



## Chapter 9 Conclusion and Discussion

In this thesis the focus was on disability inclusive development and the question how to support the process of change towards this goal. The development and adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has resulted in a body of literature on disability inclusive development that largely describes and reflects on the international context. However, even though the CRPD has implications for member states globally, in order to effect change in terms of ensuring that persons with disabilities are truly included in development programs, the CRPD stressed the importance of focussing on development organisations that implement development programmes. The CRPD and the World Report on Disability stress the importance of promoting participation of persons with disabilities in mainstream development programmes as an integral issue in all aspects of the programme cycle (UN, 2006; WHO, 2011). Furthermore, the experiences of NGOs like Light for the World, Netherlands, and World Vision International show the importance of including the needs of persons with disabilities in policies, structures and management systems of NGOs to ensure that disability inclusion becomes embedded throughout the organisation (Bruijn et al., 2012; Coe & Wapling, 2010a; Coe, 2012). In line with this, Bruijn et al (2012) state that *'for sustainable change we need not just disability-inclusive projects, but also disability inclusive organisations'* (p. 64). This indicates the need for service deliverers in development cooperation to become agents for human rights change.

In the TLP on inclusion of persons with disabilities the change process towards inclusive development programmes and organisations was explored. The focus on the organisational and programme level was shaped by previous literature which has shown that one pertinent challenge for NGOs is to realise disability inclusive development in practice. Despite the fact that attention to disability inclusive development at the international level is gaining momentum, the practice of disability mainstreaming remains underexposed in research and does not receive much attention in development programmes (Albert et al., 2005; Grech, 2012; Stone, 1999). As a result, experiments with the inclusion of persons with disabilities in development programmes are few, ad hoc and not systematically evaluated. This phenomena is also referred to in the field of mental health as the implementation gap; a dissonance between policy/law and practice (Shields, 2013).

To address the implementation gap in disability inclusive development, this thesis focuses on understanding the change process towards disability inclusive development. This thesis

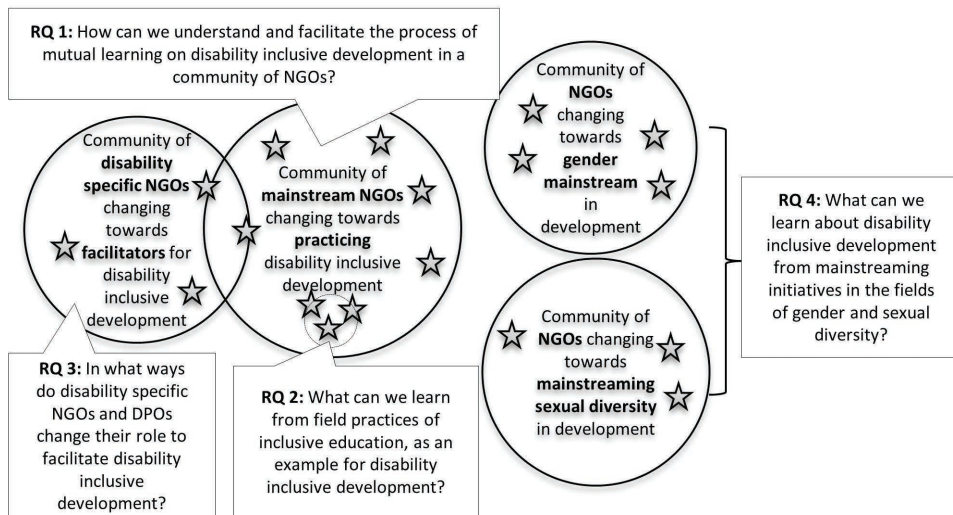
endeavoured to do two things: to extract lessons learned on disability inclusive development at the programme and organisational level and to create the grounds and conditions for further experimentation. Collecting lessons learned from programmes and organisations is important in the process towards disability inclusive development. This process is largely informed by literature and by the practical experiences TLP participants gained through implementation of disability inclusive development programmes. While acknowledging the importance of practical lessons on disability inclusive development, we also consider that social change is not a straightforward process of adopting new practices. Often, despite practical guidelines and readiness and commitment to change, people still find it difficult to adopt new ways of thinking and integrate it into their existing approaches and practices. Therefore, the TLP on inclusion of persons with disabilities directed explicit attention to experimenting and learning about change, wherein the facilitation of learning and the extraction of lessons learned contributed to the process of change towards disability inclusive development. From analysing learning processes, we identified possible strategies to facilitate social change processes aimed at realising disability inclusive development.

In this conclusion we first discuss the strategies that facilitated the change towards disability inclusive development in 9.1 and 9.2. Second, we reflect on the practical lessons learned at programme and organisational level for realising disability inclusive development in 9.3. Third, we discuss the validity of our outcomes and discuss our findings within the broader discourse of development cooperation in 9.4. Fourth, we discuss how our research may contribute to various research fields (9.5). Finally, we discuss our recommendations for further research and practice with regard to the process towards disability inclusive development (9.6) and present our concluding remarks in 9.7.

## **9.1 Understanding the change towards disability inclusive development**

Understanding the change towards disability inclusive development involved an intensive systematic research process, requiring careful documentation, emergent design and multiple research methods involving a broad range of actors (e.g. practitioners, experts and academia). In order to understand the change process towards disability inclusive development in NGOs, this thesis looked at four different TLP communities which all shed a different light on disability inclusive development. The first two research questions

addressed a TLP community predominantly consisting of mainstream NGOs working in different sectors of development. The third research question related to a community of disability specific NGOs and DPOs that jointly explore and reflect on their new role as facilitators of disability inclusive development. The fourth research question links the experiences of disability inclusive development to other practices of NGOs to include marginalised groups in development programmes (figure 9.1).



*Figure 9.1 Schematic representation of the research questions in relation to the communities studied*

Chapters 4 and 5 addressed sub-question 1 and focused on exploring strategies that support and facilitate the process of mutual learning on disability inclusive development. The main conclusions relate to the importance of developing a systemic approach for mutual learning in social change processes and highlight the importance of contextualising experiences. Through reflecting on a number of contextualised experiences, we have described 'lessons learned' for disability inclusive development. Furthermore, we emphasised the importance of formulating lessons learned that are relevant for multiple actors from both science and society.

