



Mainstreaming disability rights in development cooperation

Barriers of implementing Swedish policy in education projects

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Declaration form

The work I have submitted is my own effort. I certify that all the material in the Dissertation which is not my own work, has been identified and acknowledged. No materials are included for which a degree has been previously conferred upon me.

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Date: *13 May 2014*

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Abstract

It is estimated that persons with disability (PWD) constitute about 15 percent of the world population and that 80 percent of PWD live in developing countries. Estimations also show that more than 90 percent of children with disabilities in developing countries do not attend school and that only three percent of all adults with disabilities in the world are literate. Implementing the right to education for PWD in development cooperation is thus of significant importance. The present dissertation takes its stance in Swedish development cooperation policy which adapts a twin-tracked approach to disability. This means that specifically targeting initiatives are to be combined with a mainstreaming of disability which is to be applied in all development cooperation programs and projects. The research question focuses on the latter part of the approach:

To which extent is disability mainstreamed into Swedish development cooperation projects related to the right to education?

- Which are the barriers of implementing a disability-mainstreaming policy in Swedish development cooperation education projects?

Interviews were conducted with representatives of Sida-funded projects relating to the right to education. The results show that disability is successfully not mainstreamed in the projects and that there is a large difference in policy and practice. Barriers that were identified were first that disability often-times become an invisible perspective in relation to other mainstreaming areas of Swedish policy. Second, the contextual significance was raised by the interviewees as important as to why a disability-perspective was to be applied in projects or not. Third, the organizational chain of Swedish development cooperation creates barriers in the transformation of policy to practice. A part of this issue concerns the way in which disability is understood by actors and practice suggests that disability is yet to be classified as a human rights issue at all levels. Finally, the lack of reporting mechanisms on disability limits organization's incentives to approach disability.

Keywords: human rights, inclusive development, mainstreaming disability, Sweden, disability, development cooperation

List of abbreviations

CEBU: Communauté des Eglises Baptistes Unies

CRPD: The United Nations Convention on the Rights of Persons with Disabilities

CSO: Civil Society Organization

DPO: Disabled People's Organization

DR Congo: Democratic Republic of the Congo

ICCPR: The United Nations International Covenant on Civil and Political Rights

ICESCR: The United Nations International Covenant on Economic, Social and Cultural Rights

MDG: The Millennium Development Goals

NDAP: National Disability Action Plan

NGO: Non-Governmental Organization

NORAD: The Norwegian Agency for Development Cooperation

PGU: Swedish Policy for Global Development

PWD: Persons with disabilities

SIDA: Swedish International Development Cooperation Agency

UN: United Nations

UNDP: The United Nations Development Program

UNESCO: United Nations Educational, Scientific and Cultural Organization

USAID: The United States Agency for International Development

WHO: World Health Organization

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1. Introduction

It is estimated that persons with disability (PWD) constitute about 15 percent of the world population and that 80 percent of PWD live in developing countries. Those numbers show the close relationship between disability and poverty. Yet, disability is often left out of poverty reduction initiatives and development cooperation.

The adaption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006 is a milestone in the establishment of PWD as rights-holders and for the inclusion of disability policy within the realms of human rights. This process has affected the way in which disability is considered generally and also how it is to be implemented in development cooperation. Swedish development cooperation policy distinguishes the human rights based approach to be a key approach in all Swedish development cooperation. It also affirms that PWD are to be an integral part of the ordinary development cooperation as all humans have equal value and rights. Swedish development cooperation policy thus emphasizes mainstreaming of disability.

One of the ways in which disability is to be mainstreamed is concerning the right to education. It is estimated that more than 90 percent of children with disabilities in developing countries do not attend school and that only three percent of all adults with disabilities in the world are literate. Implementing the right to education for PWD in development cooperation is thus of significant importance and will be in focus in this thesis.

Deriving from experiences of professionals responsible for development cooperation projects, this thesis will try to outline barriers as to why disability is often left out. Identifying what prevents a disability inclusive policy from becoming practice helps establishing an effective practice of implementing human rights universally and not based on ability.

1.1. Research questions

To which extent is disability mainstreamed into Swedish development cooperation projects related to the right to education?

- Which are the barriers of implementing a disability-mainstreaming policy in Swedish development cooperation education projects?

2. Background

2.1. Disability and development

Disability and poverty

Given the World Bank and the World Health Organization's estimates that about 15 percent of the world's population consist of PWD, the amount of PWD living in developing countries is indeed substantial (World Bank och World Health Organization 2011). Yet according to Mitra, Posarac and Vick (2013a), PWD has been sparsely representation in development research as a consequence of the lack of disaggregated data on PWD. A problem that according to Yeo and Moore (2003) is linked to the assumption of PWD being a small group often considered as in need of special attention and outside the perimeter of general development research.

Even though the Millennium Development Goals (MDG:s) do not specifically address disability, it is often claimed that the link between poverty and disability makes all the MDG:s implicitly significant to address disability rights (Groce 2011). Education is however given great significance and one of the eight MDG:s is to achieve universal primary education by 2015. The progress towards that goal has been relatively successful and in 2011 the number of out-of-school children had dropped to 57 million from 102 million in 2000. Additionally, primary education enrolment in developing countries reached 90 per cent in 2010 (United Nations 2014a). Yet, for PWD, the numbers are upside down as it is estimated that only 10 per cent of PWD globally have access to education (MyRight 2012). It could thus be argued that PWD in the matter of education has been left out of the MDG agenda, at least in practice.

The link between disability and poverty has however been clearly identified in numerous research (i.e. Mattioli 2008; Mitra, Posarac, och Vick 2013a; Yeo och Moore 2003) and it is estimated that about 80 percent of persons with disabilities globally live in developing countries (United Nations 2014b). The United Nations Development Program (UNDP) states that development can be inclusive and reduce poverty effectively only if it is inclusive for all. Furthermore UNDP states that people often times are excluded from development on the basis of for instance gender, age and disability (United Nations Development Programme 2014).

2.2. Development and human rights

Emergence of human rights in development

Whilst both development and human rights arose as concepts following the Second World War, they emerged as separate entities both as concepts as such and in practice. Historically, development is rooted in the decolonization process following the war and strived to reduce inequality and poverty. Progressively, development as a quest for sustainability has also emerged within the field of development (Theis 2004). Development has had a focus on the *broad* and the *general*, about reducing poverty in general in order to establish sustainability and target inequalities in access of economic, social and cultural rights. Hence, the field of development has been dominated of professionals with backgrounds in for instance social work and political science (Sano 2000).

In contrast, the human rights framework derives from an individual perspective and has therefore been an area of law and legal practice. In this sense and as a consequence of the dominance of civil and political rights in the west following the war and during the Cold war, economic, social and cultural rights has been separated from human rights practice in the field of development. Additionally, the nature of the universal and individual approach that the human rights framework is based upon does not naturally address general and broad initiatives that poverty reduction as in development practice does (Sano 2000).

The UN Declaration on the Right to Development was adopted in 1986 as a means of connecting development and human rights. The right to development has since been broadly accepted and was reaffirmed in the Vienna Declaration and Program of Action in 1993. The Human Development Report from 2001 additionally supports the merger on the

basis that the two are mutually reinforcing by sharing the common goal of dignity of all people and universal rights and freedoms (United Nations Development Programme 2001).

However, the Declaration on the Right to Development has also been criticized for its incapability of strengthening human rights in practice due to its suggestively vague approach and lack of enforcement mechanisms (Ibhawoh 2011). Ibhawoh (ibid. pp 77) states that “the common conclusion is that the notion of a right to development has not and probably cannot deliver its promise”. Rather, Ibhawoh (2011) argues that the discourse of development as human rights reflects a power dimension that could function as a rhetoric ‘trump’ in argumentation for economic empowerment and global resource distribution; in other words as a means for sustaining western interests in the global economy.

Early on in the process of incorporation of human rights in development Tomaševski (1989) gave her account on the process which sums up the two concepts interrelation and progress. Tomaševski argued for the difference in development and human rights and why the potential of human rights in development is limited by stating that “human rights concerns cannot be expected to become a dominant aim nor a key component of aid policies. Development aid cannot be built around human rights considerations [...] The main aim of the aid which goes to the recipient countries is the establishment of the basic infrastructure and economic development” (Tomaševski and Danske Center for Menneskerettigheder 1989, pp. 18–19).

