Chapter 1 Introduction

Yasmin is a young woman living in Gaibandha district in Bangladesh. She was so happy when she found a husband, because it is not easy for a visually-impaired woman to get married. But the love did not last long. After a month her husband left her. This was disastrous, because when her man was gone she found out that she was pregnant. During her pregnancy she could still work as a maidservant, but when her son Rubel was born she couldn't go to work anymore. At that moment she met a fieldworker from a food security project run by a Dutch NGO. Because of the focus on inclusion of persons with disabilities in the food security programme, Yasmin was invited to join one of the women's groups. In the women's group Yasmin is learning among her non-disabled peers how to start her own vegetable garden and over time she received seven chickens out of shared savings. But most importantly, she found some sense of belonging to a group of women that mutually respect and support each other, regardless of their disability.

1.1 Disability: from a medical to a social perspective

All over the world there are persons with disabilities, like Yasmin, who experience difficulties participating in their societies. The scale of this problem is highlighted by the World Health Survey and the Global Burden of Disease, both from 2004, which show the estimated prevalence of disability to be 15.6% and 19.4% respectively (WHO 2011). Furthermore, the World Report on Disability from the World Health Organisation (WHO) (2011) suggest that 80% of persons with disabilities live in underdeveloped, rural areas in resource-poor settings. As the story of Yasmin illustrates, disability is strongly linked to poverty. First, the factors that cause disabilities hit hardest among the poor. Second, disabled people encounter barriers preventing them from getting an education, a job, access to appropriate support and services, and so forth (Stone, 1999). As a result, persons with disabilities are the most marginalized of the poor (Swartz & Maclachlan, 2009). The marginalisation of persons with disabilities is manifested in the many environmental, institutional and attitudinal barriers that prevent them from participating in society (Bruijn, P., 2009; Harris & Enfield, 2003; Mwenda, Murangira, & Lang, 2009).

Citizens in resource-poor settings are often recipients of international development programmes. Persons with disabilities, like Yasmin, are one of the most marginalised groups in resource-poor settings and paradoxically are often not included in these programmes; either because they cannot access the programme, institutions are not addressing the needs of disabled people, or attitudinal barriers make them feel unwelcome. Recent debates on the sustainability of international development programmes emphasise that reaching and including marginalised groups in society (such as persons with disabilities) is an important aspect of poverty alleviation (Yudhoyono et al. 2013).

The importance of disability inclusive development was reinforced by the Convention on the Rights of Persons with Disabilities (CRPD) that was adopted by the general assembly of the United Nations in 2006 (UN, 2006). The CRPD pays specific attention to the situation of persons with disabilities in international development programmes (UN 2006, art. 32). Since the CRPD has come into force, scholars, organisations and governments have started discussing the importance of disability inclusion (Albert, 2006).

Despite the international attention directed towards disability issues in development, the practice of disability inclusive development does not receive adequate attention in development programmes (Albert, Dube, & Riis-hansen, 2005; Grech, 2012; Stone, 1999). As a result, many persons with disabilities living in low- and middle-income countries are still subjected to systemic social exclusion and discrimination. This phenomena of a dissonance between policy and law with practice is also described in the field of mental health as the implementation gap (Shields, 2013).

Problem statement

Realization of the purpose and objectives of the CRPD is hampered by this gap between policy/law and practice. As a result, experiences with the inclusion of persons with disabilities in development programmes are limited, often ad hoc, and not systematically evaluated. Moreover, the practice of disability inclusive development is not yet a priority in development programmes (Albert et al., 2005; Grech, 2012; Stone, 1999). Furthermore, the majority of research on disability mainstreaming is either focussed on the international debates (e.g. Stein 2013; Mwenda et al. 2009; Mattioli 2008; Lord et al. 2010) or present single, sector specific case studies (e.g. Ajuwon 2012; Morewood et al. 2011; Prinsloo 2006; Bowes 2006) that are difficult to compare and generalise.

