Placing Disability on the Policy Agenda:

An Assessment of Participation in International Policy Processes by Disabled People's Organisations

Amy Howard

February 2013

This dissertation is submitted in partial fulfilment of the requirements for the Master of Arts Degree in Development and Emergency Practice.

Centre for Development and Emergency Practice

School of the Built Environment

Oxford Brookes University

Abstract

The World Health Organisation (WHO) estimate that there are one billion people living with disabilities in the world, corresponding to about fifteen per cent of the world's population (WHO 2012). An estimated one household in every four contains a disabled member, which means that two billion people live with disability on a daily basis (UNHCHR, 2007). Moreover, the prevalence of disability is growing due to population ageing and the global increases in chronic health conditions and non-communicable diseases (WHO, 2012).

A historic mix of discrimination, lack of knowledge and unwillingness by the international community to consider disability within the realm of the development sector, has traditionally kept disability on the margins of international development policy and programs. The international community has preferred instead to view disability as a specialised problem that needed specialised programmes, resources and a welfare focus.

However, persons with disabilities (PWDs) have seen a shift in attitudes over the past ten years, culminating in a proliferation of legislative, policy, and political commitments to incorporating disability into the development sector. Furthermore, there is increasing recognition of the linkages and commonalities between poverty and disability, and the need to include PWDs throughout all stages of the development process. Participation by Disabled People's Organisations (DPOs) is increasingly being seen as a mechanism to achieve this.

The main aim of the research was to examine participation by DPOs within policy forming processes at the international level. The research has not only identified the implications and barriers that require change but it has also developed a more nuanced understanding of the causes of the barriers to participation, from the perspective of DPOs. Further to this, the role of Intergovernmental Organisations (IGOs) as facilitators and instigators of policy processes is examined.

The study is built on a review of secondary literature, particularly focused on disability within the policy sphere and past participatory processes. Primary data was also collated from three umbrella DPOs, all of whom had participated in the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) and are making contributions to the policy process for replacing the Millennium Development Goals (MDGs) post-2015.

The implications of DPO participation were identified from the literature. Acknowledging the implications exist could go a long way in mitigating the risks to DPOs. Accountability is also identified as the key driver for the future of DPOs in international participatory policy processes.

The findings of the research highlighted four themes which outline the current position of DPOs participating within international policy processes they are: practical, knowledge, engagement, and ownership observations. They have also provided a framework for recommendations for improving future processes. There are overarching requirements for improved DPO participation through mainstreaming disability, capacity building and process planning.

Many challenges lie ahead for both DPOs and IGOs, but the barriers identified are not insurmountable and positive and progressive steps are being made towards meaningful and effective participation of DPOs.

Most importantly the IGOs and DPOs have demonstrated a commitment to future participatory policy processes.

Statement of Originality

This thesis is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by explicit references.
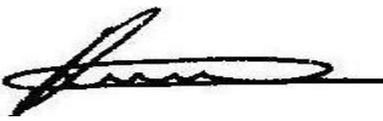
Signed: _____ (candidate)   Date: 28th February 2013

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.
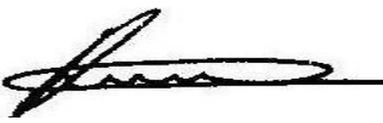
Signed: _____ (candidate)   Date: 28th February 2013

Statement of Ethics Review Approval

This dissertation involved human participants. A Form E1BE for each group of participants, showing ethics review approval, has been attached to this dissertation as an appendix

Acknowledgements

I would like to thank all those I interviewed. I hope the dissertation reflects adequately the energy of the disability movement, the DPOs and the individuals with whom I spoke.

I am also exceedingly grateful for the support received from my family, particularly my brother for proof reading and to Christopher Flavin for his eternal patience.

Finally I'd like to thank Charles Parrack for his unrelenting patience and support given over an extended period and the invaluable guidance provided.

Acronyms

CSOs	Civil Society Organisations
DPO/ DPOs	Disabled People's Organisation/s
DESA	Department of Economic and Social Affairs
DFID	Department for International Development
ECOSOC	Economic and Social Council (UN)
IDA	International Disability Alliance
IDS	Institute of Development Studies
IFI	International Financial Institutions
IGOs	Intergovernmental Organisations
IMF	International Monetary Fund
INGO	International Non-Governmental Organisation
MDG	Millennium Development Goals
NGO	Non-Governmental Organisation
OCHCR	Office of High Commissioner for Human Rights
OECD	Organisation of Economic Co-operation and Development
PRSPs	Poverty Reduction Strategy Papers
PWDs	Persons with Disabilities
SCRPD	Secretariat for the Convention on the Rights of Persons with Disabilities
UN	United Nations
UNCRPD	United Nations Convention on Rights of Persons with Disability
UNDG	United Nations Development Group
UNDP	United Nations Development Programme
UN Enable	The official website of the SCRPD
WHO	World Health Organisation

Table of Contents

.

List of Figures and Diagrams

Glossary and Explanation of Terms[1]

Actors: in the context of policy/ participatory processes, are those individuals and groups, both formal and informal, which influence the creation and implementation of policy and participatory processes. Actors is the preferred term over stakeholders, as stakeholders are seen as having an interest in or can be affected by a policy or project.

Cooperation and Consensus Building: actors negotiate positions and help determine priorities, but the process is directed by outsiders.

Consultation: actors are given the opportunity to interact and provide feedback, and may express suggestions and concerns. Analysis and decisions are usually made by outsiders and stakeholders have no assurance that their input will be used.

Contribution: voluntary or other forms of input to predetermined programmes and projects.

Decision-Making: actors have a role in making decisions on policy, project design and implementation.

Disability: See section 4.1.

Disabled People or Persons with Disabilities: The chosen terminology of the disability movement varies between cultures and languages. In this document I have used persons with disabilities. In some situations disabled people is the preferred term and may occur in the course of the dissertation.

Empowerment: transfer of control over decision-making and resources to civil society.

Human Rights Approach: See Section 4.1

Impairment: an individual's condition – physical, sensory, intellectual or behavioural.

Inclusive Policies: policies which acknowledge that socially excluded, poor or vulnerable people are not a homogeneous group and that disabled people have a right to be included in poverty alleviation and development work.

Information Sharing: actors are informed about their rights, responsibilities and options.

Stakeholders: See Actors.

Partnership: actors work together as equals towards mutual goals.

---

1 See: Rietbergen-McCracken, n.d.; Tikare et al, 2001; Yeo, 2001.

Poverty: Poverty is defined for the purposes of this dissertation, as those who are inter- generationally poor and also experience multi-dimensional poverty.

Participation: the process through which actors influence and share control over priority setting, policy-making, resource allocations and access to public goods and services. There is no blueprint for participation because it plays a role in many different contexts, different projects and for different purposes. There are, however, types of participation which are relevant to this dissertation;

> **Political Participation:** defined as taking part in the preparation and implementation of public policies.

> **Public Participation:** means to involve those who are affected by a decision in the decision making process.

The South: denotes developing countries.

The North: denotes developed countries.

Models of Disability[2]:

Medical Model: Disabled people are defined by their impairment and medical/technical solutions offered to alleviate their impairment – an individualistic approach that does not look at social barriers.

Charity/ Welfare Model: Disabled people are to be helped by welfare approaches. There is no recognition of equal rights or the role that discrimination plays.

Social Model: This rights based model sees disability as the social consequence of having an impairment and realises that the inequities faced by disabled people can only be overcome if society becomes inclusive.

---

2 Taken from: Yeo, 2001

1   Introduction

"Sustainable, equitable progress in the agreed global development agenda cannot be achieved without the inclusion of persons with disabilities. If they are not included, progress in development will further their marginalisation." (UNDG, 2011 p.13)

1.1   Context

The World Health Organisation (WHO) estimate that there are one billion people living with disabilities in the world, corresponding to about fifteen per cent of the world's population (WHO 2012). An estimated one household in every four contains a disabled member, which means that two billion people live with disability on a daily basis (UNHCHR, 2007). Moreover, the prevalence of disability is growing due to population ageing and the global increases in chronic health conditions and non-communicable diseases (WHO, 2012).

A historic mix of discrimination, lack of knowledge and unwillingness by the international community to consider disability within the realm of the development sector, has traditionally kept disability on the margins of international development policy and programs. The international community has preferred instead to view disability as a specialised problem that needed specialised programmes, resources and a welfare focus.

However, persons with disabilities (PWDs) have seen a shift in attitudes over the past ten years, culminating in a proliferation of legislative, policy, and political commitments to incorporating disability into the development sector. The adoption in 1993 of the United Nations (UN) Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and the 2006 UN Convention on Rights Persons with Disabilities (UNCRPD)[3] represent a milestone in the official recognition of disability at the international level. Moreover, the Millennium Development Goals (MDG)[4], despite no specific mention of disability, have *"acted as a catalyst, encouraging many people and organisations to affirm or reaffirm the links between disability and poverty"* (Albert, 2004 p.2).

The increasing recognition of the linkages and commonalities between poverty and disability has developed alongside a paradigm shift in attitudes towards PWDs at the international level. Disability is now on the international development agenda and has brought with it a new focus on participation by Civil Society Organisations (CSOs) and more specifically Disabled People's Organisations (DPOs). The current

---

3 The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted on 13 December 2006 at the United Nations Headquarters in New York. The Convention entered into force on 3May 2008 (UN Enable n.d.(a)).

4 189 Countries at the Millennium Summit in September 2000 adopted the UN Millennium Declaration, committing their nations to a new global partnership to reduce extreme poverty and setting out eight time-bound targets, with a deadline of 2015. They are known as the Millennium Development Goals and are time-bound and quantified targets for addressing extreme poverty in its many dimensions-income poverty, hunger, disease, lack of adequate shelter, and exclusion-while promoting gender equality, education, and environmental sustainability. They are also basic human rights-the rights of each person on the planet to health, education, shelter, and security. However, Disability is not mentioned in any documentation explicitly or set within the any of the targets (UN Millennium Project, 2006).

debates in this area focus on *"rights-based approaches, facilitating participation, inclusion and representation."* (Kett et al, 2009 p.657).

On this basis, the overall focus of this dissertation is the participation of DPOs in international policy forming processes.

1.2   Overall Aim and Rationale

The main aim of this research is to examine participation by DPOs within policy forming processes at the international level. There has been a proliferation of new policies, legislation, statements and conventions on disability over the past twenty years. This encapsulates the shift in opinion and attitude towards disability as part of the international policy arena. What is not clear is how the participation of DPOs in those processes is defined and the extent to which it has occurred. Barton wrote in 2004 that *"one of the emerging concerns in relation to disabled people is that of representation and the expression of their voice"* (p.285)*.*   Despite this, there has been little focus on disability and the extent to which PWDs have actually taken part in these debates; Kett et al (2009 p.651) questions why there has been so little discussion within the development literature about disability, claiming the reasons for this is:

 "the history of the relationship between disability and the wider development agenda. It reflects more general debates about representation, legitimacy, inclusion, participation and voice, as well as more pragmatic discussions about allocation of donor funding, how funds are spent, accountability and evaluations of effectiveness—all of which are commonplace within contemporary development discourse."

Therefore, this research seeks to address the fundamental issue of participation by DPOs in policy processes at the international level.

1.3   Individual Research Objectives

In line with the overall aim of the research, a number of objectives need to be met. The following chapters will address:

1. Assess the meaning of participation within the context of international policy formulation processes for DPOs;

2. Examine the emerging implications of increasing participation by DPOs in international policy formulation processes;

3. Evaluate participation by DPOs in international policy formulation processes; and,

4. Discern how lessons learnt can be applied to future processes for DPOs.

The research objectives require several methods including a literature review, an assessment of past policy processes from leading international institutions (i.e. UN) in case studies, key informant interviews with umbrella DPOs, and an exploration of the terms used to define participation and disability. The research was carried out over a three month period and included one month to complete the key Informant interviews, including the time spent making contact and appointments.

1.4   Scope of the Research

The discussion surrounding DPO participation in international policy processes is a relatively new area. However, participation in the wider context of development and humanitarian work is not. Since the 1980s, participatory approaches to development have been increasingly thought about, debated, and, streamlined by the humanitarian and development community (Briggs, 2011).

What distinguishes this dissertation from the majority of research on the topic of participation are three essential elements:

- the focus on disability as the overarching topic: as disability and particularly DPO participation is an under researched subject;
- the dissertation focuses solely on the policy formulation phase and will not address the policy adoption and implementation phases on which most of the research on participation is focused; and,
- participation, as it is discussed in this paper, focuses on DPOs rather than individual community members or the population at large.

The reasons for this are twofold. While participation has been written about extensively, very little of that discussion has occurred surrounding its potential and necessity for DPOs. The lessons learned from the use of participatory methods in development have been applied broadly, but few texts have looked specifically at its role in policy forming processes for DPOs. DPOs have also been largely excluded from the discussion on participation; where DPOs are included, it is more commonly in relation to their potential as implementing partners for projects.

Academic and practitioner literature is mainly based on translating the rhetoric into reality and the implementation of policy. This dissertation proposes that this approach is missing a step as many of the same pieces of literature are quick to proclaim that policies have been participatory, for example the UNCRPD. They do not explore what they mean by participation or offer evidence to show that in fact a truly participatory process for DPOs occurred.

1.5   Outline Structure

Chapter 1 outlines the topic of the dissertation, firstly by providing an introduction then stating the aim and research objectives, along with the study's significance and scope;

Chapter 2 presents the research methodology including the analytical framework, primary and secondary research tools, the research limitations and ethical issues;

Chapter 3 introduces the key actors found throughout this dissertation;

Chapter 4; is a literature review of the key concepts underpinning the study (objective 1);

Chapter 5: is a literature review which explores the emerging implications of DPO participation in policy processes (objective 2);

Chapter 6 is an analysis of three cases which represent DPO participation at the international level (objective 3), informed from a literature review and key informant interviews;

Chapter 7 presents the identified themes and reflects on lessons from the case studies (objective 3 and 4);

Chapter 8 presents recommendations for a way forward for the identified themes (objective 3) and for future policy processes (Objective 4);

Chapter 9 discusses the limitations and future research options; and,

Chapter 10 draws final conclusions for the objectives 1, 2, 3 and 4.

2 Methodology

This chapter sets out the methodologies used to fulfil the research objectives. In order to meet each of the research objectives and to answer the main research aim, it was necessary to carry out qualitative data collection techniques from several different sources. The dissertation was conducted largely as a desk-based study and the core of the research methods were structured around four areas:

- a qualitative analysis of literature on the meaning of participation and disability in the context international policy processes (Objective 1);

- a qualitative analysis of literature focusing on the implications of DPO participation in policy processes (Objective 2);

- primary data collection through key informant interviews with DPO umbrella organisations were undertaken (Objective 2, 3 and 4); and,

- a qualitative analysis of three case studies representing DPO participation in past international policy processes, the cases are: Poverty Reduction Strategy Papers (PRSPs)[5], UNCRPD[6] and the Post-2015 agenda[7] (Objective 3 and 4).

2.1.1 Development of Research Methodology and Ethics

The methodologies were devised with ethical considerations in mind as important questions are raised when researching disability. The paper by Stone and Priestly (1996) discusses the fact that Disability research has attracted much methodological criticism from disabled people who argue that it has taken place within an oppressive theoretical paradigm and within an oppressive set of social relations. There is much to consider for the non-disabled researcher, of whom the author is one. However, given that the interviews were conducted exclusively with DPO umbrella organisations, rather than PWDs directly, and that the discussions were on processes for policy formulation rather than individual experiences or feelings, ethical concerns were in many ways minimal for this particular research.

