

Summary

Persons with disabilities represent 15% of the global population, of which 80% live in low-and middle-income countries, where they are trapped in a vicious cycle of poverty, reinforced by their disabilities. Paradoxically, persons with disabilities are often not included in (international) development programmes that aim to combat poverty; 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.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) pays specific attention to the situation of persons with disabilities in international development programmes. Since the CRPD has come into force, scholars, organisations and governments have started to discuss the importance of disability inclusive development. However, despite the international attention directed towards disability issues in development, the practice of disability inclusive development does not receive adequate attention in development programmes. As a result, many persons with disabilities living in low- and middle-income countries are still subjected to systemic social exclusion and discrimination.

In order to address the lack of integration of disability issues in development practices, non-governmental organizations (NGOs) can play an important role by mainstreaming disability in development programmes through innovative practices. This is a complex matter since there are a range of NGOs with differing interests, operating in different sectors of aid and development that depend on each other in realising disability inclusive development. In addition, 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. 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.

All different actors within mainstream NGOs as well as disability specific organisations need to become part of a collective paradigm shift to change their organisations and practices to fully support the inclusion of persons with disabilities. This requires a transformative process of learning and reflection on organisational aspects and practices that support the

inclusion of persons with disabilities in development programmes. In relation to these changes at the levels of organisations and practice we 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. Looking at both inclusive organisations and programmes provides insight into the process of change towards disability-inclusive development. Therefore, this thesis intends to:

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

A substantial part of this thesis is based on the Thematic Learning Programme (TLP) on inclusion of persons with disabilities. A Dutch organisation that supports NGOs in development cooperation, called 'PSO Capacity Building in Developing Countries', developed the TLP approach to co-create knowledge around thematic issues in communities of NGOs, academic partners, and content experts. In a TLP different actors in development try to understand what works and what does not work when facilitating a social change process on a thematic issue in a specific context. With the aim to better understand the role of NGOs in realising disability inclusive development, a community was started in 2009, comprising a group of Dutch disability specific and mainstream NGOs, expert organisations and an academic institute.

To develop a deeper understanding of the social change process towards disability inclusive development, the TLP participants systematically documented lessons learned on the network level, in their respective organisations, and field practices. Furthermore, disability specific NGOs and DPOs learned about their changing role from implementers of disability specific programmes to facilitators of change. Finally, we learned from other cross cutting issues in development that are also been mainstreamed, namely gender mainstreaming and mainstreaming of sexual diversity. Despite the differences in needs among groups, they are experiencing a similar process of change, and therefore they form an interesting comparison. To capture these differences, the following research questions were formulated:

- 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?

The TLP formed a platform for learning and reflection where the process of social change was discussed by the NGOs in the light of their experimentations with disability inclusive development. The outcomes of these discussions and experimentations provided insights for research and practice on disability inclusive development. To accommodate the process of documentation, the researchers (in consultation with the NGO partners) adopted a transformative (research) approach in order to document and understand the process and outcomes of change towards disability inclusive development.

To shape the transformative research approach multiple cycles of action research were facilitated, wherein learning sessions were conducted which allowed for reflection on the vision, expectations and practice of disability inclusive development. As data collection for transformative research requires an in-depth exploration of the cases studied, we adopted a variety of qualitative methods. All methods contributed to the transformative nature of the study, which means that they were participatory (involving different actors), included a component where learning from experience was enhanced (vicarious learning), combined different ways to stimulate learning (accommodating different types of learners), and were adapted to the contexts in which they were applied (culturally sensitive). The methods consisted of new methodologies specifically designed for this transformative research project and conventional methods that were applied in such a way that they also resulted in a meaningful learning experience for participants. Studying and analysing disability inclusive development with a variety of methods and different actors involved resulted in triangulation, which facilitated more robust insights.

This thesis consists of five studies and an essay as an epilogue, which focus on understanding the change processes towards disability inclusive development of NGOs and their programmes.

Chapters 4 and 5 describe how we can understand and facilitate the process of mutual learning on disability inclusive development in a network of NGOs. Chapter 4 shows how the process of mutual learning on disability inclusive development can be facilitated in a network of NGOs. We describe how a group of different actors can co-create knowledge in a shared domain. Through mutual learning and experimentation in a community of practice, the actors develop a shared repertoire of socially robust knowledge. The balance between theory and practice during knowledge co-creation process helped to gain in-depth understanding of the process. The structured process of knowledge co-creation on disability inclusive development resulted in a wealth of practical experiences for new and revised practices with evolving theoretical foundations. To continue on the path of understanding the process of mutual learning on disability inclusive development in a community of NGOs, chapter 5 zooms in on a tool, the Dynamic Learning Agenda (DLA). The DLA integrates learning with social change by analysing and reflecting on shared issues that participants encounter in the process towards disability inclusive development in development organisations. In this chapter, we show the theoretical foundations, purpose, practical implementation and added value of the DLA. We reflect on the application of the DLA and we discuss how the DLA supports the integration of learning in social change processes.