In order to address the implementation gap, non-governmental organizations (NGOs) can play an important role by mainstreaming disability in development programmes through

innovative practices (Albert, 2006; Harris & Enfield, 2003; WHO, 2011). Systematic monitoring and comparison of these innovations can provide generic lessons for disability inclusive development. Furthermore, disability-specific organisations play an important role in supporting this process of inclusion of persons with disabilities in all aspects of international development organisations and programmes (Mwenda et al., 2009; Rimmerman, 2013; Schulze, 2010). This thesis focuses on both types of organisations.

Understanding what inclusion of persons with disabilities in international development programmes would look like is a complex matter. There are a range of NGO's with differing interests and operating in different sectors of aid and development that depend on each other in realising disability inclusive development (WHO, 2011). For instance, a disabled child may be included in an inclusive education programme but also needs accessible water and sanitation, roads and rehabilitation to study successfully, showing the importance of inter-sectoral collaboration. Furthermore, there is the challenge of ensuring that there are coherent practices of disability inclusive development at different levels of NGOs, from fieldworkers in the community, to national and international actors. It is important that all these different actors and sectors are communicating with each other and become part of a collective paradigm shift to a social perspective of disability. Adopting a new perspective on disability implies that the people involved have to leave behind prejudices and former attitudes that hinder persons with disabilities from becoming included in society (Coe & Wapling, 2010a; Harris & Enfield, 2003). Furthermore, the paradigm shift implies that practices and organisations will change to accommodate the participation of persons with disabilities in international development programmes (Bruijn 2009; Albert 2006).

In relation to these changes at the levels of organisations and practice we[1] make a distinction between learning about 'inclusive organisations' and learning about 'inclusive practices'. Learning about inclusive organisations relates to understanding how development organisations learn to adopt the principles of disability inclusive development and how these organisations change as a result. Learning about inclusive practices deals with understanding how field practices change when an organisation adopts the disability inclusive development perspective and how experimentation at field level leads to organisational changes (Bruijn et al., 2012). Looking at both inclusive organisations and

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[1] Since this thesis comprises co-authored articles I have chosen to use the 'we' form in the introductory and concluding chapters.

programmes provides insight into the process of change towards disability-inclusive development.

The paradigm shift towards the social perspective of disability is extensively described, particularly as an ideal to aspire to, but these descriptions lack connection to real practice (Stone, 1999). Therefore, this thesis intends to:

> … *provide an understanding of the change processes towards disability inclusive development of NGOs and their international development programmes.*

1.2 Defining disability inclusive development

In this section we will define disability inclusive development. To define disability inclusive development we will first take insights from different actors, scholars and the disability movement in development into account. Based on their insights we will make a definition of disability inclusive development to guide this research.

The underlying principles for inclusion relate to the theory of social justice; the idea that any person is entitled to an adequate standard of living. Scholars such as Sen (1999), Nussbaum (2003) and others, have developed new ideas on equality and produced a comprehensive capabilities approach. By analyzing the roots of people's individual desires, - and by observing how societies prevent particular groups from enjoying these desires-, Sen and Nussbaum have come to conclude that capabilities allow for a more rightful approach to dealing with development (Nussbaum, 2003; Amartya Sen, 1999). The capabilities approach focuses on what people can do, for example stressing their right of *'being able to have good health', 'being able to move freely from place to place; being free from assaults', 'being able to participate effectively in political choices that govern one's life'* and *'being able to hold property' (*Nussbaum 2003, p. 41 and 42). This approach on human capabilities has had a great influence on the formulation of modern international development programmes, like the Millennium Development Goals (MDG) (Hulme, 2010) and formed the foundation for conventions such as the CRPD (Weller, 2009). This theory enabled actors in international development to start a transition towards a social perspective based on the human agency of all people; in accordance to the theory of social justice.

Actors in international development cooperation try to include aspects of social justice in definitions for (disability) inclusive development. The United Nations Development

Programme (UNDP) refers to inclusive development as a *'human development approach that integrates the standards and principles of human rights: participation, non-discrimination and accountability'* (UNDP, 2013). These principles draw on the notion that marginalized or vulnerable people in society, that were neglected and discriminated against in the past, now need to be enabled to participate in the development process. Through the empowerment of vulnerable people in society to participate and be accountable, both their individual well-being and also the distribution of well-being in society can improve. The International Disability and Development Consortium (IDDC) specifically focuses on the principle of participation in their definition of disability inclusive development: *'ensuring that all phases of the development cycle (design, implementation, monitoring and evaluation) include a disability dimension and that persons with disabilities are meaningfully and effectively participating in development processes and policies'* (IDDC & Handicap International, 2012). In both the definitions of UNDP and IDDC, the participation of marginalized groups (e.g. persons with disabilities) have a central place in international development programmes.