Disability theorists have sought to identify a new methodology commensurate with fighting the social oppression experienced by disabled people. This is articulated in the form of an 'emancipatory paradigm' for conducting disability research, the principles for which are overleaf:

---

5 Poverty Reduction Strategy Papers (PRSPs) are a World Bank and International Monetary Fund initiative. Used to describe a country's macroeconomic, structural and social policies and programs to promote growth and reduce poverty, as well as associated external financing needs (World Bank n.d.).

6 ibid 4

7 Post 2015 (agenda): is a framework for targets to reduce poverty and inequality. It is being developed to succeed the United Nations Millennium Development Goals from 2015 onwards.

Figure One: Six Basic Principles of Emancipatory Research.

Summary of Emancipatory Principles:

- the adoption of a social model of disablement as the epistemological basis for research production;

- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;

- the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;

- the evolution of control over research production to ensure full accountability to disabled people and their organizations;

- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences; and,

- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

(Taken from: Stone and Priestly, 1996 p.10)

The principles themselves raise the awareness of the researcher about how to conduct themselves and provide a basis on which to approach research methods. The dissertation methodology does not seek to fully realise an emancipatory approach, as a desk based rather than on the ground study, it would be impossible to achieve. However, the principles above provided a guide to considering the; 'who, what and where' of conducting key informant interviews and a differing perspective when considering the rigour of peer reviewed journals.

2.1.2 Literature Review

The literature review was based on peer reviewed articles and books as well as grey literature. The literature review was structured throughout the chapters in order to meet the research objectives, and essentially was developed into three main sections:

- concepts and theory of disability and participation;
- implications and examining DPO participation in international policy processes; and,
- literature associated with the case studies.

The key sources for finding information were the Oxford Brookes Library; web based journal search engines (such as GeoBase), internationally recognised research institutes, disability specific research bodies such as

the Cheshire Leonard Society, and internet websites. The majority of information was gathered through a careful examination of UN and World Bank documents, dissertations on past policy processes, and key portals such as Department for International Development (DFID) disability and research knowledge programme and the Institute of Development Studies (IDS) portal on social change. A second strand of desk based literature was sought for those articles directly seeking to engage DPOs' opinions of participatory processes. These were mainly located on disability focused websites and through a small number of peer reviewed journals, such as Disability in Development. Key words and phrases were used to elicit a wide range of literature and results, such as: 'participation and disability'; 'DPO participation'; 'international policy process'; and, 'disability policy and UN policy participation'.

2.1.3   *Key Informant Interviews*

Discussions with key informants occurred through both formal and informal means. As the majority of research was conducted from Oxford, England, face-to-face conversations were not possible. Instead, discussions occurred via Skype and email. The initial formal interview generated follow-up questions which were conducted through emailed questions.

The main purpose of the interviews was to meet research objectives two and three, by identifying the opinions of umbrella DPOs about policy processes. There are a number of reasons for interviewing umbrella DPOs over directly talking with individual DPOs:

- the umbrella organisations represent a broad spectrum of disabled people and their organisations;
- a major critique of academic research relating to DPOs is the distribution of surveys that cannot deliver change for them; and,
- a truly representative sample of DPOs would require research in their country and face to face and on a scale beyond the research capabilities of this dissertation.

Contact with each informant began with a description of the dissertation and its goal so that the informant was fully aware of the research aims and could choose whether or not to participate. The informants were sent the forms several days in advance of the interviews. To ensure an accurate record of the interview transcript, computer software was used to record the conversation. All of those interviewed agreed to the recording of the interview. None of the interview questions were politically sensitive and nothing was discussed that could have been considered to be confidential business information. It was therefore most unlikely that there was anything that the interviewees would have been reluctant to discuss whilst being recorded. The names of the individuals remain confidential, but each informant agreed to be referred to as 'key informant'. It was explained to each informant that their responses would be placed into the research as either a direct quote or to form a general point, but confidentiality would be preserved.

Two approaches were used:

1. a semi-structured interview format with a questions sheet (See: Appendix One: Key Informant Interviews); and,
2. a time period allocated for each interview to allow the interviewees to lead their own questions and discussion (See appendix two for sample discussions held).

The two approaches to the key informant interviews allowed the author to follow a more emancipatory style of research by giving ownership of the questions to the informant, whilst meeting the demands of academic rigour. Moreover, only having a small number of core questions, meant that a broader knowledge and opinion could be gleaned about participation in policy processes. It also meant that the dissertation research could to some extent avoid the critiques that it is a one way discussion set only within the agenda of the researcher. Permission was sought from Oxford Brookes University to disseminate the findings of the research to those whom wished to view it. The participants were offered alternative formats to the interview, the option to opt out and confidentiality was made explicit from the outset. None of the informants were previously known to the author.

The sample was chosen based on the criteria for research objective 3. The interviews enabled information to be gathered from experienced and established umbrella DPOs from across the world. It was clear that there was a need to focus on those umbrella DPOs who had been involved with previous participatory processes. Limitations in time meant the aim was to conduct five in-depth interviews with key informants from umbrella DPOs which represented the global south. Requests were sent out to five international level umbrella DPOs and five regional based umbrella DPOs. Three DPO umbrella organisations were interviewed and a further two individuals were contacted via email on the recommendation of one of the key informants. The three umbrella organisations represented DPOs in around one hundred and thirty countries and had partnerships with multiple IGOs and NGOs. There DPO members ranged from other umbrella groups to local grassroots organisations. Their members have a broad-based focus and therefore presented a wide spectrum of PWDs.

Due to the factual nature of the interview questions, it is considered to be unlikely that the interviewees would have introduced a significant element of bias into their interview responses for the first part of the interview. However, it is acknowledged this could be the case for the second part of the interview. Therefore, any political or propaganda style material was not considered in the analysis. The author conducted a reflections sheet after each interview, assessing what had been learnt, gaps in knowledge and identification of follow up questions (see: appendix one).

2.1.4 Case studies

The case studies were chosen on the basis of availability of information, the extent to which the cases represent a norm from which conclusions could be drawn and applied to similar context, and how well the details of the situation fit the parameters of the research.

The three case studies were UNCRPD, PRSPs and Post-2015 agenda. In each case study the participation of DPOs had been initiated by IGOs. They provided contrasting approaches to the participation one directly (UNCRPD) with DPOs and the other relying on the participation to be initiated through states (PRSPs). The Post-2015 agenda is emerging as a worldwide consultation.

Comparing the policy processes has three purposes:

- the case studies have been described with varying levels of success, thereby, providing contrasting comparisons;
- they are the only cases where, IGOs have systemically sought the opinions of CSOs and more specifically DPOs in their policy forming processes; and,
- the lessons learnt from these case studies could inform future processes.

2.1.5 Case Study Analytical Framework

The analytical framework for the case studies is based on themes identified through the literature review and case study observations provide by the key informants. The case studies are structured in to an introduction on background, DPO participation and levels of success.

The analysis overall is brought together under four identified themes:

- Practical Observations;
- Knowledge Observations;
- Engagement Observations; and,
- Ownership of Processes.

2.1.6 Discussion

The paper ends with a discussion which attempts to bring together all the insights gained from the process of research to understand where DPOs currently sit with regard to participation in international policy processes and how this could affect future processes. This evaluates the potentials and pitfalls of attempting a participatory approach towards disability issues, what effect this could have on DPOs themselves and creating a more responsive and accurate picture of disability needs. Consequently, the author hopes that this will generate discussion amongst practitioners within the sector.

2.2   Assumptions

There are a number of necessary assumptions to be made for the completion of the dissertation as not all subject areas can be explored in depth to the extent that would satisfy every reader, this is because a focus was required and both time and the word count were limited. To prevent dismissing these issues, the following list has been included to provide sight of the assumptions made to allow this dissertation to move forward:

- DPOs that are members of umbrella organisations use that group to represent them and their views;
- DPOs and DPO umbrella organisations have an interest in international policy processes, and by extension improving participation in those processes;
- DPO umbrella organisations and DPOs have good intentions and are doing the best they can to support their members; and,
- The right to participation extends to all citizens and it transcends the citizen-state approach. Placing the importance on citizens to claim, monitor and enforce rights.

2.3   Limitations

The main limitation of the research is that it was primarily conducted as a desk-based study. Whilst a thorough review of literature, policy process and strategy papers, and conversations with DPO umbrella organisations was conducted - allowing for a fairly comprehensive understanding of participation in international policy processes - without actually being present on the ground it is difficult to discern what DPOs really believe policy participation means. Or, indeed, to completely fulfil an emancipatory approach to the research.

Although the staff members at the umbrella DPOs have been honest and forthcoming about their activities, a certain amount must be expected to be withheld. It is impossible to say exactly how much these barriers have affected the analysis and conclusions drawn in this dissertation.

The author has no first-hand experience of the organisations the case studies refer to, and acknowledges that details may have been missed during analysis. Additionally, there are undoubtedly internal dynamics within the umbrella DPOs that cannot be fully understood by someone outside the organisation. The author has never worked for an umbrella DPO or indeed DPOs directly, so acknowledges some possible gaps in a deeper understanding of DPOs functions.

Despite these potential limitations much can be learned through an external examination. In some ways being outside the organisation/s allows for a new perspective unclouded by the emotions and politics of being within an organisation or involved in the field. This dissertation will seek to highlight some of the

disparities between policy forming processes and participation that can sometimes be difficult to identify when one is too close to the projects or materials involved.

3   Key Actors

Prior to discussing participation and disability, it is important to describe the actors which are prevalent throughout this dissertation. This is key to the research objectives and methodologies.

3.1   Civil Society and DPOs

Civil society is a unique actor that can take different forms and have different roles. Therefore, civil society is not something that can be defined by one simple, universal statement. The variety of elements means *"that to imprint it with a singular purpose, function or even set of characteristics would be impossible"* (Briggs 2011, p.17). Civil society could encompass local NGOs, community-based organizations, grassroots groups, diaspora networks, and unofficial leadership structures and may be made up of any one or more groups of people. These organisations and structures, are increasingly seen as a means to influence states, the private sector and international organisations.

Those attempting to define 'civil society' often fall back on three indicators; non-state, non-political and non-profit. This does not provide insight into what civil society actually is and certainly with regard to the disability movement, DPOs have been highly politicised to varying degrees in the past and present (Lang, 2001).

The disability movement has been borne out of the historical discrimination and exclusion of PWDs. The disability movement is unique as a civil society movement because it has a democratically-organised international structure, as well as structures at national and local levels (Hurst, 1999). This structure infers that PWDs at the grassroots have a mechanism through which their voices can be heard and they can be understood, and thus supported (Hurst, 1999).

DPOs, as part of this structure, are the main format through which PWDs aim to have their voices heard. The formation of DPOs was partly in response to the oppression felt as a result of the application of the medical and welfare model and the attitudes of professionals working in organisations for disabled people. Furthermore, the formation of DPOs has also been attributed in part to the fact that disabled people have little contact with other disabled people in their own country, let alone in other parts of the world (Yeo and Moore, 2003). This leads to isolation and a lack of ability to learn from others experiences. PWDs, therefore recognised the need to influence decision makers by forming organisations, capable of networking with each other and to build a critical mass of opinion (Hurst, 1999; Thomas, 2005).

DPOs are a distinguishable part of civil society as they are organisations 'of' PWDs rather than 'for' PWDs and are *"organisations which are owned and led by disabled people and in which disabled people are responsible for decisions"* (Thomas, 2005 p.13).

Whereas their structures define the way in which DPOs operate, what it does not explain is the detail on which disabled people actually make up the DPOs, their relations to civil society as a whole, or where they fit within the international system. DPOs themselves are as complex and dynamic as the rest of civil society. There are many DPOs which represent differing and contrasting elements of society. Therefore, the definition of DPOs is not a linear one-size-fits-all, and there is a need to recognise these complexities. Their focus can be impairment specific or represent the interests of people with differing impairments on a local, national or international scale. Umbrella DPOs represent the interests of multiple DPOs typically at the national, regional and international level.

3.2   Intergovernmental Organisations.

The role of IGOs is becoming increasingly significant and sometimes, *"ultimate for international policy-making, the process coming along with the globalisation of world politics"* (Andrew, n.d. p.1). The intergovernmental organisations lead and implement policy forming processes at the international level. Their approach is instrumental in setting the tone for a policy and the level of participation and they also hold available funding for the process. They act as the intermediaries between states and provide the basis on which policy processes can take place. IGOs have the ability to exert influence over all levels of policy making (Briggs, 2011). IGOs have a large part to play in opening political space, creating the right conditions, and setting up the necessary structures and processes to enable participatory policy making (Rietbergen – McCracken, n.d.).

Andrews (n.d.) discusses that the number of IGOs is constantly growing as well as their impact on world matters. The major and most significant IGOs are those of the UN system, but there are also key intercontinental and regional organisations. There is a decentralisation of the traditional state centric approach to policy-making and this is reflected in the *"independent behaviour of state actors becoming more limited because of their obligations to international and regional agreements, regimes and institutions. The reality of growing complex interdependence facilitates a structure of global governance, radically challenging state-centric approaches to international policy-making"* (Andrews, n.d. p.1).

To research policy participation by DPOs at the international level, this paper focuses on two organisations as a catalyst for discussion: the UN and the World Bank. The choice of these two agencies was based on a number of factors. Firstly, it was important to include both a member of the UN and an external IGO. Secondly, the two most recently enacted pieces of policy which have sought the views of DPOs has been overseen by the UN in the form of the UNCRPD, and now the Post-2015 process and the World Bank which introduced the PRSPs. Thirdly, the UN and World Bank sought participation by civil society within their policy processes yet, the processes have been applied in different ways. Therefore, it offers contrasting

insights into the manner in which they apply the principles and theories of participation with regard to DPOs and PWDs in the policy processes.

3.3   Other Actors

Participation by its very definition is meant to be an inclusive process of all concerned actors. Therefore, other actors will influence DPO participation in policy processes at the international level including, but not exclusively: States and NGOs. In-depth analysis of the role of NGOs is beyond the scope and research aims of this dissertation. The role of states to an extent is discussed in chapter 5, in the context of the case studies, as the role they have to play could be pivotal for future processes.

4 Disability and Participation

This chapter is designed to draw together the literature on disability and the meaning of participation in the context of DPOs. It is designed to meet objective 1 of the research.

4.1 Conceptualisation of Disability

There is no universally agreed definition of disability. This is due in part to the fact that disability is complex and that defining it is controversial. The need to define could have a number of consequences in terms of *"identity, attitudes and access to resources"* (Carpenter and Austin, 2008). Acknowledging this, the dissertation is not seeking a definitive definition. The following text will discuss the conceptualisation of disability as it provides an understanding of the frameworks in which policy can be developed.

Disability, as a concept, is important to this research as it highlights the approach advocated for by the disability movement and which in turn should impact upon the approach taken by instigators of participatory policy processes.

Disability, can be viewed as a socially constructed phenomenon and was traditionally conceptualised and constrained within a linear model as a welfare or a medical issue (the 'problem' being with the individual) (Thomas, 2005; Wapling, 2012). Since the 1970s, *"the international disabled people's movement has challenged the outdated models, by arguing that: it is not physical or mental conditions that are disabling but social, attitudinal and physical barriers preventing equal participation in community life"* (Albert, 2004 p.5). This view has become known as the 'social model' and disability, according to the social model, is the result of discrimination and social exclusion.

