Chapter 7 Meeting the Challenge of the Rights-based Approach to Disability: The Changing Role of Disability-Specific NGOs and DPOs

This chapter relates to the role of disability specific NGOs and DPOs in supporting 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 (UN, 2006). The WHO (2011) describes that disability specific organisations have a role to increase awareness of other actors, empower persons with disabilities to stand up for their rights, participate in policy development, and monitor implementation of disability inclusive policies and services. In this chapter we want to explore different ways in which disability specific NGOs and DPOs change their role to facilitate disability inclusive development.

Disability specific NGOs and DPOs, are united in their own TLP community wherein they learn about their changing role from implementers of disability specific programmes to facilitators of change. Five disability-specific non-governmental organisations (NGOs) and disabled people’s organisations (DPOs) in East Africa - in Ethiopia, Kenya, Rwanda, Tanzania and Uganda - formed a learning community to focus on developing their role in disability mainstreaming, responding to the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). In this community, the formulation of this new role was monitored 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. In conclusion, lessons learned in the process of adopting the new role in the implementation of the CRPD are presented.
7.1 Introduction

A number of disability specific non-governmental organisations (NGOs) and disabled people’s organisations (DPOs) focus on meeting the special needs of persons with disabilities. In the past, disability specific NGOs tried to meet these needs by providing care in special institutions, social charity, and adapted norms for persons with disabilities. DPOs focussed on the empowerment of persons with disabilities and the removal of barriers to their participation, speaking out about their specific needs (Harris & Enfield, 2003; Mwenda et al., 2009). These NGOs and DPOs are also sometimes referred to as organisations for disabled people and organisations of disabled people, respectively (Mwenda et al., 2009).

Originally, both types of organisations adopted a perspective contextualising disability as residing in the individual (Roush & Sharby, 2011). Unintentionally, this perspective might have contributed to the exclusion of disabled persons from society. Persons with disability are often regarded as objects of pity, which effectively sets them apart, or excludes them, from the community (Bickenbach et al., 1999; Mwenda et al., 2009; Stienstra et al., 2002). The social approach to disability shifts the perspective from the individual to the environment’s role in defining, amplifying, and ameliorating the effects of impairments. From this perspective, disability is but one aspect of diversity and society should adapt to accommodate differences (Roush & Sharby, 2011). The human rights perspective is a social approach to disability that offers a platform for the social transformation of disabled people to transform the sense of who they are: from stigmatised objects of charity to valued subjects of their own lives (Albert & Harisson, 2006; Stein, 2007).

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), adopted by the general assembly of the UN on 13 December 2006, reflects this process of social transformation (UN, 2006). It clearly and unconditionally spells out that persons with disabilities have equal rights to full and effective enjoyment of all human rights. It reaffirms:

‘...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 rights-based approach recognises persons with disabilities as ‘subjects’ with rights, who have the agency to claim these rights and make meaningful decisions as active members of society (Bickenbach et al., 1999). Recent insights have led to the advice for disability specific NGOs and DPOs to not only respond to the special needs and protection of persons with
disabilities, but to also increase the possibilities for them to fully enjoy their human rights (Mwenda et al., 2009; Stein, 2007; Witcher, 2005).

DPOs and, to a lesser extent, disability-specific NGOs 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. The Convention also specifically refers to the role of (international) NGOs 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.

Before the adoption of the CRPD, adults with disabilities were not explicitly included in human rights treaties (Stein, 2007). Only children were protected in the Convention on the Rights of the Child, in articles 2 and 23, focusing on non-discrimination and the right to special care and support (UN, 1989). To claim their human rights, disabled individuals could invoke universal rights but, in practice, this did not offer sufficient protection (Stein, 2007). Under the CRPD, all stakeholders involved in development cooperation have a legal responsibility to consult and involve persons with disabilities in their activities (preamble, article 32). To support the implementation of these responsibilities, disability-specific NGOs and DPOs can play an important role in supporting mainstream NGOs; governments; businesses; and other stakeholders with less experience in working with disabled persons (Mwenda et al., 2009; UN, 2006, article 4 and 32).

This chapter provides insights into the new role that disability-specific NGOs and DPOs can embrace in promoting, protecting and ensuring the equal enjoyment of human rights by persons with disabilities. It describes how six organisations have translated the legal responsibilities enshrined in the CRPD into new activities aimed at breaking down the barriers to inclusion of persons with disabilities.