Realising the participation of persons with disabilities in international development programmes requires that persons with disabilities are seen as full members of society. The social change process towards this view is described by several scholars as a paradigm shift from the conventional 'individual' to the more recently developed 'social' perspective on disability (Harris & Enfield, 2003). The two perspectives can be associated with different models of understanding disability. The best known models are on the one hand the medical and the charity model, which can be associated with the individual perspective, and on the other hand the social model and the rights-based model, associated with the social perspective (Bickenbach, Chatterji, & Badley, 1999; Harris & Enfield, 2003; Roush & Sharby, 2011). The individual perspective sees persons with disabilities as people who do not fit into society, requiring rehabilitation or charity in order to function and survive in society. Conversely, in the social perspective persons with disabilities are accepted as full members of society and their impairments are celebrated as part of the vast diversity of a particular society. Full and equal citizenship means that persons with disabilities must have the same individual choices in, and control of, their everyday life as non-disabled people. Barriers that prevent persons with disabilities from leading a meaningful life should be removed from and by society, for instance by accommodating differences and addressing special needs (Bickenbach et al., 1999; Harris & Enfield, 2003; Oliver, 1986; Stein, 2007). Realising meaningful participation is an important good, but we also need to be aware of special

needs of persons with disabilities, like for instance medical rehabilitation, shelter and protection in episodes of relapse, and counselling. A way to address special needs of persons with disabilities in development is twin-tracking, which refers to the need to both mainstream disability inclusion and provide disability specific services to empower persons with disabilities to participate (Lord et al., 2010; Schulze, 2010). The individual and social perspectives are depicted in figure 1.1 below. Disability inclusive development can only be realised when the social model of disability is accepted among development actors. Then international cooperation can realise the meaningful integration and participation of persons with disabilities in international development programmes.
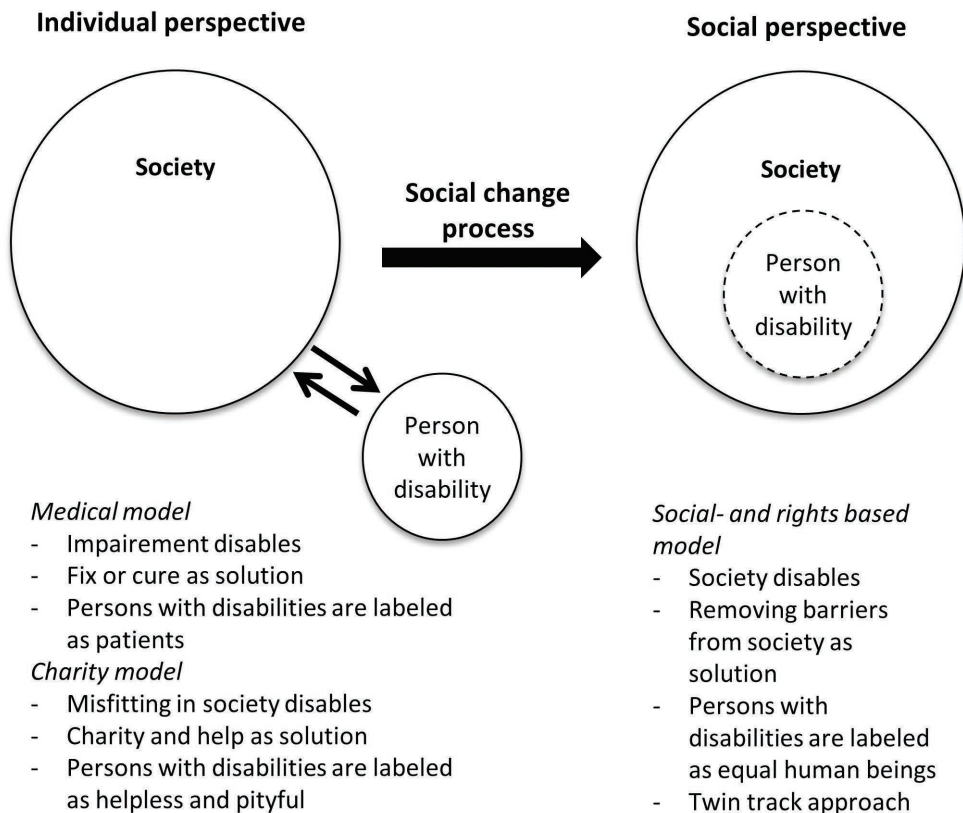