A human rights based approach to development

There is no definition of what a human rights based approach to development cooperation is and the term is subsequently open to define for actors such as States, donors and agencies. However, in 2003 United Nations (UN) agencies came to a common understanding of the approach. The result was that a human rights based approach to development should “further the realization of human rights as laid down in the Universal Declaration of Human Rights and other international human rights instruments”, that “Human rights principles guide all programming in phases of the programming process” and that “Development cooperation contributes to the development of the capacities of ‘duty-bearers’ to meet their obligations and/or of ‘rights-holders’ to claim their rights” (Qadir 2012, pp. 1). The human

rights principles that were agreed upon are universality and inalienability, indivisibility, interdependence and interrelatedness, equality and non-discrimination, participation and inclusion, and accountability and the rule of law (Office of the United Nations High Commissioner for Human Rights 2014). Along with the notion of ‘duty bearers’ and ‘rights-holders’, the principle of accountability distinguishes the human rights based approach to development from the charity model of development in which actors are not identified as responsible and to be held accountable for its practice (Sarelin 2007). Hence, the human rights based approach to development does constitute a method of merging human rights and development, at least in theory.

The UN Convention on the Rights of Persons with Disabilities

Sweden ratified the CRPD as one of the first States in 2009. The convention does not establish any new rights but reaffirms articles in other human rights treaties in relation to PWD. The convention have a few guiding principles such as non-discrimination, equality, accessibility and rights of the child. These guiding principles are relevant for the present dissertation, however article 32 and 24 are in specific focus.

Article 32 specifically targets States’ responsibility to “ensure that international cooperation, including development programs, is inclusive of and accessible to persons with disabilities”. Thus the emergence of disability-inclusive development in state policy is anchored in the CRPD.

Furthermore, the right to education is prescribed in CRPD’s article 24. The right to education also address the matter of inclusion: “...Persons with disabilities are not excluded from the general education system on the basis of disability...”. The right to education could therefore function as an example of disability-inclusive development in practice.

2.3. Swedish development cooperation policy

To summarize or distinguish the content of Swedish policy towards disability-inclusive development is problematic. First, there are a multitude of different policies and positions taken that needs to be accounted for. Relevant policy that are represented in this thesis is set up both by the Swedish government, by the Swedish International Development Cooperation Agency (Sida) and partially also through Sida’s partnership agreements with civil

society organizations. Second, policies could be of a general character significant to all areas of Swedish development practice and they could be specifically related both to human rights and to disability in particular.

This chapter will give a brief account of policy that is relevant to a Swedish disability-inclusive development. This means that both policy documents that are significant for Swedish development cooperation in general and policy on disability in particular is included.

Sweden's policy for global development (PGU)

The fundament of Swedish development cooperation policy is a parliament deliberation from 2003, *Common responsibility – Sweden's policy for global development*, commonly referred to as the PGU. The PGU sets out two main perspectives that are to influence all Swedish development cooperation practice; the perspectives of the poor and a human rights-based approach ("Utrikesutskottet betänkande 2003/04:UU3 Sveriges politik för global utveckling - riksdagen.se" 2014). With these two conditions in focus, Sida states that "human rights for PWD is not to be treated as a special area but be an integral part of the ordinary development cooperation as all humans have equal value and rights" (SIDA 2009, pp. 13).

The PGU also addresses PWD by affirming the link between disability and poverty and by specifically pointing out human rights for PWD as an important priority ("Utrikesutskottet betänkande 2003/04:UU3 Sveriges politik för global utveckling - riksdagen.se" 2014). The PGU was reaffirmed in 2007 and the focus on human rights and more specifically civil and political rights was given significant focus (Sverige m.fl. 2008). The PGU functions as the main guiding document for Sida and the channeling of funds for Swedish development cooperation projects (SIDA 2014)..

Sida: Human rights of persons with disabilities

In 2009 Sida was commissioned by the Swedish government to construct a plan, or position paper, for how the agency aims to address and secure human rights for PWD. It includes aspects of how disability is to be included in Sida's internal work as well as in development cooperation. The plan stretched from 2009 to the end of 2012 and is currently being

evaluated by SIDA. In the process of constructing the plan, Sida consulted an external working group with members from DPOs, the discrimination ombudsman, the Swedish delegation for human rights and the Swedish agency for disability policy coordination, Handisam. The responsibility for carrying out the activities set up in the plan was given to different departments within Sida with the overarching responsibility of the implementation of the plan given to the Sida policy/empowerment department (SIDA 2009).

The main objective of the position paper was that human rights of PWD are to be respected and that their opportunities and conditions to increase living standards in states where Sweden is active in development cooperation are to be strengthened. This objective was then broken down into two goals. First, that human rights and conditions for PWD to a larger extent are included and taken to account for in Sida's different working- and decision processes. Second, to achieve a greater understanding and knowledge for Sida employees and strategic actors of human rights for PWD and the rights and conditions effects Sida's work in improving living conditions of poor people (ibid.). An important note is that Sida's position paper does not carry any obligations and is guiding rather than directly steering in terms of channeling funds to specific projects.

Swedish development cooperation policy in relation to others

There has generally been relatively little research done on State strategies of including disability in development cooperation strategies. However, Andrea Matteoli (2008) has done an extensive review of national and international donors and their incorporation of disability. Matteoli states that few donor countries do consider disability in development cooperation strategies but that most countries strives and progress towards a disability inclusive approach in their initiatives.

As for the Swedish policy, Matteoli identifies it as being relatively far reaching towards a disability inclusive approach. According to Matteoli, Sida's position paper takes its stance in the human rights based approach including fundamental human rights principles. Additionally, it does according to Matteoli prioritize a mainstreaming approach in combination with a need for specific, targeting approaches. However, even though it is suggested that Sida's policy is comprehensive and adapts a social approach to disability (see chapter 3.5) rooted in the human rights based approach, Matteoli criticize practice in

relation to the policy. More specifically, the criticism is based on the fact that the policy, in form of Sida's position paper, is solely a policy and does not direct obligations in terms of practice (Mattioli 2008).

Channeling of Swedish development cooperation funds

Swedish foreign aid is distributed in several different ways. About half of the support is distributed through multilateral organizations that operate globally such as the United Nations, the European Union and the World Bank. This distribution is to the largest extent controlled by the Swedish ministry of foreign affairs. The remainder is primarily channeled by Sida through organizations, associations, companies, cooperatives and agencies as bilateral support. These are the actors that are to implement the development cooperation in practice in partnership countries. In 2014, Sweden has predominantly established different kinds of bilateral development cooperation partnerships with countries in Africa, Asia and South America. Partnerships are however present also in North America and Europe (SIDA 2014).

The way in which SIDA is able to steer and guide the development cooperation work of the partnership organizations is through the framework system. SIDA currently have such framework agreements with 14 civil society organizations. They are both umbrella organizations that handle funding applications from their member organizations as well as organizations that run their own development cooperation programs and projects. A framework agreement with Sida commonly runs for eight to ten years and organizations that are interested in becoming a framework organization Sida need to meet Sida's criteria of framework partnership. Additionally, framework organizations are required to monitor and report their work in a way so that Sida can assess its quality and gather information on the progress ("Framework organisations - Sida - Swedish International Development Cooperation Agency" 2014). In all projects funded by Sida, organizations that handle the projects are required to contribute with 10 percent of the project budget whilst Sida funds the remaining 90 percent.

Many projects that are funded by Sida are handled by the framework organization as such. Instead, there is often time a chain of different actors involved in the process of channeling funds and reporting back to Sida. The relationship between these different organizations

inherently affects the way in which Swedish policy is being put into practice. A simplified model of this relationship is presented in 'model 1' below. A common chain for a project is that Sida is in contact with the framework organization that they fund and receive reporting of the project from. The framework organization transfers the funds to a responsible organization that administrates the project and works towards implementation through the implementing or partner organization that is located in the recipient state.



Model 1: Simplified model of Swedish development cooperation policy’s transformation to practice

3. Literature review

3.1. Defining disability

There is no general or standardized definition of disability. Neither is there a general rule of which conditions that should be identified as disabilities. Hence, different reports, projects and so forth that target PWD all have their own definition of what disability is. There are however some overarching definitions both internationally as well as in Sweden.

The CRPD defines PWD, and subsequently also the right-holders of the CRPD, as “... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (CRPD, art. 1, p. 2). Thus, given the open definition of disability it could be understood differently both at an individual point of view and depending on societal context. However, the meaning of disability as deriving from impairments in interaction with barriers implies an approach that is of core importance from a human rights point of view. It stresses the focus to barriers in society limiting participation in society rather than solely towards the individual. Impairment is thus the physical or mental ability of a person, for instance being blind or having hearing deficits. Disability is however when persons with impairments are limited due to barriers of society.

Another implication in the definition of disability is the heterogeneity of the term. The CRPD specifically address long-term physical, mental, intellectual or sensory impairments. Which individual disabilities that falls into these groups is however relative and left for interpretation. The use of an overarching term such as disability could furthermore be problematic as barriers in society affect PWD differently. For instance, barriers towards education for persons with hearing disabilities are vastly different from persons with neuropsychiatric diagnoses.

Within the scope of this thesis and performing the interviews, the definition of disability was applied in a broad, heterogeneous manner. However, all interviewees were asked about what they perceive as disability and those results are given in detail in the results and analysis chapter.