Over the May 2010-June 2012 period, six disability-specific NGOs and DPOs in East Africa — in Ethiopia, Kenya, Rwanda, Tanzania and Uganda — formed a learning community, to support each other in adapting to this new role. This chapter highlights their experiences in supporting inclusion of persons with disabilities in mainstream development. Given the implementation of the CRPD, an increasing number of disability-specific NGOs and DPOs will very likely follow the path of these six organisations in providing advice and support to mainstream NGOs, alongside their disability-specific activities. This chapter provides them with ideas on how to fulfill their new role in mainstreaming disability.
7.2 Disability Mainstreaming

Some 132 countries have now ratified the CRPD (UNenable, 2013). As a result, many governments and organisations are moving to a rights-based approach to disability. Attitudes towards inclusion of persons with disabilities are slowly changing. Albert and Harrison note that there is an increased interest in disability from multilateral donor agencies, as well as from NGOs (Albert & Harisson, 2006).

In this study, mainstream development refers to organisations and initiatives that do not have a specific disability focus. When NGOs pursue equal rights for all, including those for persons with disabilities, this has implications for their programmes in different sectors, including health; employment; education; emergency responses; and so on. These implications can be explained by the concept of disability mainstreaming:

...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).

The importance of disability mainstreaming for sustainable development is explicitly stressed in the preamble of the CRPD (preamble g). Article 32 of the CRPD recognises the importance of international cooperation, particularly in low- and middle income countries. In response, many initiatives for disability mainstreaming are being undertaken by multilateral development organisations. For example, the UN Children’s Fund (UNICEF) aims to mainstream disability across all policies and programmes, in terms of both development and humanitarian action, and the World Health Organization (WHO) published the World Report on Disability in 2011 (WHO, 2011). 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 International Labour Organization (ILO) promotes ‘decent work’ for persons with disabilities, stressing the right of persons with disabilities to earn a living from freely chosen work, which is both accessible and accepting, relating to article 27 of the CPRD (O’Reilly, 2011).

International NGOs are also paying increasing attention to disability mainstreaming. One well-known example comprises the inclusion of persons with disabilities globally in programmes by World Vision (Coe & Wapling, 2010b; Coe, 2012). Another example is the Thematic Learning Programme on inclusion of persons with disabilities, which involves a
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consortium of 30 NGOs in Europe, India and Ethiopia, which learn together about practicing inclusive development (Bruijn et al., 2012).

Despite these examples, however, experiences are scattered and the majority of international development agencies do not recognise disability as a legitimate focus of mainstreaming (Bruijn et al., 2012).

**The Role of Disability-Specific NGOs and DPOs**

Disability-specific NGOs and DPOs can play an important role in anchoring the implementation of the CRPD in general development practice (Mwenda et al., 2009; Witcher, 2005). The UN acknowledged their importance in the development of the Convention, involving 11 DPOs in the working group that reviewed the Convention (Stein, 2007; UN, 2004). Although the CRPD focuses on the legal obligations of governments, it also stresses the importance of partnerships with international and regional organisations as well as civil society organisations, in article 32. It envisages partnerships focused on capacity-building that could encompass the exchange and sharing of information, experiences, training programmes and best practices. The delivery of inclusive services and assistance for persons with disability are also included. Furthermore, both the preamble and article 4 stress the role of DPOs in representing disabled people in the development and implementation of supportive legislation and policies (UN, 2006).

Thus, disability-specific NGOs and DPOs can reinforce the embedding of the CRPD, by facilitating disability mainstreaming in development. In particular, DPOs are advocates for the rights of persons with disabilities. They can convince other organisations of the importance of disability mainstreaming and thereby contribute to a broad base of commitment. Furthermore, they can be consulted regarding the representation of persons with disabilities. Apart from this new function, they can still ensure that the individual rights of persons with disabilities are respected via lobbying and advocacy.

Disability-specific NGOs, on the other hand, are experts in the implementation of programmes for persons with disabilities. They can give practical advice to other development organisations regarding the needs and abilities of persons with disabilities in inclusive development. As role models in the provision of services for persons with disabilities, they can stimulate others to make their programmes accessible. Furthermore, when inclusion in mainstream development is not fully possible, their expertise can be employed to look for a solution that does not infringe the rights of persons with disabilities. Herein, it is important that the services for persons with disabilities, like rehabilitation, are
preserved. Disability-specific NGOs and DPOs can be of great help in the implementation of the CRPD owing to their broad experience in terms of advocacy and meeting the needs of people with disabilities. The challenge of using this experience in the implementation of the CRPD was taken up by six East African organisations: in Ethiopia, Kenya, Rwanda, Tanzania and (two) in Uganda.

