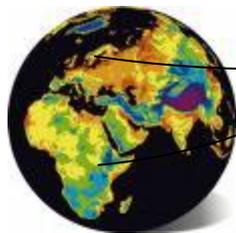


IMPLEMENTING

COMMUNITY BASED RE/HABILITATION

IN UGANDA AND SWEDEN



A COMPARATIVE APPROACH



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**IMPLEMENTING COMMUNITY BASED RE/HABILITATION IN
UGANDA AND SWEDEN**

– A COMPARATIVE APPROACH

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ABSTRACT

In our global world, ideas in general and social work models in particular are spread and implemented in a variety of socioeconomic, political and cultural contexts, generating different outcomes. Many ideas and services launched in different countries by international organisations or governments in order to bring social justice to marginalised and oppressed groups, such as people with disabilities, have been criticised for not reaching or involving those such services aim to serve. Low impact of social programs on the welfare of people and communities has put the effectiveness of such programs into question and can leave people with disabilities dissatisfied with the social services available in their environment.

The main purpose of this dissertation is to examine how an international idea for social work practice, as community based rehabilitation (CBR), is implemented in different structures and institutional contexts. To examine how an idea is implemented in different contexts, following research questions have guided the work: “How was the idea of CBR introduced to and implemented in Uganda and Sweden?”, “What contextual factors influenced the implementation of CBR in these countries?”, “What limitations and possibilities affected CBRs chances of continuity and institutionalisation in the two countries?” and finally “Can international ideas and models for social work be successfully used in different structural and institutional contexts?”.

The study is based on a qualitative design with a comparative approach using qualitative content analysis for analysing data collected through official documents and interviews with parents to children with disabilities and professionals working in the children’s surrounding. The results show how difficult it is to monitor development through projects in both non-Western and Western countries. International ideas of social work, such as CBR, can make a difference in both Uganda and Sweden for the improvement of the living condition of those in need

of services; at least, as long as there are funding for the projects and cooperation between authorities, NGOs and the parents of children with disabilities.

The results show also that there are many differences in the process of the implementation of CBR in Uganda and Sweden. The colonial past of Uganda and its weak welfare state make CBR an important project for the improvement of the life conditions of children with disabilities. Meanwhile, the Swedish strong welfare state and legal protection of children with disabilities make CBR much more marginal in Sweden than in Uganda. However, CBRs successes to promote social justice for children with disabilities and their families makes it necessary to integrate the project to the existing organisation of the welfare state in the two countries. Changing existing welfare services requires engagement in political decision-makings, cooperation, and a critical examination of structural and institutional arrangements, in order to include successful projects in the daily functions and duties of the welfare state of every country. This will prevent an international idea for social work to not only be a temporary trend to follow, but also an established working method for helping people in need of proper services.

Keywords: International Social Work, Social Justice, Disability, Travelling Ideas, Implementation, Community Based Rehabilitation.

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Östersund, 31 October 2014 – Charlotte Persson

CHAPTER 1

INTERNATIONAL SOCIAL WORK AND DISABILITY

In an increasing globalised world, many ideas, policies and concepts in social work are spread to and implemented in different countries, organisations and institutions. However, to carry out and fulfil a programme or project, which is based on an idea or policy transferred from another socioeconomic, political and cultural context different from its own, is in many ways a challenging undertaking. One way to avoid some of the challenges is to adjust the idea or policy to the local context where it is to be carried out and to consider the power dimensions surrounding the implementation (Connell, 2007; Gray & Allegritti, 2002; Mwansa, 2010). This is important for the successful outcome of providing proper welfare services to citizens, especially for people with disabilities.

Most countries have failed to meet the social welfare needs of people with disabilities. Though many international organisations, such as the World Health Organisation (WHO), the United Nations (UN), and individual governments have sought to meet these needs for the most marginalised group in society (Stainton, Chenoweth & Bigby, 2010). According to Karna (2001), people with disabilities have historically been discriminated against, stigmatised and marginalised in almost all societies. The UN (1994) has identified economic and social factors that continue to influence the living conditions of persons with disabilities today, which may lead to isolation and delay their development.

The oppression of people with disabilities has taken many forms and shapes through the years. For example, the lack of physical access to transportation, information and facilities restricts people with disabilities from enjoying equal opportunities in employment, health care and housing (Karna, 2001). Myths about disability and the lack of availability of treatments and aid are also obstacles in the social environment (Miron, 1994). Services are often scattered and focus only on certain disabilities, leaving others without assistance. Still today both physical and mental disabilities lack attention (Palme et al., 2003). Behind the oppression of people with disabilities lie decades of negative beliefs about and attitudes toward disability, which has been proclaimed by societies as not “normal”. Mackelprang and Salsgiver (1996) observe that societies have responded to people with disabilities according to their cultural systems of belief, which, according to Kizito (1993), has largely meant looking down on individuals with disabilities. Too often, people with disabilities have been restricted from benefiting from mainstream services that are available to people without disabilities. Thus, in both poor non-

Western and rich Western countries, people with disabilities encounter frequent injustices (Coleridge, 1993).

Rights for marginalised and oppressed groups, including women, indigenous people and African Americans, became important during the time of Second World War (Johnson, 2009), and the concepts of normalisation and integration were introduced, reflecting a growing awareness of the capabilities of those with disabilities (UN, 1994). However, rehabilitation services were mostly provided at institutions and dominated by a medical model, focusing on people's impairments instead of on their capacity to contribute to society (Peat, 1997). This view of rehabilitation was also transferred to non-Western countries by missionaries during the period of colonialism (Ingstad, 1990; Ministry of Education and Sports, 1999; Tomasevski, 1999). However, institutional rehabilitation services in both non-Western and Western countries limited people with disabilities integration into society and disempowered them (Momm & König, 1989).

In recent years, the provision of services for people with disabilities has undergone change and development due to increased attention to this population. The changes have resulted from demands voiced by the international disability movement, an increased focus on poverty reduction and the turn to a rights-based development approach. Despite this, disability remains a marginalised issue within the human development agenda compared to gender, race and ethnicity (Grech, 2009).

International and comparative perspectives on social work with people with disabilities have been largely ignored in international social work research, and as a result are not well-developed today. Increasing inequalities and the escalation of wars and other conflicts worldwide make it necessary to include the field of social work with a focus on disability as an important part of social work's engagement in the global struggle to seek social justice for marginalised and oppressed groups. Social workers are urged to take more responsibility and engage in changing societal structures as agents of social change (Adams et al., 2002; Dominelli, 2002; Mmatli, 2008), especially when research show that ideas used to improve social welfare services has a hard time to reach the users and create change (Dorsner, 2004; Hasenfeld, 1983: 1992; Helander, 2007; Jönsson, 2010; Lewin, 1996; Sahlin, 1996). Several authors encourage social workers, people with disabilities and the disability movement to improve understanding through cooperation so the social welfare services as far as possible will satisfy the once using them (Beaulaurier & Taylor, 2001; Dominelli, 2002; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006).

During the 1970s, the WHO observed the life situations and experiences of people with disabilities who had limited access to welfare, especially in non-Western countries where survival and the provision of basic services are still a

challenge. In response to the need to reach people with disabilities at the community level, the idea of Community Based Rehabilitation (CBR) was developed (WHO, 2003). The primary aim of CBR was to improve the living conditions of people with disabilities by promoting equal opportunities and social integration (Joint Position Paper, 2002). CBR was considered a component of Primary Health Care (Amstel, Dyke & Crocker, 1993; Chermak, 1990; Eldar, 2000; Miles, 1993) and officially announced in 1976 as a principle that locates rehabilitation resources in the natural environment and not only at institutions and clinics (Åberg, 1998).

In 1977 the World Health Assembly concluded that WHO and governments should concentrate on the health of all citizens of the world by the year 2002 (Chermak, 1990). By this time the essential services and the appropriate technology should be affordable and accessible to all (Helander, 2007). In 1978 at the international Alma-Ata conference in Kazakhstan, CBR was introduced by WHO again, which increased support for CBR in non-Western countries (Lysack & Kaufert, 1994; Åberg 1998). In 1981, this was declared the International Year of Disabled Persons by the UN, WHO discussed the issue of rehabilitation in both the non-Western and Western countries. Governments were once again urged to take action concerning disability prevention and rehabilitation by including and emphasising CBR (WHO, 1981). This resulted in a report to be used in European countries as well (Kallio, 1982).

The idea of CBR has mostly been implemented in non-Western countries such as Uganda (Baryayebwa, 2002; Claussen, Kandyomunda & Jareg, 2005; Finkenflügel, 2004; Keibanda, 1995; Lightfoot, 2004; Nganwa, Mirembe & Kisanji, 2003), although it has been used in some Western countries such as Sweden as well (Aitken & Walker, 1987; Chermak, 1990; Clarke, 1987; Freeman, 1997; Gregory, 2001; Hargö Granér, 1999). In the early 1990s, according to Miles (1993), CBR had spread to at least 80 countries, with English as its second or third language. In many non-Western countries where rehabilitation was mostly carried out at institutions in centralised locations and in larger cities, CBR was seen as a new tool to reach people with disabilities in local communities.

Mitchell (1999), as well as many researchers and persons working with and for people with disabilities view CBR as a tool for changing attitudes, increasing participation in decision making and enhancing integration into the society. However, Kay and Dunleavy (1996) point out those Western countries like Finland and Holland also used CBR to complement their existing rehabilitation programmes, even though, as Helander (2007) noted, many European countries already used home- or self-training. CBR was considered clearly relevant for Western as well as non-Western countries (Jelsma, Cortes-Meldrum, Moyo & Powell, 1995; Kallio, 1982); moreover, according to WHO (1981), a change in

Western countries' approaches was needed due to the high cost of professional rehabilitation services.

As Hartley (2001) point out, the transfer of CBR as a strategy from non-Western to Western countries represents a pioneering and path-breaking development in light of the West's dominance in transferring knowledge. Hartley state, CBR originally comes from "observations of traditional 'good practices' in income poor countries of the majority world" (Hartley, 2001, p. 26). Nevertheless, Helander (1993) mean WHO have re-packaged the idea of CBR. Even though CBR is based on good examples of rehabilitation in non-Western countries, a re-packaged strategy can be influenced by trends and international influences in the global world, and must be managed in relation to the cultures and contexts within a country. This is based on the statements of Asindua (2002), Miles (1996) and Vanneste (2004) that the implementation of CBR can occur differently between and within countries.

Pressman and Wildavsky (1973) define implementation as means to carry out, produce, complete, accomplish and fulfil a project, and they mean that the object to be implemented is naturally a policy. What is considered a good way of working and an effective means of providing services here and now may not be valid in another time and place. The success of implementation depends mainly on consideration of the impact of new ideas in the context of socioeconomically, historically and institutionally different countries. If an idea is copied without such consideration, there is a greater risk of failure (Czarniawska, 2005; Czarniawska & Joerges, 1996; Grape, Blom & Johansson, 2006).

Such lack of attention to context can affect professionals' way of working, the chance for new ideas to be implemented successfully, and the prioritising of participation of people with disabilities in their own services. In fact, many ideas and services promoted by international organisations or governments to bring social justice to marginalised and oppressed groups have been criticised for not reaching or involving those they aim to serve (Dorsner, 2004; Jönsson, 2010). Low impact of social programs on the welfare of people and communities has put the effectiveness of such programs into question and has given birth to increasing research in the field of implementation (Hough, 1975; Pressman & Wildavsky, 1973). In similar ways limited impact of evidence-based programs is questioned today (Elliott & Mihalic, 2004; Fixen et al., 2009). This can leave people with disabilities dissatisfied with the social services available in their environment (Adams, Dominelli, & Payne, 2002; Johnson, 2009). There is no question that services for people with disabilities are needed; as Lang (2011) points out, it is more a question of how they should be provided:

The question is not whether services are needed. The critical question is the manner in which they are provided, and the power dynamics and relationships that underpin this service provision (Lang, 2011, p. 172).

This dissertation arose from a curiosity about how internationally defined ideas are spread to different national contexts, how these ideas are received in new environments and how they are implemented and reach the target group. This study will explore the manner in which services are provided, including who initiates the service, how the service is implemented and the limitations and possibilities of various contexts for social work and the best provision of services. In our global world, international ideas and rehabilitation models are spread and implemented in a variety of socioeconomic, political and cultural contexts, generating different outcomes. Such models and service provision in general are subject to global debates on many aspects of their implementation, including how and by whom services should be implemented, how they should be organised, who has the power to define which service or method should be utilised and the nature of the often tense relationship between the professionals providing and the participants receiving the service. The global debates also escalate the manner in which implementation process has been carried out—for example, with a top-down or a bottom-up approach—as well as the respective roles of the state, civil society and external funders in the provision of the services. Moreover, the focus of this dissertation is the relationships involved within the service provision, with special attention to the process of participation for people with disabilities and their caretakers. This study seeks to investigate whether and how transformed ideas that enter a new nation, organisation, institution or project facilitate participation for their target group, with attention given to the power dynamics that lie behind the services.

The Main Objective and Research Questions

The aim of this dissertation is to examine how an international idea for social work practice, as community based rehabilitation, is implemented in different structural and institutional contexts. The case of CBR will be followed from its initial creation through its introduction into two countries, Uganda and Sweden, in the early 1990s. CBR is intended to serve people with disabilities in general, while also including their families and other actors involved in their daily lives. This dissertation focuses on the implementation of CBR for children with disabilities and their parents. Among people with disabilities, who are as a group disadvantaged and vulnerable, children (or specifically impoverished children) are among the most disadvantaged and vulnerable. People with disabilities experience

poverty to a greater extent than the population at large as a result of discrimination, exclusion, a reduced capability to work and unequal access to education, health care and food (Hoogeveen, 2005; Palme et al., 2003). Depending on age and disability, children with disabilities experiences same inequalities. Financial shortages also affect families of children with disabilities due to extra expenses for drugs and municipal help, and higher costs for medical care, transportation, food, housing, etc. (Hoogeveen, 2005; Palme et al., 2003). The above inequalities also provide different conditions and opportunities for people living in different countries and contexts. This means that the planned social service and its accessibility to children with disabilities in each country play a major role for well-being of the children and their families.

To examine how an idea is implemented in different contexts, this study will explore the following research questions:

1. How was the idea of CBR introduced to and implemented in Uganda and Sweden?
2. What contextual factors influenced the implementation of CBR in these countries?
3. What limitations and possibilities affected CBRs chances of continuity and institutionalisation in the two countries?
4. Can international ideas and models for social work be successfully used in different structural and institutional contexts?

Among many flourishing international ideas, I chose to examine and compare CBR in Uganda and Sweden because of its status as an international idea and policy created by the WHO. Many international organisations promote and provide ideas and solutions for social problems in countries around the world. However, research shows that these solutions, though well intended, often do not reach the ground or become re-embedded, in Erlingsdóttir's (1999) terminology, among those they intend to serve, whereby this study explore whether CBR is like or unlike these other ideas.

In this study, I also chose to examine CBR in the contexts of Uganda and Sweden due to their structural and institutional differences and their representation of the so-called "opposite" non-Western and Western worlds. I also have close connections to both countries: Sweden is my home country, and Uganda is a country in which I have been working voluntarily for many years. In addition, I have grown up with an uncle with disabilities.

Defining Disability and Rehabilitation within Social Work

There is a shortage of international comparative research in the area of disability and the welfare of people with disabilities. Pease and Fook (1999) argue that social work has an important role to play in the field of disability, and Ran, Wen, Yonghe and Honglu (1992, p. 107) note that, "Community-based rehabilitation is a sophisticated system of social work". This dissertation aims to advance the international field of social work with people with disabilities by broadening our understanding of the similarities and differences experienced by different populations in an unequal world.

I also chose CBR with the aim of promoting social change for one of the most marginalised groups in society, namely people with disabilities (c.f. Stainton et al., 2010). Despite reforms over time that have increased the opportunities for people with disabilities to live more "normal" lives (Miron, 1994), people with disabilities continue to note that welfare organisations often fail to address their needs. Thus social workers and welfare organisations themselves may further disable this group in society (Adams et al., 2002; Johnson, 2009).

Dominelli (2002) observes that the profession of social work is a small entity within a large welfare state bureaucracy—a bureaucracy that needs to assess its potential to influence practices affecting disadvantaged and oppressed people. For example, several authors have encouraged social workers to become more involved with people with disabilities, as well as with the disability movement, to encourage these groups to share experiences and knowledge that will enhance understanding (Beaulaurier & Taylor, 2001; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006). Beaulaurier and Taylor (2001) also encourage social workers working in rehabilitation or health care to reassess their practices in light of the growing demands of disability right groups and the requirements of recent legislations.

Dominelli (2002) advocates creating a collective organisation comprised of politicians, various professionals, groups formed by users of the service and community groups, to achieve social justice for marginalised and oppressed groups. Social workers must think and act both locally and globally (Sewpaul, 2006), connecting progressive communities and social movements as well as challenging the world's inequities and imperialist nations. Given a global history of colonisation and oppression, the hegemony of Western worldviews and ongoing class and race stratification, social workers must link their struggle for social justice to anti-hegemonic, anti-oppressive and emancipatory practices (Smith, 2008). Inequalities have existed throughout human history, propagated by imperialism, colonialism and its younger sibling, post-colonialism (Loomba, 2008). Such inequities can no longer be ignored in today's global society (Dominelli, 1999; Sewpaul, 2006).

The World Facts and Statistics on Disabilities and Disability Issues report states that ten percent of the world's population lives with some type of disability; eighty percent of these people live in non-Western countries (Langtree, 2011). According to WHO, "more than one billion people in the world live with some form of disability, of whom nearly 200 million experience considerable difficulties in functioning", requiring educational, social-economic and medical rehabilitation (WHO, 2011, p. 5). However, Grech (2009) notes that there is no universally agreed upon definition of disability, and to define it is problematic, because what is considered a disability in one country may not be in another. Nevertheless, since 2001 WHO has used an International Classification of Functioning, Disability and Health that sees disability as an impairment (of body function and body structure), activity limitation and participation restriction (Grimby & Smedby, 2001; Escorpizo et al., 2011). This represents a shift from the understanding of disability as individual limitations as embodied by the older International Classification of Impairment, Disability and Handicaps used in the 1980s and 1990s (Finnstam, Grimby & Rashid, 1989; Grimby, Finnstam, Nelson & Rashid, 1988; Miron, 1994).

Definitions of disability have historically been determined by professionals, mostly from Western countries and with a medical view, and have focused on the impairment afflicting the person (Peat, 1997). In recent decades, however, new definitions have arisen from people with disabilities themselves, promoting a social model that reduces individual and structural barriers in society, addressing both attitudes and physical obstacles (Coleridge, 1993). Nevertheless, the people with disabilities who have spoken out are disproportionately white, from Western countries and educated (Stone, 1999). Moreover, a close relationship exists between disability and development (Stone, 1999). This is evident in the link between impairment and poverty (Coleridge, 1993; Grech, 2009; Putnam et al., 2005; Stone, 1999), though this link varies based on where one lives, one's age and the nature of one's disability. As a development issue, the incidence of disability may be higher in non-Western than in Western countries, and the availability of prevention and disability services may be greater in Western than in non-Western countries. Nevertheless, as people live longer and longer in Western countries today, new and more widespread disability issues have emerged (Coleridge, 1993). An example relates to the service given to elderly people with disabilities where no family member is available for support (Swärd, Edebalk & Wadensjö, 2013).

The word *disability* and the phrase *people (or children) with disabilities* are used frequently in this dissertation. However, this study does not focus on disabilities themselves; instead, it explores a strategy used to provide children and their parents with needed services. As definitions of disability can vary widely between countries, as can definitions of rehabilitation. For example, in Sweden various treatments for injured adults or youth to help them regain lost abilities are referred

to as *rehabilitation*. Meanwhile, treatments for children born with disabilities that are intended to provide them with as “normal” a life as possible are called *habilitation* (Bille, Olow & Annerén, 1999). In contrast to Sweden, Uganda seems not to divide rehabilitation services by age groups. Instead, they call services to adults and children of all ages with disabilities *rehabilitation*.

According to the UN (1994), the term *rehabilitation* refers to “a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence” (UN, 1994, p. 11). In the research literature rehabilitation has many definitions, although in general it is “described as being an active, dynamic, continuing process concerned with physical, social and psychological aspects”, “which aims to improve an individual’s health status and quality of life by minimising the consequences of disease” (Davis, 2006, p. 8). A recent definition of vocational rehabilitation based on the International Classification of Functioning, Disability and Health, define rehabilitation as “a multi-professional evidence-based approach that is provided in different settings, services, and activities” to “individuals with health-related impairments, limitations or restrictions” (Escorpizo et al., 2011, p. 130). In this dissertation, the term *rehabilitation* will be used as a way of encompassing both countries’ existing rehabilitation services for children with disabilities.