3.2. Disability rights in development cooperation

Alongside DPO's, Scandinavian countries has played a significant role in connecting disability as a human rights issue into development cooperation programs. A central part to this has been through advocacy for a mainstreaming of disability rights (Albert, Dube, och Riis-Hansen 2005). A result of this was the Nordic Conference in 2000 where ministers of foreign affairs in Sweden, Denmark, Norway and Finland concluded that the major poverty reduction programs missed including disability as an aspect. The common conclusion was that initiatives needed to be taken in order to address this situation. Subsequently, the States formed a way forward for a disability-inclusive development. The plan was to establish a twin-track approach with the aim of both mainstreaming and mainstream disability in all development cooperation programs and to aim targeted initiatives in order to promote and empower PWD and DPO's which in turn could put pressure towards the local duty-bearer (e.g. States) (Norad 2012). Except from the twin-track approach there are also two other strategies of implementing a disability-inclusive development; the mainstreaming and the specifically targeting approach which are described below.

3.3. Disability and education

According to UNESCO (2014), who refers to estimates of international agencies, more than nine out of ten children in developing countries with disabilities do not attend school. Additionally, only three percent of all adults with disabilities in the world are literate, the

corresponding number for women is even lower at one percent. Sida (2009) states that children with disabilities, alongside children involved in child labor, are the people in the world with the least access to education.

The right to education as a part of the human rights framework originates from the creation of the Universal Declaration of Human Rights (UDHR) in 1948 in which article 26 proclaims the right. Since then, the right to education is a part of the 'second generation of rights', which Amartya (2004, pp. 316) labels as human rights stated in the UN Covenant on Economic, Social and Cultural Rights (ICESCR) that was adopted in 1966. The reference is about the UN Covenant on Civil and Political Rights (ICCPR), which was also adopted in 1966, being the primary framework for human rights seen from a western perspective. The quest and construction of the two covenants as the two major human rights treaties was a part of the cold war era and was represented by the west advocating for civil and political rights and the east which in turn argued for economic, social and cultural rights. In terms of development and poverty reduction, civil and political rights have been recognized as the main path so far as western states have not considered themselves as duty-bearers of economic, social and cultural rights. However, the latter is increasingly coming into focus in development practice which is evident not the least in the MDG:s (Rukooko 2010; Hamm 2001).

General and special education

One of the most debated questions in disability policy is whether rights should be guaranteed through the general system or whether special solutions for PWD are required. In relation to education this dichotomy is specifically prevalent in policy debate. In addition to pedagogical questions of how education for PWD is best practiced, the debate has also been about notions of normality and inclusion. In most countries, the school system has been separated into a dominant mainstream school system and a secondary system specifically for pupils/students with special needs. Engelbrecht, Kitching, and Nel (2009) states that this has been done in regards to the best interest both for mainstream schools and towards pupils/students with special needs in terms of receiving appropriate support and pedagogy. However, categorization is also linked to notions of normality and that the exclusion of pupils/students with special needs is linked to a medical understanding of PWD

as something that is abnormal and to be separated from the normality of mainstream education.

As the understanding of disability in many places has moved towards a social model of disability, the separation of mainstream and special education has however been challenged (Engelbrecht, Kitching, och Nel 2009). Instead, separate special education has increasingly been considered a system of oppression and exclusion of PWD resulting in increased efforts to facilitate special needs within mainstream education in order to promote inclusion (L Green och Engelbrecht 2006). The implementation of such approaches does however often meet significant barriers in terms of pedagogic strategies and design of education systems and schools. Additionally, as the social model of disability is to be practiced through the education system, meaning that disability occurs in the relationship between individuals and society, it is dependent on the way which society functions. Subsequently, in cases where marginalization and exclusion of PWD is predominant in society in general, the barriers of inclusive education are higher (Engelbrecht, Kitching, och Nel 2009). This means that the cultural context in which the education system operates is highly relevant in terms of successfully adopting inclusive education.

Article 24 of the CRPD, which address the right to education, adopts the general approach by asserting that State parties shall ensure that:

“Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability” and that “Persons with disabilities receive the support required, within the general education system, to facilitate their effective education” (CRPD, art. 24 p. A and C).

3.4. Strategies of implementation

Mainstreaming

The mainstreaming approach means that a disability perspective is to be integrated in all development policy and practice. Hence, disability consequence analysis is to be made in all development programs and at all levels (Coleridge m.fl. 2010). The main way in which mainstreaming has been practiced in development cooperation is in the quest for gender

equality. The definition of mainstreaming in this area could be used also to define mainstreaming of disability:

“Mainstreaming a gender perspective is the process of assessing the implications for women and men of any planned action, including legislation, policies and programs, in all areas and at all levels. It is a strategy for making women’s as well as men’s concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programs in all political, economic and societal spheres so that women and men benefit equally and inequality is not perpetuated. The ultimate goal is to achieve gender equality.” (UN ECOSOC (1997) cited in: Carol Miller och Bill Albert 2005, 10).

The main strengths of mainstreaming disability has been claimed to be the reduction of attitudinal barriers which creates social exclusion, institutional barriers that limits participation and environmental barriers which reduces accessibility (Hendriks 2009). In contrast to the twin-track approach, which also contains a mainstreaming element, the mainstreaming approach solely focus on making disability an integral part of all policy and practice.

Specifically targeting

The method of strengthening human rights for PWD through specifically targeting approaches could have vastly different points of departure. First, such approaches could be made with the intention of improving national or local aid-recipient states’ Disability Actions Plans (NDAP:s) and strengthening the system of Disability Persons Organizations (DPO:s). Such strategies are according to the European Commission (Coleridge m.fl. 2010) aligning with the CRPD and are even considered a necessity for the implementation of the convention.

However, specifically targeting approaches could also be practiced directly towards a certain group of PWD and are not related to strengthening NDAP:s and DPO:s but rights of PWD as such. This approach thus represents an antidote to the mainstreaming approach. Such an example is the right to education where a common strategy for guaranteeing the right is through specific schools for PWD rather than making the general school accessible for all.

Twin-track approach

The twin-track approach is a combination of the mainstreaming and specific strategy approach. Axelsson (2008) claims it to be a necessity for implementation of the CRPD through inclusive development and stresses that solely mainstreaming disability rights could be a poor strategy as it risks being limited to solely policy with no action taken. However, if a mainstreaming approach is adapted along with accordingly strengthening NDAP:s and DPO:s in aid-recipient states and communities, Axelsson (ibid.) claims that that equality of rights and opportunities for PWD and for their full participation in society could be reached.

It is this approach that is emphasized in Swedish development cooperation policy, which is debrided in detail below.

3.5. Perceptions of disability

From a social constructionist point of view, disability could be said to serve as a clear example of how a social construction could both change itself as well as it could change what disability is and what conditions has applied to this group of people through history. Different constructions of what disability is have led to different ways of enhancing living conditions for PWD.

Historically, disability has been perceived and constructed in relation to impairment. The oldest approach to disability is what Mattioli (2008) describes as the charity model. In this approach, PWD are perceived as poor victims of circumstance that society from a moral point of view must assist with aid and assistance (Mattioli 2008). Just as in the charity model, the medical ontology explains disability as deriving from disease or sickness and results in loss of physical or intellectual function. Hence, as disability is constructed medically, society has met the needs of PWD with medical care such as institutionalization, rehabilitation and special education programs (Palmer and Harley 2012). The medical model is still very much prevalent and is often considered the main barrier for societal inclusion for PWD.

However, lately the social model of disability is the most commonly advocated (Barnes 2003; Palmer och Harley 2012). The principle of the social model is a change from perceiving disability as an individual impairment but rather as something that is constructed by society. Disability is seen as a consequence of the accommodation of society. This has changed the

way in which disability rights are claimed globally and is argued to be the main path on which human rights of PWD are to be guaranteed (Palmer och Harley 2012). The most evident result of the process in which the social model is becoming predominant is the CRPD that was drafted in 2006. Adapting a rights-based approach to disability reaffirms society, in effect States, as duty bearers for rights. Hence, disability from a rights-based approach is a societal, or structural, question rather than an individual one.

3.6. Experiences of mainstreaming disability

Mattioli (2008) suggests that whereas many States have a solid national legislation and practice in terms of protecting the rights of PWD, the inclusion of disability in development cooperation policy and practice is more complicated. One of the problems is that disability in many cases is not seen as a priority in development cooperation.

In 2012 the Norwegian Agency for Development Cooperation (NORAD) made an evaluation of the Norwegian support to promote the rights of persons with disabilities through development cooperation (Norad 2012). The evaluation concluded that Norwegian policy had failed in turning policy into practice in development cooperation projects. The policy and guidelines for a disability-inclusive development was not known by the organizations that handled the projects. The evaluation had a specific focus on education and humanitarian assistance. In terms of education, the evaluation concluded that PWD were often left out of initiatives. Instead, there was found to be a greater focus on the gender perspective and more specifically projects that targeted girls.