7.3 A New Role to Support the Rights of Disabled People: A Multiple Case Study

Light for the World (LFTW) is a European confederation of national NGOs committed to saving eyesight and ensuring the rights of persons with disabilities in low- and middle income countries. In 2010, LFTW Netherlands started to discuss the willingness of their partners in East Africa to become facilitators of disability mainstreaming. They discussed the implications of this change of focus in depth: both within the organisations and together during a meeting in Ethiopia. Thereafter, six disability-specific NGOs and DPOs decided to form a learning community together. The community was set up by LFTW Netherlands to support their partner organisations in expanding their role from specialisation in disability-related topics to advocacy and facilitation of mainstreaming disability in development. According to LFTW, this new role represented an organisational development process for each of the organisations.

The six organisations have different backgrounds, located in Ethiopia, Kenya, Rwanda, Tanzania and with two in Uganda. In Uganda, the National Union of Disabled Persons of Uganda (NUDIPU) is an umbrella DPO, composed of several single impairment organisations, advocating inclusion of persons with disabilities. They work closely together with the NGO Action on Disability and Development (ADD), which specialises in capacity-building for DPOs. In response to the ratification of the CRPD in their country, they wanted to change their role from advocates of equal rights to facilitators of disability mainstreaming. In Ethiopia the Ethiopian Center for Disability and Development (ECDD) is a development NGO, governed and managed by persons with disabilities, which was created to promote and facilitate disability inclusion. It does so by working with other organisations — both governmental and non-governmental — to develop their capacity for the inclusion of persons with disabilities, as beneficiaries and participants in mainstream service delivery and development programs, at all levels. In Rwanda, the Umbrella of Person with Disabilities in the fight against HIV and AIDS (UPHLS) originated as a DPO. Nowadays they are listed as
a NGO, focused on advocacy and lobby for the rights of disabled people and the coordination, monitoring and evaluation of all health services benefitting persons with disabilities, especially involving HIV and AIDS programmes. The UPHLS is, progressively, considered by both Government institutions and NGOs as an expert in HIV/AIDS interventions aimed at persons with disabilities. Two other organisations in the learning community were involved in implementation: the Agency for Disability and Development in Africa (ADDA), which operates in Kenya as a NGO and specialises in community-based rehabilitation and empowerment programmes, and, in Tanzania, the NGO Comprehensive Community Based Rehabilitation in Tanzania (CCBRT), which works a consultancy focused on empowerment regarding employment opportunities. As specialist organisations, they wanted to share their experiences in mainstreaming disability. In the course of the programme, the consultancy organisations changed their legal status to a NGO, to be able to fulfil their new role. All participating organisations were already working from a rights-based approach to disability but wanted to change their role in terms of providing advice to others to adoption of the same principle and measures, hence increasing their impact. The authors were invited to explore the process of organisational development required for these organisations to facilitate a rights-based approach to disability in development.

### 7.4 Methodology

This research is based on an action research project undertaken by the programme officers of LFTW Netherlands from 2010 to 2012, and includes five organisations from East Africa. All data was gathered and coded by LFTW staff. The authors guided the process from design to analysis.

The six organisations met during three workshops to share their experiences. In the intervening period, the organisations individually underwent an organisational assessment with one of the programme managers of LFTW. The organisational assessment was an intervention within the process of organisational development. It was not a standardised measure but, instead, was tailored to the diversity of the different organisations. In addition, interviews were conducted via Skype and during visits to the organisations in order to reflect upon the process. To finalise the project, two representatives of the East African organisations presented their perspectives on the process in the Netherlands.

The research material for analysis consisted of personal observation diaries of employees (48); interviews with key stakeholders within the organisations (5); focus group discussions
within the learning community (9); and written reports from the respective organisations. All data was coded and analysed in collaboration with the programme managers of LFTW. A coding scheme was developed iteratively during several meetings, after which the programme managers coded their own data. The authors coded the data from shared workshops, analysed and validated the coding scheme. The analysis was cross-checked with a programme manager of LFTW for triangulation.

Given the exploratory nature of this study and the variety of research material, we cannot say with certainty that the results are directly applicable to other organisational development processes. However, the results will be able to assist the implementation of the CRPD by disability specific NGOs and DPOs.

**Research Questions**

This chapter shows how disability-specific NGOs and DPOs can adopt a new role of supporting the inclusion of persons with disabilities in mainstream development. We identified two areas of change that may provide insights into the process of changing their role. Firstly, the adoption of a new perspective — the rights-based perspective — influences the role of an organisation. Secondly, there are practical changes required to implement the new role, accompanied by new requirements of staff capacities. Related to these areas of change, we formulated two research questions that guide our exploration, dealing (in turn) with the desired role and potential challenges perceived by NGOs and DPOs in this arena.