People with disabilities have been excluded from the field of social work when disability is viewed as a medical rather than social issue, and where the aim is to “reconstruct” a person through various forms of therapy, surgery and medication to make the person as “normal” as possible (Lindqvist & Hetzler, 2004; Peat, 1997). People with disabilities have, due to a bureaucratic public-sector and to a paternalistic health service which regulates users to passive, receiving roles, neither been frequent consumers of social work services (Mackelprang & Salsgiver, 1996). As a result, few social workers are working within the field of disability and few articles related to disability are published in the discipline of social work (Mackelprang & Salsgiver, 1996). Nevertheless, social workers have been involved in disability issues as part of the process of institutionalisation, segregating people with disabilities from mainstream society, and by providing services focused on managing and supporting individuals (Johnson, 2009). They have also been a part of the movement to help people with disabilities leave institutions and live more independent lives (Johnson, 2009).

Dominelli (2002) and Mmatli (2008) encourage social workers’ involvement in the political arena to achieve social change and Adams et al. (2002) argue that social workers must work against a disabling society by taking more responsibility when it comes to people—especially children—with disabilities. However,

challenging and changing societal structures are among the most difficult and demanding tasks for those engaged in social change processes. Mmatli (2008, p. 307) argues that social workers should “participate politically and become effective agents of social change”. However, Dominelli (2002) points out that social workers are in a particularly vulnerable position when trying to transform existing practices and services, because they must work simultaneously within and against the state.

CBR – An Internationally Designed Idea

In a technical report from 1969 an important group of health “specialists” within the WHO recommended governments to put up medical rehabilitation centres – starting at the national level (Helander, 2007). The recommendations were distributed to all Ministries of Health. The centres should employ 20 different highly trained specialists in rehabilitation medicine, including occupational therapists, speech therapists and audiologists, nurses with additional training in rehabilitation, orthotists, physiotherapists, prosthetists, clinical psychologists and social workers (Helander, 2007). However, the rehabilitation specialists at these centres seemed best qualified to treat musculoskeletal dysfunctions, leaving people with mental disorders, deafness, blindness, leprosy, mental retardation and developmental disabilities etc. to find their own services. The report declared that “WHO has an important part to play because the first stage of rehabilitation is purely medical, and further stages cannot be undertaken until the medical aspect has been dealt with” (Helander, 2007, p. 4).

Since this view was declared in 1969, however, change has occurred. New services were needed that would view disability as a social rather than a medical issue. The medical model focused on people’s impairments instead of on their capacity to contribute to society (Peat, 1997). The social model focuses on reducing individual and structural barriers, including changing societal attitudes and removing physical obstacles (Coleridge, 1993). One reason for the changing view of disability is that people with disabilities started to organise themselves to spur social change, demanding equal rights and attitude change (Finkelstein, 1999). However, changing a rehabilitation system that had been in place for decades was not a prospect welcomed by many professionals (Helander, 2007). Resources from the health sector needed to be redistributed among the rehabilitation services best able to support and strengthen people with disabilities who were dependent, powerless and almost voiceless, including people with permanent disabilities and chronic impairment. Such services must also incorporate the families of these individuals and the community as a whole (Helander, Mendis & Nelson, 1983).

At the time of the 1969 WHO report, and still visible in the 1980s, a hegemonic and imperialistic perspective viewed non-Western countries as unmanageable and unable to implement change. The WHO report recommended that rehabilitation

should be established in non-Western countries while believing that it was not feasible in our time to provide rehabilitation in these countries (Helander, 2007). However, new programmes and policies were initiated in the fifteen years following the election of a new Director-General in 1973 as a result of socially, economically and politically unacceptable gross inequalities in the health status of the people, especially between Western and non-Western countries (ibid.).

The recognition of such inequality generated a new ideology within the WHO. CBR was introduced as a new way of looking at rehabilitation, a social rather than medical model that was viewed as a model of solution, escaping the medical model and unite rehabilitation workers through a cohesive framework (Chatterjee, 2001). In 1974, Einar Helander of Sweden, who was the first rehabilitation specialist recruited to the WHO, had five months to produce a new disability/rehabilitation policy within the Division of strengthening of health services that had just begun to develop new health strategies. CBR was initially based on a comprehensive study of the living conditions and of the needs and abilities among few hundred cases of family members who successfully rehabilitated people with disabilities in non-Western countries. However, these ways of rehabilitating were not new, as many European countries used home training or self-training frequently (Helander, 2007).

In the beginning of the 1980s WHO and other UN agencies issued an experimental manual entitled *Training Disabled People in the Community* (Helander et al., 1983; Helander et al., 1989), directed at people with disabilities and their families, community leaders, schoolteachers and healthcare workers (Joint Position paper, 2004). In the manual the rehabilitation process was broken down into different steps and described in simple terms so that friends, family members or people with disabilities themselves could use the methods to improve their life situation. These 32 training packages were created for all the major disability groups (vision, hearing, learning disabilities, epilepsy, motor, language and behavioural disorders (Chermark, 1990) prevalent in developing countries (Helander, Mendis, Nelson & Goerd, 1989; WHO, 2004).

CBR was based on the provision of simple rehabilitation services that included appropriate, clear and simplified descriptions of technology (Kay & Dunleavy, 1996; Lagerkvist, 1992; Mitchell, Zhuo & Watts, 1989; Mitchell, Zhuo, Lu & Watts, 1993). The manual was spread to many countries and was translated partly or entirely into fifteen different languages. The recipients of the manual shared their view of the manual's content, and field testing was organised in ten countries and evaluated by project staff between 1979 and 1982. The knowledge gleaned from these early experiences with the CBR manual resulted in a revised version of the manual, *Training in the Community for People with Disabilities*, published in 1989 (Helander, Mendis, Nelson & Goerd, 1989; Joint Position Paper, 2004). In terms of

functional improvements, the results of CBR were seen as comparable with those of the rehabilitation carried out in institutions, and CBR was regarded as a highly advanced strategy for reaching the goal of social integration (Helander et al., 1983). The first explicit definition of CBR has been found in the Joint Position Paper from 1994:

CBR stresses the equalisation of opportunities and social integration of all people with disabilities and recommends implementation of CBR through the combined efforts of disabled people themselves; their families and communities; and health, educational, vocational, and social services. (Joint Position Paper, 1994)

The definition has changed and in a draft from 2002, compiled by the International Labour Organisation (ILO), United Nations Educational Scientific and Cultural Organisation (UNESCO), United Nations Children's Fund (UNICEF) and WHO, is CBR a strategy within general community development for rehabilitation and leans on social inclusion instead of social integration of all children and adults with disabilities (Joint Position Paper, 2002). The definition can subsequently be found in the Joint Position Paper from 2004, but also including a combined effort of relevant non-governmental and governmental services when implementing CBR, such as education, training, social and health services (ILO, 2004). According to Lang (2011), who bases his statement on the definition from 1989 and earlier, describes CBR as a top-down approach to providing basic rehabilitation services through which knowledge is transferred to people with disabilities:

Community-based rehabilitation (CBR) is a strategy for enhancing the quality of life of disabled people by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights. It calls for the full and co-ordinated involvement of society: community, intermediate and national. It seeks the integration of the interventions of all relevant sectors – educational, health, legislative, social and vocational – and aims at the full representation and empowerment of disabled people. It also aims at promoting such interventions in the general systems of society, as well as adaptations of the physical and psychological environment that will facilitate the social integration and self-actualisation of disabled people. (Lang, 2011, p. 167)

This definition of CBR draws upon a broad ideology in which all resources (skills, finances, equipment, designs, etc.) for the integration and rehabilitation of people with disabilities in different nations should be centrally planned and equally distributed among the world's population (Miles, 1993). However, according to Miles (1993), no country were eager to adopt CBR nationwide, whereby WHO started to sponsor experimental local projects, often supported by international aid agencies like the WHO, the UNICEF, the ILO and the Red Cross (Helander et al., 1983; Jackson & Mupedziswa, 1988; Miles, 1993). CBR has also been implemented at a national level in for example Brazil, South Africa, Uganda, Vietnam, China and Lao (Hai & Chuong, 1999; Inthirat & Thonglith, 1999; Pollard & Sakellariou, 2008; Ran et al., 1992; Stuelz, 1999) and at local level in for example Brazil, South Africa and Sweden (Hargö Granér, 1999; Pollard & Sakellariou, 2008) by health professionals.

Since the 1970's to 2007 CBR has undergone various stages of development with widening definitions and new guidelines (see Joint Position Paper, 1994; 2004; WHO, 2007). Thomas and Thomas (2002) say the need for prevention, social rehabilitation, education and vocational training led to changes in CBR during the 1980s and 1990s. CBR started to leave a medical focus for a more comprehensive approach and to change not only the individual with disabilities, but the context in which he or she was situated. CBR has evolved as an element of community development that takes a more holistic view of the needs of people with disabilities, employing a bottom-up approach in which people with disabilities participate in planning and decision making (Lang, 2011; Lysack & Kaufert, 1994; Thomas & Thomas, 2002).

According to Lysack and Kaufert (1994), CBR can also be structured as a top-down approach. A top-down approach reflects the institutional rehabilitation managed by local governments or international non-governmental organisations (NGOs), which tend to control the services and ask community members "to participate in structured activities pre-determined by the central authority" (Lysack & Kaufert, 1994, p. 239). Debate continues within CBR over whether it should be implemented by local communities or by an external agency (Thomas & Thomas, 2002). When viewed through a development perspective, CBR should be initiated by those most affected: people with disabilities themselves, along with their family members. If initiated by an external agency, in contrast, community participation in CBR will not be feasible and people with disabilities will risk being ignored. In this model people with disabilities and their families become passive recipients of the services provided, creating expectations of charity with little initiative to contribute to society or manage their own affairs (ibid.).

The differing views on how to implement and manage CBR show that the idea is no longer a blueprint or ready-made solution; it is instead a philosophy that can

be transformed to suit the cultural contexts in which it is implemented (Miles, 1996). Lightfoot (2004) say, CBR's success and usefulness are due to its ability to take cultural aspects into consideration, which provides abundant space for local interpretations of the strategy (Payne, 2002). This also means, as mentioned before, that CBR can be found in many variations in different corners of the world, depending on the context in which it is implemented (Asindua, 2002; Miles, 1996; Vanneste, 2004).

Evaluations of CBR

CBR was developed mostly for non-Western countries and according to Finkenflügel (2004), who reviewed 128 articles on CBR published between 1976 and 2002, the majority of articles come from the Sub-Saharan African region, the next largest number from East Asian and South Asian regions, and just a few from South American countries. Several case reports reviewed by Finkenflügel reflect a generally positive attitude regarding the implementation of CBR (see Baolin & Huang, 1999; Boyce et al., 1997; Hai & Chuong, 1999; Inthirat & Thonglith, 1999; Ran et al., 1992; Stuelz, 1999) and many within the field of rehabilitation wished to implement CBR (Chatterjee, 2001; Helander, 2004; Kendall, Buys & Lerner, 2000; Lightfoot, 2004; Mpagi, 2001).

Evaluations by researchers such as Finnstam, Grimby, Nelson and Rashid (1988), Grimby et al. (1988) and Lagerkvist (1992) also view CBR as a feasible and efficient way of providing guidance and assistance to people with disabilities (Lundgren-Lindquist & Nordholm, 1993). Some reasons for CBR's success, in addition to its ability to be culturally sensitive (Lightfoot, 2004; Miles, 1996), include its cost effectiveness and its ability to reach more people with disabilities (Mpagi, 2001). CBR has been found to change the lives of people with disabilities by inviting their participation, equalising opportunities and increasing public awareness. It has also been effective in mobilising community resources (Hai & Chuong, 1999; Hartley, 2001; Inthirat & Thonglith, 1999).

Despite the success of CBR, there remain people with disabilities who do not receive basic rehabilitation services and cannot participate equally in society (Joint Position Paper, 2002). Dempsey (1995) mean, the implementation of CBR in many countries has been a disappointment. A reason can be that the expectation of integration and community participation has failed within CBR and that CBR, especially in non-Western countries, has not been translated to fit local conditions, ideas and habits (Turmusani, Vreede & Wirz, 2002). The WHO assert that even though CBR is an effective strategy according to many governments, the programme are often found in communities which already is promoted by NGOs establishing programmes (Joint Position Paper, 2004). Structural issues of cooperation, economics and communication limit the implementation of CBR in

various non-Western contexts. Hai and Chuong (1999) identify the lack of mid-level rehabilitation support as a problem, while Stuelz (1999) observes that a failure to engage CBR volunteers or public health staff due to a high workload and low incentives hinders the success of CBR.

Inthirat and Thonglith (1999) identify the absence of laws concerning people with disabilities, limited transportation for mid-level health workers to reach local communities and civil servants' lack of understanding of the concept and philosophy of CBR as obstacles to its implementation. Miles (2004) also notes that CBR is based on an ideology advocated by international NGOs and the UN, with the consequence that grassroots activities are fading away. Participants in CBR projects who have useful observations from practical experiences thus disappear behind "ideological slogans, leading to muddled and contradictory demands and priorities" (Miles, 2004, p. 4). This power relationship may encourage participants to "mumble the right jargon" to get the funds needed from donors to be able to carry out the CBR project (Miles, 2004, p. 4). From this perspective, CBR is not self-sustainable because it cannot depend on backup from outside the community, and rehabilitation would be strengthened if it were brought under ordinary community integration programs (Momm & König, 1989). According to Miles (1996), disability should be understood as a development issue and CBR should work with the disability rights movements to avoid becoming just another way of providing services that fails to meet the various needs of people with disabilities. Some recommendation several authors have encouraged social workers to engage in (Beaulaurier & Taylor, 2001; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006).

The need for research on CBR

CBR has thus been viewed variously as a successful or an unsuccessful strategy. One reason for this may be insufficient research on CBR's strengths and weaknesses (Mitchell, 1999). Jackson and Mupedziswa (1988) point out that little research has been conducted worldwide on the problems of CBR. A 2001 conference held in Uganda concluded that more effort is needed to increase information about CBR and to get a better understanding of how to carry out good practices (Hartley, 2001).

Although research on the implementation of CBR is not considerable, there has been a minor increase of research during recent decades (Finkenflügel, 2004). One reason for the lack of research on CBR in Western countries may be that CBR was created initially for use in non-Western countries. Another reason may be conceptual confusion over CBR, with researchers referring to CBR by such terms as "rehabilitation in the community" or "community rehabilitation". Kendall, Muenchberger and Catalano (2009) notes, practises implemented in Western

countries that are labelled as CBR are very diverse, despite utilising components of the original CBR. For example, in the UK a variety of models of CBR have been found that work in various ways (Aitken & Walker, 1987; Kendal et al., 2009; Clarke, 1987). Finkenflügel (2004, p. 25) found that the Western articles about CBR, viewed CBR as “an auxiliary service to existing hospitals, rehabilitation centres, [and] institutions”.

Some authors suggest that if CBR is to be implemented in Western countries the prevailing system of implementing CBR has to change (Aitken & Walker, 1987; Gregory, 2001; Kendall et al., 2009). Many researchers emphasise the important role of the relationship between healthcare providers and other professionals involved in the lives of people with disabilities (Aitken & Walker, 1987; Clarke, 1987; Gregory, 2001; Kendall et al., 2009; Kivelä, 1985). According to Aitken and Walker (1987), healthcare professionals can no longer work in isolation; they must interact with other professionals who provide transportation, personal services, and education and employment services. Clarke (1987) points out that the undeclared war must end between social workers and medical rehabilitation workers, and argues that the key issue is not whether a medical or social model is best. Instead, the focus should be on placing the person with disabilities in focus when providing services, letting them guide and select what is offered. Sometimes it is most appropriate with no assistance at all, other times suitable with medical or social assistance (Clarke, 1987).

This study takes a comparative approach to exploring the implementation of CBR in Sweden and Uganda. Comparative studies involving Western and non-Western countries can illuminate common principles and challenges (Finkenflügel, 2004; Lightfoot, 2004). Boyce and Johnston (1998) and Boyce et al. (1997) compared collaborations between CBR agencies with a focus on NGOs in non-Western and Western countries. Boyce and colleagues found that it was common for CBR NGOs to be dependent on resources and funding, especially in small or non-Western countries. They argued that non-Western countries can influence local policy reforms as a scaling-up strategy, as such governments lean more heavily on NGOs and NGOs use more vertical support from governments or donors in non-Western than in Western countries. Western countries are more likely to collaborate horizontally with NGOs, creating a scaling-up strategy more accessible to international lobbying (ibid.). Lysack and Kaufert (1994) compared CBR in Southern countries with Independent Living, a model of rehabilitation used in North America, and concluded that these ideas have a lot to learn from each other and that the two models has been spread in both directions. A comparative analysis of CBR in Uganda and Sweden can likewise expose similarities and differences in the implementation process, and developing an understanding of how international ideas of social work can be translated into different

socioeconomic, political and cultural contexts as well as which factors hinder or frame the implementation of an idea.

Outline of the Thesis

This study compares the introduction and implementation of CBR for people with disabilities in Uganda and Sweden. Whereby, this chapter presented the focus and major objective of the study as well as the research questions that guide the work. It explored the importance of the area of disability for social work practice and examined CBR as an internationally designed idea. It sought to explain the origins of this international idea, present its definition and content, and examine its relevance in non-Western and Western countries. Chapter Two introduces the major theoretical perspectives employed in this study. It discusses the power dynamics involved in transfer of knowledge and models, and explores the spread, transformation and implementation of ideas, policies and concepts in various cultures. Chapter Three presents the different institutional contexts of Uganda and Sweden within which CBR has been introduced and implemented. This will help create a theoretical framework for analysing and understanding the introduction and implementation of CBR in two very different institutional settings.

Chapter Four presents the methods and methodological considerations involved in the study. The process of collecting and structuring the data is discussed and the study's analytical method—content analysis of semi-structured, in-depth interviews—is introduced. Ethical considerations related to the study's relevance, the researcher's role in researching children with disabilities and the undertaking of research in a non-Western country are also examined in this chapter. Methodological problems arising during the research process are also discussed. At the end of this chapter, the controversy surrounding the researcher's identity as a "white European" researcher who is "there to study them" and privileges that may affect the study or/and its participants are explored.

Chapter Five explores the introduction, translation and implementation of CBR in Uganda and in the district of Bushenyi. It describes the background of how CBR was introduced: the living conditions of families to children with disabilities, and the demand for a less paternalistic model of rehabilitation. It also analyses the implementation process: CBRs transformation and how it has been put in action, the economic conditions during the implementation, the motivation for participation in the project, and how knowledge received from the project has changed attitudes. The analysis is based on statements from an initiator of CBR in Uganda, parents of children with disabilities, as well as people involved in CBR in Bushenyi, including Community Development Officers (CDO), teachers and a physiotherapist. The chapter also examines how CBR have affected receivers' situation and which factors influencing the implementation process.

Chapter Six highlights CBR's introduction, translation and implementation in Sweden and in the province of Värmland, and describes the same themes as used in chapter five: background, the implementation process, how CBR has affected receivers' situation and which factors influencing the implementation process. The analysis is based on statements from an initiator of CBR in Sweden, parents of children with disabilities, as well as people working with CBR in Värmland, including principals, social workers and teachers. Chapter Seven presents a comparative discussion of the study's findings. CBR as a case are compared under headlines such as the introduction and implementation of CBR, contextual factors influencing the implementation of CBR as well as the possibilities of the continuation and institutionalisation of CBR in Uganda and Sweden. Further, the role of welfare state for implementation of CBR and the relevance of globalised international ideas for social work are discussed. Finally, this study's contribution to the field of social work, its limitations and recommendations for further research are discussed and presented.

CHAPTER 2

THEORETICAL FRAMEWORK

Many researchers with various perspectives are more or less active in the examination of how ideas, strategies or models circulate and are transferred into different contexts. A common thing reviled is that ideas cannot be transferred between different contexts, countries and/or levels of society without being modified and transformed. Although ideas are important for existing needs of people, it is found that many models formed based on those ideas do not help the people who are supposed to be served by such models and ideas.

The purpose of this chapter is to highlight some theoretical aspects that are considered important for understanding how an idea is spread between and transformed and implemented in different contexts. When following the case of CBR in the two countries Uganda and Sweden a mix of various theoretical approaches is required. To shed light on power structures surrounding ideas which travel across nations and between societies, a postcolonial perspective is used. The power of transferring and defining knowledge and ideas is examined and are especially important when comparing two very different welfare contexts. To understand and explain an idea or policy's spread, transformation and implementation, certain concepts are highlighted which unite the field of implementation, project research and a neo-institutional perspective.

