, but they try to have conversations to avoid further isolation.
The Republic of Zambia is situated in Southern Africa and has a population about 13 092 666. The former British colony Northern Rhodesia became independent from the United Kingdom and was named Zambia in 1964. According to the Global Competitiveness Report Zambia is ranked as 102 out of 144 countries, which looks at factors that affect economic growth.\textsuperscript{425} According to the UN Human Development Index, which represents a push for a broader definition of well-being and provides a composite measure of three basic dimensions of human development (health, education and income), Zambia is ranked as 164 out of 187 countries. Social indicators, such as life expectancy at birth (about 40.9 years) or maternal mortality (830 per 100 000 pregnancies) are still very worrying in the developing country, such as the estimated adult life expectancy (15 – 49 years) and the HIV prevalence (13.5%).\textsuperscript{426}

Zambia signed the CRPD on 9 May 2008 and ratified the Convention on 1 February 2010. It has also signed but not yet ratified the Optional Protocol of the Convention on 29 September 2008. In this chapter we present how Zambia implements Articles 4(3) and 33 of the CRPD with special regard to the participation of Disabled People’s Organisations in monitoring the implementation of the CRPD. Similarly to the New Zealand country visit, the interviews with different stakeholders in Zambia helped to understand the perspectives of the government, the Law Development Commission and various DPOs on the strengths of the current situation and the challenges ahead. Unfortunately no interview could be conducted with representatives of

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the Human Rights Commission. Between 9–20 July 2012, altogether nine interviews were conducted in Lusaka. Most of the interviews were one-to-one interviews, except two interviews where two respondents were present. In total 11 people have been interviewed. People with different kinds of impairment were represented in the sample: blind people and persons with visual impairment, persons with intellectual disabilities, persons with physical impairment, deaf people, persons with mental health problems. A parent organisation was also represented in the sample. The following table shows the roles and the dispersion of the respondents:

<table>
<thead>
<tr>
<th>Number of interviewee</th>
<th>Role(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>1 Manager</td>
</tr>
<tr>
<td>Law Development</td>
<td>2 Advisor, legal officer</td>
</tr>
<tr>
<td>Disabled Persons</td>
<td>4 Director (2), project coordinator, advocacy officer</td>
</tr>
<tr>
<td>organisations</td>
<td></td>
</tr>
<tr>
<td>Civil society</td>
<td>3 Manager, project coordinator</td>
</tr>
<tr>
<td>organisation</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1 consultant</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
</tr>
</tbody>
</table>

**Table 9 Information on people interviewed in Zambia**

The sample covers a broad range of stakeholders including directors and managers of organisations as well as project coordinators or consultants working more on the grass-root level. As it was mentioned

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427 More information about how interviews were conducted, recorded and analysed is available in Chapter III. Methodology.

428 Organisations for persons with disabilities (e.g. family organisation).
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in the Methodology chapter, the interview transcripts are coded like Z1, Z2, etc. This table shows the number of participants in each interview to give a better idea about the interviews that had more than one participant:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Z1</td>
<td>1</td>
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<tr>
<td>Z2</td>
<td>2</td>
</tr>
<tr>
<td>Z3</td>
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<td>Z5</td>
<td>1</td>
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<td>Z6</td>
<td>2</td>
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<td>Z7</td>
<td>1</td>
</tr>
<tr>
<td>Z8</td>
<td>1</td>
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<tr>
<td>Z9</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>

**Table 10: Number of participants in interviews in Zambia.**

9.1 Public participation in the African context

With regard to the roots of a civil society movement in Africa, voluntary associations were first constructed as a response to the disruptive effect of market economy during the colonial period.\(^{429}\) According to Bratton, those organisations soon became explicitly political. Despite aspirations of the ruling elite to eliminate these groups around the time of independence, most of them successfully proved to be a strong alternative institutional framework. In Zambia, associational life mostly started with mineworkers’ unions, which could provide a ground for formulating opposition, together with economic networks against post-colonial autocracy by the end of the 1980s. Responding to the popular protest of civic actors, African governments created political openings,

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which led to a more favourable atmosphere for free expression and association.\(^{430}\) For instance, in Zambia a number of NGOs were created to monitor the government’s performance on human rights since the 1980s. These associations were essential to educate people about citizenship and democracy.

In South Africa, the Constitution provides a framework to guarantee public participation in the legislative process.\(^{431}\) As a consequence of the involvement of citizens in public life, the democratic system functions in a representative and participatory way at the same time.\(^{432}\) As Nyati points out, it is a government’s duty to facilitate meaningful participation of the public in the legislative process and guarantee that everyone’s opinion is considered.\(^{433}\) The aspiration behind this provision is to avoid continuing any exclusive policies that deprived people of fundamental rights in past regimes. The Constitutional Court decision in *Doctors for Life International v. Speaker of the National Assembly*\(^{434}\) is a very important milestone in addressing the extent to which public participation in the legislative process is protected by the South African Constitution. The judgment set the standard of the constitutional obligation to facilitate public participation and to develop more accountable legislation.

In Kenya, the *Endorois* case is a very important source to illustrate the legal concept of people’s participation as a duty of the state.\(^{435}\) The African Commission on Human and Peoples’ Rights stated that the lack of meaningful participation of the Endorois community was a violation of the right to development.\(^{436}\) As Kamga’s commentary explains, the right to development is binding in the African Charter on Human and

\(^{431}\) Secs 59 (1)(a), 72 (1)(a), & 118 (1)(a).
\(^{432}\) Nyati, L. (2008), ’Public participation: What has the Constitutional Court given the public?’, *Law, Democracy & Development*, 12, p. 102.
\(^{433}\) Nyati (2008), p. 104.
\(^{434}\) (2006) 12 BCLR 1399 (CC).
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People’s Rights (ACHPR) and was first tested through this case. The court’s decision highlights the state’s role as a duty bearer to guarantee people’s participation, and clarifies the beneficiaries of the right to development. The right to development includes a number of elements, such as non-discrimination, participation, equity, accountability, and the threshold of people’s participation.437

The participatory provisions of the CRPD therefore come for many African countries as a familiar practice in public policy-making and indeed stand as a right already guaranteed by domestic law. In the African context, Bratton claims that there is a strong link between democratisation and the concept of civil society empowerment.438 This can be a very important point of reference when filling up the new space after ratification of the CRPD. Nevertheless, Cohen and Arato describe the participatory model of democracy in which both the governing elite and citizens play an active role in forming opinions and develop a conception of civic virtue through political experiences.439

9.2 Monitoring the implementation of the CRPD in Zambia

Since the CRPD entered into force in Zambia in March 2010, the government was due to submit its State Report by March 2012. A number of DPOs participating in the implementation process have highlighted that no report was sent to the UN by this deadline. Civil society is still planning to make its own shadow report on the implementation of the Convention, and hopes to present it to the UN in a few years.440 This section builds on the relevant documents that have been reviewed for the purpose of the research (Persons with Disabilities Act of 1996, first draft Constitution, submission to the

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440 It is important to note that the UN CRPD Committee is facing some delays in evaluating the state reports. Since many countries ratified the Convention right after it was open for ratification, a large number of reports were submitted around the same time.
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Technical Committee on the Draft Constitution by ZAFOD, Town and Country Planning Act, Mental Health Disorders Act) and the interviews that were conducted with various representatives of civil society, in particular DPOs and high-level representatives of government agencies and the Law Development Commission. The Periodic Report of the Independent Monitoring Unit of the implementation of the CRPD issued in 2011 is an especially important source in understanding the local context.

9.2.1 Article 33 implementation in Zambia: the structure

Zambia initially chose to designate several focal persons in the relevant Ministries under Article 33(1) of the CRPD to co-ordinate the implementation of the Convention. However, civil society representatives were not satisfied with the performance and level of collaboration of these bodies. The Zambian Federation of the Disabled (ZAFOD) called on the Permanent Secretary of the Ministry for Community Development, Mother and Child Health Care to designate a fully competent focal person.\(^441\) The government department made a clear statement in February 2012 indicating that they are in the process of re-appointing focal points in every Ministry who will be in charge of disability issues.\(^442\)

Due to the lack of any state action to designate a CRPD-compliant Article 33(2) framework, ZAFOD initiated the establishment of the Independent Monitoring Unit (the IMU) to advance and monitor the implementation process of the CRPD. As they write in the Preamble of their periodic report:

\[\text{Zambia Federation of Disability Organisations (ZAFOD) is an umbrella body of all disability organisations whose vision is to have a society where persons}\]

\(^{441}\) ZAFOD is the umbrella organisation of DPOs, representing 12 disability organisations.

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with disabilities, enjoy equal rights and opportunities that are generally available in society and are necessary for the fundamental elements of living and development.'

Furthermore, as a respondent explained:

'It was ZAFOD's idea, doing a lot of advocacy and presented to the stakeholders and to the Ministry of Community Development. If you look at Article 33 CRPD, it finds a way to form a framework working the government, and civil society side by side to make sure the implementation goes well.' (Z9)

The purpose of the IMU is to assist in the 'domestication' of the CRPD into Zambian legislation. It is important to emphasise that the IMU was not formally acknowledged by government decision since its creation as an Article 33(2) CRPD body. This is probably a direct consequence of the fact that the establishment was based purely on the advocacy work of civil society.

The IMU was an 18-month project, so there is no guarantee of its sustainability. Operation of the framework started in January 2011 after capacity-building workshops had been carried out for staff members of the participating DPOs. According to the first progress report of the IMU, the project has the specific objective to encourage civil society to independently promote and monitor domestication of the CRPD in Zambia. As a disability advocate emphasised:

'IMU is a very good idea, it's like a watchdog to make sure things are needed to be involved in order to implement the Convention and it will be covered in the government programmes.' (Z5)

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443 Zambia Federation of Disability Organisations (ZAFOD), Independent Monitoring Unit of the implementation of the domestication of the UN CRPD (IMU), Periodic report to the government by the IMU (December 2011).
444 Ibid.
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The composition of the IMU is pluralistic, including government departments and agencies, international human rights organisations, the National Human Rights Institution and a number of umbrella DPOs.

The disability movement in Zambia, under ZAFOD’s leadership, interprets Article 33 of the CRPD as a ‘way to form a framework for the government and civil society to [adequately] implement ... the Convention’. ZAFOD emphasised the necessity to collaborate with a broad range of stakeholders, including NGOs outside of the disability movement. However, they believe the leading role should be played by DPOs who have first-hand experience. It was actually a common misunderstanding within the disability movement, that a platform including different stakeholders would fulfil the requirement of pluralism under the Paris Principles and therefore could serve as an independent body. The IMU is far from being independent in the current structure, as its membership consists of governmental bodies.

The Zambia Agency for Persons with Disabilities (ZAPD) is also part of the IMU, among other ministerial departments. The Agency carries out a number of activities such as promoting and administering services for all persons with disabilities, keeping statistical records, advising the Ministries on the economic situation of persons with disabilities, and co-ordinating rehabilitation with government bodies. Several interviewees clarified that the role of ZAPD in the framework is to be the link between government and civil society by facilitating an exchange of information. As one interviewee pointed out, the Agency

445 Ministry of Community Development, Mother and Child Health Care; Zambia Agency for Persons with Disabilities (ZAPD); relevant domestic government ministries (e.g. Health, Education, Justice); Zambia Law Development Commission (ZLDC).
446 Action on Disability and Development (ADD); Opportunity Zambia (OZ); International Labour Organisation (ILO); Power 4 Good/POWER International.
448 ZAFOD; Sight Savers International (SSI); Zambia National Federation of the Blind (ZANFOB).
449 IMU periodic report.
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could act as the watchdog and transfer the message from stakeholders to the Ministries. In many countries there is a communication gap between government and civil society which eliminates any constructive dialogue or collaboration. It is an interesting initiative in Zambia to resolve this problem.

9.2.2 Activities of the Independent Monitoring Unit

Right after the establishment of the IMU, they wanted to identify the issues they should deal with. According to the director of one of the DPOs:

‘Identify and analyze the issues, that is how advocacy starts. Make a strategy. In Zambia, the Ministry of Community Development and ZAPD are key stakeholders to meet them.’ (Z9)

Due to the available financial and human resources, the Independent Monitoring Unit had had two main focuses. On one hand, they produced a periodic report in 2011 to review the implementation of the CRPD and disseminated it widely to the government and civil society groups. On the other hand, as one of the interviewees pointed out, the main priority for the IMU was the review of the Persons with Disabilities Act\textsuperscript{451} to ensure the new disability legislation is compliant with the CRPD. Beside the Persons with Disabilities Act, there were a number of other legislative reform processes at the time of the country visit, thus the IMU was busy with following and contributing to these processes. According to the Periodic report:

‘A critical part of the work of the IMU is the review of existing legislation to assess whether it is compatible with the State’s obligations under the CRPD. While the importance of domestic disability legislation such as the Persons with Disabilities Act No. 33 of 1996 is recognized by the community of

\textsuperscript{451} 33 of 1996.
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disabled persons, the 1996 Act itself is not far reaching enough and it fails to address the many problems that affect disabled people in everyday life.\textsuperscript{452}

The IMU also actively raised awareness and promoted the CRPD and disability rights issues across Zambia through meetings with local disability groups. The IMU often works in smaller working groups to provide a better atmosphere for discussions. Interviewees found ‘it is a good way to make in-depth recommendations and improve effectiveness’. Members of the IMU went to villages to raise awareness of the CRPD by bringing hard copies of the Convention in large print, Braille and easy-to-read versions. They wanted to educate members of the local disability communities on the provisions of the Convention and asked for input on the submissions the IMU was planning to prepare.