The same problem was addressed in a research on international donor agencies' policies on disability mainstreaming and if they were being effectively implemented (Albert, Dube, och Riis-Hansen 2005). The four agencies that were studied were the United Kingdom Department for International Development (DFID), NORAD, the United States Agency for International Development (USAID) and the World Bank. One of the major conclusions of the research was the failure to communicate policy. Albert et. al. (2005) claims that a good policy as such is of no good unless it is continuously lobbied. As policies had not been enough communicated, the disability area becomes one of many concerns that agencies are to integrate such as age, children and ethnic groups. The result is subsequently that disability policy is not implemented in practice. The problem of different groups 'competing' to be

targeted in initiatives was well demonstrated by interviewed representatives of DFID. They stated that “it would be easier to move people out of poverty who were closer to the line than disabled people” and that this was “linked to the political imperative for the organization of finding ‘big hits’ and quick results, neither of which it was felt could be achieved by focusing on disability issues” (Albert, Dube, och Riis-Hansen 2005, 30). Similar problems have been raised by Mattioli (2008) who claims that the lack of desegregated data on PWD makes disability less of a priority. If the situation for PWD is not monitored, initiatives are not likely to include that aspect as it is impossible to determine the effectiveness of such initiatives (Mattioli 2008)

Another key barrier that was identified both in NORAD’s evaluation and in Albert, Dube, and Riis-Hansen’s research is that the development cooperation partners had different understandings of disability. For instance, as Norwegian policy adapts a social approach, it was common for implementing organizations to have a medical understanding of disability. The perception of persons with disabilities is under constant change both in a historical, cultural and global context. In many states where a rights-based approach is under construction, the understanding of persons with disabilities has previously been both marginalizing and discriminatory. Interestingly, Mattioli (2008) distinguish an example of the significance of understandings of disability by claiming that mainstreaming gender rights is found to be easier as there is an, almost collective, understanding of structural gender issues as something related to social structure. Mainstreaming gender related programs is therefore less problematic as there is a consensus on how they are understood. However, some scholars (Carol Miller och Bill Albert 2005) argue that there have been problems on the consensus in gender mainstreaming where some projects adapts a pragmatic approach to the concept where it is shaped in regards to the institutional needs of projects and organizations.

The NORAD evaluation concluded that the result was that PWD were found to be left out of many initiatives, even in projects that were specifically focused on reaching the most vulnerable groups. The best outcomes were instead reached through targeted initiatives and by the focus on working towards local DPOs. In these cases, the local DPOs were found to have been empowered and have stronger capacity to affect local government and policy which in turn enhanced the situation for PWD (Norad 2012).

4. Methodology

4.1. Data collection

In order to answer the present dissertation's research questions a variety of data collection methods could be applied. Barriers of mainstreaming disability could be discussed in a theoretical manner building on previous research and evaluations of such approaches. The link between policy and practice could be researched similarly. However, no evaluation of Swedish initiatives to mainstreaming disability in development cooperation has been done. In order to answer the research questions from a Swedish policy and practice point of view, a primary data collection was necessary. For this purpose a qualitative method was chosen. The qualitative approach enabled a more exemplified and detailed account for identifying barriers to mainstreaming and how Swedish policy is put into practice.

The benefit of the qualitative approach is that it is possible to go more in depth in answering the research question. It enables the researcher to get closer to the research in terms of interacting with the respondents and thus define the structure of the data collection (Bryman 2012). As the interviews were done inductively, this was a necessity. By being open to which barriers to mainstreaming that the interviewees themselves refer to, the interviews could be adapted to and adjusted depending on the specific interviewee's answers. In this regards, a cumulative method also benefited the data collection. After each interview, the guide as such and the performance of the interviews were evaluated and slightly adjusted in order to design the interviews to answer to the research questions as good as possible. A critique towards the qualitative research design is that it is too subjective and that the researcher draws in his or hers own experience and knowledge. This in turn affects both the way that data is collected and analyzed. In this regards, the process of reflexivity is of great significance (Bryman 2012). By problematizing my own knowledge and experience of human rights for PWD, the problem of subjectivity was reduced, yet it is always present in qualitative research. A quantitative research design would have enabled more respondents and thus a better generalization of results. However, it would also have demanded a more deductive approach in which existing conceptions of barriers to mainstreaming disability and the relation between policy and practice would have had to be tested towards the respondent. Neither would it enable to capture in depth-experiences of the interviewees. Hence, the open-end inductive research design was chosen.

Three interviews were carried out with representatives of the responsible organizations of the projects. The interviewees had different positions within the responsible organizations but were involved in the projects at both strategic and to some extent operational level. An important part of the selection of interviewees was that they had to have detailed knowledge of the project as such and how it is carried out by the implanting organizations. Before carrying out the three interviews that are used as data, another interview was carried out with another representative of a civil society organization (CSO). However, drawing on the experience of the first interview, the research questions were slightly adjusted which resulted in that the gathered data from that interview was left aside.

The focus on the interviews was to gather data on the projects as such. The information that was necessary to conduct was related to the practice of the project as well as how the organizational process of the projects related to Swedish development cooperation policy. Attitudes and discourses of professionals carrying out the projects were not in focus as the interviewees are solely responsible for the projects in terms of their positions within the responsible organizations. Such results did however emerge in the interviews and is applied and analyzed in the research, however this part is limited as to describing the way in which the projects operate, and not the professionals themselves.

The interviews were done using a semi-structured interview guide that was constructed so that basic information on the organizations and projects were collected as well as the practice of the projects. The guide was structured into thematic areas such as the significance of culture and context in the recipient State or region, how the organization worked towards PWD and how the interviewees considered the relation to Sida or other international policies relating to disability. Even though the interview guide was used in all interviews, the interviews were done in a relatively open manner. If an interviewee mentioned something of interest, the interview followed the same direction given the significance for the research questions.

All interviews were done in Swedish and all quotations are translated with the best of the researcher's ability.

4.2. Selection

The projects were selected using Sida's online project database where all projects that are financed by Sida are listed. The selection benefited from the fact that the database enables a selection of projects of interest. In this case, a selection of projects that related solely to 'education' was made. The database also provides basic information of projects in terms of its budget, its target groups and where the project is practiced. There is also information of which framework organization, responsible organization and implementing organization that is involved in the project.

Many of the projects that are financed by Sida relating to education are about reinforcing DPO's work towards affecting governments and governmental bodies to increase standards in general education. There are also several projects that are related specifically towards capacity building of making education disability-inclusive. Such projects are also mostly directed towards strengthening and empowering local DPO's. However, the projects selected for this thesis were selected on the premise of them being general and not directed specifically towards PWD. This was necessary in terms of the approach of the research questions, e.g. to study mainstreaming of disability in general projects. Another consideration in the selection was that one of the framework- and responsible organizations had a lot of projects within the scope of the thesis and there was only one selectable project that was carried out by other organizations. This resulted in two of the projects having the same framework- and similar responsible organizations. The interviewees are however different and the projects as such are furthermore vastly different in their approach.

4.3. Data analysis

Notes were taken during all three interviews. The notes were written simultaneously as the telephone interviews were done, enabling a beneficial level of detail. After all the interviews, the notes were themed in relation to the research questions, i.e. barriers to mainstreaming was one theme and Swedish development cooperation policy was another. The notes from all three interviews were then put together, enabling another theming of the data. In this process, different aspects of barriers and the relation between policy and practice were identified. As the data was themed, an inductive approach was used. Neither theory nor literature review thus affected the process of theming the data. However, as Bryman (2012) concludes, most inductive research designs entails elements of a deductive approach as the

data indeed will be studied in relation to the adapted theories. Furthermore, other experiences of mainstreaming disability that are presented in the literature review are used in order to analyze the present dissertation's data as well.

In the analysis of the results is supported by the literature review. It includes experiences of other evaluations of mainstreaming disability but also on mainstreaming gender. It furthermore includes aspects both of political science, sociology and law. The results are thus analyzed with an interdisciplinary approach.

4.4. Scope and limitations

The three projects that were finally included in the research all represent projects relating to the right to education. As Swedish development cooperation policy encourages mainstreaming of disability through all projects, there are a multitude of other projects that could also have been of great significance in terms of identifying barriers to mainstreaming. However, education was given the solely focus for all studied projects as it enables shared experiences between the projects which in turn enhances both validity in to some extent generalization of the findings.

Just as the interviewees themselves mention, there are a lot of human rights issues that are to be mainstreamed in Swedish development cooperation practice. However, all such issues are vastly different in nature and thus withhold different barriers of mainstreaming. Hence, the focus of the present dissertation is solely on disability even though other mainstreaming areas that are mentioned such as for instance gender and HIV are used in relation to mainstreaming disability in education.