The Transfer of Knowledge and Ideas

Ideas produced in Western countries have been and still are spread by Western economic, cultural and military dominance all over the world, influencing many non-Western countries' local communities and forming uneven social structures and institutions (Kamali, 2006; Tomlinson, 1999). In preserving Western privilege it is not only weapons that are sold, and not only the culture of mass consumption that is exported to non-Western countries; knowledge-based models and strategies are also among the predominant exports of the west.

The transfer of knowledge has its roots in the colonial era, when Western countries like England, France and Belgium restricted many non-Western countries, including colonised African countries like Uganda, according to their ideas of the colonised world. For example, in Uganda, Western education and colonisers' policies were introduced by missionaries (Tiberondwa, 1998). Today this imposition of ideas and knowledge is viewed with suspicion by various academic fields. For example, social work models transferred from Western to non-

Western countries are now seen as inappropriate for addressing the real needs that exist within local cultures (Payne, 2002). Historically, it can be seen that also social work in Africa was a product of European colonialism, and many social work teachers at African universities were trained in North America and Europe, resulting in the importation of inappropriate models (Rwomire & Raditlhokwa, 1996). However, non-Western countries have also provided ideas and knowledge, which were used by other non-Western countries. Since the Second World War, non-Western countries has supplied important welfare models where the Nigerian model influenced for example Tanzania, Kenya, Uganda, Ghana and Zambia (Kasza, 2002). However, one thing to bear in mind is that Nigeria was colonised by England in the beginning of the 1900 century, which have influenced the organisation of the welfare system in Uganda.

Even welfare model of a certain Western country did not developed on its own and has been influenced by welfare models in other countries. An example of such mutual influences of welfare models is the German welfare model from 1880s that, twenty years later, influenced the British model (*ibid.*). Some years later German reforms also influenced the Swedish pension insurance which the Swedish parliament 1913 introduced as a general pension system, one of the first in the world, including a pension for people with disabilities unable to work (Edebalk, 2000; Swärd et al., 2013). Even rehabilitation models are not entirely national, but are influencing each other. For example, the Minnesota model from USA is also a model transferred and implemented in Sweden during the 1990s and has become a well-known way of working with people dependent of alcohol and drugs (Gerdner, Bodin, & Söderfeldt, 1988). Ideas about project planning and project expressions, such as research projects, pilot projects and project team, have also been transferred from the United States to Sweden (Engwall, 1995). However, there are ideas, knowledge, policies and models which are transferred with a good intention though the outcome of the implementation was not always as expected. One such model transferred between Western welfare states, from New Zealand to Sweden, is the Family Group Conference (FGC). This model, in the same way as CBR, focuses on the power and responsibility given to families in the process of finding proper service to vulnerable children (Sundell 2002). Both FGC and CBR are models transferred to Sweden with a hope of integration in the regular service.

However, many ideas and models that are transferred between countries, especially from Western to non-Western countries, are copied instead of being transformed to local conditions, based on indigenous knowledge and consumer's experiences. One example is the medical model of rehabilitation. Over the last 30 years, social work researchers have tried to raise awareness of Western influences on social work and emphasise the importance for non-Western countries of developing indigenous education and practices that are not based on dominant

Western theories and models of practice (Gray & Allegritti, 2002). Mwansa (2010) argues that African countries need to transform Western-based social work practices into Afro-centric models grounded in community-based interventions, indigenous knowledge, and local practices and values. It is found that the Western world has rarely cited non-Western countries' ideas of social theory in their texts, evidence that Western dominance and power structures still flourish (Connell, 2007). Yet Connell (2007) notes that theories from non-Western countries are key to understanding our global, changing world, and that Western countries' must reconsider and transform their social theories to match the worldwide transformation.

The Power of Definition

Just as the power to transfer ideas, knowledge, policies and models is most often held by Western countries, the power to define disability also resides in the west. This power structure developed from the colonial and imperialist mission of Western countries, a mission that is still present and influential in shaping a new postcolonial world order. The meaning of disability and the needs of people with disabilities have been, and remain today, determined primarily by either rich, white people with disabilities, or people without disabilities in Western countries (Stone, 1999). Grech (2009) means that Western theorists still have a monopoly on disability studies, based on Western industrialised settings and permeated with historical, cultural, ideological and theoretical assumptions. Jönsson (2010, p. 395) reveals for example that "many local elites in non-Western countries are highly influenced by westernised ideas of development". This can influence the uncritical adoption and implementation of modern Western ideas and models in non-Western countries and ignore the socioeconomic and cultural context of those countries.

According to Tiberondwa (1998) colonialism can be expressed political, cultural, economical and worst of all mental. Edward Said analyses, in his classical book *Orientalism* (1978), how Western constructs of the Other have created an imagined Orient that encompasses a huge geographic area with widely varied socioeconomic, cultural and political formations and institutional arrangements (see also Loomba, 2008; Thörn, Eriksson & Eriksson Baaz, 1999). Said and other postcolonial researchers, such as Gayatri Chakravorty Spivak, Homi Bhabha and Ania Loomba, build on Frantz Fanon's earlier work *Black Skin, White Masks*, published in 1952.

Fanon (2008), who is generally considered to be the father of postcolonial theory, explores the creation of cultural identities in a global society. According to Fanon, the struggle against stereotypes and racism creates the possibility of developing alternative identities which go beyond those created by the

modernised west. This remains important for us today. The postcolonial movement has argued that non-Western countries have affected Western countries as well (Macqueen, 2007). The colonisers' psyches were not already defined but were formed through their exposure to colonial victims (Rattansi, 1997).

In colonial identity formation, the "native" or the colonised "Others" were defined as black, uncivilised, irrational, pre-modern, pagan and libidinous. The Western colonisers, in contrast, were defined as the opposite: white, civilised, rational, modern, Christian and sexually disciplined. Thus the view of the European as superior, with a positive duty to civilise and govern, was established. Today, Africans living either in African or Western countries in general, and the most powerless and marginalised individuals in particular, experience the same hierarchies of colonial inequality based on their ethnicity, 'race', gender and economic status (Rwomire, 2001).

This process of identity formation affected more than the relationship between coloniser and colonised; it also influenced dynamics inside Western nation-states, where internal "others," such as the rapidly growing urban working class, women and children, were disciplined and regulated in the formation of Western modernity (Rattansi, 1997). The mission of modernisation and discipline created other "deviant groups" as well. Striving for a modernised world also meant excluding people with disabilities and labelling them as unnecessary. Oppressive attitudes towards people with disabilities can be traced as far back as the Neolithic period, where such individuals were seen as possessed by spirits. To escape the possession, holes were drilled in their skulls (Mackelprang & Salsgiver, 1996).

The ancient belief systems of Greeks as well as Romans dictated abandoning people with disabilities and leaving them to die. During and after the Middle Ages, the Judeo-Christian belief system on which much of Western culture is based viewed people with disabilities as cursed, possessed by evil demons. As a result, such individuals were stereotyped and shunned (ibid.). In Ethiopia for example, disabled family members were believed to represent God's punishment and were therefore hidden from the community (Miron, 1994).

Ingstad (1990) does not deny the existence of oppression, but objects to "the myth of the hidden (and abused) disabled." Ingstad argues that this narrative is generalised to all people with disabilities in all situations and only prevalent in non-Western countries, while in Western countries this view has become outdated (Ingstad, 1990, p. 13). According to Miron (1994), the public's degree of dislike and acceptance of people with disabilities is expressed, in most societies, as a "hierarchy of disabilities". This can be seen in the Poor Law in England, established in 1601, which was created to address the dilemma of maintaining the labour force for industrial development while at the same time caring for people in need. Poor people were classified in two categories, deserving and non-deserving,

also illustrating the “hierarchy of disabilities”. “Orphaned, blind, and ‘crippled’ people were deemed deserving and received charity less begrudgingly than so-called nondeserving poor people” (Mackelprang & Salsgiver, 1996, p. 8).

This citation not only expresses the “hierarchy of disabilities”, but also shows its relationship between disability and a country’s development in the industrial era and with the rise of capitalism. Such a view can be traced as far back as Plato (427-347 Before Christ), who viewed “people with disabilities as standing in the way of a perfect world”. It is worth noting that Plato’s works provided the foundation for much of Western culture’s ethical framework (Mackelprang & Salsgiver, 1996, p. 8).

The inequalities created during colonisation influenced national identities as well (Rattansi, 1997). As a result, different conceptual frameworks and terms have been defined and used to separate various parts of the world from each other and assign them different qualities. Accordingly, repressive and stereotyped images were created that characterised Africa as a homogeneous socio-political block, designating the people of Africa as intrinsically “different” (Rwomire, 2001). Historically, the dichotomous terms “West” and ‘East” grew out of North American and European imperialism, expressing inequities in wealth, cultural influence and power (Connell, 2007). Similar dichotomies, such as “centre/periphery”, were based on an unequal international trade and economic relations, in which the strong countries in the centre could introduce terms and conditions that benefited themselves and disadvantaged the weaker countries on the periphery (Wallerstein, 2005).

A dichotomy introduced in 1940 and still frequently used is *developed* vs. *developing countries*. The term “developing countries” was applied to a very heterogeneous group of countries in Latin America, Africa and Asia, which were exposed to economic and/or humanitarian aid to accelerate their development. However, the term has been criticised for its west-centric perspective, which views Western countries as the model that non-Western countries around the world should strive to emulate (Loomba, 2008; Mohanty, 2006). Concepts related to development are mainly based on a linear understanding of modernity and history in which all countries must follow the “modern west” (Jönsson, 2010; Kamali, 2008; 2006). From this perspective, the development that has taken place in Western countries is seen as the only “true” model of development.

As many researchers in the field of social work have shown in recent years, the “development” in Western countries, from Sweden to Australia, towards a more neo-liberal organisation of societies that is disarming the welfare state in those countries is not “a move to the better” compared to the development of welfare state models in the twentieth century (Burkett & McDonald, 2005; Ferguson, Lavalette & Whitmore, 2005). Therefore, the concept of “developing countries” is

not used in this work. Instead, this work refers to the concepts of non-Western and Western countries.

Moreover, the phrase “Western countries” itself needs clarification. The concept of a singular and homogenous “West” is as problematic as the concept of an equally homogenous “East” (Kamali, 2006). In recent decades new concepts have emerged in an effort to avoid many problematic concepts within the social sciences that form the dominating west-centric scientific discourse (Fredrickson, 2000; Jönsson, 2010; Kamali, 2008; 2006; Mohanty, 2006). One effort to redefine “Western countries” is George Fredrickson’s (2000) concept of “Europe and extended Europe”, referring to Europe and the countries established by European colonisers, including the USA, Canada, Australia and New Zealand. Fredrickson’s phrase “Europe and extended Europe” is synonymous in this work with the concept of “Western countries”. The phrase “non-Western countries” will refer to countries that were colonised and/or are still dominated, in one way or another, by Europe or extended Europe. The terms used to separate countries contain a hierarchy of wealth and dominance that also affects the transfer of ideas in the world.

Given Western countries’ centuries-old power to define and the resulting transfer of knowledge from Western to non-Western countries, it is not surprising that the field of social work has created practices not suitable or wished for by participants or practitioners. According to Stone and Maxwell (2005), governments and professionals who seek to implement services other than those provided by the hegemonic structure face a difficult task, as institutions seek to establish global consensus around certain ideas that only serve to reinforce their international image, policy and purposes. As Foucault (1984) observed, people create and use power, it is exercised. Thus it is especially important to bear in mind Said’s (1993, p. 8) warning that:

In our time, direct colonialism has largely ended; imperialism lingers where it has always been, in a kind of general cultural sphere as well as in specific political, ideological, economic, and social practice.

However, it is not only power structures behind the transfer of knowledge and definition of concepts which may influence practices to suite existing demands or not. How an idea is implemented is also vital.

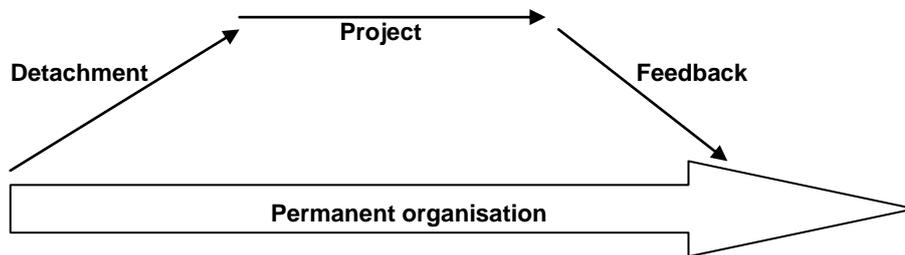
Implementing new Ideas, Policies or Concepts

In the 1970s, the same decennium as WHO created the idea of CBR, efforts to develop government interventions to address social problems increased rapidly because of awareness of ineffective interventions (Hill & Hupe, 2009). A reason for

the ineffective interventions could be as Johansson (2010) expresses a lack of correctly implemented programs and projects. Projects as a mean of implementing policies are used in a greater extent than before (Johansson, Löfström & Ohlsson, 2000). In Uganda and Sweden, during the 90s, CBR was implemented through what can be defined as experimental local projects (Helander et al., 1983; Jackson & Mupedziswa, 1988; Miles, 1993).

As mentioned in the first chapter, implementation means to carry out, fulfill, complete, accomplish and produce, and the implementation object, what is being implemented, is naturally a policy which contains both goals and means for achieving them (Pressman & Wildavsky, 1984). Or as Hill and Hupe (2009, p. 7) puts it: "implementation is the carrying out of a basic policy decision". Defining the very concept of project is ambiguous (Blomberg, 1998; Engwall, 1995, Johansson et al., 2000) and its meaning has shifted over time. Before the 1960s projects were defined with drafts, proposals and wild ideas meanwhile in the 1970s the concept of project received a meaning generally used in project management literature today, namely "a project is a temporary and from other operations defined function, which by controlled assigned resources shall achieve established goals" (Johansson et al, 2000, p. 22). A "project" promises a beginning and an end, and between innovation, experimentation, and entrepreneurship. Projects are started mostly by actors within an organisation but sometimes also in response to external expectations. In most cases, projects starts because of clear needs of development and change (Johansson et al., 2000).

This study examines two cases, which can be considered as development and change projects. That is to say that there are already relatively stable regular activities both in Uganda and Sweden for people/children with disabilities, but where a development and change project such as CBR is implemented to develop such activities. When to examine changes and the relationship between a permanent organisation and a temporary project, Johansson et al. (2000) provide a rather simple model (Model 1). The idea is that a permanent organisation is not always stable and that the implementation goals of a project are not always fulfilled when the project has ended.



Model 1. Relation between project and operating activities

During the models detachment, objectives, activities and resources are separated from the regular activities, and are defined as a project. During the feedback from the organisation, experiences from the project are implemented in the permanent organisation. For Johansson and colleagues (*ibid.*), the concepts of learning and change can be helpful in studies of projects whose experience shall be integrated into the main organisation and its activities. Organisations' members learn new things through education or through investigation. The new things can then be implemented in the organisation's regular work. Implementation is in this perspective synonymous with change.

However, for development projects to implement policies which are able to change existing organisations and to suite existing demands seems difficult. According to Lewin (1996) changes within for example social agencies happen far more because of organisational and administrative reasons, rather than projects creating new knowledge which changes and improve existing practices of the organisation. It is found that it is difficult to change the permanent organisations within social services with projects or other equivalent administrative methods (Hasenfeld, 1983: 1992; Sahlin, 1996). Even in organisation research, the system of projecting changes has been criticised as a mean to create growth and change. The term "reflection-in-action" are instead advocated because of its power of continual change (Schön, 1983). According to Johansson et al. (2000) a project separated from the main organisation can create a free zone for thoughts and reflection and advance new types of interaction. A project organisation can thus provide more opportunity for reflection of the regular operations where the knowledge can be implemented continually.

However, the main function of projects is to legitimise the organisation, says Sahlin (1996). Researchers within neo-institutional organisational theory (see for example Meyer & Rowan 1977, Powell & DiMaggio, 1991) agrees and says that projects has a great symbolic charge whose function is to legitimise the organisation in relation to important stakeholder groups. Johansson et al. (2000) argue, however, that projects can be as a barrier between the permanent organisation and its environment. The legitimacy of the mother organisation outside can make a project to remain uncoupled from the permanent organisation,

and thus counteract the change sought by the permanent organisation. Projects can also be started to legitimise external organisations or to obtain external resources. Engwall (1995) means that it is the legitimacy of the work form, the status of the project assignment and the originality of the project process that determines a project's success.

When new ideas, policies or concepts are implemented through a project, different processes occur. Implementation is a process in which many actions are taken to put a policy decision into effect (e.g. Buse, Mays & Walt, 2005; Hill & Hupe, 2009; Lester & Goggin, 1998; Van Meter & Van Horn, 1975; Meyer & Goes, 1988; Paudel, 2009). Van Meter and Van Horn (1975) means that it starts from an initial policy decision and highlights the need for the applier to *understand* the decision, *being able* to implement it and not at least to have *the will* to implement it. According to Paudel (2009, p. 38), the will or motivation of a policy "reflect the implementer's assessment of the value of a policy or the appropriateness of a strategy". Within implementation studies a far-reaching review in the area of public administration is made by Hill and Hupe (2005), examining "what happens between policy expectations and (perceived) policy results", with a "concern to *explain* what happens and a concern to *affect* what happens" (Hill & Hupe, 2009, p. 2).

When implementing policies the first step is to find out what a policy is trying to achieve before attempting to examine its implementation (Hill & Hupe, 2009). However, according to Hill and Hupe it is often hard to distinguish between "policy outcomes" and "implementation output", because dependent variables may be either. Nevertheless, outcomes are not government actions, instead they are real results, actual things achieved, whether intended or not. To avoid the challenges of examining established policies' goal-achievement (outcomes) and instead focus of the implementation output, Hill and Hupe suggest researchers to search for behavioural output variables. As mentioned earlier, outcomes do not have to be dependent of government actions; instead the outcome can be affected by other factors which have nothing to do with the governmental policy. However, implementation can be carried out in a good way even though there are no specific governmental policies for achieving concrete goals. This can be characterised as "symbolic policy" where governments have noticed a problem but have no intention to solve it. Another problem with investigating outcomes lays in the assessment of whether or not the changes which have been carried out by using a new policy really leads to better outcomes as well as, if the expectations of the target group are the same as those implementing changes. Instead of giving what the target group needs, there may instead be an intention to control behaviours (ibid.).

When examining the possibility for implementing a policy in different context, several factors have been found which may hinder or frame the implementation. Prior to the 1970s, implementation was not problematised and in the beginning of the 1960s implementation research was mostly based on top-down models which mostly focused on the policy process up to the level of decision (Johansson, 2004; 2010; Nilsen, 2010). Nevertheless, in the 1970s, researchers realised that the actual implementation carried out by officials was problematic. Empirical implementation studies show that successful implementation requires clear formulated goals and strategies as well as knowledge of the cause-effect relation, competent organisational management and support from important groups of interest such as politicians, officials and target groups. Enough resources such as education and incitements, a control system for follow-ups and to measure effectiveness as well as provide feedback to the management were also important (Johansson, 2010; 2004).

Within the field of public administration, Pressman and Wildavsky (1984) carried out one of the most important policy implementation studies at the time to find out if successful implementation depends upon linkages between local organisations and agencies. In other words, what is happening between political intentions and expected local actions? The study show that even though participants, in the seemingly simple and ready-funded plan, agreed on the basic idea that working opportunities must be arranged for unemployed minorities in Oakland, the program ran into many obstacles. The simple and funded plan evolved into a complex program with many complicated decision situations and with numerous stakeholders involved with different perspectives. Some hinders for successful implementation was noticed such as weak leadership, a dependence on others who did not experience the program as particularly important, the program was not consistent with laws and regulations and other programs were preferred.

Guldbrandsson (2007) also note hardships when examining an implementation of a plan to reduce overweight among children and adults in a Swedish county. Obstacles to the implementation of the plan were lack of local roots (presence), participation, clarity and resources. There were also experiences of low priority, lack of commitment to implementation in practice and great distance between levels. According to Pressman and Wildavsky (1984) successful outcomes may be expected where there are close links, and shortfall in desired outcomes will be experienced where the links are missing. Hargrove (1975) means the interaction between policy and action as well as between different roles of decision-makers and implementers were ignored for a long time within political sciences, and calls it a missing link. The missing link can depend on different management cultures and as Thomas and Thomas (2002) note, that government organisations have a top-

down management culture, in contrast to for example NGOs, which often have a bottom-up approach. The differences between the means of implementations used by these two management cultures not only affect the target group's opportunities for participation, but also raise questions about the role of government and civil society as service providers.