Thomas (2005 p.3) describes the re-conceptualisation into a primarily social phenomenon:

"This social model of disability draws a clear distinction between impairments and disability. Society disables people with impairments by its failure to recognise and accommodate difference and through the attitudinal, environmental, and institutional barriers, it erects towards people with impairments. Disability thus arises from a complex interaction between health conditions and the context in which they exist. Disability is a relative term with certain impairments becoming more or less disabling in different contexts."

The disability movement utilises the social model as a *"political platform and tool to secure the 'rights' of disabled people, with the objective of ensuring that they enjoy the status of full citizenship within contemporary society"* (Lang, 2001). The focus on the securing of 'rights' for PWDs is in line with the rise of the rights based approach to development which, for disability has become intertwined with the social model.

The human rights link to development[8] has become the basis on which many IGOs now claim to base their policy processes, and through which DPOs now advocate for change. With many now proclaiming disability is a human rights issue (Albert and Hurst, n.d.). However, the application of the social model and the realisation of human rights are not mutually exclusive.

Vic Finkelstein[9] in 2001 attacked the UK disability movement, for using the social model as the starting point for a rights-based approach (Albert, 2004). Finkelstein (2001 p.4) wrote, *"…the campaign for 'disability rights' does not depend on, nor is it a reflection of, the social model of disability"*. Later going onto discuss that human rights are a legalistic approach, granting rights to those it deems 'disabled' and *"the focus is on identifying characteristics of the individual, rather than the nature of society, and then making selected 'concessions' to those so defined"* (Finkelstein, 2007 p.5). Hurst (1999) asserts that sustainable development cannot exist outside the paradigm of human rights and social change must be working in partnership and complement the human rights agenda. Whereas the envisaged social model was not resting within a human rights approach, they are inextricably linked through the emerging approaches taken to development.

This is supported by Disability Awareness in Action (n.d. p.2). They define the differences and similarities as follows;

"The Social Model defines difference and disadvantage, thereby, indicating what social change needs to take place to ensure equality and justice for all."

"Human rights are fundamental, universal and indivisible principles by which every single human being can gain justice and equality."

Therefore, one provides the means to define, the other to as the means to gain equality and justice. If one develops without the other, effective change will not result even though they are not mutually exclusive.

4.1.1   Disability on the Agenda: Acknowledging the New Normative Ideas

The link between disability, human rights and subsequently development has been established. There are two further dimensions which confirm the requirement for disability on the development agenda and subsequently within the realm of international policy processes. In order to allow this dissertation to progress, there is a need to draw together a summary of the new normative ideas on disability as

---

8 The UN General Assembly formally adopted the declaration on the rights to development in 1986, recognising the relationship between human rights and development. Article 1.1 of the declaration states: " *The right to development is an inalienable human right by virtue of which every human person and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realized.*" (UN, 1986)

9 Vic Finkelstein's pioneering work in the 1970s, on interpreting disability inspired the subsequent formulation of the social model of disability (Albert, 2004)

formulated from the review of literature. It is important to identify them at this stage because they are assumed as accepted by the author and are referred to throughout this dissertation.

A further two generally agreed norms have been identified during the literature research and are outlined below;

Poverty – Disability Nexus

Drawing on the social and human rights focus, there is growing discourse on the 'poverty – disability nexus' (Moore and Yeo, 2003). Due to the increasing inequality within society, disability is further recognised within the development arena due to the fact that *"disability and poverty are complex, dynamic, and intricately linked phenomena"* (The World Bank, 2012). Again the one cannot be resolved without addressing the other. This is opening up space within the policy arena previously closed to disability. It is interesting to note that within the DFID Research Gap Analysis; *"there was no question among Southern DPOs, that poverty was a major problem for disabled people. Rather they were concerned with how to get disabled people more fully recognised as part of this agenda, particularly as poverty reduction is the central MDG, and disability is not mentioned."* (Albert et al, 2005 p.18).

In other words, it is necessary to move the debate forward to include research on how DPOs can engage effectively in the policy process (Albert et al 2005). In line with the above, not all disabled people are poor, and not all poor people are disabled, but disability is over-represented and more prevalent amongst poor people. Furthermore, whilst anyone can be born with or acquire a disability, those in poverty are significantly more likely to become disabled, and once disabled, are more likely to slide into ever greater poverty (See: Kett, 2009; Thomas, 2005; Wapling, 2012; Yeo, 2005).

Disability is a cross-cutting issue

No one sector can say that disability should not be part of their considerations. Whether its health, education or humanitarian assistance, disability is prevalent in societies at all levels (Albert, 2004).

4.2   Participation

Arnstein (1969) was among the first to recognise that participation can be used to stand for a broad spectrum of meanings and those meanings are likely to vary on each occasion and in each location in which contact occurs. Therefore, civil society participation in decision-making is a complex concept and by its very nature might result in varying views on what might be expected to be achieved (UN, 2012). Definitions of participation vary greatly; ranging from a narrow focus on nominal membership in a group to a much broader emphasis on interactive processes in which the disadvantaged have voice and influence in decision-making (Briggs, 2011). Therefore, there is *"no blueprint for participation because it plays a role in many different contexts, different projects and for different purposes"* (Tikare, 2001 p.3). Generally, it can be accepted that participation is based on the premise that sustainable policies require local voices to be heard and that participation is the process by which actors can influence and share control over priority setting and policy-making (See: Holland et al, 1998; Tikare, 2001).

Participation traditionally occurs as a result of a 'top down' process, normally instigated by governments and IGOs, or through 'bottom up' processes through actors such as DPOs advocating a participatory approach, by seeking to influence a specific policy (Rietbergen – McCracken, n.d).

There are four traditional levels of participation as used by key institutions such as The World Bank (McGee and Norton, 2000). These distinctions echo the 'ladder of citizen participation' that Sherry Arnstein (1969) introduced:

- Information Sharing (Low Participation);

- Consultation;

- Joint decision making;

- Initiation and control by stakeholders (High Participation).

Drake (2002) contends that a much wider spectrum of participation is required and a clearer definition of what each level of engagement might mean. The extremes of his spectrum show that participation might be at one end described as little more than tokenism, but it might refer to extensive democratic power sharing and genuine collaboration at the other.

The spectrum of participation is (Drake, 2002):

- Absolute control (User governance);

- Specific decision-making powers (High participation);

- Joint decision making with others (Medium participation);

- Being consulted prior to action (Low participation);

- Being informed of outcomes (Very low participation);

- No contact with decision making (No participation).

Mladenov (2009) argues that it is necessary to distinguish the different levels or degrees of participation as a possible way out of the impasse of the interaction between people and state. Through making this distinction the status quo might successfully be overcome when *"participation; as changing a particular system of relationships and, therefore, particular patterns of power distribution"* (Mladenov, 2009 p.43). Drake's (2002) presentation of the hierarchy is presented in the non-traditional format by showing firstly the high participation activities and other low participation activities after, representing a reversal of the power balance within the participation 'ladder' and giving emphasis to high participatory activities.

4.2.1 Participation in Policy Process

Understanding how policy 'processes' work is key to understanding how change in policy can occur through participation. Traditional policy making can be conceptualised as a linear, dichotomous process of rational decision-making. The linear model is formed of a series of steps that flow in a logical sequence from identification, to formulation, to implementation and then to evaluation.

The positivist view sees policy processes as decision-orientated, top-down, relying on rational actions in decision-making and implementation and resting on the assumption that an optimal policy is possible. This places strong emphasis on technical expertise and the production of generalised, universal statements (McGee and Brock, 2001). Disputing this, reformists claim that the linear model fails to capture the more complex and contested realities of participation in policy-making (Lazarus, 2008).

The way in which policy process is now beginning to be understood and conceptualised can be related to broader changes in the mainstream development approach. The latter has increasingly come to embrace a wider range of actors, and their activities in the sphere of policy making (McGee and Brock, 2001). Therefore, policy making is shifting from a positivist paradigm to being seen as *"a complex, political processes in which power and agency are key dynamics"* (McGee and Brock, 2001 p.9), encompassing a

much broader constellation of actors who engage in various ways with the process of making and shaping policy. These dynamics bring a clearer view on uncertainties within the policy process which reformists accept is a step in the right direction, but nothing short of full change within organisations themselves would be satisfactory, otherwise inclusion of wider actors, could in fact become tokenism (Mladenov, 2009; McGee and Brock, 2001).

Participatory development was traditionally rooted in participation at the project level. It was often set apart from the state, but it has now begun to turn towards political participation and increasing poor and marginalised people's influence over the wider decision-making processes at the policy level (Cornwall, 2000). This has opened up space for discussions of citizenship which are being shaped by parallel moves within both human rights and development thought (Gaventa, 2002). Participation is being reframed as a fundamental human and citizenship right. The right to participate is intrinsic to other rights and therefore participation is becoming a prerequisite (Cornwall, 2000; Ferguson, 1999).

4.2.2   Disability and the Changing Landscape of Policy Participation

The mainstreaming of participation in development may have *"opened up new spaces and places for citizen participation, little understanding exists of what actually occurs in these spaces, and how they differ one from another"* (Gaventa, 2002 p.6). This is a particular pertinent point for the disability movement. Research on DPO participation has highlighted that *"where other marginalised groups, such as women, who have been increasingly brought into participatory processes at the project level and subsequently see a mainstreaming of the issue at a political level, disability still remains on the margins across all levels of participation, whether it is at the project, political or policy level"* (DFID, 2000).

The social model and human rights approach is clearly distinguishable from the welfare or charity model. This means that IGOs can base their approach to policies on the accepted model. However, the differing models, find an equally mixed approach to policy and policy development (Albert, 2004), often resulting in compromises between the models and/or attempting to integrate different models into the approach (even though they are quite opposing ideas). For example DFID's Issues Paper, considered both models and then decided it was preferable to go for a twin track approach: *"an integrated approach using best practice in both social and medical terms."* (DFID, 2000 p.8).

Moreover, participation is a necessary and accepted form for eliciting the views of the poor and marginalised, however, methodologies are being challenged by those who aim to ensure they have their voices heard. In the case of DPO's, there is increasing movement towards a *"need (for DPOs) to take a lead role in research or project work around the most effective ways to enable this participation"* (Albert et al, 2005 p.20). Being participants as opposed to leaders is actually hindering their ability to come to the

forefront of the research and funding, thereby, always placing them on the back-foot as it was claimed that as long as DPOs were simply used as participants, they could *"never build their own skills and organisational capacity"* (Albert et al, 2005 p.17). Therefore, this is a direct challenge to the traditional role to participation played by DPOs.

4.3   Key Actors' Philosophies on Participation

4.3.1   UN Philosophy on Participation in Policy

The United Nations is both a participant in, and a witness to, an increasingly global civil society. More and more, NGOs and other CSOs are UN system partners and create valuable UN links to civil society. CSOs play a key role at major United Nations Conferences and at the international level (UN, n.d.). This was recognised in 2009 by Secretary-General Ban Ki-moon[10];

"Our times demand a new definition of leadership - global leadership. They demand a new constellation of international cooperation - governments, civil society and the private sector, working together for a collective global good."

There is also an important point to note about the UN language. NGOs are 'consulted' on UN policy and programme matters but not viewed as participants. Furthermore, the UN provides a platform for information sharing as it organises and hosts briefings, meetings and conferences for NGO representatives who are accredited to UN offices their programmes and agencies (UN, n.d.).This is not participation but rather information sharing.

However, the UN within its Post-2015 literature is explicit in that participation by civil society is not easily defined and that the responsibilities of such participation rest with states themselves as the *"decentralized governance should be improved by national and subnational policies to enhance bargaining power of the disadvantaged groups."* (UN, 2012 p.42). The UN declares its role as an enabling partner for involvement of CSOs within policy processes. Within this enabling role, the UN is investing in supporting NGOs to take part through the Department of Economic and Social Affairs (DESA) and the UN Democracy fund, and the non-governmental liaison service (UN, 2012; UN, n.d.). Nowhere within these elements is a definition explored as to what it actually means to be part of a policy process at the UN. The emphasis on states to ensure participation in public and political life does not define the responsibilities which the UN has itself to ensure participation is occurring on an optimal basis within its own systems. Many of the UN agencies such as UNCHCR do have their own definition on what consultation constitutes but this is mainly focused on the project implementation phases rather than a policy development phase.

---

10 Secretary-General Ban Ki-moon, Speech at World Economic Forum, Davos, Switzerland (29 January 2009)

4.3.2 *World Bank Philosophy on Participation in Policy*

Throughout the envisaged PRSP process, the international financial institutions (IFIs) of the World Bank and IMF saw participation as a process of national dialogue through which stakeholders influence and share control over priority setting, policymaking, resource allocations, and/or program implementation (World Bank, 2007), and from which some level of national consensus is formed around policy priorities (Guerrero, 2003).

However, this has moved to a more holistic approach to participation. Currently The Participation and Civic Engagement Group of the Social Development Department promotes the participation of people and their organisations to influence institutions, policies and processes for equitable and sustainable development. The Group supports World Bank units, client governments and CSOs to incorporate participatory approaches in the design, implementation, monitoring and evaluation of World Bank supported operations (World Bank, n.d.).

The Participation and Civic Engagement Group within the World Bank focuses on the following themes:

Figure Two: CSO Engagement at the World Bank

Social Accountability promotes the participation of citizens and communities in exacting accountability;

Enabling Environment for Civic Engagement promotes conditions that enable civil society to engage effectively in development policies and projects;

Participatory Monitoring and Evaluation promotes the participation of local beneficiaries in the monitoring and evaluation of projects and programs; and,

Participation at the Project, Program & Policy Level promotes participatory processes and stakeholder engagement at the project, program and policy level.

(World Bank, n.d.)

The language used by the World Bank refers to participation over consultation. The current ways in which they describe their role is enabling and promoting participation, rather than leading to ensure it occurs within policy processes.

4.3.3   Umbrella DPO Opinions on Participation in Policy

A discussion was held with the key informants about their organisations understanding of participation. Most held the notion on an idealistic level that participation should be "free, fair, equal and respectful" rather than specifically relating back to the levels of participation. The slogan of the disability movement was cited by all *"nothing about us without us".* Any policy or decision making should have PWDs at the forefront (as its 'our' life) and the PWDs should be taking the decisions. All the informants expressed the view that DPOs and PWDs should be leaders of policy process and that PWDs should be more prevalent throughout the work force of IGOs and NGOs alike.

Two of the informants went on to discuss that participation needs to be progressive and continuous, present at all stages of the policy forming process, and within post policy programmes.

Each of the informants were resolute that consultation is not participation and one key informant described the changing rhetoric between the two as *"confusing and is causing a misinterpretation by organisations attempting policy processes with DPOs"*. Another, key informant described an example with regard to the UN where participation *per se* is occurring at differing levels. There is a working group of at least 20 countries, led by Mexico and New Zealand, meeting biannually to discuss the prominent issues affecting PWDs. This the key informant described as being participation on an equal basis. They felt able to talk freely and openly about matters. This was in contrast to the way in which they described their overall role within the UN – *"as advocacy as a means of ensuring that disability is considered across the board as an issue within resolutions and General Assembly meetings"*. However, the key informant was clear that this did not detract from the *"value their organisation placed on being able to hold such a role"* and it is a major step forward for disability that they are able to sit within decision-making committees to advocate for the inclusion of PWDs.