Another limitation of the dissertation is that it only targets the mainstreaming part of the Swedish twin-tracked approach to making development cooperation disability-inclusive. The original idea of the research was to identify Swedish development cooperation projects that represent strategies of enhancing the right to education for PWD. Except from the mainstreaming approach, projects that practice a specifically targeting approach were to be included. However, after conducting one such interview, the scope was considered to have been too big creating limitations in the data analysis process.

The reason to why only three interviews were done was first that there is a limited number of Sida-funded general education projects. As pointed out above, many projects focus on capacity building and strengthening local CSO's to affect State legislation or policy. Other general education projects are being practiced, however they are either practiced by PMU InterLife (which two of the studied projects are) or not funded by Sida.

4.5. Generalization

An important note to be added is that the projects selected for this thesis does not represent either the practicing organization as such or even the project itself as interviews only have been carried out with representatives of the projects. The results are therefore not quantifiable. However, the aim of the selected projects and the interviews that have been made with representatives of the projects do contribute to a solid ground for researching, problematizing and analyzing the relationship between policy and practice and identifying barriers to mainstreaming disability in development cooperation.

The data is only collected from three interviewees and three projects. This should be kept in mind when analyzing the results. However, the process of triangulation where the results are analyzed in relation to other research enables generalization to some extent. As the approach of the research is inductive, other evaluations and experiences of mainstreaming disability in development cooperation that aligns with the present dissertation's results raises the level of generalization (Bryman 2012). However, foremost the research provides examples of barriers in mainstreaming disability and how policy is transferred into practice.

4.6. Ethical considerations

The collected data in the present dissertation was gathered from interviewees representing organizations. This inherently lessens possible ethical concerns in relation to the research as they are not in a position in which the results of the study could do harm on them.

Furthermore, individual beneficiaries of the projects that the interviewees were representing were not of interest in the research and the data could thus not affect or harm them in any way.

In the beginning of each interview, the interviewees were asked if they approved for the research to identify names of the projects, which organizations that they represented and which position that had in the organization. All three interviewees approved this. These are

used in the dissertation as it both enabled readers to get a better insight in specific Sida funded projects but also as it increases the reliability of the research. The interviewees also approved notes to be taken during the interviews and for citations to be printed.

5. The projects

5.1. Ethiopia: “Education for social development”

In the Afar region of Ethiopia where the project is practiced, the literacy level among adults in 2005 was 27 percent among men and 15,6 percent among women (“Ethiopia Atlas of Key Demographic and Health Indicators 2005” 2008). This could be compared to the rate of overall Ethiopia which is higher at 39 percent (“UNICEF - Ethiopia - Statistics” 2014). The Afar population is about 1,5 million and they consist of both nomads and of permanent residents.

The World Report on Disability (2011) concludes that there is a lack of data on the inclusion or exclusion of disadvantaged groups in the Ethiopian education system. There is however an estimate based on the Ethiopian Ministry of Education’s data that only 6 000 identified disabled children in Ethiopia have access to education out of the nearly 15 million primary school population (World Bank och World Health Organization 2011).

Ethiopia signed the CRPD in 2010 and disability rights are a part of the Ethiopian constitution. There is also a plan of action for rehabilitation of PWD, even though it has not yet been implemented (Lewis 2009).

The interviewee for the ‘Education for social development’ project represents PMU InterLife which is the framework organization of the project. PMU InterLife is a federation of Swedish a branch of Swedish churches to which ‘Pingstmissionen i Jönköping’, the responsible organization is a part. As with all Sida financed CSO projects, the responsible organizations are obligated to fund 10 percent of the project. It is Pingstmissionen i Jönköping that is responsible for the contact with the implementing organization in Ethiopia, however PMU InterLife have an important function as a controlling and responsible organization towards Sida. The implementing organization is the Ethiopian Mulu Wongel Amagnoch Church Development Organization. They are located in Ethiopia and this specific project takes place in the Afar region in the north-east of Ethiopia.

The aim of the project is to strengthen the Afar people by creating access to education. According to the interviewee, there is a lot of mistrust or suspicion from the Afar people as the implementing organization comes from a Christian context whereas the Afar people themselves are Muslims and practice a clan culture. For instance, according to the interviewee, it is the clan leaders who make the decisions if children are to go to school or not. The focus of the project is to take a first step towards gaining confidence and trust from the Afar people. This is done by focusing on children that are outside the education system and educate them so that they can enroll in the general education system. The aim is also that the access to education in the long run changes attitudes to education and increases women's possibilities to gain reading and writing skills. Another aim of the project is to mainstream other human rights related issues such as gender equality, environmental questions and HIV in the education.

5.2. Nepal: "Literacy Nepal"

93 percent of the primary school aged population in Nepal is enrolled in education. According to the Ministry of Education of the Government of Nepal, 1,1 percent of these are PWD (Human Rights Watch 2011). The occurrence of PWD according to that estimation should be seen as very low and it is most likely not representative. As a comparison, WHO estimates that 15 percent of the world's population consists of PWD. The adult literacy level of Nepal is 57,4 percent ("UNICEF - Nepal - Statistics" 2014).

In 2006 the Nepalese government adopted a policy of inclusive education. The policy guarantees free primary education for all children and promotes the establishment of resource classes for children with disabilities. Nepal also became signatories of the CRPD in 2010.

The interviewee for the 'Literacy, Nepal' project represents PMU InterLife, the same organization as the Ethiopian project. In this case, it is 'Pingsförsamlingen i Lycksele' that is the responsible organization and that are the funding 10 percent of the project. Just as in the case of the Ethiopian project, it is 'Pingsförsamlingen i Lycksele' that is responsible for the contact with the implementing organization in Ethiopia, however PMU InterLife have an important function as a controlling and responsible organization towards Sida. The implementing organization in Nepal is an NGO named 'Grace Community Development

Nepal'. They work with the support of PMU InterLife and are to report and analyze results towards PMU InterLife.

PMU InterLife's objective is to target the most vulnerable groups. According to the interviewee, as for the case of literacy in Nepal, illiterate women best represented this target. The aim of the project is to strengthen and create better living conditions for women in Nepal by learning them how to read, write and count. Additionally, the women are to get new knowledge about rights, health and human rights.

5.3. Democratic Republic of the Congo: "Literacy II"

There is a great lack of disability statistics on the situation for PWD in the Democratic Republic of the Congo (DR Congo). In 2009, the literacy level was measured at 55 percent and there are estimates that there are about 10,5 million PWD in DR Congo representing about 15 percent of the 70 000 000 population (Pierre Olivier Lobe 2013). DR Congo signed the CRPD in 2007 but has not yet ratified the convention.

The interviewee represents the responsible organization 'Equmeniakyrkan' (The Equmenia Church) which reports to the framework organization which is 'Svenska Missionsrådet' (Swedish Mission Council). The aim of the project is to raise literacy levels among adults in DR Congo. The project has been ongoing since 2000 but has only been financed by Sida since 2006. The project is carried out by the implementing organization Communauté des Eglises Baptistes Unies (CEBU). The Equmenia Church has a lot of contact with the organization through dialogue and regular visits to the project sites. In the beginning of the project, the main focus was on children and agriculture. However, as the project is currently practiced, a larger focus is put on mainstreaming human rights- and democracy elements within the literacy training. The direct target group is about 3000 individuals from the age of 15 and older that cannot read and write Lingala/Kikongo and/or French and that lives in within the areas in which the The Equmenia Church's partner organization CEBU operates in the northern Bandundu province in western DR Congo.

6. Results and analysis

To which extent is disability mainstreamed into Swedish development cooperation projects related to the right to education? Building on the results of the research, the answer to the overarching research question to this dissertation is simply 'to none extent'. In all three projects, there are other human rights issues such as gender rights, HIV and environmental concerns that are mainstreamed in the projects. These areas are also found in Swedish development cooperation policy. However, none of the organizations responsible for the projects have targeted disability as a mainstreaming area, even though they are aware of it being a part of Swedish policy. On the other hand, all interviewees claim that the projects do accept PWD to take part in the education programs. One of the projects differs from the others as the implementing organization targets disability, a process that is described below. However that initiative has been taken by the implementing organization itself and is thus not a result of Swedish policy or initiatives from Swedish organizations.

6.1. Disability is invisible unless addressed

Only the interviewee of the Ethiopian project was able to give an example of PWD having enrolled the education programs. The interviewee also gave examples of adaptations made in order to address potential needs of these persons, even though the resources for it such adaptations are described as scarce. The Ethiopian project also differs from the others in terms of approaching disability. The implementing organization, Ethiopian Mulu Wongel Amagnoch Church Development Organization, includes disability as a crosscutting issue along with gender equality, the child perspective, HIV-issues and environmental concerns. The implementing organization target disability by in a routinely manner analyze actions taken through the lens of disability. However, this initiative has not been taken by PMU InterLife but from the implementing organization itself. The reason to why disability is present as such a cross-cutting issue is, according to the interviewee that the partner organization itself has contacts with other organizations that fund other projects carried out by the partner. These other projects have included disability and have thus influenced the work in the PMU InterLife-funded project.