Changing towards a new role can be described as development from a current state to a future desired state (Todnem By, 2005). Senge (1990) describes the desired state as a ‘guiding idea’ that relate to the organisation’s identity, mission, vision and purpose. Cooperrider and Shrivastra (1987) consider that the organisation’s passion and integrity are also part of the desired state. The formulation of a desired role can help an organisation to guide its change process. Other organisations that want to embark on the same route towards supporting the inclusion of persons with disabilities can learn from the formulated desired role. Therefore the first research question is:

What do disability-specific NGOs and DPOs perceive as the desired role for their own organisations if they start to support the inclusion of persons with disabilities in mainstream development from a human rights perspective?
Putting this new role into practice entails many practical changes. For example, although these organisations already work from a rights-based perspective in their own programmes, they now need to convey this perspective to their partners. This requires changes in the design and execution of programmes and expansion of new activities that aim to convey this perspective to others. New daily practices and an altered organisational identity require new skills and qualities from programme staff. This brings us to the second research question:

What are the practical changes and capacities that disability specific NGOs and DPOs have developed after they started to support the inclusion of persons with disabilities in mainstream development from a human rights perspective?

The answers to these questions demonstrate the transition for disability-specific NGOs and DPOs towards a new role that supports the implementation of the CRPD. At the same time, we see how their original activities remain important but are put in a different light. We hope that other organisations can learn from the experiences of the disability-specific NGOs and DPOs in this research, so that they will be better prepared when they embark on a similar journey.

7.5 The Desired Role: Embedding the Human Rights Perspective

The CPRD provides international recognition of the rights of disabled people. Disability-specific NGOs and DPOs have long been working towards the recognition and achievement of these rights. They now have the option to become involved in the actual implementation of the CRPD, which implies a change of roles from influencing or supporting the development of the CRPD to putting the rights of persons with a disability into practice. This new role was one of the main issues that were explored as part of this action research project. In this section, we will consider the desired role that the organisations formulated in mutual learning sessions and organisational assessments.

From the discussions, it appeared that the desired role involves a change in the identity of the organisation and in its strategic direction. In terms of identity, organisations changed from being implementers/activists to being facilitators of change. In terms of the strategic direction, organisations changed from executing activities for persons with disabilities to executing activities for social actors who may then include persons with disabilities in their
work. While they are familiar with working with rights-based values, they now actively aim to convey the rights-based approach to disability to other organisations. Therefore we want to stress that change in this context does not mean that the original values were left behind: the organisations described their new role as deepening their origin. For example, CCBRT in Tanzania had a great deal of programme experience with the empowerment of persons with disabilities in the community and wanted to translate this into supporting the inclusion of persons with disabilities in mainstream development, showing the abilities of persons with disabilities. ECDD in Ethiopia was already involved in promoting disability inclusion from a rights perspective and wanted to expand their role of a facilitator to support the actual implementation of what they were promoting.

From extensive discussion in the learning community and within the organisations, it became evident that the new role implied doing things fundamentally differently, rather than adding a ready-made activity to their toolbox. Being a facilitator of disability mainstreaming implies a new way of working and thinking that needs to be internalised by all employees and to be embedded in the organisation’s programmes. This had implications for strategic structures, responsibilities, existing activities, human resource management and funding structures. Hence, the new role has a considerable impact on the organisations, which can be seen in table 7.1 wherein the current and the desired role are compared. The discussions on the desired role formed a strong basis for the organisations to adapt their strategic direction accordingly.

A change like this does not happen overnight. All organisations expressed their worries and uncertainties about this radical change. Furthermore, they questioned the relevance of their other activities. If an organisation has become a facilitator, is it still feasible to continue to execute long-standing programmes with the original focus? Can the organisation still aim to protect the individual rights of the disabled?

The organisations were also confronted with challenges regarding collaboration with their partners when putting this new role into practice. This occasionally led to tensions with the beneficiaries enrolled in existing programmes and partners or supporters that were involved in the organisations over a longer time. For example, CCBRT in Tanzania had always been the sole provider of community-based rehabilitation for persons with disabilities. Now their beneficiaries of their disability-specific programme did not always want to be included in mainstream development practices because they were afraid of losing their existing benefits. The DPO NUDIPO in Uganda noticed that their members, who were often focussed on single impairments, were afraid that their group would be forgotten in more general
mainstreaming. Through extensive discussion on the desired state with all stakeholders, the organisations slowly regained clarity of their identity and strategic direction.