When the interest of policy implementation reached Europe from the United States the condition of receivers were more noticed and led to a development of bottom-up models which emphasised policy as actions instead of decision (Nilsen, 2010). The founding father of the bottom-up perspective, who challenged the top-down model in the 1980s, is Michael Lipsky (1980). He analyses the behaviour of front-line staff in policy delivery agencies, so called street-level bureaucrats, and argues that the decisions of street-level bureaucrats, the routines they establish, and the devices they invent to cope with uncertainties and work pressures, effectively become the public policies they carry out. Other important researchers within the bottom-up perspective is Hjern and Porter (1981) who stresses the cooperation and interaction between organisations and agencies to put policy into effect, referring to the concept of implementation structures.

The top-down and bottom-up perspectives is often debated and many use a mixed perspective in their empirical works. Such researchers focus on the intentions behind a policy rather than on the policy just as a text. For two contributors within this perspective, Lane (1987) and Rothstein (1998), trust is a central aspect. Lane (1987) proclaims the combination of trust and responsibility in any implementation meanwhile Rothstein (1998) more focus on legitimacy and claims that implementation is likely to fail if citizens do not trust in the institutions implementing the policies. Although a top-down or a bottom-up perspective has aspects of truth which is relevant in any implementation situation, Matland (1995) argues that under certain conditions it is most appropriate to hold on to one of them.

Implementation research has continuously been linked to other fields such as the field of New Public Management in the 1990s where the implementation problem is defined as a management problem and to the area of public administration in the decennium of 2000 by the concept of governance. However, when giving the concept of implementation the synonymous of change there is also a need to take a closer look at an idea, policy or concept's dispersal and its adjustment to fit in a new context.

The Spread and Translation of Ideas, Policies or Concepts

For ideas to be spread and fit into a new context in order to improve existing services, adaptation to new contexts are necessary, not least because those who receive the idea should be sensitive to the service users' need. CBR is an idea which

has been spread and implemented differently between and within countries (see Asindua, 2002; Miles, 1996; Vanneste, 2004), and its success and usefulness is proclaimed to depend on its ability to take cultural aspects into consideration (Lightfoot, 2004). However, the way ideas, policies, methods or concepts spread between different operators and organisations have not been problematised in the early implementation research and no direct fruitful models have been available to examine it. However, Scandinavian researchers within the field of neo-institutionalism, which developed in the 1990s, have further developed how ideas and concepts can be adapted and adjusted (Czarniawska & Sevon, 1996; Johansson, 2004). They are critical to how earlier research, carried out within different fields, have explained the spread of ideas in terms of the dominant concept of diffusion (Czarniawska & Joerges, 1996; Johansson, 2002). According to Johansson (2004) diffusion seems to be used in the early implementation research as well. Diffusion suggests that ideas' internal properties are the energy behind the spread. Setbacks in the spread can only be explained by sluggish intellect and lack of channel capacity (Johansson, 2004).

Too some researchers (Forsell & Jansson, 2000) within the Swedish neo-institutionalism it is needed to study the spread of ideas as a transport process where transport operators are active to carry the idea further in the field and where the idea constantly changes when being transferred between them, rather than a transfer of unchangeable performances between actors as the model of diffusion proclaim. This transformation or translation process can be viewed within the development of CBR (see Joint Position Paper, 1994; 2004; WHO, 2007) when leaving a medical focus for a more comprehensive approach to change the life situation for individuals with disabilities (Lang, 2011; Lysack & Kaufert, 1994; Thomas & Thomas, 2002).

In order to understand the process of changes which happens when ideas or policies travel, the central concept of *translation* (Czarniawska, 2005; Czarniawska & Sevon, 1996; Grape et al., 2006), borrowed from sociologists as Latour (1986) and Callon (1986), is used in this study. In the model of translation the receivers of the idea is in centre and are therefore also seen as not only transporters but also transformers of the idea, where the ideas further survival depends on the transporters possibility to adjust the concept after their own interest (Johansson, 2002; 2004). In other words, with diffusion the spread of the idea is seen more as a pure copying, whereas translation theorists view it as a constantly changing, collective creation (Czarniawska, 2005; Grape et al., 2006). Ideas that travel are also exposed to friction and resistance, which result in changes to the idea. The concept of diffusion regards these changes as hindrances to be avoided, while the concept of translation views them as unavoidable yet enriching to the idea (Czarniawska, 2005).

Czarniawska and Joerges (1996) has formulated a model expressing the process of change, of how ideas travel and are accepted and incorporated by organisations

or individuals within an organisational field. An organisational field occurs when several organisations with the same goal interact and carry out similar work with a shared frame of reference (DiMaggio & Powell, 1983). Vocational rehabilitation for people with disabilities represents one field in which many organisational actors carry out various parts of the same working process to serve the same target group (Lindqvist, 1998). Erlingsdóttir (1999), among others, subsequently used the model by Czarniawska and Joerges to study the travel of two ideas concerned with quality improvement in the health care sector. The model outlines the various steps involved when an idea travels across space and time.

The first step in the model is called *decoupling*, referring to the moment of inspiration when an idea from one time or place is picked up by an individual or organisation in another time or place (Erlingsdóttir, 1999). The decoupling can also be explained by Giddens' (1991) concept of disembedding, i.e., the idea first has to be *disembedded* to travel. Røvik (2008) calls this episode of an idea's journey *separation*. By separation, Røvik means to give an ideological and linguistic representation to a localised, concrete praxis within an organisation.

Separation is the first phase of two within Røvik's decontextualisation of transferred and translated ideas. The second phase is called *packeting*, a process in which the idea is removed from its original context and transformed into an idea that is less dependent on that context and thus more transferrable to other contexts. The more a practice is connected to its context the less transferrable and translatable it is. This second phase may also be referred to as *packing*, in which an idea is translated into a prototype, model or code that can be further presented in the field (Erlingsdóttir, 1999). For an idea to be able to travel it must first be transformed into an object, for example, a picture or text (Grape et al., 2006).

Only as a picture or text can it leave the local context and enter the translocal arena. The perspective of neo-institutionalism argues that NGOs, governments and other organisations around the world which provide services may be attracted to various ideas that are shared by others in a translocal arena (Johansson, 2002). According to Jonsson (2006), translocality occurs when an idea is shared or adopted by like-minded individuals or organisations across geographical and cultural divides. However, how an idea or policy is followed depends on the standardisation of an idea i.e. the content of the idea and how it was packed. Standards are a type of rules that are optional and it is in the recipients' own interest to follow them (Johansson, 2006) when for example promoting new approaches to rehabilitation.

The third step in the model of ideas, *the travelling idea*, is reached when the idea is presented further in the field (Erlingsdóttir, 1999). The fourth step, the *turnover to local action*, occurs when the model meets the existing practices in the context in which it will be used (Erlingsdóttir, 1999). In the final step the idea becomes *reembedded*. At this stage of the process the idea has a receiver and, if judged successful, is on its way to becoming an institution—which will need to be

decoupled again to be able to travel (Erlingsdóttir, 1999). Too Giddens (1991), the idea's abstract character becomes embedded again, filled with the local actor's specific context when it meets its receiver. From there the transformed idea is put into action. Once a transformation has taken place and the idea has been converted to an act that is repeated and has a normative explanation, an institution has been created (Czarniawska, 2005). Berger and Luckmann (1966, p. 72) made this point when they observed that "institutionalisation occurs whenever there is a reciprocal typification of habitualised actions by types of actors. Put differently, any such typification is an institution". Gulbrandsson (2009) state, a method is institutionalised when taken for granted no matter which political changes occurs, reorganisations in an organisation and changes in workforce.

Similar to the model of travelling ideas, Said (1983) identifies four stages that describe how an idea or theory travels. There is first a point of origin, where the idea was born and entered discourse, followed by a distance transfer. Here the idea moves through a passage with pressure from various contexts to another time and place, where it will receive a new status. Thirdly, there is a set of conditions that is bound to the degree of acceptance the idea receives. Resistance will confront the idea and create possibilities for tolerance or introduction, even if the idea appears to be alien. Fourthly, the idea has now partly or fully been incorporated or accommodated, transformed by its new position or uses in time and place. Thus the original idea can never be identical with the idea that has entered a new place, whether it has travelled a short or long distance (Czarniawska, 2005; Forssell & Jansson, 2000). Payne (2002) agrees that the importation and internal adaptation of an idea in order to adjust it to local conditions, often lead to the occurrence of new ideas.

How the translation of the idea in the local context occurs depends on the idea's content. If the content of the idea is abstract and unspecified it leaves considerable space for local interpreting. In contrast, if the idea has a fixed framework there is less room for interpretation (Erlingsdóttir, 1999; Grape et al., 2006; Payne, 2002). Thus adopting an idea from another context does not mean that an organisation must abandon its existing way of working; instead, it can transform and translate the idea to make it suitable for the local context. However, Sandström (2008) argues that implementing an idea that can compete and take hold in the world requires acceptance from various institutions, organisations and governments, and that collaborating networks must agree to collective action to achieve the aims of policy programs. Rowley and Gibbs (2008) support the need for cooperation, asserting that collective thinking and dialog are important tools in developing an organisation. To survive, "organisation are coming under increasing pressure not only to learn, change and adapt, but also to take actions that are ethically acceptable and sustainable, and which balance the interests of a range of different stakeholders" (Rowley & Gibbs, 2008, p. 357). Forssell and Jansson (2000) observe that although organisations in all sectors of society have plans of action, these

plans follow different systems of rules and have different relationships to their respective environments. Thus, for example, in some contexts identifying who provides social services may be a key consideration in understanding the organisational structure.

When an idea is taken from one context and introduced in a new organisation or field, the idea often lacks references to the new context. Only through social interpretation and the process and creation of meaning does an idea acquire certain marks that bind it to and make it known within a certain local context (Røvik, 2008). Røvik calls the process through which an idea is translated into the local context in time and space *registration*. He identifies two rules of registration: rules for localisation and rules for an idea's time mark. *Localisation* describes the process through which generalised ideas, which have only global points of reference when entering new fields, are adapted to local organisational contexts in a way that gives the idea more and more references to the local (ibid.). Czarniawska (2005) describes the process of localisation as when a global concept is the framework for the creation of a local identity. References to the local context may include a local understanding of problems as well as local places, authorities, actors, episodes that are bound to successes or failures, or earlier solutions to or experiences of problems within a field or organisation, as well as local emotions, conflicts and dimensions of interest. An idea's registration may be quite unplanned, as when a field or organisation rather spontaneously creates stories which gives an idea local reference, or planned, as when actors have a goal to develop (Røvik, 2008).

An idea implemented in a new field or organisation begins with no local history. Instead, the idea often has references to what is called global or international time, i.e. references to the ideas history outside the field or organisation in question. When contextualising an idea it is important to time mark it by giving the general idea a local past (history) as well as a local present and future. This is done through social interpretation and the process of creating meaning. Nevertheless, research shows that an idea's history often is explained as a solution to a problem found in a field or organisation. According to Røvik (2008) "this illustrates the complex cooperation which exists between a heavy international "timesignal", a current of ideas and the construction of the idea's local history" by people inside a local organisation (ibid., p. 260).

An idea can also be given a local future when it is incorporated into a plan of action and becomes part of the long-term plans of a field and/or organisation. Røvik (2008) notes that when an idea is marked and thereby registered in the local time, references from international and global history outside the field or organisation may become less important. However, even if an idea can be transformed to fit the local context, thus becoming less dependent on its international and global history, it is important for social and health care workers, fighting for social justice, to understand how the global issues can affect their

working conditions (Esteva & Prakash, 1994). Thus it is crucial to examine an idea's representation and registration when implementing a new idea.

Despite the potential for ideas to transcend the boundaries of a particular country or culture, a specific historical, socioeconomic and institutional context may also either help or hinder the implementation of a new idea. For example, DiMaggio and Powell (1983) note that professionals in a field, as well as the state itself, can exert a significant influence over the establishment of norms and the adoption of a particular idea or trend. The spread of ideas, policies or concepts are according to Powell and DiMaggio (1991) done by imitation, professionalism and restraint, and are described by the concept of institutional isomorphism i.e. regimentation as a necessary quest for legitimacy. Legitimacy is also important for organisations' survival, as Rowley and Gibbs (2008) also pointed out before. Organisations are for example forced to adapt to each other to survive, planning methods mimicked those organisations with less goal-oriented activities, and ideas becomes professionalised through involvement in education (Johansson et al., 2000). Whereby, one can ask if CBR is just a trend, an imitation, or a continuous model to stay.

Theoretical Framework

This chapter deals with some important theoretical aspects which will be used when analysing the data collected from interviews and documents, as well as when comparing and discussing the two countries implementation of CBR in the final chapter. To understand the structural context in which CBR was implemented, some theoretical assumptions of organisational fields, top-down and bottom-up structures and projects are used. When examining the process of implementing CBR, the concepts of translation and diffusion, and the ideas possibility to adapt to the local context are in focus. In an implementation process inputs should help a project to reach expected outputs, which is examined in the analysis as well. When searching for different factors which have influenced the implementation of CBR, the issue if CBR follows a trend, is an imitation, or is translated and there to stay, a theoretical perspective of power relations is used. However, in the last chapter of this dissertation, the theoretical aspects of translation, legitimacy and institutionalisation are discussed to answer how international ideas of social work can be implemented in different contexts.

CHAPTER 3

THE INSTITUTIONAL SETTINGS OF UGANDA AND SWEDEN

I have chosen to compare the countries of Uganda and Sweden in this study because they have very different institutional settings, yet both countries implemented CBR in the 1990s. Uganda and Sweden differ significantly in their socioeconomic development, participation in the world economy and the nature of their political systems. Uganda, with a life expectancy of 52 in 2008 (WHO, 2011) and a Gross Domestic Product per capita of \$16 in 2009 (World Bank, 2011), is considered a non-Western country. Sweden, with a life expectancy of 81 in 2008 (WHO, 2011) and a Gross Domestic Product per capita of \$406 in 2009 (World Bank, 2011), is considered a Western country.

The differences between the countries are also shown in the Human Development Index, which measures life expectancies at birth, mean years of schooling, expected years of schooling and gross national income per capita, and gives Sweden a ranking of nine and Uganda a ranking of 143 among 168 countries (UNDP, 2011). However, the terms used to categorise countries have been criticised as a legacy of imperialism and colonialism (Connell, 2007; Rattansi, 1997). Connell (2007) argues that the terms used to categorise countries express wealth, cultural influence and power disparities and grew from North American and European imperialism. According to Rwomire (2001), the terms have in particular served to create repressive stereotypes that represent Africa as a homogeneous socio-political block.

Uganda, like other non-Western countries and postcolonial formations, has been and remains today politically and economically influenced by former colonial powers and other industrialised nations through the conditions of "foreign aid", "debt management" and trade negotiations (Altbach & Kelly, 1984; Eriksson-Baaz, 2002). Sweden is not subject to such influences. Thörn et al. (1999) argue that even though Sweden was not directly involved in the colonial process as a coloniser, no country can be defined as neutral in relation to post-colonialism. "Despite the fact that Sweden did not participate directly in the colonisation process, the attempts to define and set boundaries for the "Swedish character" - and the way to regard other cultures - is analyzed in relation to the global process" (Thörn et al., 1999, s. 17). Holmberg (1994) regards Sweden as an imitator whose identification with Europe, the West, the White race and Christianity made them just as prejudiced as the colonising agencies from France, Britain and the Netherlands. However, Fanon says that man wherever from" have to move away from the inhuman voices of

their respective ancestors so that a genuine communication can be born” (Fanon, 2008, p. 206).

Social Welfare for People with Disabilities

The colonisation of Uganda by Great Britain (Hokenstad, Khinduka & Midgley, 1992) resulted in the economic, political and cultural exploitation of Ugandans by, among others, missionaries serving as agents for their home governments (Tiberondwa, 1998). The creation of education and rehabilitation centres for children with special needs can be traced back to this time (Ministry of Education and Sports, 1999; Tomasevski, 1999). The institutionalisation of services for children with disabilities inherited from colonialism created a distance between people with disabilities and their families and made people with disabilities “objects” for charity during the 1950s and 1960s (Kangere, 2003). The Ministry of Health (1999) point out, the rehabilitation system was influenced by a Western medical model of providing services to people with disabilities. However, rehabilitation services were not available for many people with disabilities in Uganda (ibid.), and according to Ojwang and Hartley (2002) institutional services were in 1989 seen by international experts as narrow, unsustainable and outdated.

In 1965, three years after Uganda gained its independence, the government in conjunction with the ILO established rehabilitation programs to help people with disabilities become independent and contribute to their country’s development (Keibanda, 1995). This recognition of the needs of people with disabilities resulted in a national vocational rehabilitation programme with focus on identifying people with disabilities and offering them job placement and vocational training. The government’s efforts on this issue were supplemented by the work of many volunteer organisations created for and by people with disabilities (Sengendo et al., 2000). This work, however, led the government to see these organisations as mainly responsible for disability issues (Ministry of Health, 1999).

Since 1986 the Ugandan government and the Norwegian Association of the Disabled (NAD) have cooperated in renovating and supporting many of the rehabilitation centres around Uganda, which now offer training in a variety of vocational skills (Keibanda, 1995). In 1987, the National Union of Disabled Persons of Uganda (NUDIPU) was created and its existence is considered synonymous with the growth of the disability movement in Uganda. NUDIPU is an umbrella organisation representing all disability groups in Uganda; as a result of its efforts the voices of people with disabilities started to be heard and policies that hindered disability rights in the country were challenged. “Nothing for us without us” is a general principle within NUDIPU, whose main aim is “to influence change in the provision of services to persons with disabilities in Uganda” (ILO, 2004, p. 12). To ensure full involvement for women, NUDIPU has also implemented a Gender and

Development programme. In 1992 a new strategy of rehabilitation called *community based rehabilitation* was introduced by the government and NAD (Baryayebwa, 2002; Claussen et al., 2005; Keibanda, 1995).

Sweden, on the other hand, has provided services to people with disabilities in institutions since the 1900s due to rapid industrialisation of the country. Before that, support for persons with disabilities was mainly the responsibility of the family. Sweden has a deeply rooted tradition of popular movements and many Swedes are members of associations and organisations, although those numbers are declining. However, this has been an important factor in the development of Sweden's disability policy. The first organisation for people with disabilities was founded in 1868 as Stockholm's association for the deaf. Today an umbrella organisation, The Swedish Disability Federation, which consists of 39 national disability organisations, serves as the voice of the Swedish disability movement within the government, the parliament and national authorities. The federation was established in 1942 and is involved in areas such as opinion formation and studies in politically important disability issues (HSO, 2011).

In the middle of the century, Sweden established a number of residential institutions for people with disabilities (Ericsson, 1999). In the 1960s a direct focus on children with disabilities and their families emerged due to the care-allowance for children who were disabled or had long-term illnesses. The need for economic support for these children was acknowledged at the same time women started to enter the labour market more seriously. From the values of normalisation and integration introduced in the 1960s and 1970s emerged a modern Swedish disability policy that was part of the general welfare system (Hugemark & Roman, 2007; Åkerström & Nilsson, 2004).

The golden years of edification of the 1960s (Bille, Andersson & Olow, 1992) saw the rapid development of re/habilitation programmes for children with disabilities as a result of the experience gained through rehabilitating military personnel after the Second World War. The 1970s, on the other hand, were "the years of integration" (Bille et al., 1992), where re/habilitation was informed by experiences from different occupational groups and children with disabilities were integrated into preschools and regular schools. During this time re/habilitation was coordinated at many places in the country, bringing together activities for children with mental impairments and children with disabilities. During this time many residential institutions were closed as a result of the dramatic change in the ongoing work to a community based approach (Ericsson, 1999). The 1980s became "the years of investigation" or "the years of development and research" (Bille et al., 1992), establishing re/habilitation with a focus on the development of knowledge and working methods (ibid.; Qvarsell & Torell, 2001). The Individual Service Program based on the International Classification of Impairment, Disability and

Handicaps theoretical definition of disability, became a popular model for the re/habilitation for children with disabilities and their families in the 1980s and 1990s. The aim of the Individual Service Program is “full participation, equality and extremely good quality of life for children, adolescents and adults who have injuries or disabilities and their families” (Sjögren, 1996, p. 16). To achieve these principles, a team is created around a specific child and their family, and professionals from diverse institutions participate. The family is present at all discussions and is involved in the planning and coordination of all services and support. The everyday environment of the child and the family is mapped, existing needs noted and service and support needs addressed (Larsson, 2001).