Chapter 6 answered sub-question 2 and focused on identifying lessons learned from disability inclusive education practices in Ethiopia as an example of disability inclusive development. We hypothesised that facilitating the exchange of experiences at the

grassroots level leads to a better understanding of constraints and solutions for inclusion of children with disabilities in schools. Our findings demonstrated that stimulating vicarious learning requires the need for detailed, personal and contextual experience sharing. Vicarious learning resulted in improved disability inclusive education practices in schools in Ethiopia and increased the understanding of opportunities and challenges to including children with disabilities in education for NGOs.

In chapter 7 we addressed sub-question 3 by exploring the new role of disability specific NGOs and DPOs in supporting the realisation of disability inclusive development. This study looked at how these organisations adopt their new role as facilitators of change towards disability inclusive development, expanding their focus from disability specific aspects to inclusion in mainstream development. In addition, we analysed the strategic changes this new role imposes on all aspects of their organisations.

Sub-question 4 was addressed in chapter 8, which focused on the importance of building capacity in NGOs and how this could be used as leverage to enhance inclusion of marginalised groups in society. This required identifying important lessons in realising disability inclusive development in other chapters of this thesis, such as the importance of contextualisation, combining intangible and tangible changes, involving multiple actors and documenting the process via thick description. We reflected on lessons learned from other mainstreaming activities (such as sexual diversity and gender) in order to potentially identify strategies for realising disability inclusive development.

## **9.2 Strategies that stimulate change towards disability inclusive development**

In all chapters there are four cross-cutting elements that we applied to facilitate the process of knowledge co-creation towards disability inclusive development in NGOs. In the different chapters of this thesis these elements were concretised leading to strategies for implementation of these elements, as can be seen in table 9.1. The four cross-cutting elements are 1) enhancing collaboration between multiple actors, 2) stimulating learning and reflection, 3) enhancing vicarious learning, and 4) combining tangible and intangible outcomes of change. In the following sections, we will elaborate further on each of the implementation strategies for these cross-cutting elements, and describe how these strategies emerged from chapters 4-8 of this thesis.

Table 9.1 Strategies that facilitate change towards disability inclusive development in relation to the research questions

| Cross-cutting elements for change   | 1. How can we understand and facilitate the process of mutual learning on disability inclusive development in a community of NGOs?  | 2. What can we learn from field practices of inclusive education, as an example of disability inclusive development?   | 3. In what ways do disability specific NGOs and DPOs change their role to facilitate disability inclusive development?  | 4. What can we learn about disability inclusive development from mainstreaming initiatives in the fields of gender and sexual diversity?       |
|-------------------------------------|---|--|---|--|
| Enhancing collaboration             | <ul style="list-style-type: none"> <li>• Build a CoP as a platform to learn by combining theory and practice</li> <li>• Cross boundaries between different actors involved to facilitate shared learning.</li> <li>• Involve actors at different levels to discuss responsibilities and realise shared ownership.</li> </ul>  | <ul style="list-style-type: none"> <li>• Involve actors at different levels to discuss responsibilities and realise shared ownership.</li> </ul>   | <ul style="list-style-type: none"> <li>• Unite the different actors in a CoP in a safe and enabling environment to discuss drivers for change.</li> </ul>   | <ul style="list-style-type: none"> <li>• Enable the participation of marginalised groups in finding solutions for their challenges.</li> </ul> |
| Stimulating learning and reflection | <ul style="list-style-type: none"> <li>• Apply participatory tools to uncover and articulate the process of change.</li> <li>• Ensure regular moments for learning and reflection as a systemic element in programme planning and implementation.</li> <li>• Embrace emergent changes in order to adopt lessons learned.</li> <li>• Involve change agents to share their drive for change and adopt lessons learned.</li> <li>• Combine the experiences from multiple organisations to learn and reflect together.</li> </ul> | <ul style="list-style-type: none"> <li>• Involve change agents to share their drive for change and adopt lessons learned.</li> <li>• Combine the experiences from multiple organisations to learn and reflect together.</li> </ul> | <ul style="list-style-type: none"> <li>• Embrace emergent changes in order to adopt lessons learned.</li> <li>• Combine the experiences from multiple organisations to learn and reflect together.</li> </ul> | <ul style="list-style-type: none"> <li>• Combine the experiences from multiple organisations to learn and reflect together.</li> </ul>         |

## CONCLUSION AND DISCUSSION

|                                |  |  |  |   |
|--------------------------------|--|--|--|---|
| Enhancing vicarious learning   | <ul style="list-style-type: none"> <li>• Connect like-minded people that share similar problems.</li> <li>• Connect novices with more experienced organisations to learn from their change process.</li> <li>• Organise field/ organisational visits to enhance vicarious learning in a realistic environment.</li> </ul>  | <ul style="list-style-type: none"> <li>• Apply participatory tools to aid the sender to tell their story and the receiver to re-live the experience.</li> <li>• Create a safe environment where all aspects of an experience (positive and negative) can be discussed.</li> <li>• Facilitate sharing of experiences that are applicable and concrete leading to a clear action perspective.</li> </ul> |  |   |
| Tangible vs intangible changes | <ul style="list-style-type: none"> <li>• Change practical activities and strategic direction so that they strengthen each other, resulting in accelerated change processes.</li> <li>• Make changes explicit by applying:               <ul style="list-style-type: none"> <li>• Dynamic Learning Agenda</li> <li>• Documented lessons from change</li> <li>• Learning and reflection</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>• Apply participatory tools to aid discussions on tangible and intangible lessons learned.</li> <li>• Make changes concrete and negotiable by giving special attention to the explication of intangible challenges and solutions.</li> </ul>  |  | <ul style="list-style-type: none"> <li>• Unravel tangible and intangible changes by ensuring a context specific approach.</li> <li>• Make use of the individual drive of participants to spot new changes towards the shared goal of social change.</li> <li>• Alternate activities on intangible changes with concrete tangible activities to make use of the synergy between tangible and intangible changes that drives change.</li> </ul> |

## Collaboration between multiple actors

Literature shows that in order to really effect social change, it is important to have a multi-actor participatory perspective (Chetley, 2011; Cooperrider & Srivastva, 1987; Senge, 1990). In this thesis we draw on Wenger's (1998) social theory of learning, in which social change involves a constellation of 'communities in practice' (p.45) where collective learning is fostered over a period of time. Regeer and Bunders (2009) further explored processes of collective learning by asserting that social change can only be realised when knowledge from multiple actors in both academia and practice are brought together in a process of transdisciplinary knowledge creation. Transdisciplinary collaboration is discussed in the development sector as well, as it *'enriches academic debate and gives new impetus to practitioner's reflections on what works and what does not'* (Stremmelaar and Berkhout, p 233).