Table 7.1: Comparison between current and desired role

<table>
<thead>
<tr>
<th>Disability-specific approach</th>
<th>Facilitator of disability mainstreaming from a rights-based approach</th>
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<tbody>
<tr>
<td>Identity related to empowering persons with disabilities</td>
<td>Identity founded on building bridges between disability issues and mainstream</td>
</tr>
<tr>
<td>Disability as cross-cutting issue</td>
<td>Human rights as cross-cutting issue</td>
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<tr>
<td>Focus on disability-specific issues</td>
<td>Focus on how disability-specific issues fit in with mainstream initiatives</td>
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<tr>
<td>Disability-specific focus in policies and strategic plans</td>
<td>Human rights of persons with disabilities in policies and strategic plans</td>
</tr>
<tr>
<td>Advocate for disability-specific needs.</td>
<td>Assisting mainstream organisations to include persons with disabilities</td>
</tr>
<tr>
<td>Implement disability-specific programmes.</td>
<td></td>
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<tr>
<td>Clear individual responsibilities</td>
<td>Shared responsibilities in a network</td>
</tr>
<tr>
<td>Funded for disability-specific activities</td>
<td>Paid for their work as advisors for disability mainstreaming</td>
</tr>
<tr>
<td>Employ (medical) specialists on disability issues</td>
<td>‘Practice what you preach’: employ persons with disabilities</td>
</tr>
<tr>
<td>Focus on accessible programmes</td>
<td>Focus on accessible organisations</td>
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</table>

Within one year, most employees of the organisations and their partners had found a collective drive, confidence and fostered the ambition to realise the new desired role. The motivation of staff and management was vital in accomplishing this. The new perspective of human rights at the core of the organisation required a new attitude from employees. In particular, persons with disabilities employed by the organisations were easily motivated and committed to work on the implementation of their human rights. Regular reflection upon the desired state during the process of change helped to link conceptual thoughts about the rights-based approach to concrete activities of disability mainstreaming, and stimulated ownership. This relates to the consensus among scholars that desired states are
not static, as they evolve during reflections on the organisational development process (Senge, 1990; Todnem By, 2005). The immaturity of the field of disability mainstreaming was experienced as an obstacle for change, as there were few success stories to build on and organisations needed to be constantly inventive.

The organisations enrolled in this research were all able to change their strategic direction and formulate a new desired role that deepened their current practices. However, even before they became part of the learning community, they had felt the urgent need for such a change. For organisations that are new to the rights-based approach to disability, it may be more difficult to start the process, particularly if involvement in disability mainstreaming itself is under debate. Then it is important to first focus on attaining the commitment to change before embarking on adopting a new role and responsibilities.

Parallel to the formulation of a desired role, from a specific disability focus to a human rights focus, there was also a need to initiate practical changes. The organisations directly experimented with new activities to bring this desired role into effect. The outcomes of these experiments led to new discussions on the desired role.

### 7.6 Practical Changes to Implement the New Role

When the disability-specific NGOs and DPOs started to put their new role into practice, they made many, albeit sometimes small, practical changes. Through these changes, the new role was embedded in their work. These practical changes were supported by certain capacities of staff. The practical changes can be grouped into three categories:

- The organisations adapted and renewed training activities.
- The organisations found ways of guaranteeing their funding so that they could actively support the inclusion of persons with disabilities in mainstream development.
- Attention was paid to new and existing partnerships with mainstream, non-disability focused organisations to stimulate disability mainstreaming.

Furthermore, external factors influenced the process of change, providing windows of opportunity that positively influenced the implementation of the new role. In this section, we will show the changes that disability-specific NGOs and DPOs implemented to embed their new role in more detail (see table 7.2).
Implementing New Ideas

In line with the CRPD (2006, article 4, 32) and their newly formulated role, the disability-specific NGOs and DPOs aimed at capacity-building of mainstream development organisations to include persons with disabilities. Through the adaptation of existing training activities and the development of new ones, the organisations supported this capacity-building process. The disability-specific NGOs, like CCBRT in Tanzania and UPHLS in Rwanda, maintained a focus on the delivery of inclusive services for persons with disabilities. However, they now paid specific attention to sharing their experiences with other stakeholders.