None of the interviewees had a clear perception of how common it is for PWD to take part in the programs. Neither was the need for PWD in the given villages or regions to enter such education program anything that had been investigated or that was known by the

interviewees. Hence, as for the Nepalese and DR Congo projects and also partly the Ethiopian project, the participation of PWD in education is an invisible problem for two of the organizations, a common problem in development cooperation practice (Hendriks 2009).

Education is given to the people that enter the programs and in cases where PWD do participate; the programs make adaptations in order to address potential needs of these persons. The interviewees of the Nepalese and DR Congo projects states that the implementing organizations does not make any general adaptations in terms of making the physical environment accessible or adjusting the curriculum or teaching in terms of pedagogical accessibility. Adaptions would rather be made in relation to potential individuals with special needs. As for the project in Ethiopia, adaptions that are made in terms of accessibility are not known by the interviewee as this is not reported to PMU InterLife by the implementing organization.

The approach of making adaptions in relation to the individual could be claimed to represent a medical model of disability in which adaptions are made in relation to the individual impairment. What would represent a social and human rights based model of disability would be to make the programs as widely accessible for all as possible without focusing on individual impairments. Making the physical environment accessible for all is a fundamental approach of human rights for PWD that is also found in article 9 of the CRPD and in relation to education in article 24. If adaptions are only made in terms of the individual and no efforts of creating general accessibility, it is likely that PWD will not enroll in the programs, as they will not function for them. Subsequently, as PWD do not enroll in the programs for such reasons, the issue of also providing education for PWD remains invisible for the projects resulting in a situation in which PWD would be continuously excluded from the programs.

The interviewees also states that they most likely would find problems in terms of the accessibility of the education programs for PWD if they would specifically address the issue. Two of the interviewees stated that they should address the issue and that the interview functioned as eye-openers motivating them to start looking into these questions. The interviewee of the Nepalese project also stated that PWD are included in other projects that

PMU InterLife operates in South-East Asia and that they are so because they have been specifically addressed as group of concern in these cases.

Furthermore, the interviewees have a lack of knowledge on the situation for PWD in the regions where the projects are practiced even though they all have a general perception. For instance, the interviewee representing The Equmenia Church argues that the situation for PWD in DR Congo is specifically critical with children being hidden away and suppressed. The interviewees are however relatively unaware of the prevalence of PWD in the regions. This is expressed by the interviewee representing the project on DR Congo:

“We don’t know what the need is, how many persons with disabilities there are in the regions and that are involved in the projects”

According to Mattioli (2008), the lack of desegregated data on the situation for PWD makes disability less of a priority. As the situation for PWD is not monitored, initiatives are not likely to mainstream it as the possibilities of determine the effectiveness of such initiatives are scarce. This in combination with development cooperation projects not addressing disability results in a situation in which the situation and potential problems of PWD remains hidden and unknown. This way, development cooperation projects could be very successful and show great accountability towards broad groups of people with for instance education programs without the inclusion of PWD.

The results are also aligning with the criticism of disability having been left out of the MDG’s. Even though it has been argued that the close link between disability and poverty makes disability an implicit part of the MDG’s (Groce 2011), it is left out of initiatives. As the United Nations Development Programme states, poverty reduction programs can never be successful without them being inclusive to all, e.g. also addressing rights of PWD (United Nations Development Programme 2014). This could also be seen as an explanation for the fact that 90 percent of people in poverty now have accessibility to education but that the numbers are upside down in terms of poor PWD. This mechanism reinforces the notion of the close relationship between disability and poverty that many scholars have confirmed (i.e. Palmer 2011; Yeo och Moore 2003; Mitra, Posarac, och Vick 2013b).

6.2. Competition of perspectives

“PMU could be doing a lot more, the problem is that there are a lot of questions we could do a lot more about. I could be asking the implementing organization a lot of questions, but they would not be able to handle all the perspectives at the same time. That is why it is hard to include the disability aspect. But if we would specifically address disability as a mainstreaming area, we could probably do a lot”

The statement that is given by the interviewee of the Ethiopian project is rather typical as a barrier of mainstreaming disability. Disability is one of many aspects that are to be mainstreamed in the projects. The interviewee furthermore states that:

“If we worked with it more specifically we could probably achieve change in the question of disability. As for working with HIV it was tough, but it was decided and it was hard but it ended up being very successful. PMU has the power to put the focus on one question, but in that case we really have to commit to it. Currently the areas that are to be prioritized is gender by reproductive health and obstetric care along with environmental questions, provision and internal democracy”

Similarly, the interviewee of the Nepalese project indicated that there are other prioritized target groups for the project than PWD. In this case there is a strong focus of gender mainstreaming:

“If a woman with disability has been reached in this project, it is because she is a woman and not that she has a disability”

The matter of focusing on women is according to the interviewee based on the policy of PMU InterLife to reach ‘the most vulnerable groups’. This specific project intentionally targets women due to the situation and high prevalence of illiteracy among women in these areas. As the project’s focus is on women, disability becomes a secondary matter. The same interviewee states that:

“vulnerable groups are so many and so different, if you try to involve as many groups as possible it will get tough and that could be a risk for the work in the project”

Similar results were found in NORAD's evaluation of mainstreaming disability in development cooperation education projects (Norad 2012). Such initiatives were found to mainly focus on reaching the most vulnerable groups, which in practice resulted in a significant gender perspective.

An explanation to why disability is not seen as a primary importance in terms of persons that the projects are targeting is that the projects adapt what could be described as a 'utilitarian' approach. As the projects only have as much resources as it is funded, it intends to reach as much of an effect as possible. The interviewee of the Nepalese project gives one such example:

"It is a big step just giving these people education in the first place. Perhaps not everything is good and all questions answered but that has to emerge progressively"

In all three cases such effect would be to raise literacy and education levels among as many people as possible and to mainstream human rights related issues (yet not disability). When reporting back to the funder, Sida, the success of the projects is based on these results. This explanation has been used by Albert et. al (2005) in their investigation of barriers in mainstreaming disability through the United Kingdom Department for International Development's policy. In the study, several interviewees gave a general perception that "it would be easier to move people out of poverty who were closer to the line than disabled people" and that this was "linked to the political imperative for the organization of finding 'big hits' and quick results, neither of which it was felt could be achieved by focusing on disability issues" (Albert, Dube, och Riis-Hansen 2005, 30).

Both PMU InterLife and The Equmenia Church as organizations have tried to emphasize mainstreaming of human rights in their development cooperation projects. All three interviewees mention this. The mainstreaming of human rights is adapted in the projects by making them a part of the education. While at the same time providing basic education and reducing illiteracy among the participant, they intentionally include questions of for instance genital mutilation, women's rights and rights of the child as parts of the education curriculum. The organizations are thus responsible for several mainstreaming areas. The projects involve and work with a multitude of questions within the realms of the education programs including health, hygiene, income-related activities, gender equality, HIV, and the

importance of education. There seems to be a possibility of making disability rights as one of these mainstreaming areas; however the multitude of areas that are to be covered is considered a risk for the projects. This is one of the answers to the unsuccessful implementation of disability in the projects.

Another explanation as to why disability is left out of the human rights mainstreaming is that it is not yet seen as a human rights issue. This links to the notion of how disability is understood. Even though all three interviewees mention disability as a human rights issue, it could be understood differently in the implementing organization or in the contexts in which the projects are practiced. This barrier is presented in detail in chapter 6.6.

6.3. Contextual significance

The interviewees of the Ethiopian and DR Congo projects gave examples of how the context of the State or region in which the project is practiced is of significance for the way that the project is practiced. The interviewee of the Ethiopian project states that the situation for PWD in Ethiopia is tough as disability is generally considered as something shameful and that PWD because of this often are hidden away. In relation to this statement, the interviewee claims that his organization could be doing a lot more concerning disability and develops the argument by stating that:

“that is why it is hard to include the disability related questions in such a concrete manner, you have to take account of the complexity of the situation”

According to the interviewee of the project in DR Congo, PWD are not generally marginalized or discriminated. The interviewee compared this to the situation in Tunisia where the responsible organization he represents are involved in a project specifically addressing children with intellectual disabilities. According to the interviewee, discrimination against PWD is widespread in Tunisia and it is common to hide children with disabilities as it is considered as something shameful. The specific approach that is practiced in Tunisia is motivated as the importance of working with disability in the projects is relative depending on the context. The context appears to be an important factor as to why disability is considered a priority area or not.