Individual perspective

Social perspective

Society

Social change process

Society

Person with disability

Person with disability

Medical model
- Impairement disables
- Fix or cure as solution
- Persons with disabilities are labeled as patients

Charity model
- Misfitting in society disables
- Charity and help as solution
- Persons with disabilities are labeled as helpless and pityful

Social- and rights based model
- Society disables
- Removing barriers from society as solution
- Persons with disabilities are labeled as equal human beings
- Twin track approach

Figure 1.1 Differences between the individual and social perspective on disability (adapted from Coe & Wapling 2010b; van Kampen 2013)

The movement towards inclusive development programmes was founded on the notion that social change must begin with the involvement of persons with disabilities themselves (Mwenda et al., 2009; Stone, 1999; WHO, 2011). Local, national, and international Disabled People Organisations (DPOs) '*have taken a strong role in promoting social change based on their own analysis of disability and society*' (Stone 1999, p. 9) to urge actors in international cooperation to take disability issues on board. Stone (1999) describes how '*disabled people worldwide are forming their own organisations to bring about rights-based change*' (p 3). Hence the slogan 'Nothing About Us Without Us' which has been used by DPOs to achieve the full participation of and equalisation of opportunities for, by and with persons with disabilities. The focus on participation of persons with disabilities in advocating for disability inclusive development is in line with the principles of human rights and social justice, utilizing the capabilities of persons with disabilities.

Many countries worldwide are slowly adopting a social perspective on disability as part of the process of implementing the CRPD. However, universal acceptance of one disability perspective has been criticised due to the huge diversity in how persons with disabilities are viewed worldwide. Due to this diversity the interpretation of the social perspective may also differ by locality. Grech (2012) criticised the applicability of the social model in international development programmes , stating that this model only expresses '*the concerns of Western disabled people through the work of predominantly white, middle class, Western (British) disabled and other academics*' (p 74). Therefore, the social model does not appear to fit in a more general cultural epistemology and implementation problems across cultures may arise. Nussbaum (2003) emphasises the diversity of aspirations that people with disabilities may have in different cultures. Indeed, the social model runs the risk of gross generalisation, reductionism and over-simplification (Grech, 2012; M. Miles, 1995). To prevent such undesirable phenomena, Grech (2012) highlights the importance of studying context and culture of disability in local communities before embarking on mainstreaming projects.

Taking all these notions together, from the insights of actors in development, scholars and the disability movement, we have formulated the following working definition for disability inclusive development for this thesis:

> '*Disability inclusive development is the meaningful participation of persons with disabilities in all aspects of development, taking into account the context and culture in which it is implemented, striving to fulfil the rights of persons with disabilities and empower them to optimise their own well-being.*'

1.3 Disability inclusive development: guidance, roles, and responsibilities

In the previous section we formulated a definition for disability inclusive development for this thesis. Here, we want to sketch an action perspective towards the inclusion of persons with disabilities in international development programmes, using existing literature. To this end, we will show how the CRPD attempts to provide guidance to disability inclusive development programmes in formulating its legal articles. To support the practice of disability inclusive development, we will introduce the concept of mainstreaming disability as a means for including persons with disabilities in international development programmes. Then we will discuss the roles of relevant actors in realising disability inclusive development, and the responsibilities of NGOs therein.

The CRPD's call for action

The importance of disability inclusive development was reinforced by the CRPD. Overall, the CRPD stresses the rights of persons with disabilities (UN 2006).