\subsection*{9.2.3 How independent is the Zambian Article 33(2) framework?}

The Human Rights Commission, Zambia (HRC Zambia) is the National Human Rights Institution in the country. HRC Zambia is accredited by the International Coordinating Committee (ICC) as a fully compliant NHRI with the Paris Principles. It was established under Article 125 of the Constitution of Zambia and mandated by the Human Rights Commission Act\textsuperscript{453} to, inter alia, investigate and remedy human rights violations, conduct human rights education, monitor the conditions under which persons are detained in prisons and elsewhere, and monitor government’s fulfilment of international and regional human rights treaties and human rights obligations under national law. In order to achieve compliance with the CRPD, the HRC Zambia shall play a role as an independent element in the framework established under Article 33(2) of the CRPD to promote, protect and monitor implementation. Surprisingly, the institution does not actively

\textsuperscript{452} IMU Periodic report.
\textsuperscript{453} 39 of 1996.
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participate in the work of the IMU even though it is formally listed among the members.

The Zambian solution to implement Article 33 is lacking the active contribution of the independent element, and therefore cannot be considered fully compliant with the CRPD. Drafters of the Convention logically incorporated the concept of independence into the framework to guarantee effectiveness and checks and balances of the mechanism. The NHRIs traditionally have experience in human rights monitoring but also play the role of ‘watchdog’ to check that government decisions are in line with international human rights standards. Independence is essential to be able to monitor human rights effectively.

When looking for the reasons for the lack of collaboration between disability organisations and the HRC Zambia, the problem of miscommunication immediately became clear. As a Director of a DPO said:

‘I am not sure whether we approached them properly, so they chose not to be part of that, or not? I need to find out why. Did not we approach them or we did and then what are their reasons for not joining?’ (Z9)

The Commission claimed not to be invited to IMU meetings, but ZAFOD expressed their wish to collaborate with the HRC and thus guarantee sustainability and effectiveness for the monitoring framework.

‘As an organisation they are stakeholders and important to be involved. They are protecting human rights of all.’ (Z9)

In fact, the HRC Zambia has not yet been active in monitoring the rights of persons with disabilities, despite their aspirations articulated in the draft National Plan of Action for the period 2010–2020.454 According to this working plan they are willing to carry out advocacy for the enactment of effective legislation for the protection of persons with

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disabilities and advocate for their involvement in the labour market. They acknowledge the importance of collaborating with the organisations of persons with disabilities, and plan to establish a better working relationship with civil society on the occasion of the forthcoming Universal Periodic Review (UPR) and the UN CRPD Committee hearing. All of this shows that the working relationship between the NHRI and the disability movement is not yet developed to be able to carry out the tasks under Article 33 together.

9.3 The implementation of Article 4(3) of the CRPD in Zambia: involvement in law development

A number of laws and policies are currently under revision in Zambia. In 2011, the newly elected government promised in its electoral campaign to ‘change and benefit within 90 days’. Several interviewees reported that the government really is serious about law making, and is keen to consult with civil society to ensure a dynamic law-making process. It was a very important time for human rights advocates in Zambia to participate and incorporate provisions of the CRPD into disability-related pieces of legislations being reviewed by parliament.

The extent to which civil society wants to be involved in policy-making varies significantly depending on the issue in question. If there is a debate on the situation of children with albinism in primary education, disability organisations may wish to turn decision makers’ attention to the needs of children with disabilities in schools facing multiple discrimination but not necessarily to participate in the whole process. In contrast, if the government revises mental health legislation, disability organisations would most likely seek to participate from the very beginning to push the discussion in a CRPD-compliant direction. Therefore the adequate level of participation could be defined briefly as the highest possible presence that satisfies disability organisations.

In this section a number of current legislative proposals will be presented from the perspective of the involvement of persons with
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disabilities in the whole process. It is important to note that the organisations of persons with disabilities in Zambia are involved in these law development processes mostly through IMU. It is of great concern that some groups of disabled people might not be represented when negotiating with the government.

9.3.1 The Persons with Disabilities Act

The Persons with Disabilities Act was enacted in September 2012.455 The IMU submitted comments during the review, which were included in the draft text. Representatives of DPOs were satisfied that their voice was being heard. As one of them pointed out:

‘It takes a longer while for government to actually implement an international human rights treaty, but the IMU and civil society could provide them with sufficient guidance on how to do it right.’ (Z9)

The priority areas the IMU focused on in its submission were education, employment, accessibility, mental health and legal capacity. Although the previous Act from 1996 contains a few solid provisions on anti-discrimination, education and accessibility, in general it refers to the old medical model by looking at persons with disabilities in a pitiful way, seeking only medical care and focusing exclusively on rehabilitation and the prevention of disability. DPOs working in the IMU agreed that different pieces of legislation shall be CRPD-compliant, and the new Disability Act must cover all civil and political rights and social, economic and cultural rights guaranteed in the Convention. Paragraph (b) of the Objectives of the new Persons with Disabilities Act includes a provision to ‘promote the participation of persons with disabilities with equal opportunities in the civil, political, economic, social and cultural spheres’.456 Nevertheless, Part V of the Act deals with specific areas in

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detail, such as education, employment and social protection, health care, rehabilitation, accessibility, and political and public life.

Most interviewees evaluated the participation in the development of the new Persons with Disabilities Act as successful, and noted that the combination of first-hand experience of the advocates and the knowledge of adapting international provisions into domestic law were key factors in that success.

‘For example, at the moment the Disability Bill is at the second reading in the Parliament and we took part of it and made sure that the aspects of the UN CRPD will get into it. We are also trying to involve these aspects in the Constitution.’ (Z6)

9.3.2 The constitutional review process

In early 2013 Zambia was in the process of negotiating a new Constitution under the lead of a Technical Committee of Experts, appointed by the government. The Technical Committee started drafting the new Constitution on 1 December 2011. The review is a response to demands for a more democratic political system in the country. The State intends to promote transparency, accountability and the participation of people in governance by developing viable institutions.

According to Ndulo, the draft Constitution of Zambia retains dictatorial presidential powers as contained in the 1996 Constitution instead of moving towards a more democratic State. He argues that the draft even expands dictatorial powers by allowing the president to unilaterally divide and create provinces or districts or to appoint all the important posts without consultation.

The constitutional review aimed at least formally to be consultative and to reach a broad range of social groups.

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457 Ibid., Part V.
459 Ndulo (2012).
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government showed its willingness to involve public opinion in a meaningful way, and promised that contributions would be taken into account systematically.

The Constitution making process, we are involved in all levels, we have distributed 600 copies of Braille version, 500 large prints, 150 version audio, people get these copies, they make their comments and the federation will call a consultative meeting, we had one the last time, we are supposed to have a follow-up with the Technical Committee.’ (Z6)

This openness during the drafting procedure may create a favourable atmosphere for the disability movement to effectively advocate in a number of issues relating to the CRPD. Given the important momentum when the government put the concept of participation and democratisation on their political agenda, a highly marginalised group may find effective ways to advocate for real change. Democratisation in general facilitates the empowerment of civil society by stimulating the creation of a strong grass-root movement. ZAFOD and the Human Rights Commission have both submitted comments to the Technical Committee in regard to the new Constitution.461 As a representative of a DPO of blind people summarized their involvement in the review process:

‘Lobbying and fighting for the rights of the visually impaired, there is the Constitution making process now, we have taken part and make sure the disability aspect will be included and in this case to transcribe the draft to Braille, like a week ago and go back to our people to make comments to the Technical Committee. We work in collaboration with ZAFOD.’ (Z6)

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461 Submission of the HRC Zambia is available here:  
<http://www.hrc.org.zm/media/hrc_submission_to_technical_committee_on_drafting_zambian_constitution.pdf> (accessed 4 July 2013); submission of disability organisations is available here:  
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ZAFOD lobbied for including the provision of equal recognition before the law of persons with disabilities, in line with Article 12 of the CRPD.

9.3.3 Other legislation under review

Two other acts were recently under review in Zambia. One is the Town and Country Planning Act,\textsuperscript{462} which is expected to include accessibility provisions in line with the CRPD.\textsuperscript{463} The Human Rights Commission reported in 2010 that chapter 283 of the Act is lacking adequate regulation on accessible environments.\textsuperscript{464} They suggested that the government revise the instruments of area planning. The report also emphasises the importance of involving persons with disabilities from the very first stage in drafting the development plan and in prioritising which currently available financial resources can be spent on improving accessibility.

In addition, there was a review of the out-dated Mental Health Disorders Act 1951,\textsuperscript{465} which fails to promote the dignity and autonomy of persons with psychosocial disabilities.\textsuperscript{466} The Mental Health Users Network of Zambia (MHUNZA) and ZAFOD have been actively involved in drafting the new Mental Health Act since July 2012 by collecting data, generating evidence and developing mental health policies in collaboration with international experts on mental health law. The main capacity builder in the region, Opportunities Zambia (OZ), emphasised that decision makers should meet with advocates to avoid drafting

\textsuperscript{462} Town and Country Planning Act (Cap 283).

\textsuperscript{463} For further information on the Town and Country Planning Act, see: <http://faolex.fao.org/cgi-bin/faolex.exe?rec_id=038789&database=faolex&search_type=link&table=result&lang=eng&format_name=@ERALL> (accessed 17 January 2013).


\textsuperscript{465} The Mental Health Disorders Act represents the old medical model, and allowed detention of anyone who was suspected to be a person with a psychosocial disability. The law further went on to address people with psychosocial disabilities as idiots, imbeciles or morons.

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legislation influenced by the medical approach to disability. It is important to educate government officials on the principles and obligations of the CRPD.

9.4 Strengths of the work of the IMU

First and foremost, the greatest strength of the IMU lies in the commitment of members of the Zambian disability movement. They allocate their time and limited resources to review pieces of legislation, even if they have to do it on a voluntary basis. Their monitoring activities currently aim to incorporate the CRPD provisions into domestic law.

Although the intensity of the members’ contribution within the IMU varies significantly, all interviewees were aware of the current national legislative changes, such as the review of the Constitution or the Persons with Disabilities Act. They also contributed to the submissions prepared by the IMU in one way or another. Representatives of DPOs seemed to be familiar with the provisions and national-level implications of the Convention, and used very CRPD-compliant language. Being able to apply appropriate concepts of the CRPD, such as accessibility, reasonable accommodation, and supported decision-making, certainly facilitates a stronger position of civil society during negotiations with the government bodies.

A number of the IMU member organisations emphasised the importance of engaging in strategic advocacy work by planning and lobbying in a structured manner. Proactivity and initiating meetings with previously identified stakeholders also promotes sustainability of participation. As mentioned above, the IMU raises awareness of the CRPD and involves the voice of the community through maintaining connections with the grass-roots level. This facilitates better representation. There is no available data on the frequency of such

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meetings, but the initiative can certainly be considered a great example and may be followed by other countries.

Another important achievement of the established IMU is that it could help to bring together the fragmented disability movement for a common purpose, namely to address disability rights to the government effectively. A representative of a big organisation emphasised that it is a success of the IMU that the government now recognises the State obligations under CRPD and shows willingness to implement the Convention in different legislations and policies.

9.5 Challenges and recommendations

The following section has a brief overview of some of the challenges the IMU is currently facing, and makes a number of recommendations on the changes necessary to improve the sustainability of the platform.

9.5.1 Lack of government support

Since the funding of the IMU came to an end in January 2013, the project faces some serious challenges in the near future. The informational webpage of the IMU has already been de-activated for budgetary reasons. After the evaluation of the progress report, the platform still expected 25 per cent of the EU fund to come to the IMU. In the meantime they have received some funding from the Open Society Initiative of South Africa (OSISA) to cover activities for the next two years, focusing on mental health issues and the Persons with Disabilities Act, which has now been enacted. 468

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with disabilities at a higher scale, we hope all of our partners will keep
working on those issues.’ (Z9)

The sustainability of the Monitoring Unit is still uncertain, and a
guaranteed fund would be necessary to enable them to strategically
plan future activities.

Although Article 33(2) of the CRPD imposes a duty on States to
maintain, strengthen, designate or establish a framework that
promotes, protects and monitors the implementation of the Convention,
the Zambian government has not formally acknowledged the IMU as the
monitoring body. Moreover, the State has not provided any funding for
the IMU since it was established by civil society. A DPO representative
highlighted that:

‘It is good that the government recognises it, but it has to take into account our
recommendations. Government cannot despise the opinion of civil society
then.’ (Z5)

This raises serious concerns for the effective operations of the IMU in
the future and clearly questions its financial viability.

9.5.2 Unbalanced participation

The fact that ZAFOD as the umbrella organisation of DPOs in Zambia
takes the leading and co-ordinating role in the work of the IMU is
understandable, although it is slightly concerning how much ZAFOD
dominate the whole framework. Although ZAFOD represents 12
organisations, it does not represent every person with disabilities in the
country. The IMU and ZAFOD are not distinguished by some IMU
member organisations. The following quote from one of the interviews
with the head of an IMU member organisation clearly shows that:

‘I have interacted with them (IMU) for 3-4 occasions; they did a good job with
the submission on the Disability Act, that input was tremendous. Without
Some of them consider the IMU as a business of ZAFOD rather than a common project. It may affect their willingness to share the tasks in the monitoring process. The reason for ZAFOD’s dominance could be that they provide the secretariat for the IMU and organise the capacity-building training for other DPOs. It might affect the work of the IMU positively if participants had a clearer understanding of the mutual contribution they are supposed to make.

Those members representing government entities did not feel actively involved in the work of the IMU. For instance, the Zambia Law Development Commission, which is tasked with ‘review[ing] and consider[ing] proposals for law reform referred to the Commission by the Minister or the members of the public’, has not interacted with the IMU on a regular basis. The Commission was unable to review the Disability Act due to the short deadline provided and certain procedural burdens. However, it refers to its limited mandate and capacity to act only upon a government request; the legislation which established the Law Development Commission does not include such a limitation.