Furthermore, there was particular attention paid to the issue of tokenism. One of the informants stated that *"some governments are legitimising their commitment to PWDs through inviting a few handpicked and compliant PWDs to meetings with IGOs"*.

4.4   Summary

Key observations from this chapter are summarised under the headings below;

Participation as a concept is fluid

Participation and its relation to policy processes has evolved and changed since its inception. This process will continue as a wider perspective as policy-making develops and new spaces are opened for discussion on citizen participation. However, there have been examples of failures to recognise the diversity of DPOs. This may be a reflection of a move towards the human rights approach as all disabled persons have the same rights, but not all disabled persons have the same needs.

IGOs as organisations need to be clear on their philosophy to participation

Changing rhetoric and inconsistent approaches is causing confusion and misinterpretation of processes. IGOs have started to more clearly define their role, but the IGOs need to acknowledge that stating their role and encouraging or inviting DPOs to participate, is simply not enough.

Disconnect between the recognised definition of participation and how DPOs refer to participation

DPOs focus on a 'rights' based perspective of free, fair and equal participation whereas the theory places participation under what it constitutes (i.e. the level of control).

State centric versus decentralised

The contradiction is that participation, as a concept within the literature and the adoption by IGOs of the human rights approach, is challenging the traditional state centric and top down approaches to policy processes. However, the language and philosophies' of IGOs seem to support a maintaining of the state centric approach. Therefore, maybe only an 'optimal level' of participation can be achieved as opposed to the 'full' participation advocated for.

Capabilities of DPOs need to be recognised

The relation between DPOs and IGOs is such that IGOs hold the power over the policy process and have the ability to decide what level of participation will take place. DPOs, on the other hand, are a strong voice representing PWDs but their role continues to remain within lobbying or activism. DPOs need to be within the forefront of policy processes and not just passive participants. The top-down approach to participation and policy should be reconceptualised into bottom up approaches, as shown within Drakes (2002) hierarchy of participation levels. In contrast DPOs do have a structure through which their voice can be heard: it is whether their voice is listened to outside of that structure which is key focus of this dissertation.

5 Emerging Implications of DPO Participation in Policy

The purpose of this section is to review the emerging implications for DPO participation in policy processes and is designed to meet research objective two. The chapter has been formed from a literature review of journal articles and DPO specific studies, albeit in a smaller part from the key informants.

5.1.1 Does Policy Participation Equal Charity?

The dis-empowering structuring of charities to 'help' PWDs and the work carried out under a welfare focus, were two of the founding reasons for the formation of the disability movement and DPOs in the first instance. But the increased recognition of the need to include disability in development policy could reignite the welfare approach again. This reductionism is as a result of the demands of the international policy arena and process, meaning that information must be presented in a form that is digestible by decision-makers and/or presentable to an audience or institution; the homogenising of PWDs by removing the complexities of disability is failing to take account of the wider social issues - supporting a medical model approach - as it looks for quantitative, expert and not political solutions to the problems encountered by disabled people (See: Barnes, 2003; Hurst, 1999; McGee and Brock, 2001; Mladenov, 2009; Mohan, 2006; Nustad and Sending, 2000.)

5.1.2 Depoliticised and Depersonalised

The current definition and approach to participation could cause the de-politicisation and de-personalisation of the DPOs. By bringing DPOs in to a position which seeks change from within institutions, it can place DPOs at odds with the campaigning and lobbying disability movement, and removes some of the objectivity of the process.

A paper published by Teodor Mladenov (2009), highlights that when organisations become too integrated into the structure of state power they risk becoming a '*mechanism*' (by which to maintain rather than challenge the status quo). Therefore, there exists a very real risk of DPOs being drawn into a process, that as DPOs and their umbrella organisations grow in political status, it effectively depoliticises them, as they are no longer able to exert true influence through their lobbying or advocacy and augments state power. Noteworthy is Van Houten and Jacobs (2005) who describe the professionalisation and bureaucratisation of the Dutch National Council of Disabled People which in turn led to the distancing of its umbrella structure from its social base. The authors pointed out that:-

> "the Council has developed a different voice compared to that of the original movements. It is the voice of policymakers, government officials and politicians, and not the voice of its members with their daily experiences and struggles" (van Houten and Jacobs, 2005 p.648)

*And s*ignificantly:-

> *"In this process, the critical consciousness and direct action of the original movement vanished, in cooperating with mainstream institutions"* (van Houten and Jacobs, 2005 p.648)

Therefore, in a depoliticised and depersonalised state, DPOs and umbrella DPOs could easily be transformed into an instrument for legitimising the status quo and equally legitimising a 'participatory' process which is far from it. This phenomenon was further highlighted by one of the key informants: *"they felt that they lost some of their autonomy as an organisation by handing over responsibility to larger international DPOs, whom represented them within the international arena."*

A clear distinction needs to be drawn between being brought 'within' a policy process and leading a policy process. The former suggests becoming incorporated within the IGO system whereas the later suggests that DPOs have the capacity and set up to lead. DPOs must exercise caution on which they advocate for.

5.1.3   *Interplay between DPOs and their Governments*

Whereas the key actors identified in this dissertation are IGOs and DPOs, the role of states cannot be underestimated nor neglected, and especially when considering the philosophies to participation of the IGOs; that participation rests within the responsibilities of states. A reformists perspective would claim that the World Bank and other institutions' theory, underpinning their vision of 'participation', is simplistic by removing considerations of a political nature (Lazarus, 2008); and according to Booth et al (2006 p.7-8), is one which assumes that governments, once obliged to debate the sources of poverty and options for reducing it with their citizens and their organisations, *"would become compelled to take the matter more seriously and would enter into new bonds of accountability for policies and their results as a consequence"*. However, this does not take account of the underlying causes of the reasons for poor DPO participation in the past nor indeed the prevalence of inequality as a whole. The complexities of historical relations between state and DPOs could determine the level of accountability which can be applied to nation states. Lazarus (2008) opines that ignoring political and structural causes of inequality consequently renders participation impotent in tackling poverty at its roots. This has led in some cases too participation in a realm of 'policy' quite apart from the sphere of 'politics' in which the real battles are fought over the control of state institutions and resource allocation.

5.1.4 Legitimacy and Accountability

The longer term implications of increasing DPO participation also needs to be considered. It could be argued that accountability, having been drawn as a theme from the previous three implications, suggest that DPOs are losing sight of their core values through the process of losing accountability to the people which they represent. Moreover, the increasing acknowledgement of new actors within international policy processes, *"does raise issues of CSOs needing to come to terms with the problems of legitimacy, representativeness and accountability"* (Pianta, 2005 p.4).

This also raises questions over the legitimacy of DPOs representing PWDs. DPOs have a very strong, unique identity and therefore a legitimacy in representing the needs and rights of disabled people which organisations 'for' disabled people can never have (Thomas, 2005). However, Yeo and Moore (2003) believe this could be a more divisive issue because it assumes that PWDs (as a group) have a set of common and distinct interests. Notwithstanding this assertion, DPOs do hold a legitimacy of representation on the basis that PWDs chose to join the DPO; the focus of the DPO will be influenced by their own political and social environments, but these should also reflect those of the countries or local areas in which they work. There still remains a risk that certain PWDs could be excluded from DPOs. Thomas (2005 p.13) points out that *"many (DPOs) have low capacity, poor democratic credentials and many do not adequately represent the needs of disabled women and children and people with certain kinds of impairments, especially those with intellectual and mental health problems"*. Whilst DPOs do not have to act as accountable and democratic bodies - unlike government based policy-making - the question which remains is *"how far civil society can increase its influence over global decisions prior to addressing the issues of accountability?"* (Pianta, 2005 p.4).

However, this should not detract from the fact that DPOs still represent a large number of PWDs worldwide. The emphasis of policy-makers should be to ensure that DPOs participating truly represent a cross section of the disabling social and environmental factors, local to the DPO.

5.2   Summary

In summary, the implications evidenced are:

- Disability approach reverting to a charity/ welfare model;
- DPOs could lose touch with their core values;
- DPOs become depoliticised as a result of being brought within policy processes;
- DPOs are within a participatory process that is apart from the political policy process; and,
- DPOs will need to address issues relating to accountability.

6   Participation in Practice

The chapter aims to evaluate three case studies that represent DPO participation in international policy processes. The chapter links to research objectives 2, 3 and 4. Looking at the case studies may allow for the isolation of specific factors which hinder participation by DPOs and where chosen in line with the criteria set out in the methodology.

6.1   Case Study One: UNCRPD

6.1.1   Background to UNCRPD

In December 2001, Mexico proposed the establishment of an Ad Hoc Committee to the UN General Assembly which was later enshrined in Resolution 56/168 to consider a comprehensive and integral convention to promote and protect the rights and dignity of PWDs (UN Enable, n.d. (b)). The resolution invited:

 "States, relevant bodies and organizations of the United Nations system, including relevant human rights treaty bodies, the regional commissions, the Special Rapporteur on disability of the Commission for Social Development, as well as intergovernmental and non-governmental organizations with an interest in the matter to make contributions to the work entrusted to the Ad Hoc Committee, based on the practice of the United Nations." (UN Enable, n.d. (b)).

The UNCPRD negotiations allowed the participation by CSOs which had gained consultative status with the Economic and Social Council (ECOSOC). The consultative status was achieved through application to Department of Economic and Social Affairs (DESA).

The representatives from CSOs accredited to the Ad Hoc Committee, by attending any public meeting of that committee, were able to participate in its work in the following ways:

i.   making statements subject to the availability of time and in accordance with current United Nations practice;

ii.   with time is limited, selecting a spokesperson from amongst their number on a balanced and transparent basis, taking into account equitable geographical representation and the diversity of non-governmental organizations; and,

iii.   receiving copies of the official documents, as well as making written or other presentations although written presentations are not issued as official documents except in accordance with ECOSOC resolution 1996/31 of 25 July 1996. Furthermore, non-governmental organizations may

make their material available to delegations in accessible areas designated by the Secretariat (UN Enable, 2002).

The Ad Hoc Committee later extended its procedures through the General Assembly resolution 56/510 to regional commissions, United Nations bodies and mechanisms, national human rights institutions, experts, and national disability institutions (UN Enable, 2002). However, the resolution still required accreditation of CSOs to the Ad Hoc Committee and that accreditation was only granted to all CSOs enjoying consultative status with the ECOSOC. However, those CSOs not previously accredited to the Ad Hoc Committee could apply to the Secretariat for such accreditation but member states had the ability to object to the inclusion of a CSO.

The First Session of the Ad Hoc Committee took place from 29 July to 9 August 2002 and the last session took place 14 to 25 August and 5 December 2006 making it one of the fastest negated conventions in the history of the UN (UN Enable, n.d. (a)). The Ad Hoc Committee held eight sessions and on 13 December 2006 The Plenary of the General Assembly adopted by consensus the Convention and the optional protocol. The Convention and the optional protocol opened for signatures at the United Nations Headquarters in New York as of 30 March 2007. The Convention came into force on 3 May 2008 (UN, n.d. (a)). To date there have been over 125 ratifications.

6.1.2 *Participation by DPOs*

The involvement of PWDs in policy-making emerged at a supranational level with the development of the UNCRPD. For the first time in the history of the United Nations, NGOs and national human rights institutions were granted permission to attend the informal sessions of the Ad Hoc Committee. Twelve civil society representatives with a focus on DPOs and a representative from each of the accredited national human rights institutions were also included in the Working Group, established to produce a working draft of the Convention. Moreover, some State Parties included PWDs on their official delegations to the United Nations (UN Enable, 2005).

The influence of PWDs in the negotiation of the Convention contrasts with earlier research that highlights the marginalisation of PWDs in participatory processes (Moriarity and Dew, 2011). Therefore, the development of the UNCRPD could arguably be seen as providing a remarkable example of the participatory process within an international arena.

The UNCRPD was unique in its inclusion of members of DPOs. There has much said about DPO members as full and equal participatory actors at every stage of its development. However, there is very little analysis in the literature as to whether this is actually the case; there was also a reluctance from the key informants to provide insight on this issue. The impasse, coupled with a reluctance to evaluate the participation in the

policy process, may be a reflection of the fact that DPOs and their international counterparts fought long and hard to gain the recognition this convention brings and have their voices included within it. However, for progress to be made on future policy processes, for example the Post-2015 agenda and international level participatory exercises, lessons from UNCRPD would be beneficial.

6.1.3   Levels of Success

A review of the UNCRPD process for DPOs and disabled persons involvement in New Zealand found that the convention negotiations were generally regarded as a success. This was put down to two key factors: firstly, the active political involvement of PWDs; secondly, its (New Zealand's) officials being supportive of participatory processes (Moriarity and Dew, 2011). The success of the participatory process was spurred on in part within a favourable political opportunity structure, notably the manifesto of The Fifth New Zealand Labour Government (1999–2008) supported collaborative processes with its concomitant benefits for PWDs (Moriarity and Dew, 2011).

Some of the participants in that study went on to say that a level of trust had been established between the New Zealand representatives and the DPOs thereby building bridges between the government and the DPOs. These views were generally supported by the Key Informants. However, the key informants did point out that the governments wield a great deal of power, and therefore they had to be receptive and continue to be so. This is supported by the observation of the informants in Moriarity and Dew's 2011 study that in fact *"not all countries allowed their disabled people the same level of involvement as the New Zealand Government"* (2011, p.694).

One of the key informants believed the voice of PWDs had been heard through the UNCRPD process and the resulting convention does reflect their views. The involvement of PWDs arguably helped to make the Convention a more relevant and practical document (Moriarity and Dew, 2011). However, one of the key informants observed that the negotiations culminating in the final UNCRPD documentation excluded youth and young people.

The wide ranging reach of DPOs are highlighted in the New Zealand Case Study. One of their respondents noted that the processes required people to compromise on emotionally charged issues; this resultant compromise could produce tension between different sets of actors involved in the process (Moriarity and Dew, 2011).

Two of the key informants explicitly stated that they were pleased with the level of participation overall but they did specifically question the representation within the process of grass-roots organisations. However, it was put to the informant that the purpose of the umbrella DPOs in this instance was to represent the views of PWDs and their member organisations. This was not accepted as a valid point by

one of the key informants - the real practical day-to-day issues faced by PWDs could not be truly represented without grass-root organisations. The two key informants believed the reasons for the lack of grass-root organisations in the process was due to a chronic lack of funding married with an inability to attend the UNCRPD meetings as a result.

The UNCRPD, with its uniqueness and ambition to include PWDs set a precedent for future policy processes at the international level. The UNCRPD raised the profile of disability amongst the development sector, and as one key informant put it, has "woken" up the development professionals to the need to include disability in their programmes; effectively focusing the need for participation of PWDs through Articles 29 of the Convention, as summarised in figure three below.

Figure Three: Article 29 of UNCRPD

Article 29 of UNCRPD states that participation is required on a political and public basis, and the states should promote an environment where PWDs can participate on an equal basis.

Article 29 demands that:

"To promote actively an environment in which PWDs can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

(ii) Forming and joining organizations of PWDs to represent PWDs at international, national, regional and local levels."