Table 7.2: Practical changes to implement the new role

<table>
<thead>
<tr>
<th>General strategies towards a human rights perspective</th>
<th>Implemented, for example, by:</th>
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<tbody>
<tr>
<td>Creating pre-conditions for implementation</td>
<td>Adding disability mainstreaming in existing materials</td>
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<tr>
<td></td>
<td>Developing new materials on disability mainstreaming</td>
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<tr>
<td></td>
<td>Preparatory research</td>
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<tr>
<td>Executing new activities</td>
<td>Training for different stakeholders</td>
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<td></td>
<td>Support in the implementation of inclusive programmes</td>
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<tr>
<td></td>
<td>Participating in political activities</td>
</tr>
<tr>
<td>Attracting financial resources</td>
<td>Identifying funding opportunities</td>
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<tr>
<td></td>
<td>Following additional training</td>
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<tr>
<td></td>
<td>Applying for funding</td>
</tr>
<tr>
<td>Creating partnerships with stakeholders</td>
<td>Initiation of new partnerships</td>
</tr>
<tr>
<td></td>
<td>Taking time to reach consensus on the same ground</td>
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<tr>
<td></td>
<td>Making partnerships official through</td>
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<tr>
<td></td>
<td>Training agreements</td>
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<tr>
<td></td>
<td>Implementation plans</td>
</tr>
<tr>
<td></td>
<td>Memoranda of Understanding (MOUs)</td>
</tr>
<tr>
<td>Creating partnerships with peers</td>
<td>Exchanging experiences</td>
</tr>
<tr>
<td></td>
<td>Learning from each other’s processes</td>
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Firstly, training materials were adapted and developed to create the conditions for implementation. The existing training materials were checked to ascertain whether they were consistent with the integration of the rights-based approach to disability. In addition, new training materials were developed on mainstreaming disability, aimed at different stakeholders concerned with the implementation of the CRPD. Furthermore, preparatory research was conducted to assess the training needs and interests of target groups and partners.

After the preparation, the organisations started to experiment with the new training materials in accordance with their new role. They mostly focussed on awareness-raising to change attitudes towards persons with disabilities. In cases where inclusion was perceived as urgent, they also started to support their partners practically in including persons with disabilities in their work. Multiple stakeholders were involved, including state, regional and local government; DPOs; international NGOs; businesses; trade unions; transport departments; healthcare centres; universities; teachers; and religious leaders. Sometimes the organisations were asked to provide training and at other times they offered their services.

In these training activities, the disability-specific NGOs and DPOs acted as facilitators of change. They aimed to show the participants the importance and feasibility of inclusion of persons with disabilities and to break down the barriers that prevent the participation of disabled people. As a result, they expected that persons with disabilities could be included in development practices. In order to accomplish this, they provided tailored support to their partners.

The organisations often used role models to demonstrate both the barriers to inclusion and the capabilities of disabled people (see box 7.1). Role models helped to focus the participants’ attention on their own responsibility in terms of disability mainstreaming and the possibilities of inclusion. Awareness-raising initiatives, which involved persons with disabilities as role models or facilitators, were regarded as highly effective by the organisations and their partners. Exposure to persons with disabilities worked as an eye-opener, showing the need for equal opportunities and the capabilities of disabled people.

In the learning community, the disability-specific NGOs and DPOs exchanged their experiences with carrying out these adapted or new training modules. Furthermore, they created room for reflection within the daily practices of the organisations. The organisations considered that experimentation and reflection played a valuable part in the embedding of
their new role. In particular, reflection on how the new activities resulted in clear outcomes in different organisations motivated further transformation towards the new role. However, the learning process was also felt to be time-consuming and the staff workload was high throughout the process. The organisational assessment showed many aspects in need of change and the organisations were very ambitious. In the end, the organisations were proud of the progress made within the learning community. Even though the pressure was high, they felt strengthened by the connection to like-minded organisations in this process of becoming facilitators of disability mainstreaming.

Attracting Resources to Support Disability Mainstreaming

To ensure the sustainability of the new activities, financial sustainability was addressed. The organisations worked hard to attract resources and support. This was a new and challenging process for all organisations involved. In their original role, their funding was related to programmes with clear outcomes for their beneficiaries: persons with disabilities. The new role implied finding resources to support others to mainstream disabilities in their work. Initially, the organisations were hesitant to exploit this change of focus.

At the start of the action research programme, the disability-specific NGOs and DPOs were concerned about the likelihood of obtaining funding for disability mainstreaming. At the time of the organisational assessment, they addressed the weakness of their ability to attract resources and support. One year later, the motivation of staff was praised by the management of the organisations and was seen to be an important factor in obtaining

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**Box 7.1: Example of using role models in training to show responsibilities**

As priority was given to first creating a safe environment for Aragesh, she shared her constraint with the rest of the class only during the second session:

“When we organised a training programme of a faith-based NGO, we asked one of the church members, a famous blind singer, to give a lecture on disability and theology. He delivered a very impressive speech explaining that some important biblical persons had disabilities: Moses stuttered, Paul was blind for some days. The impact of this speech was enormous. It really touched people’s hearts. During the final prayer, the participants asked for forgiveness for the discrimination they had exercised towards persons with disabilities in the past. We strongly believe that these church leaders will do their utmost to include persons with disabilities from now on.”
resources to support the new role. For instance, at ADD in Uganda, staff attended a training course on European Union (EU) proposal-writing. With the umbrella DPO NUDIPO as partner, their programme proposal on disability mainstreaming was approved for funding by the EU. Another example concerns ECDD in Ethiopia, who were slightly insecure about asking for financial support. They performed services for a client but left the initiative for payment with them. To their surprise, they were paid for their activities. This encouraged them to ask for a budget on subsequent occasions.