The Mental Health Users Network in Zambia has remarked that the Anti-Gender-Based Violence Act 2011 reviewed by ZLDC still includes a discriminatory section on persons with mental health disabilities. According to the law, persons with mental health disabilities could only apply to a court for a protection order if they are assisted by a third party, and not on their own behalf. Disability advocates expressed disappointment that a non-CRPD-compliant Act could be passed without any consultation between them and the Law Development Commission. Considering the current focuses of the IMU, the Commission could be a key strategic partner in reviewing draft legislations.

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469 Zambia Law Development Commission Act (Chap 32) Part II 4. (2)(c).
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9.5.3 Representation

It is very challenging to ensure that the voice of the whole disability movement is being represented in submissions of the IMU. As many of the interviewees emphasised, one of the key elements of effective participation is to find a common direction that all relevant civilian actors agree on. Having broader co-operation facilitates better lobbying. In Zambia some umbrella DPOs do not have nationwide membership but they claim to be national organisations and legitimate enough to represent a large number of people. This is why the Norwegian Disability Consortium seeks to provide smaller grant schemes available for capacity building of fragmented parts of the disability movement in Zambia.471

9.5.4 Lack of an independent element

As mentioned earlier, it is essential to involve the HRC Zambia in the work of the IMU, as it would ensure independence and compliance with the Paris Principles. In Zambia, the disability movement has taken the leading role in establishing the monitoring mechanism, but at the same time missed out on the opportunity to facilitate an active collaboration with the independent Human Rights Commission. In the drafters’ vision, the three core elements of the Article 33 framework (government, NHRI and civil society) are conscious of the need for collaboration when sharing tasks with each other on CRPD implementation. A lack of trust or bad experiences during previous collaboration between the NHRI and NGOs could be the reason for such isolation. Considering that the HRC Zambia has not done extensive work on disability matters before the CRPD entered into force, it is a learning process for the Commission as well. Presumably, the working method of the NHRI was neither accessible nor transparent to civil

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society in the past. This can be seen as the reason why civil society does not consider closer collaboration with the NHRI. It is certainly necessary to tackle isolation and establish a basis for a more inclusive and balanced relationship between the entities involved in the Article 33(2) framework.
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Conclusion

The following table summarizes the findings of the two field trips in New Zealand and Zambia about the implementation of Article 33 of the CRPD vis-à-vis the involvement of the representative organisations of persons with disabilities:

<table>
<thead>
<tr>
<th>1. Structure of the Article 33 framework</th>
<th>New Zealand</th>
<th>Zambia</th>
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<table>
<thead>
<tr>
<th>2. Activities of the independent mechanism</th>
<th>New Zealand</th>
<th>Zambia</th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) Financial allocation:</td>
<td>Internal. Government provided three years funding 2010-2013. Human Rights Commission was looking for further funding opportunities.</td>
<td>(b) Financial allocation: External (European Union, Power International).</td>
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<tr>
<th>3. Independence of the monitoring framework</th>
<th>New Zealand</th>
<th>Zambia</th>
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</thead>
<tbody>
<tr>
<td>The Human Rights Commission is an A-status NHRI in line with the Paris Principles.</td>
<td>The Human Rights Commission, Zambia is an A-status NHRI in line with the Paris Principles.</td>
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<tr>
<th>4. Implementation of Article 4(3) CRPD</th>
<th>New Zealand</th>
<th>Zambia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happens more on an ad-hoc basis without funding provided for DPOs to follow policy and law-making processes.</td>
<td>Engagement in legislative review process: Persons with Disabilities Act, Constitutional review, Town and Country Planning Act, Mental Health Act.</td>
<td></td>
</tr>
</tbody>
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472 Formally listed as member of the IMU, but DPOs reported that the Human Rights Commission has not played an active part in the activities carried out by IMU.
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<table>
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<tr>
<th>5. Strengths of the framework</th>
<th>Public awareness about the CRPD.</th>
<th>Commitment of the disability movement to monitor legislation and policies.</th>
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<tbody>
<tr>
<td></td>
<td>Strong collaboration between different sectors of the disability movement.</td>
<td>Awareness-raising across the disability community on the CRPD.</td>
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<td></td>
<td>Joint work on the report of the IMM.</td>
<td>Bringing together the otherwise fragmented disability movement.</td>
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<tbody>
<tr>
<td></td>
<td>Involvement of the Maori community in CRPD monitoring.</td>
<td>Representation/unbalanced participation of the disability movement.</td>
</tr>
<tr>
<td></td>
<td>Representivity of the whole disability movement in the IMM (esp. persons with psychosocial disabilities).</td>
<td>Lack of active independent element in the framework.</td>
</tr>
</tbody>
</table>

Table 11 Summary of findings at the country visits

We consider New Zealand as a promising practice for having formally established one of the most CRPD-compliant Article 33(2) monitoring frameworks and for having a clear commitment at State level to comply with the obligations of the Convention. Furthermore, the Independent Monitoring Mechanism has a composition that is fully in line with the provisions of the Convention, in terms of its independence, involvement of DPOs and mandate to carry out promotion, protection and monitoring. While the financial sustainability of the framework was questionable at the time of the country visit, the government showed clear intention to further finance the activities of the framework.
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**VI. Discussion and analysis**

In this chapter, we bring together the evidence and data to answer the central research question and other sub-questions that we raised in the beginning of the thesis. In the beginning of this thesis we described that the UN CRPD includes a number of provisions to ensure that persons with disabilities will participate in society on an equal basis with others. The participation must be active and meaningful and cover all policy and law-making processes, as well as the monitoring of the CRPD.

As a result of the long-term exclusion of persons with disabilities from such processes, it is indeed a challenging provision to implement for all States Parties. Considering that the participation of persons with disabilities and their representative organisations is a key element in making the CRPD real, it was timely to carry out research in this area and see the status of the implementation of these provisions of the Convention. The participation of Disabled People’s Organisations would also contribute in narrowing the implementation gap that lies between international law and domestic implementation.

In the previous chapters we presented the methodology that was developed to collect data on the current level of involvement of persons with disabilities and also the initial aim of the research to explore the criteria of meaningful participation through good practice case studies. The previous chapter presented the findings of the field trips, thus we are now going to summarize what the research has found regarding achieving meaningful participation of persons with disabilities and their representative organisations in monitoring the implementation of the CRPD.

The main findings therefore will be discussed in the broader context of policy and implementation building on the theoretical framework of new social movements’ involvement in the development of law, policy and monitoring the implementation of the international Treaty. We will particularly focus on the challenges for Disabled Person’s Organisations
Main findings and remarks on achieving meaningful participation of persons with disabilities
to engage in these processes and develop meaningful working relationships with the governments and the human rights system.

10 Main findings and remarks on achieving meaningful participation of persons with disabilities

10.1 Participation in policy and implementation

As we discussed in Chapter 1 of the present thesis, policy-making and implementation are very complex processes. The meaningful involvement of persons with disabilities and their representative organisation draws a number of challenges to policy makers and the human rights system that did not collaborate with DPOs in a systematic way before. This section will discuss the findings of the empirical data collection in light of the main theoretical concepts that were highlighted in the literature review.

10.1.1 Active involvement-effective involvement

Regarding citizen’s participation in policy-making processes, we have discussed earlier Arnstein’s ladder typology and the participatory provisions of the UN CRPD, especially under Article 4(3) and 33. Article 4(3) CRPD requires States Parties to closely consult and actively involve persons with disabilities and their representative organisations in law and policy-making processes. Arnstein considers the participation of groups that were excluded from decision-making in policy-processes as a cornerstone of democracy and developed a typology to assess the quality of involvement. What the Convention requires under active involvement does not guarantee that the government would consider the contribution of civil society organisations. Even in Arnstein’s typology, active participation falls under ‘Placation’ and would be considered tokenism as long as the power holders have the right to judge the legitimacy or feasibility of the advice they receive from civil
Main findings and remarks on achieving meaningful participation of persons with disabilities

The main limitation in the concept of active involvement is that while it requires a great amount of contribution from civil society to maintain the semblance of participation, it does not guarantee that these ideas will be considered in the final outcomes. During active participation, civil society organisations regularly attend meetings and dedicate their time to the process. They carry out extensive preparatory work, collect information, prepare submissions, write position papers and consult with their membership on finalising the suggestions towards policy makers. Without any adequate compensation or available resources, civil society organisations could easily be exploited for their heavy workload. In contrast to active involvement, effective involvement occurs only if the contribution of organisations of persons with disabilities is reflected in the final version of the adopted laws, policies or programmes. As a representative from a Zambian DPO highlighted about the difference between active and effective involvement:

‘If you facilitate a platform where you meet then you make a unified submission to the government, and the government should listen to you. Practical example of this process: the government want consultation to review the 1996 Disability Act, the process was consultative, IMU got involved, the draft went to 2nd reading to the Parliament with the opinion of different stakeholders. Effectiveness is when the opinions are not left out.’ (Z3)

The best possible case for organisations of persons with disabilities is when all of their suggestions are included in the final text of the document. However, most commonly contributions are only partially considered. One of the greatest challenges is to measure the effectiveness of participation and define whether the level of involvement is satisfactory for the disability movement. More research

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474 If the contributions of allies of the disability movement, such as human rights organisations, make it into the final texts, but those provided by DPOs themselves do not, then the involvement could not be evaluated as effective.
Main findings and remarks on achieving meaningful participation of persons with disabilities

is necessary on exploring what percentage of proposals of DPOs are usually considered by the government and what would be the minimum level of consideration that would satisfy civil society depending on the issue and other circumstances.

However, we need to be realistic about the feasibility of some demands of civil society and to accept that just because advice comes from disability organisations does not mean it’s the right advice under given circumstances. Admittedly, the contribution of civil society organisations will not always provide policy makers with high-quality input. In assessing participation it is extremely important to develop effective indicators to measure the difference between the governing bodies’ reluctance to involve the voices of persons with disabilities in policy making and the disregard of their contribution on a purely professional basis. In the latter case, the government should still consider the same civil society organisations as partners in future policy-making even if the collaboration sometimes does not meet with their expectations. This chapter will also present some indicators that have been developed on the basis of the findings of the empirical research.

Potentially, the input of DPOs based on previously identified advocacy goals could represent a completely opposite approach to the initial plans or policy directions of the government. Nevertheless, the interests of other lobby groups should be also considered by the State. Yet the ratification of the CRPD guarantees that the views of representative organisations of persons with disabilities are heard in policy- and decision-making processes. It must be a guiding principle for decision-makers when they choose their advisors on issues that are clearly disability-related. Having said that, the government could still evaluate DPOs’ contributions negatively to justify its lack of effort in establishing the space for meaningful participation.

Considering all the abovementioned arguments, when evaluating the implementation of Article 4(3) of the CRPD it is important to assess whether the participation of civil society through various methods is
Main findings and remarks on achieving meaningful participation of persons with disabilities

not only active but also effective. We suggest that a conceptual division between ‘active’ and ‘effective’ participation should be applied in further studies focusing on the involvement of persons with disabilities in policy processes.

Respondents of the questionnaires highlighted several important factors that would be necessary to achieve effective involvement. Interestingly, there were many overlapping points regardless of the respondent's country of origin or satisfaction with the current level of involvement. The factors mentioned in the questionnaires as prerequisites of effective involvement are:

<table>
<thead>
<tr>
<th>Factors to achieve effective involvement</th>
<th>Example on area of application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education/capacity-building for the organisations of persons with disabilities</td>
<td>On democracy, human rights, public policy, legal and policy, building networks with politicians and other stakeholders</td>
</tr>
<tr>
<td>Training for decision-makers</td>
<td>Meeting techniques, accessibility, transparent and accessible communication and information</td>
</tr>
<tr>
<td>Financial support and remuneration for DPOs that participate in public processes and in monitoring the CRPD</td>
<td>Defining a per-head figure, independent funding to be used for monitoring CRPD</td>
</tr>
<tr>
<td>Giving a voice to all persons with disabilities including those who are not members of the umbrella organisations</td>
<td>Mapping the disability movement, recognizing the diversity of it and developing various expert groups in different policy areas, shared responsibilities, and equal opportunities for all persons with disabilities</td>
</tr>
<tr>
<td>Obtaining the necessary knowledge, adequate complaint procedure, advisory services</td>
<td>Consideration of disability as a cross-cutting issue instead of a social issue</td>
</tr>
<tr>
<td>Participation from the beginning throughout the whole process</td>
<td>Transparent policy-making processes by the government</td>
</tr>
<tr>
<td>Continuous evaluation of participation</td>
<td>Developing indicators, traceability</td>
</tr>
<tr>
<td>Hiring persons with disabilities in administrative positions as experts</td>
<td>Advisory boards, external consultation, impact assessments</td>
</tr>
</tbody>
</table>

Table 12 Conditions of effective involvement

10.1.2 Tokenism in involving persons with disabilities in policy processes

The literature review showed that while civil society groups have several ways to influence and engage with those processes, the quality of involvement is often tokenistic and unable to influence the outcome
Main findings and remarks on achieving meaningful participation of persons with disabilities of policy processes significantly. Because of long-term social exclusion, the admittance of people with disabilities as partners in various spheres of public life is still on-going or has just barely taken off. The binding nature of the UN CRPD as a legal instrument and its various provisions regarding the participation of persons with disabilities – most importantly in Articles 4 and 33 of the Convention – guarantee entry for persons with disabilities to participate in the community. First and foremost, the State must show clear commitment to plan the form of engagement with disability organisations. Without an intention to acknowledge and use the contribution of persons with disabilities, the involvement will remain tokenistic. It seems very challenging to successfully avoid tokenistic practices and to create a space where persons with disabilities are treated as equal and acknowledged partners. Unfortunately, past stigmas still dominate the discourse about persons with disabilities as participants and rely on the medical model instead of the social or human rights model of disability.