Other rehabilitations models occurring in Sweden in the beginning of the 1980s are two case management models: The assertive community treatment model (ACT) and the strengths model (Solomon, 1992). The models grew up independently of each other and occurred as a reaction to the de-institutionalisation of mental hospitals. Of these two rehabilitation models, the strength model is considered to have a greater emphasis on “the individual’s right of self-determination regarding his/her rehabilitation” (Marnetoft, 2000, p. 36). In 1994 another rehabilitation model entered in Sweden, the community based rehabilitation strategy, and introduced by a physiotherapist in two counties in a municipality in Sweden. The new model was financed by the county council with support from the National Board of Health and Welfare in Värmland (Hargö Granér, 1999).

In many non-Western countries as well as New Zealand, the USA and Australia, there is a trend of relating laws and policies concerning disability issues to the growth of the general social welfare system to increase the number of people with disabilities in the workforce and encourage work as an aim of rehabilitation. Europe, however, has had this ambition for a long time, supported by political principle declarations as well as legislation (Åberg, 1998). In Africa social welfare programmes were originally created during the 1950s and 1960s as a safety net for white workers (Dixon, 1987). In Uganda’s traditional welfare system, communities took care of their members through collective efforts (Manyire & Asingwire, 1998). According to Midgley (1997), non-Western countries primarily provide welfare through non-formal institutions (individuals’, families’ and communities’ own efforts to solve social problems and increase well-being). This is evident in Uganda, as in many African countries, where extended families provide retirement pensions, schools and other social services that Western governments typically provide from taxes (Black, Namwadda, Mugambe, Walugembe & Esanu, 1999).

Unlike Sweden, where the public sector dominates health care, social services and education (Swedish Industry, 2004), Uganda’s philanthropic institutions (including religious or international organisations, i.e., NGOs—which Midgley

(1997) identifies as the formal social welfare institution—have for over a century been an important provider of social services (Eade & Pearce, 2000). However, colonisation changed role of non-formal institutions, which were viewed as obstacles to the implementation of social policies and a modern system of administration. Technological changes and community urbanisation created difficult social problems and new social needs, requiring the creation of a more formal service system, which led to an increased need for the state to provide social services, instead of relying on non-formal institutions. As traditional social relations, social institutions and the country's economic situation changed, changes were necessary as well in the social provisions for both communities and individuals.

The first decade after Uganda's independence in 1962, the state was energetically involved in areas such as social development and implementation (Manyire & Asingwire, 1998). However, the social welfare system was later affected by the instability produced by war and other conflicts that caused the economy to collapse, the social sector to break down and expansion to halt, which left many communities without services (Nabuguzi, 1995). Today, social policies in Uganda are dictated by a "post welfare agenda" (Bennet, 1990) in which policy beneficiaries become active participants in an enabling environment created by limited state interventions (*ibid.*; Manyire & Asingwire, 1998).

Western influences can also be noted in the development of legislation in Uganda. Policies in areas such as CBR, health, education, representation, discriminatory practices and human rights relate to international guidelines established by the UN and the WHO (Millward, Ojwang, Carter & Hartley, 2005). Concerning legislation affecting people with disabilities, an example can be found in the UN standard rules from 1994, which outline a general policy that includes disability issues. This document subsequently influenced a 1999 Ministry of Health policy document in Uganda in which the government pledged to increase access to rehabilitation services at the district level for people with disabilities, following the promise of the 1995 Ugandan constitution that "the state shall take all practical measures to ensure the provision of basic medical services to the population" (Millward et al., 2005).

The Salamanca statement and framework for action on special needs education (UNESCO, 1994) is also found in the 1996 policy of Universal Primary Education, which gives children with disabilities priority in their family to receive an education, though the policy was not implemented until many years later due to Uganda's financial situation at that time (ILO, 2004; Millward et al., 2005). The Ugandan government has also instituted several laws containing articles or sections related to human rights and the equalisation of opportunities for people with disabilities (UN, 1994), including the Local Government Act of 1997, which

insured the representation of people with disabilities in all levels of government, as well as the Ugandan Constitution of 1995, the Children's Statute of 1996, the Parliamentary Elections Statute of 1996, the Traffic and Road Safety Act of 1998 and the Land Act of 1998 (Millward et al., 2005). Uganda also has a number of other national policies that address disability issues, including the Educational Assessment Resource Services Act, the Uganda Communication Act of 1997, the Uganda National Institute of Special Education Act of 1998, the Movement Act of 1998 and the Universities and Tertiary Institutions Act of 2001 (ILO, 2004).

In contrast to Uganda's recent efforts, the effort to establish a general social welfare system in Sweden was launched by Per Albin Hansson in the Swedish Parliament in 1928, as the idea of "The good Swedish Welfare State". Hansson advocated for a general welfare policy that included access to social services on equal terms and the right to basic economic security (Kerz, Werner & Wesser, 1995). Some researchers argue that the social insurance system in the Swedish welfare state was initiated as early as 1910 and was one of the first such systems established internationally (Edebalk, 1996). The social insurance system mainly provided pensions, occupational injury insurance, unemployment insurance and health insurance.

Initially, the system did not have any other international systems to serve as a model for its growth (Edebalk, 1996). However, some years later German reforms influenced the Swedish pension insurance, which the Swedish parliament introduced in 1913 as a general pension system—one of the first in the world to include a pension for people with disabilities unable to work (*ibid.*). Montan (1988) also points out that Sweden was influenced by the English safety system after the Second World War. The Swedish debate over medical and vocational rehabilitation was also influenced by the Anglo-Saxon, and especially English, interventions that resulted in the creation of the Disabled Persons Act in the UK in 1944 (Kerz et al., 1995; Montan, 1988).

What differentiated the Swedish system from the systems in Germany and England was for example the inclusion of the whole population. However, the key element in the social insurance system was the general health and occupational injury insurance (Edebalk, 1996). In 1955, the whole Swedish population was insured (Broberg, 1973; Classon, 1988; Kerz et al., 1995) and was thus guaranteed care by the Social Insurance Office if they were sick or injured at work (SOU, 1958, p. 17). Decisions concerning rehabilitation were included in the general insurance beginning in 1962; at this time rehabilitation treatment started to include persons who had previously worked but who had become disabled or fallen ill for a long time (Kerz et al., 1995).

Other important laws were established in Sweden in the 1980s. The National Plan of Action on Disability Issues of 1981 proclaimed that society had to change if

people with disabilities were to have equal access and participation in their communities (Socialdepartementet, 2000). In 1982, the Social Services Act emphasised that people with mental or physical impairments should be able to live as others and to be active in the community (Swedish Institute, 2000). The debate during the 1990s in Sweden concerned the quality of public services and care provided for people with disabilities, the right to full participation in society as well as the creation of individual rehabilitation plans (Larsson, 2001). In 1992 a rehabilitation reform took place based on recognition of the need for more effective rehabilitation; the importance of early, coordinated and active rehabilitation efforts; and the role of a better working environment in reducing work absences due to illness (SOU, 2003). Employers were given the responsibility of providing workers with vocational rehabilitation if needed (Marnetoft, 2000).

In 1993 the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) and the Compensation for Assistance Act (LASS) came to force (Swedish Institute, 2000; Wolmesjö & Zanderin, 2009). This disability reform was created for those with the most severe functional impairments through the introduction of special rights legislation (Palme et al., 2003). According to Hargö Granér (1999), the disability reform emphasised the perspectives of children and families and the individual's right to self-determination, influence and participation. Within the LSS, individual plans are established if the person requests them, and in cooperation with that person. The plans include decided and planned achievements and the municipality and the county council must inform each other about the content of the established plans. The established plan is reconsidered at least once a year (Wolmesjö & Zanderin, 2009). Other national policies and programmes that involve people with disabilities include the Health and Medical Services Act, the National Insurance Act and the Education Act (Swedish Institute, 2000).

The Effects of Economical Constraints

Despite the apparent legal advances for people with disabilities in the 1990s, Bille et al. (1992) describe the 1990s as "the decennium of shortages". In both Uganda and Sweden, people with disabilities are especially disadvantaged by the economic constraints affecting countries worldwide (Hooegeven, 2005; Palme et al., 2003). For example, in the 1990s in Sweden disability policies could not compensate for the deep economic recession, which relegated people with disabilities to the same situation at the end of the decade as they were in at the beginning. They faced financial difficulties due to extra expenses for drugs and municipal help, and higher costs for medical care, transportation, food, housing, etc. (Palme et al., 2003). These dynamics occurred in Uganda as well: Hooegeven (2005) notes that people with disabilities experience poverty to a greater extent

than the population at large as a result of discrimination, exclusion, a reduced capability to work and unequal access to education, health care and food.

However, financial shortages do not affect only people with disabilities themselves; they also affect families of children with disabilities (Palme et al., 2003) or families in which the head of the family has a disability. A 1992 estimate in Uganda, “shows that 27% of the urban dwellers are poor and that poverty amongst those who live in a household with a disabled head is much higher, 43%” (Hoogeveen, 2005, p. 3). Hartley, Ojwang, Baguwemu, Ddamulira and Chavuta (2004) says, the families of children with disabilities in Uganda lack funds for schooling, transportation, assistive devices, medical treatment and even basic needs. Hartley et al. (ibid.) also note that mothers in the eastern and central regions of Uganda are the practical helpers for disabled children, caring for their bodily needs; when a house is motherless the responsibility falls on the grandmother. Fathers, on the other hand, are seen as “gatekeepers” who control incoming and outgoing money, though this study found many fathers were absent (Hartley et al., 2004).

During the whole decade of 1990s in Sweden, relatives and friends to people with disabilities were constant practical helpers. The disability reform created in 1994 has meant a concentration of resources to those with greatest functional impairments and less help for people with disabilities with less need. Despite the fact that many other welfare areas declined, the welfare support for people with disabilities was relatively plentiful during this decade, creating the laws of LSS and LASS. However, during this period less well-equipped individuals—for example, people with mental disabilities, or children with disabilities and their caretakers—found it difficult to get their voices heard and their needs met (Palme et al., 2003). In 1998 the Disability Public Advocate in Sweden reported to the government that parents of children with disabilities have to fight for their rights as well as for needed services (Åkerström & Nilsson, 2004). The Disability Public Advocate has the task to combat discrimination and promote human rights, including investigating cases of discrimination based on disability. Some parents have argued that the concept of parents’ “normal responsibility” to their children is not well defined and has been used to decrease support for children with disabilities and their families (Socialstyrelsen, 2004).

The “decennium of shortages” (Bille et al., 1992), affecting the provision of services to people with disabilities in Sweden, was influenced by a flourishing neoliberal agenda. According to Ferguson, Lavalette and Mooney (2002), the global neoliberal agenda also affected many non-Western countries. The idea of neoliberalism in Uganda is, as Okuonzi (2004) state, a misguided strategy that favours the greedy market for multinationals in Western countries. Donor countries, especially the USA, advocate free-market policies but do not practice such policies

themselves, while donor countries stabilise and prioritise social welfare, poor countries concentrate on macroeconomic stability.

The Socioeconomic Context of Rehabilitation

Various reforms have been enacted to support the creation of the private sector, with the promise of improved social benefits and social services. However, these improvements have not materialised (Okuonzi, 2004). Instead, as Ferguson et al. (2002) argue, poverty reduction programmes (structural adjustment programmes) imposed by the World Bank, the International Monetary Fund, banks and governments have had a devastating impact on the provision of education, healthcare and other welfare services. Uganda, like many other African countries, has borrowed money from the World Bank and the International Development Association (Tomasevski, 1999) to manage the economically devastated country and try to reverse the breakdown of the social sector, which people in Uganda faced under presidents like Obote II and Idi Amin during two decades of tyranny, political unrest and war (Hokenstad et al., 1992).

The Ugandan government has often acknowledged its overdependence on external funding, which arises from low income generation. As a result of its heavy burden of debt, Uganda's economic development leans on foreign investments and exports; this constrains the distribution of available resources and makes education as well as health and social services dependent on donor support (Cannon, 2000; Tomasevski, 1999). A vicious circle is created when Uganda has to pay back past debts to rise further funding, which creates a new burden of debt (Tomasevski, 1999). In 1995 Uganda was the ninth largest recipient of US aid; in 1996-97 it was the second largest recipient of aid from the UK and Denmark's top aid recipient (Hearn, 1999).

In 1998 Uganda was the first highly-indebted country to receive debt relief. However, despite this the debt relief of \$43 million, transferred to poverty eradication and earmarked for primary education, has not been a considerable amount. Nevertheless, donors have shifted their aid from loans to grants (Tomasevski, 1999) and "contract out" work to NGOs, making them a useful resource for governments working with limited budgets. However, donors' conditional grants to NGOs, as implementers of programs, do not give policymakers much choice in using NGOs to implement programmes. With shrinking aid in general and an increased number of NGOs in Uganda, where resources for indigenous and Western NGOs have grown rapidly, there is a risk of service delivery being based on profit instead of service (Cannon, 2000). Other possible reasons for a failing social welfare are poverty, HIV/AIDS and conflicts. Even though Uganda faces a decline in the social welfare system and has shown no sustainable improvements (Ewald & Närman, 2001; Okuonzi, 2004), the country is

seen by many as experiencing rapid economic growth (Macrae, Zwi & Gilson, 1996; Okuonzi, 2004; Oloka-Onyango, 2000).

Sweden, on the other hand, which had quite stable economic growth from 1945 until late 1970 under the Social Democratic Party (Hedlund, 2004), showed clear signs of change in 1989, after trying to resist a more particularistic/selective characteristics of welfare pluralism for some time (Gould, 2001; Martin & Schumann, 1997). According to Dominelli (1999), neo-liberalism in Sweden argues against regulating the market, though it is heavily involved in regulating the public sector (i.e., service delivery and workforce). Professionals like social workers, nurses and doctors who are contracted to provide services to citizens are especially affected by such regulation.

In Sweden the economic crisis has also affected the welfare policy systems and the welfare of individuals dramatically (Bergmark & Palme, 2003; Bergmark, Thorslund & Lindberg, 2000; Palme et al., 2002). Sweden, which together with other Scandinavian countries was seen as a model welfare state with a high level of social inclusion, a low degree of inequality, high economic growth, and a high level of participation in the labour force (Burkitt & Whyman, 1994; Palme et al., 2002), suddenly faced an economic crisis in the 1990s that led to unemployment and budget shortfalls (Palme et al., 2002). The result was fewer resources for various social services and less generous compensation levels in virtually all social policy areas (Bergmark & Palme, 2003). In particular, immigrants, single mothers, young adults and families with children were disadvantaged during the 1990s (Palme et al., 2002).

The decade of the 1990s also marked a worldwide period of greater decentralisation as a way to scatter power and “to bring representative governance closer to citizens” and to the services carried out (Akin, Hutchinson & Strumpf, 2005, p. 1418; Burkitt & Whyman, 1994; Palme et al., 2002; Peat, 1997). Bitarabeho (2003) note that democratic decentralisation in Uganda was adopted “to improve systems of governance and foster economic growth especially in rural areas, both of which are essential to eradicate poverty” (Bitarabeho, 2003, p. 2). Another reason for decentralisation, as Akin et al. (2005) point out, was dissatisfaction with the centralised public services provided.

According to NUDIPU (2004), the decentralised policy structures in Uganda were formulated to increase involvement of people with disabilities and their parents. The policy relies on a hierarchy of councils and committees which have the important task of examining the needs of their village (Local Council I), parish (LC II), sub-county (LC III), county (LC IV) and district (LC V). Each local council is headed by a chairperson. The committees within the local councils have areas of responsibility that include education, security and gender, finance, and work and transportation (Golola, 2001). Findings at the village level should be presented by

LC I representatives to LC II and so on until reaching the district level. A report of issues raised at the various levels should then be compiled and finally presented to the government (NUDIPU, 2004). This bottom-up policy structure could favour people with disabilities and their families by providing them with a greater voice in identifying needed services. In Sweden, on the other hand, it is the municipality who takes care of issues concerning health and social care, elderly, disability and education. At the County Council, health and re/habilitation issues are handled.

In ways similar to Uganda, Sweden has decentralised such services as health care and special needs education, transferring the responsibility from the county council at regional level to the municipalities at the local level (Hargö Granér, 1999; Wolmesjö & Zanderin, 2009). The Ministry of Health and Social Affairs at the national level also has the important duty of following up and evaluating the services to find out if they correspond with the goals established by the central government (WHO, 1996). However, it seems that decentralisation worldwide has started to change the structures, not only by shifting power from the state to the communities, but also by decreasing the government's role as a service deliverer while increasing the private sector's influence. This is evident in Sweden, where private, social and medical services have been established and where counties' and local authorities' responsibility for providing services has increased (Lilja, Månsson, Jahlenius & Sacco-Peterson, 2003). Similar changes can be seen in Uganda, where decentralisation has shifted power from the government to communities (Okuonzi, 2004; Golola, 2001) and where NGOs have taken on greater responsibility for providing social services (Eade & Pearce, 2000; Midgley, 1997).

Institutional Similarities/Differences between the Countries

While the institutional settings of Uganda and Sweden differ in many significant ways, some similarities can also be found, though with a more explicit character of power and force in Uganda. Uganda's social welfare has been affected by a colonial past, by a continuing neoliberal agenda and postcolonial era that may maintain only a weak welfare system for its citizens. In contrast to Uganda, Sweden has a strong welfare system that serves its citizens and is not affected by a colonial past—nor, for that matter, is it influenced by the neoliberal agenda to the same degree as Uganda. Nevertheless, both countries' social welfare systems are influenced by foreign countries. In Uganda, services to people with disabilities have followed Western development and have been influenced by such international organisations as ILO and NAD, among others. In Sweden, on the other hand, some parts of the general social welfare system, and specifically the Swedish social insurance system, have been influenced by the organisation of services in other countries such as Germany and the UK, though to a much lesser extent than the international influences upon Uganda.

To provide social welfare to its citizens Uganda relies much more heavily than Sweden on NGOs. Moreover, while external funders form a pillar of the state's social welfare system in Uganda, the responsibility for social welfare in Sweden is contracted out by the state to county councils and municipalities. The judicial system in Uganda is weak compared to Sweden, which has a strong, well established legal welfare regime in which laws and policies protecting people with disabilities were institutionalised much earlier than in Uganda. Further, only two methods of rehabilitation, institutional rehabilitation and CBR, are used in Uganda, whereas in Sweden several methods including individual service program, assertive community treatment, the strength model and CBR have been used to improve services for people with disabilities. These differences result from both the laws and policies implemented over the years in each country and from the greater access to knowledge and availability of technology in Sweden compared to Uganda.

Nevertheless, both Uganda and Sweden have been influenced by the WHO's directive to involve people with disabilities and their families in re/habilitation services. Chapter one highlighted the WHO's directive to all governments to implement CBR. In Uganda, clear signs of involving people with disabilities and their families in service provision were seen in the 1990s through CBR. In contrast, Sweden has been involving people with disabilities and their families in service provision for a longer period of time, yet not using the name of CBR to define the re/habilitation services until 1994. CBR was implemented during the same period in Uganda and Sweden's different institutional contexts. This provides an opportunity to compare how different contexts can influence an international idea for social work practice at a time when the welfare state retreats and civil society have a stronger role in service provision.

Neoliberal Revival of Civil Society

According to Martin and Schumann (1997) the state as a provider of social welfare services has retreated giving the private, informal and volunteer sector a bigger task and more responsibility. This shift occurred as a result of the increase of neoliberal political influences since the 1980s, supported by leading politicians (Jackson, 2010) such as Margret Thatcher in Britain and Ronald Reagan in the USA (Wallerstein, 2003) and practiced by the World Bank, the World Trade Organisation and the International Monetary Fund with the expectation that everyone would benefit from them. Such organisations believe that social problems, including social exclusion and poverty, will be solved by integrating low-income groups in the labour market, and thus encourage the privatisation of health, educational and welfare services as well as enforcing more rigorous criteria to qualify for welfare services (Strier, Surkis & Brian, 2008).

Nevertheless, the neoliberal agenda has been criticised by many who say that rather than benefitting the less fortunate, it has only increased inequality (Dominelli, 1999; Ferguson, 2004; Sewpaul, 2006; Smith, 2008). Moreover, globalisation has also opened the provision of welfare services to new markets, enabling worldwide financial corporations and individual private entrepreneurs to invest in the public sector (Dominelli, 1999). Many social policymakers now believe that a mix of welfare providers is needed, comprised of the state as well as voluntary organisations, rather than placing the responsibility for welfare entirely in the hands of one or the other.