> *…the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination (preamble c).*

The Convention also specifically refers to the difficulties in realising these rights in low- and middle income countries in article 32, emphasising:

> *… the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries.*

Emergency relief is one aspect of international development. In this respect, the Convention refers to emergency relief by calling state parties in article 11 to take:

> *… all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*

These statements reaffirm the need for disability inclusive development and emergency relief in development cooperation for realising the rights of persons with disabilities in low- and middle income countries (Schulze, 2010). As Mwenda et al. (2009) states, '*The*

Convention offers both a human rights and a development framework to move towards inclusive development' (p 663)*.*

The CRPD came into force in May 2008. On this occasion UN Secretary-General Ban Ki-moon stated:

'Now we must take concrete steps to transform the vision of the Convention into real victories on the ground. We must address the glaring inequalities experienced by persons with disabilities. We must counter discrimination and prejudice. We must deliver development that is truly for all.'

This remark shows the importance of narrowing the dissonance between policy/law and practice in order to implement the CRPD. By ratifying the CRPD, state parties are bound to implement the convention and thereby stimulate all organisations in their country to work towards inclusive development, stressing the holistic and interdisciplinary nature of development (Lord et al., 2010).

Mainstreaming disability to implement the CRPD

In The World Report on Disability, the WHO (2011) recommends mainstreaming as an approach to implement disability inclusive development. Mainstreaming, in this context, implies that provisions for persons with disabilities, and the policies to realize them, are no longer the exclusive domain of specialised departments and organisations (Stone, 1999). This means that when NGOs pursue equal opportunities for all, they must include and accommodate persons with disabilities. The need for inclusion of persons with disabilities in international development programmes are felt in different sectors, including health; employment; education; emergency responses and so on. Disability mainstreaming can help NGOs to give form to disability inclusive development, as:

…a strategy for making concerns and experiences of persons with disabilities an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes (Albert et al. 2005: p 6).

The importance of disability mainstreaming for sustainable development is explicitly stressed in the preamble of the CRPD (UN 2006: preamble g). In response, many initiatives for disability mainstreaming are being undertaken by multilateral development organisations and (international) NGOs (Coe & Wapling, 2010a; Harris & Enfield, 2003; Sanchez & O'Reilly, 2011; Stienstra, Fricke, & D'Aubin, 2002). In this way these organisations, involved in service delivery, became agent for human rights change.

Actors and their roles in disability inclusive development

In this section we will give an overview of all important actors involved in disability inclusive development. We will start with the actors that are specifically mentioned in the CRPD as stakeholders in disability inclusion. Then we will continue with actors that are not specifically mentioned in the CRPD, but who have a stake in realising disability inclusion in practice.

The CRPD particularly addresses the responsibilities of **governments** to ensure disability inclusive services in their countries and supportive legislation in line with the CRPD. To date, 130 countries have ratified the CRPD (UNenable, 2013), showing the commitment of governments in ensuring the rights of persons with disabilities. Stein and Lord (2010) describe how CRPD implementation needs to involve a broad range of actors, including '*state parties, relevant United Nations agencies, DPOs, NGOs, and others to provide a forum for discussion and reflection on how to best operationalise the Convention'* (p 700). In line with Stein and Lord (2010), many scholars and development organisations plead for a multi-stakeholder process to realise disability inclusive development (amongst others Bruijn, P. 2009; Mattioli 2008; WHO 2011; Guernsey et al. 2006).

Disabled People Organisations (DPOs) and, to a lesser extent, **disability-specific NGOs** are trying to influence disability inclusive development. These organisations are also presented as organisations *of* persons with disabilities and organisations *for* persons with disabilities (Mwenda et al., 2009). They are explicitly mentioned in article 4 of the CRPD as stakeholders who should support the national governments with the implementation of the rights of persons with disabilities (UN, 2006). The WHO (2011) states that disability specific organisations have a specific role in increasing awareness of other actors, empowering persons with disabilities to stand up for their rights, participating in policy development, and monitoring implementation of disability inclusive policies and services. This indicates these actors have a powerful role in the protection of the rights of persons with disabilities alongside their important task of responding to the special needs of persons with disabilities.