We applied Arnstein’s typology to assess the quality of participation in policy processes. It is important to note that Arnstein’s typology has certain limitations in the context of disability. In its original form the model dealt only with citizen participation, excluding those who are deprived of their citizenship rights. This would potentially exclude people with intellectual or psychosocial disabilities who are under guardianship. Another potential limitation of the model is that it reflects the formal equality model and is thus unable to consider persons with disabilities who require reasonable accommodation to participate. It is therefore necessary to expand the scope of the theory and include those persons with disabilities who are deprived of their citizenship rights contrary to international legal

475 See: Frawley&Bigby, Gubbels, Arnstein.
476 Furthermore, persons with disabilities should not be considered solely as disabled people, but as individuals who have expertise on issues beyond their impairments as well.
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Furthermore, the typology was designed to explain the participation of citizens in the 1960s, so it offers no real answers on how to remove the longstanding social barriers that have prevented other marginalised groups from participation. Considering that persons with disabilities have lived in extreme oppression and segregation for centuries, collaboration with power holders is a fundamentally new experience. Although capacity-building is mentioned in the typology, it will be necessary to consider other factors to provide a more comprehensive list of the changes required. This is important to keep in mind when adapting the model to the participation of organisations of persons with disabilities and using it as a basis for further developments.

We found that the concept of tokenism describes well the lack of meaningful participation in policy processes and implementation. Unfortunately, the barriers between various tokenistic and meaningful forms of involvement are not commonly recognised, so tokenistic consultation is often regarded as participation. Even in cases when persons with disabilities are formally involved in policy processes, they may barely influence the outcomes in a significant way. In Arnstein’s typology, both consultation and placation represent tokenism; however, we consider active participation a form of participation that at least ensures the involvement of persons with disabilities from the planning stages. This is already a key shift from past practices, and governments should be commended for this act. We perceive that an additional division is necessary to overcome the challenges that occur in the process of involving persons with disabilities.

Presumably, tokenistic practices are easily maintained under circumstances where change is enforced externally – for instance through the obligations of international law – and has not arisen genuinely from the community as a response to common dissatisfaction about exclusionary practices. It is extremely difficult to prove tokenism,

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477 Article 12 of the CRPD requires States Parties to recognise ‘that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. UN CRPD.
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especially because the victims are often groups that have never experienced full participation and the level of tokenistic consultation might already seem a great achievement. For instance, organisations of persons with disabilities were rarely consulted during public policymaking in the past, and that could lead to appreciation of any form of consultation instead of complaining about the lack of full participation. Nevertheless, capacity building and empowerment of organisations of persons with disabilities are essential to enable persons with disabilities to have a real voice and address dissatisfaction with ongoing practices. The situation is not even satisfactory in wealthy countries, where human and financial resources would be available to challenge tokenistic practices.478

10.2 Challenges for the disability movement in the course of participation

During the empirical data collection of the present thesis, all the strong disability movements that we saw evolved as grass-roots movements and were initiated by persons with disabilities themselves. Past examples also show that this is the only way to tackle oppression effectively. It would hardly have been possible for the black movement to achieve any of its goals had it been organised by a group of privileged white people. The exact same logic applies to the disability movement if we want to ensure that the development of their new social movement results in the restoration of their voice and their full participation in society. Without taking a clear approach on that, it is feared that the disability movement will just reproduce in its internal mechanisms the same exclusive, paternalistic patterns that were dominant in the past. The disability movement must seek a position of equal recognition as other new social movements, so that discrimination on the basis of

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disability becomes as inadmissible in public discourses as racism, xenophobia, homophobia or male chauvinism.\footnote{According to scholars like Abberley, working on disability can be compared to undertaking research on the subjects of racism or sexism. This is part of the scholarly notion of disability as a form of social oppression. See: Beckett (2006), p. 96; Abberley, P. (1993), ‘Disabled People and normality’, in: Swain, J. et al (eds), Disabling Barriers – enabling environments. London: Sage in association with the Open University.}

10.2.1 Fragmentation and its affects on collective participation

The issue of fragmentation of the disability movement as a realistic concern was addressed in the literature review. Fragmentation was also a re-occurring issue during the empirical data collection of the present thesis. Mostly the voice of persons with intellectual disabilities and psychosocial disabilities were absent in the joint actions of DPOs to engage with the implementation and monitoring of the CRPD. Self-advocacy groups faced a number of barriers. At the individual level the most common barrier was the lack of leadership skills and experience in acting as an advocate. Some people might lose motivation if results do not come progressively or in line with the invested commitment. Training and peer support can help to overcome these barriers effectively. At the group level both structural and practical barriers were mentioned. Beside personal conflicts, the most common problems were the overprotection of support people and the difficulties of ensuring transportation to attend all meetings. At the systematic level, self-advocacy groups have to face barriers in accessibility, the lack of acknowledgment by service providers or parents, and the lack of general public awareness of the activities and importance of groups composed of persons with learning difficulties. It is extremely difficult for self-advocates to challenge deeply rooted antipathy and scepticism of the community's ability to stand up for their rights and articulate their own needs. However, the more visibility self-advocacy groups enjoy, the more effectively they can challenge longstanding stereotypes.
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It is important to note that accessibility requirements for persons with intellectual or psychosocial disabilities reach beyond the commonly known technical devices or services, such as ramps for wheelchair users or sign language interpreters for deaf people. If a group of blind advocates need to work together with advocates who have physical impairment, they could easily create a comfortable working space by ensuring the meeting is accessible with a wheelchair\textsuperscript{480} and for blind people as well.\textsuperscript{481} Other than providing the generally known accessibility features, meetings could be carried out in a regular way. In order to be reasonably accommodated, persons with psychosocial disabilities for instance might require a flexible working schedule, shorter meeting sessions with regular breaks, natural light, less assertive ways of communication, and other comforting facilities. Regarding persons with intellectual disabilities, most likely there is a lack of willingness to make the world more accessible for them by slowing things down and providing all information in plain format. The complicated language used in academia, in the judiciary, in governance and in science prevents persons with cognitive impairments from understanding material. This applies to persons with lower levels of education or illiteracy as well.

These are just a few examples to demonstrate the different needs and the lack of commonality in reasonably accommodating persons with psychosocial disabilities and other impairment groups. The existence of the Hearing Voices Movement shows that it is possible for people who have less common disabilities or psychological problems to carry out human rights advocacy. The Hearing Voices Movement aims to provide peer support for people who hear voices to cope in a non-medical way with their experiences.\textsuperscript{482}

\textsuperscript{480} For example, ramps, accessible elevators, accessible toilets.
\textsuperscript{481} For example, Braille signs on the elevator, using PowerPoint presentations that are in accessible format, permission to bring a guide dog in the building.
\textsuperscript{482} More information about the Hearing Voices Movement is available at: \texttt{<http://www.intervoiceonline.org/>} (accessed 17 April 2014).
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The main reason for fragmentation lies therefore in the heterogeneity of the disability movement and the wrong assumption that people with different impairments have a lot in common. Fragmentation occurs not only between different groups of disabled people, but also among people having the same or very similar impairment. This draws attention to the fact that persons with disabilities are very different people with different needs and attitudes. It is commonly known, but was also drawn out during the interviews in New Zealand that some parts of the deaf community advocate for special education. In their views, using sign language is part of their culture and they would argue that, similarly to ethnic minorities, deaf people should be accepted to use their own language. They are fighting for deafness to be acknowledged and respected as a cultural issue. This part of the deaf community would advocate for the right of deaf children to attend special schools where education is provided in sign language, and would emphasise the importance of mainstreaming and preserving national sign languages and deaf culture. Other segments of the deaf community might think differently and argue that in the scope of international human rights provisions, deaf students should be included in mainstream education. Article 24 of the CRPD states that inclusive education is the appropriate form of education to be provided to children with disabilities, opposing traditionally segregating educational practices. However, a policy maker should be aware of the existence of these completely different approaches and incorporate them somehow in new laws, policies or programmes. Variety in the movement shows that persons with the same impairment cannot be expected to share the same views and fight for the exact same purposes.

Similarly, an activist belonging to one segment of the disability community does not necessarily want to advocate for all persons with disabilities. Having certain impairment does not mean full understanding of all the struggles other people with different impairments and socio-economic backgrounds face every day. This is particularly true of persons who are facing multiple-discrimination.
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Likewise, members of the disability movement could have very diverse value systems and approaches to human rights. In other words, having one type of impairment won’t automatically make a universal human rights activist willing to promote social inclusion for everyone.

Furthermore, we saw that fragmentation can result from a natural characteristic of political movements, notably that some organisations are weaker over a certain time. Ideally they eventually become stronger through empowerment and capacity building to make their voice heard. Although social movements are constantly changing structures, it is expected that not always the exact same organisations be excluded from the movement. For instance, if it is always the organisations of people with learning disabilities who are marginalised in the movement, it can result in a very fragmented movement where the voice of persons with learning disabilities is never heard.

The disability movement is an important space to internally adopt and manifest the paradigm shift. The disability movement must be the main engine of the social change towards the full inclusion of persons with disabilities. This means that no persons with disabilities should feel excluded from the disability movement on the basis of their impairment. The results of the present thesis convincingly show that the CRPD will only bring forth significant change if the full and effective political participation of persons with disabilities is being realised. Governments, policy makers, society and families of disabled must make significant changes in their attitudes and practices. However, the reproduction of exclusion within the disability movement would be very concerning and might eliminate the realisation of the rights of persons with disabilities. If persons with cognitive, psychosocial or multiple disabilities cannot participate effectively in the work of the movement, their voice won’t be represented at local, national or international level either.

483 The abolishment of guardianship, full inclusion in education, or combating ill-treatment are example areas where even some parts of the mainstream disability movement could express concerns.
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A fragmented disability movement therefore risks maintaining the exclusion of those who require more support to fully participate in the mainstream movement. The isolation of such groups does not help to make the paradigm shift from the medical to the social or human rights model widely accepted across all layers of society. The disability movement should be inclusive of all persons with disabilities, and work together to present a joint force by valuing the differences of its members.

It is also necessary to clarify the extent of interpretation of the motto 'Nothing about us without us!' when it comes to actual policy- and decision-making. 'Nothing about us without us' could refer to both processes and their outcomes that affect the lives of persons with disabilities. If we want to interpret 'Nothing about us without us' literally and read it together with Articles 4(3) and 33 of the CRPD, it would mean that no law or policy affecting the lives of persons with disabilities should ever be adopted without the agreement and authorisation of persons with disabilities and their representative organisations. This would be an extremely strict burden on policy makers and would also present a concerning shift for power holders in the redistribution of powers. Civil society becoming an owner of policy would have numerous long-term impacts. As explained earlier, there is a distinct independent role dedicated to civil society to oppose and criticise the work of the governing bodies. This critical and preferably independent voice characterises civil society. Therefore it is feared that the more the organisations of persons with disabilities get involved in policy-making, the more they would lose their credibility as civilian forces. A direct consequence would be that these organisations merge into an advisory role serving the government. There is a thin line between policy ownership and meaningful involvement; however, it has to be clarified that the aim of the CRPD is to restore the voice of persons with disabilities and not to create anti-democratic structures. It would be an unequivocally anti-democratic decision to support some civil society groups in practising the act of policy-making instead of leaving
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this role to the government. It is the government that has legitimised power from society to create new laws and adopt short- and long-term policies and programmes. When civil society advises the government it is doing so from an external role, maintaining its mandate to provide criticism or organise direct demonstrative actions.

Since the disability movement intends to contribute usefully to policy-making, the value of the participation of persons with disabilities, as ‘experts by lived experiences’ should be acknowledged widely. Having said that, it would be too ambitious to claim that members of the disability movement are experts in all fields of policy. The incontestable and primary benefit of their contribution is to bring first-hand experience to negotiations on matters that directly affect the lives of disabled people. The input of the disability movement will ideally be considered and used by policy-makers, but the resources of advocacy groups should not be exploited. Incorporating local experiences would help to find answers to real problems, and decrease the voice of professionals.484

10.2.2 Representation, participation, centralisation of the disability community

The rapid increase in the number of organisations that represent persons with disabilities at local level requires some co-ordination. It would be quite challenging for small and medium-sized national NGOs to ensure representation at higher level, for instance at European or international levels. It would also be insufficient to lobby in an isolated way instead of concentrating limited resources. DPOs in almost all EU Member States create national associations to represent disabled people more effectively before government.485

485 For example, the Austrian National Council of Disabled Persons, an umbrella organisation representing 78 member associations with over 400,000 members.
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Umbrella organisations in the disability field often claim to represent the interest of all persons associated with their member organisations. In reality, it is likely that their initiatives have little impact on the lives of those living in rural settings and hardly even reach the local branches. When it comes to contributing to law and policy-making and negotiating with governing bodies, only a limited number of advocates can represent the disability movement. The space opened up by the CRPD in Articles 4(3) and 33 is therefore available only for a small, rather privileged part of the movement. In order to ensure that democratically elected leaders will represent the voice of persons with disabilities, umbrella structures are still the best available structure.

There are a number of potential burdens that could prevent members of a national or international umbrella organisation from participating in its work. First, it requires considerable human resources to provide input to policy documents. At national level, many NGOs continuously struggle for sufficient resources to carry out even their regular local activities. As mentioned earlier, many disability organisations face difficulties in getting funding for advocacy, and some have to provide services to maintain a stable income.

Another concern is that according to recent studies, in a number of developing countries, persons with disabilities are unable or unwilling to use their voice. It is assumed to be the lack of activist culture and consciousness of human rights advocacy.\textsuperscript{486} If no local advocacy groups exist, global organisations cannot be the representative voice of persons with disabilities living in these areas. It is necessary to emphasise, in order to avoid being too ambitious, that umbrella organisations represent only their members and not all persons with disabilities. Furthermore, there will always be people who are not represented by any of the big umbrella organisations. Having said that, the global advocacy work could still have a positive impact on their lives.