Chapter 6 extracts lessons learned from field practices of inclusive education in Ethiopia, as an example of disability inclusive development. Inclusive education was chosen as an example of disability inclusive development since although challenging, most countries have committed themselves to achieving Education For All by 2015. In this chapter we zoom in on one of the field practices of the TLP on inclusive education to learn about the process of change in schools in Ethiopia. We explore the constraints on inclusive education for children with disabilities in Ethiopia and how they can be addressed by stimulating learning from grass-root level experiences. To study inclusive education in field practices in Ethiopia, we applied an internationally agreed upon framework for understanding the quality of education to the Ethiopian context in order to identify the main constraints to implementing inclusive education for children with disabilities. We then attempted to address the most important constraints by stimulating learning from the experiences of all actors involved, trying different approaches in three different schools. The constraints, related to inadequate teaching methods, disruptive peer effects and lack of community awareness, were found to be positively affected by tools that consisted of exchanging lessons learned through an intermediary, developing an eye-opener workshop and performing a play. We conclude that using these tools at least reduced the burden of the constraints through

enhancing dialogue and reflection and stimulating vicarious learning. The focus on learning from experiences at the school level enabled the transfer of lessons learned to different levels of the education system.

Chapter 7 deals with the changing role of disability specific NGOs and DPOs when moving toward facilitating disability inclusive development. The CRPD explicitly mentions in article 4 the role of disability specific NGOs and DPOs as stakeholders who should support national governments with the implementation of the rights of persons with disabilities. Chapter 7 explores different ways in which disability specific NGOs and DPOs change their role to facilitate disability inclusive development. Disability specific NGOs and DPOs stressed the importance of monitoring the formulation of this new role to explore the transition from working for persons with disability to facilitating others in development cooperation to adopt a rights-based approach to disability through inclusion of persons with disabilities. Our analysis highlights experiences of disability specific NGOs and DPOs as they expand their focus from disability specific aspects to inclusion in mainstream development and their role from that of implementers/advocates to facilitators of change. Both internal capacities and external factors influence this transition.

Chapter 8 explores what can be learned about disability inclusive development from mainstreaming initiatives in the fields of gender and sexual diversity. From the nineties, development actors have embraced the principle of inclusion to address the needs of discriminated or marginalised groups in society. Mainstreaming is the overall adopted strategy to build an inclusive society for women, disability, HIV/AIDS and sexual diversity. All these initiatives together are referred to as inclusive development. Despite the differences in needs among different distinct groups, they are experiencing a similar process of change, and therefore they form an interesting comparison. Therefore, this chapter focused on learning about the process towards disability inclusive development from mainstreaming initiatives in the fields of gender and sexual diversity. In order to understand these different fields we explained first the history of how various mainstreaming issues have caught the attention of development organisations. We found that influencing societal change through fostering inclusive practices is difficult. Then we showed how capacity building initiatives within NGOs can be used as leverage for including marginalised groups in society. The experiences described in this chapter may help development practitioners to reinforce and strengthen their emancipatory work.

Chapter 9 synthesizes the findings of the research, drawing conclusions on how we can understand the process towards disability inclusive development and discussing theoretical

implications and suggestions for further research. 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. 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. An overview of the lessons learned is displayed in the conclusion, described at both the programme- and organisational level.

While acknowledging the importance of practical lessons on disability inclusive development, we also considered 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. In all chapters there are four crosscutting elements that were applied to facilitate the process of knowledge co-creation towards disability inclusive development in NGOs. The four cross-cutting elements for facilitating the process of knowledge co-creation are 1) enhancing collaboration between multiple actors, 2) stimulating learning and reflection, 3) enhancing vicarious learning, and 4) combining tangible and intangible outcomes for change.

The research presented in 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. The research has led to the formulation of the following recommendations: first there is an ongoing need for awareness-raising to empower persons with disabilities and to keep disability issues on the agenda, second it is of great importance to move beyond awareness-raising to ensure experimentation and the embedding of disability inclusive development in practice, and third, the importance of monitoring CRPD implementation in a systemic manner from practice to state level initiatives.

In conclusion, we would like to highlight the considerable progress all participating organisations made in their individual change process towards disability inclusive development. 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.