Multilateral organisations, like the United Nations International Children's Emergency Fund (UNICEF), the International Labour Organisation (ILO) and the World Health Organisations (WHO), try to influence social change towards disability inclusive development through publications, lobbying and advocacy (Mattioli, 2008). For example, UNICEF aims to mainstream disability across all policies and programmes, in terms of both

development and humanitarian action. Another major multilateral development institution, the World Bank, includes disability as the third pillar in its Policy and Human Resource Development programme. In addition, the ILO promotes 'decent work' for persons with disabilities, stressing the right of persons with disabilities to earn a living from work of their choice, which is both accessible and accepting, relating to article 27 of the CPRD (Sanchez, 2011). This attention to disability mainstreaming is also visible in the funding opportunities for international development programmes from these multilateral organisations. For example, recently the European Union adopted a development cooperation instrument wherein the rights of persons with disabilities are included in the section on cross-cutting issues, including budget allocations for 2014-2020 (EU, 2013; IDDC, 2013). Multilateral organisations therefore have a powerful role in disability mainstreaming, since they can set the requirements for the local organisations that they oversee.

In social change processes aimed at realising disability inclusive development, the central actors are *persons with disabilities and their families* themselves. The CRPD stresses in the preamble (f) the importance for persons with disabilities to influence the promotion, formulation and evaluation of policies, plans, programmes and actions at national, regional and international levels to further equalize opportunities for their peers (UN, 2006). Fostering empowerment to enable full participation of persons with disabilities in development programmes is an important condition for change. Persons with disabilities can be powerful role models in the facilitation of disability inclusive development, through providing peer support for other persons with disabilities and in advocating the rights of persons with disabilities in their communities (Bruijn et al., 2012; Harris & Enfield, 2003). Furthermore, they can contribute to disability inclusive development by actively participating in forums and research projects to influence decision makers (WHO, 2011).

Communities in which persons with disabilities live are also important actors in realising a disability inclusive environment. To foster the empowerment and participation of persons with disabilities, communities need to recognise the rights of persons with disabilities and include them in all community activities. In the process, they may challenge and change their own beliefs and attitudes (Bruijn et al., 2012; WHO, 2011). When awareness is raised, communities can play an important role in protecting the rights, and promoting inclusion of persons with disabilities. Communities are in the best position to take action against violence and bullying of persons with disabilities (WHO, 2011).

(International) mainstream NGOs are also part of the social change process due to their development programmes that aim to reach marginalised people in society. In this thesis,

mainstream NGOs are organisations and initiatives that do not have a specific disability focus. Bruijn et al. (2012) state that mainstream NGOs should *'open up their programmes for persons with disabilities, remove the barriers and make the services accessible. Nothing more, nothing less.'* (p 26). By relating to international cooperation in article 32 of the CRPD, mainstream NGOs are recognised as actors realising inclusion of persons with disabilities in development (UN, 2006). The WHO (2011) stresses the responsibility of NGOs: to include disability in development and emergency programmes; to exchange information and coordinate action; to gather lessons learned and reduce duplication; to provide technical assistance to countries by building capacity and strengthening existing policies, systems and service; and to collect and analyse data relating to persons with disabilities to create internationally comparable research. Since the adoption of the CRPD many initiatives of NGOs have been started to mainstream disability in their development programmes. One well-known example is the inclusion of persons with disabilities globally in programmes by World Vision (Coe & Wapling, 2010a; Coe, 2012). Another example (and the subject of this thesis) is the Thematic Learning Programme on inclusion of persons with disabilities, which involves a consortium of 30 NGOs in Europe, India and Ethiopia learning together about practicing inclusive development (Bruijn et al., 2012; Veen, Bunders, & Regeer, 2013). These kinds of initiatives for disability mainstreaming by International NGOs can be seen as exemplars for other actors wanting to realise disability inclusive development. Since this thesis focuses on the role of NGOs in the change towards disability inclusive development, we will elaborate more on their responsibilities in section 1.3.