\textsuperscript{486} Meyers (2014).
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Nevertheless, the more persons with disabilities make their voice heard, the more likely they will say different things. Too many opinions could lead to the weakening of the disability movement, as some leaders believe that ‘the international disability movement can only advance if the disability community continue to speak with one voice’.487 Brysk notes that recent human rights campaigns have only been effective when all the participants lobbied along the same agenda. This means that in order to form a unified message, many distinct voices and views must be neglected. Thus, despite the intention at the grass-root level to designate national representatives to speak up on their behalf, leaders of the advocacy movement are the ones setting the goals and strategies. The main problem with this shift of powers is that local actors are often obliged to stick to a predetermined advocacy strategy instead of determining the directions themselves and making their voice and opinions heard through the international human rights campaigns.488

It naturally arose during the data collection that the challenging aspect of representation is always to identify those people or groups who are in fact not represented by any of the organisations that claim to represent the whole group. The representation of persons with profound intellectual and multiple disabilities in policy processes and in monitoring the CRPD is completely absent based on the data collected for the purposes of this research. This group have complex needs, often face difficulties expressing themselves and likely have problems using the most common forms of communication, such as verbal communication. 489 They therefore rely heavily on other people’s support and ability to understand their needs.

One of the most challenging questions for participation is what could the CRPD and its obligations offer persons with profound intellectual disabilities who have limited communication skills and more complex needs than persons with other impairments. Is it too

488 Meyers (2014).
489 Inclusion Europe (2003).
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Idealistic to claim their participation on an equal basis with others? Or does active involvement in the development of law- and policy-making processes and in monitoring the Convention apply only to those whose special needs are easier to accommodate? Certainly, the category of ‘all persons with disabilities’ includes those with more severe impairments if we take inclusion seriously. However, this research shows that there has not yet been considerable attention to involve persons with profound intellectual disabilities and multiple disabilities in the implementation of Articles 4(3) and 33 of the CRPD.

Who will represent persons with profound intellectual and multiple disabilities in decision-making processes is therefore of great concern. There should be a paradigm shift in public discourses from a care model towards a social or human rights model including this group effectively. Participation is a very important human rights principle regardless of the severity of someone’s impairment. Persons with profound and severe disabilities also need to be listened to and informed about changes and decisions that affect their lives. It is essential that they be recognised as persons and not considered as second-class citizens. The ability to make decisions about how they want to live their lives and what services they want to receive is the key element of independence and must not apply only to the better-functioning members of the disability community. At this point, there is a clear contradiction between the universality of human rights and the lived experience of persons with more severe disabilities.

We do not deny that many persons with profound intellectual and multiple disabilities face significant difficulties in expressing whether they have an interest in participating. At the same time, not applying alternative communication methods could lead to psychosomatic reactions. It has been proved that ulcers or depression often occur if changes in the life or daily routine have not been explained properly to the person.490 During the interviews with stakeholders of the research project it was said several times that persons with severe intellectual

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disabilities would never be able to understand issues happening around them. It was considered naïve to expect their meaningful participation in advocacy. In other words, it is only tokenistic participation that could be expected from people who do not have the cognitive or mental capacity to understand on-going issues and their relevance to daily life. In general, strong renunciation and neglect characterises the attitude towards the participation of persons with severe and profound intellectual disabilities. Beyond the general attitudes, the self-advocacy movement itself excludes the voice of this group. As Inclusion Europe notes, despite some promising models of good practice, self-advocacy remains underdeveloped in the group of persons with severe and profound intellectual disabilities.491 Their representation through their families is the most common form of representation today.492 Even academic literature shows scepticism towards the ability of persons with profound intellectual disabilities to express their will and represent themselves.493

As Inclusion Europe recognises, ‘people with severe and profound intellectual disability require a re-thinking of the concept of self-advocacy’.494 This means that the scope of self-advocacy might be limited to decisions about their alimentation, support person or daily activities and lack a more political angle. However, it should not be assumed a priori that persons with profound disabilities couldn’t even make these basic decisions themselves. Members of society and self-advocates with intellectual disabilities must try to understand the wishes and needs of persons with profound disabilities as much as possible. Within the self-advocacy movement it is essential to avoid reproducing further discrimination and marginalisation in the group by excluding persons with profound disabilities from participation.

491 Ibid.
492 Ibid.
494 Inclusion Europe (2003).
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Inclusion Europe provides recommendations on how to involve persons with severe and profound intellectual disabilities in a more meaningful way.\textsuperscript{495} According to them, the most important thing is to ensure basic needs are satisfied, for instance providing medical and technical aid, and ensuring the position of the body is as comfortable as possible. Communication is marked as the most challenging area, as significant time is needed to develop efficient communication methods tailored to the individual needs of the person.\textsuperscript{496} However, participation in various everyday activities such as household, social or leisure activities remains challenging, according to the study. The presence of a close relative or a steady supporter who is familiar with understanding the signs and wishes of the person could be very helpful during interactions. Undoubtedly, persons with profound disabilities face great challenges to participate in complex policy-making or decision-making at national or global level. We therefore need to identify the minimum satisfactory level of their involvement and aim to achieve at least that level. It might be useful to look at Mansell’s suggestion on the adoption of the ‘active support model of care’\textsuperscript{497} by staff in residential facilities that significantly increases the participation of persons with severe and profound disabilities in meaningful activities.\textsuperscript{498} Active support is a very useful approach to enhance the involvement of persons with severe and

\textsuperscript{495} Inclusion Europe (2003).
\textsuperscript{496} Some of the alternative communication methods are: ‘basic communication’ (developed by Winfried Mall, it focuses on the interpretation of muscle tone, movements and respiration); ‘conductive education’ (developed by András Pető, it aims to teach children to achieve the maximum level of independence in daily life); communication methods based on symbols and pictograms; various communication methods with the use of computer and technology. See: Inclusion Europe (2003).
\textsuperscript{497} According to Mansell et al. (2002), active support has four main components: 1. Service users are offered opportunities to take part in everyday activities at home and in the community, instead of childish or special therapeutic activities; 2. Staff pay particular attention to working as a team and to scheduling and co-ordinating the choices and opportunities they offer; 3. Staff focus on helping service users take part minute-by-minute, finding the parts of complicated tasks that even the most disabled person can do, and doing the other parts themselves, so the person is almost guaranteed to succeed; 4. Staff carefully monitor, using simple record-keeping procedures, the degree to which service users are taking part in ordinary activities with the right level and kind of support. See: Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B. & Macdonald, S. (2002), ‘Engagement in meaningful activity and “active support” of people with intellectual disabilities in residential care’, Research in Developmental Disabilities, 23 (5).
\textsuperscript{498} Mansell et al. (2002), p. 342.
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profound disabilities in making decisions that affect their lives, or in monitoring the violations of their human rights as part of Article 33 of the CRPD. Without reconsidering complex working methods in policy- and decision-making processes, and the willingness to apply alternative forms of communication at all levels of the support system, persons with severe and profound disabilities will continue to be excluded even from simple but important decisions where they could express their wishes. We argue that creating accessible structures and processes must also aim to achieve greater involvement of people with the most severe impairments as much as possible.

10.3 Article 4(3) and 33 CRPD: DPO’s participation in the newly opened spaces

In this thesis, we considered the framework that is to be established under Article 33 of the CRPD as a dynamic one and we suggested taking a process approach when evaluating whether the collaboration between government and DPOs during implementation, and the cooperation between NHRI and DPOs during monitoring, are both active and effective. Based on the experiences of the case studies, we can say that the members of the Article 33 frameworks change frequently, and this often affects the functioning of the framework considerably.

The figure below demonstrates the three pillars of the Article 33 framework and the bilateral interactions addressed in the CRPD. The left side of the figure shows the relation between the government and NHRI. The State provides all necessary structural requirements for the NHRI to carry out its ‘watchdog’ role independently in light of the Paris Principles and provide legal expertise to the governing bodies to interpret international law. On the right side we can see the relation between the State and DPOs. The government is required to implement the provisions of the Convention with the strong involvement of persons with disabilities in the development of law, policies and
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programmes. DPOs must retain their critical voice as civil society organisations, advocate against bad laws and policies, and provide the government with information on the lived reality of persons with disabilities. At the bottom of the diagram we present the relationship between NHRIs and DPOs during monitoring of the implementation of the CRPD. They can contribute to the monitoring with their different expertise and viewpoints on human rights violations. Nevertheless, NHRIs must clearly understand the importance of considering the most credible voices: persons with disabilities themselves. While NHRIs have top-down legal expertise to monitor human rights violations, persons with disabilities have the bottom-up knowledge based on first-hand experiences. NHRIs therefore should expand their partnerships with DPOs instead of engaging with traditional human rights organisations. NHRIs must develop more accessible and transparent working methods to ensure meaningful engagement with DPOs. As a parallel process, DPOs should build their capacities to gain a great understanding of the UN human rights system and international human rights law in general.

Considering that the Paris Principles explicitly require the involvement of persons with disabilities in the management board of NHRIs, we can expect NHRIs to more ambitiously involve members of the disability rights movement in monitoring the implementation of the CRPD. This research found that in countries where the NHRI employs people from the disability movement for the role of Disability Rights Commissioner or an equivalent position, the working relationship between the Human Rights Commission and national DPOs is a lot more meaningful than where the Commissioner has a purely professional legal background. The collaboration between NHRIs and DPOs could certainly have a mutually positive impact on each other’s work. Monitoring is dynamic, and a well-established framework will not itself guarantee sustainable and continuous evaluation. Without building the capacity of DPOs on human rights law and monitoring practices, and NHRIs committing to build partnerships with the organisations of persons with all kind of disability, it is unfeasible to carry out all functions in a systematic way.
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During this research, when asking interviewees about the implementation of Article 33 of the CRPD, some NHRIs and DPOs seemed more to be competing entities than co-operating partners. NGOs often consider themselves as ‘independent voices’ that could potentially conflict with the independent mandate of NHRIs. In reality, DPOs often rely on government funding, which makes confrontation with the government difficult. One of the main areas where NHRIs could make a particular impact is independent reporting on human rights violations to the State and internationally. Indeed, it is a concern that those states that have no intention to comply with CRPD obligations would designate a less independent body with smaller international influence and power, like a disability advisory committee or a local disability organisation, to carry out CRPD monitoring.

Admittedly, in times of the emergence of NHRIs worldwide, NGOs rightly question whether human rights conditions have improved. The UN has spent significant resources promoting the establishment of NHRIs as a top priority in order to achieve greater protection of human
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According to Goodman and Pegram, some local NGOs believe they would have received more funding from domestic and external sources in the absence of the NHRI. NGOs in that sense somehow compete with the human rights institutions for the limited resources available in the human rights field. This may cause tensions, as NHRI have a more stable status and funding guaranteed by law, unlike civil society organisations. However, the activities of NHRI and NGOs should complement each other as they have a common goal in removing current barriers and tackling human rights violations against persons with disabilities effectively.

The Concluding Observations on the implementation of Articles 4(3) and 33 of the CRPD showed that there is a lack of effective involvement of persons with disabilities and the lack of governments’ efforts to comply with their international obligations when establishing the monitoring mechanism. We were right in assuming that the implementation of Article 33 and the establishment of a CRPD-compliant monitoring framework are a great indicator to measure governments’ willingness to open up spaces for persons with disabilities. If the monitoring framework is not adequately established, and persons with disabilities are not involved in promoting, protecting and monitoring the implementation of the Convention, it is likely that their general involvement in law- and policy-making will fail to be accomplished. The CRPD Committee could help States Parties to understand the exact requirements of Articles 4(3) and 33 of the CRPD by issuing General Comments on both articles.

Regarding the current level of involvement in policy- and decision-making, it is already clear from the research results presented above that there is great variety at national level. For example, in Denmark, the national umbrella organisation is considered an expert by the government and is regularly asked to contribute to law- and policy-

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Making. In contrast, in Malta the umbrella DPO is refused permission to take part in any such processes and lacks funding to maintain its operations successfully. Many respondents highlighted that meaningful participation can be guaranteed by offering membership of government body committees to disability advocates and by giving DPOs sufficient funding to carry out their tasks.

It is already a positive sign if the views of DPOs are taken into account by the government, but it should be ensured that they influence the outcomes and are directly involved in developing important disability-related legislation and national disability strategies. Governments need to have a great understanding of the internal politics of the disability movement and involve also the voice of those NGOs who are not represented by the umbrella organisation. Considering that having dialogues and collaboration with disability organisations is a novelty for governments, the respondents for the questionnaires highlighted the importance of providing them with training and developing toolkits. It was also suggested that the representivity of DPOs should be improved by capacity building to enable a broad range of people to contribute to policy-making.

The research also found great diversity in the current levels of involvement in the Article 33 monitoring framework. In countries that have not ratified the CRPD, we got information on involvement in the preparation to establish a monitoring framework. DPOs greatly appreciate being involved in planning the monitoring framework and having a voice in its composition. Involving DPO representatives in the management board of the NHRI designated as the Article 33 independent mechanism is also evaluated positively. Some respondents expressed satisfaction about the good collaboration with the NHRI as independent mechanism, while others lobbied for the establishment of a new type of commission that is independent but involves the voice of persons with disabilities. Some respondents emphasised that currently the greatest concern is that DPOs are involved in the work of the
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monitoring framework on an ad hoc basis without any additional funding provided for them.

10.3.1 New Zealand

During the country visit in New Zealand, on the basis of our qualitative interviews with a number of stakeholders we found, that New Zealand is a good example of opening the space created by the CRPD between governments and the organisations of persons with disabilities in a meaningful way. Based on the collected data, we do not claim that all policies and programmes are currently in line with the provisions of the CRPD, but we argue that the government makes exceptional efforts to fulfil its obligations under the Convention and involve the voice of persons with disabilities in policy-making and monitoring the CRPD through an effective mechanism.