The importance of collaboration between actors in a transdisciplinary setting was highlighted throughout this thesis. Although literature describes very clearly the importance of collective learning among multiple actors, there is little guidance on how to realise transdisciplinary knowledge co-creation processes. In chapters 4 and 5, the focus was on finding strategies that can enhance collaboration to co-create new knowledge that contributes to learning and change. Chapter 4 specifically shows how the theory of CoPs can be applied to build a community of actors that learn together by bringing theory and practice together. Also other scholars describe how they formulated a community of practice in their specific field (amongst others Brandon & Charlton, 2011; Carvajal, Mayorga, & Douthwaite, 2008; Skalicky & West, 2006) to build a platform for knowledge co-creation. In their papers the importance of creating a sound structure for knowledge co-creation becomes clear (Brandon & Charlton, 2011; Carvajal et al., 2008). The Dynamic Learning Agenda (DLA), presented in chapter 5, is introduced in this thesis as a tool that can help to structure the process of exchanging all the different practices in a CoP by identifying shared knowledge needs in the community. This process showed the value of crossing disciplines and boundaries between different actors in order to facilitate a sense of shared learning. The DLA tool was first introduced and experimented with in several projects within TransForum - an innovation programme to stimulate sustainable agriculture in the Netherlands in the period 2005-2010 (B. J. Regeer et al., 2009). In the TLP on inclusion of persons with disabilities the DLA helped to give guidance to the actors of different levels that came together in the TLP communities, to discuss their responsibilities openly and to

built a shared ownership for social change towards disability inclusive development. This resulted in a safe learning environment, where all participants could show genuine interest in each other's work and insights, and think about ways of adopting these new ideas and perspectives to their current realities. Chapter 6 illustrates this strategy by showing how educational actors, like teachers, headmasters and programme staff, through discussing the challenges and opportunities for inclusion of children with disabilities in educational programmes, start to share the responsibility and ownership for realising disability inclusive education. Taking a bird's eye view, Chapter 8 shows in three cases of mainstreaming issues in development cooperation (disability, gender and sexual diversity) how the involvement of multiple actors creates fertile grounds for knowledge co-creation that is connected to challenges in real practice. Furthermore, genuine collaboration between different actors, including the beneficiaries themselves, opens up possibilities for marginalised groups to participate in finding solutions for their challenges. Chapter 7 discusses the role of the facilitator in ensuring collaboration in a safe and enabling environment. Which was also shown to be very important in the work of Wenger (1998) and Nonaka and Takeuchi (1995). In addition to stressing the importance chapter 7 also gave practical examples for facilitators of CoPs to enhance fruitful collaboration between multiple actors.

### **Stimulating learning and reflection**

Learning and reflection are essential in processes of supporting and understanding social change in a CoP, and are considered an essential strategy for mutual sense making of theory and practice (Kumar & Singhal, 2012). As previous literature shows, social change processes are full of uncertainties (amongst others: Elzen & Wieczorek, 2005; Koppenjan & Klijn, 2004), therefore strategies applied to enhance social change need to be flexible to deal with uncertainties and adopt lessons learned. This flexible process is characterised as an emergent design (Guba & Lincoln, 1989; Smith & Hauer, 1990). In development cooperation, *learning and reflection* on development practices and purposes is increasingly common, especially when addressing social change movements (Waddell et al., 2013). However, methods on how to effectively stimulate *learning and reflection* in practice are rarely disseminated. As Stremmelaar and Berkhout (2010) state '*This is not to say that there is no learning and reflection taking place, but often the systemic element is underrated and underutilized*' (p. 235). Therefore the research underlying this thesis aimed to identify strategies that can help to implement learning and reflection in development cooperation.

Although, the importance of learning and reflection in social change processes is clearly described in literature, structuring this process is still a challenge for facilitators of change. Throughout the thesis we experimented with using participatory tools to stimulate *learning and reflection*. This provided us with strategies that help to structure learning and reflection towards disability inclusive development. In chapter 5 we described how the DLA embeds *learning and reflection* in common practice and integrates learning and reflection as a systemic element in programme planning and implementation. In chapters 4 and 5 we presented additional participatory tools which make tough issues easier to approach (such as timeline exercise, eye-opener workshop, theatre performance) and support the DLA in facilitating *learning and reflection*. In chapters 4 and 7 we have learned about conditions that facilitate learning and reflection in change processes. First, the extent of an organisation's openness for emergent changes is an important factor in adopting new lessons learned. Second, all chapters show the importance of involving multiple change agents in activities aimed at *learning and reflection*. This is beneficial as change agents coming from different perspectives can understand their role in the social change process while simultaneously contributing to a wider learning process that will result in social change. Change agents can share their drive for a shared concern in *learning and reflection* and implement lessons learned in innovative practices. This is in accordance with Wenger (1998) who describes change agents as knowledge brokers who can bring knowledge from a network into practice, resulting in change. This thesis adds insights into how change agents can be supported in the process of translating learning and reflection in innovative practices.