(See: UN Enable n.d. (c))

However, what the UNCRPD neglects to place emphasis on is how states should allow those organisations to partake in international processes: they can be formed or joined, but how they take part in decision-making processes is unclear. Moreover, the role which IGOs have to play in ensuring PWDs achieve political and public participation in international policy processes is much less clear and ill-defined.

6.1.4   Observations on the Process

The following observations were derived from the literature review and key informant interviews.

The DPOs' reflections on the process are under researched

The numbers of DPO participants and representations to the working groups within the UNCRPD process is uncertain, and even their reflections on the process itself are also notably absent in published research. This could be a reflection of the fact that the key informants discussed how DPOs and PWDs are proud of what has been achieved in the UNCRPD. They did acknowledge that the process was far from perfect yet at the same time it had been better than experienced in the past. It could, therefore, be assumed that had the process not lived up to expectations there would be more DPO discussion on this issue (as the disability movement is known for its direct action).

No 'lessons learnt papers' have been completed from the UN perspective

The UN is an inherently bureaucratic institution, which, by its own sets of rules, means the UNCRPD process could never have truly been participatory, that is, in the sense of achieving absolute control and user governance by DPOs. The pre-approval process for DPOs through DESA, could have automatically excluded some DPOs due to the application process being complex and requiring significant amounts of information this presenting a first hurdle to full participation. Furthermore, the reliance on governments by the Ad Hoc Committee to include DPOs coupled with a lack of a subsequent review by the Secretariat to the UNCRPD, considering how DPO participation actually worked in reality, does bring to bare the question of just how 'participatory' the process was and raises concerns about the actual commitment of UN to participation. The process may have included DPOs and human rights organisations within discussions, but, from an outsider's perspective, the process was seen only as ostensibly participatory - in reality it was a top-down process instigated by the UN with the power within negotiation remaining centrally focused with it and the member state. In its dealings, the voices of PWDs were heard, but the power balanced remained firmly in the favour of the UN preventing some control being exerted over the process by DPOs.

The process and outcomes of the UNCPRD are too technical

All of the key informants stated that the UNCRPD process was highly bureaucratic and complex and the resultant document highly technical. One of the key informants went on to argue that the position of the disability movement has been weakened to a degree by the fact that the UNCRPD is difficult to interpret and an unnecessarily complex tool. They evidenced this fact by referring to an example in the business sector which has arisen since the UNCRPD including non-disabled organisations and consultants being funded to 'train' DPOs and PWDs on what the UNCRPD actually is and what it means for them. This was seen by the key informant as a regressive step in terms of inclusion of PWDs.

This highlights an inherent contradiction: on the one hand, the evidence shows that DPOs believe participation made the documentation more relevant and PWDs voices are reflected in the convention; but on the other, the output documentation is too technical for DPOs to understand and apply in use, thereby devaluing the convention for PWDs because it effectively prevents them from being able to hold their respective governments to account if they cannot understand the principles and procedures enshrined in it. This could be a reflection on the fact that the final documentation was produced after participation had occurred within the UN system.

Increased understanding

Participants noted the participatory process was educational for both government officials and PWDs. Having PWDs involved in the process helped officials to understand the extent of the discrimination faced by PWDs. It was also felt the officials developed first-hand knowledge of PWDs' capabilities (Moriarity and Dew, 2011). This also occurred on a cross-cultural basis through the mixing of member states' leaders and representatives of PWDs contributing to a more positive perception of PWDs being formed. Yeo and Moore (2003 p.577) describes the increased visibility of disabled people as having *"the potential to provide a positive role model for others, and help overcome negative societal perceptions of disablement"*.

Reduced political machinations

Participants noted that another benefit of involving PWDs in the development of the Convention was that it reduced political machinations, or game playing, between nations. The inclusion of PWDs made the issues more real and ensured the process moved forward (Moriarity and Dew, 2011). The 'energy' within the negotiations was significantly improved and it helped prevent negotiations from becoming side-tracked as a result of having PWDs representatives within the room, and a desirable consequence of this was that the negotiations were kept on track from a time perspective.

Increases accountability to the wider public and civil society

According to the participants (including PWDs), the negotiation process was also helpful in that it increased government accountability to the public; the transparency of the negotiations meant that civil society could report on the actions of governments to the wider community (Moriarity and Dew, 2011).

Improved quality of policy

Inclusion of PWDs in the negotiation process resulted in a Convention that is more relevant and practical than other treaties. The participation of PWDs ensured that *"the Convention reflects a social model of disability, rather than a medical model"* (Moriarity and Dew, 2011 p.692). One of the informants in Moriarity and Dew (2011) discussed how it has prevented the definition of the lives of disabled people in a negative manner for generations.

Lack of involvement from disabled youth

The key informants noted this as a fundamental element lacking in both the final CRPD documents and the policy processes.

Grassroots organisations

The key informants noted that the representation of DPOs and PWDs was achieved through those organisations that had the *"voice, resources and capability to take part"*. Therefore, grassroots DPOs (i.e. smaller DPOs whose capacity are limited) were not participants in the negotiations. This was countered by another key informant who believed that if an organisation, such as the UN, wanted to *"reach out to grassroots DPOs on the scale and level required for international policy, umbrella DPOs were the only way to achieve this because they have the contacts and kudos with the grassroots organisations to galvanise their interest and encourage participation"*. Therefore, the UN should have had more of a focus on ensuring that umbrella DPOs, did in fact seek the views of the grass roots organisations.

Planning the process

The UNCRPD was instigated by a UN Resolution which in turn set in motion the establishment of the Ad Hoc Committee and therefore a series of reporting meeting deadlines all in line with UN protocol. The need to include CSOs came within the second and third Ad Hoc Committee meetings. It placed little emphasis on planning and left states to provide the CSOs with the resources and space to take part. This led to states being accused of tokenism or selecting compliant DPOs only.

Time scales

The point at which CSOs were involved in the process necessarily provided for a tight time-frames in which actors could participate. The UNCRPD is celebrated for the length of time it took to negotiate; however, this was also seen as a hindrance to achieving participation as it limited the amount of time governments and larger DPOs had to consult with their citizens and/or members.

Practicalities of the Process

The UNCRPD addressed practical aspects of participation to the extent of taking account of physical barriers to participating in the meetings and working groups (see: figure four). The *"methods to ensure accessibility during the negotiation process increased in sophistication over time"* (UN Enable, n.d. (c)). The internet access described below was still in the context of those DPOs who were accredited to the Ad Hoc Committee or able to communicate with a DPO or another organisation which was.

Figure Four: UNCRPD Accessibility Measures

The UN Enable website lays out the accessibility measures taken by UNCRPD:

- Methods progressed from diskettes and documents in Braille, to email and website facilitated communication, the website was created to be accessible to differing users;

- Within meetings assistive technology was available: for example screen readers for enlarging text;

- Working documents of the Convention text were posted to the website as soon as they were discussed during a session of the Ad Hoc Committee, an innovative practice for United Nations convention negotiations;

- The website thus provided instant worldwide access to the rapidly changing progress of the discussions, giving the opportunity for groups around the world to feed into the process in a timely manner and on precise issues;

- In addition, the conference room at United Nations headquarters in New York where negotiations were held was made WiFi-accessible mid-way through the negotiation process. The WiFi allowed persons in the room to electronically access and read the documents being discussed using assistive devices as necessary; and,

- All Ad Hoc Committee meetings were held in a wheel-chair accessible conference room, and neck loops were provided upon request for persons with hearing impairments.

(UN Enable, n.d. (c))

6.2 Case Study 2: PRSPS and Disability

6.2.1 Background

Poverty Reduction Strategy Papers (PRSPs) arose from a critique of the structural adjustment policies promulgated by the World Bank and International Monetary Fund (IMF) during the 1980s and 1990s (Mwendwa et al, 2009). PRSPs are supposed to be prepared by member countries through a participatory process involving domestic stakeholders, as well as development partners including the World Bank and IMF (2013).

Updated every three years with annual progress reports, PRSPs describe a country's macro-economic, structural and social policies and programmes over a three year or longer horizon to promote broad-based growth and reduce poverty, as well as addressing associated financing needs and major sources of financing (IMF, 2013).

Although PRSPs are produced on a national level, they are a suitable case study in the context of the dissertation because they are derived from an international context and the methodology and outputs required are predetermined at the international level.

The switch to the PRSP process was meant to ensure that poverty reduction strategies were 'owned' by their respective governments, and that such strategies were developed with the full participation of civil society institutions (Mwendwa et al, 2009). Through this process, the PRSPs are supposed to become *"the product and property of a government and its citizens"* (Lazarus, 2008 p.1206).

The ideological shift that underpinned the move from the structural adjustment policies of the 1980s and 1990s, to the PRSP process instituted after 1999, could not be more pronounced. In essence, then, the PRSP process was instituted to create a nexus between poverty, accountability and governance. Such an approach to policy-making is underpinned by the notion that a strong relationship exists between the state and society whereby each interacts with the other to negotiate national objectives, as well as negotiating modalities for how these will be achieved (Mwendwa et al, 2009). As discussed in chapter 3 this is not always the case.

In addition, the PRSP process was developed during the time when the very nature of poverty was being redefined, moving away from a purely economic understanding to one that reformulated poverty as a multi-dimensional phenomenon embracing economic, political and social factors, and which perceived poverty reduction in terms of freedom (Sen, 1999). Hence, it is now understood that people are poor and remain trapped in poverty because they are powerless (Mwendwa et al, 2009).

6.2.2 Participation in PRSPs

A major element of the PRSP process should constitute a public consultation exercise conducted through public discussions and workshops, mass media coverage, and Poverty Social Impact Assessment surveys (Lazarus, 2008). The outcome of the process should, therefore, be a unique, country-specific document detailing a PRSP designed to *"suit local circumstances and capacities' and to prove 'useful to the country, not only to external donors"* (World Bank, 2003 p.3).

Guidance notes and documents have subsequently been produced by the IFI on how to conduct PRSPs. McGee and Norton (2000) contend the roles played by each of the key actors in a PRSP participatory process are portrayed by the process documents. They are:

- Facilitators: Government

- Main Participants: National Civil Society Actors

- Enabling Participants (can place financial and human resources at the disposal of the facilitators): World Bank, IMF, bilateral donors.

N.b. this outlook maintains the status quo of the hierarchal top-down approach and power relations to participatory methods in the PRSPs.

6.2.3 Levels of Success?

There have been varied critiques of the PRSP's, the focus here is purely on DPOs and the participation process. There have been numerous calls that the inclusion of PWDs has been limited and disability in general has been extremely ill served by the vast majority of PRSPs: *"[i]t is apparent that the inclusion of PWDs within such processes has to date been limited and largely ineffective"* (Mwendwa et al, 2009). When disability is mentioned, it is generally in relation to social protection or disabled people are acknowledged with other vulnerable groups (Albert et al, 2005). An ILO study (ILO, 2002) found that disability had been almost totally excluded from the first round of PRSPs. There has been some improvement in the following rounds, but a report published in 2004 still characterised the coverage of disability as visibly limited and a *"patchwork of fragmented and uncoordinated interventions".* (World Bank, 2004 p.5)

6.2.4   Observations on the Process

PRSPs have been highly criticised and case studies from around the world *"portray a reality of PRSPs and participation that is greatly divergent from that envisaged by its architects"* (Lazarus, 2008 p.1207). The following observations are derived from a review of relevant literature.

Participation was in fact consultation

The rhetoric of participation has in fact shown that participation has at best been consultative in nature. *"The level and nature of participation in PRSP processes has been largely* shallow and narrow...*almost everywhere the process has constituted a public consultation exercise at best and, at worst, participation has taken the form of 'theatre' staged by governments to satisfy donor demands in which civil society's policy input has been largely or entirely ignored"* (Mwendwa et al, 2009 p.38).

Whose agenda? Process conditionality prevented policy creating change

The PRSPs as a process needed to ensure that policy formulated actually created change, but as Kammruzzaman (2009) argues that 'process conditionality' as applied by the World Bank in its 'best' practice documents is actually preventing a participatory process and therefore stifling the required outcomes to create change. This approach by the World Bank runs counter to the outlined objectives of participation in the PRSP process. The World Bank believes participation can *"help build ownership over the strategy, make it more equitable to and representative of various stakeholder interests, increase the transparency of the policy formulation process, and make the strategy more sustainable"* (World Bank, 2002 p.240). Unless participation results in policy change, it rapidly loses all credibility and could raise doubts as to how much latitude governments actually have (McGee and Norton, 2000; Kammruzzamna, 2009).

Poorly defined ownership of the process

Kammruzzaman (2009 p.62) declares that the PRSP framework itself is problematic because it *"purports to promote local 'participation' to ensure 'ownership', while the whole idea and need for a PRSP has been generated by the IFI think-tanks, not by the client countries or the poor people concerned"*. Furthermore, the idea of 'ownership' of the PRSPs is also a contentious issue as the IFI boards have the power to reject or endorse any PRSP; therefore, countries cannot have full ownership of the process in any meaningful sense. As a result, there has been an overwhelming focus on the part of donors to meeting the demands of the process rather than the principles of participation (Lazarus, 2008). The idea of 'country ownership' is confusing while the World Bank and IMF have in various publications outlined the tentative contents, good practices, and expected nature of participation. (Kammruzzamna, 2009)

Governments despite the ownership arguments still maintained control over who to consult

This is in line with World Banks philosophy and the envisaged PRSP process. The result is governments' chose who they consult, decide on which areas to seek advice on from non-government sources, and defining poverty reduction targets and monitoring indicators. This means the emphasis is placed firmly on states to ensure all areas are considered in the processes. This, for disability, has resulted in further marginalisation. Oxfam in 2004 published a report on the PRSP process and declared that their *"experience suggests that almost everyone involved in formulating the PRSP is a middle-class technocrat, regardless of whether these people are women or men, or represent donors, government, international or local NGOs, or other CSOs"* (Oxfam GB, 2004 p.8). Therefore, without a representative body of PWDs for whom the policies are aimed at, the actual relevance of PRSPs to PWDs is doubted. Booth (2003) goes further *"there is strong anecdotal evidence to suggest that governments consult with compliant civil society institutions, who are in broad agreement with government policy and ideology"* (Quoted in: Mwendwa et al, 2009 p.664). By not seeking representations from wider interests in civil society clearly limits the scope and breath of the outcomes achieved during the policy process, and shows that the process is inherently steered by political forces.

Ability and function of DPOs to be able to participate

The level of involvement of DPOs and other civil society organisations in the formulation of PRSP in Uganda seemed to have been *"a function of the experience and preparedness of local DPOs, NGOs, CSOs and individual members of civil society and the willingness of the government to consult and take civil society views into account"* (Dube, 2005 p.7). DPO organisations have had to be proactive in their approach and in the case of Uganda it *"earned them the right to participate in the annual consultative group meetings held in Uganda."* (Dube, 2005 p.21) However, from the basis on which the PRSPS process was conceived, DPOs should automatically be included and not have to earn the right or lobby to be able to participate.

Poor understanding of disability

The PRSP process has also shown a fundamental disconnect between the theory and the knowledge of that theory by policy leaders, politicians and states. Policy-makers and senior civil servants are not understanding disability issues from a rights-based perspective (Mwendwa et al, 2009). Moreover, the incorrect impression of PWDs is provided within the treatment of disability and PWDs in the PRSP Sourcebook to guide countries in the development and strengthening of PRSPs. An ILO report in 2002 claimed that: *"the PRSP Sourcebook conveys the wrong impression about the abilities and aspirations of the majority of poor PWDs, and is not in keeping with the current human rights approach to disability. The limited "Social Protection" approach of the Sourcebook has negatively influenced a number of PRSPs, including those that have tried to include measures concerning disability and disabled persons"* (ILO, 2002

p.2). It in turn makes the work of DPOs who are participating harder as they need to address the knowledge gap first before being able to progress with the outcomes.

Time constraints on participation

A review of the Ugandan PRSP process highlighted a push for the PRSP to be written and for the financial arrangements to be agreed by the IMF. DPOs felt as if they were 'squeezed' out of a process which only lasted six months (Dube, 2005).

Capacity of DPOs to participate

DPOs felt the PRSP process requires deliberate efforts to first build capacity within DPOs. In Uganda, it was felt that they *"had insufficient numbers of staff (whether at national or local level) qualified to engage donors and policy makers in dialogue on macro-economic policy issues"* (Dube, 2005 p.25). The paper concluding that *"[i]t is clear that the disability movement in Uganda did not have adequate capacity to engage in the PRSP/ PEAP process"* (Dube, 2005 p.9).

World Bank has reviewed and learnt lessons from the first round of outputs of the PRSPs process

The World Bank has under taken a review process and provided states with guidance notes, in light of the over whelming issues raised with the PRSPs. It is obvious this review process was not inbuilt to the process. Rather, it was necessitated following over whelming criticism. It should be taken as positive that the World Bank, however, obtusely, was willing to review its own policy process.

6.3   Case Study 3: Post 2015 Agenda

The discussion in the introductory chapter outlined the linkages between poverty, disability and inequality. The Post-2015 agenda is now in full progress, the methods for reaching consensus on what if anything should follow the MDG is being approached to address some of the fundamental issues with the MDG. Firstly, that the beneficiaries are part of the process and secondly that previously unrepresented groups such as disability are part of any future targets.

Therefore, the inclusion of the Post-2015 agenda in the context of this dissertation on participation by DPOs is an indicator of the differences in approach between the PRSP, UNCRPD and this process. It is recognised that the process cannot be evaluated as it is only mid-way through, but key observations can still be drawn.

6.3.1   Post-2015 Process

There are several levels of consultations happening during the process - the focus here are those consultations likely to affect DPOs and PWDs.

National consultations

They are to be held in at least fifty countries (UNDG, 2012) although one of the key informants understood that up to one hundred consultations are being aimed for. The UN Development Group (UNDG) has produced a guidance book on national consultations and has allocated 64,000 dollars per country for consultations and human resource support is to be provided through the UN Volunteers (UNDG, 2012). The results of the consultations (to be recorded by June 2013), will feed into a global report from the UNDG, which aims to:

"Build a shared global vision with clear recommendations for governments, civil society and other stakeholders; amplify the voices of the poor and other marginalized groups; and influence intergovernmental processes so they align with the aspirations of civil society." (UNDG, 2012)

The key informants emphasised the importance of the national consultations. Two of whom have been writing to their DPO members to encourage their participation and awareness. Funding has also been made available for one of the umbrella DPOs to undertake training within seven countries on the national consultations with the aim to train DPOs on how to effectively participate.

Intergovernmental Process

The country-level consultations are intended to complement the intergovernmental process on the post-2015 development agenda, which also *"includes the work of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda announced by UN Secretary-General Ban Ki-moon on 31 July, and a 30-*

member Working Group on Sustainable Development Goals (SDGs), to be established by the UN General Assembly (UNGA) at its 67th session in September 2012" (UNDG, 2012)

Thematic Consultations Online

DPOs could be involved is the online forum through The World We Want Website. Twelve thematic consultations are in the process of taking place. A simple registration process allows users to add comment to any of the thematic consultations being proposed. Each thematic consultation is producing summary reports and recommendations to the high level panel. Disability is being 'addressed' under the inequalities thematic consultation.

Whilst a process of reporting has begun, it is still unclear as to who or what will be involved. The reporting from all the consultations will eventually feed into a High Level Meeting on 23rd September 2013. The meeting in September is being seen by the key informants as the most important phase of the Post-2015 agenda for disability. The meeting will have representation from Human Rights, DPOs, PWDs, as well as the UN and State representation. The key informants pointed out that this is the most important event in ensuring disability is given the political commitment it needs as part of the Post-2015 agenda and to *"move disability away from being a silo agenda to one which includes development at its core".*

6.3.2 Observations on the Beyond 2015 Consultation

The key informants noted a number practical observations to the Post-2015 agenda process. It is not possible to comment on the other country consultations as so few have taken place. Comment on the thematic consultations can be made and are derived from the key informant interviews.

Access and form of the consultation

Firstly, the key informants noted that the majority of the consultation process is taking place on the internet. Whereas they recognise the importance of the internet, they dispute the ability of small organisations to utilise the site. This was cited for several reasons:

- that many are in remote locations with sporadic electricity and unlikely to have permanent access to the internet;

- that the entire consultation is happening in English and the location of the majority of the world's poorest and by default their organisations are located in the global south, where English is not the first language; and,

- the translation of the pages are available into French, Russian and Chinese, but only the page content translates and not the content of the responses. The consultation does not offer

alternative formats beyond different languages for the consultations – contradiction considering the subject matter.

Disability as a cross cutting issue

Disability is not seen throughout all the thematic consultations, as is the case with gender, and adds to a feeling that disability is being treated in isolation or as a 'special' topic. This reduces the likelihood that disability will be integrated into and across all target areas, leading to concerns that a disability specific focus will not result and be excluded from future programmes.

Timeframes

The time frame for the thematic consultation questions were too short running for only twenty two days. The legitimacy and true commitment by the UN to participation was questioned.

Limitations on responses

The consultation aimed to *"be as broad and open as possible, so we encourage everyone to share their thoughts and information on this important issue"* (Cuk, 2012). However, to allow for the facilitation of the discussion, the responses were requested to be no more than five hundred words. Opposing this argument is the fact that the nature of the consultation meant a wide variety of responses, and to be able to glean useful information from them, the limit may have been necessary in order to allow focus in the process to prevail.

7   Reflections

Chapters 3 and 4 highlight the complex nature of participation by DPOs in policy processes at the international level. This chapter builds on the derived observations and attempts to extract key points for improving future participation by DPOs in policy processes.

7.1   Reflections

The observations made throughout chapters 3 and 4 highlight common factors which can be summarised into four identified themes relating to DPO participation.

7.1.1   Practical Observations

Greater consideration is required by IGOs on the practical elements of participatory policy processes. The practicalities are important to consider as the key informants made clear a seemingly small thing can have a profound effect on the ability of PWDs and DPOs to participate. Each of the case studies has highlighted practical issues relating to:

- Access to and the form the participation takes;

- Funding to allow for costs incurred by participation;

- Lack of clarity on the process;

- Limitations on responses;

- Technicality of process and resultant documents; and,

- Time available in which participation can occur.

These issues present real barriers to DPO participation at international level. It also further highlights the disparities between the rhetoric of IGOs and the reality of the processes they promote.

The factors identified above for PWDs may be compounded by further physical, mental or social factors. There are some positive signs, as practical measures were taken to ensure accessibility during the UNCRPD. However, the key informants noted this is not the case across all UN buildings and gave the example: *"that in Delhi the UN building has not been designed for access by PWDs, therefore, how can persons in wheel chairs or other mobility devices enter and participate, if they can't even reach the meetings."*

7.1.2   Knowledge Observations

The knowledge theme is a two-fold barrier to DPO participation. The literature and the key informants clearly identified an evident lack of knowledge by IGOs about disability and understanding of the social model as a major barrier to participation. This is reinforced by the belief which IGOs' hold that the real and apparent knowledge gap rests with the DPOs: in that there 'capacity' deficit means they do not know how to engage with the policy process. For example, this is highlighted by the money being made available for training DPOs on how to engage or interpret documentation. This is representative of the IGOs and DPOs not understanding each other's perspectives.

Furthermore, knowledge transfer is not efficiently occurring following policy processes. Accountability for IGOs can only be achieved if self-reflection happens following a meaningful process and evaluation is built into the process time-frame. DPOs also need to reflect hard on their own positions within a participatory process because many were reluctant to critique processes (learning cannot take place without proper reflection). The lack of research with DPOs on policy processes has also identified that they are put into a difficult position - the importance of maintaining relationships with states and IGOs is seen as necessary to ensuring future participation, making it difficult to openly critique processes.

The positive outcomes of the participatory process must also be acknowledged, in that New Zealand DPOs felt that their participation in UNCRPD increased the knowledge of their state and its institutions.

7.1.3   Engagement Methods

Despite a space opening up for DPOs to be part of policy processes, IGOs are limiting this space by failing to see that participation must form an integral part of the whole policy process. This can be seen with the PRSPS - with participation being seen as a special part of the policy process - it is as if the IGOs are doing a favour to DPOs. In consequence of this, tokenism presents a real barrier to the participatory processes.

Yet further, perpetuating the status quo is evidenced through the post-2015 process: consultation is occurring widely but final decisions on what targets are to be agreed remain within the ambit of the UN system and state negotiations. Therefore, the IGOs and states retain primacy over the overall decision-making power at the expense of DPOs thereby preventing them from coming to the forefront of policy processes, although to some extent umbrella DPOs are taking a lead in managing the online discussions forums and reporting on this.

It could be argued that IGOs description of their role as 'enabling' constitutes little more than advocacy in practice as played out in the international arena. IGOs are making huge assumptions about the state's willingness and desire to seriously engage DPOs in a meaningful process, as evidenced in the case with PRSPs. It is noted that retrospective guidance was required from The World Bank to encourage states to

engage with disability and DPOs. This was born out from a lack of clarity on the policy process and competing terminology by advocating for participation, but referring to outputs as consultation. The positive element is that the World Bank did reflect on lessons learnt as part of the guidance to improve the participation for civil society.

7.1.4   Ownership

The ownership discussions focus on three barriers which are as follows:

1. Whose agenda is being promoted is questioned if participation by DPOs cannot be fully realised? Problems are evident in the system if the process and its end product of the policy, has been formulated prior to and not with the inclusion of PWDs and DPOs. Therefore, it creates a situation whereby DPOs are required to enter into a process that they have had little or no say in developing, and thus reducing their ability to have a leading role in that process.

2. Ownership is questioned in relation to IGO – state relations when IGOs are actively promoting state leadership on the one hand and facilitating meetings and guidance on the other. This could place DPOs at odds with their state institutions by working directly with IGOs.

3. Ownership emphasis by IGOs is firmly placed on governments. It is a false assumption to make that states will automatically go out and conduct such a process if IGOs or indeed DPOs advocate for participation, which is echoed by the reality that states often select DPOs whom are politically sympathetic to their ideologies, and/or supportive of the political agenda of the day. Some DPOs which have been engaged by states have traditionally been populated by technocrats with middle class backgrounds. Some DPOs are also losing out to those organisations supported by international NGOs who are considered consulting partners of the state or IGOs. Grassroots organisations are therefore being excluded to the detriment of wider participation.

There are many challenges for DPOs in the realm of policy process ownership and the barriers that need to be broken down.

8   A Way Forward for Future Processes

The suggestions made in this chapter are designed to be general so they can be applied across regions, sectors and organisations. They also directly address research objective 4 as well as adding to the analysis of objectives for 2 and 3. In some ways, what is stated is nothing new but the points do highlight that, in the case of participation of DPOs and PWDs, seemingly basic points have been forgotten or not practiced as part of the policy process. This is both a cause and a symptom of the four themes identified.

It is necessary to summarise the implications for DPO participation which could be conceived as a barrier to policy processes. In summary the implications evidenced are:

- Disability approach reverting to a charity/ welfare model;
- DPOs could lose touch with their core values;
- DPOs become depoliticised as a result of being brought within policy processes;
- DPOs are within a participatory process that is apart from the political policy process; and,
- DPOs will need to address issues relating to accountability.

The implications which are identified in this paper should not be taken in a negative context in which they are framed. Acknowledging that they exist could go a long way in mitigating the risks to DPOs. In essence, it comes back to DPOs and their membership having a clear understanding as to why they are participating in the process, and what exactly they hope to achieve through advocacy. It also requires DPOs to recognise that one participatory policy process cannot resolve all the disabling social or environmental factors in existence. Such weight has been given to the UNCRPD, but the shortcomings in it also need to be acknowledged by the DPOs.

Policy decisions emerging within the state political sphere have had major implications for all marginalised groups especially in relation to participation. However, the position of DPOs in the processes have, in some instances, been strengthened rather than weakened in countries: there have been positive signs in New Zealand showing the strengthening rather than weakening of DPOs positions within that country. This case study demonstrates a willingness on the part of the state to engage DPOs to participate in the political sphere; however, the DPOs in this instance did have the capacity to do so which is often not the case in other jurisdictions.

Accountability for DPOs

One of the assumptions of this dissertation at the outset was that PWDs joined DPOs and Umbrella DPOs to represent their views. Throughout the research the relations of PWD and DPOs have not been discussed but what has become apparent is that DPOs themselves need to seriously consider the issue of

accountability to their members. This is often because they become more involved in policy processes at the expense of their membership. As the implications have highlighted, DPOs need to be clear where they stand on key issues within or outside of IGOs.

IGO and State Accountability

Whereas the need to evaluate a process is discussed later in this chapter, the overall accountability of IGOs have to be to civil society as a whole, which is an issue currently under researched within the literature. Whereas the UNCRPD within its own Articles allows for civil society to hold states to account, what is not entirely explicit across the board is whether (and how) IGOs should be held accountable for poor participation in policy processes.

8.1 Practical

IGOs need to understand the contexts in which DPOs operate

IGOs should be asking themselves very basic questions about the intended participants prior to advocating for a participatory approach including the 'who, what and where' elements of the process.

Funding should be made available directly to DPOs

IGOs should make funding available to allow for the basics of participation to be covered. For example, funds to cover costs associated with travel and accommodation to attend policy meetings.

Technicality

Documents produced by the IGOs need not only to take account of their own procedures but also the requirements of the intended beneficiaries. Therefore, IGOs from the outset should produce interpretative documentation alongside the formal documents. This should be done as a matter of course and not retrospectively or by relying on outside organisations to do so. This has often been the case with PRSPs and UNCRPD.

Access and form of the participation

Participation must be in a form that is accessible both in terms of the format in which it is presented and the location of face-to-face talks. It must allow for sufficient and reasonable timescale in which DPOs can respond taking account of local conditions, heavy workloads, poor internet connections and electricity.

8.2   Knowledge

The research has shown a knowledge gap within IGOs and DPOs but that differing reasons and causes account for this. Nonetheless it is important to understand the linkages between the knowledge gap and achieving participation.

IGOs and DPOs need to understand each other's perspectives

It could be argued that understanding perspective of others is actually gained as part of the participatory process rather than a pre-requisite. This does not take account of the pluralism of views that exists on disability, and whilst the process decisions and power relations remain in favour of the IGOs, it is a pre-requisite as it could prevent a participatory process that is irrelevant or guided by inaccurate references to the welfare model for example.

Participation within policy processes needs to be a continuous process

The new spaces opening up for research and discussion on DPOs participation need to take forward and ceased upon by DPOs. They should use the opportunities to effectively pursue their agendas.

Move away from a need to quantify

The need to quantify disability is a somewhat outdated argument by the fact that disability is recognised as an issue cutting across the political spectra under the social model. Therefore, why does disability need to be quantified if disability is being included across all sectors?

Evaluations needs to be conducted both within IGOs and with the participants

Planning and funding should be allocated for this to be achieved from the outset of the process and states and DPOs should be made aware that it will be conducted.

Policy processes at all levels must include the principles of participation

The case studies (especially the PRSPs) have highlighted a stark divide between policy process demands and the demands of a participatory approach.

8.3   Engagement

Effective engagement requires clarity, consistency and commitment from IGOs and DPOs. There are several observations made in this theme which could be taken forward as a focus for future research.

Terminology and language used

The IGOs should reference their policy processes to the recognised ladders of participation thus making it clear to what extent the participation should take place or level of detail required. They also need to be clear on what they mean by 'participation' or 'consultation', and seek to align with the ideals of the

intended audience, i.e. the IGOs should listen to the DPOs' perspectives on what participation means to them. Poor terminology could deter DPOs from participating as it may be perceived as a one-way process.

Application of the social model

The engagement methods should reflect the DPOs and recognised model of disability resting within a social and human rights context. Unless the correct model is applied, the engagement methodology will be redundant and ineffectual in providing much needed social and environmental change.

Engagement methodologies should be planned with DPOs

Many of the observations could be addressed at the planning stage of a policy process. This could address the need for participation to be present throughout all stages of the policy process, for example the need to:

- identify stakeholders;

- identify practical reasons why participation may be hindered for some groups (i.e. funding);

- identify time required; and,

- identify the access and form of the participation.

Engagement Methodologies should be agreed through IGOs mechanisms to get state buy-in

It could be argued that IGOs working in tandem with DPOs to develop engagement methodologies remove responsibility, control and input from states. However, what it does provide is the opportunity to marry the policy process agenda with the needs of participation. If the planning is concluded in advance, it is something which can be adopted by states for example a resolution in the UN by the General Assembly or the equivalent of the other IGOs, rather than being imposed on them as guidance documents and best practice after the event of the policy process. This would take IGOs beyond the realm of simply advocating for participation to one of enabling actual change to occur.

Policy Participation alone is insufficient

The participation at the supranational level will only succeed if participation is present at the political level within nation states. The Articles of the UNCRPD offers a basis from which DPOs can advocate for political participation within their own state governments.

8.4   Ownership

What has not been made clear from the research, or indeed the observations, is where responsibility lies for participation within policy processes. Ownership goes beyond the planning stages and, to some extent, is the most difficult issue to address.

The research highlights the need to question:

- who is ultimately accountable for participation in international policy processes;

- how would this impact IGO – state relations and state – DPO relations; and,

- if it is realistic for DPOs to advocate for and achieve leadership (or a degree of it) within policy processes.

Addressing these issues effectively and achieving progress in this is one of the fundamental challenges to future DPO participation. This could form the basis of future research.

8.5   Overarching Requirements for Progress

8.5.1   Mainstream Disability

The knowledge, practicalities and engagement observations all point to a need to ensure that disability becomes mainstreamed throughout IGOs. The positive aspects of IGOs advocating for DPOs and PWDs inclusion in policy processes should not be underestimated. However, it does seem that IGOs are a step ahead of themselves by failing to get buy-in throughout their own organisations. This proposition is evidenced throughout the practical and knowledge themes and is making the implementation of policy processes difficult to achieve. Indeed the case studies have supported the reformists view that organisational change is required in order to truly achieve participatory approaches.

Mainstreaming could have positive effects such as:

- increased understanding between parties;

- opening up of opportunities for DPOs to lead policy processes;

- a reduced need to quantify and measure disability; and,

- allowing for the understanding of the social and/or human rights models.

(See: Albert, 2004; Albert et al, 2005; Kett, 2009; Moriarity and Dew, 2011).
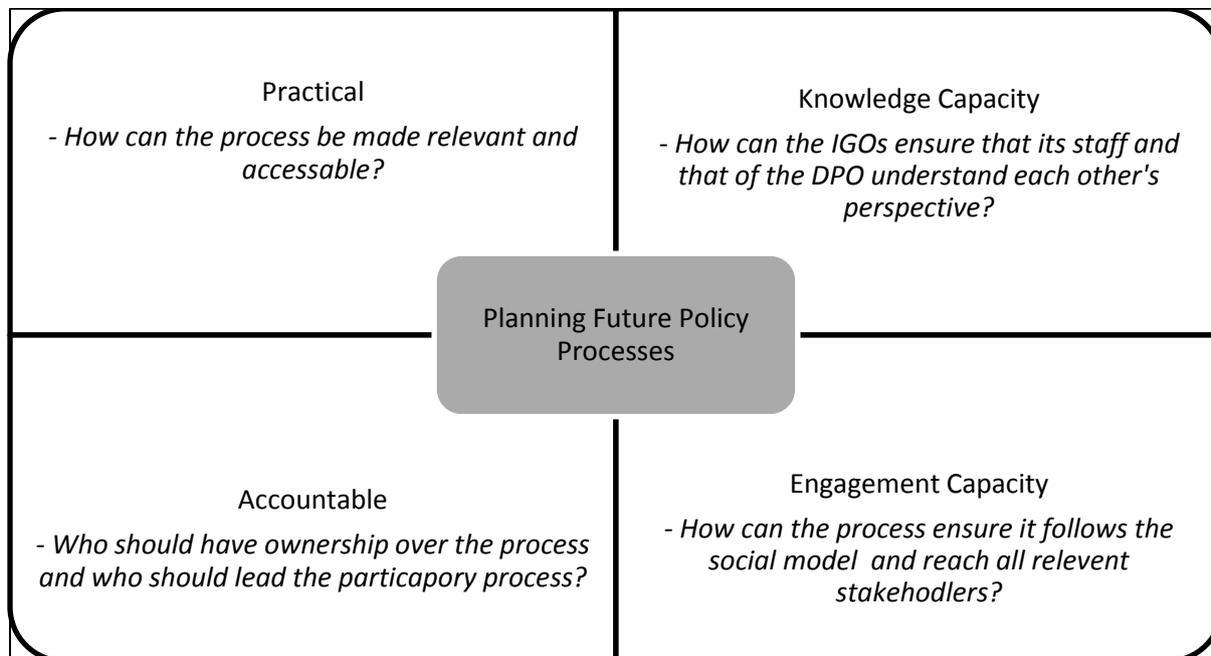
8.5.2 Capacity Building

The practical knowledge and, to a degree, engagement observations could be determined as a capacity-based issue for DPOs. For example, capacity can be seen in terms of funding, staffing or access to internet connections, as well as knowledge in the training of personnel in advocacy and understanding of the IGO policy process. However, building capacity goes beyond funding. It is about empowering DPOs to be able to take a leading role in policy processes. IGOs should acknowledge the need for DPOs and/or states to build capacity within the stakeholders they wish to consult or participate in processes. This will result in reducing the risks of tokenism and open up opportunities for PWD and grassroots organisations to network and share ideas and information not only within policy process, but also on a wider scale with each other.

8.5.3 Process Planning

Much of the focus has been on participation, however, as discussed within the analysis, it shows that the policy process itself requires participation at all stages. Therefore, there is a need for IGOs to challenge their own structures on policy planning. IGOs could consider a cooling off period prior to enacting agreed resolutions. This would allow time to reflect on the process and timing, and help identify the key stakeholders through a basic framework such as shown in diagram one.

Diagram One: Basic Framework for Planning a Participatory Policy Process.

Practical *- How can the process be made relevant and accessable?*	Knowledge Capacity *- How can the IGOs ensure that its staff and that of the DPO understand each other's perspective?*
Planning Future Policy Processes	
Accountable *- Who should have ownership over the process and who should lead the particapory process?*	Engagement Capacity *- How can the process ensure it follows the social model and reach all relevent stakehodlers?*

9   Future Research and Limitations

9.1   Limitations

The stated research objectives have provided a platform upon which to investigate the main aim of the research and to examine the participation by DPOs within the policy forming processes at international level. Whereas the research has addressed each of these objectives, a definitive answer to the objectives has not been reached. This is reflected by the subject matter itself and the fluid and constantly evolving concepts of disability, participation and policy processes driven off the back of research, political emphasis and agendas such as the human rights approach. It also reflects that disability within international development is a relatively new area. Other marginalised groups (such as women) have been mainstreamed within this evolving conceptual framework for much longer, but gender advocates continue to press for better participation, access and mainstreaming (Miller and Albert, 2005).

A further two limitations have been identified:

- This paper (in hindsight and with a larger word count) could have included an assessment of different policy process methods which may have alluded to a better approach by IGOs;

- As acknowledged at the outset of this dissertation, the desk based nature of the study was cited as a limitation and more interviews could have elicited from a wider perspective.

9.2   Future Research

The individual points identified in chapter five do warrant much further investigation which is beyond the scope of this dissertation.

Future research could revolve around:

- The consequences of DPOs becoming de-politicised and depersonalised during policy process which is one of the most important elements as an outcome of this research. Investigation is required to establish how and where DPOs fit within the policy spaces currently being created for them, and how this in turn impacts upon their relations with their members.

- The question of ownership requires more research as discussed in section 6.1.4.

- The approach to planning participatory policy processes by IGOs is a relatively new area. It would be logical to determine how IGOs plan to involve CSOs from the outset and how groups like DPOs could participate in this area. At present, there exists a traditional top-down format requiring DPOs to comply with the agendas of the IGOs which, more often than not, works to their detriment.

- Accountability of IGOs within the policy sphere. Accountability is identified as the key driver for the future of DPOs in international participatory policy processes.

- How the experiences of the other marginalised groups compare to the findings from this dissertation. Drawing conclusions from this suggested comparative approach would be useful in identifying if disability participation is unique or if it exhibits similar challenges faced by other marginalised and minority groups.

- Furthermore, inter-sectional analysis could form a future study. The technique is currently being used by gender researchers to identify the unique and differing needs of women. It could offer a valuable insight into understanding needs of PWDs, if applied by IGOs at the initial planning phase.

10 Conclusion

In order to explore the main research aim of this dissertation, the following four research objectives were set:

1. Assess the meaning of participation within the context of international policy formulation processes for DPOs;

2. Examine the emerging implications of increasing participation by DPOs in international policy formulation processes;

3. Evaluate participation by DPOs in international policy formulation processes; and,

4. Discern how lessons learnt can be applied to future processes for DPOs.

This study has explored DPO participation in international policy processes. It has both identified and examined approaches by IGOs and appraised strategies for increasing the participation by DPOs. The combination of a literature review and interviews identified many of the root-causes underlying poor participation by DPOs at international level. The research has identified significant barriers which, whilst not insurmountable, do require change. What has also developed is a more nuanced understanding of the causes of the barriers to participation given that the research for this dissertation was conducted with the aid of first-hand accounts and from literature leading to the identification of practical barriers – an area under represented within research, but which was highlighted as being of fundamental importance by the key informants.

Much of the research is framed within a negative light: it is a by-product of the subject of disability *per se* and a history of discrimination and exclusion. However, there have been positive steps taken to place disability firmly on the agenda, but capitalising on that momentum and being able to translate this into policy in reality - policies which accord with what PWDs expect and rightly deserve - remains a key challenge. The implication of the research is that IGOs do have the resources, funding and the ability to know how to conduct effective participatory policy processes. What is needed is a clearer understanding of what has worked well in the past and how it can be applied in the future. DPOs should be quick to recognise that the space for discussion on policy process is opening up within the development arena.

Moreover, judging all of IGOs' participatory processes solely on the PRSPs would present a discouraging picture for DPOs. Not only did the process become confused, it has consistently failed to facilitate a meaningful and effective participatory process for DPOs. It requires future learning whereby a balance is achieved between ownership, methodology and terminology, and accords with expectations of IGOS, DPOs and states. However, as discussed by the ILO, the PRSPs have made progress with regard to disability since

they were first introduced; for example, this was evidenced in the Ugandan PRSP process discussed in the case study.

It is apparent that UNCRPD did recognise the value of DPOs in that it demonstrated a remarkable participatory process and actively sought opinions of DPOs. Although not perfect, it has proven to be a catalyst for change. Furthermore, the UNCRPD provides a window of opportunity for increasing political participation by DPOs and in this IGOs must recognise it is crucial to achieving participatory processes at the policy level.

The observations show that neither IGOs nor DPOs are to blame for poor participatory processes. Rather the observations identify, what are on many levels are, basic elements which are preventing effective participation. It is a reflection of the identified themes of lack of knowledge, ownership, engagement and practicalities which have all contributed in their own right to the differing levels of success of the case studies. Future learning needs to be founded on effective planning of processes and building the capacity of DPOs in an empowering manner.

Whereas some of the lessons have called for funding of the practical elements, funding in isolation should not be viewed as a panacea: it is insufficient on its own as a tool to building the capacity of DPOs. The concepts of engagement and knowledge capacity are equally as important and should not be disregarded.

What is beyond doubt is that the participation in UNCRPD, and to a lesser extent PRSPs, has been a huge step forward and evidently beneficial for PWDs. It is acknowledged that progress is hard to measure, but by taking a view in the longer term there are positives which are highlighted in the case study on the Post-2015 agenda. Despite the pitfalls of the online consultation process, it is different to other previous consultations in terms of the approach it takes to the policy negotiations to place disability on the agenda at the outset rather than retrospectively including it. If, the Post-2015 agenda fulfils its promises and includes the voice of PWDs firmly throughout, the process and any agreed targets, it will represent an opportunity for disability to be mainstreamed across the development and humanitarian sectors, as well as firmly placing it within the political and policy sphere. This will further bolster the progress made through the UNCRPD.

These successes might only be short-lived unless IGOs begin to tackle not only the basic, as well as the complex, barriers to participation. IGOs need to set an example and move towards mainstreaming disability throughout their own organisations and breaking down some of the basic practical barriers faced by DPOs. At some point both IGOs and DPOs will have to reflect on their own accountability to their members and state institutions as DPO participation becomes the norm.

Ownership and who should develop and lead firstly in the policy process, and the participatory element of that process, remains one of the key future challenges to IGOs and DPOs. It would require a fundamental shift in the way in which IGOs currently operate but it would only work in reality if this delegation of power is accepted by state institutions.

The interviews with the key informants revealed not only frustration and critiques of policy processes; it also highlighted shades of optimism and a determination to participate more effectively. Most notably, key informants held the view that PWDs will remain on the agenda in the future. The approach by IGOs should be what DPOs can aspire to achieve with regard to poverty reduction rather than fixating on what they cannot achieve. The most important ideal highlighted by the key informants is the belief that the policy process, no matter what form it takes, should not undermine the disability movement's slogan of "nothing about us without us".

Bibliography

Albert B (2004*) Is disability really on the development agenda? A review of official disability policies of the major governmental and international development agencies*.
Available at: http://www.dfid.gov.uk/r4d/PDF/Outputs/Disability/RedPov_disability_on_the_agenda.pdf. (Accessed 20th January 2013)

Albert B, Dube A.K, Hossain M, and Hurst R (2005) *Research Gap Analysis Report*. Disability Knowledge and Research Programme, DFID, London. June 2005.
Available at: http://www.dfid.gov.uk/r4d/PDF/Outputs/Disability/thematic_gap.pdf. (Accessed 20th January 2013)

Albert B and Hurst R (n.d.) *Disability and a Human Rights Approach to Development*. Available at: http://hpod.org/pdf/human-rights-approach.pdf (Accessed 24th January 2013)

Alexander A (n.d.) *To What Extent are International Organizations (IOs) Autonomous Actors in World Politics?* University College London. Available at:
http://www.ucl.ac.uk/opticon1826/archive/issue2/VfPS_HS_International_Organisations.pdf.   (Accessed 3rd February2013)

Arnstein S (1969) *'A ladder of citizen participation'.* American Institute of Planners Journal, 35(4): 216–24.