A number of interviewees, including the Human Rights Commissioner, highlighted that although New Zealand created aspirational visions, the effective implementation of many of those still lies ahead. New Zealand is a country that is keen on raising the bar and the government is taking on provisions that might be difficult to implement, but that contribute to the effective inclusion of persons with disabilities. While some government departments are working hard on creating processes that ensure the full and meaningful participation of persons with disabilities in policy-making, representatives of DPOs still gave accounts of tokenistic practices and the exploitation of DPOs’ limited resources.

The designation of the Independent Monitoring Mechanism as the framework to promote, protect and monitor the implementation of the CRPD has a structure that is compliant with the Convention, unlike many other States Parties. The Mechanism fulfils all the five criteria that ensure compliance with the CRPD, and it is an especially positive sign that the government secured some funding for the operations of the framework. The framework goes beyond its direct function and
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provides a platform for the organisations of persons with disabilities to improve their working relation, identify common goals, and overcome on-going tensions. The disability movement in New Zealand is also fragmented, but maybe less than in other countries. Persons with psychosocial disabilities and intellectual disabilities are not yet represented in the participatory mechanisms on an equal basis with others. In order to overcome the implementation gap and create a fully inclusive society, capacity building for governing bodies, sustainable funding for the Monitoring Mechanism and systematic work are necessary to be carried out in the future. In the case, where persons with visual impairment expressed their negative feeling about working with some persons with psychosocial disabilities, the lack of reasonable accommodation was probably the main reason that led to the unbearable working atmosphere.

10.3.2 Zambia

The country visit in Zambia clearly showed that there is a very strong, well-organised disability movement actively involved in implementing the CRPD through a grass-roots initiative, the IMU. However, the government has neither formally designated the IMU as an Article 33(2) monitoring framework, nor provided funding for its operation. Therefore, the Zambian solution cannot be considered as a promising practice for the Article 33 implementation. Yet the disability movement raises awareness of the Convention, actively participates in law-review processes, and strategically plans its advocacy work. In its view, persons with disabilities should play the leading role in advocacy from the very start.

According to Article 33 of the CRPD, an independent element, preferably the Paris-Principles-compliant National Human Rights Institution, shall be involved in the framework to promote, protect and monitor the implementation of the CRPD. In Zambia, despite the fact that the Human Rights Commission is currently not participating in the
Main findings and remarks on achieving meaningful participation of persons with disabilities

monitoring activities, civil society seems satisfied with the functioning of the framework and finds its own involvement active and effective. It may be time-consuming but it is definitely necessary to establish good relations between the Human Rights Commission and the disability movement based on mutual trust and acknowledgement. This would stimulate important structural changes and engagement when implementing the Convention.

Since the current focus of the IMU is on law review, some other tasks on protection or monitoring CRPD implementation under Article 33(2) may be neglected. They work closely with the government, which shows willingness to provide a supportive atmosphere for civilian participation and to consider seriously the submissions and professional advice of the DPOs. Facilitating the strong involvement of the disability movement in monitoring the CRPD could enrich democratisation in Zambia.

After creating a CRPD-compliant legal basis in national legislation, the IMU next aims to monitor the implementation of those Acts and the CRPD countrywide. Even if the IMU faces financial challenges, members of the disability organisations make an enormous effort to be able to sustain the monitoring activity and make a real change in line with the UN CRPD.

Drawing from the experiences of the Zambian case study, developing countries likely experience serious burdens when implementing international human rights treaties. The fact that the IMU project was founded by two major international donor organisations – the European Commission and Power International – draws attention to the obstacle that systematic monitoring activities, including data collection, require sufficient resources from the State.\textsuperscript{501} The question is to what extent a State Party should use sources of international co-operation to implement the Convention if there are no internal sources available in line with Article 4 of the CRPD.

\textsuperscript{501} The European Commission financed the project with €89,993 and Power International contributed €9,999.
11 Criteria for meaningful participation from New Zealand and Zambia

The following section presents the suggestions of the disability movement in New Zealand and Zambia to form the criteria of meaningful participation in the implementation and monitoring of the CRPD. The criteria was set up based on the issues that appeared in more than one interview in the answer of this question: ‘What do you think, what are the key factors of effective involvement?’ (Q9) This set of criteria is not exhaustive, but could serve as a great starting point in assessing the participation of the representative organisations of persons with disabilities in policy and decision-making processes. At the end of the section, we provide a table that summarizes the criteria and attach proposed indicators to each of them.

The answers in Zambia and in New Zealand showed surprisingly many similarities despite of the obvious economical and social differences between the two countries. DPO representatives of the IMU and IMM member organisations gave a clear idea of what they believe the key elements of effective involvement are. Some of the answers certainly overlap each other. It is important to note that the opinions presented here do not necessarily reflect the views of the disability sector as such.

Generally speaking, the range of critical success factors seems to be broad and sweeps beyond the common argument that the State Party is lacking money to invest in disability rights. Rather, it includes elements such as on-going democratisation and the willingness of government to build up a collegiate relation and use the expertise of civil society.

(a) Active and effective involvement

Many of the respondents stressed the importance of distinguishing between what in this thesis we call ‘active’ and ‘effective’ involvement,
Criteria for meaningful participation from New Zealand and Zambia

relating to whether or not DPOs’ contributions are considered. As a blind advocate summarized:

'I think it is really valid (to distinguish between active and effective participation)... so basically, government is constantly consulting with the disability community. But they are terrible at it, they are absolutely shocking. The best one, I think was the consultation on the UN CRPD report, so the government report: they invited us to a meeting room... at least the meeting room was accessible that was the one thing they did, physically accessible.' (NZ2)

A leader of an organisation of persons with mental health problems in Zambia highlighted that:

'Our desire is to be actively and effectively involved. We need to change the status quo, need to get out people from they are suffering. We need to be very very effective and it is key in this situation. Look effectiveness in two angles: First, for us to be very effective means, is it true that we have power to influence change?' (Z8)

With regard to the drafting of the government’s report to the UN CRPD Committee, a number of New Zealander advocates remembered inaccessible consultations in which DPOs were only provided with the draft report to comment on along with some focus questions, instead of discussing the content of the report from an early stage.

'They didn’t have materials in accessible formats, they didn’t discuss what they told people they will discuss then. So, they sent the draft report, people had commented on the draft report, but there was discussion about something entirely different. And they sent like focus questions and nobody understood what is happening.' (NZ2)

This was considered a tokenistic form of participation, as it did not give persons with disabilities the chance to influence the outcome of the process, and even the process itself was far from inclusive. In order to shift towards effective involvement, an advocate mentioned that the
Criteria for meaningful participation from New Zealand and Zambia

government must provide access to all information and be honest about the broader circumstances of policy changes.

A DPO representing blind people in New Zealand emphasised that in light of ‘Nothing about us without us’, participation must start from the very beginning of any process. It explained, through the example of changing the Auckland transport system, that early involvement of DPOs could have saved the government from making a discriminatory system for blind people, and could even have saved money if the government had made facilities accessible from the beginning instead of fixing the system later. The director of a DPO in Zambia considers that:

‘ “Nothing about us without us” it should involve disabled persons themselves, other stakeholders should be on board, but the leading role should stay at the disabled people themselves. (...) What I am saying is that let the disabled people lead the process, but they should not be left alone.’ (Z9)

A simple but straightforward definition was given by Sight Savers Zambia on how to measure the impact of civil society participation: ‘We can talk about effectiveness when our opinions are included in the final text of the law or policy document.’502 Most interviewees in Zambia expressed their disappointment when their involvement was tokenistic by being invited to meetings but not considered as partners in policy-making. They recognised when their involvement was only active, not effective. There was also an interviewee who expressed satisfaction with the involvement in the on-going law reform processes:

‘Yes, I personally feel that those comments and opinions we had, we made the Disability Act from the draft with all the comments, those comments were effective and included, so I feel we actively and effectively participated.’ (Z6)

502 See interview Z3.
(b) Commitment of the decision-makers

In New Zealand, the government in the last 10–15 years showed unprecedented commitment to ensure the full inclusion of persons with disabilities as equal citizens in society. One of the interviewees emphasised that this is not because the government particularly believes in disability rights. What has probably been very useful for the disability movement is that the current government is in power since 2008 and firmly believes in transparent governing. This leads to a very open governing style, where ministries frequently turn to people outside of the government, including the business sector and civil society. As one interviewee emphasised, ‘the public servants need to ask others, facing outwards, and talking to people in the community, in the business world, in the health system, rather than talking to themselves’. Several respondents confirmed that the government is open for discussions and invites the organisations of persons with disabilities to consult on issues affecting their lives.

In Zambia, decision-makers did not show any commitment to designate a monitoring framework in line the obligations of Article 33(2) of the CRPD. Once the IMU was established from external funding as a result of the advocacy work of the representative organisation of persons with disabilities, the government still did not take any actions to recognize it. It raises some concerns over whether the state will recognise recommendations submitted by the IMU in the future.

(c) Transparency

As we mentioned, the New Zealand government put a particular emphasis on transparent governance. This affects the implementation of the CRPD positively as well. The empirical field trip showed that transparency is taken seriously and appreciated greatly by members of

503 It spent its second term during the field trip to New Zealand in 2013.
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the disability movement. One of the key measures is the webpage of the Office for Disability Issues, which includes all relevant information and reports on the implementation and monitoring of the New Zealand Disability Strategy and the CRPD. The webpage has a very user-friendly structure, including plain-language summaries of the reports and legal texts to ensure their accessibility to the broader public. The most relevant sections for deaf people are available in sign language videos as well, respecting those who prefer to use sign language as the primary form of communication.

In the view of Opportunity Zambia, transparency is an absolute prerequisite for facilitating engagement and effective involvement.

‘There are certain types of general things on effective and successful involvement. For instance, the governance, whoever facilitates it, if it is not transparent and not getting the people on board, it makes difficult to participate in a meaningful way. (…) Open, transparent manner is a key to success.’ (Z4)

(d) Active working relationship between stakeholders

Many respondents emphasised that maintaining active and respectful working relationships is key to successfully promoting disability rights. During the interview, ODI highlighted that they maintain close personal connections with members of the disability sector, including DPOs, family organisations, and service providers, to be aware of the most pressing problems and channel them to the relevant government departments. Ministry staff goes to meet with disability advocates around the country and organise regular conferences to create platforms for exchanging views and practices. The Disability Rights Commissioner evaluated the Minister for Disability Issues’ process for picking up advice from the disability community as very effective.

DPO representatives suggested developing a knowledge-based system where people could share their experiences with the government and each other, and hopefully create a more efficient form of participation. Creating such an online platform would be more sustainable than just sharing knowledge and suggesting solutions at meetings of small groups of advocates, which often just exploit DPOs' capacity without further distributing their knowledge and ideas with the wider disability movement.

(e) Participation from early-stage of policy process

Most interviewees in Zambia noted that civil society need to be included from the very beginning in any policy-making process to ensure their voice is being heard.

'When you look at those issues, first of all, we talk about inclusion, this is number one. If the people are accepted, but not included it won’t work. (...) We want to be part of the process from the very beginning, and we want our views to be carried on board. E.g. with the Bill and the Constitution, our rights to be articulated.' (Z6)

(f) Broad collaboration

A great challenge for an advocacy platform is to ensure the participation of a broad range of people from the grass-roots level. In Zambia, ZAFOD has already established close working relations with a number of DPOs, and intends to find consensus before sending joint submissions to the government. International human rights NGOs, service providers, family organisations and researchers are important allies of the disability movement, though no considerable collaboration on CRPD monitoring has happened so far with organisations outside of the IMU.
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(g) Awareness-raising at grass-roots level

The IMU’s work in smaller villages where they bring the CRPD to raise the awareness and expand the knowledge of members of the local disability groups is certainly an important initiative to reach local people and ensure their opinions are considered when promoting the rights of persons with disabilities at a higher level.

Among other respondents, the Zambia National Association of the Deaf highlighted the necessity of capacity building and empowerment of the disability movement. This can happen through professional training sessions to teach disability organisations to write submissions and plan advocacy work. There is already interest expressed by the Zambia National Library and Cultural Centre for the Blind to attend more training on contributing to law reform.

(h) Continuous evaluation

Several interviewees emphasised that the work of the monitoring body also has to be monitored on a regular basis. The designated IMU should report back on any on-going issues to their local members in order to prevent arbitrary decision-making practices in the platform.

(i) Direct influence by providing evidence-based information

As an advocate of a DPO for persons with mental health problems emphasised, evidence-based information is an absolute pre-requisite of effective involvement in policy processes. According to this respondent:

‘In terms of influencing policy one of the biggest problems is to approach government with evidence-base information. (...) Amendments should not be made without consulting DPOs, they have information on the issue, not the government. (...) What civil society says should influence what is happening (...), convince them with information’. (Z8)
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Yet, collecting representative data across the country and providing evidence-based information seems to be the area that requires most financial resources in monitoring activities. In this regard, challenges were reported due to the limited resources in disseminating results of research carried out by disability organisations.