## Enhancing vicarious learning

The concept of *vicarious learning* (Cox et al., 1999) means learning from the experiences of others. *Vicarious learning* can thereby help participants of a CoP to reflect and learn from the activities of others. The rationale behind *vicarious learning* is that one can learn from the problems others encounter and especially from the way they solve or deal with these problems in a specific context (Cox et al., 1999). Early theorists already introduced the importance of learning within a social context (Bandura, 1977) pointing out that experiences of others play an essential part of learning. Several scholars have shown that sharing experiences in a group can help an individual to learn and adopt new strategies (Bandura, 1977; Cox et al., 1999; E. G. Guba & Lincoln, 1989). *Vicarious learning* focuses on describing the process of the success or failure of a certain practice in detail. Often it is

challenging to describe a learning experience as it can be difficult to tease apart the particular moments where learning occurred, which is often a combination of successes and failures acquired from a number of situations over time. Little research has been done on this problem of the operationalisation of *vicarious learning*. Therefore we have identified strategies that can help participants of an CoP to implement *vicarious learning* in their process of learning and reflection.

The chapters of this thesis show how *vicarious learning* is enhanced in relation to disability inclusive development. In chapter 4 we describe how *vicarious learning* can be enhanced by small interventions. Connecting people with similar problems together or connecting novice organisations with more experienced organisations can facilitate vicarious learning. Furthermore, organisational visits can make the vicarious experience more realistic. Participative tools can enhance the experience of vicarious learning as we have seen in chapter 6, where storytelling, the eye-opener workshop and theatre performance have aided the sender to tell their story and the receiver to re-live it. This shows that thick description (Geertz, 1973) is not only realised through writing, but can also be realised through verbal communication in many forms. Some preconditions for enhancing vicarious experience are encountered in chapter 6. One precondition is the need to create a safe environment for the sender to tell/show the experience. This is necessary to build rapport and create an environment where all aspects of an experience can be discussed, ranging from positive to negative accounts. Another precondition is the importance of ensuring that the experience is applicable and concrete for the receiver, leading to a clear action. Only then can vicarious learning contribute to a process of change. In Chapter 6 we see that vicarious learning can lead to emergent change. We have shown how actors exploring disability inclusive education are able to translate the experiences of others into concrete changes in their own work. Interestingly, these changes seem to be sustained over time and lead to a snowball effect of subsequent opportunities for vicarious learning, amplifying knowledge transfer.

### **Combining tangible and intangible outcomes of change**

Since social change is a non-linear process, it requires experimental practices that are adaptive to emerging changes and that are embedded in different contexts (Geels, 2002). Wenger (1998) describes how experiences from different contexts can be brought together in a CoP, as a platform for learning to support change. The experiential knowledge brought together in a CoP, that forms the basis for learning and reflection and can be used to

stimulate vicarious learning, can result in both tangible and intangible outcomes. Tangible outcomes relate to explicit knowledge that can be expressed in words and numbers and is easily shared in different forms of hard data or universal principles. Intangible outcomes relate to tacit knowledge which is highly personal and hard to formalize, making it difficult to communicate and share with others (Nonaka & Takeuchi, 1995). Unravelling the structure of both types of knowledge can help to understand the change process (Senge, 1990). In the development cooperation sphere, scholars often discuss the importance of tangible and intangible outcomes of aid, to tackle the increasing complexity of problems addressed by development programmes (Dart & Davies, 2003a; Harris & Enfield, 2003). However, development actors face the difficulty of showing tangible and intangible outcomes, in a development sector that has a highly quantitative orientation in its documentation. In this section we will show what strategies we identified to visualise tangible and intangible changes.

The chapters of this thesis show how tangible and intangible outcomes are combined and result in change. Chapter 4 shows that tangible and intangible changes in the practice of development programmes and in the strategic direction of a development organisation strengthened each other in the process towards disability inclusive development. For instance, tangible outcomes (for example the implementation of tools to support persons with disabilities in a development programme) accelerate intangible lessons (such as strengthening commitment for disability inclusive development) since both are necessary for realising disability inclusive development in a sustainable manner. In chapter 5 the DLA is presented as a tool to document these tangible and intangible outcomes in change processes. Here, change agents in all participating organisations played an important role in revealing tangible and intangible outcomes from experimentation with disability inclusive development. It is important to note that revealing intangible changes can be challenging since these outcomes are not explicit in practice (B. J. Regeer et al., 2009). The DLA helped to reveal intangible outcomes in a systematic way through regular sessions of learning and reflection. Also participatory tools aided the discussion on intangible changes in the work on inclusive education in Ethiopia (chapter 6). Here we learned that through explicating intangible outcomes, the process of change became more concrete and steps to take became more clear and negotiable. All these findings were also confirmed in our comparison of three different mainstreaming initiatives in development cooperation (namely, disability, gender and sexual diversity). Furthermore, we learned that the individual drive to spot new changes is very important for participants in different TLPs.

People who are personally very dedicated to the issue of change can more easily track new (intangible) outcomes. Last, we learned from this comparison how the synergy between tangible and intangible outcomes drives the change process. Both types of insights can strengthen each other, which is carefully exploited in the TLP by alternating activities focussing on developing intangible outcomes into concrete tangible outcomes. For instance, awareness raising activities on the capabilities of children with disabilities to be included in mainstream schools were alternated with clear tips and tricks to bring the inclusion of children with disabilities in education in practice.

### **9.3 Lessons learned on realising disability inclusive development**

In this thesis we wanted to provide insight in activities that can facilitate the integration of disability issues in development programmes and organisations. We focussed on documenting good practices of inclusion of persons with disabilities in a community of development organisations that wanted to experiment with disability inclusive development. Table 9.2 shows the lessons learned in implementing disability inclusive development at organisation- and programme level.