As the projects intentionally targets to most vulnerable groups, PWD are left out of initiatives in contexts where they are not considered as fully marginalized and suppressed as in other places. However, given the low education enrollment rate of children with disabilities in Ethiopia, the generally low literacy rate in Nepal and lack of statistics in DR Congo, PWD is indeed a vulnerable group. It could be argued that a reason to why disability issues to a large extent is considered in relation to the contextual significance is that they become issues of human rights only when PWD are actively marginalized and suppressed. Structural exclusion of PWD that, from a social model of disability point of view, emerge from a non-accessible environment, are thus left out in the consideration of who is the most vulnerable and what is to be considered as human rights issues. These problems links to the notion of how disability is understood and how it is progressing as a part of the human rights framework, issues that are targeted below.

6.4. A long way from policy to practice

The studied development cooperation projects are all carried out by implementing organizations active in the recipient State. It is thus the work on this level that defines Swedish development cooperation's achievements and struggles. At the same time, this is precisely what Swedish policy is to define. The Swedish system of development cooperation is described in chapter 2.3. The main guiding document is the governmentally decided PGU which does address disability as one of many mainstreaming areas. Additionally, Sida's position paper on disability is intended as a complementary guideline for a disability-inclusive development. However, the organizational chain of Swedish development cooperation involving Sida, framework-, responsible- and implementing organizations creates a distance between the policy documents and practice. The distance is evident solely by studying the organizational system as such but it is also a significant result of the interviews.

The interviewees are familiar with the PGU and its demands of a rights based approach. They are also familiar with disability being a part of Swedish policy. The link between the policy and the rights based approach is however not clearly described by any of the interviewees. The interviewee of the Ethiopian project recognizes that they are demanded from Sida to work from a human rights based approach. In this sense, the interviewee primarily considers

the rights based approach as an opposite to the charitable approach. It is about making the process of implementation a value in itself. The interviewee states:

“It shouldn’t be humanitarian; you shouldn’t make things for them but with them. The process is important. To present the idea of drilling a well instead of just drilling it”

The same interviewee states that working from a rights based approach is a demand from Sida that is put down in the framework agreement between PMU InterLife and Sida. There is furthermore a demand of considering the mainstreaming areas. However, disability has never been specifically addressed in this regards but is supposedly included in the ‘most vulnerable group’ that PMU InterLife target in projects. The same interviewee identifies the rights based approach as withholding rights holders and duty-bearers. In relation to the project in Ethiopia, the rights holders are primarily children but also illiterate adults. As the projects aims at working with and not for the target group, the interviewee considers the government in Ethiopia as well as the Afar clan-leaders as duty bearers and do not mention neither PMU InterLife nor the implementing organization as duty bearers.

The interviewee representing the project in DR Congo specifically mentions the PGU and its far-reaching approach. At the same time, the policy is considered as being problematic in terms of implementation:

“The problem with the PGU is that it hasn’t been applied in practice”.

This is not the least evident in the present results as only one of the three studied projects have some form of active disability mainstreaming. In fact, the result of that approach is not deriving from the PGU but from the implementing organization itself. It is thus a long way not only between what the policy strives for in relation to practice but also in terms of the organizational chain of Swedish development cooperation. The latter thus creates a barrier for a successful mainstreaming of disability. The long chain between policy and practice in development cooperation has also been identified in Hendriks (2009) study.

6.5. Lack of reporting mechanisms

As a governmental agency, Sida operates on the basis of instructions of the Swedish government. This means that Sida as an organization is not independent but must conform to standards of development cooperation that is set up by the government such as the PGU.

On the other hand, partner organizations to Sida are civil society organizations. The role of such organizations is in many aspects more independent than state organizations such as SIDA. CSO's can set their own agenda and base their work on independently formulated agenda and policy. However, the independence of civil society organizations is also many times infringed in practice as they are dependent on stakeholders in terms of donors. Organizations thus often align with policy and practice of donors in order to receive funding, a process of institutional isomorphism (DiMaggio och Powell 1983).

Even though Swedish development cooperation policy commends mainstreaming of disability, it is not a part of the reporting in any of the studied projects. This is true even for the Ethiopian project where disability is treated as a crosscutting issue by the implementing organization. Even though the disability perspective is active at this level, it is not reported by the responsible organization PMU InterLife. If institutional isomorphism was to be applied to this, it could be argued that the projects do not report their work on mainstreaming disability, as they are not dependent to do so in order to receive funding. Hence, if Sida would raise the demands on projects that are not specifically targeting PWD work from a disability perspective, it is likely that the projects would report this work back to Sida. As for the three studied projects, they all refer to Sida's requirements on reporting on other mainstreaming areas and more specifically gender. Subsequently all three projects practice an active mainstreaming of gender, which is also reported back to Sida.

The reporting procedure is furthermore a process of accountability. Responsible organizations are accountable towards Sida both for carrying out the projects that they receive funding for and to follow Swedish development cooperation policy as well as Sida policy. Accountability is a key factor in the human rights based approach to development cooperation. In opposite to a charitable approach, the rights based approach holds active organizations accountable for human rights issues (Sarelin 2007). The lack of requirements for the responsible organizations in the present dissertation could thus be argued to represent a gap between what would be defined as solely 'development' and 'a rights based approach to development'.

6.6. Different understandings of disability

Development cooperation is based on a relationship in which one state transfers capital to another, may it be economic, social or cultural. The process in which recipients of such capital is selected inherently involve a normative aspect, e.g. donor states do not select recipients from a random order. The relationship thus also withholds power dimensions. As the bottom line of the human rights framework is about global norms aspiring to affect national policy and in the end rights and freedoms of individuals, the discourses of the human rights framework as such is relevant in terms of understanding how it is used within the practice of development cooperation.

The human rights framework has been understood differently historically and there are several controversies among scholars on the way forward for the human rights framework. A common approach to understand the discourse of human rights is the philosophical. In short, the philosophical approach strives towards the establishment of a common understanding and fundament of the human rights framework. As the construction of the human rights framework evolves, the remainder of the human rights project is a matter of elaboration and implementation of the common norms. Critics argue that this puts human rights as norm aspiring to establish a definite answer to what human rights actually are and what they mean, a closure that is considered neither possible nor desirable (Mutua 2002).

If human rights are to be considered as a set of given norms that are to be implemented universally, they could be argued to represent knowledge. This knowledge would be attributed to the actor that possesses the power of using the human rights framework as a means. Thus, donor States that explicitly stress the value of human rights within development cooperation also possess the power of knowledge.

Within the scholarship of disability, a number of models have been constructed for the concept of disability, models that represent different ways of understanding and portraying what disability is. Both historically and presently, disability has been attributed to the individual whose impairments lead to marginalization from society. However, disability has increasingly been placed outside the individual, to the structure of society and that disabilities occur in relation to societal barriers and not solely at the individual. This development is not the least present in the CRPD. A key reason to why these different

models have been central to the field of research is that different understandings of what disability is subsequently leads to different views on what measures needs to be taken in relation to PWD. This is true also within development cooperation, different concepts of disability is significant in terms of approaches and strategies which affects practice and in turn living conditions and the enjoyment of human rights for PWD.

Swedish development cooperation policy is based on the PGU, which untidily has been adopted by the Swedish parliament. It is constructed from a Swedish point of view and its policy is thus foremost influenced by conceptions that are prevalent in Sweden and less in the contexts in which the policy is to be transformed into practice in development cooperation. The PGU specifically point out that Swedish development cooperation is to be operated with clear reference to human rights. Thus, by funding development cooperation projects, Sweden inherently possess the power of defining what strategies of implementing human rights should withhold. In the case of disability, Sweden has adapted a clear social approach to disability that is to define its development cooperation practice.

The projects are however carried out by implementing organizations that origin and operate in the specific regional contexts in which the projects take place. As the Swedish development cooperation policy and its social approach to disability is not directly known by the interviewees representing the responsible organizations, it is not likely that representatives of the implementing organization are aware of it either. Hence, the transformation of the social model of disability is likely to not translate or to be retranslated when the policy is turned into practice through the organizational chain that Swedish development cooperation is built upon. Keeping this in mind, it is rather more likely that implementing organizations base their perceptions of disability in relation own experiences and more importantly, the regional context or domestic State policy.

One example of a difference in the perception of disability is mentioned by interviewee of the project in DR Congo:

“Persons with disability are a part of society and there is no attitude of marginalization. There is however no tradition of adjusting society so that it works towards the individual”

The statement indicates that the general perception of PWD in DR Congo represents a medical model of disability where it is ascribed to the individual. This perspective is also present in the following statement regarding the project in DR Congo:

“the physical environment is not made generally accessible. If it is not accessible, the problem is solved by lifting the persons by hand”

This approach is thus a contrast to the social model represented in Swedish policy. In the process of transforming policy to practice, the concept and understanding of disability is interpreted differently by actors involved in the process, from Sida to responsible and implementing organizations, creating barriers in the way in which Swedish policy is put into practice.