Finally, the organisations considered the financial implications of the start-up phase of disability mainstreaming projects to be challenging. They needed success stories to build new relationships and to obtain funding for programmes. On the positive side, the organisations noticed that, due to the ratification of the CRPD, donor NGOs were devoting more attention to project proposals focusing on inclusion.

**New Partnerships**

As we have seen in the previous section, the organisations envisioned their role as being more than just awareness-raising through training. They highlighted the importance of partnerships for the inclusion of persons with disabilities. Traditionally, the disability-specific NGOs and DPOs had maintained partnerships with other like-minded organisations, either for referral or in terms of activism. Now they wanted to build more transdisciplinary partnerships to jointly realise the inclusion of persons with disabilities. They therefore focused attention on forming new partnerships and on developing existing partnerships in accordance with their new role (see table 7.2).

Partnerships were initiated in different ways. In the beginning, the emphasis was on finding new clients to support the implementation of the CRPD. Later, they focussed more on developing strong relationships with others for joint implementation of the CRPD. Some organisations added disability mainstreaming as a new component to their already existing partnerships. For instance, one DPO’s partnership for advocacy adopted a more supportive character in terms of the implementation of the CRPD. Furthermore, UPHLS in Rwanda; NUDIPO in Uganda; and ECDD in Ethiopia; took part in decision-making processes as representatives of disabled people in the development and implementation of legislation and policies supporting the CRPD.

Building transdisciplinary partnerships was experienced as new and was out of the comfort zone of the disability-specific NGOs and DPOs. The involved staff members were anxious and excited to collaborate with new people that were not necessarily like-minded. Gaining
the trust of others and balancing power and control were experienced as highly challenging. On the other hand, the formation of new partnerships was also very satisfying. The staff members were able to experiment in terms of positioning themselves in their new role. In this way, they built up their confidence as partners in the implementation of the CRPD.

In the end, the organisations learned that they needed to take time and to be patient in the process of alliance-building. They experienced that building real partnerships, based on similar values and equality, is a lengthy process of balancing all interests and powers. Diversity of viewpoints and, at the same time, commitment to shared goals was experienced as beneficial for developing partnerships.

In addition to partnerships with stakeholders, the organisations reflected on the positive influence of partnerships with peers in the learning community; they all emphasised the importance of the exchange of experiences. The discussions of each other’s first results, successes and challenges in adopting a new role were important factors in terms of their own process. Although the contexts differed, they found it very helpful to be connected to others undergoing a similar process of change.

**Dealing with the External Environment**

The influence of external factors was apparent for all disability-specific NGOs and DPOs. It provided the organisations with a window of opportunity to start adopting their new role in the implementation of the CRPD. The LFTW programme staff thought that the organisations were very creative when it came to embracing windows of opportunity. They were well aware of their context and they structured their new activities wisely, in the face of external opportunities.

A number of external factors created a sense of urgency in the inclusion of persons with disabilities in mainstream development practices. For instance, in Uganda, disability became a cross cutting issue in the poverty reduction strategy and in the health sector strategic plan (International Monetary Fund, 2010). Kenya formulated a new constitution with much more attention devoted to inclusion of persons with disabilities (Fitzgerald, 2010). The three organisations in these countries used this attention for inclusion of persons with disabilities as a means to build commitment for a rights-based approach. This attention reinforced their awareness-raising activities and highlighted the responsibilities of mainstream organisations. In Ethiopia, new civil society organisation directives hampered the work of NGOs but, despite this, ECDD managed to take advantage of opportunities by negotiating financial incentives for the employment of persons with disabilities within the
government (personal communication ECDD, May 2012). This encouraged their partners to employ persons with disabilities, and thereby contributed to the inclusion of persons with disabilities in development practice. Also at ECDD, the director received an assignment from the US government as an advisor on inclusion; this strengthened their links with the government, NGOs and the USA.

7.7 Conclusion

Disability-specific NGOs and DPOs play an important role in breaking down the barriers that prevent persons with disabilities being recognised and accepted as equal members of society. Previously, these organisations saw themselves as being responsible for advocacy or for supporting persons with disabilities in claiming their rights. Given that these rights are now ratified in the CRPD, disability-specific NGOs and DPOs are considering expanding their role in creating an equal society for all. Some of the organisations now aim to be involved as facilitators of disability mainstreaming in development.