*Table 9.2: Lessons learned towards disability inclusive development (adapted from Bruijn et al., 2012)*

| Programme level   | Organisational level  |
|---|---|
| <ul style="list-style-type: none"> <li>• Create pre-conditions for inclusion of persons with disabilities</li> <li>• Train project staff on disability inclusive development (attitude change, knowledge and skills)</li> <li>• Remove the barriers that prevent participation of persons with disabilities</li> <li>• Ensure the inclusion of persons with disabilities in programmes</li> <li>• Identify persons with disabilities</li> <li>• Ensure the participation of persons with disabilities in the whole programme cycle</li> <li>• Include disability data in planning, monitoring and evaluation reports</li> <li>• Allocate budget for inclusion of persons with disabilities</li> <li>• Build networks for referral system for disability specific needs</li> </ul> | <ul style="list-style-type: none"> <li>• Create commitment for disability inclusive development</li> <li>• Address common excuses for ignoring persons with disabilities (awareness-raising).</li> <li>• Anchor disability inclusion in organisational strategies and systems</li> <li>• Ensure disability inclusive human resource management</li> <li>• Include disability issues in planning, monitoring and evaluation systems</li> <li>• Create access to facilities and information in your own organisation</li> </ul> |

## Lessons learned at programme level

At the programme level, the TLP participants learned about the importance of creating the preconditions for enabling inclusion of disabled persons. Two important preconditions identified for the inclusion of persons with disabilities in development programmes are well-trained project staff and the removal of barriers that hinder participation of persons with disabilities. The TLP participants gained experience with training project staff on disability inclusive development. They have learned the importance of involving persons with disabilities as role models in training to challenge stereotypes and make barriers visible, as seen in chapter 5 and 6. The TLP participants stress that their personal experience with persons with disabilities has been very important to experience first-hand how urgent it is to remove participation barriers for persons with disabilities. Furthermore, the TLP participants developed and co-created strategies through learning and reflection on

disability inclusive development for identifying and removing attitudinal, environmental and institutional barriers that hinder the participation of disabled people.

Once the preconditions were identified, the TLP participants started to experiment with the identification of persons with disabilities in different ways. Identification is important to select beneficiaries for development programmes. The TLP participants realised that persons with disabilities are often invisible in communities and there is a need for extra attention to disability issues to make sure they are included in the identification of beneficiaries. Persons with disabilities need to be approached with sensitivity and empathy to acknowledge years of repression. Furthermore, the inclusion of persons with disabilities in a mainstream development programme requires careful facilitation in the community to ensure openness of all beneficiaries to the contribution of persons with disabilities (chapter 4 and 7). The visibility of attention to disability inclusive development was enhanced by including disability issues in baseline studies, monitoring of programme activities and outputs and reporting in programme reports. By doing this, field staff were constantly reminded of the importance of including persons with disabilities as beneficiaries. One innovative approach that TLP participants applied to identifying PWD was working with community change agents or children to identify PWDs in their communities (chapter 7).

When persons with disabilities are identified as potential beneficiaries of development aid, the next step is to actually include them in the programme. In order for inclusion to occur, there must be a shift from presence to participation, which means that persons with disabilities can develop their capabilities to their fullest potential. Throughout the different communities, we agreed that one should not be satisfied with presence of persons with disabilities alone, but that being present can be a good start for experimenting with disability inclusive development since it enables all actors involved to become more acquainted and at ease with the inclusion of persons with disabilities. To support the participation of persons with disabilities in the programmes, NGOs learned about the importance of the twin track approach. On the one hand, they have learned the need for mainstreaming disability issues in all aspects of the programme, such as planning, monitoring, evaluation and budgeting. On the other hand, they stress the importance of building referral networks with disability specific NGOs and health services to address disability specific needs that are outside the scope of mainstream NGOs. These referral networks are experienced as a necessity to improve the participation of persons with disabilities in and their compliance with mainstream programmes (chapter 8).

The approach for encouraging experimentation with disability inclusive development in the TLP was carefully designed (based on other work of, amongst others, Coe & Wapling, 2010 and Harris & Enfield, 2003), tested, refined and documented by the participating NGOs in the TLP. In particular, the partner organisations in India and Ethiopia applied the activities in their programmes, captured and documented this process and exchange lessons learned with one another. The associated lead NGOs in the Netherlands followed these initiatives with great interest, providing incentives for change through their field visits and monitoring requirements. The practical examples of realising disability inclusive development in different programmes and sectors created a foundation for changes at organisational level.

### **Lessons learned at organisational level**

At the organisational level the TLP participants realised the importance of including the needs of persons with disabilities in policies, structures and management systems to ensure that disability inclusion becomes embedded in the organisation (chapter 5). The need for organisational change to embed disability inclusive development was earlier described based on experiences of World Vision (Coe & Wapling, 2010b) and Oxfam (Great Britain) in collaboration with Handikos in Kosovo (Harris & Enfield, 2003). These experiences show the importance of creation of pre-conditions, like creating awareness of and commitment to disability inclusive development at the organisational level. The TLP participants learned from the training in the TLP on inclusion of persons with disabilities that an open and informal discussion, preferably with the participation of persons with disabilities or by using video material to show their capabilities, was helpful in their own awareness-raising. Later they applied the same strategy to raise awareness of disability inclusive development in their own organisations (chapter 6). Furthermore, an important aspect of awareness raising is to diminish prejudices against disability inclusive development. Therefore, the change agents in the participating NGOs were trained to handle common excuses for ignoring persons with disabilities in development organisations.

When awareness was raised, the change agents and their colleagues have started to experiment with strategies to embed disability inclusion in all organisational strategies and systems. As a result, the TLP participants include disability in policies, planning, monitoring and evaluation (chapter 8). In order to 'practice what you preach' some TLP participants consider it important to adopt disability inclusive human resource management (that is including disabled people in the workforce of an organisation). Furthermore, it was considered to be important to ensure that all communication and information of an

organisation is accessible for persons with disabilities. The TLP participants agree that all these organisational changes are relevant for NGOs working on disability inclusive development, though the pace and mandate of changes vary for each organisation, depending on its culture and opportunities (chapter 4 and 5). These changes in organisational structures and culture create fertile grounds for anchoring disability inclusive development in development programmes.

But how do these two levels relate to each other? In the beginning of the TLP we often discussed how to begin implementing disability inclusive practices. We questioned if we needed to focus first on organisational change to ensure a right based focus on disability, or to start implementation in the programmes and learn from good practices. We have learned in chapter 4 and 8 that a combination of both works best and that facilitators of inclusive development need to listen carefully to participants in order to support their needs. Preferences and opportunities in realising disability inclusive development differ for each organisation, but because of the linkages in the network the TLP participants also experienced similar needs and learned from the journeys of each other. This was also observed in another research programme on knowledge management in development, wherein the importance of ‘widening the ripples’ of action is described, referring to the metaphor of the ripples of a stone in water that spreads out, getting weaker and less defined as they lose momentum (Newman & Beardon, 2011; Powell & Cummings, 2010). Throwing in stones (actions) at several places in the water (different levels and organisations) lead to more ripples that may strengthen each other and reach further in facilitating social change.