During the 1990s, the new societal approach to organising collective action and overcoming economic and social problems gained strength. By emphasising a civil society, social progress could be achieved and the consequences of a failing state and market could be addressed. According to Edwards (2004), past years have been marked by too much state intervention and an overreliance on the market. Civil society, a term that has been debated for centuries (Pollock, 2001; Whaites, 2000), is sometimes along with the state and the market seen as the third sectors (Edwards, 2004). Even though the concept of civil society has been questioned for a long time, only in the past ten years has civil society become of more international interest due to the fall of communism, the rise of democracy, the failure of past economic models and a rapid increase in the number of NGOs, as well as an urgent need to secure and cooperate in an increasingly insecure world (Edwards, 2004).

Lavalette and Ferguson (2007) argue that both in the UK and across much of the developed world, civil society is used to mask an ongoing project of privatising state welfare provision. Many recent debates about the definition of civil society revolve around who should be counted in and who should not. However, this is a very complex issue that depends largely on who defines it. Edwards (2004) explains that civil society may be seen as a specific product of the nation state and capitalism. A product articulated differently in all countries and stages of development because of history and context, expressing the collective life of individuals.

The meaning of civil society in non-Western countries differs from that of Western countries, because of their weak market economy and because many of these countries were colonial creations (Edwards, 2004). Civil society organisations are seen as key sources of mobilisation and resistance to the impact of global neo-liberalism, imperialist war and the dependency relations created by debt, argue Lavalette and Ferguson (2007). The idea of civil society was visible in Africa in the mid-1980s, following the idea's revival in Europe (Comaroff & Comaroff, 1999). Intellectuals in South Africa, Latin America and Eastern Europe saw civil society as a form of resistance against an overbearing or totalitarian state that had invaded social life to such an extent that the vast majority of population was effectively

excluded from political life and economic power. Civil society was seen as a concept that could mobilise people against an unjust, corrupt and unequal society (Lavalette & Ferguson, 2007).

Researchers like Smith, Hegel and Tocqueville define civil society as a concept including a surplus of institutions outside the state (Alexander, 1998). According to Marx's theory of industrial capitalism between 1842 and 1845, civil society is a sphere of purely private interest working as a structure, only consisting of markets, the groups formed by markets, and states. In the middle of the nineteenth century the interest in civil society faded away and attention was directed entirely towards the state (ibid.). For example, research on the welfare system of Nordic countries did not concentrate on civil society. The golden years of the Swedish welfare system in the 1970s viewed the voluntary sector as an idea whose time had passed and whose work was best taken over by professionals.

However, the end of the 1980s witnessed a general reawakening of interest in civil society, particularly among people working for socially directed voluntary organisations (Svedberg, 2005). Civil society became a sphere divided and independent from the state, the market and other social spheres (Alexander, 1998). Alexander (1997) defines the sphere of civil society as follows:

Civil society should be conceptualised as a realm of solidarity, a 'we-ness' that simultaneously affirms the sanctity of the individual and these individuals' obligations to the collectivity. The solidarity sphere, in principle and in practice, can be differentiated not only from markets and states but from such other noncivil spheres as religion, family and science. (Alexander, 1997, p. 115)

Kamali (2001) means, defining civil society as a purely political relationship between the state and the people neglects the concept of social solidarity. Kamali argues that Alexander is mistaken in excluding religion when discussing the concept of civil society, because religion is politically, economically and culturally institutionalised in some countries.

However, some definitions of civil society include the family as a social solidarity partner (Cohen & Arato, 1992; DENIVA¹, 2006; Svedberg, 2005). Cohen

¹ DENIVA is the Development Network of Indigenous Voluntary Associations, a Ugandan organisation which as part of an international initiative composed a document for the Civil Society Index (CSI) project, coordinated by CIVICUS: World Alliance for Citizen Participation. "The CSI assesses the state of civil society in more than 50 countries around the world, in order to 'enhance the strength and sustainability of civil society and its contribution to positive social change'" (DENIVA, 2006, p. 1).

and Arato (1992) define civil society as a sphere of social interaction between economy and state, especially including the family, social movements, the voluntary associations, and several forms of public communication. Svedberg (2005) has a similar definition in which civil society may include the informal achievements of friends, colleagues, relatives and neighbours who do not live together, as well as encompassing the activities of voluntary organisations. The Civil Society Index Report for Uganda, which focuses on civil society's sustainability, strength and contribution to positive social change, defines civil society as "the space between family/households, state and the private sector, [which] is characterised by its emphasis/focus on the common good of the society" (DENIVA, 2006, p. 1). Civil society is thus used in various ways and, as Brunell and Randell (2008) argue, should be accepted as an unclear and imprecise concept. If civil society is defined too strictly it will be hard to understand how people mobilise themselves voluntarily to solve problems the state for several reasons do not can or want to solve for individuals.

Nevertheless, as Edwards (2004) say, civil society is something to strive for: a good society that provides a method of non-state action and a public sphere in which discussions and negotiations of how to reach social goals in a strategic way are important. The public sphere, as explicated by Habermas, has the potential for social integration based on communication rather than domination, where the debate over the common good is influenced by "the 'free space' of society rather than a state-centred approach to public authority or political development" (Calhoun, 1992, p. 319). Edwards (2004) argues that when we face each other in dialogue and discussion, and turn away from our separate affairs to face common problems, publics are formed. He also states that the public sphere within civil societies becomes an arena for institutional and associational collaboration.

In this dissertation, civil society is defined as a public, unified and social sphere comprised of the family, state and voluntary activities. In this sphere collaboration occurs in varying degrees as groups work together for the common good. Nevertheless, the complexity of civil society in each country needs to be considered in discussions of a given civil society's role and functions. For example, in Uganda the civil society has a larger role when it comes to providing social services to citizens than the state has, in contrast to Sweden where the state has the main responsibility. Such differences affect social workers' ways of working in different countries as well. Social workers engage in the discourse of civil society under the assumption that it will allow them "to work free from the restrictions placed on us by the state, and to work positively alongside many of the campaigning, voluntary and non-governmental organisations that we come across in our practice" (Lavalette & Ferguson, 2007, p. 447). However, engaging in civil society does not mean being free from restrictions, rather an opportunity to create fruitful

communication and understanding of each other's limits and strengths, as well as an opportunity to work together with the once using the services.

Lavalette and Ferguson (2007) note that social workers should treat the concept of civil society with care because it can advance the neo-liberal agenda. According to Wright Nielsen (2009) too much reliance on civil society with empowerment as a political strategy can undermine the responsibility of the welfare state. Though the concept of civil society may be used to broaden opportunities for different types of organisations to have a say in service delivery, it may also be used to undermine the state health and welfare service provision for all (Lavalette & Ferguson, 2007).

CHAPTER 4

METHOD AND METHODOLOGICAL CONSIDERATIONS

This chapter discusses the methodological approach used in this study. Since one of the objectives of this study is to compare the implementation of CBR in Uganda and Sweden, the first part of this chapter discusses the comparative methodology approach. The second part describes the method used for data collection and presents a study design that shows the different levels of the study. The third part of the chapter describes the selection of CBR projects and the interviewees in the study. The fourth section describes the process of analysis, and the chapter concludes with a discussion of ethical considerations and their implications for the study.

A Comparative Method

Studying the similarities and differences between at least two social phenomena requires a comparative social scientific approach. For example, comparing various political systems, countries, or organisations illuminates the structures behind them, the forces that drive them and their relationship to one other (Denk, 2002). According to Denk there are three different types of comparative studies: descriptive, explanatory, and predictive. Descriptive studies depict incidents or objects for the purpose of comparing them, while explanatory studies go a step further to not only portray situations but also to explain why they look like they do. Explanatory studies draw on theory to explicate prior or current situations. The present study utilises these two types of studies. The third type, predictive studies, forecast future situations. Carrying out a predictive study requires advanced theories and analysis and this method is not included in this study.

The study of one particular aspect of two countries comprises what Denk (2002) calls a *focused comparative study*, which aims to delve deeply into a limited number of factors in a limited number of countries. For the purposes of this dissertation, the kind of focused comparative study used will be the *most different systems design*. Denk (2002) identifies this design as a useful method for comparative studies of countries that are different in most respects, yet which have similar outcomes in at least one respect; the method thus seeks to explain a similarity between countries that are otherwise different. This method is appropriate for this study because Sweden and Uganda provide, as mentioned earlier, very different contexts but share the commonality of their implementation of CBR.

There are diverse opinions about how appropriate it is to compare contrasting countries with different socioeconomic, political, cultural structures. However, comparing two vastly different countries is not without problems. Cochrane, Clarke, and Gewirtz (2001) note the difficulty of understanding social and political systems when similar terms may be interpreted differently in the two countries under comparison. Hofstede (1984) points out the importance of inspecting these different interpretations to achieve a high level of functional equivalence. With this in mind, it is crucial to examine how the social welfare system, and especially the provision of rehabilitation services, is expressed in the two countries to identify how each country's system may affect the implementation of CBR.

Furthermore, there is a risk that the researcher's home country may be taken as a norm. However, according to Dogan and Pelassy (1990), a contrasting comparison may lessen this risk by providing an understanding of processes, definitions, and recognised parts of the issue under study. It might also show certain contextual variables that influence the similarities or differences between the CBR projects as well as explore its sustainability, the cooperation between CBR and other re/habilitation services, and CBR's implementation into existing re/habilitation services for children with disabilities. Overemphasising the differences between Uganda and Sweden would make comparison impossible and prevent knowledge from being shared across cultures, as Cochrane et al. (2001) also points out. This dissertation employs a comparative approach to explore how two very different contexts have implemented the same idea, namely CBR.

A Qualitative Approach and Study Design

In this dissertation a qualitative research method was chosen to examine how an idea travels, how it has been received in two very different contexts, and how those contexts have influenced the implementation of CBR. This case study of CBR in Uganda and Sweden draws on the scholarly literature as well as on semi-structured interviews with professionals within the field of disability and the parents of children with disabilities. Using a qualitative research method enabled the researcher to gather the information needed and at the same time observe the respondents' emotions in response to their involvement in the CBR project. Through the initial and follow-up questions presented in the interviews, the respondents had a chance to develop thoughts and remember opinions and feelings that might otherwise be forgotten from the time of their involvement in the CBR project.

This study requires examining the concept of CBR on various levels. According to Jonsson (2006), an idea can be studied on five different levels: the translocal, mega, macro, mesa, and micro levels. An overview of the levels in relation to this study can be found in Table 1. The first two levels address the idea of CBR in

general. The content of the idea is studied at the *translocal* level, which, according to Jonsson, focuses on the idea itself and not on its acceptance or establishment. On the *mega* level the focus is on the initial spread of the idea globally. These two levels are described in chapter one and provide knowledge of how the idea of CBR is decoupled, packed, and able to travel in space and time (Erlingsdóttir, 1999). To capture this understanding, relevant literature has been studied. However, although these levels provide a background and explanation for CBR and its context, this was not carried out as a first step in the research. Instead it has developed, as the structure of the monograph has become clearer, alongside carrying out interviews.

The three remaining study levels are explored and analysed in chapter five and six. On the *macro* level, document studies and informant interviews has highlighted the initial spread and translation of CBR to Uganda and Sweden, exploring such background information as who initiated CBR and the intention behind introducing the idea. The two other levels—*mesa* and *micro*—examine the process through which CBR is turned over to local action (Erlingsdóttir, 1999). At these levels the idea of CBR meets the existing practices in the location where it gets a receiver, is to be translated and implemented, and, if judged successful, is subsequently institutionalised. To capture this, relevant literature and documents were studied and interviews were carried out. At the *mesa* level the focus is on professionals' reception of CBR, how they experience the idea, and how the idea were translated and implemented. The *micro* level focuses on the reception of CBR by parents of children with disabilities, how they experience CBR, their involvement, and the support they receive from CBR. The study design provided a structure for following the idea from its origin to the countries' reception of CBR.

Table 1. Study Design: study levels, empirical focus, data collection, and guiding questions

Study levels	<i>Translocal</i> →	<i>Mega</i> →	<i>Macro</i> →	<i>Mesa</i> →	<i>Micro</i>
Empirical focus	The idea of CBR	Initial spread globally	Initial spread and translation of CBR to Uganda and Sweden	Local reception of CBR among professionals in Bushenyi and Värmland	Local reception of CBR among Parents of children with disabilities' in Bushenyi and Värmland
Data collection	Literature studies	Literature studies	Document studies Informant interviews	Interviews with respondents (professionals)	Interviews with respondents (parents of children with disabilities)
Guiding questions	What does CBR consist of?	Which countries received CBR? How is CBR evaluated by researchers globally?	Who initiated CBR? The intention behind CBR?	How was CBR translated in Bushenyi? How was CBR implemented? How did professionals experience CBR?	How was parent's involvement in CBR? Which support did the parents of children with disabilities receive from CBR? How did they experience support from CBR?

Sampling and the Data Collection Process

Before collecting the data through interviews, there were several decisions to consider. First, which CBR projects should be included in the study? Second, who should be interviewed? Third and finally, which tools should be used to collect data?

Why Bushenyi and Värmland?

When it came to determining which CBR projects in Uganda and Sweden to include in the study, some difficulties had to be solved and some criteria established. First, the selected projects would run for about the same time period. The project in Sweden ran from 1994 and 1998 and was situated in a sparsely

populated region of Sweden. To compare this with a similar project in Uganda, the Ugandan CBR project should also run approximately the same period of time. However, a project that was started around 1994 could also be considered appropriate because of having approximately the same time frame. It was also important that the project included children with disabilities.

CBR in Uganda started as a national programme with pilot projects in three districts. The project chosen for the study ran from 1992 and 1998 and was the first CBR project introduced in Uganda, which matched very well with the Swedish CBR project, which in 1994 was the first project in Sweden. By identifying these projects as the focus of the study, the research area in the two countries was limited to two provinces, Bushenyi in Uganda and Värmland in Sweden, rather than focusing on the entire countries. In 2002 Bushenyi had a population of 731,392 (UBOS, 2006) in an area of 4,292 square meters (UBOS, 2010). In contrast, in 2005 Värmland had 273,288 inhabitants in an area of 17,586 square meters (Regionfakta, 2010).

Bushenyi is a district divided into five counties: Igara, Sheema, Ruhinda, Buhweju, and Bunyaruguru. These, in turn, are divided into 29 sub-counties, including the two town councils in Igara and Sheema. The sub-counties are then divided into 162 parishes and 2034 villages (Kiberu & Karyeija, 2007-2012). In this dissertation, one of five counties (Igara) in the district of Bushenyi has been chosen as the focus of research. Igara was chosen because it was the county most exposed to the CBR program between 1992 and 1998. Igara itself consists of seven sub-counties, of which one sub-county was chosen when interviewing parents of children with disabilities. Värmland, the site of the CBR project in Sweden, is a province that is divided into 16 municipalities, of which two (Sunne and Torsby) were involved in the implementation of CBR.

Participants

As mentioned above, professionals within the field of disability and parents of children with disabilities in Uganda and Sweden were chosen to discuss various aspects of the implementation and maintenance of CBR. Informants and respondents were selected strategically using the snowball sampling method. Identifying participants for the study required not only finding individuals who could provide information, but also exploring the place where to find them, which is important when sampling (Flick, 2007; Sandelowski, 2000). Investigating the issue on a *macro* level implicated consulting with people involved in disability issues in Uganda, and establishing a contact at the Ministry of Gender, Labour and Social Development in Kampala. By consulting this contact, others were located who had knowledge of CBR's introduction in 1992. This contact resulted in an informant interview with one of the initiators of CBR in Uganda, a rehabilitation

officer likewise social worker, and also assisted in establishing another contact at the District Rehabilitation Office within the local government in Bushenyi. In Sweden the process was carried out in the same way. After reading the literature and consulting with a person at the Swedish disability organisation for international development cooperation, called Shia (Solidarity, Human Rights, Inclusion, and Accessibility), contact and an informant interview was established with a physiotherapist i.e. re/habilitation worker who introduced CBR to Sweden. From out of this contact several other respondents were located within the local government. The time frame between the interview in Uganda and the interview in Sweden was two years. This time lapse should not affect the participants' responses because the interview questions were based on what happened in the 1990s during the implementation of CBR.

From the Rehabilitation Officer in Bushenyi, Uganda, and from the initiator of CBR in Värmland, Sweden, further inquiries yielded connections to professionals at the *mesa* level. The professionals can be divided into head of departments and field workers. In Uganda four interviews were carried out, one with a rehabilitation officer at district level likewise a CDO when CBR was implemented in Bushenyi. Two field workers were also interviewed who served as CDOs during the time of CBRs entrance in the district Bushenyi. The CDOs in Uganda are often social workers. Other interviews held were with two teachers engaged in education for students' with disabilities, an accountant assistant handling school teachers' salaries, a social worker, a physiotherapist and three interviews with rehabilitation workers. Two of the rehabilitation workers were based at hospitals in Bushenyi and Mbarara, and one in an institution. Totally 12 interviews were made, however, other discussions were carried out with people involved in disabilities issues at national and local level in the country. In Sweden four interviews were carried out with respondents at the municipality level: a head of social work, and three school principals. Other interviews carried out on this level was with field workers such as two LSS-administrators, a social worker and a teacher engaged in education for students' with disabilities. At County Council level a rehabilitation worker likewise the initiator were interviewed. All respondents provided services for children with disabilities and their parents. Totally 12 interviews were made. One more professional rehabilitation worker, who was asked to participate, rejected to participate by claiming not knowing so much about CBR.

At the *micro* level, parents of children with disabilities were found through the Rehabilitation Office in Bushenyi, Uganda, and in Sweden through the initiator of CBR. A criterion for parents of children with disabilities to be selected for the study was a previous involvement in the CBR project. Families whose children had passed away were not included. In all, four interviews were carried out with

parents in Sweden in 2008 and four with parents in Uganda in 2009 (though during one interview in Uganda, both parents of a child with a disability were present). All parents who were asked in Uganda participated meanwhile in Sweden one parent reject participation because of personal difficulties faced during the time period of the project.

During the sampling of parents, differences occurred between the countries. In Sweden all but one of the parents interviewed were mothers; in Uganda all but one of the parents interviewed were fathers, not counting the woman who participated with her husband in one of the interviews. This difference probably relates to the cultural aspect of who is in charge of the family. In Uganda the man is the head of the family, responsible for caring financially for the family, while the mother takes care of the family's food, clothes, and cleanliness (Hartley et al., 2004). "Food" includes farming, bringing the food to the home, and preparing it for the table. According to the parents interviewed in Uganda, it is the woman who also has the responsibility for taking care of the children. In many parts of Uganda where few jobs are available, husbands are forced to leave their families to find work elsewhere, which can create difficulties in the homes and give women a heavy burden. Two of the three men interviewed were at some time during their children's upbringing, working elsewhere, but were available for interviews because now working in or close to home. Men were interviewed about CBR activities instead of women because they were the ones often attending CBR meetings. These gendered roles of men and women in Uganda, expressed by all the interviewed parents, may be the reason why so many men were interviewed in Uganda compared to Sweden.

In Sweden, some might assume that men and women are completely equal, given that Sweden is a country with higher level of equality than many other countries. However, this is in many aspects not the case, as reflected by the fact that only one of the parents interviewed for the study was a man. It was mostly mothers who seemed to be active in the CBR project, even though the fathers was included in CBR and for the first time had an opportunity to share their experiences of having a child with disabilities. This indicates that the mothers in Sweden are the voice of the family concerning their child with disability, while also working and having much of the responsibility at home. In Uganda, although the mother has the main responsibility of caring for a child with disabilities, it is the man who represents the voice of the family when it comes to their child with disabilities.

In both Uganda and Sweden more parents and professionals were involved in the CBR project than are represented in this study; thus the study cannot claim to represent all parents' or professionals' views of being involved in CBR. Moreover, it cannot claim to provide a complete picture of whether or not CBR is a good

service for parents and their children with disabilities in general. However, it can provide an understanding of how parents and professionals have been involved in the CBR project and the opportunities they've had to participate. It can also offer an understanding of how an international idea is implemented in two diverse contexts, identify the similarities and differences between the two countries' implementation of CBR, and explore how these dynamics affect the services created for children with disabilities and their parents.

Collecting data

Before collecting the data, different interview guides were created for each group of participants at the macro, mesa, and micro levels. The interview guide for initiators at the *macro* level was constructed based on the same themes in both countries. These themes are reception, obstacles and opportunities, and sustainability. However, the interview questions themselves differed between countries, as they were designed to elicit background information and broaden my understanding of the cultural context, which is important in carrying out a comparative approach.

Each country's interview guide for professionals at the *mesa* level was constructed around same themes of reception, translation, intentions, implementation, cooperation, obstacles and opportunities, and the sustainability of the CBR project. Here again, different interview questions were asked to broaden the understanding of the context. The aim of the interviews was to better understand the reception and translation of CBR in each country as well as to explore the intention and implementation of the strategy. They also provided information about how the strategy has been maintained.

The last interview guide for parents, at the *micro* level, in both countries was constructed around the themes of parents' contact with CBR, their understanding of the meaning of CBR, and the sustainability of CBR. As before, the questions asked differed to enlarge the understanding of the context in which the parents live. The interviews provided an understanding of the meaning and maintenance of CBR as well as insight into the parents' contact with its services.

The means of contacting participants prior to the interviews was different in the two countries. In Uganda, most of the professional participants were contacted by phone and visited at their workplace for an interview. Parents, on the other hand, were visited in their homes together with one of the CDOs who worked in the area, and therefore knew the families and whether their children still were living or not. Upon arriving at a family's home, an introduction was made and the parents were asked to participate; if they agreed, a time for the interview was set. All interviews with parents were carried out in their homes.

In each call made to prospective participants in Sweden, the researcher gave the reason for the call and asked if the person was interested in receiving a letter explaining the purpose of the study. The information letter was sent to them by e-mail or by post. The letter also contained information about a second call from the researcher in which they were asked to participate in an interview of approximately 60 minutes. Once the person accepted the invitation to participate, the date and time of the interview was set. When carrying out the interviews with the persons involved in CBR, at different study levels and in both countries, a recorder was used. To assure the confidentiality of the interviewed respondents, the records were kept safe for the duration of the study and the names on the computer files were coded and known only by the researcher.

When collecting the data in Uganda an interpreter was needed. In this study two different interpreters were involved when interviewing the parents. The interpreter mostly involved was a person who had worked as a CDO in the area fifteen years before. Choosing a person from the same area as the parents may seem questionable, as it might have made the parents unwilling to express themselves freely. However, when arriving at the parents' home they were very happy to see the CDO worker again after so many years. His presence thus contributed to a comfort and a confidence among the interviewed parents in discussing their experiences with the CBR project and the challenges they face in their daily lives. Further evidence that the parents were not inhibited by the presence of the interpreter is that the parents discussed weaknesses as well as strengths of the CBR project.

The other interpreter was not from the area, although she had mastered the language of Bushenyi. She was knowledgeable about the situation for people with disabilities in Uganda, both from working within the field of disability for many years and because she has a disability. This interpreter also helped in transcribing the interviews in English and noted when there was information that had been missed in the translation from the local language to English.

Analyses and Comparison

While proceeding to analysis and comparison the interviews carried out on the study levels *macro*, *mesa* and *micro* are in focus. The interviews carried out on these three levels highlight the implementation process of CBR in the two countries, revealing how each country's context influences the translation and implementation, and if CBR as a project has become institutionalised. In Uganda, CBR was a pilot project introduced by the government and in Sweden CBR was a project introduced by a professional. This probably affects the funding of CBR in the two countries. However, the matters of the budget of the two projects have been left out of the study. Instead the focus of the analyse and comparison is on the

projects' capacity to change the situation for the children and their parents within the time frame of the project, what may have hindered or favoured the change and implementation of CBR, as well as if the project have led to institutionalisation of CBR and have the possibility to change existing services.

To collect data and compare results on how CBR was translated, implemented and institutionalised in the two countries, the researcher interviewed participants who share common perspectives or experiences of the subject of the study. Patton (2002) notes that parents or other participants, as well as entire programs or local projects, can comprise units of analysis. A unit of analysis is according to Graneheim and Lundman (2004) whole interviews because being manageable when creating meaning units during the analysis process. In this study, interviews from both parents and professionals participating in CBR were used to gain an understanding of the implementation of CBR, and thereby are seen as units of analysis. In addition, local projects were also used as units of analysis to identify who initiated and funded CBR programs in the two countries, why these programs were implemented, and how CBR services has been carried out. To structure the data collected, a qualitative content analysis was used.

In the first step of structuring the data for analysis, each interview was transcribed either fully or selectively. The English interviews were transcribed in full and the Swedish were transcribed selectively, where the most important parts were transcribed. The reason for transcribing the Swedish interviews selectively was because of knowing what to search for in the interviews. Next, the researcher read through and listened to the interviews several times, alternating between the two countries' data and reviewing it over and over again. The next step in the analysis process was to capture meaning units in the interview text. The meaning units in the form of words and sentences were marked with different colour pens depending on which content area they were considered to belong to. A content area are parts of the text based on theoretical assumptions or parts of the text that address a specific topic in an interview, i.e. text related to the implementation of CBR in the two countries. The meaning units for each country were thereafter structured in tables (see an example in Table 2). The meaning units were condensed and thereafter abstracted directly into codes, which define and direct the data that should be analysed (cf. Gibbs, 2007; Graneheim & Lundman, 2004).

The codes were later analysed into sub-categories and categories, which is the core feature of qualitative content analysis, revealing the visible and obvious components in the text, the manifest content (Graneheim & Lundman, 2004). The sub-categories were named after what they stood for and expressed. The sub-categories were later sorted and joined under broader categories. The analysed texts are based on experiences of being involved in CBR, which can make it hard to create mutually exclusive categories. To identifying sub-categories and categories

required a process of going back and forth between the whole interview text and the meaning units to insure that the sub-categories represented the meaning units, before creating the categories. The sub-categories and categories were thereafter examined and abstracted again so the underlying meaning of the text, or latent content, was reflected in themes. In that stage, the themes take a more topical or categorical form which symbolise the whole context (Patton, 2002).

The analysis yielded ten themes for each country, based on the process described in Table 2. These themes were thereafter sorted under four wider themes as presented hereafter. *Background*: The living conditions of families to children with disabilities; The demand for a less paternalistic model of re/habilitation. *The Implementation Process*: Packing the idea of CBR; Planning, arranging and acting; Adequate resources; Motivation for participation in the project; Knowledge-based changing attitudes. *CBR Affecting Receivers Situation – Results*: Endeavours for the improvement of children's living conditions. *Factors Influencing the Implementation Process*: CBR as a new international idea; CBR at the national and local level.

Finding themes was very challenging because of the need to identify the most essential issues that highlight the focus of the study, and at the same time compare the countries and examine the idea of CBR on a structural level. To accomplish this, quotations from parents, professionals, and the two initiators are used in the results (chapter five and six) to explain and elaborate on the themes that emerged from the analysis. The quotations were chosen to show both consensus and variations among the participants' experiences in relation to these themes.

Table 2. Example of meaning unit, interpretation, codes, sub-category, category and theme from content analysis of implementing CBR in Bushenyi, Uganda

Theme	ENDEAVOURS FOR THE IMPROVEMENT OF CHILDREN'S LIVING CONDITIONS				
Category	KNOWLEDGE CAPITAL			EXPECTATIONS	
Sub-category	Awareness	Strength	Skills	Not met	Met
Codes	Rights Values Feelings	Educated Positive attitude Achievements	Advising Informing Supporting	No materials gained No school fees	Materials gained School fees gained
Inter-pretation	The knowledge from CBR helped parents gain awareness of their children's rights and values, changing their feelings towards the child.	CBR strengthened the parents through education, changing attitudes, and positive achievements.	CBR gave parents skills used in advising, informing, and supporting other people in their surroundings.	Other than the knowledge capital gained, expectations for materials and school fees were not met.	One of the parents gained materials and school fees for their child with disabilities.
Meaning units	<p>(Amos) The programme was making parents and children with disabilities come together and telling parents to know that those children with disabilities are like others.</p> <p>(Fred) Before, and even before I had produced a child with disability, I saw that there were many children with disabilities but they were not regarded as real human beings; they were like to whom it may concern.</p> <p>(David) It changed me to love my disabled child like any other child; that is the biggest advantage I recognise in CBR.</p> <p>(Gloria) It has changed; the love for the child is increasing.</p>	<p>(David) We were given knowledge and sometimes they could give some additional help where it was needed.</p> <p>(Fred) It was encouraging us and training us to handle, how to live with people with disabilities.</p> <p>(Gloria) I was helped by being educated to have a positive attitude about my child.</p> <p>(Gloria) My child is my life; now I even have an appetite to eat because my child is improving, and I feel okay.</p> <p>(Amos) The knowledge they were giving was helping with how to take care of the child.</p>	<p>(David) After that I also advise other parents who have children with disabilities on how helpful it can be if their children are attended.</p> <p>(Gloria) I used to be asked about the child, but those who were asking about how the child had been worked on, and I was sharing experiences with them, had no children with disabilities.</p> <p>(Amos) I'm using the skills when I meet other people with disabilities, other parents, I talk to them and tell them about being a person with disability you can be able to work.</p>	<p>(Fred) But what was not okay: there was no material gains, the promises were not coming so expectations were not met.</p> <p>(Amos) I had an expectation that if the CBR could give school fees for the child it would be good; that was the only thing I was thinking to get from them.</p> <p>(Gloria) The expectations were not met because she did not get material support.</p>	<p>(David) He was getting free books and pens. When he completed senior four he was taken over, he was given a scholarship. It should be recorded that the scholarship was from the government, it was because of CBR, even that it gave me something, to go for courses and workshops outside the district, only as a parent.</p>

Ethical Considerations

Internationally, the daily lives of families of children with disabilities have been well documented scientifically (Lindblad, 2006). According to Seligman and Darling (2007), research on family members in the area of childhood disability is often based on the views of the mothers, while forgetting fathers, siblings, and grandparents. When carrying out this dissertation, my primary ethical considerations concerned interviews with parents of children with disabilities. The parents can be seen as a vulnerable group because they are often their children's most important advocates. In both non-Western and Western countries, parents of children with disabilities have to fight for their children's rights in the community and must be involved in rehabilitation services for their child, while at the same time managing their family and working just like everyone else.

Even though these are ordinary families with special children, they face challenges other ordinary families do not face, which make them more vulnerable. Too Liamputtong (2007), vulnerability occurs when an individual's independence is limited because of unequal status or her/his mental or physical deviance from the established norms. Such individuals lack the opportunity to make life decisions that would maintain their independence. In one sense, parents' self-determination disappears when a child is born, in that the child's needs will come first. For parents who give birth to a child with a disability, their independence can also disappear when the parent becomes dependent on the authorities' provision of services for their child. Caring for someone can also imply a stigma for the caretaker (*ibid.*). The parents in both Uganda and Sweden may be said to be vulnerable as a result of caring for their children with disabilities, being exposed to stigma, and being dependent on authorities' provision of rehabilitation services.

This research presents a dilemma for the researcher, a responsibility to protect the parents, in both Uganda and Sweden, from problems caused by the research. However, when interviewing parents in Uganda other considerations have to be taken into account, as these parents are more vulnerable than parents in Sweden. Compared to parents in Värmland, parents in Bushenyi face more financial restrictions and fewer educational opportunities. Interviewing parents of children with disabilities in Uganda also requires special attention due to the history of dependency between non-Western and Western countries. This situation is exacerbated by the fact that I as a researcher comes from a Western country—a country that has been involved in the construction of CBR—and is carrying out research in a non-Western country. Therefore, it is important to be aware of the consequences of this situation and to avoid making demands and obligations that may result in more harm than good for parents of children with disabilities.

This study was conducted before it was obligatory to apply to the regional Ethical Review Board in Sweden. However, due to the parents' vulnerable

situation it is necessary to assess some ethical principles in relation to this study, to avoid negative effects for study participants as much as possible. The Swedish Research Council (2002) established four key requirements for conducting research: information requirement, consent requirement, confidentiality requirement and use requirement. The first two, *information requirement* and *consent requirement*, were dealt with in the information letter that in Uganda was read and translated for the participants and in Sweden was sent by e-mail or by post. The information letter for participants in the two countries described the purpose of the study, identified who was conducting the study, and informed them that an interview of approximately 60 minutes would be conducted and would be recorded unless they objected. The letter also stated that they had no obligation to take part in the study; this was a choice made of their own free will and they could cancel their participation in the interview at any time.

The consent requirement is also regulated in the act of protection of sensitive personal data (PUL, 1998). The requirement is greater if the study involves any personal data or sensitive information, such as religious affiliation, political opinion, race, ethnic origin, sexuality, or health information. This study does not involve disclosure of such sensitive personal data. However, the health information could be discussed because parents mention the type of disability their children have. Nevertheless, the disability is not exposed in this study.

In Uganda another situation occurred among some of the persons asked to participate. At the end of each interview, each person was asked if there was anything they wanted to share or any questions they wanted to ask. Some participants said they wanted to know more about me. This may show my genuine interest in the subject of study or indicate that the information I provided in the beginning was not clear enough, that more time was needed to go through the information, or that the translation of the information into their language was poor. Whichever was the case, the question asked at the end provided an important opportunity for the participants to request more information. Thus, the necessary information and consent requirements have been satisfied in the study.

The *confidentiality requirement* concerns securing the participants' integrity and safety during their participation in the study and protecting personal data. Although this study did not involve collecting personal data, the typed interviews were coded and kept safe in the computer and in a locker. The participants were also informed that the data collected during the interviews was accessible only to the interviewers and would be presented in such a way that the participants could not be identified. The *use requirement* specifies that records gathered on individuals must be used only for research purposes. The interviews completed for this study have not been used for any purpose other than the completion of the study.

While the ethical principles mandated by the Swedish Research Council (2002) and the act of protection of sensitive personal data (PUL, 1998) comprise all the requirements for researchers in Sweden, other ethical considerations and decisions must be addressed when carrying out research in non-Western countries. For example The European Commission's 7th Framework Programme points out that carrying out research in a non-Western country requires the highest ethical standards. Therefore, identifying the necessity of carrying out research with such a vulnerable group as parents of children with disabilities is not enough. The involvement of a non-Western country also has to be justified. This research is motivated by the recognition that few comparative studies have been carried out on CBR between non-Western and Western countries, and that this is an area in which valuable knowledge could be shared. The comparison between parents' experiences of CBR in Sweden and Uganda can highlight CBR's capacity for providing necessary services, as well as illuminating similarities and differences in the two countries' ways of providing the services.

Parents of children with disabilities possess a lot of valuable knowledge and information that can help authorities in the two countries to provide suitable services for children with disabilities. However, will the parents themselves gain anything from being involved in the research? Vulnerable people may mistrust researchers and may not benefit directly from such research. In Sweden, parents have faced unhelpful attitudes and the misuse of power by authorities when trying to get the services they consider necessary for their child to improve. This can make participants uncomfortable and disapproving when a researcher seeks to elicit personal and private information. Conversely, the parents may feel that the research offers an opportunity to make their voices heard, and may appreciate that someone has taken the time to listen to them with the intention to understand their problem.

By using consequence-based ethics as a method of decision-making, researchers can identify various actions to minimise the harm to research participants involved in research (Blennberger, 2005). Especially when carrying out research in a non-Western country, I must review some moral considerations. For example, I have a moral duty to help alleviate suffering, even though the country under study has the primary responsibility. I should bear in mind that people in the country being researched have the capacity to create their own lives. This capacity gives everyone a unique source of value and makes each individual worthy of respect (Nuffield Council on Bioethics, 2002).

The Uganda National Council for Science and Technology has established national guidelines for research involving humans as research participants, facilitating the conduct of research at the same time as protecting the welfare and the rights of research participants (UNCST, 2007). The guideline mentions that the

respect lies in the self-determination and protection of persons with impaired or diminished autonomy. Ensuring that the researcher does not exploit the vulnerable is another moral imperative, as where possible, the participant's communities in developing countries should benefit from the research conducted on them (Nuffield Council on Bioethics, 2002).

This research seeks to bridge the knowledge gap between the two countries by giving the dissertation, written in English, to the Ministries working with CBR in Uganda and to the local authorities in Bushenyi as well as in Sunne and Torsby in Sweden. However, will this benefit the participants? Because it can influence existing services in both Uganda and Sweden, the answer might be yes. However, it remains doubtful whether the parents and their children with disabilities will immediately benefit, other than by having their views and concerns made more visible.

This research should therefore be viewed in a longer perspective. Although the concern lies with children with disabilities and the rehabilitation available to them, they are not the only ones who will benefit from the research. Children with disabilities were excluded from the research because of their vulnerability and because of the possibility to gather the information needed in a more proper way from their parents. The parents, in turn, are also a vulnerable group, as explained before, who may benefit by getting their voices heard. This can help authorities better understand the parents' life situation and the support they need for their children, which may help them provide the necessary services. Authorities who participated in the study are also able to express the successes and failure they experienced in cooperating in CBR. However, I do not foresee any risks in carrying out the research that are significant enough to believe that the research should not be done. As long as an ethical analysis of the consequences of the research, based on moral principles, values, and norms, is carried out in advance, there are reasons to assume that the participants will gain more than they risk losing from participating in the research.

Being white and European

This comparative study has confronted me with a variety of difficulties. One of those is the controversy surrounding my identity as a "white European" researcher who is "there to study them". This situation raises several issues that must be addressed before proceeding with the study.

According to the Nuffield Council on Bioethics (2002), researchers have a duty to be sensitive to cultural differences. Researchers studying cultures that are different from their own must demonstrate a "willingness to explore such differences without prejudice and to seek as far as possible to understand them informed by knowledge of local traditions and material circumstances" (Nuffield

Council on Bioethics, 2002, p. 52). Liamputtong (2007) expresses the importance of being sensitive to cultural differences:

When a researcher is willing to get his/her hands dirty by becoming involved in the worlds they are studying, they are much better able to understand what they are studying. And sometimes being involved in “different” world allows researchers to both gain information they would not otherwise be able to get, as well to be better able to understand what they are seeing, hearing, feeling, and experiencing. (Liamputtong, 2007, p. 116)

A researcher’s own involvement in the world is, according to Liamputtong (2007), essential to gaining a deeper understanding of the persons or phenomena being studied, and therefore also provides a context and a tool for analysis. However, Liamputtong also points out the importance of examining my own experiences of being a “white” European researcher and exploring how those experiences may affect the results of the study and my interactions with the research participants. Examining one’s own story is important both for understanding the stories of the participants and for analysing the interaction between the researcher and the participants (Lundqvist, Davies, & Mulinari, 2005).

Several researchers have explored the discourse of identity and belonging, examining how identity is constructed, how individuals positioned as the “objects” of study are treated and influenced by the research process, and how research can be a part of the discrimination practiced (Dyer, 1997; Eliassi, 2010; Eriksson Baaz, 2002, 2005; Pease, 2010). For me, the belonging I experience as a result of being “white” and European is not as obvious as the colour of my skin, eyes, or hair, which provide the first impressions upon which many people consciously or unconsciously make judgments about me (Dyer, 1997). What does my skin really say about my way of acting and speaking? I am a person who has interacted with people from different corners of the world since childhood, through travels and friends. As an adult I spent several months during 12 years as a volunteer worker in Uganda, and I have been married and have two children with a man from the Democratic Republic of Congo. Thus many incidents over the course of many years have caused me to question my own identity, as well as continuously shaping it in ways that suit my belief and knowledge of the world. While all of these occasions are not to be explored here, my experiences have intensified such questions of identity, which often have occupied my thoughts.

Being called *mzungu* is something I and many other “white” people travelling or working in Swahili-speaking countries in Africa have experienced (Eriksson Baaz, 2002). *Mzungu* literally means a white person. However, in the contexts in

which I have spent most of my time in Uganda through the years, *mzungu* also implies the word money, giving the word the meaning of “a white person with money”. This meaning can be explained by the privileges many Western people have in the eyes of most non-Western people, privileges inherited from the colonial past (Pease, 2010) when countries such as Tanzania, Kenya, Uganda, and the Democratic Republic of Congo were colonised by England and Belgium. These privileges include, for example, being able to travel, to buy more than the necessities, and to support people who are less privileged. A parent in Uganda described these privileges:

You know, money is on top of everything. Like now you have come here, if you would not have any money would you have come? It is like how I took the child to Jinja, if I had no money maybe I will be aware that the child can be okay but without money I cannot take the child to the hospital.

The parent notes that without money he could not have taken his child for rehabilitation, just as without money I could not have travelled to Uganda to carry out my study. However, there is a huge difference between having money to travel and conduct research and having money to help relieve your child from suffering. There is an enormous difference as well between a parent in Sweden, who can access services free of charge, and a parent in Uganda who sees what can be done but what they cannot do for their own children due to a lack of money or available services nearby.