The problem of having different understandings of disability in the organizational chain of development cooperation has been identified both in NORAD’s evaluation and by Albert, Dube, and Riis-Hansen’s research. The latter states that “if the understanding of key concepts are diluted, even if for pragmatic reasons, the mainstreaming project can easily be sidelined and then lost”. The different understandings of disability thus form a barrier for an effective mainstreaming of disability. This could relate to the relatively successful implementation of gender mainstreaming that is not the least present in this study’s results. According to Mattioli (2008), the common definition of what human rights in relation to gender issues is has benefited its mainstreaming in development cooperation. Actors in the organizational chain of development cooperation are more coherent in the perception of gender marginalization and discrimination is based on societal structure rather than the individual.

7. Concluding thoughts

The scope of the present dissertation is limited to study the mainstreaming part of the Swedish twin-track approach in its disability-inclusive development cooperation. The process of putting the other part of the approach, specifically targeting initiatives, into practice is thus left aside. However, the results of the studied projects show that there are significant difficulties in putting the mainstreaming approach into practice. A number of barriers have been identified which are also similar in all three studied projects. In most cases, similar

barriers have been identified in previous evaluations and research on the approach of mainstreaming disability in development cooperation.

In Sweden's first concluding observations from the Committee of the Rights of Persons with Disabilities (2014) that was given in April 2014, the committee commended Sweden for its work in relation to development cooperation and article 32 of the CRPD. Policy-wise, the Swedish twin-track approach is thus considered to be aligning with the standards of the human rights system. However, given the lack of successful examples of putting the policy into practice both in Sweden as well as in international evaluations of similar twin-tracked approaches, the policy could be questioned from a number of perspectives. One such criticism in regards to the development of mainstreaming disability is presented by Kuipers (2012) who argue that the means should not be confused with the ends in the sense that mainstreaming disability within the realms of inclusive development as a strategy risks functioning as a label on which development programs could be argued to have a disability rights approach.

Is mainstreaming the most effective strategy?

As for a disability-inclusive development, there are three given strategies: mainstreaming, specifically targeting and the twin-track approach. The focus in the present dissertation is on the mainstreaming approach, which is one of the two parts of the Swedish twin-tracked approach. The other part is specifically targeting, however foremost in terms of affecting domestic policy in recipient States through capacity building and support to DPO's. In terms of education, a solely specifically targeting approach could however also be practiced by specifically targeting PWD in initiatives. For instance, it could be about building or supporting schools for PWD in contexts where the regular education system makes no adjustments or does not provide education for PWD that do not fit into the regular system.

Given the lack of results that has been identified both from the three projects studied in the present research and from other evaluations, the specifically targeting approach comes forward as a more effective alternative in terms of implementing the right to education for as many PWD as possible. For instance, the fourth interview that was made in the present research but was not included as data represented a project in Egypt where children with intellectual disabilities were given education in a special school, needs that were not met by

the general Egyptian education system. However, such approaches has been questioned (Palmer och Harley 2012; Mattioli 2008) as they are considered to align with a charitable or medical model of disability in which efforts are focused in relation to individual impairments whilst barriers created by structures of the general systems are maintained. Such approaches could also be criticized in relation to the meaning of the human rights based approach and its fundament of equality, non-discrimination, participation and inclusion as the approaches inherently establishes or reaffirms differentiation and to some extent subsequently exclusion.

The difference in approaches also represents the relationship between development and human rights that is presented in the literature review. Whilst the development approach would focus on establishing education systems as such, the human rights based approach sets the level somewhat different in terms of inclusion and accountability. It additionally represents two different traditions that are to merge, the legal approach that is traditionally connected to the human rights framework and the development approach which is more influenced by the social and political sciences. In terms of mainstreaming disability through a human rights based approach, the two are required to merge to function appropriately and in line with Swedish development cooperation policy.

If mainstreaming approaches fails to include PWD, the different approaches are in conflict to each other. Whilst the mainstreaming approach is aligning both with the standards set up in article 32 of the CRPD, is commended by the Committee of the Rights of Persons with Disabilities and the human rights based approach, the specifically targeting approach might have a better success of actually implementing the right to education. The bottom-line is if short-term specifically targeting approaches are favorable to long-term development that takes its stance in human rights principles of inclusion and participation. The right to education is a part of the ICESCR and is a negative right in opposite to the positive rights prescribed in the ICCPR. Thus, in terms of the right to education, initiatives that are needed in terms of violation of positive rights such as the right to life are not as much of an immediate concern. In order to encourage long-term development towards inclusion and participation of PWD, the mainstreaming approach is the way forward. However, as long as it is not put into practice, the policy is only words put down on paper. Thus, a more effective

way of mainstreaming disability is the way forward. In that sense, barriers of mainstreaming need to be met and handled.

How are barriers of mainstreaming to be broken?

First, the problem of accountability is a key. Accountability is a key element in the human rights based approach which, in contrast to the more charitable approach of development hold organizations responsible for its actions in relation to human rights norms and standards. As long as responsible organizations are not held accountable by Sida to report their work on disability mainstreaming, there is a contributing lack of incentives for projects to mainstream disability. If the aims and objectives of initiatives solely is to reach 'vulnerable groups', it is likely that projects will be directed towards people that, from the implementing organizations' point of view, are 'easier' which in many cases do not include PWD.

Furthermore, if Sida explicitly would encourage results in the disability-area from funded projects, it is likely that the process of institutional isomorphism would encourage CSO's towards a greater focus on disability in the long-term.

Second, there is a lot to learn from other mainstreaming areas. For instance, gender mainstreaming is prevalent in all three studied projects. According to Mattioli (2008), the common definition of what human rights in relation to gender issues is has benefited its mainstreaming in development cooperation. A similar initiative is thus needed in terms of disability. A key aspect in this is from Sida's side to specify and encourage disability as a human rights area. In that sense, the social model of disability needs to be defined and presided so that both responsible-, implementing organizations as well as DPO's are able to have a common understanding of what the Swedish policy means and intends.

Third, none of the interviewees or any other professional involved in the projects are specialized in disability. Even though they all consider it as a human rights issue, they do not have the knowledge or experience in order to encourage an effective mainstreaming of disability. In order for responsible, and in turn implementing organizations, to apply such knowledge in projects, expertise or guidelines needs to be applied. In that sense, the benefit of the twin-tracked approach should be applied. Sida already works with specifically targeting initiatives through DPO's, organizations that both have the knowledge and experience for successful initiatives in terms of inclusion of PWD. The DPO's should be able

to create guidelines and assist an effective mainstreaming of disability even though they are not responsible for the projects themselves. In such processes, the contexts in which the projects are practiced should be evaluated in regards to every project. If the local understanding of disability is something other than the social model, this needs to be identified, problematized and considered in terms of working towards inclusion of PWD.

Fourth, the monitoring system of PWD in recipient States needs to be further developed in order to follow needs of initiatives and successes of both mainstreaming and specifically targeting initiatives. This also enables disability to become visible for CSO's active in development cooperation. The establishment of a better monitoring system of disability is not done overnight; it requires changes both in regional, national and global levels. Sweden could however play a significant role in the process both at an international level through multilateral organizations and more specifically the UN, but also through its development cooperation. If projects are required to report effects in terms of reaching PWD in initiatives, they are also likely to get involved in and develop processes of evaluation and monitoring.

Finally, the global agenda of development cooperation is based on the MDGs. It has been noted that whilst disability both literarily and in many cases practically has been left out of the agenda, a disability-inclusive development is the only way to fully succeed and reach the goals. In the post-2015 MGDs process, an inclusion of disability would specify the need for development cooperation initiatives both to target disability specifically but also to mainstream disability in initiatives. It would furthermore benefit aid that is distributed through international donors such as the World Bank and the EU. In this regards Sweden should be an active part in the development of the new agenda, not the least as 50 percent of Swedish aid is distributed this way. A more specified inclusion of disability in the MDGs would furthermore contribute to the development towards disability becoming a significant part of the human rights agenda.

7.1. Recommendations

Recommendations concerning ways in which to overcome barriers of mainstreaming disability in development cooperation are integrated in the concluding thoughts above. I would furthermore like to recommend further research on the topic.

The scholarship on mainstreaming disability in development cooperation is very scarce. Considering the close relationship between disability and poverty and the bad access to education for PWD globally, the area should be given more attention. It would be of significant importance to research all levels in the mainstreaming process, from policy to framework-, responsible-, and implementing organizations. This way, the barriers of implementation could be identified at separate levels which enable the identification of possible solutions to the problem. In this sense, it is of specific importance that Sida's evaluation of their position paper withholds such a holistic perspective. In order to accomplish change, the evaluation should not solely focus on Sida's internal work but in relation to the organizational chain of Swedish development cooperation.

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