Providers of rehabilitation services are also part of the social change process. In accordance to the twin-track approach, they need to shift the focus of services from a solely medical orientation, focusing on aspects of impairments, towards supporting recovery and integration of persons with disabilities in society (Mattioli, 2008; Schulze, 2010; Stone, 1999), as is visualised in figure 1.1. As Stone (1999) states, '*existing professions, services and ideologies need to be transformed in ways that promote disabled people's self-empowerment and real social change. Professionals should be allied to disabled people and the community, not allied to medicine or administration*' (p 4). Although the main role of health professionals is still to provide the highest quality of health and rehabilitation services (WHO, 2011), they also need to be open for collaboration with societal actors to help lift remove barriers to inclusion.

The ***private sector*** is increasingly important in development practices. For example, the rapid emergence of public-private partnerships globally serves as an example showcasing

the need for governments and donors to involve the private sector in realising international development initiatives. The WHO (2011) states the private sector can play an important role in the social change process by promoting diversity and inclusion in working environments (for example, by removing barriers to microfinance initiatives for PWD so they can start their own businesses). Table 1.1 provides an overview of the actors described above and their role in disability inclusive development.

Table 1.1 An overview of the actors and their role in disability inclusive development (adapted from Bruijn et al. 2012)

Actors in disability inclusive development	
Governments	• Ensure access to basic services for persons with disabilities – bring laws and legislation in line with CRPD
DPOs and Disability specific NGOs	• Lobby and advocate for the rights of persons with disabilities • Empowerment of persons with disabilities and their organisations • Support the realization of disability inclusive development • Monitor the progress towards the implementation of the CRPD
Multilateral organisations	• Influence the social change process towards disability inclusive development through publications, lobbying, advocacy ,and funding requirements
Persons with disabilities	• Provide peer support to other persons with disabilities in their surroundings • Advocate for the rights of persons with disabilities in their communities
Communities	• Recognize the rights of persons with disabilities • Include persons with disabilities in all community activities.
Mainstream NGOs	• Include and target persons with disabilities in their programmes • Refer for disability-specific needs • Become disability inclusive in management systems and structures • Include the issues of disability in mainstream alliances
Rehabilitation services	• Provide medical and rehabilitation services • Empower persons with disabilities to participate in mainstream programmes
Private sector	• Promote diversity and inclusion in working environments. • Remove barriers of access to microfinance for persons with disabilities. • Make information and quality support systems accessible for persons with disabilities and their families throughout their life.

We have introduced the most important actors that influence and take part in the social change process towards disability inclusive development. Although there are many more actors in the disability sphere (such as media, religious institutes, politicians, and knowledge institutes) we have chosen not to describe them specifically. Although highlighting the key actors involved in disability inclusive development is important, the most important aspect is the need for meaningful collaboration *between* these actors (Bruijn et al., 2012; Mattioli, 2008; WHO, 2011). As the WHO (2011) states: *'through international cooperation, good and promising practices can be shared and technical assistance provided to countries to strengthen existing policies, system, and services'* (p 82). In this thesis we will focus on the process of bringing different actors together to learn about the process of realising disability inclusive development with a specific focus on mainstream NGOs, DPOs, persons with disabilities, and communities.

1.4 Mainstream NGOs in the change towards disability inclusive development

In the previous section we have explored the roles and responsibilities of mainstream and disability specific NGOs in realising and influencing the social change towards disability inclusive development. Since NGOs dedicate their work to working with the most marginalised in society, it is important that they take responsibility for the inclusion of persons with disabilities in development programmes, in accordance with their rights (Bruijn et al., 2012; Stein & Lord, 2010). NGOs can play a role model function for governmental organisations and the private sector because of their connections with different actors at different levels of society. In addition, NGOs are active in different sectors of development, positioning them as ideal change agents for a multi-faceted issue, like disability inclusive development. Therefore, this thesis focuses on understanding the change towards disability inclusive development through the role of NGOs. In this section we will go more in depth into the practical responsibilities for NGOs in realising disability inclusive development.

In order to realise disability inclusive development, NGOs need to change from the individual to the social perspective on disability in all aspects of their work. To adopt the social perspective, our hypothesis is that NGOs need to acknowledge the importance of disability inclusive development at different levels. First, the CRPD and World Health report in disability stress the importance of addressing the needs persons with disabilities in

mainstream development <u>programmes</u>. Disability inclusive development programmes can be achieved by promoting the participation and well-being of persons with disabilities as an integral issue in all aspects of the programme cycle (UN, 2006; WHO, 2011). The inclusion of persons with disabilities by NGOs may originate from different rationales. For example, some faith-based and charity NGOs may include persons with disabilities to honour their obligation to reach the poorest of the poor, which are often persons with disabilities, whereas other NGOs may be more rights-focused and include persons with disabilities in an attempt to align with human rights principles (Harris & Enfield, 2003; WHO, 2011). Practically, the inclusion of persons with disabilities in development programmes implies that environmental, institutional and attitudinal barriers for inclusion need to be identified and addressed in development programmes (Coe & Wapling, 2010a).

Second, the experiences of NGOs, like for example Light for the World Netherlands and World Vision International, showed us the importance of including the needs of persons with disabilities in <u>policies, structures and management systems</u> of NGOs to ensure that disability inclusion becomes embedded in the organisation (Bruijn et al., 2012; Coe & Wapling, 2010a; Coe, 2012). To foster the embedding of disability inclusive development, policies and guidelines of NGOs should reflect diversity in society (Albert, 2006; Harris & Enfield, 2003). Anchoring disability inclusion in all veins of the organisational culture may lead to a situation where disability issues become a normal part of the NGOs' policies, systems and practices.

Third, the CRPD stresses the importance of international cooperation in realising disability inclusive development (UN, 2006). This implies the need for agenda setting at the level of international development cooperation. Partnerships of NGOs, academics and others can play an important role in lobbying to ensure that disability issues become integrated with the <u>global development agenda</u> (Albert, 2006).

When changes at these three levels are realised, we hypothesise that disabled persons will be visible in development programmes, disability needs will be integrated in organisational management systems, and disability issues will be present in alliances that try to influence the global development agenda. By addressing all these levels, disability inclusive development can be seen as an exemplary movement, leading to an inclusive society for all. Figure 1.2 gives a schematic representation of the responsibilities of NGOs at different levels of aid for disability inclusive development. In this thesis we focus specifically on the first two levels.
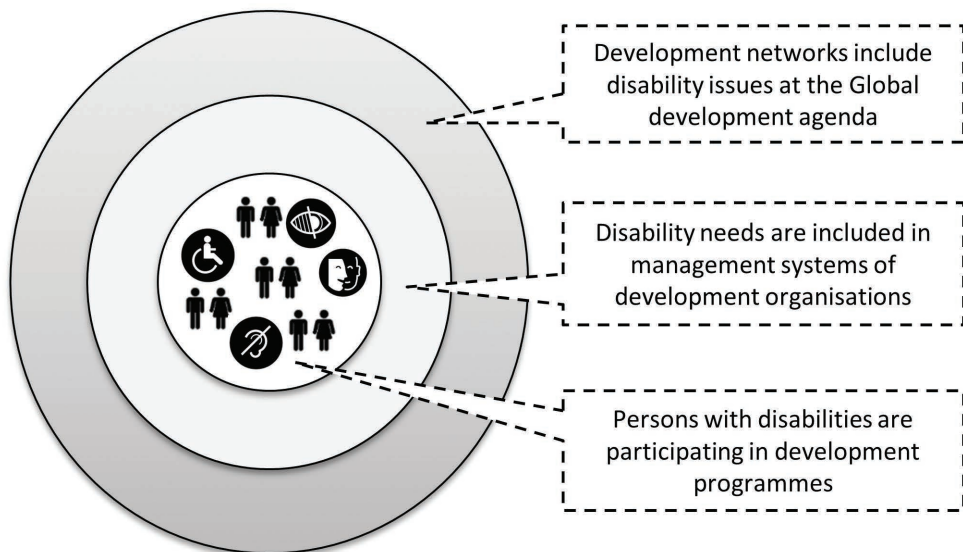
Figure 1.2 Disability inclusive development at three levels of development cooperation

INTRODUCTION