



Epilogue: Torn between rights and reality

In this thesis I⁴ have tried to contribute to the understanding of the process towards disability inclusive development for NGOs. In this thesis I describe how change processes towards disability inclusive development of NGOs and their programmes can be supported and what possible strategies can be identified to facilitate the change. The epilogue will shed insight on the facilitation of learning in the TLP on inclusion of persons with disabilities by showcasing an example of lessons learned on the costs and benefits of disability inclusive development. It is written in the form of an essay to show how the community of practice, including me as a researcher, of the TLP on inclusion of persons with disabilities learned together about the meaning of disability inclusive development.

Setting the scene

‘Being a blind person does not imply being concerned with the costs to make the world accessible to me’, said my colleague, Yetnebersh, executive director of the Ethiopian Centre for Disability and Development. Yetnebersh is a blind woman and a well-known media personality and activist in her home country. We were together because of our common involvement in the facilitation of the Thematic Learning Programme (TLP) on inclusion of persons with disabilities. In this programme, mainstream development organisations in the North and their partners in Ethiopia and India learn about their experiences of including disabled persons in their mainstream programmes. Personally, I fully agree with the statement of Yetnebersh that society should ensure an accessible environment for all, regardless of costs. Her view is even supported by a legal instrument, the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which reaffirms the human rights of persons with disabilities (UN, 2006). However, a recurring question throughout the TLP network was: *‘What are the costs and benefits of inclusion of persons with disabilities in development?’*

⁴ In the introduction of this thesis I presented the rationale for practicing the ‘we’ form in this thesis. Though, since this epilogue is an essay that represents my individual viewpoints I have used the ‘I’ form in this chapter only.

Rajendra, my colleague and former executive director of the South Asia Regional Office of Leonard Chesire Disability in India also joined the discussion. He has thirty three years of experience in humanitarian programmes related to disability and development in Asia and Africa.

‘Although I think Yetnebersh is right, we need to be realistic. No matter who is responsible for the barriers that exist, there are costs to remove them from our world.’

This is a valid point. Inclusion of persons with disabilities is a humanistic goal and all individuals should be able to develop to their full potential. However, if disability is to appear on the development agenda, there needs to be an open discussion of the costs involved. We cannot ensure definitely that all barriers for persons with disabilities can be removed by society. Furthermore, sometimes adaptations conflict with each other. For instance, ridged tiles to support the visually impaired may hinder someone in a wheelchair.

The inclusion of persons with disabilities needs to be approached in a practical manner if ideals are to be translated into practice. As Rajendra also pointed out, broader support for disability issues in development is needed if the CRPD is implemented: *‘My whole point is to recognize disability as any other development issue. As you are aware, disability is last and lost on the priority list of the development agenda.’* This is an important issue because most support for inclusion comes from family and disability networks. State inputs are insufficient and policy design usually fails to consider the needs of persons with disabilities (WHO, 2011).

In response to the discussion between Yetnebersh, who does not want to talk about costs and benefits of inclusion, and Rajendra, who wants to approach the costs and benefits of inclusion realistically, I myself feel torn between the two perspectives. On one hand, I can understand that non-governmental organisations (NGOs) involved in the TLP want to be able to calculate their investments and need to be convinced of the need for their involvement. On the other hand, I feel that this issue violates the rights of persons with disabilities because it appears to offer a choice not to intervene if the costs are too high. It is a challenge to consider costs and benefits of inclusion and, at the same time, do justice to the human rights of persons with disabilities. To find out what tensions underlie this discussion I started a participatory discussion on the costs and benefits of persons with disabilities within the TLP network. During this discussion, I tried to find an answer for my own struggle to balance a rational approach with a rights-based vision.

Posing a question from a rational perspective with a hint of rights based thinking

When I started working with the participants of the TLP on inclusion of persons with disabilities, I expected that there was a general agreement about the rights of the disabled. Disability mainstreaming was proposed as a strategy to make concerns and experiences of persons with disabilities an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes (Albert & Harisson, 2006; Witcher, 2005). This requires that disability issues become integrated in development practice.

The inclusion of persons with disabilities involves multiple stakeholders at various levels (Mwenda et al., 2009; WHO, 2011). Governments should ensure legal implementation, service providers need to support disability mainstreaming with high quality rehabilitation services, the commercial sector should open up for inclusion, disabled people themselves need to share their wishes and needs. Last but not least, NGOs have an important role to play. They can set a good example by sharing good and promising practices and providing technical assistance to countries that are implementing the CRPD (WHO, 2011). In this way NGOs are forming a central point between the different stakeholders involved.

The TLP network focused on NGOs because of the important role they can play in the implementation of the CRPD in international cooperation. The participating NGOs were convinced of the importance of addressing disability issues in mainstream development, so I thought they could set the stage by showing good examples of the implementation of disability rights. Therefore I assumed they would take the rights-based approach as foundation in their work.

However, this assumption was not self-evident in reality. When we were discussing how to implement disability mainstreaming the costs and benefit discussion arose. For some, this was a shameful question and they did not dare to pose this question on their own initiative. Others did not consider their role in disability mainstreaming to be very obvious, and they tried to challenge their responsibility by playing the devil's advocate. Several participants took a more practical attitude towards this question, considering that the benefits need to outweigh the costs. For yet another group, this issue was of less importance because the underlying values of inclusion are all important and beyond question. A member of programme staff expressed this as follows: *'My colleagues see disability mainstreaming as a fundraising opportunity. I do not feel comfortable to approach a human rights issue in such a way.'*

In a similar way, Hubin (1994) and Seymour and Pincus (2008) argue that weighing the costs and benefits of disability inclusion might be immoral and that it is a challenge to discuss human rights in economic terms. I understand these critiques but, as human rights cannot be imposed (Hathaway, 2002), any approach which can act to make inclusion feasible is acceptable to me. Even though I really agreed with the last group, that the values underlying inclusion are beyond question, I did not want to ignore the persistent call for a rational overview of the costs and benefits of inclusion. Their needs were illustrated by the questions they posed, as the following examples show.

'We want to include persons with disabilities in our programmes. But what are the costs of necessary adaptations?' (expressed by the management)

'We noticed that our teachers are not equipped enough to teach inclusive classes. What are the costs of training?' (posed by the programme staff)

'If we mainstream disability in our organisation, our target groups will expand. How can we afford to accommodate all needs of persons with disabilities?' (stated by the field staff)

As many of the participating NGOs expressed the need for such an overview, I felt we needed to take this seriously to keep them all on board. I hoped that a cost and benefit analysis would take into account the practicalities of the implementation of inclusive development in a rational way. This connects to the focus of the Dutch Ministry of Foreign Affairs, an important donor for many of the participating NGOs, on social return on investment (Ministerie van Buitenlandse Zaken, 2007).

Social return on investment seeks to reduce inequality and environmental degradation and improve wellbeing by incorporating social, environmental and economic costs and benefits (Nicholls, Lawlor, Neitzert, & Goodspeed, 2009). I hoped that a realistic exploration of the costs that are involved and the benefits this would generate would help participants in the TLP on inclusion of persons with disabilities to determine their position in this struggle between reality and rights based thinking. At the same time, this would help my personal quest to explore the tension between rights and reality.

Checking reality: the background of cost benefit analysis

Cost benefit analysis originates from mainstream economics, such as welfare economics, public finance and resource economics. It involves the quantitative or qualitative enumeration of all relevant costs and benefits, and is considered to be a practical way of assessing the desirability of projects from a long-term view and a wide perspective (Prest & Turvey, 1965; Rogers, Stevens, & Boymal, 2009). Although cost benefit analysis is challenged by some scholars (Brent, 1998) because it highlights the number of people affected by a development project, as a separate social objective (Brent, 1998) it is practiced regularly in development. I hoped that it would be an appropriate, practical approach to address the NGOs' concerns about the costs of disability mainstreaming.

Conventional cost benefit analysis focuses on a determined set of costs and benefits. It might reflect power differences rather than consensus because it does not pay attention to stakeholders representation in the process (A. Sen, 2000; Stewart, 1975). Inspired by the discussion between Yetnebersh and Rajendra and based on an extensive literature search and expert interviews, I instead opened a participatory discussion on the costs and benefits of inclusion. During these discussions, I focused on exploring all possible costs and benefits of inclusion. I hoped that through discussion the NGOs would determine their position and ambition level concerning their role in the implementation of the CRPD.

The fluidity of the implementation of the cost benefit analysis

As the discussions developed, I noticed that it was not possible to offer an overview of the costs and benefits of inclusion in international cooperation because the lists of costs and benefits became too long, too complex and too confusing for the NGOs. There were two reasons for this complexity.

First, there was a substantial variation in costs and benefits of inclusion in different contexts. A hospital in New Delhi, for instance, will have radically different costs and benefits of disability mainstreaming than a small farmer cooperative in rural India. A donor organisation at the macro level will have different costs and benefits than a small NGO working on inclusive education in rural Ethiopia. When we tried to list all barriers to equal participation of persons with disabilities, the challenges seemed insurmountable.

Given the different contexts, the costs to remove the barriers could not be standardized. In the discussions, however, NGOs were able to distinguish between the costs that would devolve to them and the costs that would accrue to others. For example, do they feel responsible for the costs of assisting devices (like crutches and wheelchairs), or do they opt for a strong referral network with specialized care providers to meet these needs?

This is illustrated by two examples. A programme manager from an Indian NGO told me that his organisation wanted to provide medical assistance: *'When we started to include people with disabilities in programmes in rural areas, we realised there are some special services they require. So depending on the disability we will look around for a wheel chair (or other appliance). We are not an organisation working on disability specific actions but we will do it [undertake action; SvV] because there is nobody else who will do it for us.'*

Field staff of an NGO in Ethiopia chose not to do anything themselves but, instead, build a strong link with a disability specific organisation: *'In our water and sanitation programme we raised awareness on the inclusion of persons with disabilities and a disabled man was appointed supervisor of one of the water points. A side effect was that people with disabilities started asking for wheelchairs and medical treatment. As a water and sanitation programme, we were not in a position to deal with these requests. Therefore, we referred persons with disabilities to a disability specific organisation for assistive devices and medical treatment.'*

These examples show how organisations, after discussing the contextual implications, can determine the costs they are facing to include persons with disabilities in their programmes. Both examples show that the NGOs aim to meet the needs of persons with disabilities so that they can participate equally in their programmes. From these discussions, I learned about the differing needs in different environments and how human rights can be taken into account while being realistic about the costs involved.

Second, the dynamics of the process of disability mainstreaming also profoundly influences the debate. Many costs and benefits can be identified in a rational manner, as can the complicated and indirect relations between them. In education, for example, costs relate to adaptation of the curriculum, training of teachers, raising awareness of the importance of inclusive education, and special assistance in the classroom. Some are required initially, such as training costs, whilst others are permanent, such as support in the classroom. Some costs and benefits relate to the process of mainstreaming disability in programme implementation, others to organisational change and, finally, there is a macro process of

change required if society is to become more inclusive (WHO, 2011). This is illustrated by a programme manager from an Indian NGO: *'It is important to realize that disability mainstreaming is a process; you can't go from segregation to mainstreaming without doing all the steps in between. We have to be allowed to go through the journey ourselves, not to make the same mistakes as others, but it's through the journey that attitudes change.'*

This shows that adopting disability mainstreaming is more than a matter of concrete, measurable adjustments. It is a process of organisational change in which organisations needed to change direction, structure or capabilities to better serve their beneficiaries.

The participatory process of discussing the costs and benefits of inclusion created space for the organisations to gain insights into the changes that were needed for them to become inclusive organisations. By facilitating discussions in which several stakeholders were involved, I recognized differences in pace and ambition for change. I saw that becoming an inclusive organisation is a fluid, dynamic process, with many ups and downs. Often disability mainstreaming was seen as one of the many issues on the agenda. Changing priorities decreased the pace in which disability mainstreaming took place. The metaphor one could use is sailing the ocean; it can be quiet and serene at one moment but rough and bumpy the next. The destination is not always in sight and the wind may blow you off course.

When determining the different costs in the process of disability mainstreaming I realized that taking a human rights approach is not 'one choice in time'. When the path towards the inclusion of persons with disabilities becomes clearer, more obstacles arise but also opportunities to deal with them. I wanted the NGOs to make a rational choice, but when we got deeper into the discussion of the process the driving force of the rights-based approach became visible in the discussions.

From reality to rights: values that underlie the discussion

The driving force of disability mainstreaming became visible in the underlying values that supported decision making in the discussion on the rational costs and benefits. The values that formed the basis of the discussions on the costs and benefit of persons with disabilities correspond to the three models of disability (medical, charity and social), described by several scholars (Bickenbach et al., 1999; Shakespeare, 2006; Thomas, 2007). Even though

we can clearly distinguish three groups of values, we also found that all participating organisations showed an indication of rights-based thinking.

The organisations with a rights-based perspective think that inclusion is meaningful both to persons with a disability and to society. This can be illustrated by the following quote from a programme manager of disability mainstreaming in an Indian NGO: *'It becomes the responsibility of the society and the state to promote human rights and to invest initially to make it an inclusive society. Every state's responsibility is to ensure and accept disability as a human diversity and to make appropriate investments on creating an inclusive society. NGOs should advocate for this and give a good example.'*

The emphasis on social responsibility and recognition of human diversity shows the value of human rights that underlies the reasoning of this participant.

Other organisations were more concerned with responding to those most in need. They refer to the need for compassion to help the poor: *'Mercy and righteousness are our values. Reasoning from our values and vision, we want to do justice to those who have fewer chances in society. Persons with disabilities are among the people with fewer chances.'* (remark from a decision maker from a Northern NGO)

By linking mercy to vulnerable people, this statement illustrates the charity paradigm. From this perspective, persons with disabilities are described as unfortunates or victims of circumstance for whom society must care as a moral responsibility (Mattioli 2008, p. 10). However, the reference to righteousness and justice also links to rights based thinking.

A third group of organisations referred to the costs of the special assistance required in disability mainstreaming. For example: *'They [disabled persons; SvV] should be offered a chance to participate, by giving them crutches or a wheelchair. But there is also a group that needs nothing at all. If you look at children with a physical impairment for example, they do not need any special adjustments to participate in education.'*

By referring to assisting appliances and certain types of disabilities, this programme manager from an Ethiopian NGO shows her medical viewpoint. From this perspective, disability is a description of deficiencies of an individual at the physical, mental, psychological, and sensorial level, which limits his or her activities (Mattioli, 2008). However, the reference to children with disabilities who can participate in education without special adjustments shows that this participant is moving towards the inclusion of persons with disabilities from a rights based approach.

The viewpoints mentioned here illustrate that the paradigm or fundamental values one adheres to influences the interpretation of the costs and benefits of inclusion. For example, somebody with a medical background perceives very high costs for medical assistance and corrections to make persons with disabilities fit into society. Discussions of these paradigms with different stakeholders in the TLP aided the NGOs gain insights into their fundamental beliefs about inclusion. This helped them to understand different possible perspectives on costs and benefits. For example, this discussion led one organization to understand that persons with disabilities are not a separate group but represent diversity among their beneficiaries. Another organisation came to understand that it is their responsibility to invest in disability mainstreaming.

For me it became apparent how the rights-based perspective to disability becomes visible in the values underlying a discussion of cost benefits analysis. Through the discussions on values, the urgency for disability mainstreaming became clear for me and the participants. It is to be expected that NGOs show respect for values like equality, dignity and justice because they aim to empower the poorest of the poor (Welch, 2001). Connecting these values to the rights of persons with disabilities enhanced the development of sincere viewpoints and an action perspective for implementation of the CRPD. It stimulated organisations to think out of the box and to determine their own values in relation to the inclusion of persons with disabilities. The fact that all organisations referred to the rights-based approach shows that awareness was raised about underlying values and that they were respecting the human rights of persons with disabilities. When I realised that the discussion on costs and benefits had facilitated NGOs to adapt their underlying values to accommodate the inclusion of persons with disabilities, my personal struggle came to an end. Through the pragmatic estimation of the costs and benefits of inclusion, I found the underlying foundation that justifies rights-based thinking.

Crystallizing my point of view

In this essay, I have explored the struggle between rights and reality in disability mainstreaming for development. It started with an individual struggle to balance the request for enumeration of the costs and benefits of inclusion with my rights-based values. In the quest to find my own balance, I took the NGOs through a dynamic discussion. In this way, my individual struggle became a collective one.

I soon discovered that conventional cost benefit analyses do not fit rights-based subjects. However, I did decide to conduct a cost benefit analysis - a participatory one - because of the expressed needs by the participating NGOs. It appeared that the discussions about the costs and benefits of inclusion of people with a disability functioned as a sounding board for NGOs to determine their current position and ambition level in the implementation of the CRPD. Whilst on the one hand I felt it was immoral, talking about the costs and benefits of inclusion, this particular perspective did help the NGOs to better understand their own reality and possibilities with regard to disability mainstreaming, which I had hoped for from a human rights perspective. From the participatory discussions, I learned how the complexity of both the context and the process of disability mainstreaming hamper the development of a clear, unambiguous overview of the costs and benefits. In the search for this overview, rights-based reasoning illuminated the rational arguments. Finally, when we were discussing the values underlying the analysis of cost and benefits, I saw how rights-based values became more important than the rational overview. The NGOs started to think out of the box and developed their own authentic viewpoints with regard to the implementation of disability rights. With this recognition, our struggle between rights and reality came to an end.

In conclusion, I think we cannot impose human rights but, through the facilitation of a dialogical process on the costs and benefits of inclusion, people can better understand the urgency and their own responsibility in disability mainstreaming. On the basis of this understanding, they can change their viewpoints. The process of participatory discussion was very valuable in developing understanding of the need for NGOs to become involved in the implementation of the CRPD. This experience created a platform for Dutch mainstream NGOs to become involved in the lobby for the ratification of the CRPD in the Netherlands. Though the Dutch government has not yet ratified the CRPD, NGOs that work in international cooperation are already confronted with the need to become inclusive for persons with disabilities in their work, for instance because of the ratification by the European Union, a major donor for Dutch NGOs. The experiences in the development sector concerning the costs and benefit discussion can be an example for Dutch organisations who will deal with the same struggle when the Dutch government ratifies eventually. For Disability Studies in the Netherlands, I hope my experiences are helpful to assist the Dutch organizational system to overcome this struggle.

During this process, my own personal viewpoint also became crystallized. I am still convinced of the need for a human-rights approach to disability in development. However,

rational considerations can highlight the importance of these rights. I hope that the insights developed here can make the vision of human rights more immediate for development organisations. This should contribute to the implementation of the CRPD. Full implementation of the CRPD will result in a more equal society, with participation of all individuals.