## 9.4 Validity of the outcomes

In this section the validity of the case studies presented in this thesis is discussed. In chapter 3 strategies to support valid outcomes are discussed. We reflect below on how these strategies worked out in retrospect.

### Internal validity

Information about the relationship between the researcher, the research setting and the participants can shed light on the interpretation of the data (Maxwell, 1998). In action research, the researcher is taking part in the action under study, supporting the transformation towards the aim of the research (Mertens, 2003). In addition, action

research can empower marginalised people to take part in finding solutions for tough problems. This results in a shared effort of researcher and society to answer the research question. In this constructivist epistemology, theorists are not looking for a single valid methodology in science, but rather apply a diversity of useful methods (E. Guba & Lincoln, 1994). The research is seen as valid when the analysis provides insight and is useful in countering systems of oppression and domination that limit human freedom (Mertens, 2003). In this section we will explain how we implemented this transformative action research in the current research process.

The transformative research approach taken in this study, assumes that the presence of the researcher and the interventions practiced in the research process enhance the attention given to disability inclusive development. The researcher has an influential role in designing, facilitating and stimulating reflection in the learning process on disability inclusive development. The active role of the researcher was part of a cyclic action research approach (Kemmis & McTaggart, 1988). We chose to focus on learning from practices to understand the process of change towards disability inclusive development. This relates to the adopted strategy of appreciative inquiry which can be used in action research approaches when focussing on social innovation instead of complex problem solving (Cooperrider & Srivastva, 1987; B. J. Regeer et al., 2009). The cyclical nature of design and the focus on good practices contributes to the transformative nature of the study and provides data that helps to understand the change process towards disability inclusive development.

The design of the study inherently assumes that all participants joined the research out of their own interest, since they want to contribute to the process of change. The TLP could be seen as a CoP, wherein like-minded people jointly learn about an issue of interest to them (Wenger, 1998), in this case disability inclusive development. Though, as the TLP participants represented a broad spectrum of NGOs active in different sectors of development, we can say in retrospect that selection bias was minimized since a broad range of cases has been studied. For further research it would be interesting to extend the scope from NGOs to all actors involved in disability inclusive development. Furthermore, the numbers of countries actively implementing such development could be increased for further research.

Data collection in a cyclical form from planning and action to reflecting on observations helped to gain insight in how the change processes towards disability inclusive development could be supported and what possible strategies can be applied to facilitate the change in NGOs. During data collection, research bias was minimized by triangulation of methods and

data sources, member checks, analysis by multiple researchers (academic and non-academic) and thick description. Furthermore, attention was directed to the multi-cultural nature of the research, particularly in the Indian and Ethiopian case studies. The researcher cross checked the meaning of disability in the different contexts in collaboration with the participants in the TLP. Furthermore, the local participants acted as co-researchers in the different contexts, through discussions on the design, data collection and the meaning of the results.

Providing meaning to the data was a shared effort between the researcher and TLP participants in processes of learning and reflection. The participants reflected regularly on the outcomes of actions in their organisations and the meaning of these outcomes in their specific context and for the process towards disability inclusive development at large. Furthermore, the network participants reflected together in regular workshops on their positions in the process towards disability inclusive development and further directions for change. The main contributions of the academic researchers in the process of analysis were quality management, by ensuring structure in actions and observations; knowledge embedding, by making outcomes available and clear; and translating outcomes into theoretical ideas, published as academic papers on the process towards disability inclusive development. The shared effort in analysis helped to keep researchers' bias at a minimum.

### **External validity**

A second issue is the extent to which the outcomes of this research project are generalisable to other contexts (Gray, 2004). Since this study is of a transformative nature, generalisability was not our main objective; we regarded it as more important to understand the process towards disability inclusive development in different contexts. The multi-case study approach allowed us to gain an in-depth understanding of the process towards inclusion of persons with disabilities as experienced by NGOs active in a variety of sectors, at several levels of development cooperation, and in different contexts. Since the design of the TLP on inclusion of persons with disabilities was tailor made and contextualised to the needs of the participants it cannot be used as a blueprint for other learning programmes or disability programmes. However, in the different TLPs we studied there are shared outcomes that increase our understanding on the process towards (disability) inclusive development. These general outcomes could be further explored to test their transferability to other actors working in different regions on disability inclusive development. For instance, Light for the World started a similar network of disability specific NGOs and DPOs as described in

chapter 7 in South East Asia and they support new groups of European mainstream NGOs working on disability inclusive development on specific themes like inclusive education and inclusive economic development. Since the shared outcomes are based on a broad range of case stories they are probably also applicable in a range of other issues that are mainstreamed in development cooperation, like we have seen in the examples of gender and sexual diversity in chapter 8. Further research can explore if the lessons learned are also applicable outside the realm of NGOs and development cooperation.

With the question of generalizability comes also the question of sustainability. To what extent are the results of this research sustainable in the involved organisations, and how will the change process towards disability inclusion continue in these organisations? The transformative research approach aims to contribute to sustainable change in a community (Mertens 2003). Sustainability is emphasised by the participative nature and the cyclical approach of transformative research, which allows all participants to be involved in research design and analysis. This was also the case in all TLP networks under study in this thesis. Therefore, we expect that the results that are adopted by the organisations are likely to be sustainable and embedded in their work. However, a longer time frame is needed to evaluate the extent to which the changes in the organisations are sustainable.

## 9.5 Contributions to various relevant fields

This research project has resulted in a wealth of lessons on the change processes towards disability inclusive development for NGOs and their international development programmes. These lessons may be meaningful to a diverse group of scholars from a variety of perspectives.

First, these lessons are relevant to scholars in the fields of disability studies and human rights. We have shown in the introduction that much international attention is directed towards disability issues in development, but that the practice of disability inclusive development does not receive adequate attention in development programmes (Albert et al., 2005; Grech, 2012; Stone, 1999). The lessons that were developed, captured and shared during the programme by all participants on the change process towards disability inclusive development can be helpful to further the implementation of policies on inclusive and rights based development.

This relates to a second academic field in which the lessons may be relevant, which is the field of implementation sciences. Increasingly it is recognized that policies, interventions or

innovations, however well designed, are not automatically translated into practice. The field of implementation science or research seeks to understand the conducive and hampering factors in the uptake of interventions or policies by professionals in the field. Whereas some scholars direct their attention to promoting systematic implementation practices (e.g. Fixsen, Naoom, Blase, & Friedman, 2005), others advocate a more intricate relationship between the development and the implementation of innovations and interventions in order to circumvent the infamous implementation gap from the start (Regeer & Bunders, 2009). The insights into the dynamic relationship between policies, interventions and practices resulting from the current research project may add value to much of the work already done in the field of implementation research.

The third field which may benefit from this study is the field of (programme) evaluation. In the field of evaluation increasing emphasis is placed on obtaining learning goals next to accountability goals as part of an evaluation endeavour (Guijt, 2010; Lonsdale & Bechberger, 2007). Current questions in the field are 'how to conduct programme evaluation in such a way that learning takes place, not only on the part of the researchers, but also on the part of the participants', 'how to construct dynamic and contextualized indicators for progress' and 'how to involve stakeholders in the design and execution of evaluation' (Abma & Stake, 2001; Mierlo et al., 2010; Patton, 2008). The transformative research approach taken in the current study accommodates these questions from the start and can be considered an example of the next generation of programme evaluation.

Finally, the insights gained in this research project may contribute to the field of system innovation. In the last decade, complex societal issues, such as the depletion of natural resources, quality and safety of food, or the vicious circle of poverty, are recognized to be very hard to resolve (Geels, 2002; Koppenjan & Klijn, 2004). System innovation has been introduced as a way to address these types of problems; it encompasses multiple actors, at multiple levels and problems are considered multi-faceted (Koppenjan & Klijn, 2004; Rotmans, 2005). The inclusion of persons with a disability in development can clearly be seen as a complex societal issue that requires a multi actor, multi-level approach. The experiments on inclusive development that were conducted by the participants of the current project can be seen as so called 'niche experiments' (Loorbach, 2007) at micro level that take place in a relatively safe environment, but at the same time need to align with incumbent institutional environments at meso level (Geels, 2002). At one point these experiments may lead to the full-fledged adaptation of a rights based and inclusive approach by actors in development cooperation.

These four scientific disciplines could be further involved in researching the change processes towards disability inclusive development. By involving a variety of scientific disciplines the understanding of change processes becomes more comprehensive. Furthermore, studying disability inclusive development can also be a good learning ground for these different scientific disciplines to further develop their theories and practice.

## 9.6 Recommendations for further research

The research underlying this thesis opens up a range of questions for future research on the development of strategies towards disability inclusive development for NGOs and other actors and the facilitation of learning and reflection to learn thematically. In this section, we highlight a few.

### The on-going need for awareness-raising

Many scholars and practitioners working in the area of disability and development stress the importance of raising the awareness on disability issues of mainstream actors to realise disability inclusive development (for example: Albert et al., 2005; Coe, 2012; Harris & Enfield, 2003; Lord, Posarac, Nicoli, Peffl, & McClain-nhlapo, 2010; Nussbaum, 2003). Only when prejudices about the capabilities of persons with disabilities are diminished is real inclusion possible. From our experiences in the TLP, it appears there is an on-going need for awareness-raising. Despite our efforts in awareness-raising and despite the change we saw in attitudes of participants in our programmes, the work is on-going as it takes time for attitude change to spread through institutions. We see three levels of disability inclusive development where awareness-raising plays an important role. First, at the local level there is a need for attention to awareness-raising among people in practice and communities themselves. In chapter 6 we have seen how peer effects, parent and community attitudes on children with disabilities determine the success of inclusive education. We experimented with strategies to support vicarious learning on inclusion of persons with disabilities in practice to raise awareness on the capabilities of children with disabilities in inclusive education. Several tools, like the DLA (chapter 5), most significant change (Dart & Davies, 2003a) and learning histories (Kleiner & Roth, 1996a) were developed to support vicarious learning. However, these tools need extensive facilitation and training for the people involved to come up with suitable stories to exchange. Further research could focus on how to make vicarious learning methods more user-friendly. When exchanging experiences on

issues like disability inclusion becomes a part of community life, knowledge transfer from community to community can result in fast growing awareness on the capabilities of persons with disabilities. This may empower the persons with disabilities involved to show their capabilities to the fullest.

Second, chapter 4 and 8 illustrate that the strategies applied in the TLP to raise awareness on disability inclusive development brought clear changes in the attitudes of the change agents towards disability inclusive development. However, embedding these lessons learned in the respective organisations proved to be more difficult than anticipated. Further research could focus on dissemination of outputs of lessons learned among change agents in their respective organisations. This is especially relevant in complex organisational structures, as in development cooperation, where NGOs depend on donors and on the independent partner organisations that implement their ideals.

Third, it is important to keep raising awareness on the importance of disability inclusive development at the international level. This is especially important with the current negotiations on the role of disability in the post 2015 development goals. The UN (2013) acknowledges the importance of inclusion of persons with disabilities in their vision and framework for the post 2015 development agenda by stressing the importance of the transformational shift to *'leave no one behind'* (p. 7) and *'transform economies for jobs and inclusive growth'* (p. 8). A challenge we foresee in realising the attention for disability in the post 2015 development goals is the current preference in international development cooperation to work with predefined quantitative targets for development outcomes. 'Soft' issues like attitude change as an outcome of development programmes are not of interest to many actors in international cooperation. Our research shows that synergy between tangible and intangible outcomes can enforce change, especially when dealing with social change processes like disability inclusive development. Pre-determined targets often do not explicate intangible challenges and usually are not flexible enough to take intangible changes into account. Further research could analyse how intangible outcomes might be integrated in donor requirements in development cooperation. At the same time it is important for disability studies to develop more measurable targets for disability inclusive development.

### **Moving beyond awareness-raising**

Although awareness-raising is important, it is also important to start action. In her book on disability and development, Stone (1999) states that *'the importance of building a shared*

*vision should not be underestimated... but that should not stop us from moving forward, and from wrestling with the practical and conceptual difficulties'* (p. 14). In taking action on disability inclusive development we want to highlight two issues. First, disability inclusive development is about the people with disabilities. Therefore, persons with disabilities should not be overlooked in design, planning and implementation of inclusive activities. In the TLP we regularly invited people with a disability as speaker or participant in learning sessions and stimulated the participants to ensure the participation of persons with disabilities in all aspects of their work. However, in the outputs of this research we did not specifically focus on how we facilitated a high quality of participation of persons with disabilities in all aspects of our research. Future research could focus more on how to empower persons with disabilities to take active part in research and development programmes, ensuring a high level of participation.

Second, international cooperation is highlighted in the CRPD as very important to the achievement of disability inclusive development (UN, 2006, art. 32). In this thesis we focussed primarily of the role of NGOs in the realisation of the rights described in the CRPD, although in chapter 1, we also introduced other actors that have a stake in realising disability inclusive development and in chapter 4 we learned about the importance of referral networks to realise disability inclusive development. For further research it would be interesting to obtain a deeper understanding on how other actors in disability inclusive development are working towards inclusion. Furthermore, stimulating a dialogue on (best) practice and challenges for inclusion among all actors involved is important to reach synergy in their accumulated activities. Future research can support the establishment of an effective dialogue on disability inclusive development with all actors involved.

## **Monitoring the implementation of the CRPD**

The monitoring of the CRPD was designed at a time that the UN was responding to critiques that the treaty monitoring system imposed overlapping and burdensome reporting obligations (Stein & Lord, 2010). Furthermore, the monitoring framework of the CRPD needed to deal with the challenges in finding reliable disability data (Bickenbach, 2011). This led to some new innovative monitoring practices with regard to the CRPD. According to Stein and Lord (2010) the most important innovations in monitoring of the CRPD are the inputs requested from DPOs and UN specialised agencies and new procedures that are explicitly described in the optional protocol, to manage reporting deadlines.

Despite the innovative development in monitoring the CRPD, Stein and Lord (2010) also point out some remaining challenges in monitoring the inclusion of persons with disabilities in international development programmes. One of the challenges discussed by different scholars is the difficulty of ensuring facilitation and support in practice for the inclusion of persons with disabilities (Bickenbach, 2011; Stein & Lord, 2010). In this respect Stein and Lord (2010) see an important role for NGOs. This is also acknowledged in the CRPD itself in article 38 that states the NGOs have the responsibility *‘to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates’* (UN 2006, art 38). This implies that NGOs can provide valuable input for monitoring the CRPD from their best practices of disability inclusive development.

The research of this thesis has contributed to the challenge of ensuring facilitation and support in practice for the inclusion of persons with disabilities in international development programmes. We learned about strategies for awareness raising to get support for disability inclusive development and experimented with the practical implementation of inclusion of persons with disabilities in development programmes (chapter 4, 5, and 6). In our research the experimentation with practical implementation was all about ensuring the presence of persons with disabilities in international development programmes. The next step for further research and practice is to explore how the capabilities of persons with disabilities can be used to their fullest potential. In chapter 6, especially, we found it difficult to ensure that the inclusion of children with disabilities in inclusive education moves from presence to participation. In other programmes we studied, there were also not always strategies in place to realise full participation. Future research could therefore also focus on designing strategies to ensure that persons with disabilities that are included in international development programmes actually participate and reach their full potential.

In our research we sought to extract lessons learned from implementation in practice and to reflect on these lessons to generate generic insights for successful disability inclusive development. In this thesis we drew on Wenger’s (1998) social theory of learning, in which social change involves a constellation of communities of practice (CoP), in which collective learning takes place over time. In the TLP on inclusion of persons with disabilities, this community existed of appointed change agents from the participating NGOs. The next step would be to extend the membership of this CoP, involving all actors in disability inclusive development. In this way, the lessons learned in this CoP can really inform the monitoring of the CRPD, bridging the gap between the international and the local level.

## Mainstreaming issues in development to inclusive development for all

The universal declaration of human rights (UN, 1948) intended to promote equity for all. When implementation proved to be difficult, separate conventions were designed acknowledging the rights of children (UN, 1989) and persons with disabilities (UN, 2006). At the same time, development cooperation started to mainstream human rights into international development programmes. Other global issues, like gender, HIV/AIDS and sexual diversity were added to the mainstream agenda. 'Disability' was added to this list, in response to the notion that eradicating poverty is not possible without the inclusion of persons with disabilities in development programmes (Albert et al., 2005; Guernsey et al., 2006). Now 'disability' as an issue has become a part of international cooperation, in the sense that many agencies have included persons with disabilities in their programmes (Lord et al., 2010). This thesis shows how NGOs are trying to make their international development programmes inclusive for persons with disabilities in practice. Now we want to look ahead, into the future of disability inclusive development. In this respect some scholars and practitioners dream about combining all mainstreaming issues in development under the notion of inclusive development for all (Bruijn et al., 2012; Squires, 2005; Stein, 2013). It would be good for further research to explore the advantages and disadvantages of adopting the more overarching concept of inclusive development for all in theory, practice, and advocacy.

## 9.7 Concluding remarks

The research in this thesis aimed to contribute to the better understanding of the change process towards disability inclusive development. The participants of the TLPs that were part of this research, were encouraged to take into account all aspects of development, in accordance to our definition formulated in 1.2:

*'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.'*

Although, we may not be able to say that all persons with disabilities that are beneficiaries or actors in the programmes under study were able to fully optimise their own well-being, we would like to highlight the considerable progress all participating organisations made in

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this respect. Progress made is different for the participating organisations but all these organisations now consider the inclusion of persons with disabilities in their programmes as a 'normal thing to do'. In this way these organisations, involved in service delivery, became agent for human rights change. We hope that this thesis contributes to further attention for these good practices as a complement of international and state level actions. Hopefully, in the future, persons with disabilities, like Yasmin, who live in under-resourced areas can be assured full possibilities for development in accordance and relation to their peers.