This chapter relates the experiences of six organisations as they rose to the challenge of adopting a new role as facilitator of disability mainstreaming in development. This new role led to change in terms of the adoption of a rights-based perspective, and practical changes for implementation.

With the adoption of the new role, disability-specific NGOs and DPOs have to change their identity (from implementer/activist to facilitator of change) and strategic direction (from focus on persons with disabilities to focus on social actors that implement the CRPD). While they are used to working bearing rights-based values in mind, they now actively aim to transmit the rights-based approach to disability to other organisations. The human rights perspective now needs to pervade all of their activities. To ensure the embedding of this new perspective, there is a need for strategic changes to all aspects of the organisation.

Such strategic changes have implications in terms of the practical changes that are required to implement the new role of facilitator of disability mainstreaming, alongside existing activities. The lessons from experimenting with this new role are described below and presented in box 7.2. Practical changes are important to ensure that the new perspective is embedded at all levels of the organisation. The disability-specific NGOs and DPOs learned that adaptation of existing training activities and development of new training materials, explaining the rights-based approach to disability, are necessary to build the capacities of mainstream organisations. They experienced that, to enhance the impact of training
participative methods, the use of role models is effective in emphasising the equality of persons with disabilities. At the same time, the disability-specific NGOs continued to maintain their focus on the delivery of inclusive services for persons with disability. However, they now paid specific attention to sharing their experiences with other stakeholders.

<table>
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<tr>
<th>Box 7.2: Lessons learned in adopting the new role as facilitator of disability mainstreaming</th>
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<tr>
<td>• Move the rights-based approach to disability from internal mission to conveying this perspective to the outside world.</td>
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<tr>
<td>• Formulate a desired state that relates to the identity and strategic direction of an organisation.</td>
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<tr>
<td>• Embed the rights-based approach to disability by making strategic changes to all aspects of the organisation.</td>
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<tr>
<td>• Include the rights-based approach to disability in training curricula.</td>
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<tr>
<td>• Design the training sessions in a participatory way and use role models as eye-openers for mainstream development organisations.</td>
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<tr>
<td>• Obtain funding for supporting others in disability mainstreaming.</td>
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<tr>
<td>• Build transdisciplinary partnerships for inclusion.</td>
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<tr>
<td>• Embrace opportunities for disability mainstreaming in the external environment.</td>
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To execute new activities of training and support, new resources need to be found to build capacities in disability mainstreaming, rather than simply directly benefitting persons with disabilities. In the new role, funding is needed to support facilitation of disability mainstreaming within other programmes. The disability-specific NGOs and DPOs were, at first, hesitant to market their new approach but they gained confidence through experimentation. They learned that their new services were valuable for their clientele and that they were professional enough to market their services.

To increase their capacity to facilitate programmes on a larger scale, they needed to build more transdisciplinary partnerships. Together with others, they aim to bring about the inclusion of persons with disabilities in development. In these new partnerships, the disability-specific NGOs and DPOs learn to experiment with their new role; this can be challenging and rewarding at the same time.
The new facilitators of disability mainstreaming can learn to make use of the opportunities that arise from the external environment. The growing attention regarding the CRPD helped the disability-specific NGOs and DPOs in their awareness-raising efforts. The fact that governments of all participating countries had ratified the CRPD opened new doors for NGO and DPO cooperation with governments. Furthermore, they could use this attention to build the capacities of different stakeholders regarding the rights-based approach to disability, to form new transdisciplinary partnerships, and to support decision-making processes as representatives of persons with disabilities.

The facilitator of the learning community in East Africa, LFTW Netherlands, learned how they could support their partner organisations in exploring this new role. They are now gradually expanding the learning community in East Africa to support the implementation of the rights-based approach to disability in their partner countries. Owing to the success of this programme, LFTW Netherlands has also started to build a similar learning community in Asia.

We hope that the experiences of the learning community described in this chapter can support the growing number of disability-specific NGOs and DPOs that are changing their roles in response to the greater demands for disability mainstreaming. We have tried to highlight the experiences of the organisations involved as they experimented with their new role in disability mainstreaming. This provides an example for other organisations that are experimenting with their role in the implementation of the CRPD. However, adapting to a new role will always invariably be affected by interrelationships and unpredictable, unintended events. Other organisations embarking on the same process should also share their experiences. Together, disability-specific NGOs and DPOs can shape their new role in promoting, protecting and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities.