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DISABLED VOICES IN DEVELOPMENT?

*The Implications of Listening to
Disabled People in Burkina Faso*

Lara Bezzina

**THESIS SUBMITTED FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY**

2017

Department of Geography
Durham University

Perhaps the very success or failure of every form of 'development' should
be measured by the extent to which it is inclusive of disability.
(Power, 2001: 93)

ABSTRACT

Development discourse and practice have generally ignored, even silenced, people with disabilities. In response, this thesis draws on the case of Burkina Faso to bring geographies of development and disability into dialogue with postcolonial theory, which seeks to recuperate the voices of the marginalised and oppressed. It adopts a mixed ethnographic methods approach, including participatory techniques and interviews, in order to understand the lived experiences of disabled people in Burkina Faso. The thesis first examines the general context of Burkina Faso and the different aspects of Burkinabe life and society in which disabled people's lives unfold. These aspects are interlinked with the perceptions of disability in Burkina Faso, both in how society perceives disability and in how disabled people view themselves. These perceptions, which are explored subsequently, affect the lived experiences of disabled people, which are often not taken into account by development practitioners who intervene in disabled people's lives using western models and ideologies. Furthermore, development interventions influence the creation and functioning of grassroots disabled people's organisations, and here the thesis looks at the challenges these organisations face with regard to their heavy dependence on external partners as well as the lack of 'organisational spirit'. Finally, the thesis examines disabled people's perceptions of development and the emphasis on economic independence as an essential element in a disabled person's life to challenge the predominant perception of disabled people as a burden. It highlights the significance of opening up spaces in which disabled people's voices can be heard, using techniques such as participatory video, and the significance of having these voices heard by development practitioners. The findings indicate that there is a need to theorise disability from Global South perspectives, as well as to facilitate development through an engagement with the voices and agency of disabled people.

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LIST OF ABBREVIATIONS

ADD	Action on Disability and Development
AfDB	African Development Bank Group
AIDS	Acquired Immunodeficiency Syndrome
BBC	British Broadcasting Corporation
CBR	Community-Based Rehabilitation
CDP	Congress for Democracy and Progress
CEO	Chief Executive Officer
CRPD	Convention on the Rights of Persons with Disabilities
DFID	Department for International Development
DPO	Disabled People's Organisation
ECOWAS	Economic Community of West African States
EFA	Education for All
FEBAH	Burkinabe Federation of Organisations for the Promotion of Disabled People
GDP	Gross Domestic Product
GRO	Grassroots Organisation
GS	General Secretary
GTM	Grounded Theory Methodology
HI	Handicap International
HIV	Human Immunodeficiency Virus
HSB	Handicap Solidaire Burkina
ICS	International Citizen Service
IGA	Income-Generating Activity
IIRE	International Institute for Research and Education
ILO	International Labour Organization

IMF	International Monetary Fund
INGO	International Non-Governmental Organisation
INSD	National Institute of Statistics and Demography
LAFB	The Franco-Burkinabe Friendships
MASSN	Ministry of Social Action and National Solidarity
MFPTSS	Ministry of Civil Service, Work and Social Security
NGO	Non-Governmental Organisation
OCADES	Catholic Organisation for Development and Solidarity
PAR	Participatory Action Research
PD	Participatory Diagramming
PV	Participatory Video
ReNOH	National Network of Disabled People's Organisations
RTB	<i>Radiodiffusion-Télévision du Burkina</i>
SDGs	Sustainable Development Goals
SDKP	Sustainable Development Knowledge Platform
SIAO	International Craft Show of Ouagadougou
UDPO	Umbrella Disabled People's Organisation
UK	United Kingdom
UN	United Nations
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UNRISD	United Nations Research Institute for Social Development
US	United States of America
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION

Disability is, simply put, a vitally important human experience
that Geography cannot afford to ignore.
(Gleeson, 1999: 1)

Disabled people make up the largest minority in the world (United Nations (UN), 2006). They have been “isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group” (Davis, 1997: 1). In spite of all this, disability remains a marginal topic in human geography¹. Significantly, despite eighty percent of disabled people worldwide living in the Global South (UN Enable, 2006), disability has also been neglected by development (McEwan and Butler, 2007), both in practice and in theory. Since Davis’ (1997: 1) proclamation that “[d]isability studies is a field of study whose time has come”, the same studies have become relatively well-established in western academia, and there has been considerable movement towards including disabled people in geographical discourse (for example, Gollledge, 1993) in the last twenty-five years. Gleeson (1999), for example, calls for various sub-disciplines in geography to take up the study of disability. Nonetheless, there is little or no onus on development geography to do the same. In response, this thesis posits a case for why disability in development merits greater attention than it has thus far received, whilst also engaging with critiques of development that have called for a more ethical engagement with the subjects of development.

¹ The Royal Geographical Society (United Kingdom) does not comprise disability as one of its twenty-six research groups (<http://www.rgs.org/OurWork/Research+and+Higher+Education/ResearchGroups/Browse+Research+Groups.htm>).

DISABILITY AND DEVELOPMENT

The need for the active exploration of the experiences of the 400 million disabled people living in the Global South² (Meekosha, 2008) is evident. The relationship between poverty and disability is undisputed (Groce et al, 2011), and both are a cause and a consequence of the other (Department for International Development (DFID), 2000). Nonetheless:

a great deal of the evidence used to support these assertions remains anecdotal and the complex relationships that exist between poverty and disability remain ill-defined and under-researched, particularly the inter-relational dynamics that exist between the causal factors driving this disability–poverty nexus.

(Groce et al, 2011: 1493)

The UN Economic and Social Council (2008) reports that one in five of the world's poorest people is a disabled person. Disabled people tend to be “disproportionately represented among the world's poor and tend to be poorer than their counterparts without disabilities” (ibid: 2). To achieve international development goals, therefore, it must be ensured that disabled people are integrated into all development activities (ibid). However, disability “has been routinely left out of development efforts” (Groce and Kett, 2013: 12). Disabled people in the Global South remain widely excluded from education³ (Education for All (EFA), 2006), employment⁴ (European Commission, 2004), society⁵ (HI, 2014), and are usually the poorest of the poor (DFID, 2000). At a UN level, not only did disability go unmentioned in the Millennium Development Goals, but development “remains far from even considering disability a

² The term ‘Global South’ is used here according to Rigg’s (2007: 3) explanation that the term “is not a strict geographical categorisation of the world but one based on economic inequalities which happens to have some cartographic continuity”. The term ‘developing countries’ is sometimes used in this thesis to reflect an author’s usage of the same term. Other authors (for example Grech, 2011; Sheldon, 2005) use the related term ‘majority world’.

³ More than one third of children who do not attend school in developing countries are disabled; and, in Africa, less than ten percent of children with disabilities attend school (EFA, 2007). The EFA (2010) reports that in Burkina Faso, having a disability augments the risk of children being out of school by two and a half times; and that only ten percent of children with a hearing or speech impairment were in school in 2006.

⁴ In 2009, research found that 76.8 percent of disabled people in Burkina Faso were unemployed (Handicap International (HI), 2014).

⁵ 43.7 percent of disabled people in Burkina Faso said they felt socially isolated (HI, 2014).

development issue beyond the realm of rhetoric” even in the post-2015 Sustainable Development Goals (SDGs) (Grech and Soldatic, 2014: 1). The SDGs include seven direct references to disabled people (UN SDKP⁶, 2016). However, while people with disabilities (and sometimes their needs) are specifically mentioned in the inclusive education goal (Goal 4), the economic growth goal (Goal 8) and the inclusive cities goal (Goal 11), disability was mentioned only as a ground of discrimination in Goal 10 (reducing inequality) and in Goal 17, specifically with regard to capacity building in developing countries in order to gather high-quality data. The SDGs do not seem to take any concrete measures with regard to disabled people in employment, such as reasonable accommodation⁷. In Goal 8, which endeavours to promote “sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all” (UN General Assembly, 2015: 14), disabled people are mentioned briefly in 8.5, which has the goal of achieving “full and productive employment and decent work for all women and men, including for young people and persons with disabilities” (ibid: 20). They are not mentioned in goals such as those dealing with poverty, hunger and malnutrition, health and well-being, gender equality, sanitation and water, infrastructure and inclusive societies, all of which deal with issues that relate directly to disabled people. It might be assumed that disabled people are included in the SDGs as part of the ‘vulnerable groups’. However, while it has been established that disabled people have been, and still are, much discriminated against, it is doubtful whether being referred to as ‘vulnerable’ serves any purpose. Morris (2015: n.p.) argues that:

By using the terms ‘vulnerable’ and ‘most vulnerable’, we are voluntarily taking ourselves back to those days when to be disabled was to be shut out, shut away from society, the object of pity, not part of mainstream society.

⁶ SDKP stands for Sustainable Development Knowledge Platform.

⁷ Waddington and Hendricks (2002: 409) define a reasonable accommodation requirement as prohibiting “an employer from denying an individual with a disability or other relevant characteristic an employment opportunity by failing to take account of the characteristic, when taking account of it – in terms of changing the job or physical environment of the workplace – would enable the individual to do the work”.

Morris' argument seems to reflect what is happening with disability in the realm of development. At an NGO (non-governmental organisation) level, disability is rarely mainstreamed in development work, and the majority of development organisations do not include policies ensuring equal opportunities with regard to disability (Hurst, 1999). In the relatively rare instances when disability has received attention as a development issue, this has been driven largely by the agendas of specialised international non-governmental organisations (INGOs), who are the main suppliers of support for disabled people in the Global South. In this context:

[n]ot only are people with disabilities being excluded from the mainstream programmes to which they are entitled, but such specialised charities also often... operate... with little or no accountability to government or to their consumers.

(Grobe and Kett, 2013: 15)

Interest in disability in African contexts can be traced back to the UN International Year of Disabled Persons in 1981, after which “disability became part of the agenda of governments, churches, and ‘development’ agencies” (Devlieger, 1999: 439). Significantly, indigenous knowledges and experiences were not considered important factors for organising development services for disabled people. Although the UN and other development agencies emphasised cultural sensitivity, efforts have been sporadic (Devlieger, 1999). Grech (2011: 87) argues that:

Communities in the majority world are often bypassed or repositioned to accommodate the neoliberal development project, the history and practices of which remain largely unquestioned.

Support for disabled people by development agencies tends to be formulated in western disability models, which are not always appropriate in a Global South context. DFID (2000: 8), for example, in a report on disability and development, talks about the recent “changes in attitude” toward disability, which emphasise the social model of disability and promote “social change that empowers and incorporates the experiences of people with disabilities, asking society itself to adapt”, without noting that

this change took place in western societies, rather than worldwide. It then cites an example of good practice by a western NGO which “promotes a rights-based approach to sustainable development for persons with disabilities” (ibid). However, in Global South contexts, basic issues such as quality of life might be more significant (McEwan and Butler, 2007) than human rights legislation. As Zimbabwean disability activist Joshua Malinga (in Baird, 1992: 1) points out, “[w]hile people in the rich world are talking about Independent Living and improved services, we are talking about survival”. Often, western disability viewpoints and ideologies are exported to the Global South, ignoring vital societal, political, economic, cultural and historical elements connected to the contexts in which these western concepts and theories were developed (Grech, 2011). In this way, Grech (2011: 87) argues, “the implications for disabled people remain confined to epistemological silence”. Disabled people’s voices and agency are thus often not heard in development.

The hegemony of the western disability ideologies and the approach of transferring ideas from the west to the rest of the world is not specific to disability, but “reflects the continued dominance of Western knowledge and practices” (Grech, 2011: 88). Subsequent critiques of what is claimed to be a western-controlled industry and its lack of cultural sensitivity form part of the wider critiques levelled at development in general. Development interventions in the disability domain do not exist in a vacuum and, thus, it is crucial to understand these in this wider context of development.

DEVELOPMENT: A MUCH-CONTESTED CONCEPT

Defining development is a complex undertaking: “the term actually has no clear and unequivocal meaning and is in a sense truly the stuff of myth, mystique and mirage” (Power, 2003: 1). Among definitions that have been put forward, one finds those such as “the use of resources to relieve poverty and improve the standard of living of a nation” and, “the means by which a traditional, low-technology society is changed into a modern, high-

technology society, with a corresponding increase in incomes”, a notion which is rooted in the western definition of modernisation⁸ (McEwan, 2009: 12).

While earlier perspectives of development focused on economic growth, the concept then broadened to include, among other dimensions, political, social, ethnic, cultural and ecological issues (Potter, 2008). The idea of development rooted in the Enlightenment period in Europe (which remains very relevant to international development approaches today) saw the emergence of the idea of the “West” being placed at “the pinnacle of human achievement” and “modernity”, in contrast to the rest of the world, where regions such as Africa were viewed as “distant, uncivilized and immature in the progress of humanity” (Power, 2008: 73-4). These views were revived after World War II, when much of the Southern hemisphere⁹ was declared as “underdeveloped areas” (Truman¹⁰, 1949: n.p.), opening up the possibilities for the ensuing “arrogant interventionism” of the North (Sachs, 2009: xvii) in the name of development. It is significant here to note the difference between what Hart (2006: 14) calls the “big D” and “little d” development, which builds on the distinction that Cowen and Shenton (1996: viii) make between, respectively, intentional development (and the belief “that it is possible to act in the name of development... and that development will follow” from these actions); and the immanent process of development, an “ongoing, historical process” (Turner et al, 2015: 258) of change, in particular processes of capitalism (Willis, 2013) which are often understood as linear notions of progress (for example from agrarian to industrial to consumer societies). Thus it can be said that the ‘big D’ includes interventions that states, global organisations and INGOs have to make, in order to deal with the inequities and unevenness of the ‘little d’ development. Significantly,

⁸ Chakrabarty (2002: xix) claims that “[w]estern powers in their imperial mode saw modernity as coeval with the idea of progress”.

⁹ A “new geography of poverty” is identified today, that is, the majority of the world’s poor do not live in low-income countries or those labelled as the least developed countries anymore, but in middle-income ones (Alkire et al, 2013: 20).

¹⁰ Harry S. Truman, the 33rd president of the United States, said this during his inauguration speech in 1949.

disabled people, who are amongst the groups most marginalised by capitalist development ('little d') are thus most in need of intentional development ('big D'). However, even the post-2015 development principles are accused of failing:

to take stock of what is actually happening in the informal economies of the developing world and... to address the underlying structural causes of inequality and exclusion.

(Gore, 2015: 726)

Sachs (2009: xvii) claims that "the age of development", is now "on the decline" and that "development's hidden agenda was nothing else than a Westernization of the world". Post-development scholars like Rahnema (1997: ix-x) observe that the "unanimous" support for development has started to disintegrate, for "now it appears clearly that such a unanimity was far from being shared at the grassroots level, where it was supposed to reach the suffering populations"; and call for an end to development (Rahnema, 2000). Nonetheless, Rahnema (2000: 319) himself proposes that the "search for new possibilities of change" continue.

Doing away with development would mean doing away with the possibility of advancement in life chances, health and well-being for people living in the Global South (Sidaway, 2008). This is even more significant when considering the life chances, health and well-being of disabled people. According to UN estimates, up to twenty percent of disability is caused by basic malnutrition and over ten percent by infectious diseases (Inclusion International, 2005). After all, "[d]evelopment is... an issue about which we should all be concerned, even passionate, because we are all potentially implicated in and affected by it" (McEwan, 2009: 11). Thus, rather than "reject[ing] all development" (Sidaway, 2008: 17), it might be more beneficial to employ "an alternative conceptualization of development" (McEwan, 2009: 78) that might enable a more ethical engagement with those most marginalised by structural relations of inequality and injustice. Postcolonial theory arguably provides a means by which to enable this ethical engagement, reshaping development in practice and in theory through "transforming the production and

circulation of knowledge” (ibid: 249). As Sylvester (1999: 703) claims, postcolonial theory “has the greatest potential to be a new and different location of human development thinking” and, as this thesis argues, this has particular significance for rethinking disability and development.

POSTCOLONIAL THEORY AND DISABILITY

Postcolonial studies have been gaining an ever-increasing importance since the 1980s (Blunt and Wills, 2000). They seek to: challenge the “dominant discourses of imperial Europe” which are based on European cultures and reflect a “dominant Western world view”; dispute “the experiences of speaking and writing by which dominant discourses come into being”; criticise and endeavour to rewrite the domination of history and the “spatial distribution of knowledge (power) that constructs the Third World”; and, lastly, recuperate the voices of “the marginalized, the oppressed and the dominated” through a thorough “reconstruction of history and knowledge production” (McEwan, 2008: 124-5).

The need to view development through a postcolonial lens has informed development studies in recent years; and, although there is yet “no coherent project of postcolonial development geography”¹¹ (Radcliffe, 2005: 291), postcolonial studies have challenged geography in powerful and wide-ranging ways (Blunt and Wills, 2000). Power et al (2006) argue that development geography is in a unique position to contemplate questions of postcoloniality in geography: postcolonialism and geography are “intimately linked” and their connections provide countless occasions to delve into the spatiality of colonial discourses and of representation (Blunt and McEwan, 2002: 1). Furthermore, McEwan (2003: 340) insists that:

[g]eographers are particularly well placed to respond to criticisms of postcolonialism as remaining overwhelmingly textual, cultural and/or historical in focus by contributing towards a productive engagement between postcolonialism and the material realities of

¹¹ Nevertheless, as Sidaway (2000: 593) maintains, “any postcolonial geography ‘must realise within itself its own impossibility’, given that geography is inescapably marked... by its location and development as a western-colonial science”.

global inequalities and towards a revived political and ethical project.

In a context where the disability experience in the Global South has been homogenised, generalised and simplified “in line with the social model as one of disproportionate oppression, intensified by a homogenised ‘third world’ constructed as backward, undeveloped and often brutal towards its weaker members” (Grech, 2011: 89), the need to hear disabled people’s voices is acutely felt. The fundamental importance of listening to the voice of the marginalised Other is intrinsic to postcolonial theory, and increasingly of significance in development studies. Postcolonial perspectives take on particular relevance with regard to disability studies in the Global South since they help “explain the dominance of perspectives from the metropole” (Meekosha, 2011: 677) and open up the possibilities of alternative ways of theorising and practicing development aimed at benefiting disabled people in poorer countries. In Global South contexts, postcolonialism is also significant in understanding “how colonial projects were concerned with rearranging social relations – so that traditional ways of supporting impaired people would be undermined – the kinship, family and community systems” (Meekosha, 2011: 677). Alas, research on disability in Global South contexts “has tended to be undertaken by specialists from the North concerned with establishing quantitative data sets on specific impairment groups and examining the usefulness of rehabilitation programmes”, silencing disabled people’s voices (Meekosha and Soldatic, 2011: 1394) and ignoring “[t]he role of the Global North... in the production of disability in the periphery” (Meekosha, 2008: 2). Meekosha (2011) argues that disability studies rarely build on social theory formulated in the Global South. Thus “critical disability studies... needs to be re-formulated” (ibid: 669). With regard to disability in southern contexts, Meekosha (2008: 2) also argues for the need of a “paradigm shift in thinking about disability”:

We need to understand that the new disability studies has emerged out of the northern metropole and is now being imported/ exported

to the southern metropole without reference to the work of southern disability theorists or southern contexts.

Disability, however, has been largely ignored by theoretical debates concerning postcolonialism (Goodley, 2011), despite some attempts in recent years at linking postcolonial approaches and disability. Sherry (2007) discusses the ways in which authors have connected the two, warning against the use of postcolonialism and disability as superficial metaphors for each other (such as characterising disability as exile or apartheid) without sufficient analysis of the connections between them. Sherry (2007) also explores the power dynamics which link postcolonialism and disability, delving into such issues as racism and disablism, and the need for a culture-specific exploration of disability. Apart from the obvious implications of the way disability has been colonised by the medical and caring professions in the past (Shakespeare, 2006a), postcolonial theory is, as this thesis argues, of fundamental importance in accounting for how disabled people's voices have gone unheard, and in critiquing how the disabled person is represented in development discourses. Theorising disability through postcolonial lenses offers possible answers to the critiques of development discussed earlier. In exploring the possibility of a 'method' for postcolonial development geography which gets outside of what Sidaway (2000: 606) terms as "Eurocentric world-picturing", Raghuram and Madge (2006: 270) state that it is necessary to have:

A commitment to take up issues raised by those who are researched [and] a willingness to engage in constructive dialogue that takes into account the conceptual landscape of those with whom we engage.

The central tenets of this thesis take up Raghuram and Madge's proposals with the view of exploring ways of practicing development through grounded research that enables spaces where disabled people are able to speak and be heard, and become active participants in their own development. These arguments have particular salience in African

contexts and, specifically, in the context of Burkina Faso, which provides the ideal case study through which these ideas are developed.

WHY BURKINA FASO?

As difficult (and ineffectual) as it is to generalise research findings across the whole continent of Africa, many disabled people's lives in sub-Saharan Africa share at least one important characteristic: what Power (2001: 86) identifies as the institutional neglect of disabled people who are habitually relegated to the farthest margins of society. And, while research with disabled people within development in sub-Saharan Africa has been scarce, the little that there is has mostly focused on Southern Africa. This thesis thus focuses on Burkina Faso (see Figure 1.1), a West African country and one of the poorest countries of the world, where issues of disability and development have so far been under-researched.



Figure 1.1 Burkina Faso

Prior to the commencement of my doctoral research, I spent two years in Burkina Faso, where, employed by an INGO, I worked as a development worker with a grassroots DPO in the role of a capacity builder focusing on advocacy. My experiences there motivated me to pursue this research to further explore development work carried out with disabled people in Burkina Faso, and to delve further into why disabled people still face dire socio-economic situations after years of intervention by INGOs, and, less conspicuously, the state. I was also struck by how little Francophone West Africa is known in the English-speaking world. Burkina Faso is a country little heard of by the western world until the recent political upheaval (in October 2014) and terrorist attack (in January 2016).

As in most of the developing world, disabled people in Burkina Faso are in dire socio-economic situations despite having a high rate of INGO intervention (Atampugre, 1997), including in the disability domain. Burkina Faso is also the location of a multitude of grassroots DPOs, some of whom are the recipients of INGO support. Despite the large number of grassroots organisations, the disability movement in Burkina Faso is not strong and most DPOs continue to be dependent on INGO support. Burkina Faso thus provides the ideal context in which to explore disability in development and the significance of the agency, voice, and participation of disabled people in their own development; and provides a basis for exploration of this project's core research questions.

AIMS AND OBJECTIVES

This research attempts to bring to the forefront the need to theorise disability from the Global South and through disabled people's lived experiences in countries like Burkina Faso. While Mawdsley (2008: 524) asks how people and organisations in Africa can ensure "more say over a wider developmental impact", this thesis seeks to contribute to the possibility of disabled people in sub-Saharan Africa having more say in the development interventions that affect them. It does so through examining

the possibility of creating spaces in which they can be heard by the development actors who make the decisions affecting disabled people's lives. Adopting a mixed qualitative methods approach, including traditional and participatory methods, the project involves disabled people in Burkina Faso in the research process as co-producers of knowledge. Drawing on Spivak's recommendation to speak to others in such a way that they are "able to answer back" (Landry and Maclean, 1996: 4), it strives to listen to disabled people's views and experiences while facilitating the possibility of their being part of decision-making processes, rather than simply being the objects of development. This is also based on Lang's (2000: 6) postulation that effective social transformation cannot take place unless marginalised groups collectively "analyse the constraints placed upon them by their social, economic and political environment... and devise strategies for their subsequent alleviation". Without having a space where the subaltern can speak and where their voices can be heard, it is argued that appropriate development cannot take place. This postulation gains significance when applied to disabled people everywhere, but even more so to disabled people in sub-Saharan Africa. Through the participatory methods that are used in this research, disabled people analyse their lives, constraints and difficulties, and formulate possible approaches to addressing these issues. The research also strives to gather disabled people's perspectives on disability and development through interviews with individual disabled people and grassroots disabled people's organisations. It also analyses the role of INGOs and state authorities working with disabled people.

The overarching aims of this thesis are to:

- understand the lived experiences of disabled people in Burkina Faso;
- create spaces within development approaches in which disabled people's voices can be heard and are listened to; and

- investigate the necessity and the implications of theorising disability from the Global South, and thus the possibilities of rethinking disability in development.

Thus, based on research conducted in Burkina Faso, this thesis seeks to explore and answer the following research questions:

1. How do disabled people in the Global South experience and perceive disability, and what are their lived experiences?
2. What are the roles of grassroots disabled people's organisations, international non-governmental organisations and the state in development and disabled people's lives?
- 3: To what extent are disabled people involved in their own development and decision-making and what is the significance of their agency and voice within development?
- 4: How and why might development policies and practices pertaining to disabled people in the Global South be improved by engagement with the voices and agency of disabled people?

DISABILITY: DEFINITION AND TERMINOLOGY

At this juncture, I would like to briefly clarify definitions of disability and terminology used in this thesis. Disability is hard to define “because [it] means different things to different people across cultures, histories, contexts, bodies, spaces and places” (Grech, 2015: 1). In western contexts, disability has been defined according to the perceptions of disability and impairment dominant at the time. Cameron (2008: 22) provides definitions of impairment and disability based on the affirmative, non-tragic model of disability, which can be taken as the broad definitions informing this research:

- Impairment: physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society.
- Disability: the loss or limitation of opportunities to take part in community life on an equal level with others due to physical and social barriers.

Different terms referring to disabled people have been adopted in western theory and global discourses. The term ‘handicapped person’ was abandoned in favour of the term ‘disabled person’. This, in turn, was set aside for ‘people with disabilities’, putting the emphasis on the person instead of the disability, as reflected in the UN Convention on the Rights of Persons with Disabilities (CRPD)¹² which came into force in 2008. However, some prefer the term ‘disabled person’, which emphasises society’s disabling of the person. Without contradicting any terminology¹³, I use the terms ‘disabled person(s)/people’ and ‘person(s) (or people) with disability/disabilities’ interchangeably. The former is used by Britain’s disability rights theorists¹⁴ and is preferred in this thesis in accordance with disabled persons like Egan (2012: n.p.), a blogger from England, who writes: “I am not a ‘person with a disability’. I do not ‘have a disability’.... I am disabled by a society that places social, attitudinal and architectural barriers in my way.”

Specific impairments also require the use of specific, but not entirely unproblematic, terminology. A person who is completely blind is referred to as ‘blind’, while someone who is partially sighted is referred to as ‘a person with visual impairment’¹⁵. People who have total hearing loss are referred to as ‘deaf’, while people who have partial hearing loss are referred to as ‘hard-of-hearing’. ‘People with intellectual disabilities’ in this thesis generally include people with developmental, cognitive and learning disabilities. As explained in more detail in Chapters 3 and 4, in Burkina Faso I rarely encountered a differentiation between different types of intellectual disabilities, which were thus not always easy to identify. Regrettably, therefore, the term ‘intellectual disabilities’ is used

¹² United Nations Convention on the Rights of Persons with Disabilities can be found at: <http://www.un.org/disabilities/convention/conventionfull.shtml>.

¹³ And while also acknowledging that even the term ‘disabled’ is being debated, as Atkinson (2015: n.p.) shows: “I began to wonder if ‘disabled’, had become outdated, and needed a replacement”.

¹⁴ As detailed in: <http://www.disabled-world.com/definitions/disability-disabled.php> (Accessed: 11 September 2016).

¹⁵ As detailed in: <https://wordwatchtowers.wordpress.com/tag/correct-terms-for-blind-people> (Accessed: 11 September 2016).

as a catch-all term. A distinction sometimes needs to be made between people with ‘mild’ and ‘severe’ (intellectual) disability¹⁶ and thus these terms are utilised for this purpose.

THESIS OUTLINE

Having introduced the corer arguments of the thesis, Chapter 2 outlines in more detail the conceptual framework. It sets out the importance of postcolonial theory as a framework for the research and its implications for the methodology employed in the research process. It also explores the importance of viewing disability in the Global South through a postcolonial lens, in particular the importance this places on the representation and silencing of disabled people, and in contextualising the disability models that have been proposed in the west. Chapter 3 explains and accounts for the methods employed in carrying out the fieldwork in Burkina Faso. The chapter not only describes the research process, but also explores the limitations and ethical aspects emerging from such research. Chapter 4 explores the Burkinabe context in relation to disability, explaining aspects of life in Burkina Faso that are important in understanding the lives of disabled people, such as social structures and cultural attitudes, the nature of family, education, and employment, which all affect disabled people’s lives. Additionally, it gives an overview of disabling illnesses and their impact in Burkina Faso, as well as the traditional and western health practices exercised in the country. The subsequent three chapters examine the research findings in the context of the theoretical frameworks outlined earlier in the thesis. Chapter 5 examines how disabled people in Burkina Faso self-identify, the ways in which disability is understood and categorised, and how this affects the perceptions of disability both by disabled and non-disabled people. Chapter 6 then explores the impact of the disability movement, INGOs and the state in disabled people’s lives. It also explores the

¹⁶ A discussion on the social construction of intellectual disability is beyond the scope of this thesis; however it is briefly acknowledged here as being the topic of many scholarly arguments (for example, Finlay & Lyons, 2005; Rapley, 2004).

significance of the politics of, and between, DPOs and INGOs, and the need to contextualise assumptions made by western-based international organisations in contexts such as Burkina Faso. Chapter 7 brings together the research findings and the discussions in the previous chapters to explore the agency of the research participants. By examining findings from both the interviews and the participatory videoing, the chapter examines what development means for disabled people in Burkina Faso. It explores the significance of economic independence and its relation to how disability is perceived in Burkina Faso, as well as its importance in disabled people's concept of development. The final chapter reflects on the analysis of the research findings and its implications for the wider context of disability and development in the Global South. It concludes with suggestions for improving development policies and practices by engagement with the voices and agency of disabled people.

CHAPTER 2

RETHINKING DISABILITY AND DEVELOPMENT THROUGH THE LENS OF POSTCOLONIAL THEORY

INTRODUCTION

Disability has been neglected as a concern of development, both in discourse and in practice. Thus, development scholars and practitioners, including geographers, are being called upon to end the silence surrounding disability in development studies (Power, 2001). There have also been calls, recently, to recognise that impairment in Global South contexts “is often the result of the *continued* dependency on the northern metropole” (Meekosha, 2011: 677). Meekosha (2011: 667) argues that disabled people’s experiences in the Global South have been marginalised as a result of “the dominance of the global North in the universalising and totalising tendencies of writings about disability”. The field of disability studies was:

constructed as a field of knowledge without reference to the theorists, or the social experience, of the global South. There has been a one-way transfer of ideas and knowledge from the North to the South in this field.

(ibid: 668)

Furthermore, Meekosha (2011: 671) argues, “responses to disability in the periphery” are also ignored: “rarely are examples of disabled person’s movements outside the metropole cited” (Meekosha, 2008: 6). In ignoring “the lived experience of disabled people in... the global South” (Meekosha, 2011: 670):

The key debates around disability and impairment, independent living, care and human rights are often irrelevant to those whose major goal is survival.

(ibid)

In challenging these dominant discourses and enabling spaces in which the disabled subaltern can be heard, postcolonial theory proves

essential, both theoretically and methodically, to disability and development. Drawing on the works of key postcolonial theorists and scholars such as Gayatri Spivak and Edward Said, this chapter explores the implications of postcolonial theory for understanding and problematising the ways in which disabled people are silenced and represented as the Other. It then examines the perspectives of disability “from the metropole”, the models of disability proposed in recent years in western contexts, and the challenges these models encounter when faced with the lived experiences of disabled people in sub-Saharan Africa. Dipesh Chakrabarty’s proposal of “provincialising Europe” – recognising that western thinking is not necessarily universal and that models of development cannot easily be universalised – resonates with the necessity of provincialising western disability models and opening up to the possibility of theorising disability from non-western contexts. The chapter explores the particular resonance that postcolonial theory holds for disability studies in contexts where “[d]isability in the global South is firmly linked to northern imperialism, centuries of colonisation and globalisation” (Meekosha, 2011: 671). The final section of the chapter examines the appropriation of disability in Global South contexts by international non-governmental organisations (INGOs), and problematises their role as potential new colonisers within the development industry.

DISABILITY AND DEVELOPMENT THROUGH A POSTCOLONIAL LENS

Postcolonialism is concerned with “ways of criticizing the material and discursive legacies of colonialism” (Raghuram and Madge, 2006: 271), predominantly as they “relate to power relations” (McEwan, 2009: 4). Historically, there has been little connection between postcolonial theory and development studies (Sharp and Briggs, 2006): they differ in traditions, political tendencies, the concepts they deal with, and even the language they employ. Furthermore, while development might be one of the dominant western discourses subject to postcolonial critique, postcolonial approaches have also been criticised by development studies

scholars as “being too abstract and of little relevance” (McEwan, 2009: 1). Postcolonial approaches have been accused of failing to “connect critiques of discourse and representation to the realities of people’s lives” and dealing with urgent material problems such as poverty (ibid). These mutual criticisms notwithstanding, it is a central premise of this thesis that development can be enriched by the perspectives provided by postcolonialism (ibid). Endeavouring to have an understanding of development that is informed by, and practiced through, postcolonial approaches means:

acknowledging the already postcolonial world of development in which contemporary re-workings of development theory and practice, such as grassroots and participatory development, indigenous knowledges and global resistance movements, inform postcolonial theory.

(McEwan, 2009: 31)

Postcolonial critiques, therefore, enable us to rethink some of the fundamental assumptions that development studies are based on, encouraging the provincialising and decolonising of development discourses and practices (McEwan, 2009). Often, development interventions are assumed by those carrying them out as existing in a vacuum, with no relations or ties to the past. In many development discourses, for example, ‘underdevelopment’ in the Global South is not regarded as a consequence of colonisation, nor is there a recognition of how resources extracted from Africa enabled Britain’s wealth today (Power, 2009). Postcolonial approaches demand that we look at the development agenda through the acknowledgement of the connections between present and past: between imperialism and colonialism and their effects on today’s ‘underdevelopment’ in Africa and in the Global South in general (McEwan, 2009). Spivak (1988) postulates that disowning the history of imperialism allows the westerner to neglect the connection between the west and the condition of the Global South. Placing the latter at a distance from the west, it ignores colonialism or places it so far back in history that it no

longer has a bearing over today's happenings: it is considered as a closed chapter¹⁷.

As with development theory, postcolonial theory has, “for the most part, turned a cold shoulder” to disabled people in post-colonial¹⁸ settings (Van Dam, 2016: 207). This might be attributed to the fact that disability has arrived late on the academic and development agenda when compared to such topics as gender. Nonetheless, the time of acknowledging and exploring disability in relation to both development and postcolonial theory is quite overdue. The subsequent discussion seeks to contribute to disability's “slow but steady steps out of the closet of postcolonial studies” (Van Dam, 2016: 207).

Can the Disabled Person Speak?

The term ‘subaltern’ is used within postcolonial theory to “describe groups who are excluded and do not have a position from which to speak” or be heard (McEwan, 2009: 16). According to Spivak, the ‘subaltern’ are groups of people whose “voices cannot be heard or that are willfully ignored in dominant modes of narrative production” (McEwan, 2009: 16). This resonates strongly with Power's (2001: 87) observation that part of what characterises disability in Southern Africa is the “voicelessness” of disabled people.

In her much-discussed article, ‘Can the Subaltern Speak?’, Spivak (1988: 82-83) describes the female subaltern and says that:

both as object of colonialist historiography and as subject of insurgency, the ideological construction of gender keeps the male dominant. If, in the context of colonial production, the subaltern has no history and cannot speak, the subaltern as female is even more deeply in shadow.

¹⁷ An example of this is given by Power (2000: 92), where he says that “[a]pologizing for particular episodes of colonialism and famine from Britain's imperial past seemed to be New Labour's way of sending a signal that the country was no longer stuck in the past nor confined to its heritage, but freed from all this by a conscientious group”.

¹⁸ The term ‘post-colonial’ is to be distinguished from ‘postcolonial’. The former is being used in this text to denote the era following independence from European colonisation, while the latter is used to denote postcolonial theory or studies aimed at challenging all forms of colonial and neo-colonial power relations.

Spivak (1988: 104) concludes that “[t]he subaltern cannot speak”. As McEwan (2009: 70) elaborates, this is “not because they are unable to speak but because they are both denied space in which to speak and when they do speak they are not listened to”. Furthermore, Spivak (1988: 104) says that “if you are poor, black and female you get it in three ways”. The question tackled here is, what if you are poor, black and disabled? Historically, people with disabilities have not been given the opportunity to speak: they have been oppressed and repressed. Disabled people have been virtually invisible citizens of many societies and marginalised in most cultures throughout history (Quinn and Degener, 2002). While in western contexts this led to the emergence of the disability rights movement in the late twentieth century, the situation of disabled people in the Global South remains on the whole deplorable. Often, they are the poorest of the poor and are “caught in a vicious cycle of poverty and disability” (DFID, 2000: 1). The causes of this marginalisation are also rooted in colonial histories; disabled people in previously colonised countries were even more oppressed when colonisers and missionaries set up institutions to contain the colonised that were viewed as abnormal¹⁹ (Meekosha, 2008). As Quayson (2002: 228) maintains, “colonialism may be said to have been a major force of disabling the colonized from taking their place in the flow of history other than in a position of stigmatized underprivilege”. The disabled person, both as a colonised person and as a disabled person, was thus relegated to the margins of society without their voice being heard or taken into account.

Disabled people have been labelled ‘vulnerable’ and in need of saving by well-meaning, but ultimately powerful non-disabled actors. Critics argue that non-disabled people have come to the conclusion that disabled people need curing and caring for because they deviate from the norm and need assistance (Stone, 1999). Similarly, the non-disabled

¹⁹ Even in recent times, the disabled person’s voice continues to be unheard. Stone (1999) talks of how power over the devising of social assistance has not only made it possible for certain groups to dominate others, but has also given them the possibility of defining what is ‘normal’, thus labelling the assistance required by disabled people as ‘special’.

person has decided that the disabled person wants to be like him/her, giving rise to an ableist sociology which asserts the normalcy and naturalness of able-bodiedness in contrast to the ‘abnormality’ of disability. This leads to “the assumption that the goal of society is to return disabled people back to a normal state (whatever that is)” (Imrie, 1996: 398). Thus, while the “ideological construction of gender keeps the male dominant” (Spivak, 1988: 82), the ideological construction of normalcy keeps the non-disabled person dominant and the disabled person as a subaltern.

Agency

The political agency of the subaltern, together with the “destabilisation and deconstruction of the cultural authority” of the coloniser, are two important aspects of postcolonial theory (Bignall, 2010: 60). There is a tension, however, between “destabilising colonial subjectivity and affirming oppositional subjectivity”. As Bignall (2010: 60) explains, resistance to colonialism and imperialism is possible through a collective identification, which is “asserted through counter-discourse and concrete action” against the discourses justifying colonisation, “and against the exclusive policies and social arrangements that reflect and reinforce the authority of the colonisers”. To be able to destabilise the dominant colonial subject (by highlighting its illusion of “coherence and unity”), the resisting agents need to assert a collective identity “with a unified set of political aims, as a ground for their political resistances and demands as ‘peoples’” (ibid: 60-2). The idea of a collective identity, when taken in the context of disability, encounters certain stumbling blocks. Thus far, disability has been taken to encompass all kinds of disabilities: whether they are physical, sensory or intellectual. However, one must also take into account various aspects of disability²⁰. Firstly, disabled people cannot be taken as one homogenous group; as Spivak (1988: 79) points out (albeit in another

²⁰ I am aware that by doing this, it might be taken that this is reducing the disabled person to just his/her disability, but that is far from being the intention in this thesis.

context) the “colonized subaltern subject is irretrievably heterogeneous”. Secondly, there are many different types of disability and it is recognised that different disabilities require different approaches. The idea of a disabled collective identity, therefore, is not a straightforward one. Meanwhile, the notion of silencing the disabled person’s voice takes on a significant, even literal, meaning when considering such situations as those of people with hearing impairments. The latter might be rendered unable to communicate with non-deaf people unless both of them share a common sign language. Since very few non-deaf people (including people with other kinds of disabilities) learn sign language, deaf people’s voices are rarely heard by society. Furthermore, in Burkina Faso, which, like many other countries in sub-Saharan Africa, is a multilingual country where over sixty indigenous languages are spoken (Rupley et al, 2013), communication through one national sign language might not be feasible. Meanwhile, another ‘group’ of disabled people who are silenced in virtually all sectors of society – people with intellectual disabilities – faces not only high prevalence of discrimination²¹, and poor access to justice and education, but also poor resource allocation in Global South countries (Njenga, 2009: 457), even by INGOs working with people with disabilities themselves. The social roles in which intellectually disabled people have been cast – as a sick person, an object of pity, a burden of charity and numerous other social roles which lead to dehumanising treatment (Wolfensberger, 1972) – relate also to how people with disabilities in general have been viewed at various points in history, leading up to the present day where “social discourses... and practices... [still] tend to portray disabled people as inferior, dependent and, by implication, of little or no value” (Imrie, 1996: 397). The only ethical position for scholars, according to Spivak, is to attempt to recover the subaltern agency, and reveal the injustice and oppression of the subaltern (McEwan, 2009).

²¹ For example, in a research conducted in Afghanistan and Zambia, Trani and Loeb (2012) found that people with intellectual disabilities (together with those with mental illness and multiple disabilities) were the least likely to be employed, compared with those with sensory disabilities.

However, Spivak maintains that scholars ought to combine “scepticism about recovering any subaltern agency with a political commitment to making visible the position of the marginalised” (Loomba, 2005: 195). Her problematisation of the recovery of subaltern agency, as well as of representation of the subaltern, has immense significance in the context of disability.

Disabled People and Representation

I represent a lot of people who have no voice at all... in Africa....
They haven't asked me to represent them.
It's cheeky but I hope they're glad I do.
(Bono, in Iley, 2005: n.p.)

Spivak (1988) explores how colonial representations are problematic in the sense that they tend to engage in flagrant universalisations when speaking on behalf of the Third World. She describes two kinds of representation: “speaking for” (as in political representation) (ibid: 70) and what Kapoor (2004: 628) calls “speaking about” (in the sense of representation, describing, or making a portrait of). Disabled people have been subjected to both kinds of representation. On the one hand, they have been much spoken for. As Davis (1997: 2) points out, non-disabled commentators on disability tend to think they understand disability, but their understanding is limited. They are often willing to suggest “solutions” to disability, or show their understanding by providing anecdotes or recalling a story they have read featuring a disabled person. This, he says, coupled with a large amount of sympathy and pity and “a generous acceptance of ramps and voice-synthesized computers allows the average person to speak with knowledge on the subject”. Spivak (1988), meanwhile, asks whether the subaltern can speak for him/herself or is condemned to remain voiceless. She suggests that the culturally dominant, instead of representing others, would do better to acknowledge that their privileged positions may in fact prevent access to an accurate understanding of these others. Non-disabled people have been permitted to speak on behalf of disabled people while the latter were, and still are,

presented as objects of charity, as helpless vulnerable beings who need non-disabled people's help. This invokes an observation from Shakespeare (1994: 287-8) that "[d]isabled people enable able-bodied people to feel good about themselves: by demeaning disabled people, non-disabled people can feel both powerful, and generous". Similarly, Kapoor (2004: 632) argues that we represent the Third World because we want to "be of help (to the 'less fortunate'?)".

McEwan (2009: 69) contends that "[a]lternative representations (e.g. from within the South) are similarly problematic". For example, Devlieger (2010: 89-91) illustrates the case of the Songye ethnic group in the Democratic Republic of Congo, who define the extraordinary body as a "result of an invasion of nature on the human world". Thus, children with dwarfism or albinism are thought to be inhuman and categorised as "bad children", representative of "evil, death and the supernatural world". Devlieger (2010: 95) describes how these "bad children" are considered to "belong to another world and must go back to where they belong". They "will be 'aided' to return to their world by neglect and in earlier days through a ritual that results in their death" (ibid). In this context, INGOs can "invoke the metaphor of the saviour" "when they 'rescue' victims of human rights abuses from 'savages'" (Meekosha and Soldatic, 2011: 1389):

Now that disability has been more strongly linked with development, we can see how disabled people in the global South can be seen as 'victims' of unsophisticated culture and beliefs, while development and aid agencies run awareness workshops with the representatives of the 'savages'.

(ibid)

Today, the disability movement comprising disabled people themselves advocating for their own rights is becoming stronger in the west (for example, the European Disability Forum²² is run exclusively by people with disabilities and their families), promoting the theme of "Nothing about us without us" (UN Enable, 2004: n.p.). Although this is not to say that disabled people in the west have now achieved *de facto* equality, it

²² <http://www.edf-feeph.org>

indicates that progress has been made, not least of which is the coming into force of the UN Convention on the Rights of Persons with Disabilities in 2008. However, Meekosha and Soldatic (2011: 1383) argue that “many of the everyday experiences of disabled people in the global South lie outside the reach of human rights instruments”. Disabled people in the Global South, as will be discussed in the coming sections, are fighting other battles.

In relation to Spivak’s two forms of representation, disabled people have also been much spoken about. As Edward Said (1993: xiii) argues:

stories are at the heart of what explorers and novelists say about strange regions of the world; they also become the method colonised people use to assert their own identity and the existence of their own history.

The non-disabled society often ‘encounters’ disabled people – the Other – through, for example, media (that is, the images of disabled people that media organisations choose to portray). Disabled people have been generally underrepresented in the media (Shakespeare, 1994) as they have been underrepresented in other areas. When they *are* represented, disabling stereotypes tend to be perpetuated, which “medicalise, patronise, criminalise and dehumanise disabled people” (Barnes, 1992: 19) and portray them as superhuman cripples, sinister and evil, or pitiable and wretched (Golden, 2003). A case in point are the numerous charity organisations – such as AbleChildAfrica²³ and Disability Africa²⁴ – that ask the public to donate money or participate in challenges to raise money “to improve the lives of disabled children in Africa” or to remove inequalities for disabled people which are “uncivilised and preventable”. Through these processes of representation the public gets to know disabled people²⁵.

²³ <http://ablechildafrica.org>

²⁴ <http://www.disability-africa.org>

²⁵ Until a few years ago, it was extremely plausible that a non-disabled person did not know a disabled person personally, since disabled people did not attend school or engage in employment or social activities. Nor did they, in certain cases, go out of their homes.

The second part of the quotation from Said, relating to stories becoming how colonised people assert their identity and their history, is even more significant in the context of disability. Frantz Fanon (2008), in his seminal book 'Black Skin, White Masks' (in which he explores the psychological effects of colonial oppression on people identified as black), talks about the black person's internalisation of inferiority (cultural and economic) in which he views himself to be in comparison to the white coloniser. Furthermore, Memmi (1967: xii) observes that "[e]ven the poorest colonizer thought himself to be – and actually was – superior to the colonized". Shakespeare (1996: 103-4) postulates that disabled people are socialised to think of themselves as inferior to others: people "are socialised into thinking of disability in a medical model way" as lacking or damaged, which can be viewed as internalised oppression. A disabled person's image of themselves "is reinforced by segregated education, negative images, cultural representation, absence of positive role models, social treatment of disabled people", which "parallels the experience of women in patriarchal societies" (ibid). Similarly, Morris (1991) observes that non-disabled people's reactions to disabled people affect how the latter feel about themselves. The social model of disability, meanwhile, has challenged this internalised oppression, by making it possible for disabled people to explore their experiences in a way that takes away blame for their own marginalisation and relocates this as the fault of the normalising society (Tregaskis, 2002). As will be discussed shortly, however, the social model of disability developed in the west does not necessarily apply to disabled people in the Global South. Furthermore, the inferiority complex that Fanon (2008) talks of is cultural as well as economic: aspects that are crucial to the disabled person's status vis-à-vis the society in which s/he lives. One of the major characterisations of disabled people's 'inferiority' in the Global South is their economic status and cultural responses to inability to work. According to the UN (2006), unemployment among disabled people reaches eighty percent in some countries, while the World Bank (2005) reports that disabled people are

much more likely to be poor. They not only face lower probability of employment and lower earnings, but also require more income than non-disabled people to achieve a comparable living standard. However, disabled people's lived experiences in the Global South and the "disability relationships that emerge from the politics of colonialism and neo colonialism" (Meekosha, 2008: 6) have been subjected to what Meekosha (ibid) calls the "grand erasure" in disability studies. She argues that "the imperialistic... and colonial processes responsible for disabling millions of people" are ignored (ibid). And yet:

in the global South much of the impairment or harm is a result of the legacy of invasion, colonisation and globalisation. This legacy has left many disabled people in the global South living in dire conditions of poverty.

(Meekosha and Soldatic, 2011: 1389)

Thus "[w]e need to ask why disability and poverty are so interrelated in the Global South, who is responsible and who profits?" (Meekosha, 2008: 3).

Colonisation also brought with it eugenic ideologies from the metropole. Although the influence of metropolitan thinking on the periphery in this regard is less acknowledged, the establishment of institutions for disabled people during colonisation to "prevent 'polluting' the wider population" (Meekosha, 2008: 9) is well known. Conklin (1997: 5-6), in analysing the French "civilising mission" in West Africa between 1895 and 1930²⁶, argues that:

French imperial ideology consistently identified civilization with one principle more than any other: mastery... mastery of nature, including the human body, and mastery of what can be called 'social behaviour'. To put it another way, to be civilized was to be free from specific forms of tyranny: the tyranny of the elements over man, of disease over health, of instinct over reason, of ignorance over knowledge.

²⁶ Conklin (1997: 4) criticises postcolonial theory, arguing that "despite its innovative exploration of the way knowledge and identities have been constructed through colonialism,... [i]ts concept of "coloniality", ironically, risks depriving Africans of any agency and French actions of any specificity, because it presents all colonizing cultures as essentially the same.

Colonialism was rationalised with the fact that the inhabitants of such regions as sub-Saharan Africa were “primitive savages”. These stereotypes of the “barely human”, according to Meekosha (2011: 672) “have resonance for disabled peoples worldwide.” In the postcolonial Francophone context, Van Dam (2016: 211) describes how:

sociocultural norms of bodily abilities ‘operate’ in powerful and often material ways on visibly non-normative bodies and identities... visible difference often contends with the principles of French universalism and... secularism – principles... resulting in a ‘model’ that is visibly Franco-French (white), male, able-bodied, and in all other ways ‘fit’.

Disabled people in the Global South have thus been subjected to both colonial power and patriarchal power, which speaks for and about them politically and discursively. In contrast, Soldatic and Biyanwila (2010: 77; 81), exploring “a Southern disabled standpoint as a theoretical and strategic approach to examine disability”, focus on the “dominant representation of nations in terms of able-bodied... patriarchy”. This “Southern disabled standpoint” contests “the privileged/hegemonic position of the Northern notions of development [and] disability” (ibid: 82). These northern, or western, concepts are often employed in interventions with disabled people in Global South contexts by development agencies. Western models of disability tend to be applied by INGOs in contexts where they are not necessarily applicable or appropriate.

WESTERN MODELS OF DISABILITY

In western countries, disability has tended to be understood through either medical or social models. The medical, or individual, model of disability saw the “problem” as arising from the shortcomings of the body (Shakespeare and Watson, 2001: 11) or the mind. The World Health Organization (WHO, 1980: 28) defined disability as “any restriction or lack... of ability to perform an activity in the manner or within the range considered normal for a human being”. This perspective, which dominated western societies for most of the twentieth century, deemed that the

individual's impairment required dependence on others. This started to change when disabled people called for a move from institutional segregation to community and independent living: the disability movement in the UK, which gained traction in the 1970s (Shakespeare, 1998), was based on the social model of disability. This model purports that disability is a "social construction that penalises those people with impairments who do not conform to mainstream expectations of appearance, behaviour and/or economic performance" (Tregaskis, 2002: 457). The social model's elemental postulation is that it is society that disables and excludes people by imposing barriers. These barriers are both physical, such as inaccessible buildings and transport; and social, such as discriminatory attitudes and stereotypes (Barnes and Mercer, 2003). This model, which has now become entrenched in disability discourse, studies and research in the western world (Shakespeare and Watson, 2010), has been much written about and also criticised (for example, Barnes et al, 2002). Shakespeare (2006b) acknowledges that the social model ignores the importance of impairment in disabled people's lives, that it originates from a group of white heterosexual physically disabled men, and that it defines disability as oppression. Meanwhile, there are an increasing number of academics arguing that both the medical and social models are limited in the sense that they fail to appreciate that both physiological/cognitive and societal factors are involved and interconnected in the creation of disability (McEwan and Butler, 2007). Nevertheless, critiques of the social model have been largely formulated within western contexts, often not taking into account the limitations of the same model in other parts of the world.

Building on the social model, Swain and French (2000) proposed a new model of disability: the affirmation model. Arising from British disability culture, this model espouses a non-tragic view of disability. Swain and French explore the divide "in perceptions of disability", which is promulgated by the medical and social models (2000: 570). According to the authors, the social model, which is also accepted by the large part of

the non-disabled society, disconnects impairment from disability, and is not, essentially, non-tragic (ibid: 571). Building on the arguments put forward by other authors that impairment has a negative side and that, consequently, the social model needs to be extended, Swain and French (2000: 573) explore the tragic view of disability, which is propagated not only by media and research, but also by “policies, practices and intervention”. This is exemplified by such practices as encouraging expectant mothers to undergo screening to terminate pregnancies if impairment is detected in the unborn baby. This tragedy model, which is also disabling, “denies disabled people’s experiences of a disabling society, their enjoyment of life, and their identity and self-awareness as disabled people” (ibid: 574). Thus, Swain and French (2000: 579) maintain that an affirmative model that challenges this tragic view – of disability as well as that of impairment – is emerging out of disabled people’s experiences. Whereas the social model locates the “problem” within society, the affirmation model defies the idea that the “problem” rests with the individual or the impairment. They go on to cite several examples of disabled people considering their disability and impairment as beneficial and as enriching their lives. This affirmation, they say, is not only individual, but also collective, being developed through such movements as the disability arts²⁷ one (ibid).

Although not as widely embraced as either the medical or social models, the affirmation model is establishing itself within disability discourse. It is being called upon in various disciplines such as education (for example, Raphael and Allard, 2013), health (for example, Hanisch, 2013) and occupational therapy, where, for instance, McCormack and Collins (2012) explore the importance for occupational therapists to understand the affirmative disability orientation. It has also been taken up by several disability academics, most notably Colin Cameron, who has gone on to develop definitions of impairment and disability within the

²⁷ <http://www.disabilityartsinternational.org>

model²⁸. Detrich (2011: n.p.), a blogger from the UK, acclaims the affirmation model as useful “for those who have yet to affirm a positive identity for themselves”; while validating the position of those who, like him, have already done so. Indeed, this model seems to reflect the feelings of disabled activists in the western world. In the words of a Maltese disabled activist, who is also a co-founder of the NGO Living Ability not Disability²⁹:

I’m not ashamed [of] being called person with disability... coz [sic] I am stronger and proud that I can show who [I] really... am.
(Abela, 2013: n.p.)

However, others have argued that the affirmation model should collaborate with the social model, rather than simply challenge the tragedy model (Detrich, 2011). Furthermore, while Cameron (2008) welcomes the development of the affirmation model, he criticises Swain and French’s argument that there are benefits to being disabled. Cameron (2008: 19-20) clearly outlines the distinction between affirming “one’s sense of self” and the implication that it is a positive thing to be excluded from certain opportunities only because it is possible to handle disabling experiences positively. He concludes his argument by postulating that “[d]isability is not something to be affirmed”. Nonetheless, whilst there is an active debate on these issues in western disability studies, they remain overwhelmingly, if not exclusively, focused on the Global North. The question remains, therefore, as to what relevance these models and debates have in contexts in the Global South.

Disability and Disability Models in Global South Contexts

The translatability of western models in Global South contexts cannot be understood without prior consideration of the long history of intervention by western powers in defining and dealing with disability in these contexts. This in turn necessitates consideration of the effects of European colonialism. Colonialism, though far from being a heterogeneous

²⁸ These definitions are laid out in Chapter 1.

²⁹ <http://www.landmalta.org>

experience, involved some commonalities such as “the extraction of raw materials... [the] displacement of indigenous peoples, [and the] devaluation and destruction of traditional communities, practices... cultures, and customs and beliefs” (Grech, 2011: 94). Grech (2011: 94) comments:

The experience of colonialism was a disabling experience for the subaltern subjects and also impacted disabled people as a substantial minority within these. The focus on export commodities, the privatisation of property, the introduction of an economic value on food and the exploitation of land... often led to starvation... and consequently disease and impairment.

Furthermore, the focus on production and exportation, based on forced labour, implied that those who were “unfit” (such as disabled people) “had to be normalised (to function and produce) or else subjugated and isolated” (ibid: 94-5).

The way in which disability was construed in colonial times is “poorly understood and under researched” (Meekosha, 2008: 9). Devlieger (2006) even reports that disability was not a priority in the colonial period. What is known is that in many pre-colonial societies in sub-Saharan Africa disabled people took on community tasks according to what they were able to do, thus contributing towards the daily life of their community (McEwan and Butler, 2007). During colonial times, however, institutional settings were developed, which, in many cases were modelled on developments in the northern metropolises and were initiated by the colonising country (Devlieger, 2006). The colonial authorities, with help from missionaries, “established institutions to contain and control the colonised that were often viewed as dissident and abnormal” (Meekosha, 2008: 9). Disabled people were thus relegated to the care of the church or charitable organisations, a legacy whose remnants are apparent even today (McEwan and Butler, 2007).

This attitude emphasised the medical model approach, through which the definition of disability – as well as the abilities and needs of disabled people – were defined by (western) professionals (McEwan and

Butler, 2007). Connell (2011: 1374) observes that the medical model which was “exported to the colonies” was “bound up with the culture of the colonisers” and was thus “liable to enter an antagonistic relationship with indigenous knowledge about bodies”:

Religious and cultural meanings of disability, village- and kin-based solidarities, livelihoods, and local customs of support, were all at stake and liable to disruption.

(ibid)

Thus, on the one hand, the medical model consolidated western medical knowledge³⁰ and reflected “postcolonial paternalism” (Lee, 1997: 25). On the other hand, the social model – despite being a great leap forward in western societies – is still western-centric, having roots in the civil rights movement, the advocacy for inclusion and the removal of disabling barriers within society. The availability of technical and environmental solutions (and cultural shifts), which the social model assumes, have costly implications and are sometimes not fully provided even in the Global North (McEwan and Butler, 2007). Other issues, such as employment, also take on a different angle in Global South contexts, where most employment opportunities are in sectors such as agriculture, forestry and other manual labour jobs in which people with mobility or visual impairments have difficulty participating (Mitra et al, 2011). Despite the fact that advances on the human rights front have been made by disability activists in some countries such as South Africa and Uganda (McEwan and Butler, 2007), the fact remains that “[u]ntil fundamental legislative changes are realised disabled people are unlikely to realise equal opportunities” (Frost, 1999: 52). However, McEwan and Butler (2007: 457) also argue that:

it is difficult to see how disabled people living in impoverished rural communities, where there are significant technology and service provision gaps, will be able to claim their rights under recent legislation or to improve the circumstances in which they live.

³⁰ The medical model approach is still present today. For example, in the 2000 reformulation of its international standard languages, the WHO ostensibly returned to the medical model “with all its imperial connotations” (Power, 2001: 86).

In the Global South, the quality of life, including increased literacy, having access to information, and socio-economic participation, might be more pertinent issues (McEwan and Butler, 2007) than debates about legislation and rights. Meekosha and Soldatic (2011: 1394) claim that if disabled people's voices are not heard, they "may become the 'victims' of human rights rather than agents in their own social change". According to Stone (1997), therefore, enforcing the social model and the interconnected emancipatory research paradigm on the Global South would be akin to imperialism, rather than empowerment.

The affirmation model can be subject to similar criticism. Although Swain and French (2000) acknowledge that their affirmation model arises from a British movement, most of their article is written as if the model applies to disabled people globally. One example is the reference to the rights of a disabled person to know "the basis on which decisions of medical intervention are made, [and] the consequences of taking drugs" (Swain and French, 2000: 559), which seems to assume that medical intervention and the choices surrounding it (Coleridge, 1993) are readily available to all disabled people everywhere (Barnes and Mercer, 2003). It is hard to imagine disabled people in countries like Burkina Faso being informed of medical decisions or drug side effects when disabled people (and non-disabled ones), especially those living in rural areas, may not even have access to emergency treatment or any medical facilities. In such a context, therefore, the importance of advocating for disabled people's rights to decide which treatment to undergo or the consequences of the drugs they are prescribed, pales in comparison to the importance of people being aware of the causes of impairments, treatment and prevention of illnesses and diseases, and advocating for free (or affordable) and accessible education and health and well-being services. Furthermore, McEwan and Butler (2007: 452) caution that health programmes such as those implemented by the UN in developing countries to prevent and eradicate diseases – such as leprosy, river blindness and HIV/AIDS – should not disconnect health-related disability issues from "underlying

causes relating to poverty”. Meanwhile, the number of impairments caused by injuries in poorer countries is increasing. This is exacerbated by factors such as lack of safety procedures, lack of safe areas for children to play in, and, as mentioned above, lack of access to affordable emergency health services, combined with more susceptibility to psychological stress, financial difficulties and tough living conditions. Furthermore, people with disabilities are often the ones who find it the most challenging to access health care services (McEwan and Butler, 2007). While Swain and French (2000: 581) refer to disabled people as being “proud, angry and strong”, McEwan and Butler (2007: 458) describe how, in many sub-Saharan African countries, disabled people are confronted with negative attitudes, and disability is often perceived as a result of “maternal wrongdoing, witchcraft, evil spirits or divine punishment”. What seems particularly problematic in Swain and French’s (2000) paper, however, is the missed opportunity to explore the different contexts in which disabled people around the world find themselves. The authors refer to a visually disabled Malaysian woman saying that she received better education in a special school than her siblings did in mainstream schools; and went on to become a teacher, without clarifying where this education was received. If she received her education in the UK, being Malaysian would be irrelevant. If, on the other hand, she did so in Malaysia, it would have been plausible to explore the implications of the education and employment opportunities the woman encountered. It seems ironic, therefore, that Swain and French (2000: 581) conclude by arguing that “[q]uintessentially, the affirmation model is held by disabled people about disabled people”, implying that it is held by *all* disabled people *everywhere*, which, as we have seen, is clearly not the case.

Western concepts, therefore, are not easily applied to “postcolonial societies, especially where colonial forms of power still remain entrenched” (Meekosha, 2011: 671). Meekosha (2011: 670) argues that in some Global South contexts, which are characterised by malnutrition, lack of sanitation, water and fresh food, little employment and lack of access to

health services, “the concept of *social suffering* may be more appropriate” than concepts of disability and impairment. She argues that social suffering is not the same as “the concept of personal tragedy as critiqued by disability scholars” (ibid: 671). The concept of social suffering enables the experiences of disabled people in such contexts “to be read through the dispossessing actions of the global North”, without denying disabled people’s agency (ibid). Thus, it might be time to acknowledge that universalising western-based models of disability are not representative of, or beneficial to, disabled people all around the world, and to become aware of the need to theorise disability from the context of the Global South. As Meekosha (2011: 678) points out, “[t]he non-metropolitan experiences of disability and impairment can no longer... [be] subordinated to rational western thinking”. She maintains that “[t]he time is ripe for developing southern perspectives on disability that challenge... some of the implicit values and concepts of northern theory” (ibid), which is where postcolonial theory proves essential.

DEVELOPMENT: A DISABLING NEOCOLONIALISM?

[T]o recognise development as disabling is to begin to open up a variety of quite profound questions about the margins of ‘development’ and its impulse to objectify the ‘marginal’.

(Power, 2001: 94)

While colonisation consisted of “structural, cultural, economic and political domination, usually by peoples from the Northern European metropole over peoples from the South” (Meekosha, 2008: 7), it has now come to signify many relationships. Within disability studies, it has been applied to the ‘colonisation’ of disability by the medical profession. Meanwhile, the concept of ‘disabling’ is often applied in postcolonial studies to signify the negative impact of colonisation (ibid). Power (quoted above) calls for the need to recognise development, which has its roots in colonisation, as disabling in itself. Thus, while colonialism imposed “Eurocentric knowledge on the colonised” (Meekosha, 2011: 677), Hettne (2008) explores the significance of the introduction of culture and identity in development,

that is, discarding the Eurocentric approach to development and characterising development as a process in which different perspectives of the world are taken into account and come together in a liberating and comprehensive dialogue. This emphasis on culture may provide “the greatest challenge to the rethinking of development” (ibid: 10). The notion of cultural importance gains significance when taking into account that disability is a socio-culturally constructed concept, and comprises “social, economic, political and psychological relations between both individuals and/or institutions”, a fact which “has considerable significance for conceptualising disability and development in a range of different contexts” (McEwan and Butler, 2007: 451).

Meanwhile, the twenty-first century has seen the ‘baton’ of change being passed to, or taken over by, INGOs, instead of “large bureaucratic institutions (including the state)” (Kamat, 2004: 155). Spivak (in Sharpe and Spivak, 2003: 618) talks about the “new culture of international nongovernmental organizations, involved in development and human rights”, working “on the lowest strata in the developing world”. Cohen et al (2008: 74-5) argue that:

[i]n much the same way European empires once dictated policies across their colonial holdings, the new colonialists – among them international development groups... [and] nongovernmental organizations (NGOs)... – direct development strategies and craft government policies for their hosts.

This phenomenon is also occurring in the disability domain. Western-controlled disability non-governmental organisations have spread their reach to almost every corner of the globe (Sheldon, 2005). INGOs, therefore, are key players not only in development, but also in disability and development, meriting a closer inspection as to their history, their role in the development industry, and the critiques surrounding their performance.

The Role of INGOs in Development

The category of ‘NGOs’ was created at the founding of the United Nations (UN) to define “a specific relationship between civil organizations and the intergovernmental process” (UNRISD³¹, 1997: 11). Since the 1980s, the UN Research Institute for Social Development (UNRISD, 1997) declares, NGOs have established themselves as a significant world force in meeting the needs of those most in need, protecting human rights and promoting the democratisation of decision-making. Critics, however, argue that international NGOs are not performing as successfully as expected in poverty and popular participation (Edwards and Hulme, 1995), and go as far as to say that INGOs have not had any real impact on poverty in the developing world, which remains largely underdeveloped (Nyoni, 1987).

This failure is partly due to INGOs’ inability to comprehend the processes and dynamics of social transformation (Lang, 2000). The manner in which INGOs campaign, for example, is usually very specific and most often disconnected from the “broader social realities” (IIRE³² Manila, 2009). In an analysis of what went wrong with one development project³³ in Burkina Faso, Sharp (1990: 38-9) cites five main problems. First, “the techno-fix syndrome” occurs when ‘experts’ assume that the problem they are dealing with is purely technical and thus requires purely technical solutions. The second and third problems, “ignorance of place and people” and “tunnel vision” (projects designed in a vacuum), are related to the present point of INGO projects being disconnected from reality. Similarly, Sharp (1990: 3) reflects:

[p]overty... is only one dimension of life for the people of Burkina, and many expert foreign advisers have seen their grand projects founder because they came with only one-dimensional solutions to offer.

³¹ United Nations Research Institute for Social Development.

³² International Institute for Research and Education.

³³ The five-year project was designed to increase food crop production and strengthen rural organisation in the eastern region of Burkina Faso and was financed by the International Fund for Agricultural Development, United Nations Development Programme (UNDP), France and the US.

The fourth problem is “self-interest”, in which projects are selected according to the donors’ commercial or other interests. Finally, “clientelism” determines that donors, in return for the freedom in choosing projects, do not implement any projects to which the government objects. Development projects, therefore, tend to support the interests of governments rather than those of the people.

The fact that INGOs are accountable to both their beneficiaries³⁴ and donor agencies creates problematic complexities (Lang, 2000). Meanwhile, funders are promoting the professionalisation of INGOs, rendering more pronounced the disparity between INGO workers and the people they are purporting to serve (IIRE Manila, 2009). A study of NGOs in Mexico found that they are moving away from political education and organisation of the poor and the oppressed, and are instead adopting an approach of technical assessment of the capacities and needs of the community, and the provision of social and economic inputs. This shift to a more professionally oriented approach has led to a large inflow of money and pressure to implement effective and efficient social and economic projects (Kamat, 2004)³⁵. Furthermore:

[t]he... managerial approach to community development draws upon the liberal notion of empowerment wherein the poor are encouraged to be entrepreneurial and find solutions to their livelihood needs.

(ibid: 169)

This notion of empowerment reduces the social and political aspects of poverty, while the individual is viewed as the problem (but also the solution) to poverty, taking away responsibility from the state both as a cause and as a solution. Donors thus provide micro-credit programmes

³⁴ However, Kamat (2004) argues that INGOs are not subject to accountability to the people they purport to serve, unlike state institutions. Furthermore, the management of these organisations is usually not elected, but rather self-appointed (ibid), which is one of the issues attributed to INGOs’ failure to meet the needs of the poor: NGOs are hierarchical rather than democratic (Nyoni, 1987).

³⁵ Not all scholars are critical of the professionalisation of INGOs, however. Tandon (2003) maintains that professionalisation has enabled INGOs to be more effective and lobby the state and global institutions to change.

because the state is not responsible for generating employment opportunities, and “the poor are expected to strengthen their own capacities toward livelihood security” (ibid: 169). Hence, “[l]ivelihood security becomes a matter of optimal utilization of the abilities and resources that one possesses” (ibid: 169). Meanwhile, the emphasis on the individual having to build his/her own capacities to access the market reduces public welfare to a collection of private interests and individual gains, leading to “the privatization of public good, similar to the privatization of the public sphere in the global policy arena” (ibid: 170).

In the current neoliberal context, which has seen the rolling back of state in service provision, funding for projects and programs implemented by NGOs has increased dramatically and INGOs have assumed essential roles in the social, political and economic affairs of the developing world. The ability of INGOs to respond to issues previously neglected by governments continues to encourage neglect of these matters because INGOs are addressing them (IIRE Manila, 2009). Kamat (2004: 156) argues that:

[t]he globalization of NGOs is reflective of the new policy consensus that NGOs are de facto agents of democracy rather than products of a thriving democratic culture.

Disillusionment with the ability, or will, of the state in bringing about sustainable human development, and the belief that “flexible, motivated and decentralized structures” are needed to take on this role, has led to the expanded role of INGOs, and to the transition of NGOs from local actors to international ones (UNRISD, 1997: 3). This has led to what Kamat (2004: 158) calls a “transfer of loyalties” of the international development community from state to civil society. Ironically, INGOs are increasingly implementing projects approved by the World Bank (IIRE Manila, 2009). Financial institutions (such as the World Bank and the International Monetary Fund), which promote the withdrawal of the state from social services, are now apportioning funds to INGOs to provide those same services. INGOs are called upon to manage programmes such as

literacy, health and employment programmes for the poor; these are projects that are not of much interest to private investors, and are thus generally left out of the push for privatisation (Kamat, 2004). The proliferation of INGOs, then, has been brought on by the decisions of these foreign policies, inverting the original notion of INGOs as “symbolic of a thriving political culture, independent of patronage from state and international institutions” (ibid: 160).

These debates also encompass the grassroots organisations with whom INGOs work. Grassroots organisations (GROs) emerged between the 1950s and the 1980s to fill the gap that most post-colonial states were left with regard to the needs of poor people. Traditionally liberal donors were happy to fund GROs directly, since they were viewed as having a greater effect at meeting the needs of the poor than the states of developing countries. International development agencies have today come to rely on GROs due to their effectiveness in implementing social and economic programs such as literacy programs and small income-generating activities (Kamat, 2004). Nevertheless, while GROs are seen to be accountable to the people, like INGOs they have been subject to criticism that they are more accountable to their funders because they rely heavily on external funding (Hulme and Edwards, 1997).

Sharp (1990: 41) contends that one of the problems faced by Burkinabe GROs is that western partners provide funding for the projects but rarely provide the technical assistance needed for them to become “fully-fledged development agencies”. In a bid to enhance the organisational development of these GROs, “[a] new support industry has arisen around capacity building and training” (Mawdsley et al, 2005: 78)³⁶. However, Power (2001) contends that development organisations possibly create dependency; while Kajimbwa (2006) sustains that when INGOs

³⁶ Mawdsley et al (2005) refer to INGOs as ‘Northern NGOs’ and ‘GROs’ as ‘Southern NGOs’. For the purpose of clarity, the terms ‘INGOs’ and ‘GROs’ will be used throughout this thesis. Furthermore, in Burkina Faso there is a distinction made between grassroots DPOs and (Southern) NGOs, where the latter are considered to be on a higher echelon than DPOs, which are less evolved and have fewer resources than those few DPOs which have become NGOs.

implement their own programs, it is likely that the beneficiary of the INGO will have a decreased sense of ownership and potential to act. Furthermore, monitoring and evaluation mechanisms are often designed by the ‘experts’ of the funders or INGOs, rather than by the people themselves (IIRE Manila, 2009). GROs are critical of the way in which effectiveness and accountability are being enforced. These criticisms include: the amount of time spent on reporting; the fact that smaller GROs might not possess the required technical or language capacities to be able to produce such written requirements as reports, log frames or applications; and the distortion of the original aims brought about by these forms of accountability (Mawdsley et al, 2002). As Mawdsley et al (2005: 80) argue:

The current insistence on quantifiable targets and outputs is of limited value, and in some cases even harmful to more effective change... they can distort NGO efforts towards what can be counted... [and] less tangible indicators may be equally important, but neglected. Sometimes the most meaningful changes – self-respect, the exercise of greater choice, and so on – are the most difficult to massage into figures.

These reports have become increasingly common as INGOs shift from direct intervention to a role of financial and technical support with GROs (Mawdsley et al, 2005). Mawdsley et al (2005: 79) argue that a substantial part of these reports could be substituted with “being there”, through visits, observation and interaction. These visits would not only reduce the time burden that reporting produces, but would also increase job satisfaction and motivation, and provide the opportunity for both INGOs and GROs to learn more about each other, enabling a more respectful and deeper partnership. Furthermore, these interactions not only enable “downward accountability” but also provide a more rigorous system for ‘upward accountability’, since this system, apart from helping to immediately rule out the corrupt GROs, would help monitor “*what counts*” with the genuine GROs (ibid: 80, italics in original). Needless to say, this approach is not without its limitations: visits involve time and money, are not a fool-proof way of evaluating progress and impact, can be intrusive to

GROs and might showcase only the best aspects, hiding the less good ones (ibid). Above all, Kajimbwa (2006: 61) suggests that INGOs should support the communities in which they work to realise “their own sustainable programs” in “economic, political and social areas”, rather than implement INGO programs. He contends that INGOs need to create “space for people to act”, a perspective which is at the core of postcolonial critiques of development.

Interventions with Disabled People by INGOs

What is happening... is simply an updated, less obviously imperialistic, version of what missionaries were doing in the 1890s.
(Stone, 1999: 8)

Many donors and mainstream development INGOs do not consider the particular needs of disabled persons in their programmes or projects, and do not have or practice policies of disability equality, thus excluding disabled persons from their activities (European Commission, 2004). This is corroborated by studies such as those conducted by Metts and Metts (2000)³⁷ in Ghana, which found that most development assistance donors (such as the World Bank’s International Development Agency, the European Union, and the UNDP) did not subscribe to disability policies or mandates, and none of them took affirmative steps to include disabled people in their programmes.

This gives rise to the question, posed by Jones (1999), as to which is the best approach: setting up development projects with a specific focus on disability, or integrating a disability perspective in mainstream development projects. The latter has been adopted by some INGOs like Save the Children (UK). However, disability is more than just an added issue to take into consideration in development programs: to “add disability to a development agenda as if it was some kind of cumulative list of needs means that the underlying ableist assumptions of development remain unchallenged” (Power, 2001: 94). Jones (1999: 57-8) points out that integrating disability into mainstream development

³⁷ The research is based on the period of from 1994 to 1995.

programmes might be problematic due to the increasing pressure on these programmes to be sensitive to a number of marginalised groups such as women and children. However, the claim by many development professionals that disability is a “specialist issue”, which requires specific expertise and experience such as medical services, is a misconception brought about by the perspective of difference: that is, focusing on what is different about the person, rather than on what is shared with non-disabled people. Referring to disabled children, Jones (1999: 59) suggests that the quality of life of disabled people can be better improved by targeting the living conditions of the rural population and community “as a whole”, rather than implementing special services for disabled people, such as a special school:

The logic is clear: if schools improve their facilities, teaching methods and curricula in a way that benefits all children, then access to education for disabled children will automatically become easier.

Nevertheless, the reality is not that simple. Jones (1999: 59) warns against assumptions that “development” naturally results in the bettering of disabled people’s lives, when it might also “lead to increased polarisation between those who are well-placed to take advantage of new opportunities and those who may have to wait a very long time to reap the benefits”. Furthermore, disabled people are inevitably always the minority in a mainstream programme, thus potentially risking the neglect of their needs “under the seemingly more pressing needs of the majority” (ibid: 69).

For this reason, Jones (1999: 69) claims:

It is this risk that makes specific disability programmes necessary for a while longer yet. There is still a significant minority for whom specialist services... make a huge difference to their lives.

Hence, Jones (1999: 69) contends, the best approach would be to exploit the strong points of both approaches until “the ‘integrating a disability perspective’ approach develops activities which improve access to these ‘specialist’ services”. Mainstream programmes, however, have to make explicit the inclusion of disabled people from the beginning: it is crucial

that all development programmes comprise a disability angle. Therefore, funding entities need to be persuaded to ensure that development work benefits the whole community (Jones, 1999). Evidently, as Jones (1999: 60) points out, “in a better world, marginalised and vulnerable groups would be involved in defining what ‘development’ should be”.

Precisely identifying, or drawing boundaries around, successes or failures of interventions with people with disabilities in a developing context is no easy task. One reason for an initiative not taking off might stem from the attitudes and perceptions of the community. Jones (1999: 61-3) relates how these perceptions affected certain parts of a project carried out by Save the Children in Vietnam. The project aimed at providing support to families with a disabled child through a team of local volunteers who, after receiving training, would then work with the families to facilitate their access to services, resources or information in the community. While successful in certain areas, it was less so in others, due to perceptions, not only of disability, but also of development programmes and development organisations in general. In this case, local officials expected the project “to provide everything, from money for poor families, to sending disabled children overseas for treatment”, thus leading to disappointment with the project and the development workers. In Jones’ own words, this produces “a situation in which the project is implemented as a “charity”, not a “development” programme” (ibid: 63). It is interesting to note, however, that Jones’ (1999: 63) view is that local families in this case were “unable to understand the... project from any perspective other than the dominant social view of disabled children as ‘poor and unfortunate’, and therefore deserving of pity and charity (rather than rights)”. While it is agreed that progress cannot be achieved by taking the charity view, Jones assumes that the more appropriate approach is a rights-based one. However, as discussed above, this view has been challenged as western-centric.

Power (2001: 87) maintains that development agencies themselves silence disabled people “in their representations, in their disabling politics

and in their desire for impairment-specific and technological solutions”. Spivak (1993), drawing on Foucault, maintains that if our lenses are institutionally or geopolitically tinted, our representations of the Third World will be similarly narrowed: the development discourse characterises our manner of encounter. Furthermore, Kapoor (2004: 634) is concerned with the implementation of development programmes, which, he says, are subject to various demands, be they technical, budgetary or time-related. All of these have an effect on the implementation of the development programme, which, ultimately, has “little to do with on-the-ground needs”. Here, Kapoor, also drawing on Foucault, argues that “these bureaucratic procedures and interests are integral to the disciplinary and regulatory character of development institutions” (ibid). Increasingly, INGOs working with disability in the Global South are collaborating with DPOs (Stone, 1999). However, it is essential to acknowledge that the DPO is evidently in a less powerful position than the INGO. Thus, as Kapoor (2004: 631) argues:

for Spivak, it is dangerous to assume that one can encounter the Third World, and especially the Third World subaltern, on a level playing field.

Furthermore, INGOs, even when working with DPOs, work with grassroots organisations in “supporting them to undertake the work they [the INGOs] have identified as important”, or, worse, work with them “in ‘charity mode’ or ‘expert mode’ or ‘rescuer mode’” (Stone, 1999: 36). On this note, Kapoor (2004: 635-6) argues that when the western-based development worker acts in their own “personal, professional, organisational interests”, they produce the Third World or the subaltern to suit their own “image and desire”. Their representations of the Other (in this case, the colonised *and* the disabled person), at the very least, are constructed only as they want to know it and control it. Here, Kapoor is also drawing on Said’s (1978: 3) notion that Orientalist discourse is the “Western style for dominating, restructuring, and having authority over the Orient”.

It has already been established that disability debates (both in academia and popular debates) are often rooted in an “unacknowledged Western context” (McEwan and Butler, 2007: 448). We have seen that disability models and outcomes of disability activism, such as human rights legislation pertinent in the west, do not necessarily apply seamlessly to disabled people in countries in the Global South. In his influential work ‘Provincializing Europe’, Dipesh Chakrabarty (2000: 5) discusses a central tenet of postcolonial scholarship in “engaging the universals... that were forged in eighteenth-century Europe”. Imperialist Europe imposed “the Enlightenment idea of the human” (ibid) while at the same time – as observed by the Tunisian scholar Hichem Djait (in Chakrabarty, 2000: 5) – “deny[ing] its own vision of man” (ibid). Chakrabarty’s argument, therefore, is that there is a fundamental contradiction at the heart of the colonial project: while it relied on a sense of a common humanity (the justification for the civilising mission was that the colonised have the potential to be like the colonisers); it simultaneously relied on Othering (the assumption that the colonised are not like the colonisers, hence the justification for the imposition of the coloniser’s will without granting the colonised the freedoms of civilisation).

Chakrabarty (2000: 6) also discusses at length the notion of historicism: “first in the West, and then elsewhere” that the colonisers brought with them to such places as Africa and South Asia. This notion embodies the belief that the colonising countries are developed, while the colonised will, in time, too be developed and be able to self-govern, but they are ‘not yet ready’ for the freedoms associated with civilisation, such as democracy and self-determination. Philosophers of human rights, such as John Stuart Mill, relegated the peoples of “rude” nations, such as Indians and Africans to “an imaginary waiting room of history”:

We were all headed for the same destination, Mill averred, but some people were to arrive earlier than others.

(Chakrabarty, 2000: 8)

The irony in this is what Homi Bhabha (1994: 86; 89) calls “colonial mimicry”: “the desire for a reformed, recognizable Other, *as a subject of a difference that is almost the same, but not quite*” (italics in original). According to Bhabha (ibid: 86), mimicry crystallises “the dominant strategic function of colonial power” and “intensifies surveillance”:

The success of colonial appropriation depends on a proliferation of inappropriate objects that ensure its strategic failure, so that mimicry is at once resemblance and menace.

The colonisers, therefore, not only kept the colonised in the ‘waiting-room’ of history’, but also kept them at a distance: while encouraging them to become like the coloniser, the latter did not want the colonised to become *exactly* like him. However, Chakrabarty (2000: 9) argues, the local elites rejected “the ‘waiting-room’ version of history when faced with the Europeans’ use of it as a justification for denial of “‘self-government’ to the colonized.” Furthermore, the “peasant”³⁸, or the subaltern, of the twentieth century became, in Chakrabarty’s home country of India, a “full participant” in the country’s political life while still being uneducated in “the doctrinal or conceptual aspects of citizenship”. This was contrary to the coloniser’s argument that “the subaltern classes of the third world” cannot “assume the political responsibility of self-government” (Chakrabarty, 2000: 8). This historicism is still present today: “its ‘not yet’ exists today in tension with this global insistence on the ‘now’ that marks all popular movements toward democracy” (ibid).

This pervasive presence of western thinking is reflected in the domination of western disability models (mostly the medical and social ones), and the assumption by development agencies such as INGOs that disabled people in the Global South will adopt the social model as *the* right one. Taking two examples, ADD³⁹ states that it “adopt[s] the social model of disability, whereby the onus is on society to change and become more inclusive of diversity, including disabled people” (Frost, 1999: 43).

³⁸ Chakrabarty (2000: 11) uses the term ‘peasant’ to refer to “all that is not bourgeois (in a European sense) in Indian capitalism and modernity”.

³⁹ Action on Disability and Development is a UK-based non-governmental development organisation, working with disabled people in Africa and Asia.

International Service⁴⁰ similarly states that its “approach to working with disabled people is underpinned by what is known as the 'social model' of disability” (International Service, 2015: n.p.). The assumption by western actors, therefore, is that the social model is the appropriate framework for understanding and improving disabled people’s lives everywhere. This also belies the supposition that disabled people in the Global South have not yet achieved the pinnacle of emancipation through the social model and disability rights legislation. Moreover, disabled people in the Global South have to ‘wait’ to ‘get there’, which is why they need, and keep on needing, INGOs’ support: they are not yet ‘ready’ to become self-sufficient and stand on their own, and thus remain tethered to an INGO/s for years. However, as Connell (2011: 1379) suggests, grassroots communities have the ability to change and develop new approaches:

Indigenous social knowledge is capable of development, and disability politics may find resources here that are not available from the metropole or from international agencies.... In moving beyond metropole-defined understandings of disability, and metropolitan models of disability politics, this is one of the most important points[:].... [t]he colonised and postcolonial world has intellectual resources... that can inform struggles to overcome marginality, prevent damage, and make the voices of disabled groups heard.

Thus, as Chakrabarty’s argument demonstrates, those values, ideals, models, emanating from Europe are not necessarily universal. There is a need to challenge the ‘universalism’ of western disability models and theory. This does not mean negating the value of all things western, but recognising that western models of development cannot easily be universalised and that alternative ideas about human rights may emerge from other places.

⁴⁰ International Service is an international development charity working with marginalised people (including disabled people) in West Africa and other regions in the world.

CONCLUSION

Postcolonial critiques of development are pivotal for understanding how interventions with disabled people in the Global South can be re-worked with disabled people themselves, through an understanding of disability in Global South contexts. McEwan and Butler (2007: 460) maintain that one of the challenges is “ensuring that debates within poorer countries can inform development strategies, but first there needs to be an understanding of what these debates are and an assessment of their potential to inform broader policy and practice”. This chapter has introduced the debates within both development and disability studies, showing how they have remained largely exclusive of each other. And, when viewed through the lens of postcolonial theory, models of disability remain almost entirely western-centric and yet are assumed to be universally applicable. The next step (and the focus of this thesis) is to look at how these debates can inform each other to enable development policies and practices that are conducted for disabled people’s benefit and inclusive of their voice and agency. As this chapter has argued, postcolonial approaches not only cast light on western-centrism, but also emphasise the need to listen to subaltern voices, to enable a space where these voices can be heard and to enable spaces in which subaltern peoples might shape the development discourses and practices that affect them. Central to this approach is the recognition that subaltern groups, like disabled people in poorer countries, possess valuable knowledge with regards to their experiences and the (international) decisions that affect their daily lives. This recognition has significant methodological implications. Based on the arguments outlined above that both disability and development are conceptualised in the west and that disabled people in particular have not been included in the formulation of development interventions – either in general or with disability groups specifically – it is crucial that research attempting to remedy this situation is able to translate the theoretical insights of postcolonial theory into practice, in order to ensure that development becomes more inclusive and ethical. I

suggest that this requires adopting a participatory action research approach, which assumes that “those who have been *most* systematically excluded, oppressed or denied carry specifically revealing wisdom about the history, structure, consequences, and the fracture points in unjust social arrangements” (Fine, 2008: 215). The next chapter outlines the significance of participatory research in light of previous arguments and provides a detailed explanation of the methodology employed in my attempt to explore disability in Burkina Faso through a postcolonial lens.

CHAPTER 3

METHODOLOGY: RESEARCHING DISABILITY IN BURKINA FASO

INTRODUCTION

[S]ocial research is still too often a process through which the knowledge of oppressed 'others' is appropriated and reconstructed in profoundly disempowering ways.

(Chouinard, 1997: 384)

The choice of research methods is informed by both the topic being explored as well as the theoretical framework of the research. The main methods employed in development research have traditionally been quantitative methods, while qualitative and participatory methods are “often relegated to desirable ‘frills’” (Mayoux, 2006: 116). Many development agencies have emphasised “economic growth and the economic dimensions of poverty”, an emphasis which deepened during the 1990s, “with requirements for performance assessment and targets in logical frameworks” (ibid). The Millennium Development Goals further increased the requirement to demonstrate progress through “the ‘scaling up’ of impacts and macro-level change”, thus increasing pressure for quantification. Talking about quantitative poverty assessments, Christiaensen (2001: 70) says these assessments lie in the school of logical positivism, which asserts that “there exists a single, external reality and it is the analyst's task to capture this as closely as possible”. Thus, the researcher uses statistical principles in the design of the study they are conducting, and “structure, standardization and quantification” in the collection of data, so as to achieve unbiased objective answers. The role of the researcher, in this case, is furnishing policy-makers with impartial information (Christiaensen, 2001: 70). However, Rahman (1990: 41) postulates that:

[t]here is no reason why... the notion of development... should take a narrower, predominantly quantitative, view, leaving out vital

considerations which can be assessed by analytical reasoning if they cannot be measured by numbers.

A person's standard of living involves other aspects besides income, such as education, healthcare, and also more basic aspects such as food and clothing (Rahman, 1990: 41). Rahman (1990: 41) argues that "most... indicators of personal development are not quantitatively measurable, but they may nevertheless be at the core of enlightened human aspirations".

In the 1980s, when critiques of development started gaining momentum (Nelson and Wright, 1995: 3), participatory researchers like Orlando Fals-Borda (1988: 95) were arguing that developmentalist discourse deals with such issues as poverty, capital and growth "as defined from the standpoint of rich, developed societies" to rationalise and defend "the global dominance of these... powerful societies". In contrast:

The participatory discourse or counterdiscourse... initiated in the Third World... postulates an organization and structure of knowledge in such a way that the dominated, under-developed societies can articulate their own socio-political position on the basis of their own values and capacities and act accordingly to achieve their liberation from the oppressive forms of power imposed by foreign powers and local defeatist elites, and thus create a more satisfactory life for everyone.

(ibid)

As a result, a call for participatory development was taken up, with the pressure coming mostly from organisations in the Global South (Nelson and Wright, 1995).

Participatory Action Research (PAR), which has been described as a "collaborative process of research, education and action explicitly oriented towards social change" (Kindon et al, 2009: 90), is significant in working with oppressed groups because it narrows the gap between social research and action. That is, instead of waiting for someone to discover the results of a particular piece of research in order to put them into practice, the research itself sets the ball rolling (Foote Whyte, 1991). One of the main goals of action research is to "produce practical knowledge that is useful to people in the everyday conduct of their lives" (Reason and Bradbury, 2008: 4). The ultimate aims of this knowledge are to make it possible for

vulnerable groups to acquire sufficient leverage to transform their situation (Fals-Borda, 1991). While the qualitative approach lies in the interpretivist and the constructivist traditions, which acknowledge the existence of multiple realities and the fact that science cannot be completely objective (Christiaensen, 2001), PAR lies in the social constructionism epistemology, which has at its heart “the collective generation and transmission of meaning” (Crotty, in Blaikie, 2007: 22). This suggests that the role of research in PAR is not only that of helping to understand the world, but to help “change it for the better” (Kindon et al, 2007: 13).

Whilst rooted in theoretical and epistemological concerns, postcolonial approaches also have implications for conducting research in the Global South. Mohan (1999: 42) points out that while some geographers have adopted the “textual” postcolonial approach in challenging “claims to truth, particularly our own complicity in colonising knowledge”, others conduct primary research, some of which extends into participatory research, “which involves using the research process itself as a means to change existing power relationships” (ibid). The main difference between participatory approaches and other research approaches is in the “location of power in the various stages of the research process” (Cornwall and Jewkes, 1995: 1667-8). Swantz (2008) relates her experience of PAR, where, as a researcher, she immersed herself in village life in Tanzania, living in a Swahili house with a local family. She cites a research project of which she was part, in which the villagers themselves assessed their educational level and the degree to which skills and natural resources were being made use of. The results were obtained through a self-conducted survey – which gave rise to active village discussions – and “made villagers aware of big gaps in skills and unused resources” (ibid: 32). And, Swantz (2008: 34) continues, although the survey lacked statistical rigorousness, “villagers’ involvement in it and their self-assessment made them aware of their development potentials”. This, in a nutshell, is the crux of PAR: it works with people, enabling them

to analyse their situation and empowering them to transform it. It does not take such phenomena as poverty as an occurrence segregated from everything else, but takes into account related and crucial factors, such as people's skills, as the above example demonstrates. Cornwall (in Brock, 2002: 3) discusses issues brought up by PAR skeptics, who are concerned about "the use of participating as a legitimating device that draws on the moral authority of claims to involve the poor to place the pursuit of other agendas beyond reproach". As May et al (in Carvalho and White, 1997: 14) maintain, "[s]pecial efforts may be required to analyse the key findings of the Participatory Poverty Assessment and interpret these into issues to be brought into the process of policy formulation". Furthermore, qualitative accounts have been criticised on account of making it difficult to verify information, due to the subjectivity of the research results (Carvalho and White, 1997). In the context of disability research in the Global South, however, participatory research is still the most ethical way to conduct research, particularly in "revealing the ways in which colonial discourses have impacted upon knowledge, subjectivity and power" (Mohan, 1999: 42).

Since the 1990s, human geographers working on social change "have challenged 'externally' generated knowledge and have sought ways to create more equitable and collaborative forms of knowledge" (Mohan, 1999: 42). As Mohan indicates, academics and practitioners should start by discarding the notion "that 'expert' professionals know best. This creates the space for local knowledges to be accessed and actions taken on the basis of this knowledge" (ibid: 43). The Other will "only cease being subaltern when, to use Gramsci's terms, they become organic intellectuals or spokespeople for their communities" (McEwan, 2003: 348). Thus, disabled people cease being subaltern when they are able to voice their needs and concerns and contribute to the development interventions being carried out on their behalf. This concern with voice and agency has direct links to participatory research methods. Furthermore, postcolonial theory calls attention to the enduring impacts of colonisation in current

“institutional arrangements, images, representations, and interpersonal relationships” (Kindon et al, 2009: 91). Postcolonial critiques are extremely significant in the context of PAR’s “focus on working with marginalized and traditionally oppressed groups” (ibid). One of the most significant contributions of a PAR process is “[s]elf-analysis, leading to a reworking of self-representation” (Cahill, 2007: 182). PAR’s “epistemological approach has profound implications for rethinking the politics of representation” (Cahill and Torre, 2007: 196), rendering this approach ideal to mitigate the critiques that have been leveled at academic research by postcolonial scholars as being “a conversation of ‘us’ with ‘us’ about ‘them’” (ibid). PAR researchers have used methods such as participatory video to “destabilize the masculinist and colonial gaze of mainstream media representations” of marginalised groups and provide “a vehicle for self-representation and community building” (Kindon et al, 2009: 91). The importance of self-representation takes on further significance when considering research with disabled people who are not only marginalised and oppressed but are the objects of continuous representations. Furthermore, disabled people in the Global South are also the target of continuing ‘colonisation’ by international development organisations. Fine (1994: 73) argues that:

[t]he challenge to social scientists for a redefinition of the basic problem has been raised in terms of the ‘colonial analogy’. It has been argued that the relationship between the researcher and his subjects, by definition, resembles that of the oppressor who defines the problem, the nature of the research, and, to some extent, the quality of interaction between him and his subjects.

This, according to Fine (1994: 73), is the “inability to understand and research the fundamental problem, neo-colonialism”. While she is talking about research with black people, her argument stands fast with regard to research with disabled people. In the wake of the politicisation of disability by disabled people in North America and the UK in the 1960s and 1970s (Barnes, 2001), traditional disability research has been problematised on a number of fronts. The main criticism is that it does not

represent disabled peoples' experiences (Kitchin, 2001). Oliver (1992: 102) launched an attack on the disability research agenda, contending that "the very idea that small groups of 'experts' can get together and set a research agenda for disability is... fundamentally flawed". According to Oliver (ibid), disability research should be "part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives". In response to Oliver's (1992) call for disability research to be part of the struggle of disabled people against their oppression, and Gleeson's (1999: 203) statement that "geographers must participate in the political struggle against the socio-spatial formations that oppress impaired people", PAR seems to answer this call, since it involves the construction of knowledge upon which to build power, or confront it, for oppressed groups (Fals-Borda, 1991). Kitchin (in Hall and Kearns, 2001: 240) argues that unless disability research in geography takes a PAR approach, disabled people's interests cannot be considered, and geographical research would continue to be "disablist". Participatory research with disabled people involves: a research problem being identified by disabled people (or non-disabled people who bring it to the attention of disabled people); disabled people and researchers analysing the research problem together; and partnerships formed between disabled people, researchers and other key people in the field, with the partnerships being controlled by – and in the interests of – disabled people (Cocks and Cockram, 1995). Hall and Kearns (2001: 239) recommend that disability research listens "to the 'voices' of those rendered invisible" and understands and represents "the diversity of experiences of disabled people".

Meanwhile, Mohan (1999: 49) indicates that, while the larger part of participatory approaches are inclined to look downwards to the local level, "more transformative approaches would also study the development agencies themselves and be prepared to criticise bad practice". Studying "elites and their organisations", Mohan (1999: 49) argues, "seems to be a fruitful avenue", for, as Fine (1994: 73) recounts, there has been "a collusion between social researchers committed to sanitizing/neglecting

the elite through scholarly omission”. This research thus explores ‘both sides of the story’ and involves a mix of participatory and traditional qualitative methods. While participatory methods were used with a group of disabled people, interviews were conducted with the ‘elite organisations’, that is, international non-governmental organisations (INGOs) that intervene in the field of disability and development, the state authorities working with disabled people, and disabled people’s organisations (DPOs). Interviews were the method of choice: they “are a commonly used method in development research because of the range of information that can be obtained” (Willis, 2006: 146). The participatory methods used were visual in the form of participatory diagramming and participatory video. In this research, these visual methods were also used to triangulate data obtained from interviews carried out with disabled people themselves. Carrying out interviews with disabled people rather than employing solely participatory methods also enabled the obtaining of individual views.

This chapter outlines in more detail the methodology employed in this research, with a focus on the fieldwork. It starts by looking at the semi-structured interviews that were carried out with different groups of research participants, the rationale behind this choice of method and their implementation on the ground. The subsequent section delves into the participatory video and participatory diagramming techniques employed with a group of disabled people. Following this, the next part of the chapter explores the challenges and limitations encountered throughout the research process. Finally, the chapter considers the ethical concerns arising from the research methodology and how these were mitigated.

FIELDWORK OVERVIEW

In Burkina Faso, the research was conducted mainly in three regions (see Figure 3.1): Est, Centre and Cascades, with small parts of the fieldwork being conducted in two other adjoining regions (Plateau-Central and Hauts-Bassins). The three main regions were chosen as being the

farthermost regions of the country from East to West, and covered southern, western, central and eastern regions of Burkina Faso ⁴¹. Furthermore, the Est and Cascades regions provide a contrast to the urban capital as well as an urban-rural contrast within themselves; while the Centre region, which is more or less the capital city of Ouagadougou, was also included because of its high density of DPOs. The fieldwork took place between June 2014 and June 2015 and was scheduled as illustrated in Table 3.1.

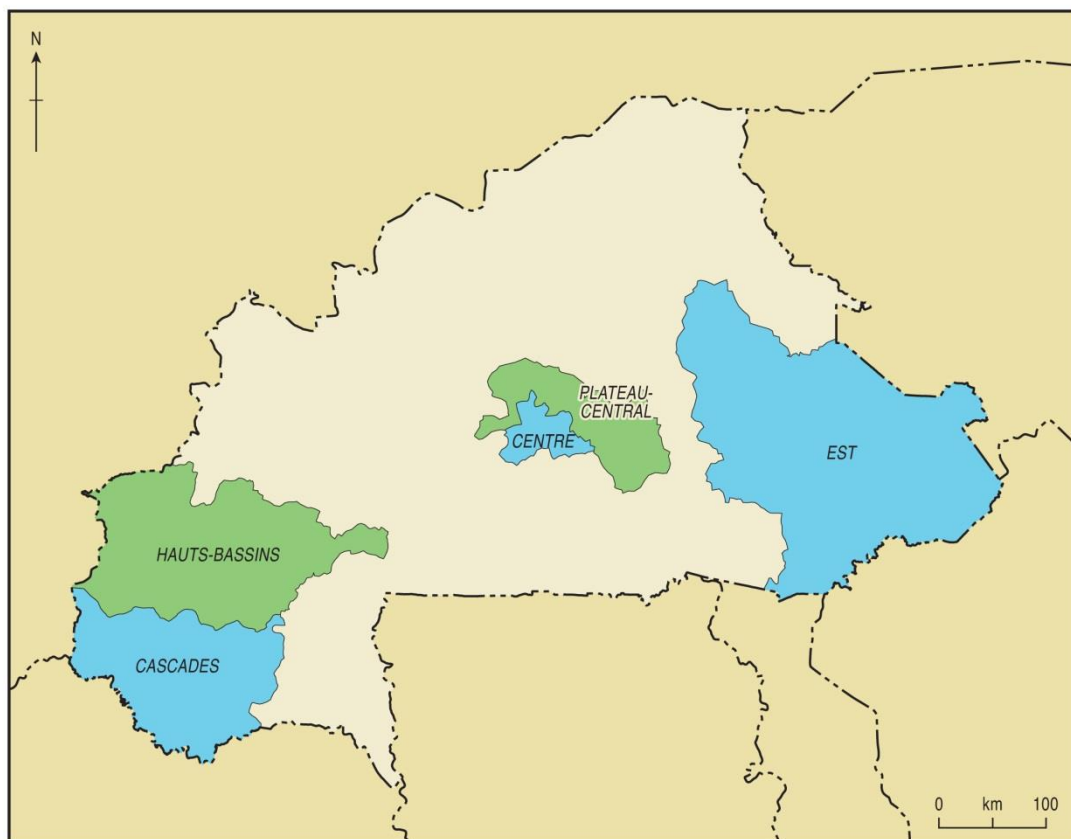


Figure 3.1 Fieldwork Regions

⁴¹ A large part of the Northern regions were, at the time, rated as high-risk areas by the UK Foreign and Commonwealth Office, and were thus avoided.

Date	Location (Base)	Activity
June 2014	York, UK	- Interviews with INGO head offices
September 2014	Ouagadougou, Fada N’Gourma and Banfora, Burkina Faso	- Preparatory meetings with INGO field offices, state authorities, DPO coordinators and individual DPO members - Participatory observation with DPOs in the Est region
September – November 2014	Fada N’Gourma, Burkina Faso	- Interviews with disabled people and DPOs in the Est region - Participatory diagramming and participatory video with disabled people in the Est region
November – December 2014	Ouagadougou, Burkina Faso	- Interviews with disabled people and DPOs in the Centre region
December 2014	Fada N’Gourma, Burkina Faso	- First showing of participatory video
January – February 2015	Ouagadougou, Burkina Faso	- Interviews with disabled people, DPOs and umbrella DPOs in the Centre region and Plateau-Central region
February – May 2015	Banfora, Burkina Faso	- Participatory observation and interviews with disabled people and DPOs in the Cascades region and the Hauts-Bassins region - Interviews with provincial, regional and traditional authorities in the Cascades region - Second showing of participatory video
May – June 2015	Ouagadougou, Burkina Faso	- Interviews with disabled people, DPOs and umbrella DPOs in the Centre region - Interviews with INGO field offices - Interviews with national authorities

Table 3.1: Fieldwork Schedule

INTERVIEWS

There are mainly three types of interviews in qualitative research: structured, semi-structured and unstructured. While structured interviews “follow a pre-set list of questions which are often standardized across interviewees”, unstructured ones “provide the interviewees with the opportunity to take the discussion in whichever direction they choose” (Willis, 2006: 144). While I had a list of pre-set questions to ask all sets of interviewees, I also wanted the interviewees to have the opportunity to “bring up their own ideas and thoughts” (ibid: 145). Thus, semi-structured interviews seemed the best choice, since, in this type of interview, “interviews follow a form of interview schedule with suggested themes, but there is scope for the interviewees to develop their responses” (ibid: 144). For this reason, “semi-structured interviews are usually the most popular” choice (ibid: 145). Table 3.2 gives an overview of the interviews⁴² held during the course of the fieldwork in Burkina Faso.

Before the commencement of the fieldwork, from the time of writing the thesis proposal, I was in contact with two DPO coordinators in Burkina Faso. During these email and phone call exchanges, I discussed my research with them, asked their opinions, and incorporated their views in the thesis proposal. Their ideas influenced my research questions and also the research design. Upon arrival in Burkina Faso in September 2014, preparatory meetings were held. These were conducted with contacts I knew through my previous work as a development worker with an INGO in Burkina Faso, when I had been placed as an organisational capacity builder with a DPO from 2008 to 2010. After meeting with the same INGO in Ouagadougou, who also put me in contact with the Ministry of Social Action and National Solidarity ⁴³ (the ministry responsible for disabled people) in Ouagadougou; several meetings with different organisations and individuals were held in each of the three

⁴² A more detailed list of the interviews carried out with individual disabled people, DPOs, INGOs and authorities can be found in Appendix 1.

⁴³ Ministry of Social Action and National Solidarity of Burkina Faso: *Ministère de l'Action Sociale et de la Solidarité Nationale du Burkina Faso*.

regions: I met with the coordinators of three DPOs and with various DPO members. During these meetings I explained my research, sought their support and opinions, and discussed the research content, design and its feasibility.

Entity	Region	No. of Interviews	Total No. of Interviews
Individual Disabled People	Est	47	228
	Centre	30	
	Plateau-Central	4	
	Cascades	146	
	Hauts-Bassins	1	
DPOs	Est	10	65
	Centre	33	
	Plateau-Central	1	
	Cascades	17	
	Hauts-Bassins	4	
Umbrella DPOs	Centre	9	9
INGO Field Offices	Centre	8	10
	Cascades	1	
	Email Exchange	1	
Authorities ⁴⁴	Centre	3	15
	Cascades	12	
TOTAL NUMBER OF INTERVIEWS			327

Table 3.2: Interviews held in Burkina Faso

Interviews⁴⁵ with the European headquarters of the INGOs aimed at exploring the interventions they carry out with disabled people in Burkina Faso, by whom these interventions are designed, the rationale behind them, the impact of these interventions from the INGOs' point of

⁴⁴ Due to a popular uprising in October 2014 and the (political and local) instability which ensued, the interviews which were planned to be held with the regional and provincial authorities in Fada N'Gourma after the filming, were postponed and ultimately not held, since by that time it was time-consuming to go back to Fada N'Gourma, since I was staying in the other regions.

⁴⁵ See Appendix 2 for sample interview templates.

view, their views of the lived experiences of disabled people in Burkina Faso, and their understanding of disabled people's concept of development. These interviews aimed at partially answering Research Questions 2⁴⁶ and 3⁴⁷, concerning mainly the roles of INGOs in development and disabled people's lives, and the extent to which disabled people are involved in their own development and decision-making. Interviews were planned with the European headquarters of the three main INGOs working in development with disabled people in Burkina Faso. Interviews were conducted with the Chief Executive Officer (CEO) and the International Programmes Director of one of them. Repeated contact was also attempted with the other two INGOs up to my departure for Burkina Faso, but they failed to respond. Upon arrival in Burkina Faso, I learnt that one of the INGOs no longer worked in the country, while the third finally put me in contact with their regional office in Ouagadougou. Interviews were then held with various INGO field offices in Burkina Faso. These were held towards the end of the fieldwork, so that the questions posed to the national directors could be informed by the information collected up to that point from people with disabilities. Interviews with the field offices aimed at building upon interviews with INGO headquarters, but also at exploring aspects specific to the Burkinabe context, including the rationale behind the areas of intervention, the selection of local partners and target beneficiaries, the types of disabilities their beneficiaries have, and the Burkinabe context with regards to disability and development. Interviews with authorities also contributed to Research Questions 2 and 3 by exploring the authorities' interventions with disabled people, the rationale behind them, and whether (and how) disabled people are involved in the planning and decision-making stages of the same interventions.

⁴⁶ Research Question 2: What are the roles of grassroots disabled people's organisations, international non-governmental organisations and the state in development and disabled people's lives?

⁴⁷ Research Question 3: To what extent are disabled people involved in their own development and decision-making and what is the significance of their agency and voice within development?

The interviews with DPOs⁴⁸ were generally conducted with their presidents (and sometimes the general secretaries) and explored the objectives, functioning, history and sustainability of the organisations. These interviews were aimed at answering part of Research Question 2 on the role of grassroots DPOs in development and in disabled people's lives. Complementing these interviews were several sessions of participatory observation, including joining the regional coordination of the Est region on a mission with one of the national federation of DPOs. The federation had come to the Est region to observe sessions of training on AIDS prevention, funding for which had been obtained by the federation on behalf of the DPOs. Sessions like these were extremely useful to observe the relationship between umbrella DPOs (the federation) and grassroots⁴⁹ DPOs, funding processes and the functioning of both the federation and smaller DPOs.

Interviews with individual disabled people explored different aspects of their lives, including the onset of disability, education, employment, family life, DPO membership and expectations for the future. These interviews were aimed at answering Research Question 1⁵⁰ on the lived experiences of disabled people, as well as their perceptions of disability. The interviews also contributed to looking at disabled people's perceptions of the role of DPOs in their lives (Research Question 2).

Apart from these recorded interviews (including only very few non-recorded ones, where participants refused to be recorded or there was too much noise to be able to record), there were countless informal conversations which were indispensable to the research, and from which a great deal of useful data emerged. Information given to me strictly in confidence, however, was not used in the thesis. Nevertheless, it helped elucidate otherwise unclear data, provide context, as well as triangulate

⁴⁸ These included interviews with grassroots DPOs, and provincial and regional coordinations comprising the DPOs in that province or region.

⁴⁹ The term 'grassroots' is here used to differentiate these DPOs from umbrella DPOs.

⁵⁰ Research Question 1: How do disabled people in the Global South experience and perceive disability, and what are their lived experiences?

data obtained from formal interviews. Informal conversations were also a source of information which interviewees would never have mentioned in formal interviews. In this I was also lucky that some of the interviewees, especially in the Cascades region, already knew me. Although this was sometimes disadvantageous, for example when asking questions about income-generating projects I had helped start with some DPOs when working for an INGO, our previous acquaintanceship served to put some people at ease and to relate things they would not have told me if I had not had previous experience in Burkina Faso. For example, in one town in the Comoé province, I interviewed the Executive Committee Members of the DPO about income-generating activities and discussed one such project, a henhouse, which had failed. In the formal interview, the members said that the chickens had died due to sickness, and, since the INGO had not given them the rest of the project funding, the DPO could not buy more chickens. However, afterwards, one of the members explained to me that the chickens had died because the previous landowner wanted her land back and had thus performed *wak* (what in western contexts would be called ‘witchcraft’ or ‘the occult’) so that the chickens died. There may be two reasons why the participants had not told me this in the formal interview. First, I had helped set up this project; thus the DPO members would have felt obliged to show me that the project was not a complete failure. Second, since I am a non-African foreigner, they would assume that I would not believe the *wak* version. Furthermore, there were interviewees who often started talking freely once I had switched off the recorder. Some actually asked me specifically to switch off the recorder before speaking about a particular topic. Again, care had to be taken as to what information to use in the thesis and how to use it so as not to harm the participants.

Fylan (2005: 65) describes semi-structured interviews as being:

conversations in which you know what you want to find out about – and so have a set of questions to ask and a good idea of what topics will be covered – but the conversation is free to vary, and is likely to change substantially between participants.

And vary they did, which also enabled me to bring in new questions on subjects the interviewees talked about and which were obviously important to them. Furthermore, I also made modifications (some of them pre-planned, some of them impromptu, since I did not always know who we were going to interview on that day), according to, for example, the nature of the DPO. For instance, if it was more of a cooperative than a DPO, then questions were modified accordingly. I also discarded or modified other questions which I found the interviewees were not understanding, were difficult to explain, or were simply not useful.

The transcription of the interviews began during the fieldwork and continued on my return to the UK. Analysis was conducted by employing coding methods used in Grounded Theory. Grounded Theory Methodology (GTM) is used “to generate a theory from the collected data” and “is one of the most used methodologies worldwide in qualitative social studies” (Stottok et al, 2011: n.p.). In GTM, the researcher reads the interview transcript and identifies concepts and links between various components of the text (ibid). The first step of the analysis is coding, which “means naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data” (Charmaz, 2006: 43).

The coding method employed in this analysis was a visual version called colour coding. Colour coding is an alternative to the traditional Grounded Theory techniques, and considered superior and easier to use by Stottok et al (2011). It “uses colours to reflect the code, concept, and finally category to which a piece of text is assigned” (ibid). Through coding the interviews, I identified trends and connections and grouped the various codes “into larger, more meaningful categories” (Stottok et al, 2011: n.p.). As Stottok et al (ibid) assert, colour coding “makes it simple to see which parts of the text belong to which category and of the importance they have had to the interviewee”. I found this to be true: for each category I had created, I created a Word document into which I inserted the parts of the interviews with the relevant colour (each category had a different colour

assigned to it). For those parts of the text which were linked to two different codes, hyperlinks were created between documents for easy reference. To say that the analysis was contained in this neat section of the research process, however, is to not do justice to the actual analytical process, which really started while I was doing fieldwork, when reflecting on the data, writing in the fieldwork diary and notebooks and discussing my findings with friends and colleagues. Even after the coding and categorising, the data analysis continued during the writing-up, with categories sometimes changing boundaries, overlapping with each other or becoming linked in different ways than they had previously been linked.

Gatekeeping and 'Selecting' the Participants

While quantitative research relies on random sampling, that is, choosing a sample in a way that every unit in the population has a (known) probability of selection, qualitative approaches choose relatively small samples and conduct more in-depth research. The rationale behind this is that much can be derived on matters of concern “from the detailed study of a few information-rich cases” (Carvalho and White, 1997: 5). The ‘selection’ of the DPOs and individual disabled people as participants in this research was not based on random sampling. I put ‘selection’ in inverted commas because it was not technically my decision, but rather that of the gatekeepers. In each region, the research was facilitated by the gatekeeper who, in the Centre and Cascades region was also the interpreter. In the Est region, the gatekeeper, a disabled person, was a contact made years previously when working in Burkina Faso as a development worker. He put me in contact with the interpreter, a non-disabled man who knows the region and its languages thoroughly and has his own motorbike with which we could travel. During the preparatory meeting, I discussed the questions I planned to ask individual disabled people with the gatekeeper, both in terms of being sensitive and inoffensive as well as eliciting the richest information. Furthermore, the gatekeeper discussed with both me and the interpreter the terms used for

disability in the region in the main local languages, Gourmanchéma and Mooré⁵¹.

The gatekeeper put me in contact with different DPOs in the region, according to his contacts and the DPOs he thought it viable to interview⁵²; however, research was conducted in all the provinces of the region (see Figure 3.2). Upon arrival in the municipality, the local DPO president would then usually choose, or would have already chosen, the individual disabled people who were to be interviewed. There was thus a double gatekeeping: the primary gatekeeper and the president of each DPO in the provinces (secondary gatekeeper). The presidents, being usually physically disabled men, tended to select physically disabled men for individual interviews, despite my insisting with the primary gatekeeper that it would be preferable to ask the DPO presidents in the provinces to select a person with each type of disability if possible: physical, visual, auditive, albinism and intellectual. Additionally, the secondary gatekeeper, that is, the DPO president or General Secretary (GS) often accompanied the interpreter and me to an interview, most often to show us the way to a person's house, but sometimes for no apparent reason other than to be present. This was frustrating and created concerns about the influence the president's presence would have on the interviewee, particularly with regard to DPO-related questions:

The GS is proposing answers... it's difficult to tell him to go away after he drove all this way!

(Interview with Moïse, Entry in Fieldwork Notebook 2: 33,
26th September 2014)

Furthermore, the primary gatekeeper of the Est region is the coordinator of a DPO in Fada N'Gourma. Thus it was difficult to gain access to another 'rival' DPO in the same town, whose president had insulted the gatekeeper and left his DPO to create another one. Had I asked the gatekeeper if I

⁵¹ The language of the Gourmantché ethnic group who inhabit the Est region is Gourmanchéma. However since the region comprises also many Mossi, it was necessary that the interpreter knows also their language, Mooré.

⁵² For example, he did not put me in contact with a particular DPO in the Kompienga province, explaining that the president picks fights with everyone and that interviewing him might not be ideal.

could interview this DPO he would have felt insulted. Nonetheless, without the gatekeeper I could not have carried out the research in the Est region. He opened many doors for me, as did the other gatekeepers:

He is gatekeeper but also the coordinator of my research, the cultural mediator, the animator, the access person (who gave me access to disabled people), the interpreter-finder, a friend, an informal information giver and so much more.

(Entry in Fieldwork Diary, 25th October 2014)



Figure 3.2 Fieldwork Provinces

In the Centre region, the gatekeeper and interpreter was a physically disabled man, Jacques, who was introduced to me by the gatekeeper in the Est region. Although his contacts with other disabled people and DPOs are considerable, they naturally tended to skew towards people with physical disabilities. I thus used my contacts from my previous work in Burkina Faso to obtain interviews with people with albinism and blind and deaf people and then used these to snowball other

contacts. I also used the interviews I had carried out with the state authorities in the Cascades region to put me in contact with their counterparts in Ouagadougou. Sometimes, especially with interviews with umbrella DPOs, authorities, and INGOs I needed Jacques less as an interpreter (many people in Ouagadougou speak French) than a driver with his three-wheel motorbike (see Figure 3.3). Jacques, however, like the other gatekeepers, was extremely useful in providing background and contextual information prior to, and post-, interviews.



Figure 3.3 Three-Wheel Motorbike

In the Cascades region, the gatekeeper and interpreter, Ibrahim, was a non-disabled man whom I knew from my previous work in Burkina Faso. He is a member of a DPO in Banfora and has extensive knowledge of the region and languages. He also has contacts with all of the DPOs in the region, which was useful, as was his motorbike, which was used as transport to the various provinces.

Thus, while the selection of DPOs and most individual disabled people was at the discretion of the gatekeepers, the goal of conducting interviews with men and women with physical, sensory and intellectual disabilities, as well as people living with albinism (see Table 3.3), was ultimately carried out⁵³. One interviewee who is not included in Table 3.3 has epilepsy. However, several people with intellectual disabilities interviewed also have epilepsy. Furthermore, I had originally planned to do the research with only adults. The major reason for this was to be able to explore people's lived experiences from the onset of the disability onwards, as well as their work experiences and relationships in the community. However, I sometimes ended up including children⁵⁴, although in Burkina Faso, fifteen-year olds are not considered children. For example, the Ministry of Youth, Skills Training and Employment⁵⁵ includes people from fifteen to thirty-five years in their scheme to help young people start self-employment ventures. With regards to INGOs and umbrella DPOs, I held interviews with the major ones and the ones I could get access to (for example, there was one umbrella DPO who refused to give an interview). Interviews were also held with umbrella DPOs dealing with each of the five types of disability; with the major INGOs working in the area of disability and development; and with the state authorities most relevant to disability and the themes of my research, meaning those working in employment, education, and disabled people's welfare. One traditional chief was also interviewed, since the gatekeeper had access to him.

⁵³ See Appendix 1 for a more detailed list.

⁵⁴ In which cases the interviews were held with an adult relative present.

⁵⁵ *Ministère de la Jeunesse, de la Formation Professionnelle et de l'Emploi du Burkina Faso*.

Gender	Type of Impairment						
		Physical	Visual	Auditive	Intellectual	Albinism	Total
	Male	87	32	11	10	6	146
	Female	48	9	13	3	8	81
	Total	135	41	24	13	14	227

Table 3.3: Number of Interviewees: Men and Women with different types of impairment

Interpretation, Translation and Dissemination

Translation is more than a technical exercise; it is also a social relationship involving power, status and the imperfect mediation of cultures.

(Bujra, 2006: 172)

Translation unavoidably played a key role in this research. Since multiple languages are spoken in Burkina Faso, it was rather difficult for the researcher to be conversant in all of the languages (or even the main one) spoken in each region. Thus, the services of interpreters were employed to facilitate communication from French to the local languages and vice-versa. Bujra (2006) contends that the better option is to employ local people (preferably from the same group or community with whom the researcher is working) as interpreters. Thus the interpreters were local to the three main regions I worked in. They were in the age range of thirty-five to forty-five, the age being significant in the respect accorded in Burkina Faso to older people: in Burkina Faso, when the person is above forty (or above thirty and have children), he / she are considered to have seniority.

The research and its process were discussed with the interpreter in detail beforehand, and debriefing sessions were used to expand on what was said during research sessions. With regard to the complex aspects of translation mentioned in this section's epigraph by Bujra (2006), these were taken into account in the processes of interpretation and translation, and were discussed with the interpreters to minimise risks as much as possible. None of the three interpreters I had during this research are

qualified interpreters, but are rather respected men who know the languages and dialects, have their own transport, know the region, and in the case of Centre and Cascades, know the DPOs and disabled people (and in Cascades, authorities) in the area. Bujra (2006: 174) states that:

[a] local interpreter is far more than a translator of language...
[t]hey can become intermediaries who will open doors; they can also help to unravel why people behave as they do, who is related to whom or why the next village is different.

I took care to double-check a sample of recorded interviews with a third person in each region to make sure the interpreter was interpreting well. Unavoidably, interpretation did not go as smoothly as intended. One of my greatest mistakes was not asking the interpreter to translate in the first person version. Thus after the interviewee had spoken, the interpreter would translate as 'He says he goes to work' rather than 'I go to work'. This meant that I would not know exactly what the interviewee said. Furthermore, when it came to transcribing the interviews I had to translate them back into '[I] go to work' for ease of reading. This of course excludes those who spoke in French and whose interviews could thus be translated directly into English. Even so, the fact of translating from one language to another means that certain subtleties are lost, let alone translating from the local language to French and then to English. In the following chapters, I avoid making the distinction between interviews translated by the interpreter first and those translated only by myself, to ensure flow of text. With regard to my translation, I strived to be as faithful to the original as possible, but I also had to write in understandable English. To translate faithfully from French and then put the same grammatical mistakes as the interviewees did, in English, is difficult, although sometimes I did leave some grammatical mistakes, as it also gives an indication of the level of education and eloquence of the interviewee. I also sought to reflect the manner of speaking of the interviewee. With regard to disability terms, whether the interviewee uses *handicapé*, *personne handicapée*, *personne vivant avec un handicap*, *personne en situation de handicap*, all were translated as 'disabled person'

or ‘person with disability’. The “politics of translation” (Smith, 1996: 160), however, merit closer inspection.

Smith (1996: 161) illustrates how “the nuances of language can be lost in translation and how the position of the researcher is problematic”. In the context of disability in a post-colonial context, this is of particular significance both on account of disability and of colonisation. Berberi and Flaugh (2016: 131) claim that “disability in world regions where French is present linguistically or culturally” is a delineation that is “complex and contested, especially because its mapping reflects legacies of colonization and masks cultural and linguistic pluralities within Europe and beyond”. Before even attempting translation from French to English, in this research the terminology describing disability was first translated from many local languages into French. However, although the vast majority of disabled people live in the Global South, “the languages they speak, although spoken by millions, enter our world of knowledge-making scarcely at all” (Berberi and Flaugh, 2016: 130). This is especially significant when considering that, as Devlieger (2010: 70) points out, the concept of ‘disability’ “that takes various impairments together in one convenient concept” does not exist in all societies. The manner in which the category of disability developed in the west does not necessarily apply to sub-Saharan Africa. The terminology used reflects “the historically evolved mindset or discourse that signifies a culture’s constructed boundaries between what it defines as its able-bodied and disabled members” (ibid).

It is after considering this that we can then consider “the primacy of English in knowledge-making and the analogous superiority that is afforded continental French (of France) vis-à-vis its Francophone cousins in the rest of the world” (Berberi and Flaugh, 2016: 130):

Questions of language define fundamentally the reach, variations, and complexity of disability, demonstrating the varied ways in which a term like *un handicap* and its cognates work across and sit within cultural, national, and historical contexts. These call for thoughtful consideration of the specific human experience of

disability and highlight the... role of multilingualism in the production of thought.

(ibid: 132)

Thus, in France, *un handicap* continues to be used. And while to an Anglophone, this term, alongside with *l'infirmité* or *la déficience*, seems outdated and politically incorrect (ibid), Ville and Ravaut (2007: 142) argue that, in French, this concept better reflects the merging of body and environment than 'disability', "covering all the lesional, functional, and social consequences of impairment".

While positionality and ethics will be discussed further in the final section of this chapter, these aspects need further attention with regard to translation specifically. Language differences "compound the relative advantage of the researcher over the research subject in producing a research outcome" (Smith, 1996: 160). Smith explores the implications of writing in the researcher's home language for the research process, including the analysis. She argues that "[w]hen analysing texts of interviews in a foreign language it is too easy to analyse the translation and not the 'original'" (ibid). Similarly, Derrida (1985: 171), talks of "the necessary and impossible task of translation". Domosh (1991: 96) argues that language "embodies and embellishes" the researcher's observation of the world, "giving form to the observation", and that:

form is not a direct representation of a separate reality – language is not transparent – but instead reflects a particular way of seeing that world.

According to Smith (1996: 162), "[a]ll interpretative research involves the representation and appropriation of Others' experiences as well as the researcher's. It requires interpretation across cultures of socially constructed meanings". However, as Opie (1992: 67) argues, "textual appropriation of the other is an inevitable consequence of research". Smith (1996: 163) concurs:

The very act of research places the researcher in a position of power in representing others through language and in the interpretation of the meanings other people give to their lives. If the research is in a foreign language or a foreign culture it becomes a more complex

but perhaps more overt operation to involve oneself in the perilous task of representing other people's worlds in one's own reconstructions or texts.

Furthermore, Smith (1996: 164-5) argues that instead of looking at this as simply translation difficulties, an approach informed by postcolonial theory and employing the concept of hybridity "can give rise to 'in-between' forms of understanding". For geographers researching other places and people, a productive hybrid strategy engaging with other languages and meanings challenges "both theoretical understandings and the dominance of the researcher over the research 'subject'" (ibid: 165). According to Bhabha (in Rutherford, 1990: 211), "[t]he process of cultural hybridity gives rise to something different, something new and unrecognisable, a new area of negotiation of meaning and representation". As Smith (1996: 165) concludes:

The hybridity of contact between self and other, between 'home' language and 'foreign' language... offer conceptual places where one need not accept the dominant structures of one or other position but instead can find ways of challenging and questioning these positions.

Thus, though the issues of power and control are still present, decentring one's concepts and taking a reflexive stance enable the exploration of "differences, tensions and conflicts" as "spaces of conceptual and indeed political opportunities and negotiations", rather than as problems (Smith, 1996: 165).

Additionally, in this research translation does not mean solely from local languages to French and from French to English. The research is meant to be accessible (especially) at a grassroots level, even though Spivak (2014: n.p.) maintains that "from the point of view of the subaltern, translations do not help because generally these translations... are not accessible at a subaltern level". Fals-Borda (1988: 13) also warns against the kind of study that would only be accessible to a limited elite group of intellectuals:

[i]t would not... reach... the communities themselves, and probably none of the local people would... be... aware of the existence of such

monographs or if they... are, they would not... be... able to understand them.

(ibid)

With this in mind, a summary of the research findings will be drawn up and translated into French to be disseminated among the research participants, including DPOs and individual disabled people, state authorities and INGO representatives. Furthermore, since the products of the participatory process such as the participatory video are controlled to a large extent by the research participants themselves, the research 'findings' in this case are not only accessible at grassroots level but can also be disseminated by the participants themselves.

PARTICIPATORY DIAGRAMMING AND PARTICIPATORY VIDEO

Visual methods "have long been used by those wanting to engage with the 'experiences' of those marginalised within society", and "can be used to 'triangulate' qualitative research methods, developing a richer relationship with views, politics and experiences beyond the restraint of written and oral practices" (Tolia-Kelly, 2007: 132). One method often employed in participatory research is participatory diagramming (PD), which is described by Alexander et al (2007: 112) as employing "graphic and/or tactile materials to create visual representations that express participants' ideas and understandings". One of the benefits of diagramming is that "it is wide open to context and topic specific innovations by researchers and participants alike" (Kesby, 2000: 426). This technique was used in this research as a means to elicit and analyse the main aspects of the lived experiences of disabled people in Burkina Faso (Research Question 1), laying down the groundwork for the participatory video.

Lunch and Lunch (2006: 10) describe participatory video (PV) as "a set of techniques to involve a group or community in shaping and creating their own film". PV provides the opportunity for "looking alongside" instead of "looking at" research subjects (Kindon, 2003: 143). It enables people to convey their ideas and perspectives and give voice to what they

think without the obstructions of consequences or of their standing in society (White, 2003). Johansson et al (in Kindon, 2003: 143) argue that it is hard to imagine “a more effective method to quickly comprehend the often-complex perceptions and discourses of local people than to produce, watch, discuss and analyse PV material together with them”.

PV sets in motion a process of change and analysis based on local knowledge and experiences: it gives a glimpse of what Lunch and Lunch (2006: 12) call “the ‘inside view’ in a... way that is accessible to people at all levels”. Most importantly, PV creates a space for voices that are not normally heard to be heard, or faces which are not normally seen to be seen. This is vital for the purpose of this research, which sought to create spaces in which people with disabilities, who are usually ‘invisible’ and unheard, can be ‘visible’ and express their views (ibid: 13).

PV can also serve as a basis for reflection about what people are doing to improve their situation, as well as about their skills and resources. Through visualising what they are currently doing, reflection is stimulated on how things can be improved. Additionally, “both the process and the products... can give development agents and formal researchers greater insight into the dynamics of indigenous knowledge, as well as into local aspirations and concepts of well-being” (Lunch and Lunch, 2006: 13). Furthermore, the video medium is easily transported, reproduced and shared (ibid: 12).

The Participatory Process

The participatory part of the research was undertaken in the Est region. The original plan was to employ participatory methods in each region. However, due to time and financial constraints, the PD and PV were only carried out in one region. Thus, after conducting interviews with DPOs and individual disabled people in the region, the selection of the participants was made together with the gatekeeper for my research in the region. This was done in order to enable as much participant control over the research as possible.

The aim was to include participants with different types of disabilities, from different age groups, and an equal number of men and women. The participants selected originally were two physically disabled men (Michel and Benoit), two physically disabled women (Regina and Laurentine), a blind man (Karim), a physically disabled man with a mild intellectual disability (Hippolyte), a girl with albinism, and a hard-of-hearing woman. However, the latter two did not show up and were replaced by a physically disabled girl (Hélène). Thus physically disabled people were the most represented. The ages ranged from 23 to 42. The participants came from three different provinces: Gourma, Tapoa and Kompienga (see Figure 3.2) and the PD and PV were held in the region capital, Fada N’Gourma⁵⁶. Kesby (2000) recommends that PD is carried out with people who already know each other. The participants all knew each other, except for the participant who was last to join, who knew only one other participant.

A preparatory meeting was held on the first day, during which the necessary introductions were made and the PD was discussed. While the broad ‘agenda’ had been discussed with the participants in the individual interviews, the specific topics to be explored during the PD were not set beforehand. It was the participants who decided (during the PD exercise on the following day) what issues they wanted to explore in the broader context of the research objectives⁵⁷. It would have been desirable to ensure that the PD followed the steps that Kesby (2000) outlines, that is, the generation of the research question(s), designation of the diagrammatic tool, discussion of possible answers to the questions put forward, development of the diagram, interrogating the diagram, and analysing and refining the diagram. However, taking note of the question Pain et al (2012) pose, as to whether our research allows others to plan it, I decided to do what Chambers (2002) suggests and recognise what to plan and

⁵⁶ Often called ‘Fada’ for short in spoken language in Burkina Faso.

⁵⁷ The broader research questions had already been identified by the researcher for the administrative purposes of the doctoral research. Thus, developing the research question(s) here consisted of the participants deciding on the aspect from which they wanted to look at the main topic (development with disabled people in Burkina Faso).

what to leave open. Nonetheless, the PD seemed at times to have a life of its own:

After the break, the group took over completely. I wanted them to generate the research questions but instead they were dividing the brainstorming ideas into 2 different themes and making it 'tidy'. Argh. I cannot control this.

(Entry in Fieldwork Diary, 25th October 2014)

Furthermore, perhaps because it had been agreed that the PD exercise would lead up to the PV, the participants did not quite see the importance of generating a diagram and were rather brainstorming ideas, recounting personal stories, and putting them in neat rows and columns (see Figure 3.4). All this relates to what Askins and Pain (2011: 809) describe as the “messy, uncontrollable and unpredictable” methodological practices and social realities, particularly when engaging in participatory research and the process is shared with the participants.

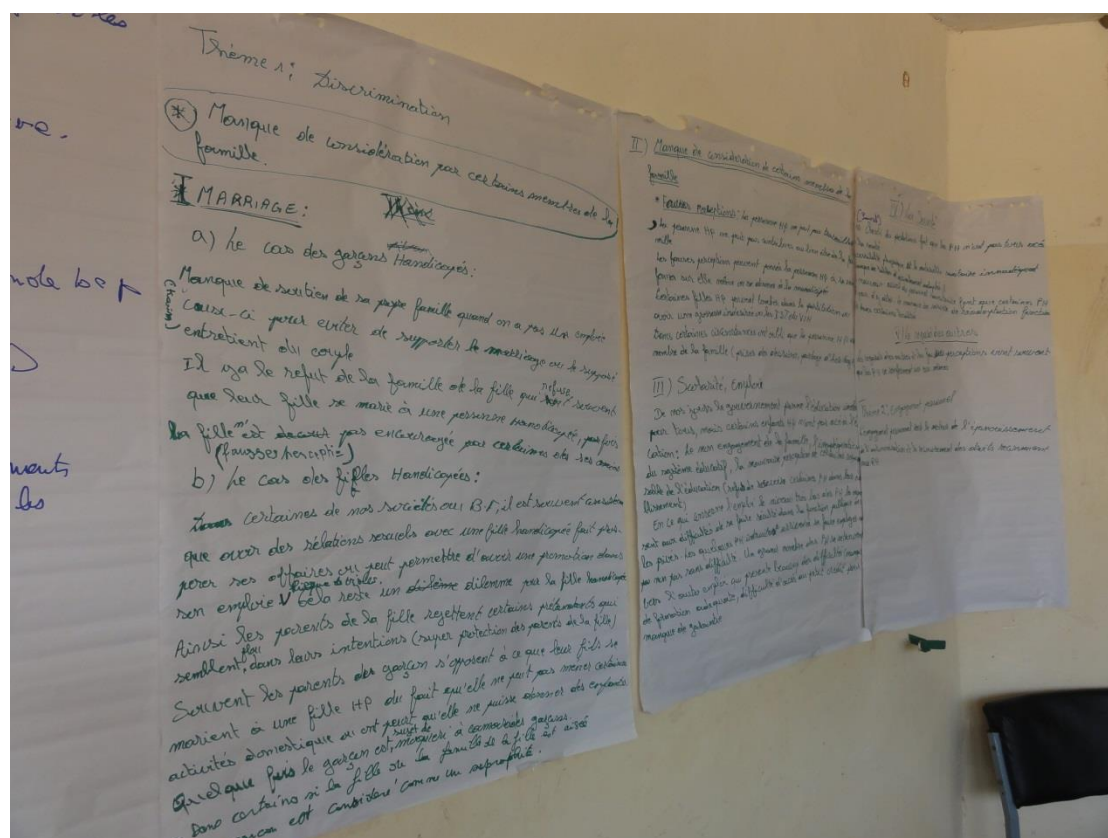


Figure 3.4 Brainstorming Ideas

Despite these challenges, these same ‘hurdles’ resulted in an extremely rich one-day session of life stories, which had not emerged in the interviews:

Lots of people are now telling... stories of their lives and experiences. I am truly honoured. Even if we are moving away from the PD... this is like a therapeutic group session.... Sometimes in the interviews it either seemed all rosy or all black. Now the grey, black, rosy colours are all coming out.... It seems for the first time that people are letting go... and talking like they were talking among friends. When they are on their own just talking to me, it's so different, and they hold so much back.

(Entry in Fieldwork Diary, 25th October 2014)

The fact that the participants talked so much more in the PD than in the interviews could have been due to several factors. Besides the longer time allotted to the PD, being in a group seemed to give courage to others to tell their own stories. The fact that the participants knew each other and the atmosphere was one of solidarity, understanding, and humour also helped. There was also no interpreter stultifying the conversation, as often happened in interviews. Lastly, they were working towards something, towards making a film (although at that time they did not have a clear idea how), so there was a goal to work towards that would result in something immediately visible, rather than the obscurity of research results (in the far-off future) after an interview.

Finally, after many detours, a diagram was generated (see Figure 3.5) which incorporated the main theme that emerged during the discussion, that is, personal engagement and its importance in all aspects of life: education, employment, marriage, health. Running through this is the discrimination encountered by disabled people, particularly in the form of lack of consideration and in the perceptions of disabled people by non-disabled ones. At the centre of the diagram is the family, whose role is essential in a disabled person's life. After the diagram was generated, the participants passed on to what Pain et al call (2012: 7) the “Action” stage, where the participants discussed “[w]hat changes are needed, according to the findings of the research”. The participants explored solutions to the issues they had discussed, mainly the various aspects of discrimination

encountered in their lives, focusing on personal engagement as a solution. Finally, Kesby (2000: 426) directs the researcher to “solicit... detailed explanations of... [the diagram’s] elements, interrogating its coherence, comparing it to other diagrams or other sources of data and pursuing the conflicts and consensus that arose during its creation”. While I carried out the first two and the fourth steps with the participants, I carried out the third on my own at a later stage in the research process, that is, during the transcribing and analysing stages of the research process described in the previous section. The other parts of the Action stage that Pain et al (2012) discuss, that is, sharing and promoting the findings of the research, as well as getting the messages across and stimulating change, were carried out through the PV process. The participants kept the diagram as a potential resource for future research, training or related activities.

The PD then served as a basis for planning and developing the PV. During the subsequent two days, the participants were trained⁵⁸ in using the filming equipment. The process Lunch and Lunch (2006) describe had to be adapted to the context of facilitating PV with a group of people who have physical and sensory impairments. For example, Karim, who is blind, could not participate in all aspects of the PV process, so his role consisted mainly of being in front of the camera, while the other participants were both in front of and behind it. Participants like Benoit and Hippolyte could not use their right hand to hold the video camera through the handle on the right hand side (see Figure 3.6). Thus achieving balance was tricky, mitigated by the use of the tripod. However, the training progressed well and, as with the subsequent filming, unfolded in a friendly atmosphere. The participants also helped each other with learning how to use the equipment (see Figure 3.7). Enthusiasm increased as time went by. The participants later told me that they had been afraid they would not be able to do the film, but that their confidence increased as they saw they were

⁵⁸ Knowledge of PV facilitation, including how to train the participants, had been gained during a course I attended before going on fieldwork, ‘Introduction to Participatory Video’. The course was delivered by InsightShare (<http://www.insightshare.org>) in Oxford in April/May 2014.

able to do so. The following selected excerpts from the fieldwork diary capture the general atmosphere and the nature of the training:

[The participants] seemed really happy with what we did. I carried out a small evaluation at the end of the day.... Even Karim, who obviously participated the least, seemed quite happy.

Later, Michel told me that since this was something new, people were really enthusiastic: they had never done this before, and this gave them the opportunity to express themselves. Of course there were a couple of times when my heart stopped beating, like when Michel and someone else forgot to clip the camera onto the tripod. Thankfully I happened to look their way just when they were flipping over the top part of the tripod and the camera was slipping off. I caught it just in time.

(Entries in Fieldwork Diary, 26th October 2014)

At the end of the two days of training, the participants developed the storyboard (see Figure 3.8). I intervened only at the end with suggestions on how to make small improvements, such as through the use of cut-away scenes. However, the participants made the major filming decisions. For example, when I suggested that they interview people in the community, they decided against. So I took only a supporting role, continuing in this role throughout the filming, as Lunch and Lunch (2006) suggest, while the video with its relevant messages was directed and filmed by the participants over the course of the following two days.

The title chosen for the film⁵⁹ was 'Disability: It is not the end of the world', which embodies the spirit of the messages the participants convey in the film. The first part of the film, or the 'short version', consists of the participants talking, individually, about their own experiences, or giving a message, for example, to INGOs. After one or two individuals would have filmed their part, the group would reunite to watch the footage and give their feedback for improvements. Sometimes this meant that the person would re-film their part if the group so suggested. This part of the film is divided into seven sections: introduction (to the region and the situation of disabled people there); the family (and its role in the disabled person's life); education; personal engagement; false perceptions (of people with

⁵⁹ See attached copy of the participatory video in Appendix 5.

disabilities); messages to development practitioners intervening in the disability domain; and a conclusion with a message to disabled people. The shorter version is targeted mainly at INGOs and authorities, while the longer version is more generally targeted at other disabled people and society at large. The 'long version' comprises a theatre piece which forms the second part of this version of the film. The theatre piece, portraying the discriminatory attitudes faced by disabled people in Burkina Faso when marrying a non-disabled person, is in Mooré (the most commonly spoken language in Burkina Faso) and is humorous, thus more engaging for an audience. The participants designed and developed the theatre piece, and chose to do it in Mooré because they felt more comfortable talking in this language, and since the theatre was mostly improvised (rather than scripted), this choice, rather than French, made sense.

The next step was the editing, which comprised several stages. The first stage was the group paper editing, where the participants decided in which order the scenes would be put, which cut-away scenes would be used and where. This was carried out during the course of one day, after the two days of filming. The rest of the editing was then done by Michel and me when the rest of the participants had gone back home. This part of the editing, which continued for days afterwards, included choosing the footage, editing the scenes, and inserting the subtitles in French. The last part of the editing was the fine-tuning of the film⁶⁰, which involved continuing to edit the footage and putting the film together for weeks afterwards, which I, myself carried out for practical reasons. I was by that time in Ouagadougou, continuing my research there, thus making it difficult for me to be in the same place as the participants. Furthermore, the participants had limited knowledge of computer use and so, it would have increased the time spent on the film, time which also translates into money spent on participants' per diems, lodging and refreshments. The video was, however, participatory in the sense that, as the filmed consent

⁶⁰ Upon returning to Durham, the Cartography Unit in the Geography Department assisted me with inserting English subtitles and the finer aspects of the editing process.

indicates, the participants took part in it voluntarily, planned and filmed it, chose what was to be said and shown (and not shown) in the film, and started the editing process. The participants gave their consent for their names to be shown in the film as well as for showing the film and publishing it on the internet. Given the nature of the film, there was thus no need to anonymise participants.

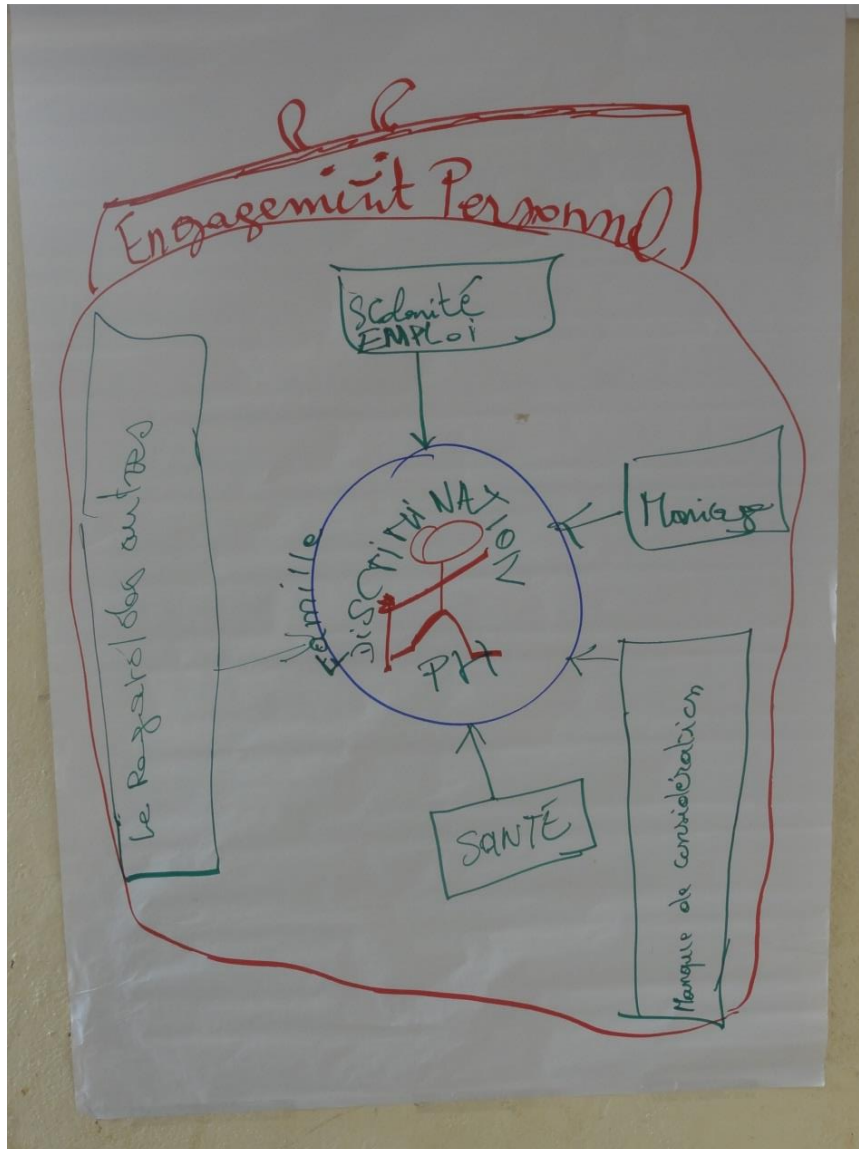


Figure 3.5 The Diagram⁶¹

⁶¹ See Appendix 4 for translation of diagram.



Figure 3.6 Holding the Camera



Figure 3.7 PV Participants Helping Each Other Out

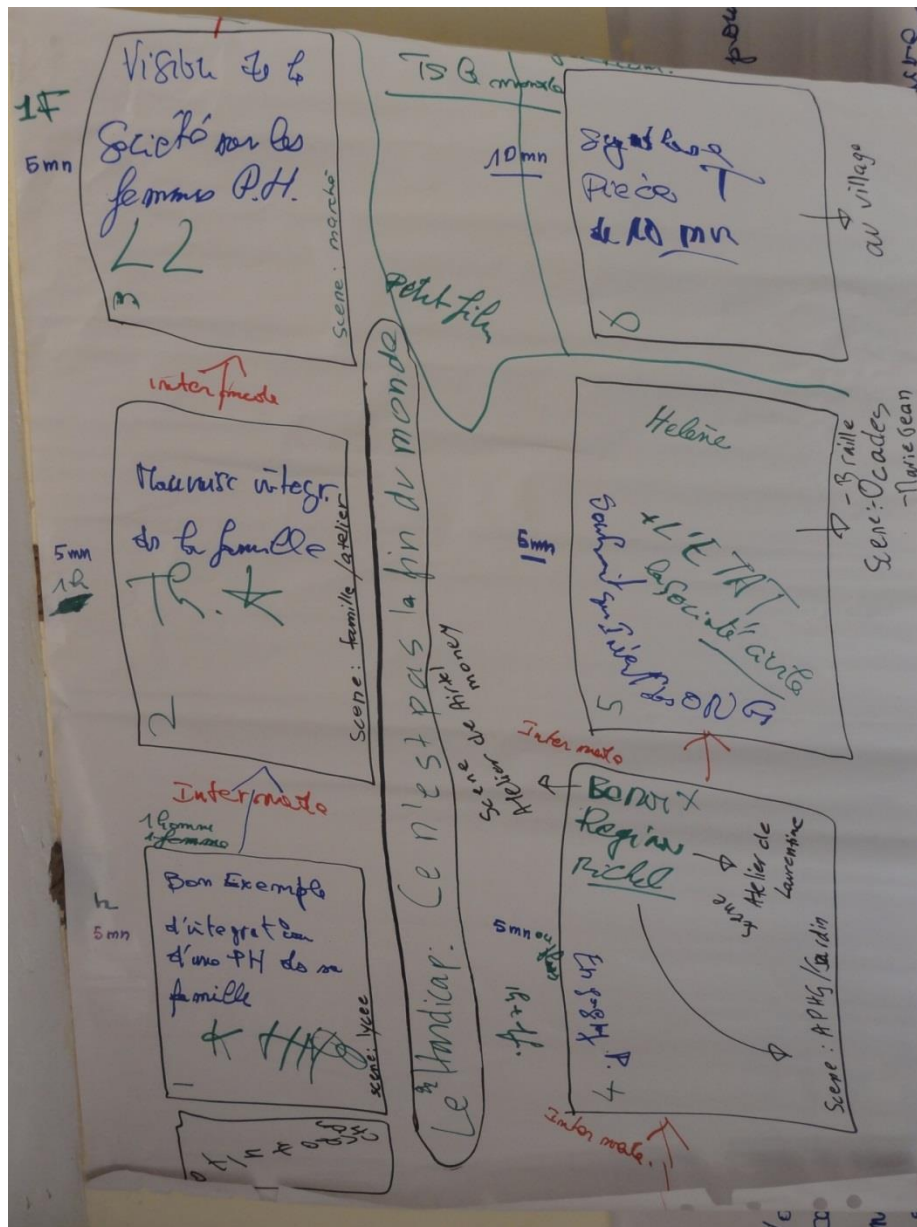


Figure 3.8 The Storyboard⁶²

Later, sign language was filmed to be inserted in the film and thus make it accessible to people with hearing impairments. However, the pace of the sign language was too slow compared to the spoken version, and was thus discarded. This was mitigated by having two sign language interpreters (physically disabled people themselves) present during the second showing of the film. Nonetheless, these practices themselves may have been exclusionary in the sense that a great number of hearing

⁶² See Appendix 4 for translation of storyboard.

impaired people in Burkina Faso are not conversant in formal (American) sign language.

The first viewing of the film took place during the International Day of Persons with Disabilities⁶³ in Fada N’Gourma in December 2014. The film was shown to disabled people and non-disabled people who had gathered to celebrate. It had a good response and was appreciated, with the audience especially enjoying the theatre piece. The participants who were present also felt proud of their film:

Benoit and Hippolyte... laughed so much during the theatre and teased each other... Benoit wants to show the film on RTB⁶⁴ [the public television and radio corporation]. He says it’s wonderful that disabled people can show their message like this. Michel says he wants to get funds from NGOs to work on the film professionally to make better, and also for another film.

(Entry in Fieldwork Diary, 5th December 2014)

In this sense, as Lunch and Lunch (2006: 12) argue, “[p]articipatory video... becomes a powerful means of documenting local people’s experiences, needs and hopes from their own perspectives”. Months later, in April 2014, while I was doing research in the Cascades region, I helped set up another viewing to disabled people and authorities in the region. The showing was facilitated by the regional coordinator of DPOs in the Cascades and sparked a discussion between disabled people, who identified with what the video participants were saying, and the representatives of the Ministry of Social Action and National Solidarity⁶⁵ who were present. In this sense, the PV created a space where disabled people could share experiences. The film was also used “to strengthen both horizontal communication” (with other disabled people to facilitate peer-to-peer learning), and “vertical communication” (Lunch and Lunch, 2006: 13) (in enabling disabled people to speak to policy-makers). Nonetheless, neither of these two showings went as smoothly as expected:

⁶³ The UN International Day of Persons with Disabilities, celebrated on the 3rd December: <http://www.un.org/en/events/disabilitiesday>

⁶⁴ *Radiodiffusion-Télévision du Burkina*

⁶⁵ *Ministère de l’Action Sociale et de la Solidarité Nationale du Burkina Faso*.

We are going to show the film at the Centre (of Disabled People in Fada), on a computer or laptop screen, without speakers, because now it's too late to get a TV.... What a disaster!

...

Now we are... waiting for... the film equipment and my DVD... Benoit and I are hungry, cold, tired... we have been waiting around and wasting time for more than 4 hours.

(Entry in Fieldwork Diary, 5th December 2014)

This morning Ibrahim⁶⁶ phoned to say he did not have the projector. So we got the TV from the Centre (of Disabled People in Banfora)⁶⁷ and Ibrahim sent someone over with a DVD player. It didn't work – it would not read my DVDs. [The director]⁶⁸ got another DVD player [but the] DVD-RW didn't work, so I went to buy a DVD-R. It worked with one of the DVD players, but we did not have a remote control.... People keep assuring me that '*ca va aller*' (it will be all right).

(Entry in Fieldwork Diary, 20th April 2015)

Furthermore, an attempt to hold a PV viewing with INGOs did not go through. Through my interviews with INGO field offices in Burkina Faso I tried to set up a PV viewing (as had been agreed with the PV participants) during a meeting of the Informal Consultation Framework of INGOs working in the disability field in Burkina Faso⁶⁹, but the plan fell through because their meeting agenda was full. Therefore I felt as if part of the PV process – of providing a space in which participants could communicate their experiences directly to practitioners – was missing (Entry in Fieldwork Diary, 29th May 2015). However, the participants used the video to reflect on the development interventions that are carried out by the state authorities and INGOs and to appeal to them to know the reality on the ground before intervening, as well as suggesting ways in which development interventions could be more beneficial to them. In this way, the PV started demonstrating the significance of providing people with disabilities with the possibility of having their voices heard within the development industry (Research Question 3).

⁶⁶ The gatekeeper and interpreter in the Cascades region.

⁶⁷ The viewing was being held at the Regional Direction of Social Action of the Cascades region (*Direction Régionale de l'Action Sociale des Cascades*) in Banfora.

⁶⁸ The regional director of DPOs in the Cascades region.

⁶⁹ *Cadre de Concertation Informel des ONG Internationales intervenant dans le domaine du handicap*.

Finally, while the PV was in progress in Fada N’Gourma, the country was going through its biggest turbulence in years, with the population rising up against the president (who fled the country) and precipitating a revolution. The president, Blaise Compaoré, wanted to hold a referendum to change the constitution to enable his re-election. Tension had been rising in the country for weeks, and it was also being felt in our small group in the Centre of Disabled People in Fada (see Textbox 3.1). Despite all the turbulence, however, the PV process was quite a success.

It feels like the whole country (or is it just me?) is waiting. Like a fire about to start. Blaise said that the referendum will go ahead and he will contest the next elections in November 2015.

...

There are nationwide protests planned for tomorrow until Thursday: on the days we are supposed to film!!

(Entries in Fieldwork Diary, 27th October 2014)

News from Ouaga⁷⁰ (through the grape vine) informs us that people have gone out to stop the members of parliament from going to vote.

(Entry in Fieldwork Diary, 28th October 2014)

Yesterday people vandalised the CDP⁷¹ (Blaise’s party)’s headquarters in Fada. The army went out to stop the people in Ouaga with tear gas...

(Entry in Fieldwork Diary, 29th October 2014)

In Fada, the roads to the centre are blocked by the protesters and the sky is black with smoke from the burnt tyres.

...

News kept coming in all morning – the [PV] participants have been on the phone all the time: In Ouaga, they burnt the National Assembly, the Town Hall, the MPs’ houses, the RTB and the radios, and now they are attacking the presidential residence. The excitement at the Centre where we are working is palpable. People are excited that they have revolted against Blaise. They want him out. Now the news says that Blaise said that the referendum won’t take place anymore. But it’s too late.

....

It’s just after noon and news came from Ouaga that an army general took over. People are feasting in Ouaga. The [PV] participants are so happy! Blaise has disappeared. At least one protester has been killed.

⁷⁰ Ouagadougou is often called ‘Ouaga’ for short in spoken language in Burkina Faso.

⁷¹ *Congrès pour la Démocratie et le Progrès*: Congress for Democracy and Progress.

...
 Michel phoned to say that our PV celebration⁷² has to be cancelled because the protesters went to his bar to vandalise it. Thankfully, they did nothing because it was closed.

...
 A state of emergency has been declared and the government has been dissolved. Curfew has been imposed nationwide by the chief of the army.
 (Entries in Fieldwork Diary, 30th October 2014)

We spent the morning at Michel's, eating and drinking what we were supposed to eat and drink yesterday. The participants from the provinces cannot leave because there is no public transport for the time being.

...
 Blaise has resigned and is allegedly fleeing to Ghana. Goody! Hope we can have some peace now and things can resume!
 (Entries in Fieldwork Diary, 31st October 2014)

Textbox 3.1 The Revolution: Excerpts from a Fieldwork Diary

The footage remained with the participants and copies of the film were made, not only for the participants and for the DPOs to whom the film was shown, but also for the INGO which was to arrange the viewing with other INGOs. The film can easily be copied and disseminated further by the participants. Furthermore, Gleeson (1999: 202-3) argues that academic work should contribute to disabled people's struggles and that geographers should "make their work accessible, and therefore relevant, to disability communities". Because of my close personal ties with Burkina Faso, I will also be seeking in future to facilitate further PV viewings especially with INGOs. The film, meanwhile, has been published and publicised on different websites⁷³, with the participants' permission and willingness to promote the film and its messages internationally.

Finally, the fact that the PD exercise served as an occasion for the participants to share experiences they had never shared before, and the PV brought about a discussion on the way forward for disabled people in the Est region and Burkina Faso in general, brings to mind Booker's (2003: 334) claim that "participation is generally approached in two ways:

⁷² The celebratory meal planned for the end of the PV week for the participants. It was supposed to be held at Michel's bar on Thursday 30th October before the participants who lived outside of Fada N'Gourma returned to their respective towns and villages.

⁷³ For example: <https://www.youtube.com/watch?v=pNygwowI4xY>

as an end in itself, and as a means to an end. It is often, both”. In this research process, it seems that together, the PD and PV served as both an end in themselves (sharing experiences in a ‘therapeutic’ manner) and means to an end (making disabled people’s voice heard).

CHALLENGES AND LIMITATIONS

No research process is smooth and this research certainly had its challenges. A blog⁷⁴ I started writing during fieldwork (see Figure 3.9) served as both a public fieldwork diary and an outlet for documenting my experience of the fieldwork. This section looks at the most pertinent challenges and limitations encountered throughout the same process.

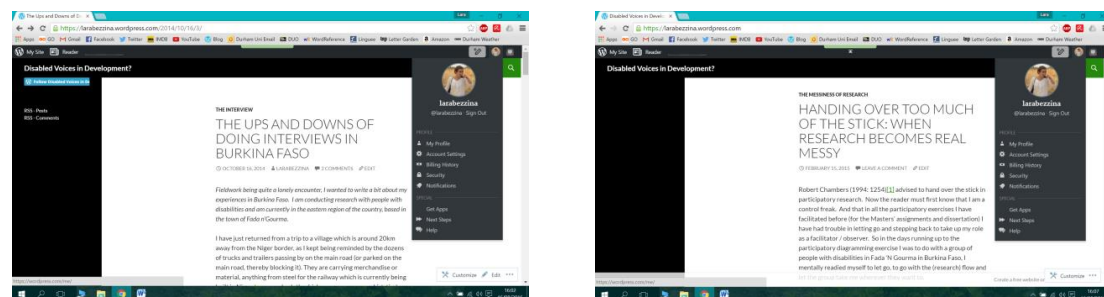


Figure 3.9 Fieldwork Blog Posts

Methodological Limitations

The methods involved in this research had numerous practical limitations, as well as ethical concerns, which are explored more fully subsequently. As discussed below, even participatory methods are not without limitations.

Participatory Methods

Participatory methods, although an improvement on traditional methods, face various criticisms. Laws and Radford (1998: 82) observe that:

Choosing to bundle together a group of people as the ‘researched’ immediately establishes us [social scientists] as the party

⁷⁴ ‘Disabled Voices in Development?’: <https://larabazzina.wordpress.com>

responsible for the construction of the object, for the construction and imposition of a certain identity.

In bringing people together to participate in the research, researchers are “voyeurs, gazing into a world of which we are not entirely part, but a world that we nonetheless help to construct” (ibid), something which I was troubled by throughout the research process. However, we can:

remedy some of the faults of traditional academic voyeurism by hearing and listening to the voices of our respondents rather than by statistically analyzing their life experiences.

(ibid)

Furthermore, as Chambers (1995) points out, there is the risk of networking with the local elite, thus missing the poorer elements of a community. There was a risk in this research of collaborating with the ‘elite’ disabled people, such as those who are active in their DPOs, thus leaving out those who are either not DPO members or are in the peripheries of the organisation (and, more often than not, society). Although the research strived to be as inclusive as possible, this was not feasible in all circumstances:

I was thinking about the selection of participants for the PD and PV.... They are... participants who can speak French [and] are eloquent.

(Entry in Fieldwork Diary, 24th October 2014)

Care is thus taken not to over-generalise the research findings and to acknowledge that the views expressed by the participants might not be those held by all disabled people in Burkina Faso.

At times I was also worried that Michel, who had taken the role of facilitator during the PD, was taking over too much; but:

How can I stop Michel from taking over? I’m afraid that if I tell him off, he will go all quiet and not animate people anymore.

(ibid)

I was therefore afraid of falling into the trap that Hall and Kearns (2001: 239) warn against, that is, of listening “to those with the loudest voices”. Alexander et al (2007: 118) note that “as with all collective methods, there [i]s a danger that minority views could get subsumed”. When I tried to

prevent this, I risked damaging the atmosphere of camaraderie among the participants and bringing discussion to a halt. Hence, I attempted to take a less dominant role and relegate myself to observing and recording group dynamics, as well as facilitating any arising difficulties, such as ensuring the involvement of Karim, a blind man who was not always included in discussion by the participants. One way in which this was counteracted was to ask a participant to give a 'running commentary' of the diagram that was being developed, so as to enable Karim to know what was going on and thus participate.

Interviews

I often questioned, especially after the richness of the data which had emerged from the PD, if interviews with disabled people were useful, particularly as I often felt they were sometimes too short or too superficial. Without the interviews, however, I would not have visited people's houses and places of work. Furthermore, keeping in mind that participatory methods have been criticised of "producing 'consensus'" (Alexander et al, 2007: 117), interviewing people individually helped mitigate this. Without interviews, I would not have had such a broad overview of the lives of people with disabilities in three different regions. I would not have had the opportunity to speak to people individually, and above all I would not have had some very important key interviews which were on a deeper level than others. Finally, interviews were also the better way to access state authorities, INGO representatives and DPOs.

Throughout the research, I was aware that interviewees might have answered questions in the way they thought I would *want* them to answer. However, scholars argue that "all knowledge is produced in specific circumstances and that those circumstances shape it in some way" (Rose, 1997: 305). As a colleague observed, the participants' truth is their truth, and even when they say what they think you want to hear, it says a lot about how they portray you and themselves. Thus, the way they answer says something about them. And yet I could not shake the feeling that:

It's really difficult to know people's issues from interviews. How can you build a trust relationship during a 10 minute or even a 1 hour interview? How can people tell you their lives and problems during an interview? I'm starting to be really disappointed and discouraged with the interviews.

(Entry in Fieldwork Diary, 24th October 2014)

There were also interviewees who were actually almost grateful that I had come to visit them and interview them, ending the interview by thanking me profusely:

[I] don't have anything to add... [except] thanking you for... coming and taking interest in my humble self.

(Interview with Emmanuel Kombari, Fada, 18th October 2014)

This, besides adding to the discomfort of holding the powerful position of a researcher (discussed in the next section), also added to the pressure of managing expectations.

Managing Expectations

Throughout the interview periods in rural areas, there was the frustration encountered when practically almost all the disabled people in a village would have gathered to wait for me to interview them:

Upon arrival at Loumana⁷⁵, a guy who Ibrahim⁷⁶ said is the brother of a disabled person, came to meet us and brought us to a mango tree where about 13 people were gathered.

...

There are now about 17 people.... We have to explain to them that they have to wait. And who to start with?

(Entries in Fieldwork Notebook 4: 80; 82, 17th April 2015)

When this happened, I would feel obliged to interview all the people gathered there, and this would result in a day of non-stop interviews. I could not ask them to leave after they had travelled to meet me, whatever their reasons, and had sometimes waited all day. This would have happened either through a lack of communication, or mis-communication between the primary and secondary gatekeepers regarding the preferred manner of interviewing; very often the interpreter and I would prefer to go

⁷⁵ A municipality in the Léraba province.

⁷⁶ Ibrahim, the primary gatekeeper and interpreter in the Cascades region.

to people's place of work, or home, rather than asking them to come and meet us. Besides avoiding asking the interviewees to travel (which would incur costs and loss of time for them, as well as difficulties for those interviewees who do not travel independently), meeting them at their place of work or living helped me gain a further insight into their lives. Sometimes people gathering in groups resulted from insistence on the part of the secondary gatekeeper:

Ibrahim said that the person he phoned had told him that it is good to assemble people, to take the opportunity to raise awareness among them.

(Entry in Fieldwork Notebook 4: 80, 17th April 2015)

This also meant that my trip to Loumana, like other trips in the Cascades region, was being used to raise awareness to bring people together to form a DPO, or, in other cases, to strengthen the DPO⁷⁷. But the biggest hurdle when people gathered to wait for me was the feeling, brought on by my work experience in Burkina Faso as well as the interviews I was conducting, that many participants thought I was coming to give them money. Some interviewees said this outright:

When you inform people that for example... there is *une blanche* [a white woman] who is coming... people think that they will come and you will give them money.

(Interview with Yada, Diapangou, 24th September 2014)

Yesterday... in Loumana... even after Ibrahim had explained to the interviewees that I had not come to give aid (he also explained this so that he won't be asked afterwards 'when will the aid from the white girl come?'), after the end of the interviews, a couple of men, who had been waiting to speak to him all day, asked him, 'so, when will the aid come exactly?'

(Entry in Fieldwork Diary, 18th April 2016)

This also made me think about the difficulty in which gatekeepers, such as Yada, the DPO president quoted above, must have sometimes found themselves, striving to put me in contact with interviewees, but also having to protect themselves from those who would think I came to give

⁷⁷ Ibrahim is also a member of the regional coordination of DPOs, one of whose tasks is to support the creation and strengthening of DPOs in the different municipalities of the region.

money and that the gatekeeper is not sharing this with them. It also brings to light the importance of the ‘protection’ that the gatekeeper offers. When doing interviews in Ouagadougou, I remember voicing doubts to my gatekeeper/interpreter about whether interviewees were expecting me to give them money, after which I wrote:

Jacques said that since the people I am interviewing trust him, I shouldn’t worry about people expecting money from me, etc., since he explains to them that I am a student and so on. How necessary someone like Jacques is!

(Entry in Fieldwork Notebook 2: 49, 26th November 2014)

Thus managing expectations was not an easy feat. I was already asking a question along the lines of ‘what would you change in your life if you could’, and most of the interviewees were replying in answers related to work and finance. This could have been also due to the interviewees’ expectations that I was going to change their lives, such as through implementing a project or financing their business, and thus they might have replied with something that they thought I could bring about.

This also raises questions about the ethics of the research, described more in depth subsequently. While managing expectations is part of the researcher’s responsibility, considering what the participants take from the research is also important. As Madge (1993: 297) asks:

Who... ‘makes’ knowledge and for whom and why? How are we, as First World academics, implicated in upholding systems of power which perpetuate poverty, debt and inequality?

Ultimately, it is doubtful that the research participants gained a great deal. There were no major changes in their lives following this research, although a summary of the research will be disseminated to INGOs, state authorities and DPOs, thus hopefully contributing to reflections on reformulating development policies and interventions with disabled people. However, as Madge (1993: 295) asks:

Will the discussion be ‘read’ in the same way by academic First World geographers, Third World academics and the Third World people involved in the research? How may the text be re-interpreted by the ‘researched’ and what are the political and ethical issues involved in this instance?

Perhaps the major contribution in this research was the PV, which is kept by the participants to use and disseminate. Additionally, as Kesby et al (2005: 147) contend:

[t]he validity of a PAR project is gauged on the quality of the data generated and by the extent to which the process of research itself develops the skills, knowledge and capacities of participants to use the results themselves to tackle problems that they have identified.

Through the PV process, the participants not only developed new skills and capacities but also participated in, and exercised power over, a research project in which a space was opened where their voices can be heard. This also relates to what Reason and Bradbury (2008: 5) contend:

Since action research starts with everyday experience and is concerned with the development of living knowledge, the process of inquiry can be as important as specific outcomes.

Thus, while the direct tangible impacts on the participants' quality of life is minimal, their involvement in the research process was a positive experience. Besides the opportunity to share their experiences, the PV also enabled the compilation of information in as ethical a way as possible.

Accessing Disabled People in the Furthestmost Margins

Since disabled people were mainly accessed through DPOs, especially in villages (in towns and cities, they were sometimes accessed through the gatekeeper's, or my own, contacts), most of the people interviewed (particularly in the Est and Cascades regions) were members of DPOs (unless no DPO existed), whether active or not. The aim was to hold interviews with men and women with different kinds of impairment: physical, visual, auditive, intellectual and people with albinism. This goal was achieved, albeit with a skew towards men with physical disabilities. Men in Burkina Faso in general are more visible in social places. Furthermore, people with physical disabilities are more visible than people with other types of disability, and easier to 'access' than people with auditive or intellectual impairments.

People with intellectual disabilities were rather difficult to include. For example, when I asked the director of an organisation of intellectually disabled children if I could interview some students at her school, all I managed to obtain was a quizzical look and an assurance that I would not be able to conduct interviews with them. The larger part of interviews with intellectually disabled people was conducted with a relative (usually one of their parents) or the heads of DPOs working with them. Thus, while it is crucial that participatory research with people with intellectual disabilities is taken up by geographers and other researchers in a partnership to pursue the exploration and analysis of how to “foreground ‘silent voices’” (Van Hove et al, 2005: 187), I had difficulty in even holding interviews with intellectually disabled people (and thus also to include them in the PV). This means that knowing and understanding what development for intellectually disabled people is, which is extremely significant especially in Burkina Faso where people with intellectual disabilities rarely have the space to speak out, even in DPOs, is rather challenging. In creating a space where disabled people can be heard, disabled people are able to provide a counter narrative to “shatter complacency and challenge the status quo” (Delgado, 2000: 61) of a disabling society. Yet the counter narratives of intellectually disabled people in Burkina Faso encounter many barriers in coming to the fore. It is rather their carers who voice their concerns when they have the opportunities to do so.

A similar case applied to people with hearing impairments. They were often chaperoned by a relative who did the talking for them. Neither the interpreters nor I are fluent in sign language. Even if we were, the interviewees usually spoke a sign language that they and their relatives/community would have developed together. However, in Banfora I did manage to do interviews with deaf people through an ex-colleague who is fluent in sign language. Finally, people with albinism, too, were harder to access than people with other disabilities: in some villages we were told that there were no people with albinism. Other DPOs did not

have members with albinism, either because the latter refuse to join or because the DPO does not extend their reach to them due to misconceptions about whether albinism constitutes disability or not.

These issues bring to the fore the importance of representation. In the previous chapter, the significance of colonial representations of the subaltern (Spivak, 1988) and more specifically of the representations of disabled people (Barnes, 1992), and the importance of disabled people representing themselves, were emphasised. Yet in this research opening up spaces for people with all kinds of impairments proved a challenge, which was not always possible to surmount. Dilemmas including having people speak on other (disabled) people's behalf emerge. At times in this research, this did not only involve speaking 'about' but also speaking 'for' people with disabilities. Questions about whether this is avoidable, and if it is another form of silencing or a valuable and necessary form of advocacy, are beyond the scope of this thesis. However, in this research, this was the only way to access people with intellectual and hearing impairments, and it hopefully paves the way for further research with the less heard and harder to reach people with disabilities.

ETHICAL CONCERNS

I endeavoured to follow the ethical guidelines provided by the Durham University Centre for Social Justice and Community Action (2012) and the Economic and Social Research Council (2015). Verbal consent was obtained from all interviewees, either by me or the interpreter. Consent was obtained both to conduct the interview and record it. Interviewees were given the option of stopping the interview or not answering any question. Either the interpreter or I gave an explanation of the research, its objectives and its purpose, explained how the findings might appear in possible publications and presentations, and also provided an account of the dissemination of the research summary in-country. Permission was also sought from the interviewees to take photos; and the option of

anonymity⁷⁸ was also presented to all research participants, who are cited here only by their first names. In the cases where the identity of the participant would have been evident because of his / her position (for example, in an organisation), one of two anonymisation methods was used: either the participant's name was not cited, or the locality was not specified. Finally, organisational identities (except for the national federations of DPOs) and the specific localities of state authorities were concealed so as to render them less identifiable.

Power and Positionality

Power is a description of a relation, not a 'thing' which people 'have'.
(Nelson and Wright, 1995: 8)

PAR is viewed as less hierarchical than traditional research practices (Kindon et al, 2009). In fact, participatory development emerged as a result of the acknowledgement of the limits of "top-down development approaches" (Cooke and Kothari, 2001: 5). PAR, however, is not without its limitations. Rahnema (1992) warns against treating participation lightly, or simply as a slogan. Cooke and Kothari (2001: 7-8) caution against cases where "participatory facilitators override existing legitimate decision-making processes"; "group dynamics... reinforce the interests of the already powerful"; and where participatory methods drive "out others which have advantages participation cannot provide". Participatory methods have also been accused of assuming that "there is one identifiable community in any location" – ignoring the changing nature of communities and their boundaries – and emphasising the "solidarity within communities" (Cleaver, 2001: 44). Furthermore, Cleaver (2001: 46) argues that:

[d]evelopment practitioners excel in perpetuating the myth that communities are capable of anything, that all that is required is sufficient mobilization... and the latent capacities of the community will be unleashed in the interests of development.

⁷⁸ When citing Facebook posts, I obtained permission from the people the post belongs to first to see if I could use their quotes and their proper names.

These arguments are extremely significant for the researcher conducting research in a Global South context and denote the need for reflexivity and thought on the part of the person intending to facilitate the research. Reflexivity, however, is not easy to achieve (Rose, 1997). I reflected on my positionality, but I still held the position of power and privilege, having access to a greater number of resources and knowledge than the research participants (ibid). Additionally, I have “the final power of interpretation” (Gilbert, 1994: 94) at the end of this research. In the PD and PV, the participants chose the topics to explore and directed the flow themselves. In the interviews, however, I directed “the flow of discourse” (Rose, 1997: 307) myself. As happens in most cases, I hold “a ‘privileged’ position—by deciding what questions to ask, directing the flow of discourse, interpreting interview and observational material, and deciding where and in what form it should be presented” (McLafferty, 1995: 437) in the thesis; although the participants decided in what form the film was to be presented. Mohan (1999: 41) even argues that “most participatory research actually strengthens” power relationships “within the knowledge creating process”. He argues that participatory research re-establishes the power relations between the expert and the other, reflecting older and newer ways of “western society in the way it confronts the non-West” (ibid: 44). There is the assumption in participatory research that “there are distinct realms of knowledge that exist prior to the research process. One is Western and familiar, the other is local, multiple and strange” (ibid: 45). Exercises like PD can even be patronising when, for instance, the participants are told to draw a diagram to illustrate their views. Furthermore, “Western models of cognition assume knowledge is mediated by language but most knowledge is non-linguistic, tacit and generated in practice”, while diagramming still relies largely on the “linguistic representation of knowledge” and thus much is “left unknown” (ibid: 45). PAR techniques themselves therefore, symbolise “a way of thinking” that “could be seen as peculiarly Western” (Robinson-Pant, 1996: 540). In disability research in Global South contexts, Meekosha (2011: 671) argues

that even though such research has considerably increased “our understanding of the intersections between disability, impairment and culture” and has contributed towards dispelling myths about disability in Global South contexts, it still uses “the metropole as the frame of reference”. In such types of research, “we still see methodological projection where the data are framed by metropolitan concepts, debates and research strategies” (ibid).

One of the central ethical tenets of this research is highlighted by Chambers (1983: 2; 3) who describes “[w]e, the outsiders”, Western-based scholars with whom lies the responsibility to better enable the rural poor “to help themselves”. While this statement is rather condescending and western-centric, an important point is the acknowledgement that western researchers are outsiders, on more than one count: in my case, not only am I a white, relatively privileged researcher, but I also identify myself as non-disabled. Hence, care was taken to be reflexive throughout the whole research process, keeping in mind Spivak’s (1988) recommendation to unlearn one’s privilege as one’s loss, and to work “critically back through one’s history, prejudices, and learned, but now seemingly instinctual, responses” (Landry and Maclean, 1996: 4). As Muelas and Green (in Schwartz-Marín and Restrepo, 2013: 999) point out, “simply knowing the other does not guarantee its respect, because knowledge can be, and in fact it has been, the foundation for a better exploitation”. Drake (1997: 644), meanwhile postulates that “whilst it may be acceptable for ‘non-disabled’ people *to join with* disabled people to lobby for anti-discrimination legislation, it is in my view unacceptable for them to lobby *on behalf of* disabled people”. Thus, I took on the role of facilitator of advocacy, rather than a lobbyist myself. Also central to the present research is Spivak’s caution to recognise the fact that our privilege might have inhibited us from acquiring another kind of knowledge: “the knowledge that we are not equipped to understand by reason of our social positions” (Landry and Maclean, 1996: 4). My position as a non-disabled researcher having lived most of my life in Europe has certainly interfered

with my gaining knowledge from the research participants. Being conscious of these possible inhibitors and striving towards minimising them as much as possible – such as through keeping a research diary and being constantly reflexive – facilitated a more ethical research process. Undoubtedly, there were many aspects of the fieldwork that sat uncomfortably with me. I recorded, for example, in my blog:

Then we sit down to start the interview: usually I am offered the place of importance, a concept which I hate but can rarely escape from, unless I want to offend the hosts. But how am I to mitigate power relations and fight inequality when I keep being offered the best (least broken) wooden chair, which is, incidentally, so much less comfortable than sitting on one of those very low wooden stools people here use, or sitting cross-legged on a mat?

(Blog Post, 16th October 2014)

As naïve as these observations might be (sitting on a mat will hardly bring about a new world order), I quote them here to give a glimpse of some of the underlying struggles I went through during my fieldwork. However, the power was always there, ever-present, even in the very fact that I was the one asking questions which I had designed:

In the interview I have power: I am asking questions, leading the interviewee in a certain direction... it's not an equal conversation...

(Interview with Henri, Ouagadougou, entry in Fieldwork Notebook 3: 132, 19th February 2015)

Thus, we need to work at gaining “knowledge of the others who occupy those spaces most closed to our privileged view” as well as endeavouring “to speak to those others in such a way that they might take us seriously and, most important of all, be able to answer back”, since this “marks the beginning of an ethical relation to the Other” (Landry and Maclean, 1996: 5). As Madge (1993: 296) notes:

It is important not to simply pay ‘lip-service’ to such reflectivity... but to integrate an understanding of our (multiple) selves into the research account, thus opening up ‘spaces’ to contest (Eurocentric) accepted systems of knowledge.

Ultimately, the “risks of research are impossible to know”, despite “vigilance, a careful consideration of the research process” (Rose, 1997: 317).

Finally, it is significant to reflect on the fact that, while my status as a white European researcher means that I have the power to represent with all the ethical issues this brings, while I was in the field as a (white) woman on my own I did not always feel powerful. Being an unmarried woman working with mainly men meant that I also spent most of my free time with them, since women are rarely seen alone in the evenings, especially in the more rural areas. However, even interviews were not ‘harassment’-free, perhaps due to my being white, perhaps due to a misplaced smile or joke. In any case, what in western contexts would be classified as sexual harassment is part and parcel of interactions with men in Burkina Faso and was almost a daily occurrence. Most of the time, joking and laughing made me feel at ease, but there were times when a line was crossed in my mind and I definitely felt uncomfortable.

CONCLUSION

Reflecting on the methodology and the research process enables a reflexivity which is, perhaps, less taken into account when reflecting on theory, findings and recommendations. The process of writing on the methodology itself makes one realise how far geography research, qualitative research and participatory approaches, informed by postcolonial theory, have come. At the same time it also brings to light the shortcomings of such research, not only concerning the representation of the disabled person in a Global South context, but also the aftermath of the research. Before going in the field, expectations were high from my side and, while on fieldwork, expectations were high from many participants. However, whilst it is not expected that this research changed disabled people’s lives in Burkina Faso, it is, perhaps, a start in exploring the possibilities of reformulating development in ways in which to take into account disabled people’s knowledge and the implications of opening

up spaces for disabled people's voices to be heard. Keeping in mind the size and timeline of this research, the following chapters explore this in more detail.

CHAPTER 4

BURKINA FASO: DISABLED PEOPLE WITHIN A DISABLING CONTEXT

This chapter explains the context of the research. It first introduces Burkina Faso with an overview of its geography, political history, its ethnic groups and languages, and the public sector and the economy. The chapter then focuses on specific issues germane to the lived experiences of disabled people in Burkina Faso, laying the groundwork for the coming chapters. First, the terminology and categories used with regard to disability in the country are outlined. The chapter then looks specifically at disability, focusing mostly on the barriers disabled people face in their everyday life. It examines disabling illnesses and the use of traditional and modern medicine. The final section explores different aspects of Burkinabe society relevant to the research, including tradition, families and marriages, education and employment, as well as the state's role in these domains.

OVERVIEW

Located in the heart of West Africa, Burkina Faso shares borders with six other countries (see Figure 4.1). It covers a surface area of 274,200 km² (INSD⁷⁹ & Macro International, 2000) and is one of the more densely populated countries in the Sahel (Howorth, 1999). The population – which was 18,105,570 in 2015 (World Bank, 2016a) – is a very young one (Howorth, 1999), with sixty percent of the population under twenty-five (Baily, 2014), and life expectancy at birth being fifty-nine years in 2014 (World Bank, 2016a). The country is home to over sixty ethnic groups (Zongo, 2004), with the Mossi making up fifty-two percent of the population (Howorth, 1999). Among other main groups (see Figure 4.2) are

⁷⁹ *Institut National de la Statistique et de la Démographie*: National Institute of Statistics and Demography.

the Peul, Gourmantché, Bobo and Lobi (LAFB⁸⁰, 2007). Besides the official and administrative language of French (Zongo, 2004; LAFB, 2007), Burkina Faso has about sixty languages (Rupley et al, 2013), with Mooré and Dioula being most commonly spoken. While Mooré is the language of the Mossi, Dioula is spoken by most of the populations in the west (LAFB, 2007). Despite linguistic and cultural differences, inter-marriages are common (Sharp, 1990), and there is little conflict between the various ethnic groups (Rupley et al, 2013). However, the mingling and sharing of the same values, education and the affiliations to the same motherland have not abolished the sentiment of belonging to a particular ethnic group (LAFB, 2007).



Figure 4.1 Borders of Burkina Faso

⁸⁰ *Les Amitiés Franco-Burkinabè: The Franco-Burkinabe Friendships.*

Today, it is considered that seventeen percent of the Burkinabe population is Christian, thirty percent is Muslim ⁸¹ and ninety-nine percent is animist, even if a number of Burkinabes (even if they are Christian or Muslim) practice animism in secret. There is great religious tolerance as well as inter-marriages between religions. Muslims and Christians celebrate each other's feasts, on top of traditional feasts purely related to animism (LAFB, 2007).

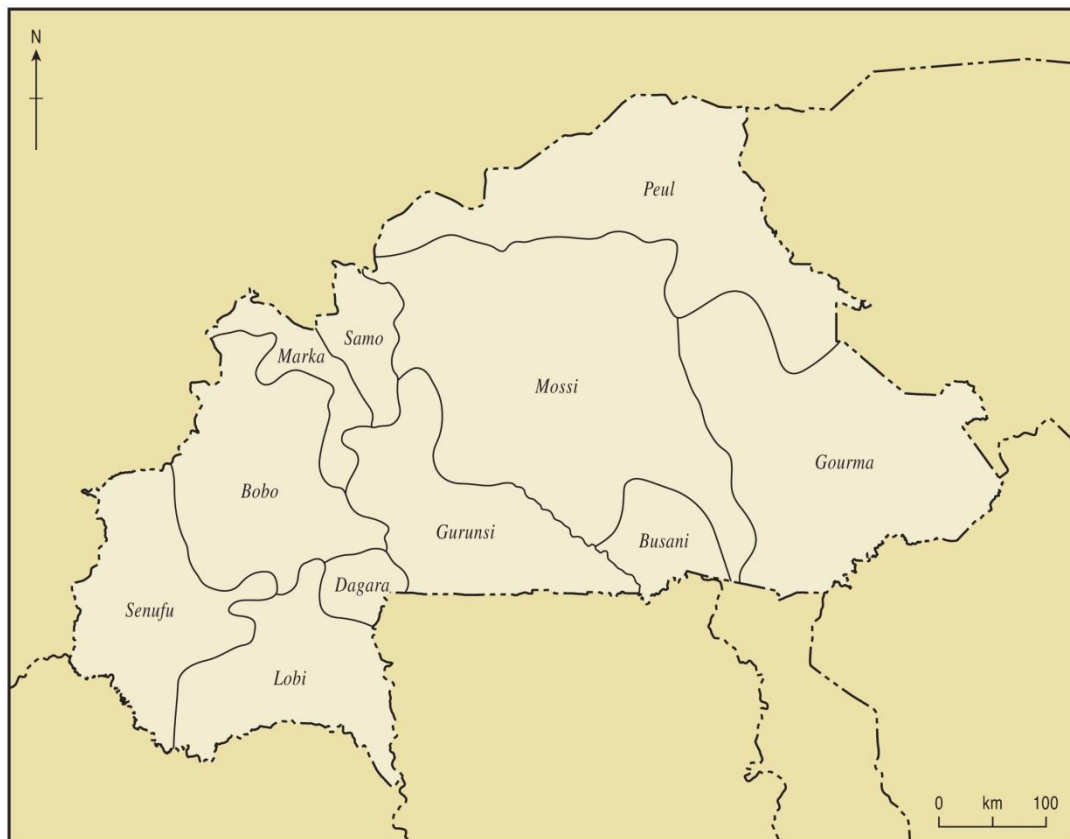


Figure 4.2 Ethnic Groups of Burkina Faso

According to the constitution established after independence, Burkina Faso is a secular country. However, all events and acts have a relationship with the supernatural: people are fundamentally religious in Burkina Faso. Religions are lived but rarely conceptualised and there is no

⁸¹ Different sources cite different figures on the number of Christians and Muslims in Burkina Faso. The largest number of Christians is Catholics, but there are also several protestant denominations (Bansé, 1997).

elaborate theology: knowledge is empirical. People believe that to reach God, it is necessary to address intermediary powers, created by him for this purpose: supernatural beings, spirits⁸², the spirits of deceased ancestors. The rites provide a bridge between the visible and the invisible world (considered to be around us). The spirits are often capricious or irritable and it is necessary to win them over with sacrifices. Sacrifices can consist of the death of an animal, donations to a specific person/s, or putting objects, food or living animals in a specific place. Animism, or as Burkinabes prefer to call it, fetishism, is not a syncretic religion and each ethnic group has its own conceptions, myths and rites. Some believe that imported religions (Islam and then Christianity) have come to add themselves to the ancestral religion without ever replacing it (LAFB, 2007).

Burkina Faso has thirteen regions and forty-five provinces. The regions are headed by a governor, while the province is headed by a high commissioner (Mahieu and Yilmaz, 2010). The three major urban areas are Ouagadougou⁸³ (the capital city), Bobo-Dioulasso⁸⁴ and Koudougou (Howorth, 1999; Zongo, 2004). Urbanisation in the large cities (see Figure 4.3) in Burkina Faso is taking place at great speed. There is also significant rural exodus due to various factors, including droughts and desertification, over-population preventing people from improving living conditions in places, and young educated people desiring ‘a better life’ in the city (LAFB, 2007). In the cities they are freer from the obligations of community solidarity, which discourages individual investment and savings; and the possibilities of finding paid employment are believed to be better (Brunel, 2004).

Burkina Faso is rated as a low income country (World Bank, 2016a) and is ranked 183 out of 188 countries⁸⁵ by the Human Development

⁸² Also called ‘*génies*’ or ‘*fétiches*’ in Burkina Faso.

⁸³ Often called ‘Ouaga’ for short in spoken language in Burkina Faso.

⁸⁴ Often called ‘Bobo’ for short.

⁸⁵ These rankings do not necessarily reflect the reality on the ground, but are rather an indication of where a country stands in relation to other countries according to these criteria.

Report (UNDP⁸⁶, 2015). The country's economic development is notably disabled by being landlocked and highly dependent on agriculture, both subsistence farming and cash crop farming. External aid plays a significant role in Burkina Faso's development, be it private (in the form of NGOs) or public, which comes mostly from France and the European Union (LAFB, 2007). While Thomas Sankara (Burkina Faso's revolutionary president from 1983 to 1987) pursued efforts "to develop a truly African form of revolutionary self-rule", Blaise Compaoré (the president from 1987 to 2014) "welcomed massive donor support and ushered in structural adjustment" (Batterbury, 1996: 599-600). In 1991, Burkina Faso began working with the Bretton Woods institutions for the first time, when it became the last African country to sign its first agreement with the IMF⁸⁷ (Azam and Morrisson, 1999).⁸⁸



Figure 4.3 Main Cities of Burkina Faso

⁸⁶ United Nations Development Programme.

⁸⁷ International Monetary Fund.

⁸⁸ In 1994, Burkina Faso devalued its currency (LAFB, 2007).

As with most countries in sub-Saharan Africa, Burkina Faso has had a turbulent post-independence⁸⁹ history, marked by several coup d'états, mass protests, and, more recently (2014), an uprising which led to the ousting of then-president Blaise Compaoré, who had been in power for twenty-seven years. Compaoré seized power in 1987 when Thomas Sankara was killed. Sankara's government was dominated by a Marxist-Leninist ideology (Zongo, 2004). A revolutionary army officer, Sankara made it his mission to transform Burkina Faso. His message to Burkinabes, "and to Africans everywhere, was that they should take destiny into their own hands, struggle proudly for their future, and reject domination or interference from any source, whether in their village, country or the world at large" (Sharp, 1990: 8). While the previous governments had left the country in a sorry state, Sankara slashed civil servants' salaries and privileges, made them accountable to the people, built schools, dispensaries, housing units and dams (ibid: 9). Mongo Beti⁹⁰ (1986) hailed Sankara's revolution as one of the most authentic in Africa, and undoubtedly the first true revolution in Francophone Africa.

For the significance of this revolution to be understood, it is necessary to take a brief look at the context in which it took place. Major divisions in Burkinabe society exist between rural and urban areas, and between the public sector (or a privileged section of it) and the rest of the population (Azam and Morrisson, 1999). Like many other African countries, Burkina Faso has urban-rural inequalities in the provision of education and health services (Bonvin, 1999). Public expenditure tilts undeniably towards urban zones: rural people are heavily taxed, while urban-dwellers are greatly favoured in public service distribution. This bias arises from the fact that urban residents are able to show their discontent more easily, since they live close to the seat of government. Hence, public budgeting (such as health and education spending) is transformed into transferring funds from the heavily taxed rural

⁸⁹ Burkina Faso gained independence from France in 1960.

⁹⁰ Mongo Beti was a Cameroonian author, one of the foremost African writers of the independence generation (Whiteman, 2001).

populations to the urban middle class (Azam and Morrisson, 1999). Burkina Faso's colonial past had a significant impact on its public sector. France established, and continued to support after Burkina Faso's independence:

centralised state structures and a civil service that was privileged with respect to income and prerogatives, following the model of metropolitan France.... [N]early all African countries where the ratio of the average civil service wage to per capita GDP is very high are former French colonies.

(Azam and Morrisson, 1999: 18)

This has often given rise to friction. Furthermore, “the number of civil servants per thousand inhabitants was much smaller in Burkina Faso... than in... other [Sahel] countries” (ibid: 12).

The more voracious this “patronage system” became in Burkina Faso (in the early 1960s and from 1975 to 1983), the more the resentment increased, especially from urban dwellers who were better informed about these privileges and corruption. Discontent and political instability, including demonstrations, strikes and attempted coup d'états brought Thomas Sankara to power in 1983. Sankara “won popular support when he called for a revolution to end this waste of resources and to place the public sector at the service of the people” (Azam and Morrisson, 1999: 12). Sankara's regime, however, rapidly lost legitimacy and the people's support when it committed acts of violence in the revolution's name, including arrests, summary trials and unexplained assassinations (Azam and Morrisson, 1999).

Compaoré's presidency (from 1987 to 2014) was marked by several upheavals, with the most marked ones starting upon the killing of Norbert Zongo in 1998. Zongo was a newspaper publisher known for his criticism of injustices committed by the Compaoré administration, and his death set off repeated protest marches, strikes and civil insurgence (Harsch, 1999). In 2011, Burkina Faso was rocked by anti-government protests and army mutinies, followed by an increased level of violence and instability (Freedom House, 2012). Finally, after mass demonstrations, Compaoré

was forced to resign on 31 October 2014. His resignation was preceded by his attempt to change the constitution to allow him to stand for a fifth consecutive term in office (Engels, 2015). After a temporary army takeover, a transition government was put in place. Shortly before the elections, which were scheduled to take place in October 2015, there was another military takeover. However, following mass protests by the people and mediation by ECOWAS⁹¹, the transition government was reinstated after a few days (Allison, 2015). Elections finally took place in November 2015, in what were hailed as the first open elections in Burkina Faso (Al Jazeera, 2015). It is in this context that the research, and the lives of the research participants, unfolds.

Terminology and Categorisation

It is in the naming process that culture plays its role
by providing meaning.

(Ohnuki-Tierney, 1981: 457)

There are a number of common terms referring to the major disabilities used in spoken French in Burkina Faso, including by people with disabilities themselves. The terms are used here according to how disabilities are categorised in DPOs and according to what is usually classified as a disability in Burkina Faso. As Barnes and Mercer (2005) point out, some conditions classified as impairment in the west, such as dyslexia, are not classified as such in the Global South. It also goes without saying that there exist different terms in the various local languages, and that some disabilities do not have a term (or are rarely used) in some of the local languages. The difference between ‘impairment’ and ‘disability’ was outlined in Chapter 1 according to how the terms and concepts are used in western literature. However, in spoken language in Burkina Faso it is rare to hear people differentiating between the two.

The term usually employed to refer to a disabled person is *personne handicapée*. Sometimes the term *handicapé* is used on its own; however, this is considered disrespectful by some, since the ‘person’ is being

⁹¹ Economic Community of West African States.

omitted. Recently, other terms have been employed, considered to be more respectful and better reflecting reality: *personne en situation de handicap* or *personne vivant avec un handicap*, which translate literally into ‘person in a situation of disability’ and ‘person living with a disability’. The former is not used in English and thus translates as such into ‘person with a disability/disabilities’. For non-disabled people, the term used by Burkinabes is *valide*, which translates into ‘fit / well and able’.

With regard to specific disabilities, people with physical disabilities are called *personnes handicapées moteur*. This term usually encompasses people who have any physical impairments, including people using a wheelchair⁹² (see Figure 4.4) or crutches, people who limp; people with burns or paralysis; people with dwarfism; people with kyphosis; and people who have amputated limbs (although they are also at times referred to as ‘amputees’). The latter also includes people who had leprosy and have amputated digits because of the same illness. It is to be noted that the ‘correct’ term for these types of disabilities would be *handicap physique* in French, while *handicap moteur* would refer to a motor disability.

Visual and hearing impairments are referred to as *déficiences visuelles* and *déficiences auditives* respectively. Therefore, impairments are referred to as ‘deficiencies’, a term which, as will be discussed in the following chapters, has implications for how disabled people in Burkina Faso see themselves⁹³. People with visual impairments are referred to as *malvoyants*, meaning ‘partially sighted people’ or ‘visually impaired people’. People who are completely visually impaired are usually referred to as *aveugles*, ‘blind’. Similarly, people with hearing impairments are called *malentendants*, while those who are completely hearing impaired are usually referred to as *sourds*, ‘deaf’. Deaf people are also sometimes

⁹² The word ‘wheelchair’ here is used for lack of a better word. The actual mode of transport physically disabled people in Burkina Faso use are *tricycles*, as shown in Figure 4.4. The actual wheelchairs (*fauteuils roulant*) are less common and are generally used for indoor purposes.

⁹³ Relatedly, a disabled person in Burkina Faso is sometimes referred to as *personne diminuée*, or ‘diminished person’.

referred to as *sourds-muets* (deaf-mute). The terms *personnes déficientes visuelles* and *personnes déficientes auditives* are also sometimes used to encompass both people with partial and full visual and hearing impairments respectively. Albinos are referred to as *personnes albinos*.



Figure 4.4 Wheelchair (Tricycle)

People with intellectual and developmental disabilities are generally called *personnes déficientes mentales* (persons with mental impairments) or *encéphalopates* (persons who have encephalopathy). The latter term is widely used especially in rural areas, but is increasingly becoming outdated in urban ones, with the preferred term for intellectual/mental impairment by the major DPO of children with intellectual disabilities⁹⁴ in Ouagadougou being *déficiences intellectuelles*.

⁹⁴ Association des Parents et Amis d'Enfants Encéphalopates: Organisation of Parents and Friends of Intellectually Disabled Children.

(intellectual impairment)⁹⁵. There is rarely a distinction made (especially in rural contexts) between different intellectual and developmental impairments, and people with such impairments are grouped together⁹⁶. In Ouagadougou, some attention is now being given to children with autism, especially on the initiatives of their parents and psychologists working with them. However, autism in Burkina Faso is generally misdiagnosed. Even when autism is identified as such, there are differences in the way people with autism are considered: some consider them as people with intellectual disabilities, while others do not. People with epilepsy are also often classified with people with intellectual disabilities. Furthermore, people with intellectual disabilities in Burkina Faso are often conflated with people with mental health problems, who are often looked at in ways ranging from trepidation – stemming from the fear of violent behaviour – to addressing them as ‘the crazy’⁹⁷. This label usually refers to people with mental health difficulties who roam the streets, often not fully clothed, dirty and living on people’s charitable donations of food.

SITUATING THE DISABLED PERSON IN BURKINA FASO

Very little statistical information exists on disabled people in Burkina Faso (Handicap International (HI), 2005). A 2009 report issued by government entities⁹⁸ states that 1.2 percent of the population of the country live with a disability. This seems to be in stark contrast to the figure of fifteen percent of the world’s population reported by the World Bank (2016b) and the World Health Organization (WHO, 2016a). The

⁹⁵ In the Est region, the gatekeeper explained that people with intellectual and developmental disabilities are locally called *bêtes*, which means ‘idiots’.

⁹⁶ Thus, intellectual and developmental disabilities are encompassed under the term ‘intellectual disabilities’ throughout this thesis.

⁹⁷ ‘*Les fous*’.

⁹⁸ *Ministère de l’Economie et des Finances* (Ministry of Economy and Finance), *Comité National du Recensement* (National Censuses Committee) and *Bureau Central du Recensement* (Central Censuses Office).

Director General of National Solidarity⁹⁹ (Email Exchange, 1st October 2015) explains this idiosyncrasy:

With regard to the figure of 1.2% of people with disabilities, one must note that these figures fall short of the reality on the ground. This could be due to the lack of knowledge on the notion of disability by the researchers, or the unfavourable social representations linked to disability, which often result in people not wanting to declare a disabled relative. There is the tendency to hide them.

A DPO in Ouagadougou, meanwhile, reports that approximately ten percent of Burkina Faso's population live with a disability (Handicap Solidaire Burkina (HSB), 2015).

As HI (2005) points out, rather than the *situation* of people with disabilities in Burkina Faso, one should speak of the *situations*: people with disabilities are a heterogeneous group, and people with different impairments encounter different situations. However, in general, disabled people in Burkina Faso face discrimination in employment, where many employers refuse to employ disabled people; in social life and transportation, where taxi drivers and restaurants often refuse entry to people with disabilities; and in accessibility to buildings, which often do not have physical accessibility for people using wheelchairs, crutches, and so on (HSB, 2015). In his document 'Beyond Prejudices', Henri ¹⁰⁰, a disability activist in Ouagadougou, reports that often, disability is seen as an incapacity (a view which is advanced further by disabled people begging), and thus as a person who cannot do anything.

People with disabilities are not excluded physically from society in the same way women accused of sorcery are banished from the community in Burkina Faso. Disabled people are physically present in society. Exclusion occurs in aspects such as decision-making at the familial, community, and national level. Not having the right to speak (or one's word having no value) is a form of symbolic exclusion. Symbolic exclusion,

⁹⁹ At the *Ministère de l'Action Sociale et de la Solidarité Nationale du Burkina Faso*: Ministry of Social Action and National Solidarity of Burkina Faso.

¹⁰⁰ Henri is one of the research participants and the document cited, *Au-Delà des Préjugés*, was given to me during the interview. It is not published and has no date.

which is more harmful because it is less conspicuous, is often ignored by development projects; and yet, the question of symbolic integration is central to the promotion of the disabled person's social validation. Disabled people feel marginalised when they are not included in family or community gatherings such as marriages, baptisms, funerals, traditional meetings, or when the family gathers to make an important decision; which is a way of assuming that the disabled person is useless for society. This means that the disabled person is removed from the place s/he would have occupied within the social system had they not been disabled. Ignoring the importance of the disabled person's voice equates to negating the person's thoughts and denigrating his/her value (HI, 2005).

Many difficulties faced by disabled people also stem from entrenched superstitions in Burkinabe society, such as the belief that having sexual relations with a disabled woman makes a man become rich (HSB, 2015). People with albinism also face prejudices often based on lack of knowledge. For example, the president of an albino people organisation (Interview, Ouagadougou, 26th January 2015) explains that:

Africans do not understand how a black man and a black woman, meaning a black couple, can have a white child. It's inconceivable, meaning people don't understand how...

People in Burkina Faso thus traditionally believe that children with albinism are not persons but rather spirits. Others think that children with albinism are a source of misfortune. Thus these children need to be disposed of (Interview with Soufyiane (person with albinism), Ouagadougou, 31st January 2015). Beliefs surrounding disability in Burkina Faso form part of similar beliefs in sub-Saharan Africa. In many African societies, disability is considered as a curse or a punishment. People who think this assume that God made a person disabled to prevent him/her from executing a misdeed (Henri, 'Beyond Prejudices'). Devlieger (2010: 89) explores how sub-Saharan African societies categorise "extraordinary bodies into a variety of organizing categories with differing conceptual and social consequences". In Burkina Faso, those who cannot

hold their head upright are compared to snakes and called ‘snake-children’. These children are often eliminated at birth, or left without care and attention, and so few survive. Coping with a child with a severe impairment can often mean that the family finds itself destitute. Believing the child is a spirit permits the mother to free herself from guilt when the child dies (HI, 2005). As Devlieger (2010: 95) argues, “[t]o mark this infanticide as mere ‘killing’ is unfair because its process involves consulting and ritual that intends to protect the spirit of the child and those of the community”.

Experiences, opportunities and lifestyles differ for people with (and without) disabilities in urban and in rural contexts. Apart from health and education (discussed subsequently), there are other differences which disabled people encounter:

In Fada¹⁰¹, people are reasonable and life is affordable; because here, disabled people are given a little consideration, compared to other towns. In Ouaga... there are people who will neglect disabled people, as if they were not human beings.

(Laurentine, 20th October 2014)

Laurentine is talking of the town of Fada N’Gourma being better than the capital. However, there are also differences between towns like Fada N’Gourma and villages. It is rare, for example, to see people begging in villages, but in urban areas beggars line the streets. People beg for different reasons: as an alternative option to staying at home and doing nothing; due to old age and being in need of survival; attending a Koranic school (children attending Koranic schools are usually sent out by their teacher¹⁰² to beg); and becoming disabled (LAFB¹⁰³, 2007). Although today begging is seen as degrading, it was not always regarded in such a manner in certain traditions. In some cases, such as a mother having twins needing to beg to feed her children, the collective would have participated in the care of these children, helping their mother in a situation which overwhelmed her (Nyamba, in LAFB, 2007). Today, although people are

¹⁰¹ Fada N’Gourma, which is often called ‘Fada’ for short in spoken language in Burkina Faso.

¹⁰² The *Marabout*.

¹⁰³ Les Amitiés Franco-Burkinabè.

obliged to give to beggars (LAFB, 2007) they are not generally regarded positively:

Begging is good for disabled people, the old who cannot do anything anymore.

I give from time to time, but mostly to those who are most in need: the old, lepers, disabled people. When it concerns fit and able men like me, this is shying away from responsibilities.

(LAFB, 2007: 152)

Begging... is a sign of... a physiological and moral inability to meet one's needs. A disabled person who begs is doubly degraded, because he is disabled and because he begs. In reality, effectively helping this person should lead him to rehabilitate himself, to be entirely self-sufficient.

(Nyamba, in LAFB, 2007: 151)

Emile (Interview 26th November, 2014), a blind man in Ouagadougou says:

E: Begging, it's not good...

LB¹⁰⁴: And why, do you think, do [disabled] people beg?...

E: ... to earn a bit... there are others who do not know [how to] work: if they knew [how to] work, they would work and not beg anymore... begging does not do honour to disabled people... there is a lot of work; if you fight... you can do it... there's a lot!... There are also those who think they cannot do anything; and there are those who do not have the means to pay for [skills] training.

However, Daouda (Interview, 26th November 2014), a DPO president in Ouagadougou, has rather different views:

LB: How do you see the situation of people with disabilities in Burkina¹⁰⁵?...

D: The life of a disabled person in Burkina Faso:... those who work are those who suffer... and those who beg... live better than those who work.

Daouda goes on to give the example of when the state issues a call for wheelchair fabrication. Even if a qualified disabled welder applies for the

¹⁰⁴ When quoting parts of interviews, rather than just a one-person quotation, the interviewee's and the researcher's initials are used. The researcher's initials are always 'LB'.

¹⁰⁵ In spoken language, 'Burkina Faso' is often called 'Burkina' for short.

post, the work is given to a non-disabled one. Thus, disabled people who try to be gainfully employed are disheartened:

A beggar, when he gets up in the morning, he puts it in his mind that he has to earn 1,000 Francs¹⁰⁶ in his bag, to eat. He goes out: if he holds out his hand, they give him 1,000 Francs¹⁰⁷ or 1,500... he puts it in his pocket, he is happy: for him it's already guaranteed.... Thus, it means that he who managed to gain money today is better than him who has nothing, who works!

(ibid)

In urban areas, therefore, disabled people can be found living in two very different situations: while in Ouagadougou, a significant number of beggars are disabled¹⁰⁸, several disabled people may be gainfully employed and have access to the necessary amenities in cities like Ouagadougou and Bobo-Dioulasso. Disabled people in urban areas have more opportunities of owning a three-wheel motorcycle in the case of physically disabled people, learning Braille in the case of blind people, learning sign language at schools for deaf children, attending intellectually disabled people's schools, or having access to sunscreen and hats for people with albinism. In more rural areas and remote villages, disabled people rarely have access to these amenities.

Disabling Illnesses and the Traditional – Western Medicine Nexus

Numerous illnesses have for a long time maintained a low life expectancy of the Burkinabe population, in particular childhood illnesses attributable to the absence of clean drinking water and to parasites, to lack of hygiene and medicine, to climate, to the lack of medical staff (who use western methods and medicine) and to lack of medical establishments, which are also under-equipped. The presence of parasites, even though less worrying than in nearby more humid countries, is still concerning. Most parasitic illnesses can be diagnosed and cured, but the principal problem is finances. Apart from cholera, tuberculosis, and other diseases, mosquitoes are responsible for a number of illnesses such as malaria, onchocerciasis

¹⁰⁶ 'Francs' refers to the West African CFA Franc currency.

¹⁰⁷ Equivalent to (approximately) £1.10.

¹⁰⁸ Some disabled beggars come to Ouagadougou from other countries.

and dengue fever. Malaria is the biggest killer of all illnesses in Burkina Faso and is also a disabling illness. However, there has been no significant research for a vaccination (LAFB, 2008). Onchocerciasis, also called ‘river blindness’, is transmitted to humans through the bite of blackflies which breed in fast-flowing streams and rivers. Ninety percent of this disease occurs in Africa (WHO, 2016b). The WHO (2016b) estimates that in some West African communities, about fifty percent of the men over the age of forty have encountered blindness through this disease, causing people to flee fertile river valleys to less productive land. This resulted in an economic loss of approximately thirty million US dollars in the 1970s. Meningitis is also a fatal (and disabling) illness in Burkina Faso, despite the fact that its consequences could be notably restricted by using simple measures of prevention and the provision and faster distribution of medicines during epidemics. Leprosy, which has been practically eradicated in Burkina Faso, was a disabling illness up until the 1990s (LAFB, 2008).

HIV and AIDS, while not being categorised with disabilities in Burkina Faso, have major disabling implications on Burkinabe society. According to the WHO (2016c), more than ninety-five percent of HIV infections are in developing countries, two thirds of them in sub-Saharan Africa (WHO, 2016d). The WHO (2016c: n.p.) reports that AIDS:

is having a major impact on social and economic development. Poverty is increasing in many countries as households lose one or more breadwinners to AIDS. And both public services and private companies are reeling from the impact of HIV-related sickness and deaths among their workforce.

BBC¹⁰⁹ News (2001a) reported that in Burkina Faso, twenty percent of rural families had cut back their farming activities because of AIDS. BBC News (2001b) refer to a conference held in Burkina Faso, where African women blamed the culture of the dominant man which prevails on the continent, and which leads to a huge number of African women being infected. These women declared that men’s practices (refusing to wear

¹⁰⁹ British Broadcasting Corporation.

condoms, intimidating young girls, exercising their sexuality with younger girls, engaging in polygamy and raping) constitute a major problem. Finding solutions depends on work with local communities not with big declarations. Added to this is the financial dependence of women, even young girls, on men (LAFB, 2008).

In the villages, many die of unidentified illnesses. People suffer from stomach aches, coughing, they become dehydrated and weak. They die and no one knows exactly why (LAFB, 2008): it could be AIDS (which is sometimes blamed on a divine curse (Bélemnaba and Kafando, 2002), or shrugged off, reasoning that “Death comes from God”¹¹⁰ (LAFB, 2008: 48, my translation); and the people around them, not knowing this, have no idea of the importance of getting themselves tested. Others, feeling healthy despite the virus, believe that they do not have the virus, or that it is a white man’s invention (LAFB, 2008). At other times, blame for illnesses or deaths are attributed to somebody else, such as a woman who has a reputation of being a witch (Toé, 2008).

Similar beliefs to those surrounding AIDS were (and sometimes are) held with regard to other disabling illnesses. Besides the diseases discussed so far, other major causes of disabilities of those who are adults today in Burkina Faso are illnesses such as polio, measles, chicken pox, glaucoma, cataracts, illnesses encountered by the mother during pregnancy, and accidents¹¹¹. However, many research participants relate their belief that their disability was caused by a vaccination, or a badly administered one:

LB: Did you have polio when you were a child?

C: ... It’s not polio, it’s an injection: the sting.

LB: ... I don’t understand.

C: For example, if I have malaria, they take me to hospital. If they see [I] have a lot of fever, they must give me a sting. They inject you, and it [might] touch your nerves.... If it touches your nerves... the leg will not function anymore....

¹¹⁰ Bourguignon (2001) observes that the Burkinabe have a sense of acceptance of one’s fate, one’s lot in life. What depends on God and nature has always been accepted with a certain sense of inevitability.

¹¹¹ Many people become disabled due to accidents, such as traffic accidents or occupational ones.

(Interview with Clementine (physically disabled woman),
Ouagadougou, 13th February 2015)

The majority of research participants who became disabled due to illnesses do not understand the cause of their disability, although there is some awareness of links with disability of illnesses like polio, a disease which has now been practically eradicated in Burkina Faso through vaccination campaigns that were unavailable when today's adults contracted the illness as children. Others believe that their disability was caused by spirits. Kemhana (Interview, Bogandé, 2nd October 2014), a man who has visual and physical disabilities, believes that his disability was caused by an external evil power:

LB: And when did [you] become sick¹¹²?

K: ... It was a long time ago.... It's been 60 years that [I] fell ill...

LB: What type of illness was it? Meaning, how...?

K: ... It's Satan... the work of Satan.

Others, even today, do not become aware of the seriousness of an illness until it is too late. Abdou Raman (Interview, Banfora, 4th March 2015), a 28-year old blind man, relates how when he was recently losing his sight he was still reluctant to apply the creams the doctor had prescribed because they disrupted his studying. Others, like Benoit (Informal Conversation, 26th September 2014), a physically disabled man in Kompienga, do not go to the hospital when infected with malaria. Many simply go to the pharmacy, buy over-the-counter medicines, and go on with their lives.

In Burkina Faso, eighty percent of the population resort to traditional medicine. Burkinabes generally practice a kind of nomadism between traditional and western medicine, and thus absorb, alternatively or simultaneously, medicines from both sources. The choice between western and traditional medicine is made based on multiple criteria: reputation, trust in the practitioner's diagnosis together with the

¹¹² I use the word 'sick' because it is the word the participant used to define his condition immediately before the question was posed.

practitioner's results (real or supposed), failure of a treatment, or accompanying a treatment to increase the chances of recovery (LAFB, 2008).

Traditional medicine is practiced by traditional doctors¹¹³ who use different methods: herbal medicine, invocations and the occult. Some traditional doctors are well-renowned and people travel far to consult them. The clientele hails from all backgrounds, including urban dwellers and developed/advanced socio-cultural classes. Traditional medicine is mainly practiced in the family or amongst neighbours. Numerous old people, particularly old women, are knowledgeable about herbal teas or massages which relieve and heal. Today, medicine (and a divination) of Muslim origin practiced by *marabouts* (not all of whom are religious) is often combined with ancestral practices (LAFB, 2008).

Western medical treatment is practiced in hospitals in large cities and towns and in health centres in rural areas, with the latter constituting the formal healthcare system for the majority of the population. A health centre, which serves a population of around 15,000 inhabitants, is placed under the responsibility of a nurse¹¹⁴. This often includes a clinic, a maternity ward and some hospitalisation rooms. The nurse, together with a midwife¹¹⁵, are usually the only health professionals treating rural populations. The nurses also conduct consultations and deliver prescriptions. Western medicine is sold in dispensaries or clinics, which, despite price decreases in recent years, remains out of reach for the average Burkinabe. Dispensaries also lack sufficient quantities of medicines. Furthermore, one finds unauthorised sales of fake medicines (LAFB, 2008). Even in Ouagadougou, public hospitals are sorely lacking. A doctor, talking about the state of the hospital where he works¹¹⁶, observes:

This hospital lacks the basic minimum (oxygen, thermometer, blood pressure monitor, beds, rooms...). Our hospital critically lacks the

¹¹³ Called *guérisseurs* (healers) in Burkina Faso.

¹¹⁴ Called *agent de santé* (health agent) in Burkina Faso.

¹¹⁵ Called a 'matron' if she has not completed her course.

¹¹⁶ *Centre Hospitalier Universitaire Yalgado-Ouédraogo*.

material for an effective treatment of the patients, and this is compounded with the extreme poverty of the population. Here, the notion of emergency does not really exist. Besides the lack of emergency material, all services are charged... Furthermore, a small number of house doctors must cope with a large population and thus are often overwhelmed... because the country lacks doctors... If nothing is done... doctors will continue to leave to go abroad or to work in the private sector.

(LAFB, 2008: 32-33, my translation)

The hospitals and clinics, which are often built and equipped through external aid from states or NGOs, function with overstretched budgets. The government, pushed by international bodies, has undertaken a sort of privatisation of the health services. Hospital doctors who were civil servants open private consulting practices or clinics, which, again, are unaffordable to the majority of the population (LAFB, 2008).

The largest number of people lives in rural areas (Campos, 1995: 82), and consequently so does the largest number of disabled people. And whilst:

rural residents generally experience barriers to access to primary health care, these problems are further exacerbated for people with disabilities.... The literature consistently emphasizes the failure of local health care systems in nonmetropolitan areas to adequately address the complex medical and related needs of individuals with disabilities. In the absence of specialized expertise, facilities, and primary care providers trained specifically to care for disabled persons, local programs rely heavily on the use of indigenous paraprofessionals and alternative models of care.

(Lishner et al, 1996: 45)

Most of the research interviewees recount how their parents took them to traditional doctors (and sometimes also to western hospitals in addition) when they fell ill with the disabling illness, not only because of a lack of affordable, accessible health care, but also because it was the preferred treatment and there was a lack of knowledge about the illness and cure (although the cure for certain illnesses was also non-existent in Burkina, or the health care professionals would have had no knowledge of how to treat it regardless). Alassane, a 50-year old blind man in Banfora, relates his story describing the pitfalls of traditional and western medicine (see Textbox 4.1).

It's in 2003 that the pain in the eyes started. So I tried to consult the hospital there... [in Ouagadougou]. I didn't obtain results there. I ended up calling my family, who told me to come to Banfora.... So I came... I used to go to Bobo to consult a doctor. He gave me a paper¹¹⁷ to go to Mali... there is a place there where they heal eyes.... Well, you know, we are in Africa... I had a friend with whom I had done my apprenticeship in Mali.... When I found him, he gave me the name of a practitioner [traditional doctor] who had healed his mother when she was ill, saying there's no need for me to go to hospital.... When I went to hospital... they told me that the doctor I was supposed to see was on holiday. Thus I remembered that my friend had given me the name of a practitioner [in Bamako]... so I went.... He made me spend around 300,000 [Francs]¹¹⁸... I had to buy a sheep.... I realised it [my eyesight] had gotten worse than before... he treated and treated... I got angry and came back [to Burkina], because I had no money left.... My brother told me to go to Ouaga: he had heard talk of a doctor.... I went there, the doctor... told me I had to go to France... if I had gone to France, my brother would have become penniless too. And since I don't see, how would we have survived?

(Interview, 19th March 2015)

Textbox 4.1 Traditional and Western Medicine

BURKINABE SOCIETY

It is important to understand different aspects of Burkinabe society in relation to disabled people's experiences, since they shape the salient aspects of Burkinabe life, which in turn influence the lived experiences of disabled people.

Traditional and Modern Society

[W]e need to understand disability as emerging through time.

Disabled people are, indeed, involved in a political process
of rediscovering their own histories.

(Connell, 2011: 1371)

In Burkina Faso, the village confers social identity: "the framework within which each person learns his or her place in the world... is initiated into adulthood... and establishes lifetime bonds with those of the same age group" (Sharp, 1990: 5). Happiness is denoted in terms of curtailing individual liberties and the submission to the collective. The village chief is an important figure, most often elderly (in accordance with the criteria

¹¹⁷ A referral.

¹¹⁸ Equivalent to (approximately) £370.

of a continent where life expectancy is weak: from forty years old onwards, one is old). In the past, wealth was the appanage of chiefs or, more precisely, of the communities they represented. It was made up of the splendour of herds of livestock farmers, of the size and wealth of fields or the impressiveness of costumes, but never of money, which, in ancestral civilisations, did not have any legal standing. Power, rather than wealth, was most often sought. The notion of individual commodities did not exist and people did not worry too much about the future. During colonisation, however, the chiefs and chiefdoms were discredited and replaced by other personnel, and chiefs were submitted to the administrator's power and political interests. Today, even though traditional chiefs do not have constitutional powers, they still have considerable influence (LAFB, 2007). Primarily, the traditional chief oversees the perpetuation of traditional practices and cultural values with regard to the thriving of the socio-ethnic group. He is the guardian of the fetishes¹¹⁹; a guide and an adviser; a judge and an arbiter of conflicts and other local disputes relevant to traditional realities (Diabaté, 2006a). The traditional chief, such as the Mossi chief the *Mogho-Naba* in Ouagadougou (Diabaté, 2006b), is sometimes consulted by the administrative or political authorities. In this case, the traditional chief would only have consultative powers, but his opinion can enlighten political or administrative decisions (Diabaté, 2006a).

Before the erosion of the traditional structures of solidarity, the disabled person was cared for by society and participated in social activities, in particular those of the larger family. For example, the Mossi society used to have a place for disabled and old people. Their care was shared by all the larger family, thus alleviating the parents' responsibility. Close kin were in charge of the construction and upkeep of disabled people's accommodation, as well as the maintenance of their fields. Thus, disabled people were almost over-protected: just like twins, they were

¹¹⁹ This is a direct translation of the word *fétiches* in French, for lack of a better word. A *fétiche* is an object believed to have supernatural powers.

considered to possess supernatural powers. As a result, bad behaviour towards them could bring about evil aftermaths on the culprit or their extended family. Equally, there was a shared responsibility with regard to disabled people's integration: this corresponded to the spirit of solidarity which regulated social relationships in the community (HI, 2005).

The introduction of the market economy in traditional societies brought about profound disruptions, including the erosion of the traditional structures of solidarity and the transformation of the domestic setup. This erosion process picked up pace from the 1940s onwards. The domestic circle, therefore, shrunk until only the nuclear family was left. Consequently, the care of 'dependants' was transferred from the extended family to the unit of biological reproduction (HI, 2005). The introduction of the market economy has also brought about a change in the way disabled people are valorised. Integration is based on the individual's participation in socially valued activities and the place occupied in the social system, among other factors. Whereas in traditional society disabled people were valued, or, at the very least, taken care of by the extended family, today disabled (and non-disabled) people are valued according to their economic independence. This in turn affects the disabled person's self-definition, which is now based on his/her capacity to be economically autonomous. Meanwhile, this valorisation of bodies based on economic value has different repercussions on people having different types of impairment.

In this context, a hierarchy, whether conscious or unconscious, is created both within the 'disabled community' as well as the non-disabled society, valuing bodies on their ability to be economically productive. With regard to office jobs (such as the coveted civil service posts), people with physical impairments can, technically, hold such posts today in Burkina Faso, and indeed some do. People with visual and hearing impairments, however, encounter many more barriers, although there have been some recent attempts to change this situation. At the bottom we find people with intellectual disabilities, who find it difficult to hold any job at all, unless it is in sheltered places specifically for people with such disabilities.

If one looks at agricultural work (the major source of employment in Burkina Faso), people with hearing impairments are the ones who find the least barriers in performing the necessary duties. People with visual and physical impairments find it more difficult (unless they are the *owners* of fields), although this also depends on the type and severity of the impairment, while people with intellectual disabilities are sometimes involved in such tasks as cattle-herding, but are usually not given full charge of a particular duty. Again, this depends on the severity of the impairment, and certainly none of them actually own fields. Most people with intellectual disabilities, therefore, do not perform any kind of economic activity, and are the least valued in the market economy.

Families and Marriages

In a context in which income-generating work is valorised, the significance of the family¹²⁰ is heightened. Within the family, disabled people are often either the object of over-protection and over-care (in the hope of removing the impairment); or mistreatment, isolation, negligence and under-care. They are often denied access to the system of production (Henri, 'Beyond Prejudices'). Furthermore, in low-income countries like Burkina Faso:

there are no social safety nets to speak of other than one's family. So if a family can't look after its disabled member, there are few options other than starvation. If one adds the fact that in most countries people with disabilities are often treated as if they are incapable of doing meaningful work, then it is not surprising to find they are amongst the poorest of the poor.

(Neufeldt, 1995: 162)

For Burkinabes, children are their 'social security' (LAFB, 2008): the child is considered as a guarantor of permanence (Sawadogo, 2004). Fertility is thus high among rural populations, modern methods of

¹²⁰ Throughout this thesis, the term 'family' is used to refer to what is considered in western contexts to be the extended family. In Burkina Faso, the family includes all the individuals who have familial relationships: brothers, sisters, half-siblings, cousins, nieces, nephews, spouses, co-spouses who live in the same compound and obey the head of the family. The *Grande-famille* includes then the relatives of the same lineage, often called the 'clan'. Sometimes, but not necessarily, the notion of the *Grande-famille* is conflated with that of the 'village' (LAFB, 2007).

contraception are almost non-existent, and there is a universal desire for large families (Hertrich, 1996). Many research interviewees have children, even when not married or living with a partner. It is common for people to have children outside marriage. Until the child is seven years old, he or she usually lives with the mother, at which age they will go to live with their father. If the father is not present, they usually live with the extended family.

Burkinabe society is patriarchal, often polygamous, with an emphasis placed on the role of women as wives and child-bearers. Respect for women is granted in accordance with age and marriage status (LAFB, 2008; Conseibo, 2005). Polygamy has certain implications for disabled children, as Ela (Interview, Ouagadougou, 20th November 2014), a physically disabled woman, recounts:

LB: In the family... was it the same for you and your brothers and sisters, or were there differences between you and your siblings?

E: Yes, it's fine. Actually, with the direct brothers and sisters it's ok, but the others: since in Africa a lot of families are polygamous, when it's your proper brothers, your proper mother, it's ok; but the others [father's wives and their children] look at you as another person, as if you don't have rights in the same way as others. They don't treat you like the others, they treat you like an animal.

In family life, women as co-spouses are responsible for all the housework and child rearing (LAFB, 2008). Men do not usually contribute in household chores (Conseibo, 2005). In villages, women and young girls get up before sunrise, prepare breakfast for the family, heat the water (to bathe with), carry the water and wood (see Figure 4.5), and then join the men in the family field. In certain societies, a woman would have another field – in which she also works in addition to working in the family fields – to be able to buy such things as spices, clothes for the children, and school stationery. During the dry season, when there is no field work, the men rest (LAFB, 2008), but the women must continue to care for husbands and in-laws (Sawadogo, 2004). Women contribute to 54.7 percent of

agricultural activities (Sougué, in LAFB, 2008). In the food sector, for example, women are present at all levels: producing vegetables, fruit and fruit products; harvesting, transporting, selling and buying (Ki-Zerbo, 2003).

In this context, it is easy to see how disabled women find it harder to marry than non-disabled ones. Carrying water and wood, working in the fields, are tasks which women with physical or visual disabilities find difficulties in carrying out. On the other hand, men are expected to provide, to be able to feed their wife/ves and children. According to Michel (Interview, Fada N’Gourma, 22nd September 2014), a physically disabled man, if a man is not married, and thus does not demonstrate that he is able to manage his family, he cannot expect to have responsibilities in the community. Michel (Preparatory Meeting, Fada N’Gourma, 7th September 2014) also observes that while today in Burkina Faso it is hard for any man to find a wife, it is even harder for disabled men. A man needs money to marry a woman, since today, women and girls in Burkina Faso look for men who have money. It is easier, therefore, for two disabled people to marry each other than it is for a disabled and a non-disabled person to do so.

Education: a ‘Disability within a Disability’¹²¹

The hurdles disabled people in Burkina Faso face are compounded by lack of access to education. Edouard (Interview, 20th November 2014), a physically disabled man in Ouagadougou, says that the fact that many disabled people did not go to school is a “disability within a disability”. The UNDP¹²² (2012: n.p.) reports that:

Burkina Faso has one of the highest illiteracy rates in the world, and a school enrolment rate of only 39.1 percent. Adults account for more than 70 percent of Burkina Faso's illiterate people.

¹²¹ Interview with Edouard, a physically disabled man, Ouagadougou, 20th November 2014.

¹²² United Nations Development Programme.

Consequently, the country suffers from a dearth of teachers. Interruptions during the school year and the size of classes (sometimes amounting to more than one hundred twenty children in one classroom) further exacerbate the situation (ibid).



Figure 4.5 Getting Water from the Well

While organisations like the World Bank, the International Monetary Fund and UNICEF ¹²³ postulate that classic schooling is indispensable to a country's progress, the means of countries like Burkina Faso are insufficient to educate all children and it is often the poorest who are excluded (LAFB, 2007). Schools are lacking or too far away from small villages. Furthermore, compared to parents' income, schooling is too expensive. Education in Burkina Faso thus only benefits a small number of children (Bourguignon, 2001).

For children with disabilities in Burkina Faso, it is even more difficult to access schooling than non-disabled children. Often, children

¹²³ United Nations Children's Fund.

with disabilities are valued less than the other children and thus parents are less inclined to send them to school. The national federation of DPOs, the FEBAH¹²⁴ evaluates that sixty-six percent of disabled people have no level of education and only 16.5 percent have attended primary school (UNICEF, 2013). Schools with the necessary facilities to accept children with disabilities, such as visual and hearing impairments, are almost non-existent in rural areas. When such schools do exist in a nearby town, other barriers are present. Numpua (Interview, 26th September 2014), a deaf girl in the municipality of Kompienga, could have attended the deaf school in the town of Fada N’Gourma; to do so, however, she would need a relative in Fada N’Gourma with whom she could stay. Physically disabled children need transport to go to school, especially if they do not have a wheelchair. Research participants relate how their relatives used to take them on their back or by other means of transport:

[I]... attended primary school¹²⁵ and got [my] certificate and then stopped... [because] there was the problem of transport. When [I] was little [my elder brother] put [me] on [his] back and took me to school. But... there is no secondary school here in Tibga, so [I] would have had to go to Fada, and... who would have taken [me] there every day?

(Interview with Innocent, Tibga, 21st October 2014)

LB: Did you go to school using a wheelchair, or crutches, or...?

G: At that time there was no wheelchair, there were no crutches either. It was my father who brought me [to school].

(Interview with Gaston, Ouagadougou, 1st December 2014)

Others found it difficult to attend school with their non-disabled classmates:

It wasn’t easy to accept that I was now disabled.... It used to hurt me, when I saw my friends running... sometimes I cried. Even to go back to school... I was so ashamed to walk in front of my friends, it was shameful for me.

(Interview with Hélène, Kompienga, 26th September 2014)

¹²⁴ *Fédération Burkinabè des Associations pour la Promotion des Personnes Handicapées*: Burkinabe Federation of Organisations for the Promotion of Disabled People.

¹²⁵ The school system in Burkina Faso is based on the French one, and thus employs different terms for different phases of schooling than the UK system. However, in this thesis they have been translated to the equivalent of the UK system to facilitate comprehension.

My parents... put me in school. Until the second year of secondary school, I was embarrassed to go into class: the shame of crawling into the classroom in front of my classmates. I told my parents I didn't want to continue going to school.

(Regina, Participatory Video, October 2014)

I: Like all disabled people, I encountered difficulties... notably the looks of others: it's the first difficulty you encounter, the looks of others, when you arrive at school... the mistrust, the discrimination. But you are obliged to... be strong to be able to go beyond all this. Me, for example, because of the looks of others, when I arrived at school the first time, I remember very well... before the lessons started, I left, because I couldn't stand it. It was after everyone went into class that I came back all alone... and went into class.... almost late.... They gave me a place... and I went to sit there next to someone. Then in the evening¹²⁶ when we came back... when I went to sit down, I see no one next to me...

LB: Why?

I: Because they are afraid. When they went home they must have said 'I am next to this person, this child is odd'; the parents most likely told them 'I don't want you to sit next to him anymore', in spite of the fact that in the morning we were together!

(Interview with Ismael, Ouagadougou, 2nd February 2015)

Lack of schooling is not a factor affecting only disabled people in Burkina Faso. Many disabled adults today are illiterate because the importance of schooling was not recognised when they were young, or there simply were no schools. Writing about his mother, born before the independence, Sanou (2008: 104, my translation), narrates:

In that period... the... recruitment of... schoolchildren was a strange concept.... If some parents consented to see their progeny travel for kilometres to join the institution, those who resisted did not hesitate to hide theirs in the fields and the granaries. This might seem curious, but when one knows that children constituted (and still constitute) 'manpower' in the fields, one easily understands this.

Even in the present day, there are people who do not acknowledge the importance of schooling. As Minoungou (Interview, Ouagadougou, 22nd

¹²⁶ School hours in Burkina Faso are usually in the morning (until around mid-day) and then again in the evening, usually from 3pm until around 5pm. Thus many children go home for lunch.

January 2015), a physically disabled man in Ouagadougou, points out, the Peul, who are cattle herders, bring up their children in the same trade and thus would not consider schooling of primary importance. This is also related to the fact that the education system in Burkina Faso is based on that of the colonisers and is thus not necessarily pertinent to the Burkinabe context. Ki-Zerbo¹²⁷ (2003: 174, my translation) postulates that while education is the heart of development, education as it exists in Africa is what he calls “education anti-development”: it mimics that of industrialised countries and is in contradiction to the elementary, nutritional and vital needs of African societies. The education that African children are receiving today is not adapted to African countries, neither culturally nor socially. There is a need to move away from simply copying the ‘white man’s school’ model. School in Burkina Faso is designed on a system copied from the French model of the 1960s. Its methods and programmes have nothing to do with life in the village. Primary school is thus disconnected from the reality of the country, and the educated child, in all probability, cannot be integrated in his or her environment anymore. A large proportion of educated people thus join the growing army of unemployed city dwellers, rather than continuing the agricultural work of their parents (LAFB, 2007). As Zenabou (Interview, 20th January 2015), a physically disabled woman in Ouagadougou asks, “why send children to school if they cannot then find a job?”

The education system in Burkina Faso continues to train the staff, primarily civil servants, which the colonisers, and subsequently the newly independent country, needed. Administrative and management staff form a caste and protect themselves while putting aside the non-qualified. It is not surprising, therefore, that they reproduce the schema through which they succeeded. Consequently, education has little chance of being radically reformed through adaption to the real needs of people (LAFB,

¹²⁷ Joseph Ki-Zerbo was a Burkinabe historian, politician, writer and activist. He was an advocate of an independent development and unity of the Africa continent (Martin, 2012; Badini, 2000).

2007), including those with disabilities. As Michel (Interview, Fada N’Gourma, 22nd September 2014), a physically disabled man, states:

A lot of people told my father not to enrol me in school, because, at this time, the civil service could not use me because I couldn’t stand up.

This brings forth two major issues, the first being that, as mentioned above, lack of schooling for many disabled people, especially for those who are adults today, meant that the civil service was not accessible to them. The second issue emerging from Michel’s story is that going to school often was, and is, associated with entering the civil service. If one has no intention, ‘capability’ or chance of entering the civil service, education is deemed pointless. Moreover, since even physically disabled people, at that time, faced barriers in entering the civil service (discussed subsequently), people like Michel had even less chance of attending school.

Employment: The Informal and Formal Sectors

Unemployment is a real calamity affecting Burkinabe society, notably among the young, but also having significant consequences for people with disabilities. Besides young graduates without jobs, there are also thousands of children (twelve to seventeen years of age on average) who leave their villages to go to the city, in search of jobs and fortunes. In the big urban centres these young people can be seen selling water, fritters or sandwiches, or looking for employment as housemaids or waiting in bars (LAFB, 2008). These housemaids, for example, often work for seventeen hours a day for a very low salary. They are not declared at the National Fund of Social Security¹²⁸ and have no right to a holiday. However, they prefer working in the city than staying in the village, where they would not be able to earn as much. These economic and financial reasons are at the base of not only the rural exodus, but also the emigration of many Burkinabes, especially to Ivory Coast (LAFB, 2007).

¹²⁸ *Caisse Nationale de Sécurité Sociale.*

Radelet (2010: 9) states that African countries like Burkina Faso have “achieved steady economic growth” since the mid-1990s. However, the African Development Bank Group (AfDB, 2013: n.p.) argues that “this has not necessarily generated decent jobs” and that:

Little attention has been paid to the role of informal sector... [which] contributes about 55 percent of Sub-Saharan Africa’s GDP and 80 percent of the labour force. Nine in 10 rural and urban workers have informal jobs in Africa and most employees are women and youth. The prominence of the informal sector in most African economies stems from the opportunities it offers to the most vulnerable populations.

The large informal sector in Burkina Faso is characterised by a great diversity of activities as well as a great ability to adapt to the evolution of the national economic situation. It contributes almost twenty-five percent of the GDP and eighty percent of non-agricultural employment. It includes informal manufacturing in textile industries, wood and metal works as well as the extractive industries (gold panning and washing). Artisan work is also a significant element in the informal sector and occupies an important place in the country’s economy (Sanou, in LAFB, 2007). Micro-enterprises provide one economic system that is within reach of the Burkinabe population. These are either individual or familial informal enterprises that have acquired accepted status by the government as an alternative to unemployment. They now comprise the greatest number of workers (LAFB, 2007). In rural areas, people:

are engaged in the same occupations as members of their extended family and local community. These include farming, fishing, livestock rearing, managing stores, food processing, vending, handicrafts or... [a] village trade.

(Campos, 1995: 82)

However, the African Development Bank Group (AfDB, 2013: n.p.) states that:

Even though the informal sector is an opportunity for generating reasonable incomes for many people, most informal workers are without secure income, employment... benefits and social protection. This explains why informality often overlaps with poverty.

In Burkina Faso, ninety percent or more of workers are without permanent contract (International Labour Organization (ILO), 2015). However, in countries like Burkina Faso – where the adult literacy rate is 28.7 percent (UNICEF, 2013) – the formal sector might also simply not be an option for a large number of people. The AfDB (2013: n.p.) also admits that:

limited access to capital is an important constraint for operators working in the informal sector. Lack of skills, education and training are also impediments to the formal sector in Africa. Other factors include the limited access to technology and poor infrastructure. Furthermore, the informal sector doesn't seem to be on the development agenda of African countries or their multilateral development partners.

Besides being the source of insecurity for many, the thriving informal economy and the political and financial fragility of African states make it difficult to achieve real progress (Fall-Diop, 2006) with regard to a social welfare system. Social Security is a social and economic necessity in promoting development (ILO, 2012). However, lack of social security protection is mostly found in informal economies (which are also a larger source of employment for women (and disabled people) than men) in developing countries. Although the right to social security is enshrined in Article 9 of the International Covenant on Economic, Social and Cultural Rights¹²⁹ – a convention to which Burkina Faso is party – only five to ten percent of the working population in sub-Saharan Africa has some social security coverage (ILO, 2003).

Burkina Faso is no different: Boyer et al (2000) observe that the situation concerning social security differs greatly between groups of people. While civil servants enjoy a reduced tariff, the national social security fund does not cover illness risk of salaried people working in the private sector. The latter are covered by internal solidarity funds or micro-insurances¹³⁰. The informal sector in Burkina Faso engages in such

¹²⁹ The Convention can be found at:

<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>

¹³⁰ There are called *mutuelles* in Burkina Faso.

informal risk management schemes as tontines and cooperatives. Nevertheless, Boyer et al (2000: 81) note that these “traditional” systems of social protection offered at community level are harshly put to test by economy modernisation (including urbanisation, geographical mobility, the rise of individualism), population growth and the persistence of economic and political crises which lead to a lowering of standard of living and insecurity. It is possible to pay a monthly sum to the National Fund of Social Security, which enables people to have a pension upon retirement. However, most of the research participants are either unaware of its process or its use, or cannot afford to save up for a pension.

Significantly, one of the most vulnerable groups outside the formal labour force is people with disabilities (ILO, 2003). Most disabled people have no choice of where to work: they are obliged to work in the informal sector. Globally, disabled people participate far less than non-disabled people in the economies of their societies (Neufeldt, 1995):

Even without accurate figures on the size of the problem [of unemployment] in developing countries, it is obvious that people with disabilities are more exposed to unemployment than the rest of the population.... Even where people with disabilities have access to good vocational rehabilitation services geared to finding the right sort of job, they can still expect to meet physical, cultural and social barriers which place them at a disadvantage.

(Campos, 1995: 71)

Within the informal sector, people are also often trained in skills informally. Ibrahim (Interview, Kantchari, 10th October 2014), a thirty-two-year old deaf man who works on trucks crossing the border with Niger, learnt to do repairs and other general work by observing others. The members of a disabled artisans’ DPO in Ouagadougou (Interview, 1st December 2014) say that they learnt their trade of manufacturing artisanal products such as bags and deckchairs¹³¹, or shoe repairing, by learning the trade informally from other artisans. They have never had formal skills training. In contrast, the coordinator of a disabled artisans’ cooperative, Zenabou (Interview, Ouagadougou, 20th January 2015)

¹³¹ Called *lipikos* in Burkina Faso.

observes that, whereas in previous times the artisanal products were not of good quality because the artisans had not been trained, most of the artisan members of this cooperative today have received training. However, this training was received through partner INGOs. Furthermore, the artisans of the cooperative are linked to the National Federation of Artisans of Burkina Faso¹³², further strengthening their work in contrast to other artisans located in smaller cooperatives.

Barriers to accessing the formal sector for disabled people exist for several reasons, including lack of schooling, lack of accessibility, and lack of opportunities. The newspaper *Sidwaya*¹³³ reports on the case of Souleymane Ouédraogo, a blind man who obtained a Master's degree in business law. However, when he came to undertake the (competitive) exam to enter the civil service, he was told that there are no legal dispositions in place to enable him to undertake this exam (Nabaloum, 2013).

The head of the department which organises the competitive exams at the state recruitment branch (Interview, 18th June 2015) of the Ministry of Civil Service, Work and Social Security¹³⁴ in Ouagadougou, comments on how the law promoting disabled people's rights¹³⁵ sets a quota for disabled civil service employees. However, as he observes, it is very difficult to enforce this law since there are not enough disabled people who have the required level of education to make up the quota. As Souleymane Ouédraogo's story demonstrates, even competing in the civil service exam is difficult for disabled people, all the more so for blind people. As an attempt to rectify this situation, the MFPTSS opened a competitive exam to recruit hundred people with disabilities on behalf of the Ministry of National Education and Literacy¹³⁶ in September 2014. The decree¹³⁷ announcing this measure followed the 2011 political unrest concerning

¹³² *Fédération Nationale des Artisans du Burkina Faso*.

¹³³ A daily Burkinabe French-language newspaper.

¹³⁴ *Ministère de la Fonction Publique, du Travail et de la Sécurité Sociale* (MFPTSS).

¹³⁵ *Loi N° 012-2010/AN Portant Protection et Promotion des Droits des Personnes Handicapées*: Law protecting and promoting the rights of people with disabilities.

¹³⁶ *Ministère de l'Éducation Nationale et de l'Alphabétisation*.

¹³⁷ *Arrête N° 2014-0873/MFPTSS/SG/SGRE/DOC*.

rising bread prices (which affected vulnerable people more intensely) and the government measures introduced in 2013 to combat poverty. These were targeted at those groups most marginalised, stigmatised and exposed to social exclusion and included specific actions aimed at people with disabilities (LeFaso.net, 2014). The hundred-people recruitment was open for people with visual, auditive and physical disabilities. However, the applicants require the same educational level as non-disabled people, which is problematic given that many disabled people do not have the same access to schooling. The head of the department which organises the competitive exams at the state recruitment branch (Interview, 18th June 2015), in fact, confirms that only ninety disabled people, out of the hundred required, made it¹³⁸. In 2014, blind people were also permitted to sit for the exam, with the support of the umbrella DPO for blind people's organisations¹³⁹, for all posts except the police force or the army. At the time of the interview, the head was unsure whether this initiative will be repeated annually or whether it was just a one-off event.

Disabled people do not only encounter barriers in finding work in the formal sector due to lack of education. One of the goals Ismael (Interview, 2nd February 2015), a disabled university student in Ouagadougou, tried to work towards when he was president of the students' DPO¹⁴⁰, was that of supporting disabled students in finding work:

- I: There are [disabled students] who are at university because they don't have work, not because they want to... they would like to work, they would like to be autonomous: at a certain point, you must stand on your own two feet...
- LB: And why do not people manage to find work...?
- I: Well, here there isn't enough work: first of all, there isn't enough work for everybody, and this isn't because you're a disabled person; but if you are a disabled person too, this is

¹³⁸ Up until June 2015, the recruited disabled people had not yet been allocated to their posts.

¹³⁹ UN-ABPAM (*Union Nationale des Associations Burkinabé pour la Promotion des Aveugles et Malvoyants*): National Union of Burkinabe Organisations for the Promotion of the Blind and Visually Impaired People.

¹⁴⁰ *Association des Elèves et des Etudiants Handicapés de Burkina*: Organisation of Disabled Students of Burkina Faso.

worse still because a lot of people, a lot of NGOs, a lot of businesses, think that the normal man is he who has hands, legs and eyes. They don't care that someone has a degree despite not having eyes or not having hands.... And yet, when we study... we study with the others... but, often you see that your friends work but you cannot: it's sad for us, it's what hurts us.

There is thus the need felt, by disabled people, to have a lucrative activity, to find employment. It is an aspect which is thoroughly explored and emphasised in the participatory video, where Michel (October 2014) states that “employment is one of the most important aspects in which the disabled person must prove to society that s/he is capable”. However, in an agrarian society such as the one most Burkinabe people live in, it is even more difficult for disabled people to find work:

More than 90% of the population of the Est region is made up of farmers. In view of this situation, people with disabilities encounter a lot of difficulties to integrate into society, given that the principal activity is farming. Thus... a lot of disabled people cannot work in the fields to get by.

(Michel, Participatory Video, October 2014)

Supporting disabled people in learning a trade is considered an important route out of poverty and a means through which to combat the employment problem. As the national director of an INGO (Interview, Ouagadougou, 19th May 2015), notes, they support some disabled children who are not cut out for school, in learning a trade:

because it was thought that, at least, if he learns something, he can be autonomous in life; because, already having a diploma does not ensure that you get a job... People with disabilities must learn a trade... because... to enter the civil service, even if you have your diplomas, it's not certain. Non-disabled people have difficulties, and these difficulties are doubled for the person, the child, with disability who has the same diplomas. Thus, I say that the employment problem is crucial for people with disabilities.

CONCLUSION

This chapter has explored and examined the context in which the research participants live. Although the research findings in this thesis are not all specific to Burkina Faso, they need to be understood in terms of the cultural, religious and political elements playing an indisputable role in disabled people's lives. The major elements influencing disabled (and non-disabled) people's lives, that is, the family, health, education and employment, affect a disabled person's experiences, decisions and life courses. Thus, while many Burkinabes face obstacles in, for example, accessing health services or finding employment, disabled people face further obstacles in a context which is disabling in many aspects. These aspects are interlinked with the perceptions of disability in Burkina Faso, both in how society perceives disability and in how disabled people view themselves. These perceptions, which play a significant role in disabled people's lives, are the focus of the next chapter, which explores the self- and social identifications of disabled people and how these affect the lived experiences of people with disabilities in Burkina Faso.

'SOMETHING THAT IS MISSING'?¹⁴¹ *Identities and Perceptions of Disability*

INTRODUCTION

In order to attempt to comprehend the lived experiences of disabled people in Burkina Faso, and the significance of creating a space in which they can speak and are listened to, it is essential to understand how people with disabilities view themselves. This means understanding how disabled people self-identify, their perceptions of disability, and how these are interlinked. The concept of disability identity has been gaining an increasing amount of attention in recent literature (Darling, 2013). However, although it has been explored with regard to disability in western contexts, Murphy et al (1988: 241) maintain that “past [disability] studies... have omitted the perspectives of the subjects themselves”. Furthermore, disability identities have rarely been looked at from the perspectives of people with disabilities in the Global South. These omissions are particularly significant when considering the perceptions of disability in countries like Burkina Faso, where, as discussed in the previous chapter, disability can be seen as a curse or punishment. More importantly, when disabled people are excluded (for example in decision-making) at a familial, community and national level, the disabled person’s social validation is affected. This symbolic exclusion is often not taken into account by development projects (HI, 2005), and yet, it affects disabled people’s image(s) of themselves and how they self-identify. Ignoring the perception of disability in countries like Burkina Faso also means that development projects are implemented in the framework of western models of disability, such as the social model, which assumes cultural shifts (McEwan and Butler, 2007) which are not necessarily present in the

¹⁴¹ Interview with Hélène, a physically disabled woman, Kompienga, 26th September 2014.

Global South. It also ignores the various cultural, religious and historical factors at play in disabled people's perceptions and identification processes in countries like Burkina Faso.

In response to these omissions, this chapter begins by introducing the concept of categorising and identifying disability, which affects the identifications and perceptions of people with disabilities. The second section then explores how disabled people in Burkina Faso self-identify, that is, what disability means for them and how this affects their lived experiences. The way disabled people in Burkina Faso self-identify and view disability is considered in light of (mostly western) literature on disability identities. A critique of the usefulness and limitations of the current literature and western concepts in understanding disability identities and perceptions in Burkina Faso highlights the need of connecting with perspectives of disabled people in Global South contexts. The chapter then looks at the significance of social views of disability and how these influence disabled people's self-perceptions. Throughout the chapter, the medical and social models are explored with regard to disabled people's identities in Burkina Faso. The research findings suggest that while partly explaining perceptions of disability in Burkina Faso, these models do not sit well in all circumstances in Global South contexts. The views of research participants suggest that whether disabled people in Burkina Faso identify negatively, positively or otherwise, the identification processes do not necessarily reflect those in western contexts. While in western contexts negative disability identities are often associated with the medical model and positive ones with the social model, the identities and perceptions of the research participants is not as straightforward. Finally, the chapter examines the emerging affirmation of disability in Burkina Faso amongst some of the research participants, as well as what these more positive identities signify in the Burkinabe context.

IDENTIFYING AND CATEGORISING DISABILITY

If we are asked to relate to the question of identity, it must be an identity to our unique selves... but we must not think of this identity as a... universal rule.

(Foucault in Rabinow, 1994: 166)

In this statement, Foucault lays down the foundation for the subject of identities: that identity is unique to the self. Shakespeare (1996: 109) suggests that, without “deny[ing] that disability is a very powerful identity..., it may be necessary to move away from the unitary, essentialist disability identity and think of a variety of disability identities”. He warns of the danger of ignoring disabled people’s “multiple identities and identity choices which people make in practice” (ibid: 108). Furthermore, “[i]dentity is a complex field” and different disciplines use the word differently. Disability studies, however, give priority to the lived experience of people with disabilities (ibid: 94).

Shakespeare (1996: 94) suggests that identity has two uses in the context of disability:

First, we can talk about identifying as an active verb, as much as to say uncovering disabled people or discovering disabled people. Second, we can use identity in a reflexive sense, in terms of identifying oneself, which is about staking a claim to membership of a collective or a wider group.

The first part of Shakespeare’s quotation refers to identifying people with disabilities. Blaxter (1976: 13) points out that the category ‘disabled’ “includes only those who have been so identified”. Similarly, Devlieger (2010: 74) observes that:

People in all cultures of the world classify other people most readily in easily identifiable categories.... These categories make the world intelligible because they assign roles and functions attached to the individuals that fill the category.

This argument is of deep significance for disability discourse in general, but also for this thesis. If disabled people were not identified as such, disability discourse and studies would be difficult:

If we don't use the term disabled... what do we use to describe someone who has an impairment to set them apart from the majority?

(Atkinson, 2015: n.p.)

However, Devlieger (2010: 74) goes on to make another essential point:

[T]he very fact of classification may question whether individuals with disabilities belong to the most essential of all categories, the human category. With classification, a statement of exclusion or inclusion in the human category is imminent.

Categories inherently diminish the human aspect of the people included in that category, whether they are classified as being part of an ethnic group, a religious affiliation, or any other classification: the person becomes primarily part of that group, and only secondly part of humanity. Furthermore, according to Blaxter (1976: 13), in categorising people with disabilities two negative stereotypes are perpetrated, “one which describes the particular impairment (blind, spastic, crippled) and one which is attached to the general category of ‘disabled’”. The former, according to Shakespeare (1996: 95), is often the approach taken when disability is seen as the consequence of impairment, an approach to identifying disabled people which focuses on physical difference:

Disabled people are defined as that group of people whose bodies do not work; or look differently or act differently; or who cannot do productive work.

Most disabled people interviewed as part of this research tend see themselves (what Shakespeare (1996: 94) calls, in the second part of the quotation, “identity in the reflexive sense”) in this way. For example, Yenupundi (Interview, Matiakoali, 11th October 2014), a physically disabled man, says:

[I] identif[y] [my]self as disabled because there are activities which [I] don't manage to do: I want to do them; and it's not because [I am] old or something: because of [my] disability [I] cannot do them.... For example, [we] are farmers: thus, to make a field, you need to cut down trees. Hence, there are moments when, to cut certain trees is difficult. Thus [I] don't manage to work in the manner [I] should be able to. Also, to cultivate, [I] plough on because [I] cannot sit around and wait for someone to help [me]; but [I] don't manage to work well.

The main components of this way of identifying, according to Shakespeare (1996: 95):

[a]re performing and conforming: both raise the question of normality, because this approach assumes a certain standard from which disabled people deviate.

This view of disability has been perpetuated over the years, and much of disability literature has, “until fairly recently... viewed disability as a form of deviance from the ability and appearance norms of Western society” (Darling, 2013: 1). However, while Darling (ibid) goes on to state that “[d]uring the past several decades, newer views have conceptualized disability as a normal form of human variation”, not everyone agrees with this statement. For example, Egan (2012: n.p.), a disabled blogger from England, argues that the medical model is still the dominant perspective through which disabled people are viewed:

It’s the idea that a person is prevented from functioning in our society by their body or brain and it’s just that person’s tough luck.

As discussed below, many disabled people in Burkina Faso see disability as residing with the individual: a deficiency in the person who has to deal with it and find a way to survive.

DISABLED PEOPLE SELF-IDENTIFYING

[N]umerous kinds of human beings... come into being hand in hand
with our invention of the categories labeling them.
(Hacking, 1986: 236)

Hacking’s description of dynamic nominalism indicates that the self-identification of disabled people is linked to the categories used to label them. Shakespeare (1996: 98) postulates that the medical view of disability “consider[s] negative self identity to be an outcome of physical impairment”; while “[s]ocial approaches view negative self-identity as a result of the experience of oppressive social relations”. There are disabled people in Burkina Faso, like Hippolyte (Interview, Fada N’Gourma, 24th October 2014), a physically disabled young man with a mild intellectual

The research participants cited above have a concept of a ‘normal’ person as being someone who can do what s/he wants to do, and whose body does not lack anything. This view of disability is also reflected in the language used to refer to some disabilities which incorporate the term ‘deficiency’ in French. This view of disability is not only specific to Burkina Faso, but is shared in the wider African context. For example, Devlieger (2010: 86-7) describes how, in the Swahili language, the majority of words referring to disabled people, or “people with bodily differences” indicate that “a person with a disability in this class is someone who is not whole, someone who is lacking something”.

This view of disability is prevalent among the majority of the research participants: their view of disability is an individualistic, rather than a social one. When posed the question as to whether disability is social or individual, Hélène (Interview, Kompienga, 26th September 2014) maintains:

According to me, it [disability] is something that is missing in you, not in society, because currently everyone fights for himself... so it’s something that is missing in you.

This approach, which is a form of biological determinism, focuses on groups of people with specific impairments (for example, people with physical disabilities, or people with visual disabilities), rather than on “the common social experiences which unite disabled people” (Shakespeare, 1996: 95). Evidently, different impairments result in different experiences (as will be discussed in the next chapter); however, when disability is experienced as an individualised experience, “the structural and cultural context is not challenged, and alternatives to the dominant biomedical paradigm are not available” (ibid: 99). Nonetheless, Shakespeare (1996: 99-100) continues to say that “[t]he person with impairment may have an investment in their own incapacity, because it can become the rationale for their own failure”:

The legitimation accorded them by non-disabled people is predicated on accepting responsibility for their own incapacity, and

not challenging the dominant order. Indeed, they may become token examples of the tragedy of disability, involved in consultations or wheeled out to highlight the problems.

At this juncture, Shakespeare's observations, written from a western perspective, are perhaps inadequate when trying to explain disabled people's lived experiences in Burkina Faso. While his arguments are useful in explaining a significant part of the research participants' self-identities, disabled people in Burkina Faso do not seem to be justifying or legitimising their failure by their own incapacity. Rather than becoming examples of tragedy, many are seeking to find work that is suitable to their abilities. For example, Bamboaro's sister-in-law recounts how Bamboaro, a hard-of-hearing young woman, found the work she wanted to do:

[I told Bamboaro] that where she comes from, girls of her age transport buckwheat pancakes... to sell. She [told me] that she is embarrassed, since she does not hear, she is embarrassed to go round and sell. So [I] asked her if she wants to learn to plait [hair]. She said yes. So [I] took her: she trained for 3 years and learnt to plait.

(Interview, Fada N'Gourma, 7th October 2014)

Mariam (Interview, Fada N'Gourma, 15th October 2014), who is currently attending sewing classes, recounts:

Before, when [I] had nothing to do, it wearied [me] out a lot, because [I] had no activity that [I] knew how to do. But now, since [I am] at sewing school, once [I] finish, [I], too will have a certificate, so if [I] manage to open a workshop and... [get] a sewing machine to work with, [I] will be very happy... [I] know that during the first year it cannot yield. But at least, during the second, third year, going on to five years, maybe [I] too will have students who [I] will teach. And, at this point, this will suit [me]. Thus, [I] will be very happy for this.

People like Bamboaro and Mariam are finding their niche in the country's economy. In a social welfare system, disabled people can rely on welfare and thus can 'afford' to 'become token examples of the tragedy' or be 'wheeled out to highlight the problems', as Shakespeare says above. However, in Burkina Faso, disabled people do not have the option of welfare: working (or begging, or depending on their family) is the only

means to survive, which in turn creates differences in how they relate to their disabilities. Bamboaro and Mariam might not be challenging the dominant order in the way it is understood in the western sense of campaigning for rights, yet they are going against the dominant view of people with disabilities as passive and helpless:

There are a lot of [disabled] people who do not know [how to] work... there are a lot of blind people... people who have newly become disabled... [who say] one cannot have the means to do the work; they are at home and don't know what to do to fight... if you stay at home, you cannot develop. But if you go out...

(Interview with Emile (blind man), Ouagadougou,
26th November 2014)

These examples also typify what being disabled means in Burkina Faso. For many research participants, being disabled means being dependent:

As a visually disabled person, disability, for [me] is dependency, meaning [I] cannot be independent. [I] have to depend on somebody: to eat, someone must give you; to drink, someone must give you; to move around, someone must help you... that is disability: [I] am dependent on another person, [I am] not independent.

(Interview with Fatimata, Diapangou, 24th September 2014)

While for Fatimata, a blind and elderly woman, dependency pervades many different aspects of her life, for many others dependency means above all economic dependence:

For [me], disability is not only the person who is visually or physically disabled, who is a disabled person: the person who has something missing is disabled... all those people who have something missing are disabled.... For example... [I] take the case of marriage: if you have a physical, visual or other type of disability, if you have the means, if you have the money, there's no reason why you cannot [marry]. So they don't see your disability anymore... but if you don't have money... even if you are in good health... you are disabled, because... no girl would accept to be with you... but if you are physically... visually or auditive disabled, if you have the means, there's no problem: you can marry without any problems: at this point they won't see your disability anymore.

(Interview with Souleymane (blind man),
Gayeri, 14th October 2014)

Thus economic (in)dependence is intricately linked with the self-identification of many disabled people in Burkina Faso. It is also linked to

the perception of disability held by non-disabled people, who tend to think that disabled people are economically dependent and thus a burden. These perceptions also influence disabled people's self-identities and generally run along two parallel paths. In one path, disabled people are generally viewed as dependent and dependent people are viewed as 'disabled'. In the other path, independent people are generally not considered (and do not consider themselves) as disabled. Thus, many disabled people frame their desires of improving their lives as being economically independent.

Being economically independent is not the sole reason for not identifying as disabled. For example, Emmanuel (Interview, 18th October 2014), a physically disabled man, does not identify as disabled because he lives in a town (Fada N'Gourma) and is free from notions of disability as a shame that persist in villages and where people hide disabled relatives. He states:

I don't see myself as disabled anymore, seeing as there is the possibility of being among so-called normal people.... Today [I] don't consider myself disabled anymore.

In town he can, for example, participate in meetings and express himself like other people. Thus, the possibility of participating in social life has led him not to feel or identify as disabled anymore. Others, like Ela and Aicha, two physically disabled women, reject the disability label as something that would have adverse effects on them if they take it too much into consideration in their daily lives:

E: If [you are] a disabled person, if you think a lot about your deficiency, you become more disabled. But if you make do, [if] you forget your disability, then you are ahead, it's finished: the others will understand that you don't have your deficiency on your mind, and it's ok.

LB: And...what does disability mean for you?

E: Disability... *[chuckling]* disability is maybe because I walk with crutches ey, other than that I don't see it; I've gone past it.

(Interview, Ouagadougou, 20th November 2014)

LB: Does this mean that you don't identify your[self] as [a] disabled person?

A: No. If you put this in your head, you will grow old quickly... It's better to remove the disability [from your head]... For me, disability, even my disability, it's over!

(Interview, Ouagadougou, 22nd January 2015)

However, research participants like Emmanuel, Aicha and Ela all live in urban areas and have resources at their disposition: Emmanuel is a trained mechanic and has two wives, meaning he is financially secure; Ela is a hairdresser with her own successful salon; Aicha attends skills training and is also studying. It is thus easier for these participants to reject the disability label, especially in a context where disability means dependence. Despite this, Aicha frequents the Centre of (Physically) Disabled People in Ouagadougou. Thus, although she says that she does not identify as disabled, there is a sense of belonging to a group of people with physical disabilities, suggesting a sense of belonging to the larger 'group' or 'category' of physically disabled people. In this sense, Aicha's statement that she does not see herself as disabled might be seen as contradictory in terms of her actions. However, her statement might be better understood as a wish to live like others, to marry and have a family like non-disabled women. Rather than rejecting or denying her disability, Aicha (Interview, 22nd January 2015) is expressing the desire to be viewed by society on a par with women without disabilities:

Disability... I don't see it as a problem. It doesn't bother me. It's only that in these parts, the Burkinabes from around here, there are some who sometimes hurt us... For example, you might have a man who wants you, with your disability. He doesn't consider your disability and all that: he loves you.... Well, the problem is, then, his family, and his friends. There are friends... who do not give good advice. They will say: '... You are taking on a problem.' Are these words that should be said? That disability is a problem?... It upsets me. I'm a woman like the others. A woman can have children; I can have children! What can a woman do that I cannot do? Where is the problem? It's this husband matter that gets to me sometimes. Otherwise, my disability doesn't scare me!

Some research participants go beyond this, and claim that 'disability is in

the mind'. Zenabou (Interview, Ouagadougou, 20th January 2015), a physically disabled woman, observes:

In comparison to the past, non-disabled people thought disabled people cannot do anything except beg, but now they realise that disability is in the mind.

This is a view also held by some non-disabled people, as exemplified by the high commissioner (Interview, 27th April 2015) of a province in the Cascades region: "Disability is in the mind, not in the body". Shakespeare (1996: 100) states that the experience of disability as a negative identity might lead to "various forms of denial... where a person claims to be 'really normal' and tries to minimise the importance of impairment in their lives". He also considers "seek[ing] to 'overcome' impairment" another form of denial (ibid). And yet, rather than a form of outright denial, seeking to 'overcome' impairment is a way of survival and of challenging stereotypes, for many disabled people in Burkina Faso. As will be discussed in the next chapter, overcoming disability on the road to success is one of the themes expressed strongly in the participatory video. It also emerges through interviews with participants such as Emmanuel and Benoit, two physically disabled men:

[I have understood] that disability is not... a catastrophe, but something that can happen to everyone, and that it can be overcome; and... today [I] don't consider [myself] disabled:... I have become an important person who takes care of myself.

(Interview with Emmanuel, Fada N'Gourma,
18th October 2014)

I became a member [of the DPO] because I saw that, given that I became disabled, I must fight to... overcome my disability.... If in town it's only me who is there, who has fought, we don't see his disability anymore, I'm like the others: it's necessary that all of society has the same vision... so that the other disabled people overcome their disability.

(Interview with Benoit, Kompienga, 27th September 2014)

Similarly, minimising the importance of impairment is a means of finding a way to function in a society that puts a value on economic independence. Without denying the importance of changing social structures, whether

physical or socio-psychological, the research findings suggest that these approaches are working for disabled people in Burkina Faso, and they are not necessarily negative. The “narratives of self” that are considered “neither psychologically nor socially healthy” (Shakespeare, 1996: 100) in western contexts might not be so in other contexts. This emerges also with another form of ‘denial’ that Shakespeare proposes: “a resignation to fate or the will of God” (ibid). As discussed in the previous chapter, in Burkina Faso there is a sense of acceptance of one’s fate as God’s will. For example, when asked if there is someone in his community whom he considers a model to emulate, Moumouni (Interview, Bogandé, 2nd October 2014), a man with visual impairment, replies:

Today it’s not good to say ‘I want to be like someone’, because... God made [me] like this... [I] should resemble [myself], and find [my] own way.

Similarly, Wali (Interview, Fada N’Gourma, 25th September 2014), a physically disabled woman, explains people’s behaviour towards her as:

Those who know God, who accept God’s will, accept [me], and those who don’t know it, don’t accept [me].

However, rather than the denial Shakespeare considers it to be, acceptance of one’s fate as God’s will is not always necessarily negative. Shakespeare (1996: 100) contends that all these ‘negative’ forms of identity:

involve an element of denial or failure to come to terms: they all involve a significant element of external definition, of accepting external disempowering agendas.

In contrast, rather than accepting external disempowering agendas, Moumouni (Interview, Bogandé, 2nd October 2014) says:

It’s true that [I] would like to be... better, in [my] life, with my children... but it’s not so simple: it’s not going to change overnight for me! One must work, and what God gives you that you are able to do, [I] think that this is what you have to accept, and fight to do the rest.

Furthermore, Moumouni works as a handyman, rather than engaging in “strategies which are ultimately self-defeating”; and, rather than being

“trapped in a prison not of their own devising” (Shakespeare, 1996: 100), he feels that it is society that traps him in a prison of misconceptions:

M: There are some people in town who think that... disabled people... cannot do... [certain things]. For [me], that is disability.

LB: ... this is what other people think: is this your opinion too?

M: ... this is not [my] opinion... [I]... find that what they say, that it's not true.

LB: So is it the disabled person's problem or is it a problem that people construct, that the society constructs?...

M: ... it is people who construct this: that [we] cannot do anything. But this is not what the disabled person thinks.... For example, at the Town Council, sometimes there are activities... [and] they are looking for people to work. But [we] are not considered: [we] are not called upon, [we] are not informed... thus they consider [us] as not being able to work. Yet, [we], too, can work.

(Interview with Moumouni, Bogandé, 2nd October 2014)

Moumouni's observation (together with Aicha's comments further above on people seeing her as a problem for a non-disabled husband) evokes the social model, which Shakespeare (1996: 96) describes as being the prime example of the approach in which disability is “conceived as an outcome of social processes or as a constructed or created category”. Disability in Burkina Faso, however is often seen in ways that mix medical and social models, interwoven with traditional and religious beliefs.

THE SOCIAL MODEL IN BURKINA FASO AND THE SOCIALISATION PROCESS

Shakespeare (1996: 100) explains the social model as:

[the] alternative to the negative identification with impairment is provided by those who resist the negative implications of the medical model and develop a response which focuses on the exclusion and injustice which characterises disability. This shift often takes the form of replacing one analytical framework (the ‘medical model’) with another (the ‘social model’) to lead to a more positive identity.

In Burkina Faso, however, this ‘road to a positive identity’ is not so straightforward. In his document ‘Beyond Prejudices’, Henri (n.d.: 75, my translation), a disability activist in Ouagadougou, evokes the medical

model when writing that one of the duties of traditional and religious chiefs is to:

Educate the population on the fact that every single person is vulnerable to an incapacitating illness or any accident likely to lead to an alteration of one or more of a person's faculties which are indispensable to accomplish the common activities of life with total autonomy.

In the same document, Henri calls for the discovery and implementation of disabled people's rights. Rather than being viewed as a binary between either a medical or social condition, the concept of disability in countries like Burkina Faso inhabits grey areas and indicates that perhaps the medical model and all it implies should not be completely discarded:

Rather than... rejecting the role of the biological outright, it may prove more fruitful... to theorize the 'interimplication' of the biological and the social.

(Roberts, 2000: 1)

As discussed in Chapter 2, western models might not be completely applicable to the concept of disability in Global South contexts. As Connell (2011: 1370) argues, a "heavy emphasis on determination by social systems... faces problems – especially when translated to the global South". In a context like Burkina Faso, where equipment and infrastructure are often not available, the reality of bodily impairment being disabling is more apparent. For example, Bamboaro (Interview, 7th October 2014), a hard-of hearing woman in Fada N'Gourma, finds difficulty in communicating with her clients in her hairdressing salon partly because she does not have access to hearing aids. An alternative conceptualisation is posited by Connell (2011: 1370-1), which she calls "social embodiment". This refers to:

the collective, reflexive process that embroils bodies in social dynamics, and social dynamics in bodies. When we speak of 'disability', we emphasise the first side of social embodiment, the way bodies are participants in social dynamics; when we speak of 'impairment', we emphasise the second side, the way social dynamics affect bodies.

However, many research participants do not make the distinction between impairment and disability. This is not to say that there are no disabled people in Burkina Faso who frame their disability in the social model. Some focus on the distress experienced when they are shunned by former friends. For example, Isaac (Interview, Banfora, 10th March 2015), who became completely blind at around fifty-three years of age and whose sole highlight of the day is going out for a drink with his friends in the evening, says that some of his friends pretend not to see him when he is out:

People like that, they want to bypass me: since they know I don't see, they do not let me know they are there.

Similarly, Karim (Interview, Fada N'Gourma, 23rd September 2014), a young blind man, relates:

My life has changed because I am not independent anymore... meaning, I cannot go where I used to go before anymore, I cannot have fun like I used to: I need people's help... there were friends with whom I used to go out: seeing as I am now disabled, there are some who will stay away from you.

Other research participants focus on physical barriers. Michel (Interview, Fada N'Gourma, 22nd September 2014), a physically disabled man, explains what disability means to him:

M: Disability is: if, for example, I come here and I cannot go in... I come to Hotel Panache¹⁴³ to see you and I cannot come in... do you see?

LB: Oh!

M: It's an obstacle... meaning there aren't any access ramps there, so this is an obstacle. Or I want to travel, and the driver says 'no, your motorbike has three wheels, I cannot take you'. This is an obstacle... do you see?... It's the way people look at you that makes you feel disabled, or physical obstacles... it's the milieu, the environment which can make us feel disabled, or the way people look at you.

However, in contrast, Michel also states:

In certain moments, I forget that I am a disabled person, sincerely, because I manage to do all that I want, that is, I travel, I go fishing, I work, I can go to meetings. But, often, it's the way people look at

¹⁴³ The hotel I was staying in at the time.

you, or the way of reacting of certain people... that reminds us that we are disabled. Or when I get to a place where I cannot access... or a driver who refuses to transport me, or something like that... there are these little things which come back from time to time to remind us that we are disabled.

(ibid)

This fluidity between feeling 'normal' and feeling disabled has been captured by Deegan (2010: 25) who argues that "[i]f a person experiences an everyday life that is meaningful and accepted, then disability becomes part of a 'normal life'". She argues that "feeling normal with a disability" is when:

[p]hysical disability is part of everyday life and incorporated within the self. When this situation... changes, however, the person may be 'feeling disabled', and the disability comes to the forefront of everyday life and consciousness. Understandings of the embodied self and relationships with others are altered, and 'feeling disabled' becomes a source of apprehension, discomfort, unhappiness, alienation, and powerlessness.

(ibid)

According to Deegan (2010: 26), then, "[f]eeling normal or disabled" "is a fluid condition, one that can change quickly and at any time". This is confirmed by some participants who suggest that they feel disabled at certain times or in certain situations. For example, Zenabou (Interview, Ouagadougou, 20th January, 2015), a physically disabled woman, recounts how she had just that morning gone to a meeting to which she had been invited by the Ministry of Social Action and National Solidarity, the Ministry charged with the welfare of disabled people. She was attending the meeting as a representative of the National Network of Disabled People's Organisations¹⁴⁴. Upon arriving at the building, she found that there was no lift to the meeting room and thus she was unable to participate in the meeting. At times like this, she says, she is reminded of her disability and of her lack of capacities. Thus, disabled people might feel that they are not disabled, but sometimes they are reminded of their disability and of the limits imposed on them by society in everyday life.

¹⁴⁴ *Réseau Nationale des Organisations des Personnes Handicapées (ReNOH).*

Furthermore, what comes out strongly in Michel's case is that one of these barriers can be "the way people look at you". This is such an important concept in Burkina Faso that Maxime (Informal Conversation, Banfora, 25th February 2015), a physically disabled man, says that "disability is in the eyes of others", meaning that disability is defined by the perceptions of others and in the way non-disabled people 'look at' disabled people. Henri (Interview, Ouagadougou, 19th February, 2015), a physically disabled man, reiterates this:

The looks of others... this manner of looking at the disabled person as an incapable person, incapable of doing something; so you are treated as a do-nothing, a person who doesn't have a lot of future... disability is a symbol of incapacity today, for a lot of... people who are not disabled.

Henri, who works at the National Assembly¹⁴⁵, continues:

At the Ministry, I say good morning... because people think I came to beg... but I came also like other citizens to carry out certain acts of my life, or make contact with the administration for certain private things: it's normal! To have access to these various structures is difficult... physically, and the looks of others when... you ask for someone... they are afraid to say, because they think you have come to beg for something: they don't want to create problems for this person... this strange idea that people have of disabled people... they look at you strangely, as if you don't have the right to live like the others... it's this way of living that makes us disabled people have... problems: if we could be integrated... considered as people in their own right.

(ibid)

Henri emphasises that the way people look at him and other disabled people, and the way the non-disabled society treats him and thinks of him affects his life.

Non-disabled people's immediate reaction is that disabled people are incapable of doing anything except beg. Consequently, this manner of looking at disabled people affects the way disabled people see themselves. A person's identity is constituted both by the content of their self-narrative as well as, to a certain extent, by other people's narratives. This means

¹⁴⁵ At the time of the interview, this was the National Transition Council (*Conseil National de la Transition*: <http://www.ent.bf>)

that “personal identity... requires social *recognition*. Identities are not simply a matter of how we experience our own lives, but also of how others see us” (Nelson, 2001: 81). Thus:

Personal identities are complicated narrative constructions consisting of a fluid and continual interaction of the many stories and fragments of stories that are created around the things that seem most important, from either the first- or the third-person perspective, about a person’s life over time. They are therefore structures of meaning, ways of understanding who we and others are.

(ibid.: 106)

Giddens (1991: 53) argues that “[t]o be a ‘person’ is not just to be a reflexive actor, but to have a concept of a person (as applied both to the self and others)”. Self-identity “is the self as *reflexively understood by the person in terms of her or his biography*” (italics in original). As Shakespeare (1996: 99) argues, negative identity of disability emerges from “a process of socialisation... in which impairment is the sole focus of analysis”:

In the absence of other socially sanctioned identities... [i]t could be conceived in terms of a tendency to ‘blame the victim’, to convert public issues in personal woes.

(ibid)

Linked to the way other people look at disabled people is the concept of stigma, exemplified in Henri’s commentary, surrounding disabled people as being beggars or incapable. The sociologist Erving Goffman’s book ‘Stigma: Notes on the Management of Spoiled Identity’ (1963) is “perhaps the most influential study of the interaction between societal views and the self-concepts of people with disabilities” (Darling, 2013: 2). Darling (ibid) explains that Goffman:

was writing at a time when prevailing views of disability were overwhelmingly negative. Consequently, he believed that individuals with disabilities needed to learn techniques to minimize their differences in order to be accepted in society. More recently, the concept of spoiled identity has been increasingly questioned and challenged.

Yet, evidence in Burkina Faso suggests that negative images of disabled people have not been completely eradicated:

In Burkina... if you had a disability... they thought that being disabled, one would think it's a crime. And people were afraid of us... they thought it was contagious too.

(Interview with Aicha (physically disabled woman),
Ouagadougou, 22nd January 2015)

In life... you must know how to manage the others, make them understand that it's something natural. And I remember when I used to go... to bars... they used to tell me 'no, we don't understand how you, as a disabled person, you come to drink beer'. [It's as if]... a disabled person doesn't have the right to... [have a beer]: it's as if it's a waste, as if I'm [already] depending financially on people and I dare to do things that everyone does!... So I think... I *should* do it: if my friends go out, I go out with them... I screw up like everyone else... just so that people know that I am like you, and like the others.

(Interview with Ismael (physically disabled man),
Ouagadougou, 2nd February 2015)

In Oubritenga... the situation of disabled children poses a problem... because... of socio-cultural factors: because the perception that people have of disabled children is as if they were phenomena, pariahs.

(Interview with INGO national director,
Ouagadougou, 19th May 2015)

In Burkina Faso, disability might be seen as a consequence of a disabled person's or their parents' wrongdoing:

There are... even religious people who prevent the disabled person from integrating... because for certain people, for example, if the person is disabled... it's in anticipation of his wrongdoings... meaning that it's because it was known that the person would commit wrongdoings that the person is disabled... it's a... wrong teaching of religion.

(Interview with Henri, Ouagadougou, 19th February 2015)

People do not want to reveal mental disability: children are hidden because... it's badly seen; people think that... the parents are to blame, and that's why God gave them children like that.

(Interview with INGO national director,
Ouagadougou, 8th May 2015)

Similarly, a conversation with Clementine (Interview, 13th February 2015), a physically disabled woman in Ouagadougou, also shows how people's perception of disabled people affects them. Clementine is recounting how difficult it is for disabled people who have a business to have clients:

LB: But why is it different for disabled people than non-disabled ones?

C: Eh! [*chuckles*] Here in Burkina, it's like that. People do not even know that disabled people can work like the non-disabled ones. For example, we at Tigoung Nonma¹⁴⁶, we do catering. There are people who do not know that there are disabled people who *can* do catering well, well-cooked. They say that 'they are dirty' and that 'they don't know how to do anything; look at them, they are dirty, their food is dirty'... they won't buy.

These messages being 'sent' to disabled people by the non-disabled society affect the way disabled people see themselves. In acknowledging the "major obstacles to developing a positive and strong disabled identity", Shakespeare (1996: 103) argues that one obstacle is that disabled people are socialised to think of themselves as inferior. He refers to Morris (1991: 22), who contends:

One of the biggest problems for disabled people is that all these undermining messages, which we receive every day of our lives from the non-disabled world which surrounds us, become part of our way of thinking about ourselves.

Morris (*ibid*) calls this the "internalisation of *their* values about *our* lives". Nelson (2001: 6) describes identity as being "the interaction of a person's self-conception with how others conceive her" or him. Furthermore:

A person's identity is twice damaged by oppression when she internalizes as a self-understanding the hateful or dismissive views that other people have of her.

(*ibid*: 21)

The values being conveyed to disabled people do not have their source only in the non-disabled society, however. INGOs working with disabled people transmit their own similar messages. As Blaxter (1976: 13) points out,

¹⁴⁶ A disabled artisans' cooperative in Ouagadougou.

“the behaviour of helping agencies will affect the development of the client’s self-definition”. Interventions by INGOs with disabled people in Burkina Faso have also brought about the idea that disabled people need to be helped by external organisations, particularly financially. This gives rise to the question as to whether this leads to disabled people identifying themselves as such so as to qualify for development interventions. Furthermore, when asked what they want for their future, many research participants say that they need financial help:

LB: What change [do you] want in [your] life? Meaning, what [do you] want for [your] future?

K: ...at the moment, [I] wish that [you] help [me], because [we] are sitting around, [we] are now tired, there is no more strength to be able to work.... Now [we] wait for help.

LB: Help [you] how?

K: ... if [I] receive money, help has arrived.

LB: OK.... Is there anything [you] want to add?...

K: ... it’s those who come to help who know, in reality, how they can help [us].

(Interview with Kemhana (physically & visually disabled man),
Bogandé, 2nd October 2014)

Whatever is possible to do so that Yempani will be happy, at any rate, [we are] waiting, whatever the type of aid that you can provide for him, that can help him be autonomous in his life.

(Interview with father of Yempani (deaf man),
Gayeri, 14th October 2014)

Aside from fostering a culture of aid-giving and receiving, and thus of dependency, INGOs also at times encourage the notion of a ‘hierarchy’ of impairments in choosing to work with people with certain ‘levels’ of disability:

Complete blindness: we... cannot support this... but we notice that there are teachers who would say ‘Ah the child has problems, he doesn’t see the blackboard’ and so on. And there... easily we can do consultations: if the child needs spectacles, we give him the spectacles to enable him to follow... but if it’s... complete blindness.... In Ouaga, we had started working with [an organisation of intellectually disabled children]: we supported children there, the organisation of parents and... friends of intellectually disabled children... but in view of the fact that it is a kind of support which is truly specific, well, it was difficult. But

when the impairment is not very... eh, big, there are children whom we support in mainstream schools.

(Interview with INGO national director,
Ouagadougou, 19th May 2015)

The ability of social processes “to create hierarchies of bodies, exalting some and abjecting others, has been comprehensively shown” (Connell, 2011: 1370). Darling (2013: 1) postulates that since:

not all disabilities are the same... societal reactions vary greatly from one disability to another. Some disabilities are readily apparent, whereas others remain hidden unless those who have them choose to reveal them to others.

There are differences in the way people would perceive someone who, for example, has a limp, and someone who is blind. Parsons et al (2015: 3) observe that people:

with visible impairments may experience discredited stigma, and are vulnerable to being identified and labelled as different. As persons and as groups, they may be seen as outsiders by others.

Amadou (Interview, Banfora, 5th March 2014), a blind man who sells mobile phone credit and sometimes approaches people to advertise his services, confirms these social perceptions of blind people:

You know that we disabled people, when people see you coming, holding the walking stick, the first thought that people have... they directly think that you have come to beg. So if I come, they start talking, to tell you that they have nothing (for you) today, so that you continue on your way... but me, when they tell me this, well, I don't mind. I thank them, first of all, for having told me that there's nothing... and then I tell them why I have come. Often, after I have finished my presentations, they are ashamed.

Disabled people's own conception of disability and self is linked to the type of impairment. Aicha (Interview, Ouagadougou, 22nd January 2015), a physically disabled woman states that “for us, it's the legs, for others it's the eyes: how will they manage?” Benoit (Interview, Kompienga, 27th September 2014), a physically disabled man whose physical impairment is a result of burning his arms and legs and is not very visible all the time, says:

I don't say that I'm better than the others... [but] people, when they see me, they don't know that I have several disabilities. Because... I used to farm in the fields, with one hand, like this *[shows movement with one hand]*... before I started working in the shop.

Thus Aicha and Benoit consider their impairments and disabilities as mild, or as 'better' than the impairments of others, thus allowing them to do more than people with severe disabilities.

This is also linked to the fact that some people with disabilities consider their disability as "the most salient component of their self-concept", while for others, being disabled does not play a major role in their perception of self (Darling, 2013: 3-4). A regional DPO coordinator (Interview, 7th November 2014) explains that the role the disability plays in one's life is linked to the person's self-identity:

There are a lot (of disabled people) who don't identify themselves as disabled people. For example we often have problems when we want to have a census of disabled people. For example when we see someone who... has one arm: they don't consider themselves as disabled people. Often, people who have one arm, who walk normally: how do we consider them? They themselves do not identify themselves as disabled people; for example someone who stammers, there are some albinos as well who don't identify as disabled people. So it depends on how the person sees things.

Thus, people with different impairments do not experience labelling or the process of identification in the same way. One noticeable difference emerges between people with physical or sensory impairments and people with intellectual ones. Often people who have physical or sensory impairments reiterate that nothing is wrong with their mind, thus they can still do the things that non-disabled people do. This implies that people with intellectual disabilities are seen as different to other people with disabilities: they do not have the same mental faculties as people with physical or sensory disabilities. For example, Brama (Interview, Ouagadougou, 6th February 2015), a student with visual impairment, says, when talking about people with disabilities taking exams and taking part in state competitions:

It's not because you cannot walk or because you don't see that your head doesn't work! It takes place in the head.

Disabled people's image of themselves, therefore, is intricately tied up with social (whether by other disabled people themselves, non-disabled people or development agencies) perceptions of them. However, Darling (2013: 3) proposes that "the larger society's views may be filtered through interactions in smaller groups", such as the family, saying that "[w]e are likely to pay particular attention to the definitions we receive from the people who are most important to us". Ismael and Michel are two examples of people with disabilities whose parents have had faith in them since their childhood. Both Ismael and Michel today have positive self-identities, are leaders, activists, and strive to be successful in their own domains. Ismael, a thirty-five-year old university student in Ouagadougou who became disabled after a train accident¹⁴⁷ which led to the amputation of his arms and legs, is a prime example of how important parents and family support are to a disabled person's success:

LB: And when you say that a person like you has never been to university, why did you succeed?

I: It's thanks to my parents; it's my parents who pushed me to get to where I am... it wasn't the state which covered my finances, nor NGOs nor anyone else...

When they first took me to school... the schools refused straight out to take me in.

LB: Why?

I: Because I'm a disabled person: they said they had never seen someone like that, and that I wouldn't be able to study. This is what they told my parents. And my dad searched and searched for years. It was only when I was 11 that I went to school... because to find a school that accepted me it was very, very difficult.... We moved to a new neighbourhood [in Bobo-Dioulasso] where there was a private establishment.... They went to see the school's founder and asked him if he could take me on. The founder asked them if I would be able to study and all this... My dad answered that he does not ask himself if I will be able to study or not, but 'My son wants to go to school, that is what's most important'. And they took me in.

(Interview, Ouagadougou, 2nd February 2015)

¹⁴⁷ Ismael was run over by a train when he was two years old.

Today, Ismael has just ended a stint as the president of the disabled students' organisation at the university and is studying law:

Well, I wanted to do it, and... I think what pushed me to do it is...as a disabled person, you feel discriminated against, and you would like to resolve the injustices that people committed towards you. So you grow up with this mentality in your head, and as soon as you find the occasion to... erase, or... fight, or... say no, or stand up, I thought that by studying law it would enable me to defend myself, defend the others to the best of my abilities.

(ibid)

Michel, a forty-two-year old man who uses a wheelchair and crutches to get around, talks of how since when he was young his family gave him responsibilities and did everything in their power to take care of him:

M: Well, before this¹⁴⁸, I was a shepherd. At five years old I had a lot of animals of my own...

LB: Before five years of age?

M: Yes, before five years, because, when you are young, often people give an animal and say 'That's for him'... when I was five years old, I already had a lot of animals, because I managed at least forty or so pigs....[then] I couldn't keep the animals because I became sick. When I had the illness, all the animals were gone...

LB: How?

M: Because... since I became sick, the family sold them to try to find medicines for me, because polio was not known at this time. And my parents sold almost everything that I had, to buy a traditional product, because at the hospital they had already decided that I couldn't walk anymore. So my parents sold everything to try to have me walk again.

(Interview, Fada N'Gourma, 22nd September 2014)

Michel's responsibility in the family when he was young has carried on to the present day:

I'm the oldest, and it is me who manages everything. We have an older sister who is married. So I am the oldest among the boys, so it is me who follows dad. And since dad is a bit too old, I manage the younger brothers. The decisions, the family meetings, it's me who decides a lot, while discussing with them.

(ibid)

Today, Michel is a coordinator of DPOs, has several small enterprises and has been honoured as a Knight of the Order of Merit. Both Ismael and

¹⁴⁸ The encounter with polio and onset of disability.

Michel have represented Burkinabe disabled people abroad and are disabled rights activists. Their experiences of their families contrast with others, like, for example Damiadi (Interview, Matiakoali, 11th October 2014), a thirty-six-year old woman who walks with a limp:

[I] didn't go to school, because at that time they hid [me] a lot because [I] was disabled; and even to learn how to ride a bike, [I] was obliged to put pressure [my]self to learn the bike.... When [I] grew older, to go to the Gourmantchéma¹⁴⁹ school, they [*my parents*] didn't want [me] to go, due to [my] disability.

Today, when asked what disability means for her, she replies:

D: Disability... is suffering, because you are sitting around, you want to do, but you cannot, you don't manage to work because of your disability.

LB: And [you] don't manage to work in the fields?

D: ... [I] *do* work in the fields, but [I] don't work as much as [I] would have if [I] were well and able.

(ibid)

The family is not the only social group which plays an important role in self-identities of disabled people. For example, from a study she conducted in North America, Becker (1980: 98) observes that a group of deaf people:

defined by the larger society as afflicted, have created a small society that has had an influence throughout life on... their disability.... Individuals in this specially created society have used group membership to achieve a nonstigmatized personal identity and normalized social relationships.

Similarly, in Burkina Faso, the research participants talk of how they find solidarity in DPOs and the comfort of knowing that there are other people who, like them, have a disability and who go through similar experiences. Some go as far as to say that they do not feel disabled when they are among other people with disabilities, as two interviews with Laurentine and Alassane, a physically disabled woman and man respectively, reveal:

LB: You became... a member of the... DPO... why did you decide to do this?

L: Because there, at least, you are with disabled people: when you see them, you [see]... that you too are a disabled

¹⁴⁹ Language spoken by the Gourmantché people.

person.... Because before, when I was in Ouaga, I did not go out, I stayed at home. I put it in my head that only I am disabled. But since I became part of the DPO, I see that it's not only me who suffers from disability, there many people who suffer from their disability.

(Interview with Laurentine, Fada N'Gourma,
20th October 2014)

[Disabled people's sport]... gives me health and... if you are alone, it's dull, but when you go to disabled people's sport, you find... that there's a nice atmosphere, well, you don't even remember you are disabled, so you feel at ease...

(Interview with Alassane, Ouagadougou,
16th February 2015)

In Burkina Faso, where there are disabled people who did not know that there are other disabled people like them before they joined a DPO, the sense of identity emerging from belonging to a group of disabled people takes on an accentuated significance. For example, Emile (Interview, Ouagadougou, 26th November 2014), a blind man in Ouagadougou recounts:

When I arrived [at *Noong Taaba*¹⁵⁰]... I was happy, because I thought, when I was alone, I thought I was the only blind person. Once I had been there [to *Noong Taaba*], there were a lot of things which consoled me: I saw that I was not alone.

The importance of these smaller 'created societies' in a disabled person's life and identity is further demonstrated by Murphy et al's (1988: 241) observation that, unlike other stigmatised groups (such as those discriminated against on the basis of racial or religious grounds) most disabled people are not brought up by disabled parents, nor do they grow up among disabled people. Thus, disabled people are not "socialised" in the same way that, for example, a person from a religious minority would have been and so would not have learnt "how to deal with a sometimes hostile world". Furthermore, many disabled people become so through accident or illness and acquire the impairment when they are already adults. Yet even those who are born disabled or become disabled when very young are

¹⁵⁰ A centre in Ouagadougou where blind people used to be trained in furniture weaving. '*Noong Taaba*' means 'We Love Each Other'.

“usually brought up by parents who have no knowledge of the social problems of the disabled” (ibid). Murphy et al (1988: 241), referring to institutions such as special schools and rehabilitation centres, observe that:

In a way, the physically handicapped have to be ‘resocialized’.... And the school or hospital environments may become so comfortably familiar that they are preferred to home.

However, disabled people in Burkina Faso who are adults today rarely had the opportunity to go to schools where they could mingle with other children with disabilities, if they went to school at all. Thus DPOs take the place of these ‘socialisation’ institutions:

I have been coming to the Centre [of Disabled People] since 2004. I started coming because I learnt that there is an organisation of people of my kind, that is, people like me, people with a visual disability... and on that day I was *very* happy because I heard that there were people who were like me, and that I can also join the organisation with them. I was very happy; I was in a hurry, even, to come and meet them.

(Interview with Amadou, Banfora, 5th March 2015)

DPOs can, therefore, be a microcosm of society where disabled people experience a non-stigmatised identity and socialise with people with similar (or other) disabilities. Nonetheless, DPOs neither mean the same thing nor serve the same purpose for all disabled people, and not all disabled people join DPOs. In the context of Burkina Faso, positive self-identity is not always dependent on being a member of a DPO.

POSITIVE IDENTITY, AFFIRMATION AND SELF-ORGANISATION

To be the same is really boring.

(Foucault in Rabinow, 1994: 166)

Shakespeare (1996: 100) contends that the “process of positive self-identification” involves “rejecting the categorisation of subjection, and affirming... collective power”, as opposed to the biological determinism approach, that, he argues, instigates a denial of social common experiences. He continues to say that:

[w]hile this can be a private and individual development or personal awakening, it is more likely to take place in a collective context: self-organisation itself prompts the process of identification.

(ibid)

As already alluded to earlier, however, positive self-identity in Burkina Faso is often linked to autonomy and economic independence. This concept is in turn often linked to joining DPOs. Often, disabled people join DPOs with the aim of benefiting financially, because they feel they need aid; or to find work by training for a skill:

As disabled people, when [we] hear that there is an... association, [we] have the hope that we will be helped. So [we] went to the association... with the intention that [we] be can be provided with aid, that is... some will... give [us] clothes, others will give [us] food, others maybe will come give [us] money so that we will be able to conduct activities.

(Interview with Issa (blind man), Diapangou, 24th September 2014)

[Florentin's] father... passed away... so [we became] part of the organisation so [we] could be helped, because it's not easy.... So, from time to time, when there is aid, they think of [us] and they give [us] to eat.

(Interview with mother of Florentin (intellectually disabled young man), Piela, 1st October 2014)

[I became] part of the organisation so that, if there is aid, [I] would be able to have some of it.

(Interview with Yenupundi (physically disabled man), Matiakoali, 11th October 2014)

At the same time, those who feel economically independent, sometimes do not join DPOs (since DPOs are generally associated with economic support). When asked why people do not identify as disabled, a regional DPO coordinator (Interview, 7th November 2014) says that it is:

because they don't understand exactly the definition. They are self-sufficient: they think that being a disabled person is someone who needs to be helped.

The theme of independence, therefore, works both ways, in the sense that those who are economically independent tend to not identify as disabled and thus not join DPOs; while others join to benefit from aid.

Consequently, Shakespeare's claim that the process of positive self-identification involves affirming collective power does not necessarily sit well when attempting to understand disabled people's positive self-identities in Burkina Faso. The latter's individual, rather than collective, positive identification also has implications for the self-organisation and the "development of disability as a political identity" (Shakespeare, 1996: 101), which is fraught with problems, as will be discussed in the following chapter. Shakespeare contends that:

[t]he disability movement provides the collective context for political identification; it involves processes which challenge views of disabled people as incapable, powerless and passive.

(ibid)

Meanwhile, Darling (2013: 4) observes that having a more positive view of the disabled self is related to the rights movement:

Since the 1970s and 1980s, many people with disabilities have become empowered as the disability rights movement (DRM) has grown.... In fact, more recent writings by disability activists and disability studies scholars have introduced the concept of disability pride (see, e.g., Swain and French 2000).

Without negating the power of disability movements and the positive effects they have had in many countries, disabled people also challenge stereotypes individually. In a response to an entry in Peckitt's (a disabled English blogger) blog, a disabled person (2013: n.p.) states:

I'm a believer in individualism, that 'I' am, and whatever I am, I 'am', but I am not my race, nor my gender, nor my sexuality, nor my disability. They are aspects of a more complex whole. A definition of an aspect of my 'self' is not a definition of me, for me these tag lines are meaningless[:]... identity, and my identity in society[,] is far more complex.

The service these notions provide is to act as a light, upon a cause, which seeks to illuminate an issue...what they then become, as discussed is a... 'badge' or notional qualification of membership.

These observations on individualism and identity are, to an extent, reflected in the individual self-identities of people with disabilities in Burkina Faso and the tendency towards individualism (rather than the development of a collective identity), whether the self-identity is negative

or positive (or a mixture of both). Related to this is the affirmation of disability that seems to be emerging among some disabled people in Burkina Faso:

[I am] a visually disabled person, and... proud to be one.
(Interview with Abdoul Karim, Banfora, 18th March 2015)

[B]e handicapable not handicapped for in today's life it is a question of capability not of disability for we don't give a damn about disability.

(Facebook post by Ali (physically disabled research participant),
17th October 2015)

The quotations above recall the affirmation model of disability, which presents:

a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of being impaired and disabled.

(Swain and French, 2000: 569)

This non-tragic view is further exemplified by Michel (Interview, Fada N'Gourma, 22nd September 2014):

Often I say to myself that if I woke up one morning and found that I could walk normally and I had to start my life all over again, I think that it would be more difficult for me, because I have already spent a big part of my life as a disabled person, and if tomorrow I became able-bodied, I would, perhaps, have to look at the relations, look at things, it would be more complicated than predicted, for me, so... I've lived in this situation, I have planned things like this, so it doesn't bother me.

Michel is explaining that he does not necessarily want to do away with his impairment, since this would now mean changing his self- and social identities. The affirmation model, however, is not without its limitations, not only when applied to a Global South context like Burkina Faso, but also in its claims that "being impaired and disabled can have benefits" (Swain and French, 2000: 574). There are several factors that need to be considered in Michel's example and the other disabled people who affirm themselves as disabled and proud. As mentioned earlier, Michel has had the support of his family and is educated. Today he is economically

independent, having his own small enterprises. Abdoul Karim and Ali (quoted further above) are also well-established: the former has his own business (selling grains) and has two wives; while Ali heads his own DPO and works as a computer technician and musician in Ouagadougou. Other disabled people do not share the same views:

LB: What does disability mean for you? When one says ‘a disabled person’, what does it mean?

B: ... disabled person, for [me]... for example, [I] take [my] case: ([I don’t] hear well: [I’m] not happy.

(Interview with Bamboaro (woman with hearing impairment), Fada N’Gourma, 7th October 2014)

LB: If you had to change something in your life, what would you change?...

L: Presently, if God could give me legs... it’s the biggest wish I wish. It’s what I wish.

(Interview Laurentine (physically disabled woman), Fada N’Gourma, 20th October 2014)

Bamboaro (Interview, Fada N’Gourma, 7th October 2014) continues to explain how her impairment (being hard-of-hearing) poses a difficulty with her clients in her hairdressing salon. When the latter do not understand her, she is obliged to call her sister-in-law or niece to interpret for her. This brings us back to people with disabilities in Burkina Faso feeling that they cannot be autonomous due to their impairment, but it also reiterates the perception of disability as an individual, rather than a social, problem, and the lack of expectancy of society, or the state, to remove the barriers disabled people encounter:

[I] would like [you] to be able to help [me]: since [I don’t] speak well, if [I] could have the hearing aids, it could help [me] to carry out [my] activities well:... [to] speak to people, so they can hear [me] and so that [I] can hear as well, because often, when they talk to [me, I don’t] hear. So, [I don’t] know what the people are saying. Every time, [I] need someone to interpret. So [I] wish, if there is the possibility, for [you] to help [me] so that [my] business can work, and... maybe if [I] can hear well and talk to people... [my] business improves so that [I] can take care of [myself]. [I don’t] like to beg and people give [me], no: [I] want help to be able to work, this is what [I] want.

(Interview with Bamboaro,

At the same time, Bamboaro is also showing her determination to work and take care of herself, a concept which is linked to challenging the stereotypes of disabled people as passive and helpless. This also has implications for the way disabled people in Burkina Faso are challenging development interventions on their behalf, and the emergence of disabled people's agency (discussed in Chapter 7).

CONCLUSION

It is clear from the preceding discussion that in order to fully appreciate the self-identities of disabled people and their perceptions of disability in contexts like Burkina Faso, spaces need to be opened up for disabled people to express their views. As Shakespeare's (1996: 11) notes:

Disability identity is about stories, having the space to tell them, and an audience which will listen. It is also about recognising differences, and isolating the significant attributes and experiences which constitute disability. Some we might choose to change, others to recuperate or celebrate. We may need to develop a nuanced attitude which incorporates ambivalence: towards our bodies, for example. Theory has a part to play in this process. But (metaphorically, if not physiologically), it all starts with having a voice. As Foucault suggests, our task is to speak the truth about ourselves.

While the research participants in this study at times express views that echo the medical, social and affirmation disability models that have been based primarily on the experiences of disabled people in the west, these models do not necessarily explain or frame the significance of identities and views among disabled people in Burkina Faso. Many research participants view their impairment as a deficiency, as something which does not allow them to conduct their lives as they would have wanted; however this does not necessarily translate into the tragic view of disability which is linked to the 'something missing' view of disability in the west. Rather, many research participants seek to find gainful employment in order to challenge the view of disabled people

(promulgated by the non-disabled society) as a burden. This does not imply that the stigmas that are often attached to disability in Burkina Faso, such as viewing disability as a punishment for a wrongdoing, do not affect disabled people's self-identification. On the contrary, these are factors that have to be taken into account as playing a significant role in disabled people's lives. However, of importance is how disabled people themselves respond to these views, how it affects them and their identities and lives, and what they are doing to challenge these concepts. While disabled people in western contexts have formed disability movements, DPOs in Burkina Faso are not formed into a coherent strong disability movement, despite offering a haven for many individuals. Many research participants are thus challenging these views individually, promoting a positive view of disability and sometimes affirming their identities. Whether research participants 'accept God's will', see themselves as having something missing, or reject the label of disability, a common trend emerges from the research findings of disabled people seeking to 'overcome one's disability' and to develop and contribute to development. As discussed subsequently, foremost in this is the importance given by many disabled people to being economically independent. The view of disabled people as being economically dependent has a great impact on disabled people's view of themselves, which gives rise to the need to recognise what is important to disabled people in Burkina Faso. It also points to the need for development practitioners to take into account the ways in which disabled people identify, perceive disability, and are perceived by the wider community. Failing to take these interlinked factors into account leads to development practices which are based on western assumptions and framed in western disability models that do not necessarily sit well with disabled people's lived experiences and aspirations in the Global South. Consequently, the same development practices do not result in significant, long-lasting and beneficial change for people with disabilities. This then highlights the significance of agency and what disabled people conceive to be constructive

development through the spaces created in which their voices can be heard.

CHAPTER 6

'IT'S GOOD BUT IT'S NOT GOOD ENOUGH'¹⁵¹ ***Politics, Rights and Representation***

INTRODUCTION

The importance of collective power and self-organisation has been demonstrated through the achievements of the disability movement in western contexts and has been documented by disability scholars (for example, Oliver, 1996; Shakespeare, 1996). In Burkina Faso, however, the terrain of self-organisation is uneven. In the larger part of rural areas, disabled people's collective organisation, activism and mobilisation are still very nascent. In contrast, disabled people in urban areas have been able to organise through disabled people's organisations (DPOs) for a number of years. Ironically, while some disabled people are just becoming acquainted with self-organisation and perceive it as a beneficial and effective way to organise, others with greater experience of DPOs are becoming increasingly disenchanted with it. In both cases, self-organisation and collective power in Burkina Faso are not strong. DPOs are often 'reinforced' by international non-governmental organisations (INGOs), which are both 'necessary' for DPOs' functioning but also keep the same DPOs dependent. Furthermore, INGOs tend to intervene with disabled people from a western standpoint, emphasising the social model and a human rights perspective that are not necessarily relevant to disabled people's lived experiences in Burkina Faso. The power of INGOs is further strengthened by the state's lack of intervention and its rather passive role in disabled people's development.

In order to understand the role of the major development entities in disabled people's lives, this chapter examines the disability movement in Burkina Faso, through a focus on DPOs, the INGOs working with them, and the ways in which these INGOs implement development initiatives. It looks at the grassroots level of the disability 'movement' in Burkina Faso,

¹⁵¹ Interview with Désirée, president of a DPO in Ouagadougou, 13th February 2015.

what motivates people to create and join DPOs, what makes these DPOs work (or not), and what are the different attitudes of disabled people towards DPOs. The penultimate section then looks at INGOs' interventions, their connections and influence with DPOs, and the postcolonial implications of their work in Burkina Faso. The final section examines the Burkinabe government's role in disabled people's lives and development.

THE ROLE OF THE DISABILITY MOVEMENT

Responding to the challenges disabled people in Burkina Faso encounter requires an active disability movement. However, the disability movement in Burkina Faso is rather weak in terms of staffing and funding. Whilst it enjoys a certain level of political access and support in the capital, Ouagadougou, its reach beyond the city is minimal due to resource limitation (International Service, 2007). At the national federation level, support which is supposed to be forthcoming for smaller DPOs does not seem to exist and politics at this level does nothing to solidify an already weak movement. Rather than a disability 'movement' in the western sense, in Burkina Faso there is a multitude of grassroots DPOs, and the INGOs working with them. In what follows, I examine the terrain of disability interventions in Burkina Faso with regards to grassroots DPOs and INGOs in the disability field.

Grassroots Disabled People's Organisations

Statistics on the exact number of DPOs in Burkina Faso are hard to come by. A report by Handicap International (HI, 2010) states that there are approximately twenty-five grassroots DPOs in the Est region and approximately ninety-nine in the city of Ouagadougou. I use the word 'approximately' because these DPOs are a mix of organisations. First of all, it is worth noting that although they are referred to as organisations¹⁵²

¹⁵² They are also referred to as organisations in French (including in Burkina Faso): *Organisations des Personnes Handicapées*.

in general, most of them are associations, and are called so in the individual DPOs' names. Secondly, the DPOs' functions, activities and sizes vary considerably. In rural contexts, DPOs tend to encompass people with all kinds of disabilities, and the trend is having a DPO for each municipality. These municipal DPOs would then be members of the provincial coordination of DPOs, which would in turn be members of a regional coordination. These regional coordinations are then members of one of the national federations of DPOs, the FEBAH¹⁵³ or ReNOH¹⁵⁴. For a long time, the FEBAH was the only national federation. However, in 2012, another national federation was created, following internal disputes. This federation (ReNOH) has a much smaller reach outside the capital and a much smaller membership than FEBAH.

In urban areas such as Ouagadougou and Bobo-Dioulasso, the DPOs are more varied. There are DPOs whose membership is limited to people with specific disabilities, or women with disabilities. There are others which are more like cooperatives, such as an organisation of disabled artisans coming together to produce and sell. Many grassroots DPOs, especially in Ouagadougou, were created more as profit-making organisations, or at least with the aim of being profit-generating. In the larger urban areas there are DPOs which have schools for disabled (and sometimes non-disabled) children as well as a few organisations (generally of parents) of children with specific intellectual disabilities, such as autism. Another category of DPOs – which for clarity's sake will be referred to here as umbrella DPOs – have memberships made up of a specific group of DPOs such as DPOs of blind and visually impaired people, or DPOs of women with disabilities, or sports DPOs. These umbrella DPOs, generally based in Ouagadougou, are also members of the national federations of DPOs. This grouping of small DPOs into larger umbrella DPOs is favoured by INGOs. For example, the International

¹⁵³ *Fédération Burkinabè des Associations pour la Promotion des Personnes Handicapées*: Burkinabe Federation of Organisations for the Promotion of Disabled People.

¹⁵⁴ *Réseau Nationale des Organisations des Personnes Handicapées*: National Network of Disabled People's Organisations.

Programmes Director of an INGO (Interview, York, 25th June 2014) explains that donors:

will want to focus in one area.... They will not want to fund a motor disability organisation here, a visually impaired organisation here, an auditory impaired... and they will want to focus it in one place that can cover all.

This ‘decentralisation’ of DPO structures has its positive aspects in that there are grassroots DPOs at municipal level, comprising disabled people from the villages of that municipality. Nonetheless, it also keeps the same disabled people from rural areas at bay, since there are always higher echelons of DPOs representing them. Hence, for example, when FEBAH calls a meeting in Ouagadougou, it would generally be the leaders of the regional coordinations who would attend. Rarely are disabled people from the farthest rural areas involved in national events.

As can be expected, DPOs in urban areas, especially those in Ouagadougou, have more access to resources (mainly INGO funding) and opportunities. They are also the primary beneficiaries of government donations such as wheelchairs and three-wheel motorcycles. Rural DPOs generally encounter difficulties in all aspects of organisation functioning: regrouping members from far flung villages, having low numbers of literate members, having less or no money for functioning and possessing no building where to meet, among others. They also have less access to training opportunities. In both urban and rural areas, however, there are a great number of non-functioning DPOs. This is due to several reasons, including the fact that most DPOs are made up of members working on a voluntary basis and thus have other, more immediate, priorities in their lives.

Another significant factor is that many members join DPOs to benefit from aid. In their 2002 annual review, Action on Disability and Development (ADD) reported that memberships of DPOs in Burkina Faso increased by twenty-one percent in that year (Albrecht, 2006). The proliferation of INGOs led to “the emergence of a new breed of indigenous NGOs” since INGOs need “partners through whom to implement their

projects, so in some cases they were instrumental in creating local organisations for the purpose” (Sharp, 1990: 40). Many DPOs in Burkina Faso were created at the behest of INGOs, who prefer to work with groups rather than with individual people. This was the case in the Est region where an INGO used to work. In the Comoé province in the Cascades region, where another INGO was intervening, the INGO helped create the provincial coordination made up of DPOs in the municipalities of the same province. Thus many DPOs today are created in the hope of receiving aid from INGOs, as will be discussed shortly. This being said, DPOs play beneficial roles in disabled people’s lives.

Becker (1980: 68) states that “[v]oluntary associations are based on common interests... [t]hey provide social nurturance to their members”. She observes that:

When the individual is continually reminded of his or her variance from others this increases the level of stress.... Stress can best be minimized by playing down the overt differences of the disability and thus its importance. Among a tightly knit reference group... the problems of coping with the disability are forgotten or dealt with by joking.

(ibid: 78)

In this example, Becker is describing a deaf community, but her observations can be extended to groupings of people with other types of disability, as well as to the Burkinabe context and the question of the usefulness of DPOs to their members. At the Disabled People’s Centre in Ouagadougou, people with physical disabilities meet up to work, socialise, eat and drink. Disabled people joke with each other, calling each other ‘hey you, disabled’ (Entry in Fieldwork Notebook 2: 50, 26th November 2014), or making jokes that they contaminated each other with disability, or that they wanted to become disabled like each other (ibid: 43, 20th November 2014). DPOs are a source of identification and socialisation for many disabled people, thus also serving as a haven and offering a sense of solidarity:

The DPO was created in ’97... to raise awareness... to form a group, an organisation, so [we] can be heard by the population, by the authorities of the municipality.... The objective of the organisation

was first of all to create a setting so that all disabled people can meet up to share ideas, their joys, their worries and their sorrows; because by staying at home, alone, you are isolated: you are sitting around, you don't go out, you are lost. So the aim was to get disabled people to come out and group them, train them, educate them and integrate them in society.

(Interview with DPO Executive Committee, Dakoro,
7th April 2015)

DPOs are also a source of awareness raising, advice and, in some cases (for example for people with albinism), health protection:

D: Thanks to the organisation... [we] learnt different techniques to protect [our]selves...: to wear long sleeves... to apply the product¹⁵⁵ they give [us] when [we] are in the sun; so, it helps [me] a lot.

LB: OK. And the products... [you] get them from where?...

D: ... [I] went to the pharmacies and I couldn't find [them], and it was thanks to the organisation that [I] saw the product and started using it.

(Interview with Daouda, Banfora, 8th March 2015)

Furthermore, DPOs have the potential to “represent... the space where subaltern, hitherto inaudible and unarticulated views can be expressed” (Tandon, 2003: 65). DPOs are one of the spaces where disabled people, whose views are often not heard by the dominant hegemonic society, can be heard. Brama (Interview, Ouagadougou, 6th February 2015), a university student with visual impairment, articulates the importance of collective mobilising:

When we come to the university here... I think... it's almost a duty... to take part and participate... in the organisation... to campaign in the organisation.... It's better to find oneself in a community, in a group: like that we can campaign together and it gives us more strength; we can claim our rights.... As we say, there is strength in unity.... Moreover, here we have practically the same realities... the same problems, so why not unite ourselves...?

Nonetheless, as mentioned previously, despite the multitude of DPOs in Burkina Faso, fully-fledged organisations that play a role in advocacy, lobbying or awareness-raising are few and far-between. One reason is that the majority of DPOs are voluntary organisations, thus the members

¹⁵⁵ Sun protection cream.

evidently give priority to their personal income-generating activities¹⁵⁶. Awa (Interview, Bilanga, 2nd October 2014), a blind woman, talks about the DPO of which she is member:

Before, every twenty-one days [we] met to talk among [our]selves and all that. But... the president has his own work; and the... [General] Secretary... it was her before who mobilised the people, and the people used to meet. But now she, too has gained an [income-generating] activity for herself, so she does not have time anymore to [gather] the people anymore, and so she does not make the effort to bring people together.

The major reason for the lack of DPO functioning, however, is explained by Henri (Interview, 19th February 2015), a physically disabled man in Ouagadougou:

- LB: What do you think is needed in Burkina so that the disabled person is able to integrate in society?
H: There needs to be a change in mentality.
LB: But how? Who is going to change the mentality?
H: The organisations of disabled people...
LB: Do you think that these organisations are... attaining their goals?
H: Well, attaining their goals is a bit complicated, because... it's the start of a beginning... and, moreover... the organisations have not understood why one creates an organisation: they [do] not have the organisational spirit.

The 'organisational spirit', or *vie associative*, that Henri refers to, is what makes up the life of an organisation: the role and contribution of the members, the functioning of the organisation, and its work towards achieving its objectives. This is the significant factor that, according to Henri, many DPOs lack, and which lead to numerous problems of self-organisation among disabled people. The high commissioner of a province in the Cascades region (Interview, 27th April 2015) observes that when disabled people come to her, it is always to "ask, ask, ask", but they never show anything that they do. According to her, disabled people need to sit down and plan the way forward. DPOs, like many other grassroots organisations in Burkina Faso, have no activities apart from sitting

¹⁵⁶ Whether this is paid employment in the formal sector, or an income-generating activity in the informal sector.

around and waiting for financial support. The commissioner asserts, however, that:

No one has 'nothing'. You have to give something in order to receive. If someone gives all the time, he will get tired, but if it's dynamic, the relationship won't end... everyone has something to give. (ibid)

A similar observation is made by an INGO national director (Interview, Ouagadougou, 18th May 2015):

Even to gather for a General Assembly, they [DPOs] will ask an NGO for the financial means; yet an organisation shouldn't be like this: [by means of] the membership fees, donations from other people... the organisation should at least be able to meet to discuss its... common interests.

The director's comment also relates to how DPOs fall into the tendency of depending on external partners for funds, rather than attempting to generate funds internally. This observation touches upon the argument made by Kajimbwa (2006) that when INGOs implement their own programs, it is likely that the beneficiary of the INGO will have a decreased sense of ownership and potential to act, an issue which is discussed further in the next section. Meanwhile, the high commissioner (Interview, 27th April 2015) makes a related observation on what is possibly hindering the functioning of DPOs:

People have associated the organisation with money.... [However,] it's not money which enables you to live, but good practices which enable the money to stay.

The high commissioner is talking of the fact that a large number of grassroots organisations (including DPOs) are created for the sole aim of receiving aid or to access funding in general, a point which is reiterated by the president of a DPO in Diapangou:

[We] have an Executive Committee: a president, a general secretary, a treasurer, but it doesn't function, because people have not understood, for a start, the interests of the organisation.... For them, when one says 'the organisation', people think that it's to call them and give them money.

(Interview with Yada, 24th September 2014)

Joining a DPO for economic reasons is not necessarily negative, as Ela (Interview, Ouagadougou, 20th November 2014), a physically disabled woman, demonstrates:

- LB: Are you a member of a disabled people's organisation?
E: Yes...
LB: Which one?
E: ... [the] national federation of artisans... of disabled people...
LB: And why did you become member of this organisation?
E: Because... since I do hairdressing... I am an artisan too. So, I am part because... when you work alone it's not good, but when you are in a group, it's better... for example if there is a market demand... and if you can do it, they give you the work.

However, Ela already has her own income-generating activity, and only joined the organisation to strengthen her work, rather than to simply access funds. Furthermore, she later specifies: "each one of us works separately" (ibid), a statement which captures one of the challenges for organisations (discussed more fully in the next chapter), that is, that many research participants prefer working on their own. Conversely, INGOs generally do not work with individuals, but with organisations, leading to the creation of numerous DPOs whose sole existence is to access external partners' financial aid and support. Emile (Interview, 26th November 2014), a blind man in Ouagadougou who created a DPO, highlights this issue:

- LB: What was the reason for which you created the organisation?
E: ... The reason for which I created the organisation: I said... if a number of people want to do something, it will always help...: I approached many people who told me 'If you have an organisation, we can help you; but if you are on your own, we cannot help you'.
LB: Who said this?
E: ... [INGOs]... : if I create an organisation and approach them, if your dossier is good, they will finance you.... So... it's for this reason I thought of creating the organisation.

The expectation for INGOs to work with DPOs seems to be present from the perspective of both the DPO and the INGO. For example, one of the reasons for the importance of unity in the DPO movement, according

to the national director of an INGO (Interview, Ouagadougou, 19th May 2015), is encouraging partners (such as INGOs) to work with them:

I think that for DPOs, there must be... unity... cohesion, because when we have an organisation that groups together all the DPOs... it's even stronger:... when... there is one structure that coordinates all this, it gives them strength.... Even with the partners, when they feel that there is one structure... they can help you; but when it's [divided]... it's two, it's three, each one fights for their school of thought, it's very difficult.

Rather than uniting DPOs, however, the expectation of being funded by INGOs seems to have given rise to the *proliferation* of DPOs. Hence, much in the same way that the international aid system has become “increasingly dysfunctional” and “has led to a system that is fragmented and duplicative, and places too heavy a burden on aid-receiving countries” (Woods, 2008: 1218), INGO intervention has precipitated the creation of many DPOs in order for these to access foreign funding.

The ‘awaiting aid’ phenomenon then creates problems of functioning, as a regional DPO coordinator (Interview, 7th November 2014) remarks:

There isn't anyone who has taken the initiative to create [an organisation] and make it function... because... in this region there is the idea that when one creates an organisation, there will be [financial] support. But what if there is no such opportunity? People create and then they wait... There isn't an organisation which has a clear policy which says ‘we will do this, we will do that’.

This idea of joining or creating a DPO to attract funds subsequently leads to members becoming discouraged over time. Numerous DPOs comment on the fact that meetings are no longer held due to the fact that the members feel they are not gaining anything. This is further compounded if the DPO has already worked with an INGO in the past and thus enjoyed financial support for its activities. The loss of these benefits is felt more acutely by the members, who then refuse to attend meetings if there is no financial support:

With the partners, people got used to having food, and so on, when there is a meeting..., so [now] we cannot... organis[e] big meetings, and so on.

(Interview with a regional DPO coordinator,
7th November 2014)

Interventions by INGOs have conditioned many disabled people in Burkina Faso into expecting certain standards that are not possible after the INGO terminates its collaboration, mostly because DPOs do not have as much financial capacity as an INGO. Many DPOs then cease to function when INGOs terminate their funding and collaboration. The phenomenon of grassroots organisations disintegrating once external support ends, is not specific to disability. Atampugre (1997: 62), writing about INGOs and grassroots development in Burkina Faso, comments on:

the extent to which groups quickly form in order to take advantage of opportunities in their external environment, disintegrating as soon as that objective has been met. It shows too that credit or financial support does not necessarily facilitate organisational development. On the contrary, it can undermine the ability of rural communities to organise in order to solve their own problems.

Dependency on external funding thus leads to the inactivity many DPOs demonstrate in the interviews, as exemplified by the following DPOs:

A: When we had the money, we went to the villages to raise awareness among the population, for example... the traditional chiefs, the religious chiefs, civil servants... so they support disabled people everywhere...

LB: When you say 'when we had the money', what does that mean?...

J: Handicap International (HI) came to help us with financing: when we had this, we did awareness raising in the villages.

LB: And now you don't have the financing of HI anymore?

J: No.

LB: So how do you do the awareness raising now?

A: At present we have almost stopped the plan, because we have nothing with which to travel. At present it's the money that counts: if you don't have the money... to travel with a bicycle it's complicated; if you have a motorbike, you can put petrol if you have money, but if you have nothing, what will you do? Without money...

(Interview with Assimi and Justine¹⁵⁷,

¹⁵⁷ Respectively, president and general secretary of the DPO in Bilanga.

Bilanga, 2nd October 2014)

At that time, apart from the different quarterly meetings... there was nothing that disabled people did to promote... their autonomy. We were quite idle and... were waiting for [a particular INGO] to come to our rescue.

(Interview with Isaac (DPO president), Banfora, 10th March 2015)

Today, the DPO which Isaac is talking about is once again doing nothing, after a period of intervention by two INGOs. The dependency of DPOs is thus clearly problematic for the long-term sustainability of disability activism and advocacy in Burkina Faso.

The factors discussed so far, however, do not exist in a vacuum but are set in the wider national context. Apart from the lack of knowledge of organisational functioning, and the related notion of creating and joining a DPO as a means of accessing aid, there is the related problem of misappropriation of funds, which is also a nationwide problem. In the context of DPOs, the high commissioner of a province in the Cascades region (Interview, 27th April 2015), observes that when the organisation *does* access funds, it is then spent all at once, or simply ‘disappears’, and thus:

If you have a tree and keep cutting its branches, the trunk, you will end up with nothing. Even the roots will die.

(ibid)

The misappropriation of funds is a problem that pervades many DPOs in Burkina Faso. The point is also made by an INGO national director (Interview, Ouagadougou, 18th May 2015):

They are always waiting... they come to see an INGO, saying ‘this is our plan of action, we want to do this’. But when they are financed... the problem of governance proves to be a problem: often, we don’t know how the funds were spent.

This is one of the major reasons that have led many disabled people, especially in urban areas, to become disillusioned with collective organisation through DPOs. Gaston (Interview, 1st December 2014), a physically disabled man in Ouagadougou, talks about this:

LB: Are you a member of a DPO?
 G: No.
 LB: And why not?
 G: ... I was, before. But I left.
 LB: Why?...
 G: ... things weren't going well, [and] I resigned.
 LB: Why?...
 G: Things weren't transparent... there... I prefer staying in my workshop.

The issue of misappropriation of funds (together with organisational functioning and the reasons underlying DPO creation) is also tightly linked with leadership, and the (lack of) transparency issues that Gaston mentions. Before going into these two issues, however, it is significant to note that underlying these structural drawbacks are the general hurdles encountered by people with disabilities in Burkina Faso, one of the major difficulties being the lack of education. In Chapter 4 we saw that the lack of access to schooling for many disabled people when they were young resulted in many adults today lacking the writing and reading skills necessary to lead and manage an organisation. This absence is felt more strongly when the DPO is working with INGOs, who often require reports and other written material (Mawdsley et al, 2002; Mawdsley et al, 2005). This often gives rise to a situation where the DPO leaders are those who possess a certain level of education, but are not necessarily the ones who have the DPO's and its members' interests at heart. Unfortunately, these leaders tend to form a group whose members are re-elected in consecutive elections, simply rotating roles from election to election. Fatou¹⁵⁸, a physically disabled woman in a municipality in the Cascades region, brings to life the issue of elite capture and other problems regarding DPO functioning in Burkina Faso (see Textbox 6.1).

Fatou came this evening to the Centre¹⁵⁹ to talk to me.... She was telling me how Marie, the supposed president of the disabled women's organisation, has the key to the office where the material for making soap and soubala is. Marie doesn't come the Centre anymore, and so the

¹⁵⁸ Name was changed to protect the participant.

¹⁵⁹ Centre of Disabled People.

women cannot work. Fatou says that the women used to come to work but when they sell the soap they do not see the profits, they do not know where the money has gone! So they gave up and don't come here to work anymore.

Fatou also says that she was not informed of the physically disabled people's DPO meeting a couple of weeks ago, nor that it has been postponed to this Friday. Last time, the meeting was cancelled because Diakité didn't show up. (Diakité was elected president in the last election; but on paper it still shows that Amadou, the previous president, is president. Diakité, who was president before Amadou, is now president again. Rumour has it that he is avoiding coming to the meetings so that they will not renew the Executive Committee and change his position.) I asked Fatou why they keep electing Diakité and she replies 'Who is there to elect apart from him? Cheick is busy with the workshop...'. I ask why not her. She says that Diakité would make trouble for her if she proposes herself.

(Entry in Fieldwork Diary, 12th March 2015)

Textbox 6.1 Fatou and the two DPOs

Fatou's observations on the disabled women's organisation highlight not only the mismanagement of the same DPO and its funds, but also the fact that the president, Marie, has absolute power over what happens. They also explain why DPO members give up on being active in the organisation when funds are misappropriated, especially when it involves an income-generating activity from which the members should be profiting financially. Her observations also illustrate the leadership problems of another organisation of which she is member an organisation of physically disabled people, whose current president avoids the Executive Committee elections so that he remains president for as long as possible. Diakité, the current president, was also president two terms previously. Furthermore, should Fatou put herself forwards as a candidate for president, the incumbent would make life difficult for her. There are not many other candidates who are eligible, that is, who possess the required level of education. Cheick, whom Fatou mentions, is an educated member and possible candidate, but he is busy with other commitments (working in the metal workshop, which belongs to the DPO itself). Finally, Fatou is not aware of the DPO meetings taking place, suggesting a lack of communication and information relaying between DPO members.

Similarly, Zachary (Interview, Piela, 1st October 2014), a physically disabled man, says that he was not aware that the person accompanying us ¹⁶⁰ to his (Zachary's) home for interviewing is the current DPO president:

[We] haven't made any renewals. To [my] knowledge, there haven't been any renewals of the Executive Committee in which [I] participated... [I] was the president and [my] deputy was a visually disabled person.... Neither [I] nor [my] deputy... know that there is a [new] president, because [for this to happen] people must be present to say 'we are going to elect a new committee, so that one became president, that one became...'

The fact that many DPOs are led by the same people, electoral term after electoral term, and elections are often not held, is also highlighted by INGOs:

There are always the same people at the head: there are no general assemblies.

(Interview with INGO national director,
Ouagadougou, 18th May 2015)

Another noteworthy factor playing a role in DPO politics in Burkina Faso are gender issues. While Fatou is a member of both the women's and the physically disabled people's DPOs in Banfora, in more urbanised centres like Ouagadougou, the fact that most DPO presidents are male has led some women to break away and create DPOs of their own. Nadine (Interview, 18th November 2014), the president of a disabled women's organisation in Ouagadougou, says that the organisation's members used to form part of a larger organisation, but, since "women come second to men" they decided to branch out and form their own DPO. Mimi (Interview, 6th February 2015), the president of another women's DPO in Ouagadougou, relates a similar story:

At first, we had a mixed organisation... [and] we thought... why don't we, the women, separately... create our own organisation? Because, often... in the organisations, women don't have decision-making roles. Moreover, in the [executive] committees, [women] hold posts... which do not have priority: often they are posts relating to women's issues and such... So, in decision-making... men

¹⁶⁰ The interpreter and me.

are in the forefront every time. Thus, together we reflected: why not create our own organisation? Because... it's true, disabled people have problems; but... women have more problems than men... We have problems in our own right, so why not... see how we can overcome them?

When asked to elaborate about the problems disabled women face, and how they differ to men's problems, Mimi continues:

Already, in our families, there are barriers between us, because, firstly, you have to sensitise the family... if you are accepted, it's already something. If you are not accepted, this is already a problem. So, together, we have to reflect on all this. And then, we have children. And children are problems: a child always has a father, but... everything falls on the mother. So she has to seek work to... meet her child's needs.

(ibid)

Furthermore, since women's issues are given more importance than disability issues by the government, disabled women have also felt the need to create women's DPOs (even if they are still members of other DPOs like Fatou, quoted in Textbox 6.1) to be more visible. Korotoum (Interview, 3rd March 2015), the ex-president of the women's DPO¹⁶¹ in Banfora, explains:

[We] noticed that now, here in Burkina... the associations of women are more listened to. The authorities have put an emphasis on... associations of women. So that's why [we] decided to... create [our] organisation.

Gender concerns are not the only reason people branch out into new DPOs. Rather than coming together into a united disability movement, disabled people seem to be separating and following their own paths:

[I] was the president of the coordination of disabled people... (the president... is the one who is in charge of all the organisations... of the district...)... [and] since... for the moment... the coordination has stopped [functioning]... [I created my DPO]..

(Interview with Daouda, Ouagadougou, 26th November 2014)

Thus, despite all the hurdles discussed thus far, DPOs continue to proliferate. Nonetheless, the DPOs run by Mimi, Nadine and Daouda are

¹⁶¹ *Association Badeya des Femmes Handicapées de Banfora*: Organisation (Sisterhood) of Disabled Women of Banfora.

based in Ouagadougou, with relatively good access to resources to create and sustain an organisation. Women, and disabled people in general, who are located in the capital also generally have a higher level of education and more opportunities to branch out on their own. Furthermore, the constant mushrooming and branching out of DPOs seems to be more of an urban phenomenon than a rural one. In rural areas, disabled people seem to be at an earlier stage of self-organising, which also means that they are more marginalised in terms of being able to access support and assistance, or to articulate their needs. This can be seen, for example, in Loumana, a rural municipality in the Léraba province (see Textbox 6.2), and Mangodara, a rural municipality in the Comoé province (see Textbox 6.3).

Upon arrival in Loumana, a guy who... is the brother of a disabled person came to meet us and brought us to a place under the mango trees where about 13 people are gathered.... Apparently they don't really have a DPO in place but... they have been trying to put one in place.

(Entry in Fieldwork Notebook 4: 80, 17th April 2015)

Textbox 6.2 Loumana: Creation of a rural DPO

Just arrived in Mangodara, 105km away from Banfora!.... [S]o today there was supposed to be the GA [General Assembly] which puts the DPO in place in Mangodara, but since the guy in charge had been in Côte d'Ivoire and the informer... failed to inform people, the GA has been postponed.

(Entry in Fieldwork Notebook 4: 93, 21st April 2015)

Textbox 6.3 Mangodara: Creation of a rural DPO

An additional problem for DPOs is that umbrella organisations, who face similar leadership, functioning and dependency obstacles as the smaller DPOs, do not provide sufficient support to enable DPO mobilisation. At an umbrella DPO level, there is also the phenomenon of multiple leadership posts, that is, one person being the president of three different umbrella DPOs, as was the case at the time the fieldwork was being carried out. Meanwhile, the national federation of DPOs is riven by politics:

LB: Can we speak of... a disabled people's movement in Burkina?

- H: It exists, but it functions very weakly...
- LB: When you say it exists, it's who?
- H: It's the two structures: ReNOH and FEBAH¹⁶²...but their actions are not translated on the ground.... The difficulty is the weak engagement of DPOs: they have a very weak engagement concerning the implementation of their rights... not to speak of the synergy... between the two organisations... having two federations... does this help us? I don't think so.

(Interview with Henri (physically disabled man),
Ouagadougou, 19th February 2015)

Henri speaks of the two national federations of DPOs. The original federation was split into two (FEBAH and ReNOH), following disagreements. According to Henri, there now needs to be a confederation to join these two federations and bring some unity to the disability movement. The problem, once again, is a problem of leadership, as attested by Henri and the national director of an INGO:

It's a problem of leadership: with white people, things are clear: you have done your mandate, you leave your place... [for someone else. But] some people have finished and don't want to let go! They modify the statute; they create an Executive Secretariat which has even more power than the president!

(Interview with Henri, Ouagadougou, 19th February 2015)

I cannot say that the DPOs work well.... You know that usually DPOs have a problem of leadership.... Besides the leadership problem, there is also... the notion of organisation per se: it's not yet well perceived, because they always put forth the problem of means, of lack of means.... Even when you look at DPOs which are well structured, there are always difficulties.... When you take the case of FEBAH, you see how it went: there is ReNOH, you have two federations.... They themselves don't foster... cohesion..., because it's always problems of leadership, internal power struggles, low blows.

(Interview with INGO national director,
Ouagadougou, 19th May 2015)

The proliferation of DPOs and their lack of strength, whether they are rural or urban based, are major contributing factors, therefore, to the weak disability movement in Burkina Faso. This is then compounded by

¹⁶² *Fédération Burkinabé des Associations pour la Promotion des Personnes Handicapées*:
Burkinabe Federation of Organisations for the Promotion of Disabled People.

the lack of cohesion amongst DPOs, reflecting a similar national context. An INGO national director (Interview, Ouagadougou, 18th May 2015), comments on the similarities between DPO organisation and governance and that of Burkinabe political parties:

I think the first thing that disabled people and their organisations should deal with, is the issue of organisation: the DPOs in Burkina are not organised.... They do not manage to get on with each other.... They do not really have an interest in uniting and... working in the same direction... It's a question of organisation and also of governance... in the sense that it's always the same disabled people who are at the head of the same DPOs. If I'm not happy here, I go to the other side. For me, this is the image of our politics: see how we do politics... I am in a political party today, if I am not in the head, I leave and create my own party. So we have a lot of organisations which exist. But what do they do? Nothing!

It is not only national politics that influence DPO politics, however. Connell (2011: 1378-9) observes that the politics among people with disabilities in the Global South are liable to differ from those in western contexts:

This is not only a matter of different cultures... the history of social embodiment in the colonised world is different. Contemporary economic structures and resource levels are different, and political opportunities and needs are different.

These differences are of particular relevance given that DPO politics in Burkina Faso are tightly linked with financing and support from external partners (mainly INGOs) and their donors.

INGOS: SAVIOURS OR STOP-GAP SOLUTIONS?

I'm not saying that it's not good: it's good, but it's not good enough.
(Interview with Désirée, Ouagadougou, 13th February 2015)

INGOs have important economic power in Burkina Faso (LAFB, 2007). Sharp (1990: 40) reports that, as the big aid-giving countries became increasingly aware of the meagre results obtained by bilateral aid, they “channelled an increasing share through their NGOs”. As a result, “in many countries like Burkina, the NGOs have become the biggest fish in the pond” (Sharp, 1990: 40).

The common thread that emerges from the research findings explored in the previous section is the deep dependency between DPOs and INGOs. In particular, there are questions concerning whether or not the DPO was created in order for INGOs to work with it, is functioning with funding from INGOs, is looking or waiting for support from INGOs, or has ceased to function due to INGO withdrawal. In his preface to Anne-Cécile Robert's book 'Africa to the West's Aid'¹⁶³, Diop (2006: 14-5, my translation) observes that:

[T]he little hope that remains is... transferred onto civil society. The latter is certainly one of the better things that still exist in Africa.... Lucidity however encourages us to temper down this enthusiasm. Indeed, African civil society is often discretely controlled from the outside, by those who, in the North, have the means to finance these activities. If nothing is done in Africa itself to reverse this tendency, civil society will become a new, particularly effective, instrument of domination of the continent. It might also have the function of bringing out of its flanks new elites, accomplices of an endless colonial pact.

Diop portrays African civil society as a puppet whose strings are still being pulled by western NGOs, an observation which seems to apply to civil society organisations of disabled people in Burkina Faso. Nearly all DPOs in Burkina Faso are dependent on (mostly foreign) partners to function. Michel (Interview, 7th November 2014), the president of a DPO in Fada N'Gourma, recounts how the organisation "experienced some dead times up until... the arrival of [two INGOs]", when the DPO members "started to work, go out in the different localities"¹⁶⁴. However, as Désirée, the president of a DPO in Ouagadougou, argues (in this section's epigraph), the current INGO intervention is good, but it is not good enough. None of the DPOs interviewed are financially independent, not even those with whom INGOs have been working for long periods of time. This supports Power's (2001) argument that development organisations may create dependency. Two DPOs, both based in Ouagadougou, have received support from an INGO for years. At the time of interview, one of the DPOs

¹⁶³ *L'Afrique au secours de l'Occident*.

¹⁶⁴ Going out to work in the different provinces of the Est region.

had eight INGO (four Burkinabe and four British) volunteers placed with it (Interview with Zenabou (DPO Coordinator), 20th January 2015) and the other one had ten (Interview with Dominique (DPO President), 10th February 2015). Neither of these two DPOs, however, has become independent: both still depend heavily on INGOs. One of them also obtains its operating funds from the INGO and has significant help from other INGOs. As Zenabou (Interview, Ouagadougou, 20th January 2015) points out, the little funds their DPO has economised so far will not go far if the partners terminate their support. The other DPO's headquarters were built and furnished by an INGO, while two other INGOs provided the computers and training, and funded the start of the activities (Interview with Dominique, Ouagadougou, 10th February 2015).

The objective of the INGO is to eventually render the partner DPO self-sufficient and able to function without external support:

We work... so that the [partner] organisation can be durable. We don't want the organisation to be dependent on us.... We want the organisation to be able to, one day, fly with its own wings.... *Tigoung Nonma* have really accepted the reinforcement of capacities... they have really wanted to learn from the volunteers and make progress... this is what we ask of our partner organisations: because at a certain point, the programme will end...

(Interview with INGO field office director,
Ouagadougou, 8th May 2015)

However, the director then continues:

LB: And usually you work a specific organisation... for how long?

Director: If it's a partner of [our organisation], it's forever.

(ibid)

The director's last statement points to the issue of INGOs repeatedly working with the same DPOs. As Dominique (Interview, Ouagadougou, 10th February 2015), a DPO president, says, INGOs are encouraged by other INGOs already working with a DPO, which means that the INGO already working with the DPO trusts that DPO, and is thus willing to work with it. Mimi (Interview, 6th February 2015), the president of a DPO in Ouagadougou, observes that INGOs "want to work with those they

know already”. INGOs and, as discussed subsequently, the state, tend to work with the same organisations. This creates an ‘inner beneficiary circle’ of bigger DPOs who have the INGOs’ trust, which is difficult to permeate:

There are other organisations which are larger than [ours], so if the partners already support these organisations, it means that they can [not]... support small organisations like [ours]. So it’s difficult.

(Interview with DPO Members, Ouagadougou,
1st December 2014)

Aid comes... and it’s not those who need... that receive aid.... Support is always given to the same organisations.... I don’t know if it’s through having relatives or if you need to have connections... it’s always the same organisations who receive help: the same and the same.

(Interview with Désirée (DPO President),
Ouagadougou, 13th February 2015)

In addition to trust and the size of the DPO, Bebbington (2004: 737) argues that demonstrating impact is an increasingly important factor in INGOs obtaining further funding. Ironically, this has led to these INGOs moving their focus away from those who are “chronically poor” and towards those who are “better-off” and “would probably show impact more quickly”. This has implications for the smaller DPOs who are ‘chronically poor’ and would not show impact quickly enough, since they are not as developed as the bigger DPOs with ongoing INGO support.

The fact that development agencies work with the same DPOs that they know and trust, helps to develop a vicious cycle, which is demonstrated by the example of the headquarters problem: in order for DPOs to receive support, a particular INGO requires them to have headquarters (Interview with INGO field office director, Ouagadougou, 8th May 2015). However, many DPOs, in particular the newer ones, do not have an office of their own. For a DPO to have headquarters, it needs funding, which generally comes from INGOs:

With regard to [my] plans... it’s to have a place to present as [our] head office, in case they tell [us] ‘we want to help you but, where are you [situated]?’.... Once [we] have an office, [we] will look for... financing, NGOs, projects...

(Interview with Daouda (DPO President),

Ouagadougou, 26th November 2014)

It is not only the newer DPOs, or those who have never had partners, who risk not gaining INGO support. Although the largest number of disabled people lives in rural areas, almost all the INGO country representations I interviewed are based in Ouagadougou¹⁶⁵, and many of them operate in the regions close to the capital:

[The programme] is primarily focused around Ouagadougou. Our office is in Ouaga; we have a project in Ziniaré¹⁶⁶, which is just... an hour and a half maybe outside Ouaga.

(Interview with INGO CEO, York, 5th June 2014)

For the moment... we focus on supporting the schooling of disabled children, and therefore we intervene... in the province of Kadiogo. We also intervene in the Oubritenga.... in Zorgho [in the Ganzourgou province].... We also have Fada, in the Gourma province... and there is also Boulgou.... So these are the 5 provinces¹⁶⁷ in which Better Life intervenes.

(Interview with INGO national director,
Ouagadougou, 19th May 2015)

These statements support the contention that many development agency workers “are urban-based and urban-biased”, with “many of them in capital cities, and have the familiar problems of paperwork, meetings and political and family pressures which tie them there” (Chambers 1983: 9).

The reasons for “[t]he proliferation of NGOs and civil societies in urban over rural spaces” and “the tendency for NGOs and civil societies to be stronger in ‘development hotspots’ over regions neglected by development agencies” (Mercer, 2002: 13) are various. Bebbington (2004: 736) argues that the “forms taken by aid flows in the nongovernmental sector have much to do with the structure of underlying social and institutional relationships”. One such underlying structure is “the historical geographies of religious institutions” (ibid: 733) influencing the geography of INGO interventions. This is the case with such INGOs in Burkina Faso as one who, as its national director (Interview,

¹⁶⁵ See Appendix 1.

¹⁶⁶ A town in the Plateau-Central region.

¹⁶⁷ See Figure 1.1.

Ouagadougou, 18th May 2015) explains, historically based their regions of intervention according to church institutions, which still influences the geography of intervention today. When asked why they work in specific regions, the national director replies:

Because [our organisation] originally worked with the church. And the divisions of the church are not the same divisions as the administration (regions, provinces). So, historically, we wanted to follow where the old OCADES¹⁶⁸ partners used to work, when we put together this project. So the OCADES makes these dioceses: divisions. They have dioceses per region.... So when they did the project in 2012, they followed this, also to facilitate the follow-up by the CBR [Community-based Rehabilitation] agents who worked for OCADES.

Besides historical geographies, another factor influencing the geographies of intervention of INGOs is donor funding. Bebbington (2004: 739) argues that in a context where financial donors play:

such an important role in NGO financing... the reduction in resource availability from... Europe... has significant effects on the overall funding base of... NGOs.... In response, NGOs have to reduce the scope of their coverage unless they find alternative sources of funding.

Bebbington's observations relate to what is happening in Burkina Faso. One INGO, for example, used to place specialised development workers with grassroots DPOs all over the country for a minimum of two years, but they now place volunteers (aged between eighteen to twenty-five) with DPOs for a period of ten weeks, through the UK government-funded scheme International Citizen Service (ICS). These volunteers, whose tasks are helping the DPO with such skills as marketing, communications and advocacy, are then replaced by another group of volunteers. The DPOs with whom these volunteers work are based in Ouagadougou (eighteen out of twenty-six volunteers) and the two neighbouring regions¹⁶⁹. The field office director (Interview, Ouagadougou, 8th May 2015) explains that one of the reasons the INGO cannot operate in regions farther away from the

¹⁶⁸ OCADES Caritas Burkina (*Organisation Catholique pour le Développement et la Solidarité*: Catholic Organisation for Development and Solidarity).

¹⁶⁹ The Plateau-Central and Centre-Ouest regions.

capital is because of the age of the volunteers (imposed by the donor) and the lack of vehicles the INGO now have:

You see, development workers ¹⁷⁰ are not like the volunteers: development workers have a certain level, and are older, so they can go to those regions for two, four years. But the volunteers: even in Reo¹⁷¹ we have problems. When a volunteer is sick... we have only one vehicle...

The International Programmes Director (Interview, York, 25th June 2014) of the same INGO explains why one of the projects that placed development workers with six DPOs, including in the three farthest regions¹⁷² of the country, came to an end:

That project was funded [by]... Irish Aid.... And, basically, during the time,... the Irish economy collapsed. So Irish Aid retracted to about ten percent of its previous size. So... basically our ability to continue project-funded support with partners really shrunk. So, we are still in the process: we've been able to secure the ICS as a means of support for our partners, but... because of the nature of the programme, there are some geographical limitations about keeping the volunteers close, given that... the budgetary restrictions on the transportation, the supervision support over some of the long distances, and the physical communication in those areas. And also, some of those partnerships weren't right for ICS: we couldn't find, necessarily, the skills for ICS volunteers to respond to what those partners¹⁷³ needed.

The director (ibid) continues to say that the interventions of the INGO are decided upon according to what ICS can provide, thus demonstrating that it is the donor, rather than the beneficiary, who mostly influences the interventions of the INGO with disabled people.

The unevenness of INGO geographical intervention unfolds in the already existing “[u]neven and inequitable geographies of poverty and opportunity” (Bebbington, 2004: 738). In fact, Bebbington points out the importance of the role played by the political economy and the fact that:

¹⁷⁰ Couldiaty uses the words ‘*assistance technique*’, which she says is different than ‘voluntary work’. ‘*Assistance technique*’ would translate into ‘technical assistance’, but here I am using ‘development workers’ rather than ‘technical assistant’.

¹⁷¹ A town in the Centre-Ouest region.

¹⁷² Hauts-Bassins, Cascades and Sud-Ouest regions.

¹⁷³ Grassroots organisations including DPOs.

livelihood and NGO geographies... are structured (if not determined) by the wider politics of aid and political economy of development. Rural livelihood strategies – and the spatial forms they take – reflect the geographies of capitalist expansion and contraction.... Urban migration reflects the overall bias of capital investment.

(ibid)

Although Bebbington is talking about South America, his observations apply equally well to Burkina Faso and reflect the reality of the urban–rural division discussed in Chapter 4. Thus, the geographies of INGO interventions, the type of beneficiaries they engage with, and the types of interventions they implement, play a role in DPO functioning and, ultimately, in disabled people's lives. The INGOs that work in the disability sector in Burkina Faso intervene in various aspects of disabled people's lives, including treatment and rehabilitation (especially church organisations), capacity building, training and awareness raising (for example, on disabled people's rights) and income-generating activities (IGAs)¹⁷⁴. The latter type of intervention is significant in this research and for disabled research participants, for whom employment, as mentioned before, is of primary importance.

Income-Generating Activities

Colonisation, in its modern form, is the product of a given economic and political system: capitalism.

(Bamouni, 1986: 23, my translation)

In the 1970s, following the argument that development should not be dependent on the state for the provision of services, but should propagate self-reliance, INGOs endeavoured “to design income-generating projects so that people would have the resources to look after their own welfare, either by providing services themselves or by mobilizing to obtain services that they determined from the state” (Nelson and Wright, 1995: 3). These approaches were then reiterated in the World Bank's Structural

¹⁷⁴ According to Neufeldt (1995: 163) “[t]he term ‘income generation’ often is used in low-income countries to describe small scale (micro-) enterprises”, often operating in the informal sector.

Adjustment Policies in the 1980s, “which moved functions from the state to the private and non-governmental sectors” (ibid). In 1990, a Burkinabe NGO¹⁷⁵ contended that NGO work should develop a stronger economic focus rather than focus on social needs, as NGOs had done up until then. Thus they proposed that NGOs should support people in becoming productive through income-generating activities and “training them so they can be more independent” (Sharp, 1990: 41).

Discussing the best way to generate livelihoods for disabled people, Campos (1995: 72) suggests that “promoting self-employment seems to offer the most hope”. Self-employment usually means that a person has and manages his/her own business, enterprise or service (Neufeldt, 1995). Campos (1995: 82) observes that:

Self-employment, properly tackled is a viable income generating option for many people with disabilities. The person with disabilities makes the decision and assumes a responsible and creative role in the enterprise. It usually involves the whole family, who provide the support, security, and often times the skills needed by the person with disabilities.

Neufeldt (1995: 163) also refers to “self-directed employment”, which includes self-employment, but extends to situations where disabled people have a primary decision-making role. This includes “groups of disabled people operating their own business, worker cooperatives, as well as organizations of disabled persons forming business subsidiaries”.

Campos (1995: 83) argues that “[i]n economic terms, self-employment represents possibly the most cost effective way of creating jobs. Capital requirements [loans for income-generating activities] are usually very small.” She continues to say that:

[l]oans, rather than grants, have proved helpful in instilling values of responsibility and commitment. The borrower tends to take the enterprise seriously and makes the effort to succeed. With steady repayments, additional loans are made available for those who need the money for expansion or to enter a new business in addition to an already established one.

(ibid)

¹⁷⁵ *Bureau d'Etudes et de Liaison* (Centre for Research and Liaison).

However, in reality, loan schemes do not always work out this way. A regional director of the Ministry of Youth, Skills Training and Employment¹⁷⁶ (Interview, 16th April 2015) describes a programme which the Ministry has put in place to help young people start self-employment ventures. The fund¹⁷⁷ loans out money (ranging from 200,000 Francs to 2,000,000 Francs for individuals and up to 5,000,000 Francs¹⁷⁸ for associations) to young people (from fifteen to thirty-five years of age) wanting to start small businesses, and gives disabled people a two percent interest rate instead of four percent for non-disabled males and 3.5 percent for non-disabled females¹⁷⁹. The director talks of how, sometimes, the funds available do not suffice to give out loans to all those who qualify, meaning there is not enough money for everyone, one of the reasons being that:

those who take [the loan], since it is the state [which finances it]... even if it [the business] works, they don't repay it, because there is no rule... to repay... if they don't repay, we cannot put them in prison... so sometimes the rate of repayment is very weak...

Nevertheless, when people come together of their own accord at a grassroots level and decide to do something with the little money they have, it may have more positive effects, albeit perhaps on a smaller scale. Adama (Interview, 2nd October 2014), the president of a DPO in Bogandé, describes how, for about ten years after the DPO's creation twenty-one years ago, the members paid contributions of 100 Francs each. They obtained a field of peanuts and cultivated it. The money they contributed was used to provide food while they worked. After the harvest, if a member needed, s/he could borrow the harvested peanuts. Thus, for instance, if in a given year the person borrowed two platefuls of peanuts, the following year the person would repay three platefuls.

¹⁷⁶ *Ministère de la Jeunesse, de la Formation Professionnelle et de l'Emploi.*

¹⁷⁷ *Fonds d'Appui aux Initiatives des Jeunes*: Fund for Supporting Young Persons' Initiatives.

¹⁷⁸ Equivalent to (approximately) £5,630.

¹⁷⁹ Ironically, the regional direction of this ministry in Banfora, where this interview was being held, is situated on the first floor of the Post Office building, which can only be reached by a long flight of steps, thus rendering the direction physically inaccessible for a large number of disabled people.

There are several of these informal ventures among groupings of people in Burkina Faso. The tontine is a system of lending and saving which consists of paying contributions in a group (of relatives, friends, neighbours), from which one member would benefit, each in their own turn, from the collected sum. It is often the means of making an important purchase which would otherwise not have been possible. The group would be restricted enough for the members to benefit without waiting too long, but big enough to have at their disposal a large sum without having to contribute excessively (LAFB, 2007). In this kind of group-based lending, peer-monitoring would act as a control mechanism in lieu of physical collateral from the part of the borrower (Lepenies, 2014). It is also becoming increasingly frequent to see women in a village create an association to develop income generating activities. The necessary resources come from their own contributions, but, most importantly they can benefit from grants from NGOs (including various organisations, associations and twinning entities), who otherwise refuse to support women individually (Sidibé, 2008). This is often the case for disabled people as well, where INGOs often refuse to support them individually.

These ventures, although on a small scale, help make up for the lack of possibilities of taking out loans. As Alassane (Interview, Banfora, 19th March 2015), a DPO president, confirms, all the banks, including the *Caisse Populaire*, require the person to provide a guarantee to take out a loan: something most people cannot do. Since banks do not have enough information on the poor borrower, the bank cannot calculate the risk which would arise by giving credit to the informal sector (Lepenies, 2014).

Despite all the hype about the role of microcredit in helping to fight poverty (Roesch, 2006), it does not seem to have had the expected results. In Burkina Faso, for example, the microfinance scene is quite opaque. Statistics are hard to come by, and the general information disseminated is often unverifiable. The rates of interest are often unknown by clients (LAFB, 2007). Most research participants do not seem to know about microcredit schemes, or else they consider microfinance in the same light

as the classic bank loan system: that is, as unreachable, both literally (because agencies are too far away) and figuratively (because of the obscurity of the scheme).

INGOs, recognising the importance of supporting livelihoods, tend to work with disabled people in groups doing artisanal work. A UK-based NGO with a country office in Ouagadougou supports DPOs in doing group-based IGAs. Another UK-based NGO working with disability (which has since stopped intervening in Burkina Faso), similarly supported DPOs, such as disabled women's organisations, in doing group activities such as basketwork. The larger part of IGAs started by these two INGOs between 2004 and 2010 today do not function anymore, especially those outside the capital city. For example, in the Comoé province, three IGAs were started with three different grassroots DPOs by the former INGO, two of which do not function any more today. One of these IGAs consisted of furniture-weaving (see Figure 6.1) with a DPO of visually disabled people. The furniture-weaving project, set up in the Centre of Disabled People in the town of Banfora, began productively but trickled down to almost nothing after a few months.

Seydou (Interview, 20th February 2015), a blind man who owns a successful soap-making business in Ouagadougou, observes that:

Artisanal work was a type of work that was there: one doesn't know where to go, so one does it to survive. But it's outdated... there are machines to produce fabric rapidly: whether we want to or not, this is what's going to work... we must go where it's cheaper!

Seydou also remarks that while he alone can produce one thousand soap bars per day, artisanal work takes much longer, thus rendering less profit. He takes the example of weaving one bag during a whole week and then selling it for 1000 Francs¹⁸⁰, which would be equivalent to earning 200 Francs per day. Seydou (ibid) suggests that instead of artisanal work, disabled people should learn how to make soap: "because even the last person on earth... buys soap", thus the disabled person who produces soap will never be out of work. On the other hand, people buy furniture like

¹⁸⁰ Equivalent to (approximately) £1.10.

deckchairs once in a while: Souleymane (Interview, 9th March 2005), the head weaver of the furniture-weaving workshop in Banfora, says that one can sell one deckchair every three or four months. This is confirmed by Alfred (Interview, 10th April 2015), the president of a DPO in Bobo-Dioulasso, who says that the market for artisanal deckchairs is disappearing because it is saturated. Furthermore, Seydou (Interview, 20th February 2015) points out that the models of furniture change; but in artisanal work, the same model is woven again and again, so people do not want to buy them any longer. Thus, as Ibrahim (Preparatory Meeting, 13th September 2014), a non-disabled person who has worked for many years with the same blind people DPO in Banfora (quoting Dr Siaka Diarra, a blind Burkinabe doctor who worked incessantly for disabled people's rights) says, blind people can do furniture-weaving very well, but it is not going to nourish them. Seydou (Interview, 20th February 2015) similarly observes that:

Disabled people... they don't manage to feed themselves from [artisanal work]... meaning they are in an old-style system, an outdated system... NGOs and others who come to help them, help them within the same system which leads to nothing... it doesn't result in anything reliable.

Furthermore, as Campos (1995: 72) wryly asks, "is it really our experience that someone who goes blind at a late age suddenly develops a burning desire to make a basket or a mat?" In advocating for Community-Based Rehabilitation (CBR), she calls "associating blind people with basket-weaving" "job-typing" (Campos, 1995: 74). It seems that, in this sense, INGOs are going back to these rehabilitation and vocational training centres that were practiced before CBR was implemented. Without singing the praises of CBR – it has been criticised on numerous fronts (for example, Lang, 2000; Miles, 1996; Murphy et al, 1988) – the point here is that 'job-typing' is not only patronising, but does not yield the best results. Furthermore, as Seydou (Interview, 20th February 2015) points out, artisanal products are not feasible to produce anymore. As the president and vice-president of a DPO made up of 4 physically disabled (and 1 non-

disabled) men (Interview, Ouagadougou, 26th November 2014) observe, people prefer to buy cheaper products – which are mostly imported from China¹⁸¹ – rather than the more expensive artisanal work, which, though consisting of better quality (and are possibly aesthetically superior), are obviously less affordable to the majority of the population. Thus, artisanal products are more marketed towards foreigners and are exhibited at expat hangouts, including at events such as the biannual SIAO ¹⁸², an international show of crafts where various African artisans show and sell their crafts. The market for these artisanal products is thus limited. Additionally, many cooperatives of disabled people producing artisanal products do not have outlets through which to advertise and sell their products, a problem plaguing many of these small organisations. Other arguments have been made that people prefer buying products from non-disabled artisans. Karim (Interview, 23rd September 2014), a blind man in Fada N’Gourma, relates:

There are several deckchair weavers... in Fada, so, you see... because you are visually disabled... if... they don’t come to see you weave, they might think if they put in an order, maybe since you don’t see, maybe you will do it wrongly [thus]... a non-disabled person can maybe have more orders than a visually disabled person.

Nevertheless, the umbrella DPO of blind people’s DPOs, UN-ABPAM, insists that blind people will have assured revenue with furniture-weaving. On its website¹⁸³ (my translation), it proclaims that:

Those [visually disabled people] who excel in this practice find an assured source of revenue.

It *does* continue to say that woven furniture sells better in the city than in the villages. Not everyone agrees with this, however. Seydou (Interview, Ouagadougou, 20th February 2015) affirms that even those blind people who work in weaving at the UN-ABPAM in Ouagadougou do not earn

¹⁸¹ What Burkinabes call *chinoiserie*, a pejorative term used for cheap, easily-breakable Chinese products, which can range from children’s toys to motorbikes.

¹⁸² *Salon International de l’Artisanat de Ouagadougou*: International Craft Show of Ouagadougou.

¹⁸³ http://www.un-abpam.bf/suite_activite.php

enough to feed themselves: “the beggars are better off than those who are there”.



Figure 6.1 Furniture-Weaving

When asked why they chose to engage in an unfeasible activity¹⁸⁴, Amadou (Interview, 5th March 2015), one of the blind participants in the Banfora workshop, replies:

We had chosen to do this because we do not want to stay with our arms crossed like this, without doing anything. We do not want to be taken care of by our relatives, and be a burden on them, or our friends or other people.

When asked why their DPO chose to engage in furniture-weaving, Daouda (Interview, 26th November 2014), a DPO president in Ouagadougou says:

[We] chose weaving because of lack of means.... [Our] action plan includes many activities: [we] want to do a welding workshop where [we] would have trained all the disabled people who would work

¹⁸⁴ This was the second time the same DPO had obtained funds to carry out the furniture-weaving activity: Years before, another INGO had funded the same activity for the same DPO. Despite the activity's failure, the second INGO funded the same activity with the same DPO some years later.

there; but due to lack of means, [we] do not have this. Thus [we] saw that weaving does not necessitate a lot of money to do, and there were some [members] who were already doing this work, so [we] thought it was better to engage these people in the meanwhile. If [we] gain the means to do the rest [of the planned activities]... such as welding... [we] would do them.

Amadou (Interview, 5th March 2015) confirms this, saying that furniture weaving is an easy activity for them to do, and not expensive to fund. Underlying Amadou's arguments are the power relations at play in INGOs' interventions with DPOs. The INGO which funded the furniture-weaving project decided to intervene with Amadou's DPO and place a fund at their disposal, which the DPO could use to implement an IGA. Evidently, the DPO is grateful for the INGO's financial support and accepts it. This is partly an issue relating to culture, as highlighted by Kafando (2007: 188, my translation):

I have met... numerous French who give a lot of their time and their money to help... Burkinabes. They should be thanked. In our African cultures, it would be discourteous not to do so warmly or to let them think that the services rendered do not go right to our hearts. This traditional manner pleases the generous people who are, in this manner, comforted... but sometimes risks altering their judgement on the real good of the service rendered.

However, INGOs in Burkina Faso have also been criticised on the non-adaptation (and the resulting inefficacy) of certain actions (LAFB, 2007). Implementing the furniture-weaving IGA is within the comfort zone of both the DPO – as Amadou indicates (it is an activity they know well, one they have already been trained in, and one they know INGOs like to fund) – and the INGO: this INGO worked with Amadou's DPO on another INGO's suggestion, thus assuming that the DPO is trustworthy and capable of producing results, and funded an IGA which is funded repeatedly with visually impaired people.

Finally, DPOs are not impervious to misappropriation of funds, or corruption, which is rampant in Burkina Faso. Corruption is common especially in the civil service (especially in, for instance, departments relating to customs and infrastructure), where government officers 'hurry

up' the process (such as signing of papers) or close an eye, if the service user pays him/her. It seems to be accepted by a large number of people. Those worse off are those who cannot pay and those less educated, thus the majority of Burkinabes (LAFB, 2007). Beti (1986: 8, my translation, italics in original) harshly criticises this:

Corruption is the major tragedy in our societies, their calamity, perhaps their shipwreck, as was the slave trade in a time where, already, in exchange for a handful of worthless objects, black indigenous chiefs handed over their brothers in their hundreds to the slave hunters.

Beti (1986: 8-9) continues to say that corruption obstructs, to the point of blocking, all the paths which could open the way to progress in Africa. Corruption also destroys the meagre heritage left by the coloniser before "devouring the entrails of the reduced black continent". Nonetheless, in the context of INGOs' interventions with DPOs, it is necessary to understand misappropriation of funds in the light of the nature of projects and programmes which are funded. In the case of the furniture-weaving IGA, the DPO members knew that the INGO's funded project would end after three years, after which the DPO would have had no more financial support. INGOs' interventions with DPOs are generally temporary, whether the duration is months or years. DPOs thus have to make the 'best' use of the INGOs' funds while they still have them. For some DPOs this means using the funds to have a few paid staff, saving as much money as they can, and engaging in some extra small profit-making activities (such as renting out their chairs) so as to be able to have enough funds to continue functioning once the INGO stops the partnership with them (Interview with Zenabou, Ouagadougou, 20th January 2015). For other DPOs, however, it means making hay while the sun shines and benefiting personally while it is still possible. As Seydou (Interview, Ouagadougou, 20th February 2015) comments:

In artisanal work, during the time that you don't sell anything, what does one do?... You become a crook: you are obliged to become a crook.... [Artisanal work] doesn't even solve the problem when your child falls ill: when you pay for his treatment, the money is

finished already. How will the person manage then? The [choices]... he is left with are either begging or lying to get money.

This is not to say that group IGAs never work. Campos (1995: 83) observes that:

If the group has the right leadership this form of self-employment [group enterprises] has some obvious advantages. The people involved can share the numerous responsibilities of business, they have company as they work together and they can benefit from the support and encouragement of each other when problems are encountered.

Campos's statement is liable to various critiques, ranging from the failure to note that group enterprises can be made up of both non-disabled people and disabled people, and not necessarily just disabled people, to the patronising tone of the statement. However, there is also some truth to this, as shown by the example of the DPO in Bogandé discussed earlier. Furthermore, it does not mean that working individually necessarily means being successful. The point being made here is that INGOs, if their interventions are to have impact on disabled people's lives, need to be more attuned to disabled people's lived experiences. This need is evident not only through the projects and programmes that INGOs implement, but also in the ideologies that frame these interventions, to which the following section now turns.

Provincialising Disabled People's Rights

[T]he human rights actor is really the latest in a lineage of European dominance that includes the colonial administrator and Christian missionary.
(Tampio in Meekosha and Soldatic, 2011: 1389)

The main ideology underlying the work of INGOs with disabled people in Burkina Faso is the social model framework. The human rights approach, which is based on the social model of disability, is given particular importance by the major INGOs working on disability in Burkina Faso. One INGO, for example, conducted a human rights awareness-raising campaign in the Est region in the mid- to late 2000s. Another INGO

adopts the human rights framework through an assumption of its importance being a commonality for disabled people:

LB: What do you think disabled people want of development...?

CEO: ... I think... there are some commonalities across what disabled people expect and that's all about rights:... we operate a human rights-based approach.... So I think that the commonality is access to their basic human rights; and that's about access to health care, access to education, access to... you know, a *normal* way of life.... So I think there is common ground in terms of the human rights approach, which is what we use across all our programming anyway.

(Interview with INGO CEO,
York, 5th June 2014)

Thus, given the importance of examining the “social model thinking about disability in the majority world and the way in which its insights have been translated in practice” (Sheldon, 2005: 16), the human rights ideology is examined here in relation to its implementation with disabled people in Burkina Faso.

Henri (Interview, 19th February 2015), a disabled activist in Ouagadougou who works as a legal practitioner at the National Assembly gives an overview of disabled people's rights in Burkina Faso:

The convention¹⁸⁵ and its protocol were ratified by Burkina Faso... on the 23rd July 2009. And... until today, the initial report... has not been sent to the committee of rights of disabled people! It had to be sent by 2011... No report has yet been sent! This text is there only to give the impression that disabled people are being taken care of. And disabled people unfortunately have not understood this, here in Burkina Faso. When I talk of rights, people haven't understood... people do not have the same vision of rights as me.... They find it's useless!... And yet everything is found in human rights: right to food, right to health, right to education, right to social security, right to participation in public life... everything is... in... the convention... and the general principles are clear!

Henri talks passionately of human rights and the need for people to know and advocate for their rights. However, a subtler point is made by the an INGO national director (Interview, Ouagadougou, 18th May 2015).

¹⁸⁵ UN Convention on the Rights of Persons with Disabilities (CRPD).

Although he emphasises the need for rights to be popularised among, and simplified for, disabled people and the country at large in Burkina Faso, the director points out that there is a difference between those who fight and benefit from their rights (who tend to be in urban areas) and those who live in more remote rural areas who neither see the benefit of human rights nor fight for them:

To ensure that disabled people really benefit from all the [legal] texts that... the country has ratified... disabled people themselves should know these texts.... Those who know them are... the strongest, and who defend the texts and manage to benefit. But the disabled person who is deep in the village, who doesn't know how to write or read, doesn't know there is an invalidity card, he doesn't know what advantages he has for certain aspects of social life... thus he cannot defend his rights. So, there is a need to popularise the texts.

The 'strongest' disabled people, that is, the ones whose voice is heard more than others', benefit more from human rights approaches than others. Furthermore, disabled people in urban areas tend to have more knowledge of human rights instruments than those in rural areas; they thus tend to defend them more and concern themselves more with the benefits they might provide. However, for someone who is struggling to make ends meet, legislation stating their rights to gain a living means little. The actual opportunity to make a living, which is discussed more in the subsequent chapter, is what many disabled people in Burkina Faso prioritise. For example, Issa (Interview, 21st January 2015), the president of a DPO in Ouagadougou, says:

It is difficult to talk to an illiterate [person] who is poor: you talk to him about rights, he does not even know what it means. But if he is educated, or if he receives training: if he has 1000 Francs in his pocket, every day, if you talk to him of rights... he will listen, because he knows he will eat. This is the reality... in the country.

Issa contends that disabled people need first to survive, recalling Zimbabwean disability activist Joshua Malinga's argument (in Baird, 1992) that while people in western contexts are talking about independent living and better services, disabled people in the Global South are talking

about survival. Yet, Henri (Interview, 19th February 2015) complains that since disabled people do not know their rights, they cannot then defend them:

Many disabled people have gained access to school, developing themselves and starting to understand that, today, we must reach out towards disabled people's rights. To promote this issue of rights, people must really know... [the texts] which are adopted in favour of... [disabled] people. And this enables them to evolve a bit... and to know the worth of [human] rights.

Henri's argument is not an invalid one: disabled people need to defend their rights to push the state to observe them. Nonetheless, as the INGO national director observed earlier, it is the relatively advantaged and less marginalised disabled people who benefit from rights: Henri has a full-time job in Ouagadougou, a good level of education and stability. Therefore, while focusing "on rights might improve the situation for some more fortunate individuals" (Sheldon, 2005: 123), a disabled person living in a remote rural village, who, as the director observes, would not generally have knowledge of human rights laws, would not concern him/herself with the same laws. The need to survive also contributes to the demise of DPOs, discussed earlier: the priority of surviving rather than dedicating time to a voluntary post which does not render any financial benefits pushes people to abandon DPOs. Thus, although people's right to life is enshrined in the rights, people need to survive in order to be able to fight for their rights. The sense of disabled people's disenfranchisement with human rights is not helped by the lack of access (including illiteracy) to human rights texts in rural areas.

Moreover, when rights are not enforced in practice, it makes little sense to give importance to written law. Benoit (Interview, 27th September 2014), a physically disabled person and the general secretary of the DPO in Kompienga, demonstrates the difference between written law and the practices that infringe the rights it supposedly guarantees:

Hélène [a disabled girl], wanted to enrol [in the school]... here. When we [representatives of the DPO] went [there], the headmaster

said no...! [However], there is a law that says that all disabled people have the right to enrol in the school closest to their locality!

Situations like these lead to the question, posed by Young and Quibell (2000: 752), “[W]hat is a ‘right’ when it means nothing legally?” This situation is also brought about by the lack of knowledge of rights by those who should implement them, as the same INGO national director (Interview, Ouagadougou, 18th May 2015) points out:

The state must make the effort so that those who are in charge of putting these texts into practice, know them.... The laws are not known by those who should put them into practice.

Besides the lack of knowledge, a problem arises from the responsibility of the individual state in implementing these guidelines, particularly in less wealthy countries where government resources are limited in bringing about drastic changes in disabled people’s lives: “‘lack of resources’ has become the rationale for ignoring, or failing to implement, policies for [the] disabled” (Sheldon, 2005: 123). The INGO national director (Interview, Ouagadougou, 18th May 2015) argues that “this is the role of DPOs: to make the texts known, not only by disabled people themselves, but also by the state”. However, as was discussed in the previous section, DPOs in Burkina Faso do not play their role as advocates to the full. Furthermore, lobbying for rights which are not implemented creates a sense of frustration, as seen in Henri’s comments. This also relates to the wider Burkinabe context, where European ways of living evoke frustrations in those who were not brought up in them and those who cannot live in the same way:

In the city, those who have left their village and who are hardly prepared to face life ‘in a European fashion’ rub shoulders with those who, at school, at university, in their ‘developed’ family environment, have learnt to appreciate the benefits of ‘civilisation’. The first group... have lost their reference points and their framework... and have not assimilated the... European ‘model’. [Europeans]... have created needs, desires, ambitions in the lives of these runners-up. But the... local resources and economical possibilities are not at the level of the aspirations stirred up.

(LAFB, 2007: 12, my translation)

Meekosha and Soldatic (2011: 1388) argue that human rights discourse forms part of the continuation of colonialism “whereby the hegemonic North determines the constitution of human rights, ignoring the inherent global power imbalances” (ibid):

Given the close connection between poverty and disability, it could be argued that a redistribution of power and wealth both between rich and poor countries and within poor countries could have more impact on the lived experience of disabled people in the global South than would human rights legislation. Human rights instruments do not address issues of the distribution of wealth and power, and wealth has not historically been redistributed without struggle on the part of the powerless.

(Meekosha and Soldatic, 2011: 1389)

This argument sets the issue of human rights legislation in the wider context of power and wealth inequality, and brings attention to the fact that at the heart of development with disabled people lie the structural inequalities both within the country as well as within the North-South divide. Tackling poverty, however, necessitates political will, the absence of which prevents progressive development from taking place (Desai and Potter, 2008). As Meekosha and Soldatic note, wealth equality has never come about without a struggle on the part of those without power. Furthermore, Russell (2002: 121) argues that:

In practice, civil rights, which primarily focus on attitudes and prejudice, have not given sufficient attention to the barriers that the economic structure and power relationships erect against the employment of disabled persons.

Russell makes a powerful argument, harshly criticising the lack of power that rights have to change an inherently unequal society, especially in such areas as employment, which is the most salient factor in disabled people in Burkina Faso’s concept of development:

If we conceptualise disablement as a product of the exploitative economic structure of capitalist society; one which creates the so-called disabled body to permit a small capitalist class to create the economic conditions necessary to accumulate vast wealth, then it becomes clear that anti-discrimination legislation, by failing to acknowledge the contradictions of promoting equal opportunity in class-based (unequal) society, is insufficient to solve the

unemployment predicament of disabled persons. Instead, the liberal rights model serves to forestall criticism of relationships of power at the centre of the exclusion from employment and inequality that disabled persons face.

(ibid)

It is in this context that disabled people in Burkina Faso are struggling to rectify the inequalities in which they find themselves, as will be discussed in the subsequent chapters.

Human rights, therefore, might not be as universal, and thus not as pertinent, as is often assumed in the west. The universality of rights has been contested by various scholars: the mere question of the universality of human rights is a western concept, according to de Sousa Santos (2007: 12), who insists that “human rights are universal only when they are viewed from a Western standpoint”. Similarly, Lang (2000: 4) purports that the western focus on rights is “rooted in the ideology of individualism” and often runs counter to cultural and social norms in other parts of the world. Individual rights are the fruit of industrialised societies, while many societies in the Global South are agrarian and reflect “more traditional community structures” (Meekosha and Soldatic, 2011: 1388). At the core of the arguments surrounding the application of human rights in a Global South context, however, is the fact that:

[t]he... ‘rights’ interpretation of the social model, whilst generally acknowledging the realities of the materialist model, understands disability to be the irrational product of deep-rooted cultural beliefs, attitudes and prejudices.

(Sheldon, 2005: 119)

In this context the emphasis of disablement is on societal prejudices:

people with impairment are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization.

(Shakespeare, 1994: 296)

However, such analyses are not only racist and colonial, encouraging a judgemental approach to traditional belief systems and practices, but also take away the focus from the connection between disability and the global economy, and disablement as a result of the “capitalist mode of

production”, leaving the capitalist system uncritiqued (Sheldon, 2005: 118-9; 123). As Gleeson (1997: 196) argues, “disability cannot be dematerialised and explained simply as the product of discriminatory beliefs, symbols and perceptions”. Disabled people cannot be emancipated through human rights alone, but only by “questioning the very basis of the rules of the market” (Russell and Malhotra, in Sheldon, 2005: 124).

Assuming that disabled people and DPOs in Burkina Faso “will evolve to the ‘higher’ standards of Western human rights, such as the recognition of individual rights” (Meekosha and Soldatic, 2011: 1388), is another version of colonialism. It evokes the colonial era where European colonisers assumed that colonised countries will achieve the ‘developed’ state of western countries at a point in the future. In the meantime, they were relegated to what Chakrabarty (2000: 8) calls the “waiting room of history”. The assumption that disabled people in countries in the Global South will achieve the ‘advanced’ state of human rights protection at some point is portrayed by such scholars as Groce and Kett (2013: 7):

Unfortunately, this progressive reframing of disability from a 19th Century ‘charity model’ to a 21st Century ‘human rights model’, has barely begun to [be] permeated within the international development community.

Furthermore, INGOs do not only lay the path for DPOs, but they also set the pace. Michel (Email Exchange, 16th January 2012), a regional coordinator of DPOs comments that:

NGOs often want results in two or three years: it’s like making someone run faster than his abilities. [And] when they [INGOs] stop, everything stops. NGOs often impose their process to follow on DPOs. NGOs should reflect on how to enable DPOs to be financially autonomous with regard to IGAs [income-generating activities].

Michel’s argument suggests that DPOs, or the disability movement, in Burkina Faso might develop in different ways and based on different values than those in western contexts. Many research participants consider the principal cause of people with disabilities to be having gainful employment:

- LB: Are you a member of a DPO?
- D: ... [I] am a member of an organisation...
- LB: Why did [you] become a member of the organisation?
- D: ... [I] became a member so that disabled people can gather and give each other advice to be able to fight for the cause of disabled people.
- LB: And what is disabled people's cause?
- D: ...For example, [we] don't have any work; most [disabled] people don't have work... so when [we] meet, those who want work... [we] can have advice and awareness raising, so when there is aid, [we] would know who can do what.
- (Interview with Dieudonné (physically disabled man),
Tibga, 21st October 2014)

INGOs therefore need to listen to disabled people, know the reality on the ground and understand disabled people's needs before designing or implementing development interventions. Ismael (Interview, Ouagadougou, 2nd February 2015), a physically disabled man, asserts:

- I: Before helping disabled people, before helping the organisations, [you]... must first of all listen to them, and know what they want, and not what you want... and the goal is to question yourself each time 'is what I'm doing enabling the person to be autonomous?' For me it's the thing that is most important:... you must do things that enable the disabled person to be autonomous.
- LB: Like what, for example?
- I: Like finding them work, or to enable them, for example, to create a business, or enable them to have housing, things like that.
- LB: And NGOs don't do this?
- I: No.

As Désirée (Interview, Ouagadougou, 13th February 2015), the president of a DPO in Ouagadougou, notes:

- D: [INGO intervention] is stuff that's already decided... it's as if there is no aid for disabled people. There is still the impression that the disabled person has no support. And yet it's aid that they don't need, that is, they [INGOs] have not first done a serious study on the real needs of the disabled person: are these his real needs? But there is aid: if someone gives you 10 Francs, you wouldn't say 'I don't want them, because it's not 10 Francs that I want'. You take it, always hoping.... Maybe it's not this that I wanted, it was something else.... As we like to say, a bird in the hand is better than two in the bush... so if they tell you 'Here, have this', you take

it... you cannot refuse it. This is, actually, the great problem of the disabled person...

LB: What is... [disabled people's] real need?

D: Each one of us has their own [individual] needs.

The detachment of INGOs from the needs of disabled people also needs to be viewed against the wider backdrop of the role of the state in disabled people's lives in Burkina Faso, which plays a significant role in disabled people's lives.

THE ROLE OF THE STATE IN DISABLED PEOPLE'S LIVES

[T]he authorities...: disabled people are their last concern.

(Interview with Henri, Ouagadougou, 19th February 2015)

INGOs play an increasingly important role in providing social services such as literacy, health and employment programmes for the poor, both in response to, and perhaps promoting, the withdrawal of the state (Kamat, 2004). However, Daouda (Interview, 26th November 2014), the president of a DPO in Ouagadougou, argues that INGOs should set the example for the Burkinabe state:

LB: So how, do you think, can the disabled person evolve?

D: ... it needs exterior aid: if [our] organisation obtains an aid which comes from exterior sources, and [we] start working, the work gets results, people see this... [and] the state will then be encouraged to help too.

Daouda's argument expresses more than dependency on INGOs for the improvement of disabled people's lives. He puts the onus on them to preempt and encourage state intervention and support. When asked whether the process would not work the other way, that is, whether INGO intervention would not encourage the state's retreat, Daouda insists that it does not work this way in Burkina Faso: the government helps those it sees as worthwhile investing in, such as established and well-known DPOs, which enhances the government's profile by helping them. Thus, as with the tendency for INGOs to support successful and established DPOs, when the government sees INGOs helping DPOs, it is encouraged to follow suit in order to boost its image. Daouda's argument in suggesting that

INGOs need to lead the way for the state to follow suit, also reflects the reality of the state's operations in the disability domain in Burkina Faso. An example is the work of the Direction of Inclusive Education¹⁸⁶ within the Ministry of National Education and Literacy¹⁸⁷. The activities of the Direction (which include promoting inclusive education through awareness raising and training) are financed by the partners including INGOs. Furthermore, the Direction operates only in the zones of intervention of the partners:

LB: Why in these regions specifically?

Officer: ...Normally we are accompanied by NGOs... and normally NGOs already intervene in these zones. So to... make their interventions easier, they advise us to go there. Also, they already have an idea of the mentality [and] the difficulties of disabled people in these regions.

(Interview with officer, Ouagadougou,
11th May 2015)

The factors discussed above set the context for the general feeling among disabled people in Burkina of neglect by the government. Clementine (Interview, Ouagadougou, 13th February 2015), a physically disabled woman, maintains:

C: The government does not take care of us at all. Instead of putting the emphasis on people with disabilities, this is not the case.

LB: What do you want the state to do?...

C: It should take care of disabled people.

LB: Like?...

C: Like, at the level that we need. For example, the people who have a skill but cannot find work: to improve their... work. They can give them loans which they can pay back bit by bit: they can do that, can't they? They can give the... market for an order to disabled people.

Clementine argues that the government can help disabled people by supporting them in their enterprises, either by giving loans with feasible conditions, or by entrusting them the market when there is a requisition order, especially when the products to be produced are destined for

¹⁸⁶ *Direction de l'Education Inclusive.*

¹⁸⁷ *Ministère de l'Education Nationale et l'Alphabétisation.*

disabled people, such as three-wheel motorcycles. Evidently Clementine formulates her views of the role the government should take in disabled people's development in terms of employment. This recalls Kamat's (2004) argument that the responsibility of the state as a cause and a solution to poverty has been removed: the onus is now placed on the individual, which is partly the result of the emphasis that INGOs have put on the poor becoming entrepreneurial and finding solutions to their livelihood challenges. This perhaps explains why disabled people in Burkina Faso view disability as an individual problem and see themselves as having to struggle alone to achieve success, which is defined mostly as economic independence (discussed in more detail in the subsequent chapter). Kamat (2004: 169) also argues that in the absence of critical education and awareness raising, "alternatives to the dominant economic regime are less likely to emerge, as are new understandings of collective good". Lacking other ways of formulating their development, disabled people like Clementine frame their needs in terms of livelihood security, which is seen as possible only within the informal sector. Nevertheless, this does not necessarily demonstrate a preference for working in the informal sector. The 'dream job' in Burkina Faso is becoming a civil servant (Domboué, 2004) and, given a choice, the poor would without hesitation opt for the protection of a salaried employment, rather than developing through entrepreneurial activity in the informal sector (Roesch, 2006). Ahmed (Interview, 10th April 2015), a blind man who is a trader in rice and other food supplies in Bobo-Dioulasso, comments on this issue:

LB: Why did you choose to go into business?

A: Well, I chose to go into business because... other opportunities were not open to me, especially in terms of the civil service.

Hélène, a physically disabled woman in Kompienga, confirms this view:

LB: What do you wish for your future...?

H: Well, for my future... you have to be a salaried worker...for example to be employed in the civil service...

The director elicits two significant challenges when it comes to state intervention with people with disabilities. First is the belief that disability is a specialised area best left to specialists, an issue stemming from the perception of difference and the focus on what is different, rather than shared, between disabled and non-disabled people. This line of thought is present at the national level, where many of the authorities interviewed do not mainstream disability in their policies and programmes. Disability is often considered as an issue to be taken care of by the Ministry of Social Action and National Solidarity (MASSN)¹⁸⁸. A regional director of the Ministry of Youth, Skills Training and Employment¹⁸⁹ (Interview, 16th April 2015) gives such an example:

LB: Does the ministry carry out interventions with disabled people, or in the domain of disability?

Director: As I said, in principle, there are no actions aimed specifically at people with disabilities, in light of the fact that in Burkina Faso... there is a ministry which... deals with [disabled people]: the Ministry of Social Action and National Solidarity; because this ministry personally deals with social cases, whether it is floods, catastrophes, unfortunate cases, people with disabilities, etcetera.

This is linked to the debate about whether disability should be mainstreamed in development projects or is just an added issue to be taken into consideration after the policy or project is designed (Jones, 1999). This second challenge that the INGO national director speaks of, relates to the belief that disabled people are 'like everyone else' and will benefit from a policy or programme from which the whole population benefits. Rather than contradicting the first argument of not focusing on difference, critics have argued that disabled people do not necessarily benefit from development policies and programmes like everyone else. For example, Groce and Kett (2013: 4) argue that while millions of people have benefited from international development efforts in such areas as health,

¹⁸⁸ However, as a regional director of the MASSN (Interview, 26th March 2015) states, this same ministry has one of the smallest budget of all ministries in Burkina Faso.

¹⁸⁹ *Ministère de la Jeunesse, de la Formation Professionnelle et de l'Emploi.*

education and economic development, disabled people “lag increasingly behind their non-disabled peers”. This ‘lag’ is the “disability and development gap” (ibid: 3). Groce and Kett maintain that when everyone in a community live in extreme poverty, there may be relatively no differences between the access to resources and services of disabled people and non-disabled ones. The differences start showing when communities start to emerge out of poverty:

For example, if no school exists and no children in a village receive an education, the life of a child with a disability is little different in many respects from her siblings or peers. But if a school is built and every child in the village, except for the disabled child, now attends school, that disabled child is at a distinct disadvantage.

(ibid: 9-10)

Thus, Groce and Kett (ibid: 4) contend:

Unless specific measures are taken to ensure inclusion of persons with disabilities in current and future international development efforts, including the new Sustainable Development Goals (SDGs), millions of persons with disabilities are at risk of living in continuing poverty and social isolation while their non-disabled peers begin to lead more prosperous lives.

This is relevant not only at an international level, but at the national level. As Groce and Kett (2013) argue, many government officials and civil society members do not consider disabled people as being within their remit: disability is either not considered or is regarded as a charitable or medical issue rather than an international development one. This resonates with the INGO national director’s argument that, in Burkina Faso, disability is considered a specialist issue. He puts the onus on DPOs and INGOs to ensure that the policies that the government designs and implements are inclusive of disabled people:

It’s the DPOs and the NGOs who should give... certain solutions to the government so that the policies which are developed are also inclusive of disabled people.

(Interview, Ouagadougou, 18th May 2015)

For DPOs to give solutions, however, they need to be formed into a coherent strong disability movement; while for INGOs to do so, they need

to listen to disabled people and recognise that disabled people's views on disability and development are indispensable in the formulation of policies and development interventions.

CONCLUSION

This chapter has explored the currents that underlie and influence disabled people's organisations in Burkina Faso, their creation, their functioning, and the interplay between DPOs, INGOs and the state. The difficulties of DPOs are partly due to interventions by INGOs, which render DPOs dependent on foreign funding and support. The Burkinabe state's lack of intervention enhances the dependency of DPOs on INGOs, rendering them more or less dysfunctional once the INGO withdraws funding. Intertwined in this precarious context is the unstable political scene that not only pervades Burkina Faso generally, but also at the scale of both grassroots and umbrella DPOs. Nonetheless, the argument here is not that there is no need for DPOs. DPOs provide a space where disabled people meet, whether or not they have similar disabilities. They provide a place in which comfort and solidarity are provided, and where ideas are exchanged. In addition, there is also a case for strength in numbers, which is important for those most marginalised and rendered invisible in society. Although the economic, political and social situation in Burkina Faso might present difficulties for many Burkinabes, people with disabilities need to be recognised in their own right. The DPOs provide an important space in which they have the possibility and opportunity to come together and speak out and fight for what is rightfully theirs. The challenge for Burkinabe DPOs is in finding the balance between being independent and having the right amount of support from INGOs and the state, without that support dictating what a DPO should be and do and without actually debilitating those same DPOs.

The arguments in this chapter raise many questions about the future of DPOs in Burkina Faso. If INGOs and the state support the bigger established DPOs, this raises the question of what the future might

be for the hundreds of smaller DPOs that are constantly created in a movement that continues to fragment. Meanwhile, the INGOs upon which many DPOs depend tend to replicate western models. Thus, while interventions by INGOs may be implemented with the best intentions, the effect of these interventions often appears as a new form of colonialism. Hence there is a need in Burkina Faso for spaces in which disabled people can speak and be heard, and their needs be properly understood by the institutions who have an enormous influence on their lives.

CHAPTER 7

DISABILITY: 'IT IS NOT THE END OF THE WORLD!'¹⁹⁰

Agency and Independence

Benoit, a 32-year old man living in Kompienga, wakes up early in the morning, takes care of his chickens, and has breakfast with his wife and child. Then he heads to the marketplace, where his store is. He opens up at around 7am and closes at around 8pm, sometimes 10pm, depending on the clientele.

Benoit was born in a village in the Centre-Nord region of Burkina Faso. At 16 years of age he was forced to quit school. The decision for him to continue his education depended on his father's brothers, who had to make the decision to sell the family cows to pay for his schooling. They decided against.

Thus, Benoit went to Bilanga to work in his uncle's banana plantation, where they had to watch over the bananas while they were growing, to protect them from cows. Thus they slept in the field at night. On Christmas Eve of 2002, Benoit and his co-workers lit a fire before putting out their mats to sleep on.

It was on the next day that Benoit came to, in hospital: his right arm and both his legs had been burnt to the bone. From then on began a series of hospital visits, to no avail. Finally, a relative of his suggested that he go to a hospital in Benin, where European specialists visit all the time. His uncle put the money needed together and they went to Benin in February of 2003.

Benoit underwent 17 operations. They took flesh from other parts of his body and put it on his arm and legs to cover the bones. He spent a year in hospital. There, he also underwent rehabilitation with the Catholic Mission. He learnt to walk and to write with his left hand. During this time, he met Sayouba, the current president of a DPO in Kompienga. He encouraged Benoit to join as well. Benoit thus moved to Kompienga and joined the DPO, of which today he is the general secretary.

Upon his arrival in Kompienga in 2005, he started working for a policeman, selling mobile phone credit. He was paid 10,000 Francs¹⁹¹ monthly. The owner later moved to another city without paying the bills due at the national telephone company, and the shop where Benoit worked was thus shut down.

So Benoit went to the phone company and made a deal with them: he would reimburse the 400,000 Francs¹⁹² owed them, after which the shop would become his. He worked hard for months, only closing the shop at midnight; barely sleeping for fear that he would not be able to pay the

¹⁹⁰ Benoit, Participatory Video, October 2014.

¹⁹¹ Equivalent to (approximately) £11.50.

¹⁹² Equivalent to (approximately) £460.

bills. However, he finally did. The shop today belongs to Benoit. Even if he does not earn a lot, Benoit says, at least what he earns is for himself. He is happy not to work for someone.

(Interview, Kompienga, 27th September 2014)

Textbox 7.1 Benoit: Life Story

INTRODUCTION

Despite the difficulties [they encounter], disabled people must make the decision to fight.

(Michel (physically disabled man),
Participatory Diagramming, 25th October 2014)

The preceding chapters explored how both self- and societal perceptions of disability in Burkina Faso are inextricably connected to notions of autonomy and economic self-sufficiency. The general view of people with disabilities in Burkina Faso is that they are unable to conduct activities in the same way as non-disabled people and are thus dependent on others for survival. Those disabled people who are more or less financially independent, tend to identify less with being defined as disabled than those who are less autonomous. Among the former, there is also an emerging sense of disability affirmation and of non-tragedy. This chapter explores what lies behind this positive outlook and what leads disabled people to be autonomous and to assert their agency. Benoit, a physically disabled man in Kompienga (see Textbox 7.1) relates the struggles he went through during the onset of his impairment up to when he became economically independent. Benoit is one of the participants of the participatory video (PV), in which he appeals to other disabled people to view disability as not being the end of the world, but rather the beginning of a process. Through Benoit and the other participants in the PV, we see disabled people's agency emerging, not only through their own accounts of their struggles in overcoming the hurdles they encounter in their lives, but also in asserting that their voices should be heard.

In Chapter 2, we saw how the agency of the subaltern and the destabilisation and deconstruction of the cultural authority of the coloniser are two important aspects of postcolonial theory. Although

Spivak (1988) points to the inevitable and problematic power inequalities that persist in attempts to recover subaltern agency, she also says that vigilance of these inequalities should be combined with a commitment to making visible the position of the marginalised (Loomba, 2005) and the creation of spaces in which their voices can be heard. Similarly, albeit from a different perspective, anchored in the disability rights movement, Shakespeare (1996: 111) contends that “[d]isability identity is about stories”, and emphasises the importance of disabled people having a voice, and of having a space in which to tell these stories and have them listened to. Drawing on both the epistemological lessons of postcolonial theory and the overt politics of disability activism, the need to make visible disabled people’s lived experiences and to create spaces in which their stories might be heard comes out clearly. This is particularly the case in a context in which disabled people are targeted for development interventions, very often without any consideration of their experiences, needs and desires. This chapter demonstrates that in Burkina Faso, disabled people’s counter-narratives, their agency and their ideas about development are present and, since they often challenge the dominant narratives established by both the non-disabled society and development agencies, they need to be listened to.

In what follows, I examine how disabled people are challenging the stereotypical portrayal of people with disabilities as passive and helpless. The ensuing discussion explores what disabled people in Burkina Faso see as important for the advancement of people with disabilities and, ultimately, what kinds of development would best benefit them. Stories emerging from the interviews and the participatory video developed with some of the research participants illustrate the importance of including disabled people’s views in designing effective development interventions. They also point to the significance of intersectionality in viewing impairment as one aspect of identity and experience (that is also fundamentally shaped by other aspects such as gender, ethnicity, age and class); and in exploring the lived experiences of disabled people in Burkina

Faso and the factors contributing towards their autonomy and independence.

ECONOMIC INDEPENDENCE AND PROVING ONESELF

Disability is... linked with poverty. So, when people know that you do not have the means, it's a bit difficult for you to do something, because... even... today, people think that when you are disabled and you do not have work, you are a burden, and often people think we are incapable of doing that thing or the other. So... you have to prove yourself, you have to prove that you are capable, before people can trust you.

(Interview with Michel, Fada N'Gourma, 22nd September 2014)

Michel, a physically disabled man, highlights an aspect alluded to in previous chapters that is also shared by the majority of research participants: that success means being financially independent. Related to this, the theme that comes out in numerous interviews with disabled people is the need to prove oneself, to prove that one is not a burden. According to many interviewees, being a burden is how the non-disabled society views disabled people. For example:

People think that you are first of all a disabled person; they don't accord you a lot of attention. And they think you are a burden for society... this is very bad for a disabled person.

(Interview with Michel, Fada N'Gourma, 22nd September 2014)

Today... sometimes people do not detest you because of your disability: it's because you are a burden, you don't have money...if you do an activity¹⁹³ and have money, why would people detest you?... [If] you don't ask for anything, you take care of yourself and you can give money to other people... why would people detest you?

(Interview with Yada (physically disabled man), Diapangou, 24th September 2014)

In proving themselves, research participants at times feel the need to emphasise that they are capable of doing things as well as, or better than, non-disabled people:

LB: And at school, how was it? Did you go to a... [mainstream] school...?

L: Yes, with normal children.

¹⁹³ 'Activity' usually refers to an income-generating activity.

LB: And how was the experience?

L: It was OK, because every time I was first in class.

(Interview with Laurentine (physically disabled woman),
Fada N'Gourma, 20th October 2014)

The founder didn't know me, but... they told him that there was a disabled child in school, and that he managed quite well; so he came to see me in class, and the following year he looked at my grades in school and found that I was the best in school... so he called my parents and told them 'Well, I am very happy with your son... if he continues like this, starting from this year, he will not pay the school [fees] anymore'.

(Interview with Ismael (physically disabled man),
Ouagadougou, 2nd February 2015)

[I] am disabled, but [I] don't put [myself] in the place of a disabled person!... Even well and able people... all that [they] do, [I] am able to do as well.

(Interview with Abdoul Karim (blind man),
Banfora, 18th March 2015)

Benoit (Participatory Diagramming, 25th October 2014) even insists that disabled people can do things that non-disabled people cannot do:

I know, and I'm sure that people who are well and able have difficulties which for us are not difficulties, and they are things which are sometimes very complicated. But perhaps sometimes they don't see us.... For them to accept, to say, 'Ah! Disabled people can do what we cannot do', we must prove it! Do you see? They would say: 'Since I cannot do this, they cannot do it either!' And yet it's not the case!

There is thus the need felt among some participants to prove themselves and go beyond expectations, also showing that they are as good as, or better than, non-disabled people. It is also with a sense of pride that they say that they are able to do things non-disabled people can do. This underlines their constant need to prove themselves by focusing on their capabilities rather than their disabilities. It also shows that they gauge themselves against non-disabled people, reflecting what Deegan (2010: 26) argues:

[h]aving a disability does not exempt a person from standards and values of 'able-bodied normalcy,'... [t]hus it is possible, if not probable, that persons with disabilities live in and reproduce the able-bodied lifeworld, sustaining, what is for the person with a

physical disability, an unattainable standard of normalcy. Approximating and ultimately achieving ‘normalcy’ in this situation or at least the presentation of ‘normalcy’... may occupy a sizeable portion of everyday life.

The need, or wish, to prove that one can do what a non-disabled person does is inter-linked, as seen in Chapter 5, with disabled people’s self-identification. Michel (Interview, Fada N’Gourma, 22nd September 2014) makes this connection, through experiences starting from his childhood and continuing into adulthood:

I think I have gone beyond the stage of reflecting on why I am disabled... I’ve gone beyond that when I was very little... because... climbing trees, swimming in the water... I’ve done everything with my friends, so I went beyond this when I was little.

Michel has ‘gone beyond’ disability because he is able to do what non-disabled people can do. Today, with regard to being economically independent, he says:

I fight to be on the same level of equality, because if an able-bodied person buys a car and I can buy a car, well the barrier is gone! So if an able-bodied person can do a particular thing and I also can do that particular thing... because, you see, we are in a society of consumption, and this means that if you can react financially, you can make your own place, then you have no worries.

(ibid)

As an adult, Michel now puts the emphasis on being able to *financially* do what non-disabled people can do, and he places importance on being as economically well-off as non-disabled people. This emphasis on economic independence is explained by Connell (2011: 1375) who sums up one of the greatest changes in perception that capitalism has brought about:

At a deeper cultural level the capitalist order draws a boundary between two categories of bodies: those whose labour generates profit, and those whose labour does not.

Connell (2011: 1375) argues that while the ways in which different people produce and consume have always differed, many cultures recognise some contribution from all sectors of the community, regardless of their age, physical strength or energy. Capitalism, however, places the value on profit, and productivity “applies only to workers in the money economy”

(ibid). This concept influences the way in which disability is conceived: disabled people become defined as people whose productivity is impaired, or who cannot be included in the labour market:

Under workfare regimes that claim to end paternalistic care and dependence... some disabled bodies are defined as work-able, others as deserving of welfare. To enable labour market participation becomes a key form of treatment or rehabilitation.... The globalisation of neoliberal capitalism has extended this logic of disability around the world.

(ibid: 1375-6)

Similarly, Soldatic and Meekosha (2012: 197) argue that:

[m]erging the ideologies of the 'free individual' with the 'free market' is of critical importance to the neoliberal understandings of the self, as the individual is represented as an active autonomous agent, free from all constraint in pursuing their own individual interests.

It is precisely this image of the 'active autonomous agent' to which disabled people I interviewed aspire. As the excerpt in Textbox 7.2 illustrates, they aspire to being free from restraints in order to pursue income-generating activities and to be economically independent.

Disability means something that prevents you from being able to do an activity according to what you want. For example, if there is an activity that you see that you could have done... as a profitable activity; but it's an activity that... you need eyesight to be able to do it. The person who has a visual disability cannot do it. So he feels disabled... So, for [me], disability is that which holds up the development of disabled people, meaning, I want to do... this, but I cannot because I have this impediment... To resolve this problem, there is a need for each and every one to have the means, meaning that disabled people have the means. Today, it must be said, it's money which is at the forefront of things:... for example someone who wants to do a business activity (he cannot do anything else, but he can sit down to sell), if he has money to be able to do a shop which can be profitable for him, well, that's a solution!.... there's a colleague of [ours] who says that today, he's seen that, actually, people do not detest the disabled person, it's not only the disabled person, it's everyone: it's because you don't have money. Even if you are in good health and you don't have money, no one wants you. Meaning, you must have money. [Our] friend said, if he had enough money [and] he could pay someone to transport him, he can transport him to go around. If you want something, it all boils down to money.

(Interview with Yada, Diapangou, 24th September 2014)

Textbox 7.2 Yada: What Disabled People Want

Meanwhile, if a disabled person in Burkina Faso demonstrates that they have the financial means to be independent, the perception is often different:

If a disabled person... has work,... has a car,... has a villa... he is not going to be welcomed in the same manner as someone who has nothing.

(Interview with Michel, Fada N’Gourma,
7th November 2014)

The discrepancy between those who are financially able and those who are not is fed into by market-driven politics in which, as Soldatic and Biyanwila (2010) contend, able-bodied people make up the valued ‘core’ while people with disabilities are to be found on the margins of the labour market. This is reminiscent of the development discourse of the core and the periphery:

The idea of the modern West as a model of achievement, and the rest of the world as an inferior derivative, remains integral to the concept of development. The metaphor of a healthy adult continues to inform analysis of the ‘modern’ or ‘core’ world and that of a child the status of the ‘traditional’ or ‘peripheral’.

(Manzo, 1995: 232)

The core-periphery discourse further heightens the importance of the perceptions of disabled (and non-disabled) people in a market-driven context, where those deemed as non-productive are situated in the periphery, while those able to engage in productive labour are at the centre. With regard to this, in a report on the economic marginalisation of disabled people and potential solutions in Burkina Faso, Handicap International (HI, 2005) asks: what are the principle elements in a life journey which enable disabled people to ‘integrate’ in a capitalist economy? Why does a disabled person do well while another one does not? As the subsequent discussion demonstrates, the answers to these questions may lie in numerous factors, pointing to the importance of an intersectional approach to understanding the lived experiences of disability in shaping people’s lives.

INTERSECTIONALITY *WITHIN* DISABILITY

Intersectionality has been much utilised in feminist and anti-racist arguments to theorise identity and oppression (Nash, 2008) and is useful in exploring the concept of success (or otherwise) in disabled people's lives. Nash (2008: 2) describes intersectionality as "the notion that subjectivity is constituted by mutually reinforcing vectors of race, gender, class, and sexuality". However, although "there is a substantial body of literature on the interacting effects of race and gender, research on the interaction between disability and other stigmatizing characteristics is almost nonexistent" (Shaw et al, 2012: 83). In their research on the intersectionality between disability and characteristics such as gender and age in the workplace against disabled people in the US, Shaw et al (ibid) contend that "[i]n intersectionality research, debate has centered on whether people with multiple memberships experience more discrimination than those with single membership". A person with multiple memberships means, for instance, a black disabled woman, who can be discriminated against on account of her sex, her ethnicity *and* her disability. If this occurs, "the effects of discrimination may increase proportionately" (ibid.). The concept of intersectionality within disability studies itself is useful in exploring the relative successes and struggles of disabled people within capitalist economies. This is influenced by the interaction of characteristics such as the type of impairment, the stage of life at which the person became disabled, and level of family support.

The Impact of Impairment

Some of the differences in the lived experiences and self- and societal perceptions of people with different types of impairments in Burkina Faso were explored in Chapter 5. The impairment and the resulting perceptions play a role in the disabled person's life choices and experiences and, therefore, in his/her autonomy. Soldatic and Biyanwila (2010: 77) argue "for a politics of impairment that combines economic redistribution with cultural elaboration of solidarity, justice and care" so that disabled people

in the Global South change “their subordination and exploitation”. They argue that:

For politics of impairment, disabling barriers generated by... poverty in the South, are inseparable from market-driven ‘development’ and global military networks. With the majority of people with disabilities located in the South or the ‘majority world’, the ongoing articulation of North-South relations is significant for elaborating a critical Southern standpoint on able-bodied masculinity.

(ibid: 82)

The focus on abled-bodiedness keeps disabled people in subjugation, as unproductive bodies. Within this categorisation, a ‘hierarchy’ of impairments relating to productivity, which can roughly be said to have people with physical impairments at the top and people with intellectual impairments at the bottom, becomes apparent. Taken very broadly, and barring other factors such as gender and location, people with physical impairments encounter fewer barriers than people with sensory and intellectual impairments. Michel (Interview, Fada N’Gourma, 22nd September 2014) admits that:

[My disability] doesn’t bother me because I’ve seen other people with disabilities more complicated than mine, and who work, and they manage very well; and I find that for me... I’m physically disabled, I cannot walk: this is a bit light in comparison to others, who manage to cope. So... I’ve gone beyond the stage of reflecting on my disability, or that I’m a disabled person.

Linked to the self-identification of disabled people, Michel talks about how he feels that his physical disability is ‘milder’ than other types of disabilities. As discussed previously, disabled people contend that both societal perceptions as well as self-perceptions differ between people with physical impairments and those with sensory impairments, such as visual disabilities. The latter are seen as more dependent and people with physical impairments feel that they can cope better than people with visual impairments. Sometimes people with physical impairments are not considered as disabled, particularly if the impairment is ‘mild’. Emile

(Interview, Ouagadougou, 26th November 2014), a blind person, illustrates this:

LB: Is your wife also a disabled person?

E: No, it's not much of a disability: she limps a little bit only.

The type of impairment is a likely indication of a disabled person's course of life in Burkina Faso, not only in the aspect of work and employment. Besides more positive societal perceptions, people with physical disabilities generally also benefit from more independence in communication and (physical) mobility. While people with hearing impairments generally need interpreters, people with physical impairments need none. Where people with visual disabilities regularly depend on others for their mobility, people with physical disabilities find it easier to be mobile if they have devices such as crutches, wheelchairs and three-wheel motorcycles that enable them to be mobile. Thus, physically impaired people in urban areas, where there is more chance of possessing such devices, are better equipped to be financially independent. Nonetheless, several research participants argue that access to mobility devices alone is insufficient and that income is equally, if not more, important:

I feel that there are a lot of NGOs, there are a lot of things that the state does, that are useless!... for example... do you see the wheelchairs that have been left there?... They're not useful... they're donations. What would have been useful is that the disabled person buys them with their own money: *that's* useful... we must eliminate donations of this kind. We must see what [the disabled person] needs: because... as long as I don't have a job, if it [the wheelchair] breaks down, how will I repair it?

(Interview with Ismael (physically disabled man),
Ouagadougou, 2nd February 2015)

As discussed subsequently, such arguments also illustrate the ways in which disabled people in Burkina Faso problematise and challenge 'charitable' interventions by development agencies. The fact remains, however, that people with physical impairments generally face fewer barriers than people with other impairments: most of the PV participants who recount how they have overcome the odds and made it to where they

are now, are physically disabled. Thus they do not have impairments which bar them significantly from moving on in life, a factor playing a role in their success.

People with hearing impairments, and particularly the profoundly deaf, face barriers in communication, so much so that they have been described as living in a Deaf-World (see, for example, Lane, 2005; Grosjean, 1992). However, in Burkina Faso, where most deaf people have not been to school, hearing and non-hearing community members often develop a sign language of their own in order to communicate the everyday necessities. In an interview with a deaf girl, Numpua (Kompienga, 26th September 2014), her mother explains:

In the places which she... [frequents], people manage to communicate with her... she doesn't find any difficulties, because people are used to talking to her, so she manages to be with them.... If she wants to plait her hair, she knows those who plait hair, so she... goes there to have her hair plaited.

The deaf people participating in this research conduct various activities, ranging from housework and food-selling, to shepherding and carpentry. People with albinism, too, are 'physically mobile', like deaf people. However, due to skin sensitivity, they cannot stay in the sun, which in hot countries like Burkina Faso tends to be a problem. This also excludes them from agrarian work, the main form of employment in the country:

They cannot farm, because you have to farm in the sun, while when they go out in the sun, they have problems. So they cannot farm, so it's more or less up to their schooling... if they don't succeed in school, it will be difficult.

(Interview with father of Celine (girl with albinism),
Diapangou, 7th October 2014)

Celine's father, who also has two other children with albinism, suggests that the best options for people with albinism are indoor activities, which consist largely of office jobs. These jobs however, may be barred to them due to lack of education opportunities, particularly in rural areas, where there is a lack of awareness (and sometimes willingness), among educators, to support children with albinism. As the following excerpts

from interviews with two girls with albinism highlight, they often need extra attention due to their short-sightedness:

LB: And what is school like?...

A: I have difficulties to see...

LB: And do the teachers do anything to... make it easier for you?...

A: They do nothing.

(Interview with Aisha, Soubakaniédougou,
3rd March 2015)

LB: Did [you] go to school?

F: [I] went to school, but [I] wasn't able to go far, because of the eyesight, because [I] have problems with [my] eyesight. So [I] limited [myself] to the second year of primary school.

LB: OK...and the teachers did not put [you] in front, in class?

F: ...[I] was in the third row.

LB: [You] didn't tell the teachers to put [you] in front?

F: [I] was scared, [I] didn't.

(Interview with Fatou, Banfora, 12th March 2015)

People with visual impairments are further away from the 'core' of economic productivity and encounter various barriers to independence in the context of capitalist economies. In terms of productive labour, either agrarian or otherwise, people with visual impairments have less choice than people with physical or hearing impairments. A significant number of research participants who are blind engage in no particular activity, although some people's visual impairments are due to old age¹⁹⁴ and thus they would not normally engage in an income-generating activity regardless. The limitations in profitable activity choices could also be a contributing factor towards the tendency of INGOs to fund such activities as furniture-weaving with blind people.

On the outer limits of the periphery of the labour market, one finds people with intellectual disabilities, who encounter the most barriers to education and employment in Burkina Faso, as they do in most countries in the world. In urban areas there are a small number of schools targeted specifically at intellectually disabled children, usually set up by a parent. However, intellectually disabled children and adults are generally

¹⁹⁴ See Appendix 1.

voiceless, even more so in rural areas. Opportunities for intellectually disabled adults are almost non-existent in urban areas and completely absent in rural ones. One of the few prospects is an INGO in Ouagadougou, which provides a family-like context in which intellectually disabled people live communally with non-disabled young employees. It houses eleven people with intellectual disabilities, with those who have ‘milder’ disabilities doing some skills training and some work at the INGO premises themselves, such as housework and gardening. Despite this lone example, in a capitalist context where the value of the person is judged on their capacity for productive labour, people with impairments who are deemed to be largely unproductive are generally relegated to a space of either care or disregard.

A ‘hierarchy of impairments’ seems to be created amongst impairments, therefore, with people with intellectual disabilities inhabiting the lowest rung. This hierarchy *within* disability recalls what Soldatic and Biyanwila (2010: 78) refer to as the “Eurocentric hierarchy of being”, a hierarchy in which disabled bodies, more specifically disabled bodies in Global South contexts, are relegated to the bottom level within North-South relations. While Soldatic and Biyanwila are talking about the disabled body as represented in the context of natural disasters in the Global South, it is reminiscent of the Enlightenment era discourse where “[i]n the hierarchy of species, humans are situated as superior to nature but certain human beings are closer to nature than others”. This:

conveys how human biology can be measured and layered into a ‘hierarchy of being’. At the pinnacle of this hierarchy are white western men.... The superiority of whiteness is in both physicality and intelligence.... The impaired and disabled represent [the] ‘sub-status of irrationality’.

(ibid: 79)

Soldatic and Biyanwila argue that at the pinnacle of this hierarchy are white western *men*. Gender, in fact, is significant here and is intertwined with the other factors impinging on a person’s life course. The type of impairment (together with gender) also plays a part in DPOs’ functioning

and leadership discussed in the previous chapter. The larger part of DPO presidents (unless they are women's DPOs or DPOs of people with specific disabilities) are men with physical disabilities¹⁹⁵. Men with physical disabilities usually have a higher level of education than the rest of the DPO members, a factor which works both ways: they generally have more opportunities to go to school, and thus have had more of a chance to be educated than women and people with sensory or intellectual disabilities. Subsequently, men with physical impairments find more doors open for them, both because they are more educated and also because they encounter less societal barriers.

The stage in life at which the onset of impairment takes place is also significant in a disabled person's success. Being born with a disability, or encountering it when one is very young, has a different impact on the person's success in later life than when encountering impairment later in life. For example, as one participant explains:

People who are born with the disability, it's a bit easier: they adapt easily. They have learnt Braille since childhood... to do an exam [in Braille]... it's not easy...

(Interview with Abdou Raman, Banfora, 4th March 2015)

Abdou Raman is a twenty-eight-year old blind man who started losing his sight when he was twenty-one due to glaucoma. He has to sit an examination in the recently-learned Braille and is comparing himself to those who have been learning Braille since they were young. Having the impairment when young generally allows the person to have more time to adjust to their disability and to explore what they want, and can, do to be independent. For example, Amadou (Interview, Banfora, 5th March 2015), a twenty-eight-year old man who became blind when he was two years old, has a small business selling mobile phone credit. He has learnt how to transfer the (mobile phone) credit¹⁹⁶ and goes everywhere on his own, even walking five kilometres on his own from the remote village where he lives

¹⁹⁵ See Appendix 1.

¹⁹⁶ In Burkina Faso, one can buy mobile phone credit by asking the seller to transfer the credit from their account.

to Banfora centre town and back every day with the help of a walking stick.

Impairment is clearly only one factor, albeit a very important one, of disabled people's lived experiences in Burkina Faso. Another significant factor is the family, which plays an important role in any person's life in Burkina Faso. While this issue was discussed in the previous chapter with regard to disabled people's sense of affirmation, here the role of the family in enabling economic independence is examined.

The Family Factor

The importance of the family became apparent in the participatory video¹⁹⁷ in which the participants chose to focus a section of the film exclusively on this topic. The title they chose emphasises the weight they place on family support: 'The family: The essential element in the respect for the dignity of the disabled person'. As Benoit's story in the beginning of this chapter shows, his extended family influenced his schooling. During the participatory diagramming exercise that formed part of the participatory video process, the participants chose the family as the first topic to discuss from the range of issues pertinent to disabled people's lives in Burkina Faso. They state that when disabled people are not taken into consideration by certain members of the family, they have to fight for recognition:

There isn't the foresight, in the family to say that, 'Ah, if we help him, if we support him, tomorrow he will, he can, help himself and maybe help the other members of the family'.... For example, if you have children in the family, you know that, if you educate them, when they have jobs, they can help themselves and help their family. For the disabled person, this is not the case.... You have to fight... if you become someone... then you are taken into consideration... A lot of us disabled people, we have not been to school... even those who are at school, are not many.... We are not considered:... we must fight, fight, fight, become someone, and then people say, 'Look, even those who are not disabled cannot do what he does!' Do you see?

(Benoit, Participatory Diagramming, 25th October 2014)

¹⁹⁷ See attached copy of the participatory video in Appendix 5.

Two main issues emerge from the claims Benoit makes. The first is that the family is the first place where disabled people have to prove themselves and, as discussed earlier, to demonstrate that they are as capable as, if not better than, non-disabled people. However, proving oneself in the context of the family takes on an aspect which is rather different from proving oneself in society. One of the results of the lack of consideration of the disabled person by the family is lack of education. Related to this, is being hidden by the family because of the shame and stigma of having a disabled child, or because of ignorance. Yada (Interview, 24th September 2014), the president of a DPO in Diapangou, a municipality near Fada N’Gourma, explains this:

Diapangou has small villages that [I myself don’t] know.... What surprises [me] is that when there are calls for medical treatments at hospital [in Fada N’Gourma]... [calling through radio broadcasts] disabled people to come for medical treatment at the hospital... When [I go, I meet] disabled children... whom [I have] never seen, and yet they are from the municipality of Diapangou... parents who have children with disabilities... do not approach anyone, meaning they hide the child: they do not want people to know.

The second issue Benoit highlights is that investing in children in Burkina Faso also means investing in their future; if the child is deemed incapable of helping or supporting the family when they are older, it is not worth investing in them. This is rooted in the fact that traditionally in Burkina Faso children are expected to take care of their parents (both financially and health wise) as adults. As discussed in Chapter 4, children provide the ‘social security’ for the elderly. The majority of Burkinabes, especially those working in the informal sector, do not benefit from pensions or any other social benefits. Thus, investment in children is often the sole security for old age. Investing in disabled children, therefore, might not be deemed worthwhile, since they are not considered to be able to financially support themselves or their families. There is therefore a paradox: in a context in which the state provides very little support for disabled people, the family is identified by disabled people as the most important source of support; however, also in a context in which the state provides little or no

support for elderly people, children are charged with the responsibility of providing for their elders. The idea of disabled children as doubly burdensome thus emerges and provides an important context for disabled people asserting their capabilities rather than their disabilities.

Family is also linked to the issue of inheritance, which, according to Michel (Preparatory Meeting, Fada N’Gourma, 7th September 2014), is one of the issues affecting disabled people in Burkina Faso in the family sphere. Michel (a regional coordinator of DPOs), explains that disabled people are sometimes left out of inheritance because the family considers that the disabled person is already being taken care of by another family member, hence they do not need a part of the inheritance for themselves. David (Interview, Tibga, 21st October 2014), a leg amputee, explains that inheritance is often considered wasted on disabled family members:

[My] father had two wives. Hence, since [my] father had passed – he had some cows – [and] in the sharing out, [I], who was disabled, they did not give [me] any, because [they believed I] couldn’t tend to them... [I] believe that... if they had given [me cows], even if [I] couldn’t tend to them, well, [I] would have found someone who would have tended them for [me].

Disabled people have to prove that they are capable of taking care of themselves, as David’s example shows, but more importantly the person needs to prove that they can take care of their spouse. Karim (Participatory Diagramming, 25th October 2014), a thirty-six-year old blind man, relates how he had a girlfriend before he lost his sight, at around nineteen years of age:

At this time... I had a girlfriend, whom I loved a lot. When I fell ill, I told the relatives, ‘Well, my girlfriend still loves me, so could you continue the process in order for me to marry this girl?’ The brothers asked ‘Since you have become disabled, can you manage a family?’... Well, I couldn’t say ‘yes’, I couldn’t say ‘no’. I said, ‘Well... it’s God who knows... if I can manage or not... so I would like you to continue the process for me to marry this girl.’ They said ‘No, it’s not possible’.

Later, when Karim started working and the girl asked her family if they could let her marry him, *her* older brother said:

No, it's not possible that you marry a blind person... because it's a humiliation for the family.

(ibid)

Today, Karim is married to a physically disabled woman. Karim's story is a common one among the interviewees, many of whom say that their families-in-law had difficulties accepting them, especially before they proved that they could 'manage' and feed a family:

The parents of my children's mother never accepted me... the mother... told me, one day... 'Do you see my daughter? She's not your girlfriend. She walks with her two legs. I never want to see you together again.'... Or else: 'My daughter is with you. I don't want her to come back here asking for food'.

(Interview with Michel (physically disabled man),
Fada N'Gourma, 22nd September 2014)

Before, it was difficult, because since [I am] disabled they did not think [I] could take care of the girl; that the girl would suffer... so they came to take back the girl, twice... but since the girl wanted, she came back. Now... since [I] manage to get by, bit by bit, they dropped it...

(Interview with David (physically disabled man),
Tibga, 21st October 2014)

Before, it wasn't easy... because they said that [I] couldn't take care of [my] wife: [I have] one arm, what would [I] do?... [People] even lied and said that [I] had stolen the woman, so the girl said that no, it was she who wanted, and she who had come back; that she had not been stolen, so it was God's will and also her will: it was she who came out of her own free will. Thus, now, that [I] farm and [I] manage to take care of [my] family, and [I] make... bricks... [I] have no problem.

(Interview with Lucien, Tibga, 21st October 2014)

The perceptions held by the in-laws of disabled people in these examples also confirm the perception of disabled people as incapable, as discussed in the previous chapter, hence the need felt by disabled people to prove themselves. The need to prove the ability to take care of one's wife and family underlies another noteworthy aspect:

When a woman returns to her parents asking for provisions to eat, it means that her husband is unable to take care of her. So in society this... means you cannot speak...: you were not able to

manage your family to start with; you cannot expect to have responsibilities in the community.

(Interview with Michel, Fada N’Gourma,
22nd September 2014)

Thus, being considered as incapable of taking care of a family also has repercussions on a disabled person’s standing in society.

An issue that stands out in the above discussion is that gender roles, too, play a part, along with the societal expectations of men and women. Expectations of being able to take care of a family in Burkina Faso mean financially supporting a family, which is assumed to be the responsibility of men. Gender norms make it especially difficult for men in this context, whereas when it comes to other areas of life (such as the economy, as the case of the DPOs shows), men have greater advantages.

The factors discussed here do not exist in isolation. The ‘severity’ of the impairment is also significant: someone who walks with a limp experiences disability differently from someone who uses a wheelchair. Furthermore, other factors in a person’s life play a role in how they experience disability and whether or not they succeed in life, some of which have been discussed in previous chapters. For example, the geographical location is a significant factor, as seen through the exploration of urbanity and rurality in Chapter 4 and how this affects disabled people’s lives and perceptions. Asch and Fine (1992: 141) also observe that oftentimes literature has “focused on disability as a unitary concept and ha[s] taken it to be not merely the ‘master’ status but apparently the exclusive status for disabled people”. It is often easy to think that “[h]aving a disability presumably eclipses... [other] dimensions of social experience” (Fine and Asch, 1988: 3). Hence the context in which these factors play a role in disabled people’s lives is important: the research participants also experience their lives as Burkinabes. Related to this, many disabled people in Burkina Faso consider economic independence (linked to a positive self and social identity) as success in life and the way to development. As discussed below, disabled people in Burkina Faso are keen to make their voices heard on what development

means for them, and methods such as participatory video enable disabled people's agency to emerge as counter narratives to the dominant discourses of the non-disabled society and development agencies.

DISABILITY AND AGENCY

[A]gency... involves estranging, contaminating or misreading the master discourse, at times imposing suppressed knowledge and at others making unanticipated, slight alterations, with the overall effect of denying or subverting dominant authority.
(Kapoor, 2002: 652)

Chapter 2 explored the way in which disabled people are portrayed by channels such as the media and western organisations, which tend to portray them as being dependent and helpless. As Roenigk (2014: n.p.) argues:

Advertisements and marketing materials depicting the suffering of the poor and soliciting financial support may inadvertently tell subjects that they are indeed helpless beneficiaries, dependent on the support of the wealthy for any lasting transformation.

However, some disabled people in Burkina Faso have a different story to tell. While it is true that they are discriminated against, Benoit (Participatory Video, October 2014) insists that:

[H]aving a disability is not the end of the world; having a disability... does not mean it's the end: having a disability is only the beginning of a process.

The process that Benoit is referring to is discussed by the PV participants in their film, 'Disability: It is not the end of the world!' They discuss the process of, in their words, overcoming their disability to be successful. The concept of 'overcoming one's disability' (which, as seen in Chapter 5, has been deemed by western scholars like Shakespeare (1996) as a form of denial) relates closely to what Becker (1980: 7) refers to as "the ability to transcend some of the differences that exist between them and the outside world and to make their way in... life". While Becker is talking specifically about deaf people in the US, her statement resonates with the PV participants' experiences. In a section of the film introduced as 'Whatever

one wants to do, personal engagement is the key to success', several participants recount how they have struggled to have their own means of living such as a small farm, or a shop, overcoming numerous obstacles to arrive where they are today:

I did not get discouraged because I am disabled, no, no, no, no! I am creative, I like to create, I like trying, I like risking. I have a restaurant; I am not a hairdresser but I had the idea of opening a hairdressing salon and putting a friend in there. I do livestock farming... I do everything!

(Regina, Participatory Video, October 2014)

Experiences such as those of Regina's substantiate Lang's (2000: 1) argument that, while both medical and social models offer valid insights into the conceptualisation of disability, neither of these models offers "an adequate, comprehensive explanation of the phenomenon". Each model only indicates a part of "the 'reality' of disability":

Both models are deficient in their explanation of how marginalised and often oppressed groups, such as disabled people, are able to recognise their potential to change their present situation, thereby becoming full and active citizens in the contemporary societies in which they live.... Both models perceive disabled people as being passive subjects.

(ibid)

The PV participants (as well as Benoit's story in Textbox 7.1) demonstrate that many disabled people are not, in fact, passive subjects. Having a space where they can be seen and their voices heard, the participants use the film they have created as a vehicle to speak out to other disabled people in Burkina Faso, state authorities and INGOs working with them. They focus on aspects ranging from personal experiences to soliciting development actors to become familiar with their needs before implementing development actions, and suggesting ways in which the same actions can better benefit disabled people. Thus, the participants use the PV to recount (and disseminate) the struggles they have endured to overcome their disabilities or disadvantages associated with their disabilities:

Given that in our society, most disabled people have problems in the employment area, I asked myself 'What should I do?'. I asked myself

this question, and I started to work in the telecommunications domain: I started from there. First of all, I started working for someone. Thereafter, I managed to open my own small shop where I sell mobile phone credit. Recently I also started offering money transfer service. It hasn't been easy. Today, I manage better, given that I manage to meet some of my family's needs. I am a married person. In our community, I am respected, and I think that I have tried to overcome my disability.

(Benoit, Participatory Video, October 2014)

I'm in the last year of sixth form. I am a girl with a disability. I fell sick when I was in my second year of secondary school. I was obliged to have a two-year gap before being able to continue. To start again, it wasn't easy for me. With my disability, I wasn't accepted back in secondary school, but we tried to explain to the Director, but it wasn't easy. I was obliged to go to Togo. When I obtained my GCSE, my father passed away, so it wasn't easy for me: I was obliged to fight to be able to continue.

(Hélène, Participatory Video, October 2014)

Furthermore, the participants want to share their experiences to send out the message to other disabled people that they, too, can overcome their disability. In its introduction, the film conveys the message:

The film was shot during the revolution of the Burkinabe population in October / November 2014.

We hope that this film brings about a revolution in the hearts of our sisters and brothers with disabilities.

(Participatory Video, October 2014)

As well as fostering communication among disabled people, the opportunity to express their experiences and concerns stimulates one of the essential and key elements of constructive development. Indeed, after sharing their experiences and encouraging others to follow in their footsteps, the participants then go further, addressing development actors directly. The PV participants appeal to development actors who intervene in the disability domain:

If they want to help disabled people, [they need to] talk to them first, to know how their life is in the community, before helping them.

(Hélène, Participatory Video, October 2014)

In view of the experience lived by each one of us, we would like to launch an appeal to the different entities who intervene in the disability field to try to add, in their intervention strategies,

personalised individual actions, in order to increase the chances of attaining the total flourishing of the disabled person in the Est Region.

(Regina, Participatory Video, October 2014)

In the video, Hélène appeals to INGOs and state actors to listen to the voices of development beneficiaries before implementing development actions, which chimes with both postcolonial theory and participatory action research. It also enables the multiple dimensions of development ‘recipients’ to come to life with their different personalities, lived experiences, wants and needs, as opposed to the western representations of (disabled) people in the Global South:

Th[e] representation of the Southern black body is firmly anchored in flattening their histories and their culturally textured daily lives. Thus, socially entrenched dominant power relations of class, gender, ethnicity and disability are made invisible, along with a multitude of contentious collective struggles for recognition, representation and redistribution.

(Soldatic and Biyanwila, 2010: 79)

In the same vein, Campos (1995: 72) argues that “people are often seen and classified by the single dimension of their disability and certain procedures are automatically prescribed, rather than considering people as individuals with a varying range of characteristics and skills”. Although Campos is here discussing rehabilitation services, her argument applies to the ways in which INGOs fund or implement income-generating activities, which rarely reap the intended benefits. Disabled people in Burkina Faso, therefore, are asking development actors to consider alternative pathways of supporting them in development. The PV participants suggest that development practitioners should know reality on the ground, as well as their lived experiences, needs and wants, before intervening. They suggest that focusing on individual capabilities, rather than group responses, would be more beneficial for disabled people. This is also an idea echoed by other disabled research participants:

NGOs should think on how to render DPOs financially autonomous. [W]ith regard to IGAs [they] should try individual funding, fostering

the emergence of economic operators capable of employing other people and of setting an example.

(Michel, Email Exchange, 16th January 2012)

It's what each and every one can do individually, because not all of [us] have the same capacity to do the same thing: according to each person, his disability...

Support should be that each person can be supported in his domain, not as an organisation, but individually.

(Interview with Yada, Diapangou, 24th September 2014)

[Our DPO is] in the phase of applying to see if [it] can have aid in the individual training domain, so that people can have something to do.

(Interview with Yamba, Matiakoali, 11th October 2014)

Michel, Yada and Yamba, all of them DPO presidents, argue that they want to be considered individually according to their talents, capacities and wishes: they are individual, different people. Having the same, or similar, impairment(s) does not mean that they all want to do the same activity. This echoes Atampugre's (1997: 62) suggestion that the "developmental use of credit" "or financial support" by INGOs and other development agencies "should [be]... tailored to meet the varied needs of poorer strata of society". As Michel says, it would be ideal to fund individual disabled people in income-generating activities (IGAs) and then use them to set an example to other disabled people. The case of Amadou (Interview, 5th March), a blind man in Banfora who used to work in a furniture-weaving workshop financed by an INGO, exemplifies the need for people to engage in an activity that not only are they able to do, but that serves a purpose in the community. The workshop at which Amadou worked failed due to the failure to make a profit from furniture-weaving; following this, Amadou started selling mobile phone credit, which today helps him make a living. While artisanal work is often funded by INGOs for groups of disabled people, some disabled people like Seydou (Interview, Ouagadougou, 20th February 2015) – a blind man who has a soap-producing enterprise in Ouagadougou – insist that artisanal work is unsustainable and that INGOs (and other development practitioners,

including the state) who insist on this as a path to development do not listen to disabled people on this matter:

We cannot go there in front so they listen to us. Here, when we speak, they would not listen to us. And those who will speak, they will listen but it is useless... what we want to say, we're not able to say.

As a result, for a lot of disabled people, nothing has changed in a long time:

When you meet them, it's the same problem of the year... 2000; when you meet them, it's the same thing... they still have the same problems.

(ibid)

Through the spaces that the PV creates, disabled people are providing their counterstories to the master narratives on disability and development interventions (in the Global South). Nelson (2001: 6) explains:

The counterstory positions itself against a number of master narratives: the stories found lying about in our culture that serve as summaries of socially shared understandings. Master narratives are often archetypal, consisting of stock plots and readily recognizable character types, and we use them not only to make sense of our experience... but also to justify what we do.

Stories about disabled people that the non-disabled society – and, consequently, disabled people themselves – accept about disabled people become the accepted image, opinion, perception of disability and disabled people. Disabled people are viewed as objects of charity, poor, sick, tragic, or, at the other extreme, viewed as super-humans, such as the Paralympic athletes. And yet, the PV participants demonstrate that there are ordinary disabled people in Burkina Faso who are neither super-humans nor poor, helpless individuals. They are people who are fighting against stereotypical representations and are telling their story “in such a way as to make visible the morally relevant details that the master narratives suppressed” (Nelson, 2001: 7). In doing so, “counterstories aim to alter the oppressors’ perception of the group” and “allow members of the oppressed group to exercise their agency more freely” (ibid). Although Nelson (2001:

8) admits that the implications of counterstories to challenge “some of the effects of oppression have not been well understood”, she sets out the epistemic context necessary to make counterstories effective. She outlines how, similar to any other story which aims “to make moral sense of something”, those who create the counterstory:

choose particulars from the array of experience and look at them in the light of important moral concepts, which in turn show up the relevance of other particulars, which suggest the relevance of other moral concepts, and so on, until the particulars and their moral interpretations have been set into an equilibrium that points to a specific understanding of the state of affairs.

(ibid)

Counterstories which have these qualities re-establish the perception of a particular person or group and challenge the oppressive master narratives while highlighting details that the latter have overlooked or dismissed (ibid). The PV participants try to challenge the master narratives that render disabled people helpless and passive by showing that disabled people can be successful:

Counterstories take up an oppressive but shared moral understanding and attempt to shift it, rejecting its assumption that people with a particular group identity are to be subordinated to others or denied access to personal and social goods. They are, then, narrative acts of insubordination.

(ibid)

The disabled participants in the PV also attempt to change perceptions of disabled people, which also influence the nature of development interventions in the field of disability. As discussed above, they propose concrete practices to change the way in which development is carried out by development organisations. Nevertheless, changing the reality on the ground is not straightforward. The PV participants are conceptualising an alternative form of development, and yet, development actors, such as INGOs, retain most of the power. Consequently, disabled people and DPOs remain “structured by a form of agency that has been complicit” (Bignall, 2010: 1) with the development institutions’ practices, and which, according to Bignall, “the postcolonial society must surely reject” (ibid). In practice, rejecting development interventions might mean losing livelihoods,

funding, and opportunities: dependency is structural and it is difficult to reverse this. Zenabou (Interview, 20th January 2015), the coordinator of a disabled artisans' cooperative in Ouagadougou, recounts how they currently have eight volunteers (some British, some Burkinabe) placed with them by an INGO to help the development of the cooperative. Three of the British volunteers are lodging with her personally as part of a cultural integration programme. When asked why she accepts this, Zenabou replies that it is because they depend on the INGO. In addition to the burden this places on hosts, the ineffectiveness of volunteers being placed with a DPO for three months is highlighted by Dominique (Interview, 10th February 2015), the president of a disabled women's organisation producing soya and cereal-based products in Ouagadougou. Dominique talks of how these young volunteers come for such a short time that "As soon as I learn their names, they leave". She continues to say that not only they have no experience (and some of them do not speak French), but they are too young (in her words, "children"), and she ends up 'babysitting' some of them who are homesick. She points to the irony that they serve to justify the donor's declaration that they have sent a number of young people to Africa, little knowing what they actually did, and she lambasts this venture as 'tourism'. Regardless of these complaints, however, DPOs continue to accept help from INGOs because they do not see any other way to support themselves. Only one DPO from those I interviewed has refused to engage with some of the interventions proposed by INGOs. Michel (Interview, Fada N'Gourma, 7th November 2014) says about the DPO of which he is coordinator:

It is necessary that [our DPO] distances itself from this; and be professional. When they [INGOs] come... [to finance] an activity which [our DPO] doesn't do, we don't do it.

Michel has made the decision that the DPO he coordinates will not follow the agendas of INGOs, but rather choose the projects and programmes to implement according to the DPO's agenda. Rather than search for INGO support and then implement what the INGO wants the DPO to do, the

DPO develops its activities and then looks for funding for those specific activities. Michel's case, however, is a rare one. In the rest of the cases encountered, DPOs are dependent on INGO finances and thus are subject to their agendas, however much they might criticise these. Furthermore, while the DPO members criticise the development interventions that they have experienced and continue to experience, their criticisms are framed from within those development interventions. The subaltern's agency, according to Kapoor (2002: 652), emerges only "from within the master discourse": what Spivak (1990: 228) describes as saying "'no' to the... culture of imperialism while recognizing that... [one] must inhabit it... to criticize it". Spivak (1987) writes of the complicity between the coloniser and the colonised. Even though disabled people are challenging the discourses and practices of INGOs, they (disabled people) inhabit the same structures upon which they depend, structures which are mostly orchestrated by INGOs. Bhabha (1994: 2; 22; 25) often refers to subaltern agency as "negotiation". Disabled people in Burkina Faso must constantly negotiate a terrain almost empty of support were it not for INGOs. DPOs are thus forced to walk a tight line between exercising their agency and making their voice heard with regards to what they want to do and what they think is best, and conforming to INGO programmes and projects to survive. Thus, although disabled people's agency in Burkina Faso is starting to emerge, there are limits placed on it by the actuality of life in Burkina Faso: poverty, structural domination by INGOs, the lack of intervention by the state, and the politics that disrupt the disabled people's movement. Moore-Gilbert (1997: 85) observes that for theorists such as Spivak and Derrida, discourse that is "directly counter-hegemonic" is more likely to be revoked or reappropriated by those who dominate. Thus, Moore-Gilbert (ibid) argues, Spivak is more in favour of "the modes of 'negotiation' and 'critique', which unsettle the dominant from within". In a similar vein, the PV participants are not asking INGOs to leave and are not rejecting their support. Rather, they are asking them to modify the nature of their interventions according to the likelihood of success. This is

exemplified by Michel (Email Exchange, 16th January 2012), who, while recognising the importance and need for INGOs, suggests that they should have less influence and power:

I think NGOs should push DPOs towards specialisation in specific domains of disability, and that they [INGOs] should remain supplementary. I think NGOs' work will always be necessary as long as there is work to do because the means of African states and the political will do not move at the same pace [as that of INGOs]; [and until] DPOs are strong enough to confront the authorities to take into consideration their specific needs.

Thus, Michel's argument suggests that INGOs should be working towards ultimately making themselves redundant, that is, working with DPOs and disabled people until the latter are independent.

CONCLUSION

Mastering disability is not an acquirement, but a perpetual quest.
(Informal Conversation with Maxime (physically disabled man), Banfora, 25th February 2015)

The discussion above builds on the exploration of the meaning of disability in Burkina Faso and its connections in a market-driven context with autonomy and, particularly, economic independence. It reveals disabled people's struggles to prove themselves in a context which emphasises the importance of the able-bodied productive individual. Interlinked with this are the factors that affect a disabled person's relative success (or failure) in becoming economically independent. In this context, the importance of listening to disabled people's voices about their ideas of development emerges. This also highlights the importance of creating spaces, such as those created by participatory videoing, in order to attempt to recover the subaltern agency and in which disabled people can be heard. Often, disabled people are considered as objects of charity and their agency and voice are hidden and ignored. They rarely have the opportunity to voice their opinions and their demands. Rarely are they consulted on what development means for them. When INGOs and the state *do* consult them, it is usually through the umbrella DPOs in Ouagadougou and, even then,

the power relations between DPOs and INGOs are quite unequal. The value of PV is that it creates an opportunity in which disabled people are able to voice their wishes, needs and wants and, together with the conversations with disabled people, bring to life the multiple dimensions of the lived experiences of disabled people who are usually considered as beneficiaries, as well as the reality of disability in Burkina Faso. The emerging agency of research participants starts to challenge the assumptions that underpin the nature of interventions by INGOs and other agencies. These voices emerge notably through the opportunity that participatory video creates for disabled people to articulate their thoughts, wishes and messages, which are aimed both at other disabled people and development practitioners. These participants, along with other research participants, are laying the groundwork for what they conceive constructive development to be, and the need for INGOs and other development practitioners intervening in the disability domain to listen to disabled people's voices in shaping more effective development interventions *with* disabled people.

CHAPTER 8

DISABLED PEOPLE IN DEVELOPMENT: WHAT FUTURE?

No one knows our lives better than us.
(Benoit, Participatory Video Preparatory Meeting,
24th October 2014)

INTRODUCTION

This thesis set out to highlight the need to theorise disability from a Global South perspective and explore the significance of disabled people having more say over the development actions that affect them. To meet these objectives, the research sought to understand the lived experiences of disabled people in Burkina Faso; to create spaces in which disabled people's voices can be heard and are listened to within development approaches; and to investigate the implications of theorising disability from the Global South, thus the possibility of rethinking disability in development.

This chapter reviews the research findings and their implications in the field of disability and development. It also explores the potential of participatory research, informed by postcolonial theory and working together with disabled people, for challenging the long-standing oppression of people with disabilities. The first section of the chapter summarises the research findings with regard to the research aims and questions outlined in the introductory chapter. The second section then reviews the implications of the findings in relation to the significance of postcolonial approaches to disability. In the third section, the implications of the research findings are reviewed in relation to the practice and politics of development in Burkina Faso, in other sub-Saharan African countries, and in the wider Global South contexts. Finally, the last section proposes suggestions for future research in the field of postcolonialism, disability and development and explains why this matters.

RESEARCH FINDINGS

The first research question concerns how disabled people in the Global South generally, and in Burkina Faso specifically, experience and perceive disability, and what are their lived experiences. It was posited that while the lived experiences of disabled people (in Burkina Faso or elsewhere) cannot be generalised, disabled people in Burkina Faso generally face discriminatory situations similar to those faced by disabled people in many other countries, including discrimination in education, employment, transportation, and accessibility to infrastructure. However, while in western contexts the disability movement has advocated for a move from the medical approach to disability towards the social model, disability in Burkina Faso is often viewed as incapacity. While the social model purports that disability is a social construction and a result of the barriers imposed by a society that disables and excludes people, disabled people in Burkina Faso often view themselves as having something missing in comparison to people who are 'fit and able'. This view of disability, held by many disabled people themselves as well as the non-disabled society, stems from various factors. It is partly the result (as well as a consequence) of the symbolic exclusion of disabled people at the familial, community and national level, where disabled people are excluded from decision-making. The most significant factor affecting the view of disability in Burkina Faso, however, is the value put on productive bodies in a capitalist system. While in many pre-colonial societies in sub-Saharan Africa disabled people contributed to the daily life of the community, during colonial times they were considered abnormal and were relegated to institutions and charitable care. Colonialism, remnants of which are still visible today, brought with it a focus on production and exportation which deemed disabled people as 'unfit', and thus either had to be normalised, or relegated to the margins of society. It is in this context that disabled people in Burkina Faso today find themselves struggling to integrate fully into society and participate in their own, and their country's, development. It is also in this context that many disabled

people, as exemplified by the research participants, view their personal development as interlinked with being economically independent and financially secure. The onus on being economically productive leads to the perception of disabled people as lacking the necessary bodily functions to do so. In Burkina Faso, where the main form of employment is agrarian, this means that people with physical and visual disabilities, as well as people with albinism, are mostly excluded from this type of work. The objective of many people with disabilities, therefore, is to be gainfully employed. This often means working in the large informal sector, which characterises a large part of sub-Saharan Africa's workforce and which is where most disabled people in Burkina Faso make a living. In a country where the formal sector is barred to many disabled people due to lack of education, and where even disabled (and non-disabled) people with university level education have a hard time finding employment, the best way out of this predicament is seen by many research participants as having their own income-generating activity.

This brings us to the second research question, which asks what the roles of grassroots disabled people's organisations (DPOs), international non-governmental organisations (INGOs) and the state are, in development and disabled people's lives. Responding to the challenges disabled people encounter requires a strong and united disability movement. In Burkina Faso, however, the disability movement is rather weak in terms of funding and staffing, and is generally dependent on INGOs. It also has little reach outside the capital city, Ouagadougou. Despite the multitude of grassroots DPOs, many of these voluntary associations do not function beyond the occasional meeting and celebration of the International Day of Persons with Disabilities. The reasons for this are various. Many DPOs in Burkina Faso have been created in order to access funding or aid from INGOs or other entities. Consequently, many members join DPOs with the aim of gaining financial benefits. While those DPOs that have had INGO support in the past find themselves not being self-sufficient once the INGO withdraws its support, others continue to be

supported by INGOs in order to function. INGOs tend to support the same DPOs, both in order to satisfy donors in showing results, and also because these DPOs have gained the trust of INGOs over the years. This creates a 'circle of trust' which other (usually smaller or newer) DPOs find difficult to permeate. Furthermore, since most INGOs are based in the capital, DPOs in rural areas not only have less access to resources, but also to INGO support. Even at a national federation level, DPOs (again, especially in rural areas) find little support. The national federation of DPOs depends on the (often sporadic) external funding of INGOs, and thus follow INGOs' agenda. This predicament is sometimes also true for state authorities working with people with disabilities. The inclusive education department in the Ministry of National Education and Literacy, for example, relies heavily on INGOs' agendas and funding. Apart from the Ministry of Social Action and National Solidarity, which is responsible for the welfare of disabled people, the other ministries and the regional and provincial authorities do not normally mainstream disability in their work. The minimal activity of the state thus continues to encourage the intervention of INGOs in the disability and development domain.

INGOs, meanwhile, having become more professionalised and more accountable to donors (who increasingly channel funds through them), need reports and accountability from DPOs. This leads to the necessity of having people with a certain level of education at the head of DPOs. Since many disabled people do not have high levels of education, the same people (who tend to be men with physical disabilities) tend to head DPOs, often excluding women and those less educated. Both this factor as well as the fact that DPOs tend to be created (and members tend to join) with the aim of accessing aid, lead to lack of responsible leadership and transparency, discouraging members from being active in DPOs. Since many DPO members are voluntary, they also tend to give priority, understandably, to income-generating activities in order to survive; thus DPOs take a secondary role in their lives. This is not to say that DPOs do not have their uses. On the contrary, they offer a haven for many, even

more so for disabled people who had not met others with similar impairments before they joined the DPO. Many research participants find solace in meeting the other members and find a sense of belonging in these associations. Others give importance to the role of DPOs in raising awareness and human rights advocacy, an issue which is based on the social model approach which many INGOs tend to apply in their interventions. Human rights, however, tend to be emphasised by disabled people in urban areas, who are familiar with rights legislation and who would benefit more from their rights than disabled people in rural areas. For disabled people struggling to make ends meet, the benefits that rights might provide mean little compared to the opportunity to make a living. And while the right to gain a living by working is enshrined in human rights legislation¹⁹⁸, human rights are not a priority in a context where the rights are not put into practice, or where large groups of people either do not have knowledge of, or do not have recourse to the law in order to claim, their rights. The priority for most research participants is thus having an income in order to survive and have financial security. In this context, INGOs sometimes fund income-generating activities (IGAs) with groups of disabled people. However, these IGAs, such as artisanal work, are often unfeasible. A prime example is furniture-weaving, an activity which is often funded with groups of blind and visually impaired people. This activity is deemed quite unproductive: local consumers tend to buy cheaper products imported from China or second-hand goods from Europe, rather than the more expensive artisanal products. Furthermore, artisanal products are not a necessary item for everyday life, so people do not buy them as often as they would buy everyday products such as soap. Finally, this kind of activity means that blind people tend to be associated with furniture-weaving, which may actually limit their opportunities. Furthermore, it is not necessarily the case that people with similar

¹⁹⁸ For example, Article 27 of the United Nations Convention on the Rights of Persons with Disabilities.

impairments want to work together in groups, do the same activity, or do the activity which the INGO wants to fund.

This leads to the third research question, which asks to what extent disabled people are involved in their own development and decision-making, and what is the significance of their agency and voice within development. The fact that after years of INGO support and funding, DPOs are still dependent on them, and many disabled people remain socio-economically dependent, indicates that development is not being implemented to benefit disabled people. Based on the research findings and interviews conducted with disabled people, as well as INGOs and state authorities, evidence suggests that the farther disabled people are from the capital, the less chance they have of being heard and of being involved in decision-making. The decentralisation of DPOs – having a DPO in each municipality – is favoured by INGOs and donors. While having DPOs in far-flung municipalities is beneficial in reaching as many disabled people as possible, these DPOs are then represented by provincial and regional coordinations, meaning that it is often the heads of these coordinations who are involved with the national federation, state authorities and INGOs. Even then, it is usually the INGO (and the donor) who sets the agenda. In this context, therefore, it is evident that disabled people's voices need to be heard, all the more so within development programmes being implemented on their behalf. With this in mind, the research employed participatory approaches, mainly through participatory video (PV) and diagramming. Through the participatory video (which was designed, filmed and partly edited by the research participants themselves), a group of people with diverse disabilities were involved in recounting their struggles to, in their own words, 'overcome their disability' and become self-sufficient. Besides sharing their messages with other disabled people and emphasising that disability is not the end of the world, the PV participants also challenge INGOs, the state and other development agencies to know the reality on the ground before taking any action, and thus to speak with disabled people themselves. The PV

participants, as well as other research interviewees, suggest that rather than treating them as a group, disabled people should be considered as individual people, with individual needs and desires.

Disabled participants in the research expressed a strong desire to be heard and for spaces to be opened up in which they can be listened to. This links to the fourth research question, which explores how and why development policies and practices pertaining to disabled people in the Global South might be improved by engagement with their voices and agency. The need to engage with the voices and agency of disabled people in the Global South, rather than considering them as simply beneficiaries, is evident: if their needs and lived experiences are not taken into account, it is likely that beneficial development cannot take place. As the PV participants and other interviewees demonstrate, they want to work, and are not helpless people solely waiting for aid. Individually, disabled people are challenging the images of disabled people as being incapable, and arguing that they can be successful if they are personally committed and if development practices are tailored to meet their needs. Some disabled people go as far as to say that rather than receiving (sometimes useless) donations, such as wheelchairs, it is better for them to have income-generating activities with which to be able to buy and care for the wheelchairs themselves. There is a need, therefore, for INGOs to review where their priorities lie, whether it is with donors or with 'beneficiaries'; and for beneficiaries to be viewed as people with multiple dimensions rather than as people whose sole, or major, dimension is disability. The research participants also challenge the 'blanket' approach to development with disabled people, arguing that the approaches should take into account people's individual capabilities. Furthermore, as long as the state does not give priority to disability, INGOs will remain the major players in development with disabled people. This means that disabled people are unlikely to have socio-economic security, but will continue to depend on INGOs' agendas and funding which, in the context of the post-2008 financial crisis, has become (and seems likely to remain for the foreseeable

future) less dependable. Education and employment ministries, for example, need to take measures to mainstream disability in their policies and programmes. Some initiatives (such as opening civil service recruitment for disabled people) are being taken, but these remain rather sporadic. Meanwhile, there is also a need for welfare support, in such cases as with people with severe intellectual disabilities and their families. In a case where the family is such an important entity, as emphasised by research participants themselves, the family takes on an even more important role in the case of people with intellectual disabilities. It is not always possible, however, for family members to take care of disabled relatives while they are also struggling to make a living. Furthermore, in a context where children are the main 'social security' of the elderly, the state might need to increase family support. In the case of people with intellectual disabilities, not only are such children unable to care for elderly parents, but they are also left without support once the parents pass away.

POSTCOLONIAL APPROACHES TO DISABILITY

[T]he epistemological disengagement from majority world disability... has given rise to a discourse characterised by... generalisations from North to South, where... Western knowledge and practices homogenise, assume and dictate, and... critical issues related to context, culture, economy, history, community and relationships of power... are often bypassed or reframed to accommodate a minority world view.

(Grech, 2011: 88)

The significance of INGOs and the state listening to disabled people's voices takes its strength from postcolonial approaches to development. While postcolonial theory has generally bypassed, and only recently started engaging with, disability, it has much to offer in approaching disability and development. Postcolonial approaches to disability in Global South contexts are significant from three different, but related, aspects. Firstly, the fact that postcolonial theory challenges dominant western discourses offers the opportunity to provincialise (that is, challenge the universality of) western disability models and their application in Global

South contexts like Burkina Faso. Secondly, by rewriting the domination of history and the knowledge that constructs the Global South, it is possible to acknowledge the effects of colonialism on disabled people as people who were (and still are) doubly oppressed: as the colonised and as disabled people, the latter being an oppressed group within the already oppressed community. Thirdly, postcolonial theory seeks to recuperate the voices of the subaltern, which is especially meaningful when considering that disabled people worldwide, but more so in Global South contexts, are marginalised and often not heard. These facets of postcolonial theory, in turn, have implications for research carried out with disabled people in Global South contexts.

The research findings point to the fact that western models of disability are not always applicable in Global South contexts. The research participants demonstrate that while disability in Burkina Faso is sometimes perceived as caused by social barriers (recalling the social model), it is more often perceived in ways that mix medical and social models, interwoven with traditional and religious beliefs. Thus an emphasis on social systems faces problems when translated to Global South contexts, and often the impairment cannot be dissociated from the social systems which disable. While negative self-identity is often viewed as the result of impairment by medical models in western disability studies and discourse, and as a result of oppressive social relations by social models, the reality in Burkina Faso is not so straightforward. While social perceptions of disability affect disabled people's self-identities through the socialisation process, and disabled people often internalise the non-disabled society's perceptions of disability, many disabled people in Burkina Faso do not take the tragic view of disability that is the result of the biological deterministic approach to disability according to western knowledge. Rather, many disabled people are seeking to find a place in which they can take effective control of their own lives and enhance their status through making an economic contribution. Furthermore, the social model assumes cultural shifts and the availability of technical and

environmental solutions which are sometimes not fully provided even in western contexts. These issues bring to light the hegemony of disability discourse from the northern metropole, often ignoring perspectives of disabled people and discourses from the Global South. While disabled people in the Global South have been subjected to both colonial and patriarchal power, and have been spoken about discursively and spoken for politically, their own views have rarely been sought. Today, INGOs, while perhaps well-intentioned, continue the colonisation of disability, in a context where Burkinabes in general struggle to find work and make a living. Disabled people in countries like Burkina Faso are thus both living in a context which is still affected by the consequences of colonialism, and are being newly colonised by INGOs. And while disabled people are not rejecting INGOs' support, they are challenging the ways development interventions are being implemented. This highlights the importance of seeking to recuperate the voices of the disabled subaltern. While Spivak (in Loomba, 2005) argues that scholars should be sceptical about recovering subaltern agency, the only ethical way is to try (McEwan, 2009). In the context of development interventions, according to Rahnema (2000: 315):

The wishes of the people in need are a myth, well maintained by foreign and national authorities for their political, economic, military and sometimes geopolitical objectives.

The implications of these observations for this research, and indeed research with disabled people (in Global South contexts) in general, is that the most ethical way to conduct research is through participatory methods. While this research was not all participatory, the participatory diagramming and video sought to bring on the research participants as co-researchers, rather than research subjects, in order to co-produce knowledge and bring about positive change in their lives. Hence, the PV enabled the articulation of disabled people's voices and the implications of theorising disability from a Global South perspective and rethinking development with disabled people.

THE PRACTICE AND POLITICS OF DEVELOPMENT

The implications of theorising disability from Global South perspectives, and practicing development which engages with disabled people's views, take on further significance when considering a number of facts: that disabled people have been historically marginalised; that the majority of disabled people worldwide live in the Global South; that disability and poverty are intricately connected; and that one in five of the world's poorest people is a disabled person (UN Economic and Social Council, 2008). Despite all this, disability has been generally ignored by development efforts. While disability is often considered as a 'specialised area' (remnants of the medical discourses surrounding disability), thus barring it from being mainstreamed in development policies and programmes, there is the need to recognise that disability needs to be specifically considered in crucial areas such as education, employment and health, where disabled people find more barriers in accessing services. In the case of health and well-being, ignoring disability means ignoring the numerous disabling and preventable illnesses in countries like Burkina Faso, together with the lack of (access to) medical services. Nonetheless, while the Millennium Development Goals completely ignored disability, the Sustainable Development Goals (SDGs) only consider disability as a ground of discrimination in some goals, and do not mention them in other crucial goals relating to poverty, malnutrition, health, water and infrastructure. There is thus the need for development efforts, government policies and INGOs (the latter being key players in disability and development) to move beyond the realm of rhetoric and put equality for disabled people into practice; the first step towards reaching this goal is to listen to disabled people themselves.

The importance of listening to the voices of development beneficiaries is highlighted by Banuri (1990: 66), who claims that development interventions in the Global South by the west have been detrimental largely because "the project has constantly forced indigenous people to divert their energies from the *positive* pursuit of indigenously

defined social change, to the *negative* goal of resisting cultural, political, and economic domination by the West.” Banuri (ibid) thus argues that:

In order for the improvement in welfare of Third World people to become possible, we have to stop believing that this is something only ‘we’ can do for ‘them’; we have to stop trying to quantify and measure the ‘quality of life’ (or other indicators of ‘development’) because these measurements become a licence to intervene in ‘their’ lives on the grounds that ‘we’ know what is objectively and undoubtedly ‘good for them’.

Such measures “disenfranchise people”, “make it unnecessary for their opinions to be sought” and “make it impossible for them to change their preferences in the face of manifest problems” (Banuri, 1990: 66). Furthermore, Marglin (1990: 8) notes that “once people are reduced to quantifiable targets, it is hard... to take their freedom seriously”. While this thesis does not claim to hold significance for all disabled people in Global South contexts, or even in all of sub-Saharan Africa, the findings are significant in highlighting the importance of listening to disabled people’s voices in development. Furthermore, many disabled people in sub-Saharan Africa share the fact that they are unheard and that they live in unequal conditions, as is the case in Burkina Faso. Besides the impositions of the pre-set agendas of donors and INGOs against which disabled people have to ‘fight’ – mirroring the ways in which according to Banuri indigenous people have to fight against western domination – disabled people tend to be quantifiable targets for INGOs to justify donors’ funding.

An emerging thread linking the research findings in this thesis is the struggles of the research participants to change their predicament, but also to change development interventions implemented on their behalf by INGOs, such that the latter might be more effective. As Marglin notes, development ‘recipients’ are not often taken seriously. In the process of this research, when INGOs were offered the possibility of including a viewing of the participatory video filmed by disabled people themselves in their meetings, the preference was to exclude this from their agenda. This might have been due to time constraints or restrictions. Nonetheless, it is

notable that INGOs working *for disabled people* refused to listen to what disabled people have to say about their work. Banuri's disenfranchisement argument also takes on an added significance when considering that, for example, none of the INGO employees I interviewed are disabled. While being disabled does not necessarily ensure that the person has the necessary skills to plan and implement beneficial development interventions in the field of disability, it is notable that no field director of the INGOs working in disability in Burkina Faso is actually a person with disability. The major development entities working with disabled people and representing disabled people – in Spivak's (1988) words, 'speaking for' and 'speaking about' them – are non-disabled people, perpetuating the power inequalities and epistemic violence inherent in such forms of representation. This is evocative of Drake's (1997: 643) observations on traditional charities "who purport to empower disabled people" and "actually *dis-able* them, may usurp their voice and can block access to resources that could be put to much better use" (*italics in original*). The implication of Drake's comments for the Burkinabe context is that funding might be more beneficial if it were fed directly from donors to DPOs. This would both eliminate the need to fund INGO staff and ensure that funding is used according to the DPOs' needs. However, Drake (*ibid*) comments that "such an analysis naturally lends support to the need for a thriving Disability Movement, and non-disabled people, convinced by these arguments, would want to encourage its development. The question is: How?" Taking the situation in Burkina Faso as an example, INGOs are in fact encouraging the disability movement; yet in the face of weak DPOs, INGOs tend to *dominate* not only the disability movement but the functioning of DPOs which remain dependent on INGOs, leading to the observation by Drake (1997: 644) that:

Charitable action and the evolution of government social policy has all too frequently reflected the hegemony of 'nondisabled' people.

Drake (*ibid*) continues to say that "[p]erhaps disabled people's organisations are now old enough (i.e.) strong enough) to counter these

kind of risks and may therefore be in a position to use the resources of ‘non-disabled’ allies”. However, as emerges from this research, though DPOs might be ‘old’, they are not united in one strong disability movement. If, then, INGOs are to continue working with DPOs (something which disabled people do not reject), the onus lies with INGOs to support DPOs in becoming independent and self-sufficient. As Drake says, “[i]t is difficult to know where the proper balance lies here”. One way of finding a balance might lie in a suggestion made by one of the PV participants that is, of INGOs employing disabled people themselves in the projects they implement (Laurentine, PV Preparatory Meeting, 24th October 2014). In this way, disabled people are directly involved in (and at different stages of) projects which affect them. From a study Flower and Wirz (2000: 177) conducted of European-based INGOs and grassroots DPOs, they found that while INGOs involve DPOs in the planning of their services and projects, this is mostly done through sharing information with them, rather than “consulting them, including them in decision-making or supporting action initiated by” the DPOs. Thus, as Kabzems and Chimedza (2002: 149) assert, there is a “need to include persons with disabilities at all levels and stages of projects”. However, “[i]t remains rare for a person with a disability to be on the project payroll, whether in the capacity of consultant, accountant or tea lady” (ibid). In view of the lack of involvement of disabled people in such programmes and projects, participatory and other methods that seek to engage with disabled people and to give voice to their needs and desires are thus of significance. They may not have the capacity to change the face of development, but they at least open up the possibility of improving development policies and practices pertaining to disabled people in the Global South by engaging with the voices and agency of disabled people themselves. As Benoit, a physically disabled man quoted in this chapter’s epigraph, says, “no one knows our lives better than us”. This statement lies at the heart of participatory research, which considers the research participants as experts of their own lives, needs and desires.

Critiques of INGOs' efforts, however, cannot be considered on their own. As discussed, the strong role INGOs play in disabled people's development is also due to the lack of involvement of the state. Without political will, it is doubtful that disabled people's predicament can really change. While development agencies do not mainstream disability in their policies, and therefore it is often INGOs specialising in disability that work with disabled people, the state in Burkina Faso has also delegated the welfare of disabled people to the Ministry of Social Action and National Solidarity, a ministry which also takes under its wing, among others, elderly people, widows, orphans and street children, and people with AIDS and HIV. Thus, while disabled people have their 'own' ministry to refer to, the same ministry also deals with people in situations very different from theirs. Furthermore, this also means that other ministries tend to assume that disability is the Ministry of Social Action's responsibility and thus do not always mainstream disability in their programmes and policies in areas such as health, education and employment. The significance of disability being mainstreamed in areas such as education, emerges when considering that, while Burkina Faso has a mixed system of inclusive and special school education, education remains unreachable to many children with disabilities, especially in rural areas where schools are not equipped to teach children with sensory disabilities (and where even specialised schools in urban areas are unreachable for many). This is also linked to the fact that rural areas are usually the last to benefit from development measures, as well as to the fact that regional authorities in Burkina Faso do not have much power in decision-making. Rather, they are subject to decisions from the centralised government. However, apart from ensuring that such important sectors as education and employment (the latter being an aspect which the research participants emphasise), are accessible to disabled people, there is also the need for the state to provide welfare for those who need it. In countries like Burkina Faso, "the inability to take care of a disabled family member is often bound to the inability to cope with extreme poverty, and not

necessarily to negative attitudes and/or lack of concern” (Grech, 2011: 90). This takes on further significance in the case of people with intellectual disabilities, who are not always able to contribute as much as other members of the family and need more care by the family. The issue of welfare is also related to the issue of social security which is lacking not only in Burkina Faso but in many countries in sub-Saharan Africa. Exploring the reasons for the lack of strong social security systems, Fall-Diop (2006) cites the lack of an overall vision which takes into account the expansion of great poverty and that of the informal sector, along with the absence of dialogue, and the lack of knowledge of macroeconomic politics by the governments.

Ultimately, the research participants’ experiences and concepts of development cannot be dissociated from the wider context, not only of Burkina Faso, but of the Global South in general. The lives of the disabled people involved in this research take place against the backdrop of the national and international contexts. While disabled people often encounter more barriers, many of the situations in which disabled people in Burkina Faso find themselves are not dissimilar to those of non-disabled people. Unemployment, a calamity which affects many disabled people, affects many non-disabled people as well, not only in Burkina Faso but in many Global South contexts. As Grech (2011: 90) observes:

the assertion that disabled people are disproportionately unemployed needs to be viewed in the midst of mass unemployment for poor people, which in turn determines the viability of enhancing employment possibilities for disabled people without creating broad-based employment.

Thus, the majority of non-disabled people in Burkina Faso, too, struggle to access secure employment in the formal sector and are thus compelled to find work in the informal sector. Obtaining loans to start income-generating activities is also hard for many people in Burkina Faso who cannot offer guarantees of loan repayment. Furthermore, there are also some research participants who, as a representative of the Ministry of

Social Action observed during the second PV viewing, are better off than some non-disabled people in Burkina Faso:

During the discussion, the Ministry of Social Action representative said that Michel [one of the participants in the film], is better off than a lot of non-disabled people: he has a small farm, and a small cafeteria.

(Entry in Fieldwork Diary, 30th April 2015)

Consequently, in a country like Burkina Faso, where the majority of the population encounter economic difficulties, the definition of exclusion with regard to people with disabilities cannot be reduced to this one criterion alone (HI, 2005), but has to be considered in the context of not only other factors such as religious and traditional beliefs and the symbolic exclusion of disabled people, but also in terms of the intersectionality within disability. As this research demonstrated, the socio-economic insertion of disabled people is also affected by factors such as gender, the urban / rural context, the family context, and the impairment, which, as the research participants themselves note, plays an important role with regards to the type, severity, and stage of life at which the person became disabled. Furthermore, it is impossible to disconnect disability from the same economic system which disables. The capitalist mode of production, causing economic polarisation both within and between countries, affects people in the Global South in general and disabled people in particular. Thus disabled people are often the poorest of the poor (Sheldon, 2005). The link between capitalism (which has its roots in colonialism) and disablement, is often ignored, and yet it can be argued that the capitalist system is “the root cause of disablement” (ibid: 118) and that “the fundamental relationships of capitalist society are implicated in the social oppression of disabled people” (Gleeson, 1997: 196). The value that the capitalist system puts on productive bodies is the same system which values the ‘able-bodied’ and devalues the disabled one. Hence, “the development of a global political economy of disability would certainly be a step in the right direction” (Sheldon, 2005: 125). This implies not only exploring how the current global economy system disables, but also its

roots in the same European colonialism which enabled an industrialised Europe in which the emphasis on productive bodies has its roots. While this research has only touched upon this, it is recognised as “a vital challenge for disability studies” (Sheldon, 2005: 115) on which future disability research could be based. Of particular importance to this research, however, is the need to recognise that while scholars like Shakespeare (1996) consider disability seen as a consequence of impairment (and as people who cannot do productive work) as a negative stereotype, it is understandable that this is the way disability is perceived by many disabled and non-disabled people in Burkina Faso. The view of people being disabled by the current economic system also substantiates the reasons for which many research participants put an emphasis on ‘overcoming their disability’ and becoming economically productive in order to be able to meet their own financial needs and take care of their families. Disabled people are struggling to survive in the same capitalist economic system which disables them and puts an onus on wealth and able-bodiedness, reflecting what Deegan (2010: 26) argues, that is, that disabled people “live in and reproduce the able-bodied lifeworld”.

Finally, in the global context, disabled people’s poverty cannot be eliminated if poverty in Burkina Faso, sub-Saharan Africa, and worldwide, is not eliminated. While it is impossible to ignore the cruciality of preventing and curing disabling illnesses, and removing barriers to health, education and employment, these factors cannot be dissociated from the wider economic system. As Charles Mutasa¹⁹⁹ argues, disease-specific interventions by the World Bank – an institution which Power (2001: 88) calls the “creator of poverty in Africa” – will not suffice while the indebtedness snare continues (Bretton Woods Project, 2001). The question of development, therefore, is firmly linked to the issue of the global economic system, and Hettne (2008) emphasises that development cannot be analysed or carried out on a nation-state-only framework.

¹⁹⁹ The Zimbabwean delegate at the First People’s Health Conference (December 2000) held in Dhaka, Bangladesh.

CONCLUSION

Unless disability in the Global South is considered in its entirety, taking into account the disabling factors resulting from historical, cultural and economic elements, the roots, and perpetuation, of disablement cannot be fully dealt with. And, unless disabled people are viewed as more than just development beneficiaries, but rather as individual people with hopes, dreams and capabilities, development efforts are likely to perpetuate stereotypes rather than autonomy. Thus, there is a need for disability research to be informed by postcolonial theory and to move this into practice by engaging with disabled people's voices in development without whose inclusion development cannot fully take place.

Conducting research and practice informed by postcolonial theory, however, is not a solution to everything. While both postcolonial and disability scholars problematise representation, questions arise with regard to the representation of people with severe intellectual disabilities. While this is an issue which has been discussed at length in western disability studies (for example, Goodley, 2000; Ippoliti et al, 1994); people with intellectual disabilities in countries like Burkina Faso are often represented by family members and, where available, teachers and psychologists. In fact, this was one of the significant challenges encountered during this research, that is, access to people with intellectual disabilities. While this partly reflects the nascent Burkinabe consideration of intellectual disability (and indicates the need for more knowledge of the different types of intellectual, cognitive and development disabilities), it also reflects the fact that some people with intellectual disabilities require support in making their voices heard. While a discussion on the complexities and ethical elements of the representation of people with intellectual disabilities is beyond the scope of this thesis, and without implying that people with intellectual disabilities cannot represent themselves, the limitations with regard to this encountered in this study indicate the importance of two issues. First, the need to conduct research specifically with people with intellectual disabilities in the Global

South, of which there is a dearth. Second, the need to explore the role of carers, assistants and teachers with people with intellectual disabilities in representing the latter. Without indicating that this is the only way in which people with intellectual disabilities can make their voices heard, and without ignoring the importance of problematising representation and opening up ways of mitigating the power relations involved here, relatives and professionals play a large role in intellectually disabled people's lives and thus need to be taken into consideration. Nevertheless, there is also a need for the exploration of how people with intellectual disabilities can contribute towards their own and their country's development.

The future of disability and development, both in theory and in practice, certainly faces a long road ahead. This research sets a humble basis on which future research in this domain could be based, and opens up the possibilities of engaging with disabled people's voices to enable their recommendations to be implemented in practice, through the continued dissemination of the participatory video with key players in development. Meanwhile, there is a need for research to further explore how disabled people's voices can be foregrounded in development efforts, not only in Burkina Faso but in wider Global South contexts. One of the avenues which would be fruitful to explore is how DPOs can be truly strengthened. If the current INGO interventions are not strengthening DPOs, despite capacity-building efforts, funding and training, then other avenues are evidently required. This indicates the need for further exploration of the balance that might be sought between the support of INGOs and the autonomy of the DPOs. It also suggests the need to look at the feasibility of the 'decentralisation' of DPOs in countries like Burkina Faso, in the face of lack of funding and resources, and the feasibility of sustaining so many 'layers' of DPOs. Such research would explore what the role of umbrella DPOs and national federations could be, in terms of effectively supporting the smaller DPOs. This leads to the importance of listening to all disabled people's voices, rather than just the 'elite' ones, and the significance of opening up spaces not only in urban areas, but also

in rural ones where disabled people are often less heard and often face different situations than those in urban ones. This also implies the need for research on how disability is understood in countries like Burkina Faso and other French colonies, where perceptions of disability have not been much researched. This research, for example, did not interview the non-disabled society members on their views of disability, which could be an avenue of research leading to a more in-depth understanding of how disability is viewed, and which could inform INGOs' and DPOs' awareness raising on disability. This would, in turn, necessitate the exploration of more coordination between the INGOs working in the disability domain, in terms of the initiatives and interventions with disabled people being implemented to maximum benefit. Certainly, this indicates that there is a long road ahead in the domain of disability and development; but it is with hope for a future in which development can truly achieve the aim of bettering the lives of disabled people in the Global South that this research was conducted, and lays down the path for future research and practice to do the same.

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APPENDIX 1

COMPLETE LIST OF INTERVIEWS

INDIVIDUAL PEOPLE WITH DISABILITIES

CASCADES REGION²⁰⁰

Comoé Province²⁰¹

Department / Municipality	Name	Gender	Age	Type of Impairment	Date of Interview	Duration of Interview (Hour: h / Minutes: m / Seconds: s)
Banfora	Abdou Raman	Male	28	Visual ²⁰²	4 th March 2015	49m 30s
	Abdoul Karim	Male	39	Visual	18 th March 2015	24m 01s
	Abibata	Female	15	Physical ²⁰³	10 th March 2015	18m 38s
	Abibata	Female	18	Auditive ²⁰⁴	17 th March 2015	12m 00s
	Abou	Male	22	Visual	27 th March 2015	19m 21s
	Aisha	Female	38	Physical	12 th March 2015	20m 06s

²⁰⁰ Regions are listed in alphabetical order.

²⁰¹ The first listed province is the major province of the region; the rest of the provinces are listed in alphabetical order.

²⁰² Includes blind people and partially sighted people.

²⁰³ Includes people who use wheelchair or crutches, people who limp, people with burns or paralysis, people with dwarfism, people with kyphosis, and people who have amputated limbs or digits (including due to leprosy).

²⁰⁴ Includes deaf people and hard-of-hearing people.

	Alassane	Male	50	Visual	19 th March 2015	27m 13s
	Ali	Male	31	Auditive	17 th March 2015	15m 64s
	Alima	Female	22	Physical	9 th March 2015	14m 43s
	Amadou	Male	28	Visual	5 th March 2015	1h 04m 04s
	Amadou	Male	46	Physical	4 th April 2015	25m 07s
	Aminata	Female	35	Physical	28 th February 2015	26m 28s
	Armata	Female	30	Physical	14 th March 2015	13m 31s
	Baba	Male	43	Auditive	18 th March 2015	14m 04s
	Barakisa	Female	20	Auditive	18 th March 2015	21m 16s
	Bié	Male	35	Auditive	18 th March 2015	10m 25s
	Bintou	Female	44	Physical	4 th March 2015	19m 06s
	Cheick	Male	31	Physical	10 th March 2015	24m 25s
	Daouda	Male	29	Albinism	8 th March 2015	16m 15s
	Daouda	Male	33	Physical	7 th March 2015	14m 11s
	Diloma	Male	6	Physical	5 th March 2015	11m 42s
	Dramane	Male	49	Physical	7 th March 2015	16m 28s
	Enza	Male	33	Auditive	17 th March 2015	18m 00s
	Fatou	Female	25	Albinism	12 th March 2015	14m 37s
	Gnebama	Female	19	Physical	5 th March 2015	27m 46s
	Ibrahime	Male	17	Auditive	17 th March 2015	16m 15s
	Idrissa	Male	52	Physical	26 th February 2015	29m 15s
	Isaac	Male	67	Visual	10 th March 2015	26m 04s
	Issouf	Male	41	Physical	28 th February 2015	53m 43s
	Kadeba	Male	57	Physical	26 th February 2015	37m 48s
	Kadiatou	Female	31	Physical	12 th March 2015	18m 21s
	Korotimi	Female	17	Auditive	18 th March 2015	09m 31s
	Korotoum	Female	51	Physical	11 th March 2015	16m 06s

	Lassina	Male	18	Physical	10 th March 2015	26m 29s
	Maïmounata	Female	28	Visual	25 th February 2015	40m 53s
	Marie Rose	Female	19	Albinism	8 th March 2015	13m 02s
	Mathieu	Male	≈ 26 ²⁰⁵	Intellectual	7 th March 2015	26m 06s ²⁰⁶
	Fitini	Male	17 / 18	Intellectual		
	Maxime	Male	36	Physical	26 th February 2015	1h 29m 01s
	Moumouni	Male	25	Physical	25 th April 2015	? ²⁰⁷
	Moussa	Male	43	Albinism	4 th March 2015	?
	Noella	Female	18	Albinism	8 th March 2015	07m 43s
	Orokia	Female	29	Visual	5 th March 2015	28m 49s
	Pedwende	Male	21	Physical	28 th February 2015	22m 44s
	Robert	Male	59	Visual	10 th March 2015	1h 42m 27s
	Seydou	Male	47	Physical	7 th March 2015	21m 56s
	Souleymane	Male	42	Visual	7 th & 9 th March 2015	1h 10m 22s
	Téné	Female	26	Visual	25 th February 2015	38m 31s
	Tomnoma	Female	27	Auditive	17 th March 2015	13m 35s
	Yakouba	Male	22	Physical	28 th February 2015	20m 57s
	Yaya	Male	48	Physical	5 th March 2015	23m 05s
	Zacharia	Male	27	Visual	18 th March 2015	26m 19s

²⁰⁵ Indicates people who know their approximate age but not their exact age.

²⁰⁶ Interview was held with both interviewees together.

²⁰⁷ Interview was not recorded, either because interviewee did not wish to be recorded or because there was too much noise to record the interview; thus length of interview is unknown.

Bérégadougou	Awa	Female	34	Visual	27 th February 2015	16m 23s
	Awa	Female	60	Physical	27 th February 2015	25m 55s
	Benjamin	Male	37	Physical	27 th February 2015	12m 14s
	Djakalia	Male	46	Physical	27 th February 2015	27m 19s
	Maimouna	Female	36	Physical	27 th February 2015	23m 36s
	Oula	Male	25	Intellectual & Physical	26 th February 2015	28m 21s
	Salif	Male	43	Physical	27 th February 2015	21m 24s

Mangodara	Awa	Female	38	Physical	21 st April 2015	34m 35s
	Bali	Male	48	Intellectual	21 st April 2015	14m 24s
	Issiaka	Male	43	Auditive	21 st April 2015	10m 54s
	Karidia	Female	30	Physical	21 st April 2015	25m 35s
	Lassina	Male	21	Physical	21 st April 2015	19m 02s
	Ousmane	Male	50	Visual	21 st April 2015	12m 20s
	Sina	Male	53	Physical	21 st April 2015	37m 18s
	Soumalia	Male	31	Physical	21 st April 2015	14m 26s
	Yakou	Male	13	Auditive & Visual	21 st April 2015	7m 33s

Moussodougou	Bakary	Male	36	Physical	25 th March 2015	11m 29s
	Fantié	Female	40	Physical	25 th March 2015	12m 52s
	Issouf	Male	41	Visual	25 th March 2015	17m 04s
	Karim	Male	48	Physical	25 th March 2015	26m 08s
	Malick	Male	34	Physical	25 th March 2015	16m 57s
	Malicki	Male	45	Physical	25 th March 2015	21m 22s
	Mousseniba	Male	26	Physical	25 th March 2015	17m 06s
	Tien Hale	Male	52	Physical	25 th March 2016	12m 23s

	Yacouba	Male	66	Visual	25 th March 2016	12m 46s

Niangoloko	Abdoulaye	Male	44	Physical	6 th March 2015	16m 18s
	Abibata	Female	21	Visual	6 th March 2015	32m 55s
	Aboubakary	Male	49	Auditive	6 th March 2015	11m 12s
	Kadiatou	Female	35	Auditive		
	Barakisa	Female	13	Epilepsy	6 th March 2015	7m 20s
	Djeneba	Female	36	Albinism	6 th March 2015	19m 35s
	Maimounata	Female	48	Physical	6 th March 2015	31m 59s
	Martin	Male	23	Intellectual	6 th March 2015	12m 49s
	Midibahaye	Male	48	Physical	6 th March 2015	23m 24s

Sidéradougou	Abdoul	Male	41	Physical	20 th March 2015	22m 09s
	Alizata	Female	60+	Visual	20 th March 2015	14m 58s
	Issa	Male	37	Physical	20 th March 2015	25m 41s
	Sibema	Male	45	Physical	20 th March 2015	20m 34s

Soubakaniédougou	Aisha	Female	14	Albinism	3 rd March 2015	20m 43s
	Alima	Female	19	Physical	3 rd March 2015	18m 35s
	Bayamo Alice	Female	41	Physical	7 th April 2015	1h 9m 53s
	Djakalia	Male	7	Intellectual	3 rd March 2015	12m 06s
	Doubé	Male	41	Physical	3 rd March 2015	18m 42s
	Etienne	Male	43	Visual	3 rd March 2015	33m 35s
	Makamsa	Female	16	Auditive	3 rd March 2015	20m 25s
	Mamadou	Male	44	Physical	3 rd March 2015	21m 30s

	Moussa	Male	49	Physical	3 rd March 2015	15m 11s
	Pauline	Female	52	Physical	3 rd March 2015	21m 32s
	Sakoulba	Male	14	Intellectual		
	Sadima	Female	26	Physical	3 rd March 2015	22m 17s
	Sombié	Male	55	Physical	3 rd March 2015	09m 14s

Tiéfora	Bakary	Male	41	Visual	20 th March 2015	22m 10s

Léraba Province

Dakoro	Bassidiky	Male	55	Visual	7 th April 2015	18m 10s
	Brahima	Male	49	Physical	7 th April 2015	11m 20s
	Djakalia	Male	14	Visual	7 th April 2015	11m 10s
	Fatimata	Female	40	Physical	7 th April 2015	6m 15s
	Fatimata	Female	27	Auditive	7 th April 2015	21m 25s
	Lassina	Male	44	Physical	7 th April 2015	23m 16s
	Mafirma	Female	21	Physical	7 th April 2015	36m 04s
	Mamadou	Male	42	Physical	7 th April 2015	11m 51s
	Mariam	Female	43	Physical	7 th April 2015	32m 13s
	Mohammed	Male	16	Auditive	7 th April 2015	11m 15s
	Yaya	Male	50	Physical	7 th April 2015	12m 12s

Douna	Abdoulaye	Male	19	Albinism	16 th March 2015	20m 19s
	Lamina	Male	41	Visual	13 th March 2015	43m 04s
	Lassina	Male	56	Physical	16 th March 2015	30m 35s
	Madjata	Female	47	Physical	16 th March 2015	12m 23s

	Mariam	Female	37	Physical	16 th March 2015	13m 03s
	Seydou	Male	48	Physical	16 th March 2015	17m 34s
	Tandro	Male	35	Physical	16 th March 2015	18m 59s
Kankalaba	Djata	Female	10	Albinism	13 th April 2015	1h 1m 33s
	Tchegué	Male	15	Albinism		

Loumana	Alimatou	Female	17	Physical	17 th April 2015	12m 17s
	Ardjouma	Male	53	Visual	17 th April 2015	12m 26s
	Djata	Female	17-19	Auditive	17 th April 2015	13m 19s
	Djenebou	Female	18	Physical	17 th April 2015	19m 45s
	Dramane	Male	52	Visual	17 th April 2015	15m 34s
	Drissa	Male	15	Physical	17 th April 2015	11m 55s
	Lati	Male	56	Physical	17 th April 2015	06m 26s
	Mabougouri	Female	30	Intellectual	17 th April 2015	07m 51s
	Madou	Male	47	Physical	17 th April 2015	09m 08s
	Maminata	Female	25	Physical & Intellectual	17 th April 2015	13m 54s
	Mariam	Female	34	Physical	17 th April 2015	13m 54s
	Minata	Female	28	Physical	17 th April 2015	13m 57s
	Mohammed	Male	53	Physical	17 th April 2015	13m 26s
	Sali	Female	16	Auditive	17 th April 2015	14m 24s
	Salif	Male	29	Visual	17 th April 2015	15m 42s
	Salif	Male	42	Physical	17 th April 2015	15m 59s
	Siaka	Male	> 20	Intellectual & Visual	17 th April 2015	09m 49s
	Sita	Female	33	Physical	17 th April 2015	07m 53s
	Yacouba	Male	66	Physical	17 th April 2015	08m 07s

Sindou	Aminata	Female	50	Physical	13 th March 2015	17m 59s
	Bissiri	Male	27	Physical	13 th March 2015	26m 02s

Wolonkoto	Abdoulaye	Male	44	Physical	16 th March 2015	29m 58s

CENTRE REGION

Kadiogo Province

Ouagadougou	Aicha	Female	21	Physical	22 nd January 2015	52m 07s
	Mamouna	Female	26	Physical		
	Alassane	Male	29	Physical	16 th February 2015	20m 05s
	Badandi	Male	28	Physical	2 nd February 2015	?
	Brama	Male	26	Visual	6 th February 2015	24m 27s
	Clementine	Female	29	Physical	13 th February 2015	29m 08s
	Desirée	Male	26	Physical	18 th November 2014	?
	Ela	Female	37	Physical	20 th November 2014	16m 55s
	Emile	Male	55	Visual	26 th November 2014	29m 43s
	Gaston	Male	38	Physical	1 st December 2014	21m 16s
	Henri	Male	55	Physical	19 th February 2015	1h 22m 5s
	Ismael	Male	35	Physical	2 nd February 2015	44m 30s
	Issifou	Male	27	Visual	20 th May 2015	30m 15s
	Issouf	Male	42	Physical	22 nd January 2015	25m 29s
	Jacques	Male	36	Physical	17 th November 2014	1h 07m 01s
	Jean-Baptiste	Male	31	Physical	29 th January 2015	?

	Linda	Female	29	Visual	16 th June 2015	8m 52s
	Madi	Male	30	Physical	22 nd January 2015	?
	Manda	Female	34	Physical	20 th November 2014	11m 00s
	Mariam	Female	27	Physical	6 th February 2015	?
	Martin	Male	?	Physical	29 th January 2015	?
	Marcel	Male	?	Physical		
	Mathias	Male	35	Visual	20 th January 2015	51m 48s
	Minoungou	Male	?	Physical	22 nd January 2015	43m 27s
	Pauline	Female	28	Albinism	31 st January 2015	17m 54s
	Remo	Male	27	Physical	20 th November 2014	21m 13s
	Seydou	Male	43	Physical	18 th November 2014	?
	Soufyiane	Male	25	Albinism	31 st January 2015	20m 58s
	Souleymane	Male	-	3 Albino Children ²⁰⁸	31 st January 2015	11m 47s
	Yaya	Male	37	Physical	3 rd February & 6 th May 2015	51m 41s + ?

EST REGION

Gourma Province

Diapangou	Celine	Female	21	Albinism	7 th October 2014	24m 04s
	Fatimata	Female	60	Visual	24 th September 2014	24m 58s
	Issa	Male	60	Visual	24 th September 2014	37m 21s

²⁰⁸ Names of children not known.

Fada N'Gourma	Bamboaro	Female	28	Auditive	7 th October 2014	29m 12s
	Emmanuel	Male	49	Physical	18 th October 2014	58m 04s
	Evelyn	Female	45	Physical	19 th October 2014	14m 15s
	Hippolyte	Male	31	Physical & Intellectual	24 th October 2014	32m 54s
	Karim	Male	36	Visual	23 rd September 2014	30m 09s
	Laurentine	Female	31	Physical	20 th October 2014	20m 32s
	Mariam	Female	27	Physical	15 th October 2014	23m 49s
	Michel	Male	42	Physical	22 nd September 2014	59m 23s
	Wali	Female	26	Physical	25 th September 2014	36m 20s

Matiakoali	Damiadi	Female	36	Physical	11 th October 2014	17m 35s
	Maïmouna	Female	40-50	Auditive	11 th October 2014	?
	Nindja	Male	77	Visual	11 th October 2014	45m 24s
	Yenupundi	Male	43	Physical	11 th October 2014	14m 03s

Tibga	David	Male	26	Physical	21 st October 2014	19m 17s
	Dieudonné	Male	34	Physical	21 st October 2014	12m 21s
	Innocent	Male	35	Physical	21 st October 2014	13m 30s
	Lucien	Male	39	Physical	21 st October 2014	24m 58s
	Zachary	Male	39	Physical	21 st October 2014	18m 19s

Gnagna Province

Bilanga	Awa	Female	36	Visual	2 nd October 2014	30m 36s

Bogandé	Adama	Male	50	Physical	2 nd October 2014	18m 21s
	Dimanchi	Female	35	Physical	2 nd October 2014	20m 57s
	Kemhana	Male	≈ 100	Physical & Visual	2 nd October 2014	17m 16s
	Moumouni	Male	44	Visual	2 nd October 2014	26m 34s
	Seydou	Male	94	Visual & Physical	2 nd October 2014	29m 35s

Piela	Florentin	Male	32	Intellectual & Physical	1 st October 2014	19m 28s
	Nicole	Female	20/21	Auditive	1 st October 2014	25m 34s
	Yendie	Male	36	Physical	1 st October 2014	17m 47s
	Zachary	Male	?	Physical	1 st October 2014	36m 20s

Komondjari Province

Gayeri	Dahani	Male	17	Intellectual	14 th October 2014	09m 33s
	Oumarou	Male	72	Physical	14 th October 2014	23m 28s
	Souleymane	Male	27	Visual	14 th October 2014	32m 51s
	Yempani	Male	27	Auditive	14 th October 2014	14m 07s
	Zenabou	Female	14	Intellectual	14 th October 2014	11m 55s

Kompienga Province

Kompienga	Benoit	Male	32	Physical	27 th September 2014	1h 24m 27s
	Fatimata	Female	21	Physical	26 th September 2014	38m 33s
	Hélène	Female	23	Physical	26 th September 2014	25m 43s
	Moïse	Male	25	Visual	26 th September 2014	38m 06s
	Numpua	Female	≈ 15	Auditive	26 th September 2014	28m 59s

	Sayouba	Male	33	Physical	27 th September 2014	1h 2m 05s

Tapoa Province

Kantchari	Banyala	Female	37	Physical	10 th October 2014	17m 13s
	Elisabeth	Female	53	Physical	10 th October 2014	?
	Ibrahim	Male	32	Auditive	10 th October 2014	16m 11s
	Regina	Female	36	Physical	10 th October 2014	35m 51s
	Veronique	Female	24	Intellectual & Epilepsy	10 th October 2014	16m 59s

HAUTS-BASSINS REGION

Houet Province

Bobo-Dioulasso	Ahmed	Male	45	Visual	10 th April 2015	31m 47s

PLATEAU-CENTRAL REGION

Kourwéogo Province

Boussé	Bangraogo	Male	66	Physical	4 th February 2015	27m 09s
	Moumouni	Male	37	Physical	4 th February 2015	09m 57s
	Richard	Male	30	Physical	4 th February 2015	18m 46s
	Seydou	Male	40	Physical	4 th February 2015	32m 00s

DISABLED PEOPLE'S ORGANISATIONS (DPOs)

CASCADES REGION

Comoé Province

Departement / Municipality	DPO	Designation (President: P / General Secretary: GS) and Name of Interviewee(s) Gender (Male: M / Female: F) Impairment (Physical: Ph / Visual: Vi / Auditive: Au / Albinism: Al)	No. of Members	Date of Interview	Duration of Interview
Banfora	DPO 1	Ex-P: Korotoum (F / Ph)	? ²⁰⁹	3 rd March 2015	28m 54s
	DPO 2	P: Souleymane (M / Vi)	68	9 th March 2015	48m 29s
	DPO 3	P: Karim (M / Al)	> 150	8 th March 2015	13m 39s
	DPO 4	P: Soungalo (M / Ph) GS: Cheickna (M / Non-disabled)	≈ 50	14 th March 2015	45m 49s
	DPO 5	ex-P: Amadou (M / Ph)	?	4 th April 2015	30m 08s
	DPO 6	GS: Enza (M / Au)	21	17 th March 2015	09m 08s
	DPO 7	P: Isaac (M / Vi)	?	10 th March 2015	40m 53s
	DPO 8	P: Issouf (M / Ph)	18	24 th February 2015	1h 13m 52s

²⁰⁹ Information was not given or interviewee did not know the number of members of the DPO.

			Executive Committee Members		
	DPO 9	P: Alassane (M / Vi)	80	19 th March 2015	33m 46s
Bérégadougou	DPO 10	P: Salif (M / Ph) Other Executive Committee Members	45 – 50	27 th February 2015	33m 51s
Moussodougou	DPO 11	Executive Committee Members	36	25 th March 2015	34m 01s
Niangoloko	DPO 12	P: Abdoulaye (M / Ph) Treasurer: Bruno (M / Ph)	53	6 th March 2015	26m 44s
Sidéradougou	DPO 13	P: Issa (M / Ph)	37	20 th March 2015	43m 08s
Soubakaniédougou	DPO 14	P: Moussa (M / Ph) Deputy GS: Mamadou (M / Ph) Other Executive Committee Members	?	3 rd March 2015	1h 02m 57s

Léraba Province

Dakoro	DPO 15	Executive Committee Members	45	7 th April 2015	1h 00m 03s
Douna	DPO 16	ex-V-P: Seydou (M / Ph)	60	13 th March 2015	31m 38s
Sindou	DPO 17	Deputy GS: Bissiri (M / Ph) Treasurer: Aminata (F / Ph)	25	13 th March 2015	22m 43s

CENTRE REGION

Kadiogo Province

Ouagadougou	DPO 1	P: Désirée (F / Ph)	21	13 th February 2015	44m 52s
	DPO 2	Members	≈ 20	1 st December 2014	23m 17s

	DPO 3	P: Daouda (M / Ph)	20	26 th November 2014	46m 30s
	DPO 4	P: Boukary (M / Non-disabled)	33 ²¹⁰	13 th February 2015	47m 34s
	DPO 5	P: Eric (M / Ph) GS: Oumar (M / Ph)	120	24 th January 2015	?
	DPO 6	P: Zama (M / Ph)	> 100	18 th June 2015	22m 04s
	DPO 7	P : Seydou (M / Vi)	16	20 th February 2015	1h 00m 07s
	DPO 8	P: Lalaïssi Siri (F / Parent of Autistic Child)	14 ²¹¹	5 th February 2015	45m 01s
	DPO 9	V-P: Timothée (M / Ph)	> 200	27 th January 2015	38m 24s
	DPO 10	P: Nadine (F / Ph)	≈ 45	18 th November 2014	?
	DPO 11	P: Mimi (F / Ph)	≈ 50	6 th February 2015	49m 26s
	DPO 12	P: Daouda (M / Vi)	> 30	28 th January 2015	24m 53s
	DPO 13	Director: Isabelle (F / Parent of Intellectually Disabled Child)	21 ²¹²	30 th January 2015	1h 59m 32s
	DPO 14	Director: Paul (M / Non-Disabled)	79 ²¹³	7 th May 2015	40m 06s
	DPO 15	Director: Boniface (M / Non-disabled)	363 ²¹⁴	12 th May 2015	50m 06s
	DPO 16	P: Omar (M / Vi)	42	28 th January 2015	46m 34s
	DPO 17	P: Agnès (F / Ph)	≈ 30	16 th June 2015	23m 31s
	DPO 18	P: Issa (M / Ph)	≈ 30	21 st January 2015	1h 16m 55s
	DPO 19	Founder: Lucien (M / Vi)	175	9 th May 2015	21m 27s
	DPO 20	P: Fidel (M / Ph)	≈ 120	5 th May 2015	?
	DPO 21	P: Sayouba (M / Ph)	50-60	11 th February 2015	33m 13s

²¹⁰ Students at the school of the organisation, which comprises children with autism and children with intellectual disabilities.

²¹¹ Students at the school of the organisation.

²¹² Intellectually disabled students at the school of the organisation.

²¹³ Students at the school of the organisation, comprising deaf and non-deaf children.

²¹⁴ Students at the school of the organisation, out of whom 27 are visually disabled (the rest are non-disabled).

	DPO 22	P: Pascal (M / Ph)	56	24 th November 2014	39m 47s
	DPO 23	Director General: Thérèse (F / Non-disabled)	3775 ²¹⁵	14 th May 2015	?
	DPO 24	Supervisor: Souleymane (M / Ph)	?	24 th November 2014	22m 21s
	DPO 25	P: Salam (M / Vi)	?	17 th February 2015	27m 23s
	DPO 26	P: Dominique (F / Ph)	45	10 th February 2015	?
	DPO 26	Garage Manager: Edouard (M / Ph)	2	20 th November 2014	48m 11s
	DPO 27	P: Pierre (M / Vi)	≈ 30	19 th January 2015	1h 09m 09s
	DPO 28	P: Ali (M / Ph)	≈ 21	18 th February 2015	32m 16s
	DPO 29	Coordinator: Simon (M / Non-Disabled)	90 ²¹⁶	15 th May 2015	48m 35s
	DPO 30	Director: Elise (F / Non-Disabled)	170 ²¹⁷	12 th May 2015	?
	DPO 31	P: Zenabou (F / Ph)	?	20 th January 2015	?
	DPO 32	P: ? (M / Ph) V-P: ? (M / Ph)	5	26 th November 2014	?

EST REGION

Gourma Province

Diapangou	DPO 1	P: Yada (M / Ph)	≈ 50	24 th September 2014	48m 56s
Fada N'Gourma	DPO 2	P: Michel (M / Ph)	?	7 th November 2014	1h 2m 45s
Matiakoali	DPO 3	P: Yamba (M / Ph)	≈ 30	11 th October 2014	29m 43s

²¹⁵ Students and trainees studying or being trained at the Centre.

²¹⁶ Children at the pre-school of the organisation, including disabled children.

²¹⁷ Deaf and non-deaf children taught at the Institute.

Tibga	DPO 4	P: Innocent (Male / Ph) GS: David (M / Ph)	65	21 st October 2014	38m 53s

Gnagna Province

Bilanga	DPO 5	P: Assimi (M / Vi) GS: Justine (F / Ph)	150	2 nd October 2014	26m 10s
Bogandé	DPO 6	P: Adama (M / Ph)	> 90	2 nd October 2014	42m 27s
Piela	DPO 7	P: Yendie (M / Ph) GS: Tiabilimani (M / Ph)	> 100	1 st October 2014	1h 10m 02s

Komondjari Province

Gayeri	DPO 8	P: Roger (M / Non-disabled) GS: Bansoangbé (M / Ph)	> 72	14 th October 2014	48m 46s

Kompienga Province

Kompienga	DPO 9	P: Sayouba (M / Ph) GS: Benoit (M / Ph)	102	27 th September 2014	1h 39m 38s

Tapoa Province

Kantchari	DPO 10	P: Banyua (M / Ph)	56	10 th October 2014	1h 00m 17s

HAUTS-BASSINS REGION

Houet Province

Bobo-Dioulasso	DPO 1	P: Abdoulaye (M / Vi)	> 60 ²¹⁸	10 th April 2015	40m 24s
		Director: Sekou (M / Non-disabled)		10 th April 2015	?
	DPO 2	P: Marie Rose (F / Non-disabled) Director: Lossani (M / Ph) Teacher: Francois Xavier (M / Non-disabled)	104 ²¹⁹	10 th April 2015	?
	DPO 3	P: Alfred ²²⁰ (M / Ph)	118	10 th April 2015	50m 08s
	DPO 4	Teacher: Julien (M / Non-disabled)	≈ 105 ²²¹	10 th April 2015	?

PLATEAU-CENTRAL REGION

Kourwéogo Province

Boussé	DPO 1	P: Lancine (M / Ph) V-P: Seydou (M / Ph)	44	4 th February 2015	45m 30s

²¹⁸ Students at the school of the organisation which comprises blind, visually impaired, physically disabled, intellectually disabled and non-disabled students.

²¹⁹ Students at the school of the organisation, which comprises students with intellectual disabilities and non-disabled students.

²²⁰ The same person is a provincial coordinator of DPOs, so this interview covered also the provincial coordination.

²²¹ Deaf, hard-of-hearing, and non-deaf children taught at the Institute.

UMBRELLA DISABLED PEOPLE'S ORGANISATIONS (UDPOs)²²²

Umbrella DPO	Designation of Interviewee(s) Gender (Male: M / Female: F) / Impairment (Physical: Ph/ Visual: Vi / Auditive: Au / Albinism: Al)	No. of Members	Date of Interview	Duration of Interview
UDPO 1	President (M / Al)	?	26 th January 2015	1h 22m 54s
UDPO 2	President (M / Vi)	21 Sports Clubs	18 th February 2015	34m 12s
UDPO 3	Executive Director (F / Parent of Intellectually Disabled Child)	≈ 300 DPOs	5 th February 2015	?
	Head of Health Matters of Disabled People (M / Ph)		13 th February 2015	1h 42m 35s
UDPO 4	President (M / Vi)	≈ 12 DPOs	18 th February 2015	22m 41s
UDPO 5	Executive Secretary (M / Al)	?	6 th May 2015	?
UDPO 6	President (M / Ph)	?	11 th May 2015	40m 35s
UDPO 7	President (M / Vi)	65 DPOs	27 th January 2015	1h 06m 02s
UDPO 8	Vice-President (M / Au)	> 11 DPOs	7 th May 2015	?
UDPO 9	Ex-President (F / Vi)	≈ 40 DPOs	18 th May 2015	44m 36s

²²² All of the Umbrella DPOs are based in Ouagadougou.

INTERNATIONAL NON-GOVERNMENTAL ORGANISATIONS (INGOS): FIELD OFFICES²²³

INGO	Designation of Interviewee	Date of Interview	Duration of Interview
INGO 1	National Director	19 th May 2015	47m 15s
INGO 2 (Banfora)	Responsible	26 th March 2015	?
INGO 3	National Director	18 th May 2015	1h 01m 51s
INGO 4	Programme Director ²²⁴	17 th June 2015	28m 20s
INGO 5	Field Office Director	8 th May 2015	34m 03s
INGO 6	Director	8 th May 2015	32m 56s
INGO 7	Country Representative	13 th May 2015	1h 10m 42s
INGO 8	Representative	19 th May 2015	1h 09m 37s
INGO 9 (Mahadaga)	Director	15 th June – 4 th July 2015 ²²⁵	?
INGO 10	Country Manager	12 th May 2015	37m 28s

²²³ All of the Field Offices (except those specifically indicated that they are in other places like Banfora and Mahadaga) are in Ouagadougou.

²²⁴ The INGO 4 interviewee was the only western national director.

²²⁵ The interview was held by Email Exchange.

INTERNATIONAL NON-GOVERNMENTAL ORGANISATIONS (INGOS): HEAD OFFICES

INGO	Location	Designation of Interviewee	Date of Interview	Duration of Interview
INGO 5	York, UK	Chief Executive Officer	5 th June 2014	1h 03m 34s
INGO 5	York, UK	International Programmes Director	25 th June 2014	1h 52m 47s

AUTHORITIES

Name in Local Language	Name in English	Designation of Interviewee(s)	Date of Interview	Duration of Interview
<i>Agence Générale de Recrutement de l'Etat (Ministère de la Fonction Publique du Travail et de la Sécurité Sociale)</i>	General Agency of State Recruitment (Ministry of Civil Service, Work and Social Security)	Head of Competitive Exams Organisation	18 th June 2015	?
<i>Chef Coutumière</i>	Traditional Chief	His Majesty the District Chief	14 th April 2015	?
<i>Délégation Spéciale (ex-Conseil Régionale)</i>	Special Delegation (ex-Regional Council)	General Secretary & Director of Financial Affairs	29 th April 2015	?
<i>Direction de l'Education Inclusive (Ministère de l'Education National et l'Alphabétisation)</i>	Direction of Inclusive Education (Ministry of National Education and Literacy)	Officer	11 th May 2015	35m 07s
<i>Direction Départementale du Ministère de l'Action Social et de la Solidarité Nationale</i>	Departmental Direction of the Ministry of Social Action and National Solidarity	Specialised Education Attaché	21 st April 2015	33m 27s
<i>Direction Générale du Ministère de l'Action Sociale et de la Solidarité Nationale</i>	General Direction of the Ministry of Social Action and National Solidarity	General Director of National Solidarity	13 th May 2015	34m 46s
<i>Direction Provinciale du Ministère de l'Action Sociale et de la</i>	Provincial Direction of the Ministry of Social Action and	Provincial Director	31 st March 2015	1h 13m 05s

<i>Solidarité Nationale</i> (MASSN)	National Solidarity			
<i>Direction Provinciale du Ministère de l'Action Social et de la Solidarité Nationale</i>	Provincial Direction of the Ministry of Social Action and National Solidarity	Provincial Director	13 th April 2015	30m 24s
<i>Direction Provinciale du Ministère de l'Education Nationale et de l'Alphabétisation</i>	Provincial Direction of the Ministry of National Education and Literacy	Provincial Director	14 th April 2015	?
<i>Direction Régionale du Ministère de l'Action Social et de la Solidarité Nationale</i>	Regional Direction of the Ministry of Social Action and National Solidarity	Regional Director	26 th March 2015	1h 13m 08s
<i>Direction Régionale du Ministère de la Fonction Publique, du Travail et de la Sécurité Sociale</i> (MFPTSS)	Regional Direction of the Ministry of Civil Service, Work and Social Security	Regional Director	27 th April 2015	18m 18s
<i>Direction Régionale du Ministère de la Jeunesse de la Formation Professionnelle et de l'Emploi du Burkina Faso</i>	Regional Direction of the Ministry of Youth, Skills Training and Employment	Regional Director	16 th April 2015	47m 41s
<i>Gouverner</i>	Governor	Governor	29 th April 2015	?
<i>Haut-Commissaire</i>	High Commissioner	High Commissioner	27 th April 2015	?
<i>Préfecture / Mairie</i>	Prefecture / Town Council	Prefect / Mayor	2 nd April 2015	15m 54s

APPENDIX 2

SAMPLE INTERVIEW TEMPLATES

INTERVIEW²²⁶ WITH INDIVIDUAL DISABLED PEOPLE

Region:

Province:

Department / Municipality:

DPO:

Name:

Gender:

Age:

Type of Impairment:

Preliminary Points:

- Introductions and presentation of research
- Consent to be recorded and option of anonymity
- Possibility of refusal to answer / stop the interview

- 1) Tell me about who you are, where you come from and what you do?
- 2) Can you tell me a bit about your daily life... how do you spend your day?
- 3) a) What was the cause of the disability and when did this happen?
b) What happened afterwards (e.g. did you receive rehabilitative treatment, etc.)?
- 4) a) What was your childhood like?
b) Did you attend school? If not, why? If yes, how was your experience?
- 5) a) What about now? What is life like now?
b) Are you in employment? If not, why? If yes, how is your experience?
- 6) Tell me about your family life:
 - a) How does / did your position in the family compare to that of your brothers and sisters?
 - b) How are your relations with your parents and in-laws? What do they expect of you?
 - c) Are you married? Why / not? If yes, how are your relations with your family of procreation?
- 7) Tell me about your community life:
 - a) How are your relations with your community?

²²⁶ This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to the person, the answers given, and the context.

- b) How does your position compare to other men / women in your community?
 - c) What role do you play in your community? What does your community expect of you?
- 8) How do people in your community view disability?
- 9)
 - a) Is there anyone in your society that you see as a 'role model'? Why / not?
 - b) Can you do the same things he / she does? Why / not?
 - c) Are there changes to your life you would make, if you had a choice?
- 10)
 - a) Do you identify yourself as disabled? Why / not?
 - b) What does disability mean for you?
- 11)
 - a) Are you member of a DPO? Why / not?
 - b) If yes, how did you become a member of the DPO?
- 12) What do you envisage for your future? / What would you like to do in life?
- 13)
 - a) What does development mean for you?
 - b) What do you want from development?
 - c) To what extent do you feel part of development in Burkina?
 - d) To what extent do you feel you contribute socially and economically?
- 14) Is there anything else you would like to add?
- 15) Are there any questions you would like to ask me?

INTERVIEW²²⁷ WITH THE EXECUTIVE COMMITTEE MEMBER(S) OF DPOS

Region:

Province:

Department / Municipality:

Name of DPO:

No. of Members:

Preliminary Points:

- Introductions and presentation of research
- Consent to be recorded and option of anonymity
- Possibility of refusal to answer / stop the interview

- 1) a) How and since when was your DPO created?
b) What was the reason it was created?
- 2) What are your DPO's:
 - a) objectives,
 - b) goals and
 - c) main activities?
- 3) How does your DPO function in terms of:
 - a) management,
 - b) elections,
 - c) accounts,
 - d) activity organisation?
- 4) Does your DPO have an office? If yes, how did it obtain the office? If not, why?
- 5) How does your DPO define disability?
 - a) What forms of disability are considered part of the focus of your DPO? Why? / Why not others (if applicable)?
 - b) What terminology is used in this region to define disability, disabled persons, etc.? How are these terms and labels viewed by disabled people themselves and by non-disabled people in this region and in Burkina Faso in general?
- 6) (If the DPO includes people with different types of impairment)
Do the members of the DPO work towards the same goal or are there different goals for people with different kinds of disabilities?

²²⁷ This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to the nature of the DPO, the answers given, and the context.

- 7) Tell me how your DPO works with disabled people:
 - a) How does the DPO identify disabled people in communities?
 - b) How do you encourage them to join?
 - c) What do you do with them once they have joined?
 - d) How do you assess their needs?
 - e) What interventions do you carry out with disabled people?
How are these decided upon?
- 8) Are there people with disabilities in the province / region who are not members of the DPO? If yes, why?
- 9) What are the relations of the DPO with the wider community, and with local, regional and governmental entities?
 - a) Is there support from these entities? If yes, what type of support? Is it enough / what the DPO needs?
 - b) Is the context of Burkina an easy one to work with in terms of disability?
- 10)a) What are your DPO's relations with international agencies / NGOs?
 - b) Is your DPO a member of a wider international organisation? Why / not?
 - c) Is your DPO a member of a national / local organisation / network? Why / not?
- 11)How does your DPO support itself?
 - a) Does your DPO receive support from an international / local organisation? If yes, what kind of support? (If not, go to question no. 12)
 - b) Does this support meet the needs of the DPO?
 - c) Is your DPO functional without the support of the international / local organisation? If yes, how? If not, why not, and how do you envisage it to be sustainable in the long-term?
- 12)a) What is the life / situation of disabled people in the province / region like? Why?
 - b) What are the positive aspects / problems (if any) they encounter?
 - c) What is the perception of people with disabilities by society?
- 13)What does development mean for you?
 - a) What do people with disabilities want from development (and if applicable: from development NGOs)?
 - b) Is what people with disabilities want the same as the NGOs think they want? If not, why?

14) Is there anything else you would like to add?

15) Are there any questions you would like to ask me?

INTERVIEW²²⁸ WITH THE EXECUTIVE COMMITTEE MEMBER(S) OF UMBRELLA DPOS

Name of Umbrella DPO:

No. of Member DPOs:

Preliminary Points:

- Introductions and presentation of research
 - Consent to be recorded and option of anonymity
 - Possibility of refusal to answer / stop the interview
-
- 1) a) How and since when was your DPO created?
c) What was the reason it was created?
 - 2) Does your DPO have an office? If yes, how did it obtain the office? If not, why?
 - 3) What are your DPO's:
 - a) objectives,
 - b) goals and
 - c) main activities?
 - 4) How does your DPO function in terms of:
 - a) management,
 - b) elections,
 - c) accounts,
 - d) activity organisation?
 - 5) How does your DPO function?
 - a) Where does it obtain its funding with regards to the DPO's day-to-day running?
 - b) Where does it obtain its funding with regards to the DPO's activities?
 - c) Does your DPO have paid staff?
 - 6) How is your DPO viewed by (and what relationship does it have with):
 - a) society in general
 - b) the other umbrella DPOs
 - c) grassroots DPOs
 - d) INGOs and international agencies
 - e) the Burkinabe state?

²²⁸ This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to the nature of the DPO, the answers given, and the context.

- 7) How are your DPOs' activities developed:
 - a) How are the objectives of activities decided upon?
 - b) Who develops the activities?
 - c) Who is consulted in the process?
- 8) a) How does your DPOs support grassroots²²⁹ DPOs? / What types of interventions does it carry out with grassroots DPOs?
 b) How does your DPO identify the needs of grassroots DPOs?
 c) How often does your DPO meet with the grassroots DPOs?
- 9) Have these interventions been effective? Why?
- 10) Are there grassroots DPOs which are supported more than others? If yes, why?
- 11) a) What types of impairment are supported by your DPO?
 b) Are there any other organisations that work with people with the types of impairments which are not included in your DPO?
 c) What are the major causes of these types of impairments in Burkina?
 d) Which impairments are considered as disability in Burkina / by your DPO? Why these and not others?
- 12) What is the situation of disabled people in Burkina with regards to social, economic and cultural development?
- 13) What is your DPO's role in disability and development?
- 14) What do you think the gaps in development are with regards to people with disabilities, that is, why are many disabled people in Burkina not socio-economically independent?
- 15) a) What do you think disabled people in Burkina require of your DPO and of the state?
 b) To what extent do you think people with disabilities are included in national development planning?
 c) What, in particular, do you think people with disabilities want from development interventions?
- 16) What do you think of the role being played by foreign agencies (INGOs, donors, etc.) with regards to disability and development?
- 17) What disability issues / concerns do you think are specific to the Burkinabe context and why?

²²⁹ The term 'grassroots' is here used to differentiate from the umbrella DPO.

- 18)What research would you like to see carried out with regards to disability and development in Burkina?
- 19)Are there any statistics with regards to disability in Burkina? If yes, where? If not, why?
- 20)Are other relevant people / organisations you think I should speak to?
- 21)Is there anything else you would like to add?
- 22)Are there any questions you would like to ask me?

INTERVIEW²³⁰ WITH MINISTRY REPRESENTATIVES

Name of Ministry:

Division:

Location:

Name of Interviewee:

Designation of Interviewee:

Preliminary Points:

- Introductions and presentation of research
 - Consent to be recorded and option of anonymity
 - Possibility of refusal to answer / stop the interview
- 1) What is the situation of disabled people in Burkina Faso in general, and with regards to development?
 - 2) What are the policies in place with regards to people with disabilities and development / human rights? Have these changed since the ratification of the CRPD? Why?
 - 3) What kind of work does your Ministry / Division carry out with people with disabilities in Burkina / this region / province?
 - 4) Does this work target people with all kinds of disabilities? (If not, please state why and go to question no.7).
 - 5) Do the kinds of intervention differ from one type of disability to the other? If yes, how?
 - 6) Have these interventions been effective? Why?
 - 7) a) What does your Ministry / Division do to enable people with disabilities to participate in policy-making?
b) To what extent does your Ministry / Division consult with / listen to people with disabilities in drafting policy, planning interventions, etc.? And how?
 - 8) What do you think the gaps in development are with regards to disabled people, that is, why have they not yet achieved socio-economic and political independence?

²³⁰ This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to which Ministry was being interviewed, which division of the Ministry, the answers given, and the context. The same questions were also adapted accordingly to the other authorities interviewed, such as governors, mayors, etc.

- 9) a) What do you think disabled people in Burkina require of the state?
b) To what extent do you think people with disabilities are included in national development planning? And how?
c) What, in particular, do you think people with disabilities want from development interventions?
- 10) What do you think of the role being played by foreign agencies (INGOs, donors, etc.) with regards to disability and development?
- 11) What disability issues / concerns do you think are specific to the Burkinabe context and why?
- 12) What research do you think should be carried out with regards to disability and development in Burkina?
- 13) Are other relevant people/organisations you think I should speak to?
- 14) Is there anything else you would like to add?
- 15) Are there any questions you would like to ask me?

INTERVIEW²³¹ WITH THE MANAGEMENT OF INGO FIELD OFFICES

Name of INGO:

Field Office Location:

Name of Interviewee:

Designation of Interviewee:

Preliminary Points:

- Introductions and presentation of research
 - Consent to be recorded and option of anonymity
 - Possibility of refusal to answer / stop the interview
- 1) What kind of interventions does your organisation carry out with disabled people in Burkina Faso?
 - 2) a) In which regions of Burkina are these interventions carried out?
b) Why these regions and not others?
 - 3) How are these interventions designed: by whom, who is consulted, how are the objectives decided on?
 - 4) To what extent do people with disabilities participate in the design and planning of these interventions? And how?
 - 5) Does your organisation collaborate with other partners (e.g. other INGOs, state authorities, DPOs)? If yes, how? If not, why?
 - 6) Does your organisation work with DPOs or with individual people with disabilities? Why?
 - 7) How does your organisation decide which DPOs / individual people to work with?
 - 8) Do the interventions differ according to the 'group' of disabled people (such as people with intellectual disabilities, disabled women) / the type of DPO? If yes, how? If not, why?
 - 9) Have these interventions been effective (in transforming people with disabilities' socio-economic status)? If yes, how? If not, why?
 - 10) How does your organisation decide which grassroots organisations / local people to work with?

²³¹ This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to the nature of the INGO, the answers given, and the context.

- 11) When does your organisation stop working with a particular DPO, and why?
- 12) Do the interventions (such as income-generating activities) keep on being functional after your organisation withdraws its support? If yes, how? If not, why?
- 13) a) What are the major issues faced by disabled people in Burkina?
b) In your opinion, why have disabled people in Burkina not yet achieved socio-economic independence?
c) In your opinion, what is needed for disabled people in Burkina to flourish?
- 14) Do you think the issues faced by disabled people in Burkina are different than those faced by disabled people in other contexts? If yes, how? If not, why?
- 15) What do you think disabled people in Burkina Faso want of INGOs and development in general?
- 16) How do you think your organisation's (and other INGOs') interventions are viewed by disabled people in Burkina Faso?
- 17) How are your organisation's (and other INGOs') interventions viewed by the state and by other key actors in the field in Burkina Faso?
- 18) Are there any particular issues your organisation faces in working with disabled people in Burkina? If yes, what are they?
- 19) Is there a particular model of / approach to / understanding of disability that your organisation uses in its interventions with disabled people in Burkina Faso? If yes, how? Is this effective?
- 20) Which do you think is the best option: mainstreaming disability programmes and policies or having specific programmes targeted at disabled people? Why?
- 21) Are other relevant people / organisations you think I should speak to?
- 22) Is there anything else you would like to add?
- 23) Are there any questions you would like to ask me?

INTERVIEW WITH THE MANAGEMENT OF INGO HEAD OFFICES

Name of INGO:

Head Office Location:

Name of Interviewee:

Designation of Interviewee:

Preliminary Points:

- Consent Form²³²

General (with examples from Burkina Faso)

- 1) What kind of interventions is your organisation currently carrying out with disabled people in West Africa?
- 2) How are these interventions designed: by whom, who is consulted, how are the objectives decided on...?
- 3) To what extent do people with disabilities participate in the design and planning of your organisation's interventions?
- 4) Do the interventions differ according to the 'group' of disabled people (such as people with intellectual disabilities, disabled women)?
- 5) Have these interventions been effective (in transforming people with disabilities' socio-economic status)? Why?
- 6) How does your organisation decide which grassroots organisations / local people to work with?
- 7) How does your organisation adapt or vary its approach depending on which organisations and communities/contexts they are working with?
- 8) When does your organisation stop working with a particular organisation / local community, and why?
- 9) Do the interventions (such as income-generating activities) keep on being functional after your organisation withdraws its support? If yes, how? If not, why?

²³² See Appendix 3.

Specific to Burkina Faso

- 10) Your organisation has been working with disabled people in Burkina Faso for a number of years (since ____). Has there been any change in your organisation's work in Burkina Faso over the years? If yes, why?
- 11) Is there a particular model of / approach to / understanding of disability that your organisation uses in its interventions with disabled people in Burkina Faso? If yes, how? Is this effective?
- 12) How do you think your organisation's (and other INGOs') interventions are viewed by disabled people in Burkina Faso?
- 13) How are your organisation's (and other INGOs') interventions viewed by the state and by other key actors in the field in Burkina Faso?
- 14) What do you think disabled people in Burkina Faso (or in West Africa) want of INGOs and development in general?
- 15) Do you think the issues faced by disabled people in West Africa are different than those faced by disabled people in Europe? If yes, how?
- 16) How does your organisation raise awareness of its work in West Africa and how does it represent people with disabilities in its campaign and publicity materials?

General: NGOs, Disability and Development

- 17) Which do you think is the best option: mainstreaming disability policies or having specific programmes targeted at disabled people? Why?
- 18) What do you think are the gaps in development with regards to people with disabilities, that is, why have disabled people not yet achieved socio-economic independence?
- 19) As you are probably aware, NGOs have been criticised of being more accountable to donors rather than the people they are working with. Do you agree? Why?
- 20) NGOs have also been accused of being ineffective in reducing poverty. Do you agree? Why?
- 21) What research would you like to see carried out with regards to disability and development?

Concluding

22) Is there anything else you would like to add?

23) Are there any questions you would like to ask me?

APPENDIX 3

**SAMPLE INTRODUCTORY LETTER
AND CONSENT FORM
FOR INGO HEAD OFFICES**



4th May 2014

To whom it may concern:

My name is Lara Bezzina. I am a doctoral researcher working at Durham University in the UK under the supervision of Professors Cheryl McEwan (cheryl.mcewan@durham.ac.uk) and Marcus Power (marcus.power@durham.ac.uk). I have previously worked in Burkina Faso with a grassroots DPO in Banfora, having been employed by the UK-based charity organisation *International Service*, from where my research interests stem. My current research looks at disabled people in Burkina Faso and the international development organisations that work with them, exploring the interventions that are carried out with disabled people's organisations and their effects on the lives of people with disabilities. I am therefore interested in talking to representatives of the major organisations working in Burkina with disabled people in the area of social, economic and political independence. Together with [your organisation], I am also contacting [this other organisation] and [this one].

In order to facilitate my research, I would like to conduct interviews with you and/or any other staff in your organisation whom you deem appropriate on the topics outlined above. Interviews would last approximately one hour and would be intended to provide me with information on how your organisation works with people with disabilities in Burkina. My research is subject to strict ethical guidelines, including securing informed consent, and guarantees to anonymity and confidentiality should these be requested. I am also committed to working in partnership with research participants and would be happy to provide you with a summary of the research findings should you find these useful.

Should you require further clarification or information from me or my academic supervisors please contact us as necessary.

Thanking you in advance for your kind attention,

Yours sincerely,

Lara Bezzina

Information Sheet

This research project looks at disabled people in Burkina Faso and the international development organisations that work with them, exploring the interventions that are carried out with disabled people's organisations and their effects on the lives of people with disabilities, as well as working with people with disabilities themselves to elicit their experiences of disability and development. Despite the fact that the majority of disabled people live in developing countries, and that most disabled people in developing countries are largely excluded from education, employment and social life, not much research has been carried out on disability and disabled people's socio-economic development. In order to partly bridge this gap in the literature, interview respondents will be asked about:

1. The development interventions carried out by your organisation with disabled people in Burkina Faso;
2. The manner of your organisation's work in Burkina Faso;
3. The perception of your organisation by various entities; and
4. Issues faced by disabled people in developing countries and gaps in research on disability and development.

For the analysis, I would like to record the interviews with a Dictaphone. There is an opt-out box in the consent form if you would not like the conversations to be recorded. I will also ask again at the beginning of each discussion to confirm that recording is acceptable. Once the interviews have been transcribed, a copy of the transcript will be sent to each interviewee to ensure that your testimony has not been misrepresented.

Should you request it, your interview will remain confidential and anonymous. Transcript data will be secured on password-protected Durham University computers and an encrypted memory stick. After the fieldwork in Burkina Faso has been carried out and the research analysis starts to take shape, I would be happy to provide you with a summary of the research findings should you find these useful.

Consent form

This form's purpose is to establish that you are satisfied with the project's objectives and are happy to proceed with interviews.

Please tick the following as appropriate:

- I have read the information sheet and know what the project is about ☐
- I give my permission for the interview to be recorded ☐
- I give my permission for the interview to be transcribed ☐
- I give my permission for a record of the interview to be stored by the researcher for future use ☐
- I understand that I can terminate the interview at any point without having to provide a reason ☐

I give my permission to take part in this project:

Name:

Signature:

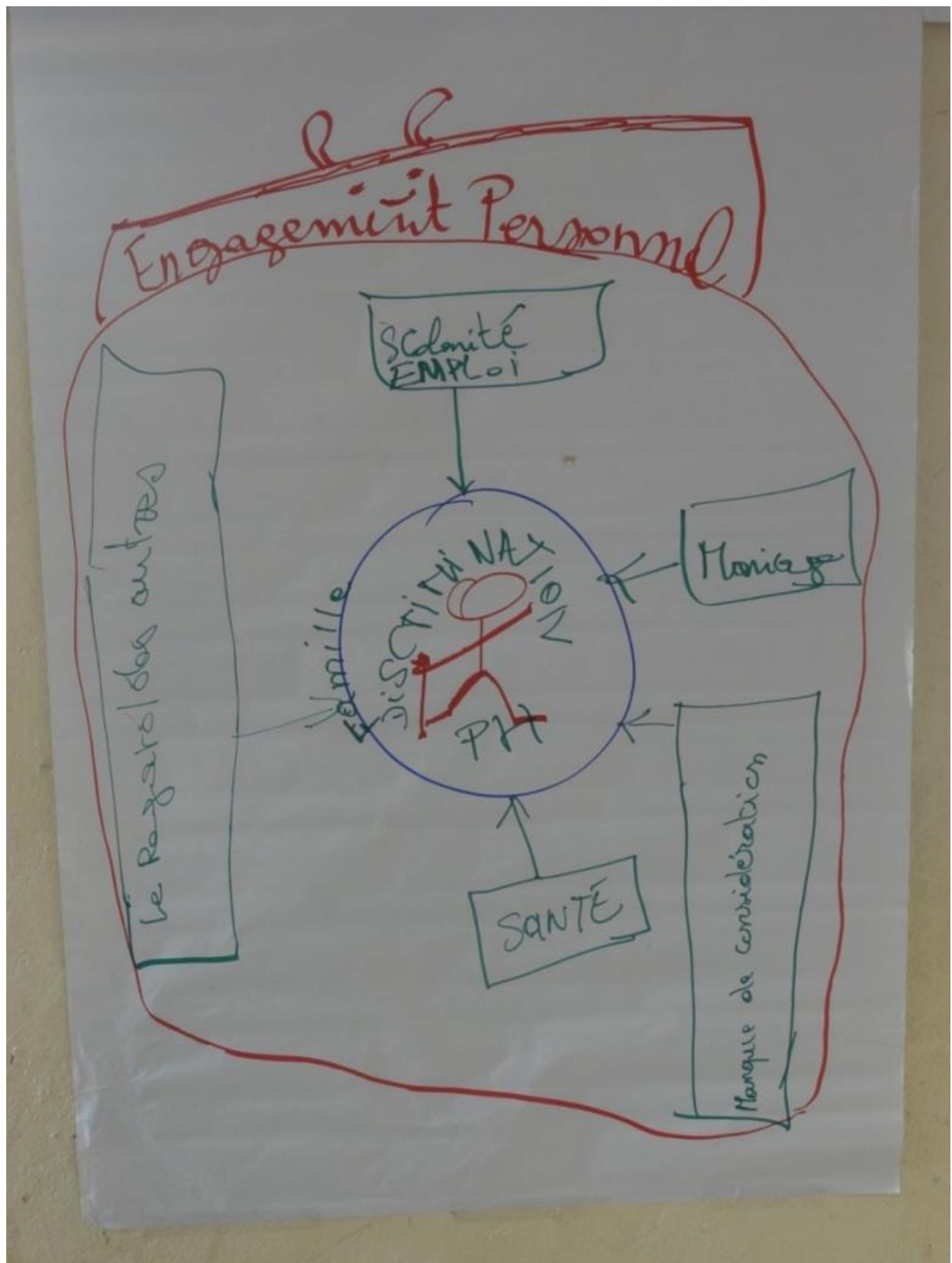
Date:

APPENDIX 4

TRANSLATION:

PARTICIPATORY DIAGRAM AND STORYBOARD

FIGURE 3.5 THE DIAGRAM



PERSONAL ENGAGEMENT

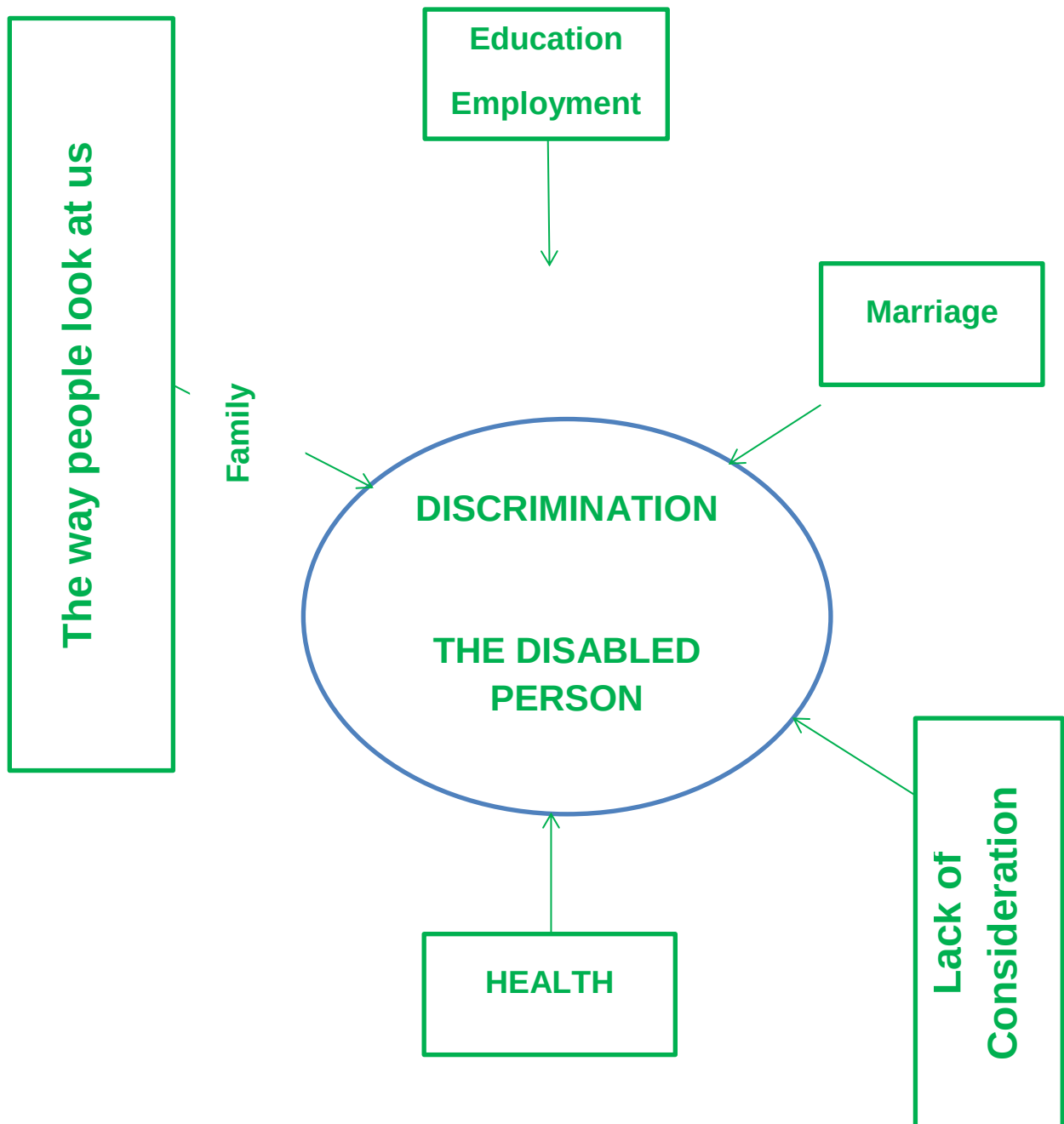
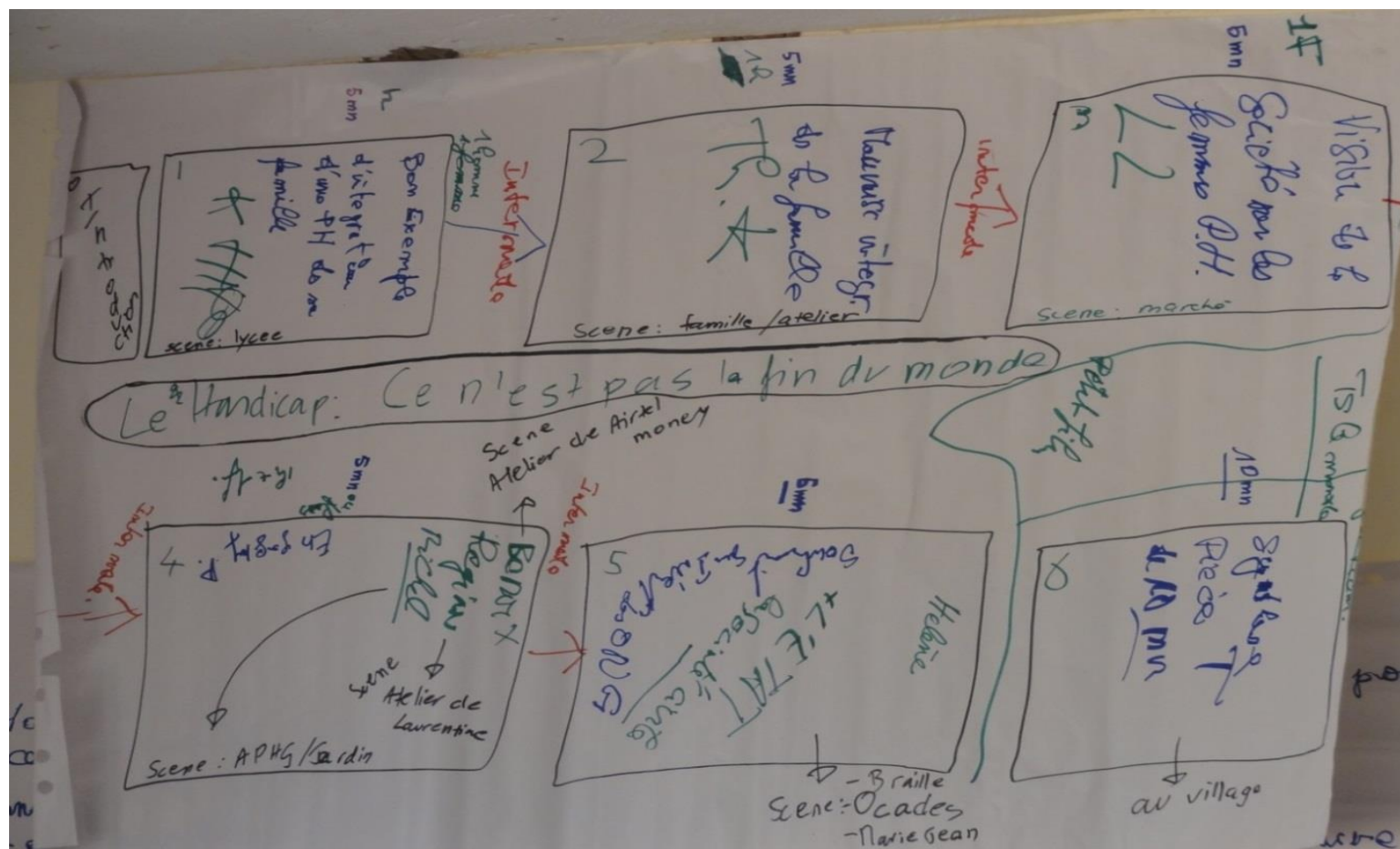
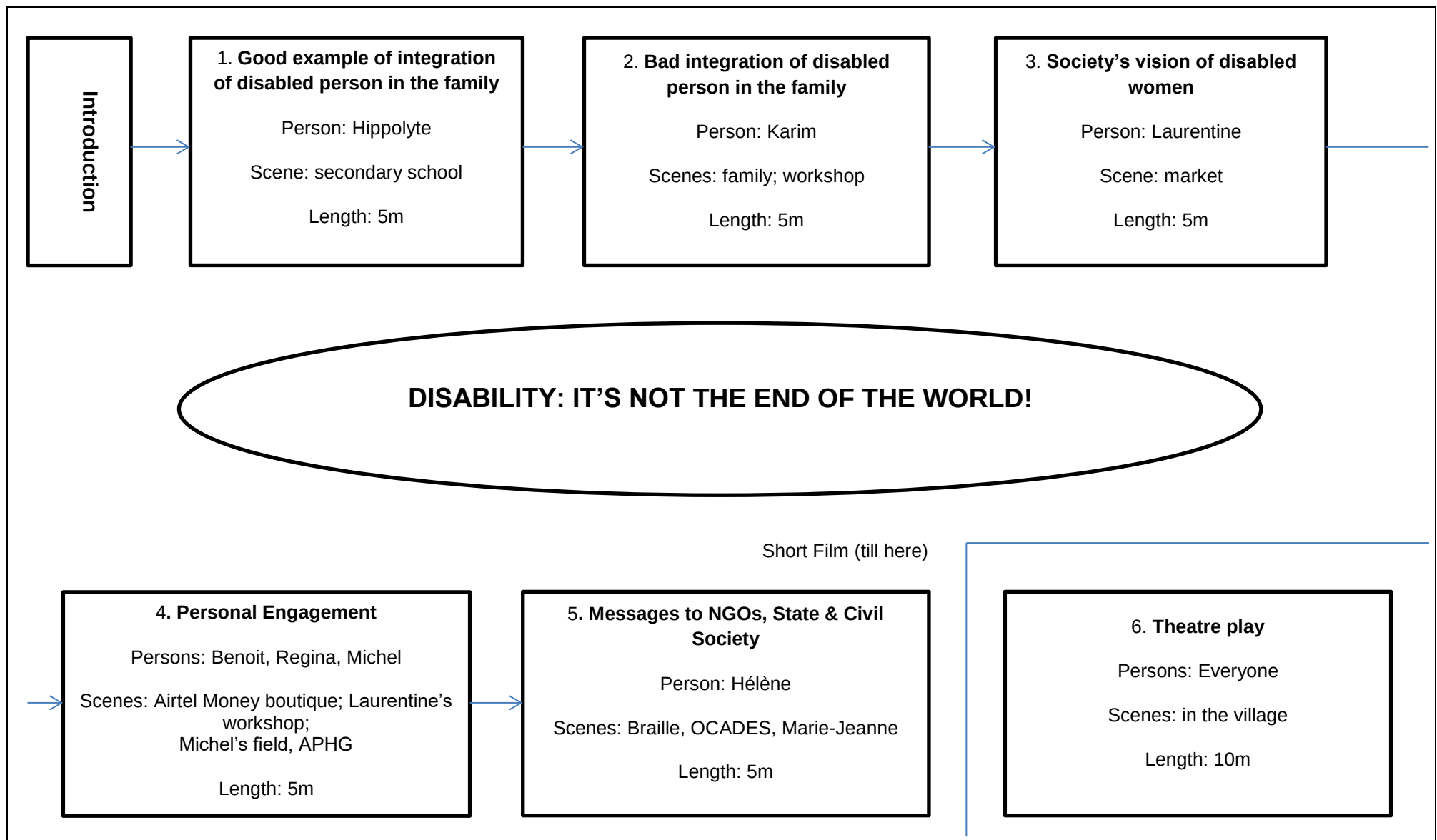


FIGURE 3.8 THE STORYBOARD²³³



²³³ The translation of the storyboard on the following page was rendered slightly simpler so as to be comprehensible. There were also some small variations from the original storyboard in the actual film.



APPENDIX 5

DVD: PARTICIPATORY VIDEO