Barton L (2004) *The Disability Movement: Some Observations*. In: Swain J, French S, Barnes C and Thomas C (2004) *Disabling Barriers, Enabling Environments,* 2nd Edition. Sage Publications, London.

Booth D. 2003. *Fighting Poverty in Africa: Are PRSPs Making a Difference?* Overseas Development Institute: London. In: Mwendwa, TN; Murangira, A; Lang, R (2009) *Mainstreaming the Rights of Persons with Disabilities in National Development Frameworks*. Journal of International Development No. 21, pg 662–672.

Booth D, Grigsby A and Toranzo C (2006*) Politics and Poverty Reduction Strategy Papers: Lessons from Latin American HIPCs*. Working Paper 262, London: Overseas Development Institute, 2006.

Briggs C (2011) *Mainstreaming Success: Civil Society Consultation in Emergency Relief and Early Recovery Programming.* Centre for Development and Emergency Practice, Oxford Brookes University.

Carpenter L, Austin H (2008) *How to be recognized enough to be included?* International Journal of Inclusive Education 12(1): 35–48.

Cooke B and Kothari U (2006) (eds) *Participation: The New Tyranny?* London: Zed Books.

Cornwall A (2000) *Beneficiary, Consumer, Citizen; Perspectives on Participation for Poverty Reduction*. Stockholm; SIDA.

Cuk V (2012) *Overview: Persons with Disabilities and Inequalities Discussion*. The World We Want Thematic Consultation. Available at: http://www.worldwewant2015.org/node/284549. Accessed 23rd February 2013.

DFID (2000) *Disability, Poverty and Development*. DFID, London.
Disability Awareness in Action (n.d.) Disability and a Human Rights Approach to Development. http://www.daa.org.uk/uploads/pdf/Disability,%20Development%20&%20HR.pdf. (Accessed 10th January 2013)

Disability Awareness in Action (n.d.) *Disability and a Human Rights Approach to Development*. Available at: http://www.daa.org.uk/uploads/pdf/Disability,%20Development%20&%20HR.pdf. Accessed 20.02.13

Drake R (2002) *Disabled People, Voluntary Organisations and Participation in Policy Making.*
Policy & Politics 30: 373–85.

Dube A.K (2005). *Participation of Disabled People in the PRSP/PEAP process in Uganda.* Disability KaR Knowledge and Research, DFID. Available at:
http://www.dfid.gov.uk/r4d/PDF/Outputs/Disability/PolicyProject_uganda_prsp.pdf. (Accessed 3rd January 2013)

Ferguson C (1999). *Global Social Policy Principals: human rights and social justice*. London: DFID

Finkelstein V. (2001) *The social model of disability repossessed,* Manchester Coalition of Disabled People, December 2001. Available at: www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm (Accessed 14th February 2013)

Finkelstein V (2007) *The 'Social Model of Disability' and the Disability Movement*. March 2007. Available at: http://www.leeds.ac.uk/disability -
studies/archiveuk/finkelstein/The%20Social%20Model%20of%20Disability%20and%20the%20Disability%20 Movement.pdf. (Accessed 20th January 2013)

Gaventa J (2002) *Introduction: Exploring Citizenship, Participation and Accountability.* Institute of Development Studies Bulletin 33(2), 2002.

Guerrero P (2003) *National dialogue: the World Bank experience*. In: *OECD, Ownership and Partnership: What Role for Civil Society in Poverty Reduction Strategies?* Paris: OECD, 2003.

Holland J and Blackburn J (eds) (1998) *Whose Voice? Participatory Research and Policy Change*. London; Intermediate Technology Publications.

Hurst R (1999) *Disabled People's Organisations and Development: Strategies for Change*. Chapter 3 in Stone E. (ed.) 1999: *Disability and Development: Learning from action and research on disability in the majority world,* Leeds: The Disability Press. p.25-35

ILO (2002) *Disability and PRSPs. How to ensure that access of persons with disabilities to decent and productive work is part of the PRSP process.* In focus Programme on skills, knowledge and employability disability programme. International Labour Organisation. Discussion Paper November 2002.

IMF (2013) *Poverty Reduction Strategy Papers*. International Monetary Fund. Available at: http://www.imf.org/external/np/prsp/prsp.aspx. (Accessed 3rd January 2013)

Kamruzzaman P (2009): *Poverty Reduction Strategy Papers and the Rhetoric of Participation*, Development in Practice 19(1): 61-71

Kett M, Lang R, Trani J (2009) *Disability, Development and the Dawning of a New Convention: A Cause for Optimism?* Journal of International Development 21(5): 649-661.

Lang R (2001) *The Development and Critique of the Social Model of Disability.* Overseas Development Group. University of East Anglia. January 2001. Available at: http://www.ucl.ac.uk/lc-ccr/lccstaff/raymond-lang/DEVELOPMMENT_AND_CRITIQUE_OF_THE_SOCIAL_MODEL_OF_D.pdf. (Accessed 10th February 2013)

Lazarus Z (2008)*Participation in Poverty Reduction Strategy Papers: reviewing the past, assessing the present and predicting the future.* Third World Quarterly, 29(6): 1205 – 1221

McGee R, Brock K (2001) *From Poverty Assessment to policy change: processes, actors and data.* Working Paper 133, Brighton: Institute of Development Studies.

McGee R, Norton A (2000) *Participation in Poverty Reduction Strategies: A Synthesis of Experience with Participatory Approaches to Policy Design, Implementation and Monitoring*, IDS Working Paper 109, Brighton: Institute of Development Studies.

Miller C, Bill Albert (2005) *Mainstreaming disability in development: lessons from gender mainstreaming.* Disability KaR Knowledge and Research. March 2005. DFID London.

Mladenov T (2009) *Institutional woes of participation: Bulgarian disabled people's organisations and policy-making*, Disability and Society, 24(1):33-45.

Mohan G (2006). *Beyond participation: strategies for deeper empowerment*. In: Cooke, Bill and Kothari, Uma (eds). *Participation: The New Tyranny?* London: Zed Books, p153–167.

Moriarity L and Dew K (2011): *The United Nations Convention on the Rights of Persons with Disabilities and participation in Aotearoa New Zealand*, Disability and Society, 26(6): 683-697

Mwendwa TN, Murangira A and Lang R (2009) *Mainstreaming the Rights of Persons with Disabilities in National Development Frameworks.* Journal of International Development No. 21, p662–672.

Nustad K, Sending O (2000) *The Instrumentalism of Development Knowledge*, in Stone, D; *Banking on Knowledge; the genesis of the Global Development Network*. London; Routledge.

OECD (2003) Ownership and Partnership: What Role for Civil Society in Poverty Reduction Strategies? OECD. Available at:
http://www.oecd.org/development/pgd/ownershipandpartnershipwhatroleforcivilsocietyinpovertyreducti onstrategies.htm. (Accessed 24th February 2013)

Oxfam (2004) *From Donorship to Ownership?* Moving Towards PRSP Round Two. Oxfam Briefing Paper 51, January 2004.

Pianta M (2005), UN World Summits and Civil Society; *The State of the Art.* Civil Society and Social Movements Programme Paper. Number 18, August 2005. United Nations Research Institute for Social Development. Available at:
http://www.unrisd.org/unrisd/website/document.nsf/d2a23ad2d50cb2a280256eb300385855/5709f9c06f 40fdbac12570a1002dc4d2/$FILE/pianta.pdf. (Accessed 2nd February 2013)

Rietbergen – McCracken (n.d) *Participatory Policy-Making.* Participatory Governance Exchange.
Available at:
http://www.pgexchange.org/index.php?option=com_content&view=article&id=140&Itemid=132.
(Accessed: 20th January 2013)

Sen A (1999) *Development as Freedom*. Oxford University Press.

Stone E; Priestley M (1996) *Parasites, pawns and partners: disability research and the role of non-disabled researchers.* British Journal of Sociology, 47 (4). p699-716

The World Bank (2002). *A Sourcebook for Poverty Reduction Strategies*, Washington, DC: World Bank, 2002.

The World Bank (2003). Quoted in F Stewart and M Wang, *Do PRSPs Empower Poor Countries and Disempower the World Bank, or is it the Other Way Round?*, Working Paper Series 108, Oxford: Queen Elizabeth House, 2003.

The World Bank (2004) *Poverty Reduction Strategies: Their Importance For Disability*, Disability and Development Team, The World Bank, Washington D.C.

The World Bank (2012) *Disability Overview*. Available at: http://go.worldbank.org/JGF4Y3E5B0. (Accessed 2nd January 2013)

The World Bank (n.d) Participation in PRSP. Available at: http://go.worldbank.org/TGL85HNSP0. (Accessed 24th January 2013)

Thomas P (2005) *Disability, Poverty and the Millennium Development Goals: Relevance, Challenges and Opportunities for DFID.* Disability KaR Programme. Available at:
http://digitalcommons.ilr.cornell.edu/gladnetcollect/256 (Accessed 16th December 2013)

Tikare S, Youssef D, Donnelly- Roark P and Shah P (2001) *Organizing Participatory Processes in the PRSP*. April 2001. Available at: http://internationalbudget.org/. (Accessed: 20th December 2013)

UN Enable (n.d. (a)) *Convention on the Rights of Persons with Disabilities* Available at: http://www.un.org/disabilities/default.asp?navid=14&pid=150. (Accessed 22nd February 2013)

UN Enable (n.d.(b)) *Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.* Available at: http://www.un.org/disabilities/default.asp?id=1423. (Accessed 18th February 2013)

UN Enable (n.d. (c)) *Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities.* Available at http://www.un.org/disabilities/default.asp?navid=24&pid=151#neg2. (Accessed 18th February 2013)

UN Enbale (2002). *Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities.* First Session of the Ad Hoc Committee. 29 July to 9 August 2002. Available at: http://www.un.org/esa/socdev/enable/rights/adhoca57357e.htm. (Accessed 18th February 2013)

UN Enable (2005). *Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities.* New York, 16-27 June 2003 Available at: http://www.un.org/esa/socdev/enable/rights/a_58_118_e.htm. (Accessed 20th February 2013)

UNDG (2011) *Including the rights of persons with disabilities in United Nations programming at country level: A Guidance Note for United Nations Country Teams and Implementing Partners*, New York, 2011.

UNDG (2012) *UNDG Prepares Guidelines for Country Consultations on Post-2015 Development Agenda*. UNDG Press Release. Available at: http://sids-l.iisd.org/news/undg-prepares-guidelines-for-country-consultations-on-post-2015-development-agenda/ (Accessed 24th February 2013)

UNHCHR (2007) *From Exclusion to Equality: Realizing the rights of persons with disabilities,* Geneva: UN/UNHCHR/Inter-Parliamentary Union. Available at: http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf (Accessed 20th February 2013)

UN Millennium Project (2006). *What Are they?* Available at: http://www.unmillenniumproject.org/goals/index.htm (Accessed: 24th February 2013)

UN (1986) Declaration on the Right to Development: General Assembly Resolution 41/128. Available at: http://www.un.org/documents/ga/res/41/a41r128.htm (Accessed 20th February 2013)

UN (n.d.) *UN and Civil Society*. Available at: http://www.un.org/en/civilsociety/index.shtml. (Accessed 12th February 2013)

UN (2012) *The United Nations Development Strategy Beyond 2015. Committee for Development Policy.* Policy Note, UN, June 2012. Available at:
http://www.un.org/en/development/desa/policy/cdp/cdp_publications/2012cdppolicynote.pdf.
(Accessed: 20.02.13)

Uvin P (1995) *Scaling up the grass roots and scaling down the summit: The relations between Third World.* Third World Quarterly 16, no. 3. September 1995: 495 - 512. Academic Search Complete, EBSCO host. (Accessed 20.02.2013)

 van Houten D, Jacobs G (2005): *The empowerment of marginals: strategic paradoxes*, Disability and Society, 20:6, 641-654

WHO (2012). *Disability and Health Fact Sheet, World Health Organisation*. Published November 2012. Available at: http://www.who.int/mediacentre/factsheets/fs352/en/. (Accessed 20th December 2012)

Yeo R (2001) *Chronic Poverty and Disability*. Action on Disability and Development. Available at: http://www.dfid.gov.uk/r4d/PDF/Outputs/ChronicPoverty_RC/04Yeo.pdf. (Accessed 22th January 2013)

Yeo R and Moore K (2003) *Including Disabled People in Poverty Reduction Work: 'Nothing About us, Without us'* World Development Journal. Volume 31, Issue 3 March 2003, p.571-590.

Yeo R (2005). *Disability, poverty and the new development agend*a. Disability KaR Knowledge and Research, DFID, London.

Appendix One: Key Informant Interviews

Semi Structured and open Key informant questions:

Section 1: Introductory questions: About your organisation

1. Number of DPO members:

2. Region/s you cover:

3. On what grounds does your organisation lobby/ advocate?

    i. Human Rights Approach

    ii. Social Model

    iii. Charity Model

    iv. Welfare Model

4. Is this a reflection of the models adopted by your DPO members?

5. How does your organisation define participation?

Section 2: Core questions on UNCRPD and Post 2015

1. From your organisations experience how would you describe the level of 'participation' of DPOs in the UNCRPD process?

2. Did you respond/ attend on your member DPOs behalf, or did they respond/ attend directly? Is this approach generally the way in which policy participation is conducted?

3. What action (if any) was taken to raise awareness about the policy forming processes for UNCRPD? Who took this action (your organisation, the government or a combination of both?)

4. What would your organisation say are the issues when DPOs/ umbrella organisations are involved in a policy forming process?

5. What would your organisation say are the opportunities when DPOs/ umbrella organisations are involved in a policy forming process?

6. How would you describe the balance of power between the DPOs and the UN during the UNCRPD process?

7. How could direct relationships between DPOs/ DPO umbrella organisations and the UN, affect their relationship with their respective governments?

8. Do you believe the inputs made by DPOs and their umbrella organisations are reflected in the outputs of the international policies?

9. What improvements could be made in your opinion to the policy forming process?

10. What needs to happen to ensure DPOs are part of future policy forming processes?

Post 2015

How would you describe your organisations level of awareness about the post-2015 agenda and what is your organisations perspective on disability being included within future targets beyond 2015.

What do you think about the post-2015 agenda consultations as set by the UN?

Section 3: Open discussion on disability in participation policy

This section is your chance to lead the discussion on DPO participation in the policy processes at the international level and disability in general.

See Appendix 2 for sample discussions held.

Section 4: Self Reflection - Post interview (interviewer only)

Main Points:

What have I learnt?

Gaps in responses and knowledge:

Follow up questions.

Appendix Two: Example Discussion Topics (Key Informant Interviews)

Example topics discussed which were instigated by the DPOs in section 3 of the key informant interviews:

- Tokenism;

- Poor practices by academics in the past has leading to a mistrust of participatory research;

- What it means to be disabled in the global south;

- Why the post-2015 is important to DPOs;

- Disability as a cross cutting issue; and,

- The focus of the DPOs on improving participation, but, the demands of other work sometimes take over.