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<thead>
<tr>
<th>Criteria</th>
<th>How to achieve it?</th>
<th>Indicators</th>
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</table>
| **1. Commitment of decision-makers** | • Develop good personal relations with relevant stakeholders in the government  
• Strategic advocacy around the obligations of the CRPD in area of participation targeting government officials | ➢ Is the monitoring framework formally established?  
➢ Does the government provide funding for the monitoring framework?  
➢ If yes, is it a regular/stable funding? |
| **2. Involvement from very early stages of policy process** | • Provide persons with disabilities and their representative organisations with the opportunity to engage with law and policy processes by producing consultation materials in accessible formats (Braille, easy-to-read, etc.)  
• Having great understanding about the disability movement, its complexities and the expertise on certain policy areas to find the right key actors | ➢ Are persons with disabilities and their representative organisations invited to preliminary discussions of policy processes?  
➢ Are they aware about the on-going legislative and policy changes?  
➢ Are documents/briefings on the planned policy or law development process sent to all relevant DPOs by the government? |
| **3. Being involved actively and effectively** | • Regular involvement  
• Involvement from the beginning of policy and decision-making processes  
• Reflect civil society contribution in the final outcome | ➢ Is the consultation accessible for all persons with disabilities?  
➢ Does involvement start at an early stage of the process?  
➢ Does the consultation |
Criteria for meaningful participation from New Zealand and Zambia

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<thead>
<tr>
<th>Criteria</th>
<th>Actions</th>
<th>Questions</th>
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<tr>
<td>• Provide accessibility to all persons with disabilities during the consultation process</td>
<td></td>
<td>process have a clear vision/code of conduct on how to consider the input of civil society?</td>
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<tr>
<td><strong>4. Transparency</strong></td>
<td>• Publishing important legislative and policy proposals on the website of the government departments in accessible formats</td>
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<td></td>
<td>• Giving civil society the opportunity to contact government officials regarding policy and law development processes</td>
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<td><strong>5. Active working relationship between government, NHRI, civil society</strong></td>
<td>• Mapping of all relevant DPOs</td>
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<td></td>
<td>• Involved DPOs in the annual work plan of NHRIs</td>
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<td>• Involvement of the voice of DPOs as grass root expertise in projects and reports of the NHRI</td>
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<td>• Inviting DPO representatives to speak at events/conferences organised by the NHRI</td>
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<td><strong>6. Broad collaboration of DPOs</strong></td>
<td>• Inclusive disability movement</td>
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<td></td>
<td>• Decreasing fragmentation</td>
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<td></td>
<td>• Mutual recognition and provision of accessibility for all during meetings</td>
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<tr>
<td><strong>7. Raising awareness about CRPD implementation at the grass-roots level+ capacity building</strong></td>
<td>• Working in smaller groups</td>
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<td></td>
<td>• Going to the countryside and bring copies of the CRPD (in Braille, easy-to-read</td>
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<th>etc.)</th>
<th>available for persons with disabilities living in rural settings on the CRPD?</th>
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<tr>
<td>• Train local advocacy groups about the CRPD and their human rights</td>
<td>➢ Do people with disabilities know where to turn when their rights are violated?</td>
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8. Continuous evaluation of the work of the CRPD monitoring framework

| • Code of conduct is developed to monitor the operations of the monitoring framework | ➢ Is there a formal evaluation put in place to assess the activities and achievements of the monitoring framework? |
| • Opportunity to change the composition or the modus operandi to improve the capacity of the framework to promote, protect and monitor the CRPD | ➢ Do members of the monitoring framework meet regularly to discuss the work together? |

9. Provide decision-makers with evidence-based information to influence outcomes

| • Making sure the contribution of DPOs gets in the final version of the new law or policy | ➢ Has the government used the evidence provided by DPOs in developing the final text of law and policies? |
| • Collecting data across the country | ➢ Are the opinions of persons with disabilities included in the final text of the law or policy document? |
| • Developing tools (e.g. online platforms) where persons with disabilities can share their lived experiences | ➢ To what extent the ideas of DPOs are included? |
| | ➢ Has the government given a reason why it did not include certain suggestions? |

Table 13: Set of criteria for meaningful participation of persons with disabilities
VII. Conclusion

The adoption of the UN Convention on the Rights of Persons with Disabilities marks a very important milestone in the history of disability rights. Participation is the most important leitmotiv of the CRPD, and probably the most overlooked in terms of its implications on government, the human rights system and the whole society. Drafters of the Convention aimed to ensure that it would contribute to narrowing the implementation gap between international human rights law and its domestic interpretation by requiring the full participation of persons with disabilities in a number of provisions. Making rights a reality for persons with disabilities would help to re-establish trust in the human rights system and improve the efficiency of other UN treaties as well.

The present thesis has been looking at the conditions and criteria of good practice in achieving meaningful participation of persons with disabilities and their representative organisations in CRPD monitoring processes. It did so by building on relevant legal and policy implementation literature, and social movement theories. We have provided a broad picture of the disability movement as a new social movement. The disability movement is expected to fill up the space created by the CRPD to ensure, the voices of persons with disabilities are heard in policy processes and participation is meaningful. Although the CPRD has a number of clear provisions addressing States Parties to involve persons with disabilities and their representative organisations in all law and policy-making processes and in the monitoring of the CRPD, the research found that while some good practices exist in States Parties, those overall structural reforms that would ensure meaningful participation have not yet begun. With regard to the effective participation of persons with disabilities and their representative organisations in policy-making and in monitoring human rights, the greatest challenge seems to be to tackle longstanding exclusionary practices and hidden forms of tokenistic consultation. There are deeply rooted barriers that prevent the establishment of partnerships between
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the organisations of persons with disabilities and governments as well as the human rights system.

The provisions of Articles 4(3) and 33 of the Convention open up two important spaces for the organisations of persons with disabilities. Article 4(3) requires States Parties to involve persons with disabilities in all law development, policy- and decision-making processes that affect their lives. Article 33 requires National Human Rights Institutions that fulfil the role of the independent element in the monitoring framework to collaborate closely and effectively with the organisations of persons with disabilities. The representative organisations of persons with disabilities are thus entitled to participate in both implementing and monitoring the CRPD. These truly innovative elements serve the overarching aim of the Convention to bring a real change to people’s lives and ensure the removal of all socially constructed barriers that prevent persons with disabilities from participating in society. It is very important to use these new spaces in the most effective way as possible, like symbolic agora of the empowerment of persons with disabilities as active citizens worldwide. Since persons with disabilities were marginalised throughout history, restoring their voice should happen through capacity building and providing the support they need.

Participation of persons with disabilities therefore requires great structural changes to provide them with access to all policy- and decision-making processes. This thesis aimed to explore promising ways to fulfil the new spaces opened up by the Convention in a meaningful way. First, the research methodology included some participatory elements by involving the voices of leaders of the European disability movement. The qualitative data collection through questionnaires and empirical field trips gathered promising practices on the meaningful involvement of persons with disabilities in policy- and decision-making and in monitoring the CRPD. The main purpose of the research was two-fold: on one hand it was seeking existing challenges, and on the other hand it intended to provide
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recommendations based on disability advocates’ preferences for ideal forms of participation.

With regard to the monitoring framework as envisaged in Article 33 of the CRPD, one of the most surprising findings of the thesis is that no monitoring framework is established in the States Parties that would fully comply with the provisions of the CRPD in terms of both structure and function. The Concluding Observations of the CRPD Committee are important source on the status of implementing Articles 4(3) and 33 of the CRPD. The Committee’s recommendations clearly show that most States Parties did not manage to involve persons with disabilities in a meaningful way either in policy- and decision-making processes or in monitoring the Convention.

Based on policy implementation literature, we considered implementation and monitoring as dynamic processes that require meaningful partnerships to be built between the actors involved. Despite the participatory provisions of the CRPD to enhance the voice of persons with disabilities in public processes, we found that in most countries the overall structural changes that would make processes fully accessible for the representative organisations of disabled people have not yet been carried out. In order to comply fully with the obligations of the Convention, we suggested a dual approach in which both the nature of the consultative processes and the influence of disabled people’s organisations on those processes are assessed. With regard to participation, we found that the main challenge is to shift from tokenism to meaningful participation. This means that instead of a semblance of participation, persons with disabilities are given the opportunity to participate from the very early phases of the processes and make a real input into their outcomes.

The thesis also showed that in some places, similar to governments, National Human Rights Institutions have not yet built up partnerships with the representative organisations of persons with disabilities. NHRIs and the whole human rights system have been operating in a very inaccessible way for persons with disabilities, and
the technicality of human rights law and court procedures did not ease the collaboration. Therefore, Human Rights Commissions and Ombudsman offices should offer transparent, accessible and inclusive working methods to involve DPOs directly in monitoring activities and in the work of the institution in general. The monitoring framework is ideally enriched by the distinguished experiences of organisations that traditionally protect human rights and the first-hand experience of persons with disabilities on human rights violations.

Regarding the challenges of the disability movement as a new social movement, representativeness seemed to be one of the main internal challenges for the international disability movement. In particularly, the participation of persons with intellectual, psychosocial, profound intellectual or multiple disabilities mainly happens through their parents or service providers. The research found that their voice is either completely absent from the umbrella organisations that represent persons with disabilities at national or international level, or is greatly silenced. This results from the fact that persons with cognitive or psychosocial impairments would need more complex reasonable accommodation to enjoy access to policy- and decision-making processes. For these groups, accessibility can be achieved through less tangible but essential changes in how policy-making is carried out, including the use of plain language or more flexible working environments.

Further, the research results showed that the international disability movement is a fragmented movement and that the voice of the most marginalised segments of the disability community must be better involved in the future avoiding reproducing inequalities. Without the disability movement internalising the paradigm shift from the medical to the social or human rights model of disability, it is less likely to challenge the exclusionary practices of governing bodies and the human rights system.

The longstanding motto 'Nothing about us without us!' undoubtedly presents the major conceptual source for the political
agenda of the disability movement, and claims participation in all processes to compensate for past exclusion. Yet persons with disabilities should not strive to become owners of policy-making, but first aim to ensure their involvement in all processes while maintaining their critical role as civil society. If the processes are transforming towards inclusive and accessible practices for all persons with disabilities, disabled people's organisations will likely have great influence on the outcomes of the processes too.

We discussed thoroughly the findings of the two field trips in Zambia and New Zealand, as well as the information received from leaders of the European disability movement. The aim of the case studies was to highlight some promising practices, reflect on the ongoing processes and recognise the challenges that need to be tackled. According to the research results, even in those countries that are considered to have promising practices in the structures created to monitor the implementation of the Convention, significant operational challenges occur along with the dissatisfaction of disability advocates over their level of involvement. Interestingly, even in New Zealand, where the government is committed to implementing the CRPD and established one of the most inclusive CRPD-compliant monitoring frameworks, the field trip revealed a number of functional challenges and anomalies. The most concerning one is the lack of systematic monitoring work carried out by the Convention Coalition and the lack of sustainable funding at the time of visit.

In Zambia, civil society initiated the establishment of the Independent Monitoring Unit to compensate for the government's lack of effort, but the independence and sustainability of the involvement of the umbrella organisation representing persons with disabilities are not convincing. Despite the great work carried out during legislative review processes and monitoring of CRPD implementation between 2011 and 2013, without future capacity building and adequate resources IMU will no longer be able to operate effectively. The information from leaders of the European disability movement showed
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very different experiences on the current level of involvement. Yet many of the challenges and the defined factors to achieve the ideal level of involvement accord with each other. That includes, among other important issues, involvement from very early stages, training provided to both the government and DPOs, adequate funding for civil society to carry out its tasks, and preferably designation as experts in administrative bodies.

Based on the findings of the case studies, we developed a set of criteria of meaningful participation in implementing and monitoring the CRPD. This non-exhaustive set of criteria can be used to assess the quality of participation of DPOs in policy processes and in monitoring the Convention. The nine developed criteria cover a broad range of areas:

1. Commitment of decision-makers;
2. Involvement from very early stages of policy process;
3. Being involved actively and effectively;
4. Transparency;
5. Active working relationship between government, NHRI, civil society;
6. Broad collaboration of DPOs;
7. Raising awareness about CRPD implementation at the grass-root level+ capacity building;
8. Continuous evaluation of the work of the CRPD monitoring framework;
9. Provide decision-makers with evidence-based information to influence outcomes.

Furthermore, the thesis hereby provides a list recommendation to the governments, the monitoring frameworks and civil society based on the findings of the research. The recommendations strongly build on the input of disability advocates, as part of recognising that it is primarily persons with disabilities who can define the ideal way of
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being involved in public processes and in monitoring the implementation of the CRPD.

**Recommendations for the governments**

First of all, the commitment of government to engage with civil society in this visionary space and to work in partnership to develop legislation and policies is a prerequisite of the successful fulfilment of this space. The ratification of the UN CRPD must be followed by a clear commitment to involve the representative organisations of persons with disabilities in these processes in a mutually beneficial and meaningful way. By recognising its international legal obligation, the government must consciously invest in building the capacity of local DPOs, especially those that intend to represent the most marginalised parts of the disability movement. This would be very helpful to decrease fragmentation within the disability movement as well.

Probably the most important practical recommendation for the governing bodies is that civil society involvement must start at the planning phases of any law- or policy-development process. It is too late when already-prepared drafts are shown to some randomly selected organisations, giving them too little time to make considerable changes and exploiting their resources with the illusion that their voice matters when it clearly doesn’t. In order to ensure the meaningful participation of persons with disabilities, governments should have a great understanding of the disability sector and choose the representative DPOs accordingly. They should not develop counterproductive tendencies or generate internal conflicts in the disability movement by selecting a few privileged organisations.

Governments should formally establish those mechanism that involve persons with disabilities in policy- and decision-making processes as well as designating by law the Article 33 monitoring mechanism to achieve greater accountability. Governments should create space for meaningful involvement by re-thinking past forms of
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consultation and providing fully accessible and transparent working methods in the drafting of law and policies. In line with CRPD obligations, reasonable accommodation should be provided for persons with any kind of impairments to facilitate their full participation in public processes. Independent funding should be provided for members of the Article 33 framework to carry out systematic monitoring activities and to achieve sustainability.

*Recommendations for the Article 33(2) framework*

The present thesis highlighted that the established Article 33(2) frameworks often face challenges in sustaining continuous operation beside the reporting process to the UN CRPD Committee. This is partly due to inadequate resources and the lack of co-ordination between members of the frameworks. All bodies involved in CRPD monitoring should lobby for additional funding to carry out all tasks under promotion, protection and monitoring effectively.

Another main challenge is the lack of collaboration between the NHRI s and the organisations of persons with disabilities. The past working methods of the NHRI s were highly inaccessible, and the technicality of human rights law made it difficult for disability advocates to engage in a meaningful way with the work of human rights institutions. NHRI s should develop new, accessible and transparent working methods, providing reasonable accommodation for DPOs representing persons with any type of impairment. An effective way to guarantee DPOs’ involvement is to appoint the umbrella organisation of persons with disabilities to the board of the NHRI. This is in line with the provision of the Paris Principles on the pluralistic representation of civilian forces in the composition of the NHRI. The recent appointment of Disabled People’s Organisations Denmark to the board of the Danish Institute for Human Rights is a great example showing the commitment of NHRI s to engage with persons with disabilities not only on disability issues, but in the course of the activities of the Institute in general.
Criteria for meaningful participation from New Zealand and Zambia

In cases where the Human Rights Commission or the Ombudsman office is not formally designated as independent mechanism in the Article 33 framework, the NHRI should demand appointment directly from the government. The UN CRPD Committee made it very clear that Paris-Principles-compliant NHRI must play a role in the monitoring framework as an independent element designated formally by the government to ensure accountability.

Once the monitoring framework is established, it should develop benchmarks and indicators to measure its efficiency and the quality of the participation of DPOs in promoting, protecting and monitoring the CRPD on a regular basis.

Recommendations for civil society

The well-known mantra ‘Nothing about us without us’ and the involvement of persons with disabilities should be considered as key elements in the successful implementation of the CRPD. Participation should start at the very early stages of any policy- and decision-making processes to ensure the voice of persons with disabilities is reflected in the draft documents. If DPOs are only provided with the opportunity to comment on drafts already prepared, they will not be in a position to enforce conceptual changes, and their involvement would remain at a tokenistic level of consultation. DPOs must therefore advocate for systematic involvement from the early stages of the process. Capacity-building programmes are necessary to ensure the meaningful participation of the organisations of persons with disabilities in public processes. Other important factors to facilitate meaningful participation are accessibility, transparency and the availability of multiple forms of involvement.

In order to maintain democratic structures, and guarantee the meaningful involvement of the representative organisations of persons with disabilities, we suggest that DPOs in the first place strive for participation in all processes and, in parallel, aim to influence as many
policy outcomes as possible. If policy- and decision-making become accessible and inclusive, presumably the input of the DPOs will be considered too.

We argued in this thesis that the disability movement is a fragmented movement and that persons with certain impairments are not participating on an equal basis with others. This mainly affects persons with cognitive, psychosocial, profound or multiple disabilities and children with disabilities. The disability movement must internalise the paradigm shift from the medical to the social or human rights model of disability and remove the barriers that prevent these marginalised groups from more active involvement. In order to achieve full inclusion of people with more complex needs, the disability movement must advocate for structural changes in carrying out processes. Full accessibility would mean slowing things down and applying plain language wherever it is possible. This would help persons with cognitive impairments to access academic, judicial, scientific and public processes. Similarly, persons with psychosocial disabilities would need less tangible changes in the organisation of meetings and schedules, and to be provided with a flexible, person-centred and safe atmosphere. Lower social skills should never result in someone’s exclusion from the work with other disability organisations. It would be as discriminatory as denying persons with physical or sensory impairment an accessible environment or accessible forms of communication.

Members of DPOs would ideally be nominated as administrators in government bodies that deal with disability issues or in the board of NHRIs, to channel their voice directly to the relevant decision-making bodies.

The necessary structural changes to fulfil the participatory provisions of the CRPD won’t happen overnight. However, it must be ensured that clear steps are made by governments, the human rights system and civil society to compensate for the past exclusion of persons with disabilities. This should happen by giving them a voice and reflecting
Criteria for meaningful participation from New Zealand and Zambia

t heir will and preferences in both the processes of law and policy development and their outcomes, as well as in monitoring the implementation of the CRPD. Without ensuring the meaningful participation of persons with disabilities by formal mechanisms at national level, the CRPD might remain a visionary law instead of bringing real change to the lives of persons with disabilities.
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IX. Appendices

1. Phase 2 of the empirical data collection: Blank questionnaire to EDF members

"NOTHING ABOUT ARTICLE 33.3 UN CRPD WITHOUT US!"

Questionnaire to EDF members
Involvement in national-level policy-and decision-making and monitoring the UN CRPD

No one but persons with disabilities can contribute the best in designing indicators which could measure effectiveness of their participation. The study, which will analyse contribution received from EDF members, could be useful for the European disability movement in terms of exchanging experiences on good practices and also to discover common struggles and gaps in their national-level involvement.

My name is Magdi Birtha.
I work at the Centre for Disability Law and Policy.
This is a research centre in Galway, Ireland.
I do a project on monitoring the UN Convention on the Rights of Persons with Disabilities.
EDF is also part of this project.
I have worked at EDF since February 2012.
I would like to see how countries monitor the implementation of the Convention.
I would like to see how countries involve civil society and in particular persons with disabilities in their work.
The Convention on the Rights of Persons with Disabilities says that persons with disabilities shall be involved in policy-making relating to their lives.
Persons with disabilities shall also be involved in monitoring the implementation of the Convention.

It would be appreciated to receive your answers until 29 June 2012.
If you have any questions or would like to get further information, please do not hesitate to contact me: magdi.birtha@edf-eph.org.

Many thanks for your cooperation.

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**Questions**

**1. Current situation**

1. Who represents civil society in policy and decision-making in your country?

2. Is civil society represented in the Independent mechanism under Article 33.2? If yes, through which organisations?

3. Is the State equipped with an advisory board or similar body? Which organisations are represented there?

4. What is the function of this advisory board?

5. How do you find the collaboration between the different organisations of people with disabilities? (e.g. exchange of information, joint efforts, number of meetings etc.) Are there any difficulties?

**Involvement in the implementation of Article 33 UN CRPD**

6. Were disabled people’s organisations asked their opinion regarding the designation or establishment of the Article 33.2 framework to promote, protect and monitor the implementation of the Convention?
7. Did they have other proposals? Does the decision comply with their feedback?

8. Do the focal point(s) and coordination mechanism involve disabled people’s organisations?

9. Are they accessible to these organisations (e.g. website, meetings, partnerships, etc)?

10. Do they consult them on a regular base?

11. Is your organisation involved in policy making regarding the implementation of CRPD? What does it mean in practice? Through which channels is it happening?

12. Is your organisation involved in decision-making? What does it mean in practice? Through which channels is it happening?

13. Is your organisation involved in monitoring the UN CRPD? What does it mean in practice? Through which channels is it happening?

Involvement in monitoring activities
14. Were disabled person’s organisations associated in drafting the State report if there was any submitted to the UN CRPD Committee?

15. If your country has already submitted a report to the UN, did civil society elaborate a shadow report as well? How did they organise this?

16. Do disabled person’s organisations have the possibility to develop their own monitoring activities? (e.g. receiving any support to do capacity building or training session etc.)

Evaluating current involvement
17. In your country what are the main achievements of disabled people’s organisations through Article 33 CRPD so far?
18. Could you provide practical examples to illustrate this (e.g. campaign, capacity building, lobby, etc)?

19. What are the problems? How should the State ensure better involvement?

II. Ideal situation – how civil society should be involved

1. What should be the key elements of civil society involvement in the implementation of the CRPD?

2. What are the key factors in achieving effective involvement? (e.g. number and type of NGOs involved in the process, transparent communication, well-functioning coordination mechanism, financial support, etc.)

3. What are the key factors in achieving active involvement?

4. What are the prerequisites of effective and active involvement of civil society in...
   - Policy-making:
   - Decision-making:
   - Monitoring of Convention:

5. How should the State guarantee representativeness of civil society members?

6. How can representativeness be assured? (e.g. involve the same or always different NGOs, who should they represent, etc.)

7. What kind of financial investment would be needed to ensure effective involvement of people with disabilities?

8. Do you think that capacity building and empowerment would be necessary conditions of involvement? If yes, in what form it should happen?

9. What would guarantee sustainability of the involvement?
Background: Questions to Civil society representatives on their involvement

According to Article 33.3 UN CRPD Civil society, in particular persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process. Article 4.3 UN CRPD refers to the importance of involving persons with disabilities in all policy- and decision-making processes concerning issues relating to their lives. The Preamble (o) also emphasises that persons with disabilities should be actively involved in decision-making processes, policies and programmes, including those directly concerning them.

Referring to the paradigm shift and to the slogan "Nothing about us without us", the effective and active involvement of persons with disabilities should be considered as one of the key elements of successful implementation of the CRPD. Most Member States are still in the process of establishing their Article 33.2 framework to promote, protect and monitor the implementation of the CRPD, therefore it is very important to ensure the participation of DPOs from the very first stage. Our knowledge is very limited on what kind of initiatives or good practices are taking place in the Member States in order to provide active involvement instead of formal consultations for persons with disabilities.

The aim of the research is to collect qualitative data directly from members of the disability movement on the current national situation and to explore key elements of effective and active involvement.
2. Phase 3: Country studies

Zambia – Information note about the project for interviewees

Monitoring: European and National Monitoring of the UN Convention on the Rights of Persons with Disabilities – Project description for a field trip in Zambia –

Purpose of the project

For the next three years I will be working as an Early Stage Marie Curie Research Fellow in the FP7 ‘DREAM’ (Disability Rights Expanding Accessible Market) network, based in the National University of Ireland, Galway at the Centre for Disability Law and Policy.

My research focuses on the National and European Monitoring of the UN CRPD with a special regard for civil society involvement. Article 33.2 requires State Parties to set up an independent framework to promote, protect and monitor the Convention. For the first time in its history, the European Union has signed and ratified the International Human Rights Treaty, thus assuming the full obligations of the CRPD. I will be researching the process of creating a self-sustaining framework as well as promising practices from all around the world regarding independent monitoring mechanisms and civil society involvement. According to Article 33.3 of the CRPD, people with disabilities shall be involved in the monitoring process, which means active and effective contribution instead of consultation. I am designing indicators in order to measure the effectiveness of civil society involvement in the monitoring process and providing recommendations for effective and independent monitoring at EU and National level. I am also collecting case studies from non-EU countries, including developing ones, as I am convinced that important initiatives relating to self-advocacy are taking place there too. I am planning to do empirical research and talk to various actors who are participating in any parts of the mechanism. By the end of the three years, I wish to have a broad picture of the different solutions that countries choose to set up their Article 33 framework and involve people with disabilities in the whole process.

Aim of the field trip:

In the last couple of months I have been in touch with the Zambia Federation of Disability Organisations and they provided me information on the work of the Independent Monitoring Unit. I find Zambian initiatives relating to civil society involvement very interesting, so my purpose is to get more familiar with disability issues in Zambia. During my field trip, I would like to meet with different actors of policy –and decision-making including government representatives, representatives from the Human Rights Commission, and Civil society (especially advocates from DPOs) who can share their experiences about monitoring of the CRPD and their involvement in the whole process. I would like to see what are the different approaches they do have and how they find the current situation. A long-term impact of conducting those interviews during the field trip could be to collect various factors that ensure successful involvement of persons with disabilities in monitoring activities (e.g. effective capacity building, grass-root initiatives etc.)

Date of the field trip: Mid-July 2012

Anticipated length of the field trip: 2-3 weeks

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New Zealand - Information note about the project for interviewees

Monitoring: European and National Monitoring of the UN Convention on the Rights of Persons with Disabilities

– Work plan for a field trip in New Zealand –

Vienna, 7 February 2013

Purpose of the project
I am working as an Early Stage Marie Curie Research Fellow in the FP7 ‘DREAM’ (Disability Rights Expanding Accessible Market) network, based at the National University of Ireland, Galway until August 2014.

My research focuses on the National and European Monitoring of the UN Convention on the Rights of Persons with Disabilities (CRPD) with a special regard to civil society involvement. Article 33.2 CRPD requires State Parties to designate an independent framework to promote, protect and monitor the implementation of the Convention. For the first time in its history, the European Union – as a regional integration organization – has signed and ratified the International Human Rights Treaty, thus assuming the full obligations of the CRPD. The aim of the project is to research the triangulation of the framework that State Parties set-up to monitor the implementation of the Convention, and trying to analyse the dynamics of the collaboration between government, the independent body and civil society. According to Article 33.3 CRPD, persons with disabilities shall be involved in the monitoring process, which means active and effective contribution instead of consultation. Indicators will be developed in order to measure the effectiveness of civil society involvement and providing recommendations for effective and independent monitoring at EU and Member State level. Promising practices are also collected from all around the world through empirical research. Field trips are organized to meet with relevant stakeholders and to identify key elements of successful Article 33 implementation by using elements of participatory research methods. By the end of the three years, it is aimed to have a broad picture on the different solutions that countries choose to set up their Article 33 framework and involve people with disabilities in the whole process.

Aim of the field trip in New Zealand
As it was mentioned above, promising practices are collected on the functioning of frameworks designated under Article 33 CRPD. A field trip was organized to Zambia in July 2012 where interviews were conducted with members of the disability movement and other stakeholders participating in the monitoring process. A non-representative qualitative data collection took place between March – July 2012 among members of the European disability movement to explore gaps between the current level of their involvement at national level and the ideal ways of participation. After some preliminary researches Australia was chosen to represent another case study. It would certainly give an additional value to the research to add New Zealand into this study trip. During my field trip, I would like to get familiar with the work of the Human Rights Commission and the Auckland Disability Law, such as relating research groups in relation to the implementation and monitoring of the Convention. Ideally, members of the disability movement themselves answer the question regarding the prerequisites of being actively and effectively involved in line with the slogan 'Nothing about us without us!' therefore I am very interested in meeting with disability advocates. It is essential to understand the exact functioning of the triangulation shaped in the Convention, therefore hoping to meet with relevant actors and ask them to evaluate the current situation by sharing their vision on necessary components of successful Article 33 implementation.

**Date of the field trip:** 3–9 April 2013

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