The issue of money in relation to my identity as a white, Western person manifested itself in the interviews in various ways. Being white and belonging to a certain category of nations creates opportunities that can contribute to increased resources. A Ugandan professional describes this dynamic:

Chances are open. Now when you come up with the report, I think you will give the government of Uganda a copy. So the government of Uganda can use that report to solicit for more funding; I think the ministry could use it to solicit for more funding from the government.

In addition to my race and national identity, my identity as a researcher also conveys a position of power through my ability to do something that can create change. This affected my experience in Sweden, where my title and role as a researcher and professional led many participants to express the hope of restarting CBR through my research and personal influence.

The parents I interviewed also viewed me as a potential resource. At the end of each interview with the parents in Uganda, I asked if there was anything else on their mind, or anything they wanted to tell or ask me. All parents then expressed their need for assistance for their child with a disability, and three of them turned directly to me for a consultation on what kind of help was available. This may mean they saw me as a possible source of assistance. In addition, one of the parents consulted the former CDO after learning that he now worked in a larger town. This indicates that the parents were trying to find ways to support their children and that their appeals for help did not have to do with me being a *mzungu* and European. However, one parent's statement did indicate that my appearance of being white and European could be seen as a resource:

It is good that you are doing social work and now that you are from a developed country you should be coming to teach, make people around aware, because people still have negative thinking.

This quotation suggests that Western countries and their knowledge may be seen as more valuable than Ugandan knowledge, suggesting that knowledge given to the community in Uganda should primarily be provided by foreign, Westernised people. It can also be interpreted as a perception of the Ugandan people as not educated and therefore not able to handle their own development. However, the parent's statement has to be viewed in relation to the colonial past and postcolonial present, and in light of the system of social welfare in the country affected by these structures.

Nevertheless, this quotation places a high level of responsibility on those conducting research in non-Western countries to expose power relations. The black man's burden referenced by Davidson (1992), with its exploration of colonialism, has also become the burden of white men and women (Eriksson Baaz, 2002). Privileged post-colonial authors born in Western countries who do not sympathize with their country's views bear the burden of caring what the colonial past has caused and the responsibility not to reproduce those dynamics in their writings, verbal communication, or ways of living (Spivak, 1990; Thörn et al., 1999). Verbal communication must be developed as a means of moving beyond the colonial past and postcolonial presence, as Fanon (2008) notes.

How have all these aspects of identity affected my research and how has my research, in turn, affected others? The greatest challenge has been to strive for objectivity, especially when I inevitably carry my own pre-understanding and experiences of the world in general and of a privileged world in particular. However, I hope I have done the participants in the study justice as far as possible. I have sought to avoid colour-blindness and the error of unconsciously interpreting

and analysing the participants' words from my own limited view of this complex issue, thereby walking right into the pitfalls of being a white European woman reproducing discriminating practices. Pease (2010) define colour-blindness as occurring when unconscious racism and radicalized structures of inequality are not seen. White people may recognize discrimination towards people of colour without understanding their own privileges (Pease, 2010).

The privileges discussed above and my presence as a white researcher and professional from a Western country raised some expectations among the study's participants. To minimize these expectations as much as possible, it is important to report back to them the results of the study by providing them with a copy of my dissertation. The expectations that arose were also dealt with during the interviews themselves. I carefully explained to the parents in Uganda where they could ask for assistance, in this case from the CDOs working in the sub-county and from the district rehabilitation office. I did not promise anyone anything, such as coming back to work or becoming the new driving force of CBR in Sweden. Nevertheless, after I completed my work in Uganda and was back home again a working proposal was presented in an upcoming NGO, which is related to me being a *mzungu*, white, from a European country.

CHAPTER 5

THE IMPLEMENTATION OF CBR – UGANDA

This section will highlight the spread of CBR to Uganda, i.e. how CBR was introduced and initiated, and why it was implemented. In this section quotation from four interviews including five parents (Amos, David, Fred, Gloria and Mary) to children with disabilities is used to describe the living conditions of families to children with disabilities. Quotations from interviews with Apollo a social worker within the field of re/habilitation likewise an initiator of CBR in Uganda and three Community Development Officers (CDOs) in Bushenyi highlight the demand for a less paternalistic model of re/habilitation in Uganda and Bushenyi. All the three CDOs (Alex (CDO 1), Bosco (CDO 2) and Jackline (CDO 3)) were community development workers when CBR was put up as a pilot program in Bushenyi and they came in contact with CBR in 1992 when they underwent a course in community rehabilitation.

Background

CBR was introduced in Uganda in 1989 by Ugandan students who took diploma and master's courses at the Institute of Child Health at London University, England. The students spearheaded the birth of CBR courses in Uganda in 1990 by creating the NGO Community Based Rehabilitation Alliance. Ready to carry out the training, they implemented the first CBR programmes in 1992 through the government (Baryayebwa, 2002; Ministry of Gender, Labour and Social Development, 2002; Nganwa et al., 2003). However, the official year of implementation of CBR in Uganda differs according to various reports. The international Norwegian Association of the Disabled (NAD) has provided support to various ministries and to NUDIPU since 1991 (Claussen et al., 2005). However, the Ministry of Health (1997, 1999) stated that CBR started as a governmental programme in 1994.

The differences can be explained by the separate agreements NAD made with three ministries: the Ministry of Gender, Labour and Social Development; the Ministry of Health; and the Ministry of Education and Sports (Claussen et al., 2005). Some authors identify 1992 as the starting point for CBR, and because individuals interviewed for this study who implemented CBR in Bushenyi were called to attend CBR training in 1992, this year will be considered the starting point of the pilot programme in Bushenyi for purposes of the study. The time frame for

the pilot programme was from 1992 until 1998 (Baryayebwa, 2002; Keibanda, 1995; Claussen et al., 2005).

While CBR was being implemented in Bushenyi, the Ugandan government, with financial support from NAD, also implemented CBR in two other districts, Mbarara and Kabale (Baryayebwa, 2002; Keibanda, 1995; Claussen et al., 2005). The experiences from the three first pilot programmes were later used to expand the programme to districts like Ntungamo, Mbale, Rukungiri, Mukono, Kamuli, Tororo and Iganga (Baryayebwa, 2002). During the same time, other CBR programs were implemented in different parts of the country by several NGOs (Claussen et al., 2005). The government hoped to expand the program to all districts in Uganda before the year 2000 (Ministry of Health, 1997), but so far this has not occurred. According to NUDIPU (2004), CBR is available in 11 out of 80 districts.

In the preparation of implementing CBR in Uganda, a National CBR Steering Committee was established to implement and coordinate CBR. The Committee contained all line Ministries (Ministry of Health; Ministry of Gender, Labour and Social Development; and Ministry of Education) and some national NGOs (Uganda National Institute of special Education, Community Based Rehabilitation Alliance; National Union of Disabled Persons of Uganda, Uganda National Association of the Blind; and Uganda National Association of the Deaf) involved in disability issues (Hartley et al., 2004; Baryayebwa, 2002). When different organisations interact and share same goal and carry out similar work with a shared frame of references, DiMaggio and Powell (1983) calls this for an organisational field. Whereby, the governmental organisations and the NGOs can be seen as an organisational field of disability, in which many actors work for the common good of people with disabilities. This also demonstrates cooperation and networks at various levels, which is important within the idea of CBR (Kay & Dunleavy, 1996; Periquet, 1989; Thomas & Thomas, 2002) and for implementation of policy programmes (Sandström, 2008).

However, according to Thomas and Thomas (2002), governments often have a top-down management structure and NGOs a bottom-up, and the implementation of CBR in this context is thus a mixture of both. At the same time the government implemented CBR through chosen district administrators, national NGOs were also implementing CBR at the local level, though not in Bushenyi. In this way many organisations act as a supplement to the government when it comes to providing services to people with disabilities in Uganda (Sengendo et al., 2000). However, as to Bennet (1990) and Manyire and Asingwire (1998), this situation resulted from limited state interventions due to restricted budgets and the shift of donor support from the government to NGOs, giving policymakers little choice

(Cannon, 2000). According to the Ministry of Health (1999), this situation has led the government to see NGOs as responsible for addressing disability issues.

When CBR had been initiated at a national level, the next step was to coordinate and implement CBR at district and lower levels (Baryayebwa, 2002; Hartley et al, 2004), turning over the idea of CBR to local action where it could become reembedded through a receiver (Erlingsdóttir, 1999). The receiver is the one who transform and transport an idea or policy (Johansson, 2002). The receiver of CBR in the district of Bushenyi, where this study was conducted, was first the district rehabilitation officer responsible for coordinating CBR activities. It was often in this officer's administration block that CBR meetings, seminars, and workshops, as well as monthly staff meetings and quarterly community meetings, were organised and held (Keibanda, 1995). At the sub-county level, CDOs implemented CBR by reaching out to parishes and villages.

Nevertheless, CBR as a strategy can be implemented in many ways in different countries as well as within a country (Asindua, 2002; Miles, 1996). Mazmanian and Sabatier (1983) and Hill and Hupe (2009) says policy implementation is the carrying out of a basic policy decision and according to Johansson et al. (2000) projects has become a new form of implementing ideas and policies. As shown before, CBR was implemented in Uganda as a pilot programme within a certain timeframe, namely from 1992 until 1998 (Baryayebwa, 2002; Keibanda, 1995; Claussen et al., 2005). Certain start and end point define the pilot programme as a project, in this case as a change and development project (Johansson et al., 2000), trying to change the living condition of, and provide services to, people with disabilities in the country.

The living conditions of families to children with disabilities

Parents of children with disabilities in Uganda face numerous challenges related to historical and socioeconomic factors in the country. All the parents interviewed for this study live in the rural area of Bushenyi in the Western region of Uganda. Bushenyi can be described as a rural district/town due to its distance from both the central region where Kampala, the capital of Uganda, is located and from any other large city. Rehabilitation centres are often placed in larger urban areas and the nearest one to Bushenyi is situated in Mbarara, one hour's drive from Bushenyi. According to Apollo, an initiator of CBR in Uganda, there was only five institutions in the whole country prior to the introduction of CBR, taking 50 people each every year, leaving many people with disabilities without assistance.

At the time of the interviews there was only one physiotherapist working in the district of Bushenyi, at a hospital in a county far from where these parents lived. Surgical specialists arrived from another district when a group of people were found who needed help. Many families of children with disabilities are challenged

by the lack of nearby rehabilitation services and a lack of specialists operating in the field of disability. Two of the parents supported this point:

I and the mother were seeing that the person who carried out surgery on the child in Jinja really did something good, but sometimes I could fail because of lack of money. You know, taking the child back and forth all the time, but the professionals there, they did something which satisfied me. (Amos)

I was limited by financial ability, though I had the ability to know what I wanted but my economic ability did not allow me to take him to the levels I wanted. (Fred)

Amos's words show that it was not the services at the hospital in Jinja that were the problem, but the distance and cost of bringing the child there. However, it is not only rehabilitation services and specialists that are missing. Fred says that he knew what he wanted for his child, but he lacked the financial means to achieve it. In both cases the parents were restricted by financial means when seeking rehabilitation services such as treatment and educational opportunities for their children with disabilities.

Financial limitations are a reality for many families having a member with a disability. They face a greater rate of poverty due to the costs of treatment and caring for an individual with a disability (Hartley et al., 2004; Hoogeveen, 2005; Palme et al., 2003). According to Hartley et al. (2004), lack of funds to provide for the basic needs and treatment of the child, including schooling, assistive devices, and transportation, is a challenge faced by many families in Uganda who have a child with a disability. The lack of rehabilitation services and the need to travel great distances to reach one relates to Uganda's history of colonialism, as well as to wars and conflicts that led to a breakdown of the social sector and to a scattered provision of social services (Hokenstad et al., 1992; Nabuguzi, 1995). Although after the fall of colonialism, a post-colonial Western development agenda prescribed loans from foreign countries as a solution to the country's socioeconomic problems, the deep poverty in the country nevertheless continued. The organisation of Ugandan society also contributed to scattered welfare services around the country (Ferguson et al., 2002). Even today, approximately ten years after CBR was incorporated into the regular services of Bushenyi, a lack of support for rehabilitation services remains.

With limited financial resources in these families and with a lack of nearby rehabilitation services, it can become a heavy burden for parents to afford services needed for their children with disabilities. This struggle was evident among the

parents in Bushenyi participating in the study. Two out of the three fathers interviewed, sometimes worked far from home during the upbringing of their child, and one still does. This may be one reason why in Hartley et al.'s (2004) study many of the fathers were absent as "gatekeepers", controlling the households incoming and outgoing money. Mary says her husband was seeking to make money to contribute to their child's education. Her husband Fred describes the situation as follows:

I was outside looking for money working in Buganda, Kampala. I was earning a small salary which was not enough for a big family. That is why I stopped that work and left it to the mother. (Fred)

According to Fred, being a farmer did not provide enough income to sustain the family and forcing him to take a job far from home. It also meant that some of the parents had to be apart for a certain period of time, giving mothers the heavy burden of taking care of both the children and the home. Like mothers of children with disabilities in the central and eastern regions of Uganda (Hartley et al., 2004), the mothers interviewed in Bushenyi were primarily responsible for caring for the child's bodily needs. When a household is motherless, the grandmother often becomes responsible for taking care of the child with disabilities (Hartley et al., 2004). This was the case in one of the interviewed families. In addition to caring for their own child with disabilities, they also take care of their grandchildren, one of whom has disabilities.

The separation of parents due to their financial situation, which was common because Bushenyi is a rural, marginalised area with limited employment opportunities, makes the family even more vulnerable. However, the hardships the interviewed families experienced in Bushenyi were somehow compensated for by their social network of relatives, neighbours, and friends. Mary describes the support received from those around:

We worked very well with friends; even the neighbours were cooperative, securing the vacancy for higher education. It is the neighbour who looked for a vacancy and even contributed materials when the child was going. (Mary)

The families identify financial and emotional support from their social network as compensation for the inaccessibility of rehabilitation services. In this way the social network provides a kind of security net for parents and their children with disabilities. Three of the five parents reported that the people closest to them did not respond negatively towards them or the child with disability. Gloria states that

there were no negative attitudes from the neighbours when she gave birth to a child with a disability. There were some rumours in the village, but not from those who were close to her. However, although parents received support from their own social networks, they often experienced negative attitudes from the community at large. The proximity between persons with and without disabilities is a factor Amos, a parent, identifies as important in determining whether attitudes will be positive or negative:

Some people may have positive attitudes and others negative attitudes depending on how often they have interacted with persons with disabilities. When they look at me they see I am a person like others, but if there is any other person with a disability passing, people look at them and may react negatively. (Amos)

This observation shows the importance of integrating children and adults with disabilities fully into society. However, Fred identifies another reason for negative attitudes in the community when he observes, “we have no problem with the social environment because my son is now working”. This indicates that people have more positive attitudes toward people with disabilities who are working, because they are seen as productive members of society instead of dependent people who must be cared for by society. This shows that negative attitudes may affect the family, though they may be reduced as a result of the child’s progress. Amos and Gloria give two other examples of this dynamic:

At first the relatives, especially distant relatives, were looking at it negatively, but later when he was corrected I think the negative attitudes reduced. Some look at them negatively, others look at them positively because they see how they are dressed well. Whatever they want they are getting, so people look at them differently. (Amos)

There are some people who used to tell me some abusive statements, challenging situations. Now they are starting to know that life can be normal with this family, when my child has improved. (Gloria)

These statements show that people with disabilities are valued more when they act as normal as possible and when they have what is needed—two characteristics that are in line with what modernity requires, as the person is not seen as standing in the way of creating a modernised society, and therefore a

perfect world (Mackelprang & Salsgiver, 1996). Such attitudes may be explained by the socioeconomic situation of the parents as well as the country's striving for development and modernity. Oppressed groups in society, including people with disabilities, are often regarded as second-class citizens in comparison to those who are able to work and contribute to the country's progresses. Tiberondwa (1998) has identified this as "mental colonisation," which he describes as the worst type of colonialism. Western knowledge and ideas that have been transferred to Uganda and many other African countries have changed the educational system and replaced cultural institutions. This transfer of knowledge can also lie behind Westernised views of rehabilitation and of what is "normal", establishing a model of rehabilitation that is neither useful nor desired.

The demand for a less paternalistic model of rehabilitation

Rehabilitation services for people with disabilities, first offered under colonial rule through missionary special schools, were later provided by the Ugandan government in cooperation with International Labour Organisation (ILO) (Kangere, 2003; Ministry of Education and Sports, 1999; Tiberondwa, 1998; Tomasevski, 1999). This original system was influenced by a Western medical model of disability services (Ministry of Health, 1999). In contrast, CBR brings services closer to people with disabilities and engages them and the community at large as participants in the rehabilitation process. In introducing CBR Uganda was striving for a bottom-up approach, a more social model, rather than a top-down approach in which people with disabilities were "owned" by professionals and the government. Apollo expresses this in following statement:

We found out that we used to own them, whatever they wanted it was done by either a social worker or a medical worker and yet it was their responsibility to manage the prevalence of their disability. (Apollo)

Under the institutional rehabilitation model with its medical, top-down approach (Lysack & Kaufert, 1994), people with disabilities did not have autonomy or liberty, and professionals expressed an attitude of superiority. The change from this paternalistic model to a more social model should empower people with disabilities and make them responsible for their own lives. However, there is a risk of placing all the responsibility on people with disabilities and their caretakers while undermining the government's responsibility. This can be one of the pitfalls of the concept of empowerment (Wright Nielsen, 2009) and an unintended result of a strong focus on civil society (Lavalette & Ferguson, 2007). One of the three

interviewed CDOs who were working in the district of Bushenyi, describe these dynamics:

The government strategy was moving away from institutionalising people with disabilities. The issue was when they are taken to institutions there is a lot of discrimination and stigma. The parents would think that a disabled child is the property of the government and that it should be the responsibility of the government. Even when a person with disabilities finish education and comes back into the community, they will not be easily accepted. More so the communities were not sensitised on how to handle their children with disabilities. (Alex, CDO 1)

By moving people with disabilities from institutions to the community, the government did not have to provide expensive rehabilitation services at centres used by only a few (Momm & König, 1989). A less paternalistic rehabilitation model was probably ideal for a government with limited resources (Cannon, 2000), giving the responsibility back to the communities and providing a chance for people with disabilities to achieve autonomy and be viewed as able. In this way prevailing attitudes could also be challenged, an important advantage of CBR because negative attitudes—which are often incorporated into the institutional, medical model of rehabilitation—are an obstacle that can prevent people with disabilities from enjoying their rights (Karna, 2001; Kizito, 1993; Mackelprang & Salsgiver, 1996; Miron, 1994). Two of the CDOs in Bushenyi describe their task of changing attitudes:

It first came to my mind as a challenging assignment because though I was a community development worker, socially my attitudes and whatever on people with disabilities did not differ much from those of people in the community. So my challenge was how really we shall come out of that negative feeling about people with disabilities. But then after getting the real information and what should be done, then it was like easy for me to adjust and explain to parents that this one is just an attitude and it has nothing to do with the potentialities of people. (Bosco, CDO 2)

Before CBR came, most of the community members were discriminating persons with disabilities because they did not know, they did not have any knowledge and even the family

itself was looking at a person with disability as a curse to the family. But with our sensitisation, now everybody became aware. (Alex, CDO 1)

Oppressive attitudes from the community towards people with disabilities occur in almost every society (Karna, 2001). Changing attitudes in the community and among professionals is one motivation underlying the demand for a less paternalistic model of rehabilitation in Uganda. The need to liberate and empower people with disabilities is another one. The government's limited resources are a factor that has affected the demand for a new approach to rehabilitation. However, involving the community does not mean the government can relinquish its responsibility, especially when considering the socioeconomic situation of families of children with disabilities.

The Implementation Process

In this section, CBRs interaction with mostly existing practises at local level in Uganda is analysed, as well as how it has been maintained in the new context. This analyse is based on interviews with the five parents and the four professionals (the initiator and the three CDOs) mentioned in the introduction. However, quotations from other interviews with professionals are also included under this section. The professionals are: Jesca, a social worker, and Joyce, a physiotherapist, who worked at different institutions for people with disabilities during the time of CBR's entrance; Benon, a teacher in Bushenyi who got in contact with CBR in 1998; Ronald, also a teacher in Bushenyi who have been working in the area for two years, and Innocent, an account assistant handling school teachers' salaries, which briefly got in contact with CBR through schools in 1994.

Packing the idea of CBR

According to Hill and Hupe (2009) and several others (e.g. Buse, Mays & Walt, 2005; Lester & Goggin, 1998; Van Meter & Van Horn, 1975; Meyer & Goes, 1988; Paudel, 2009) implementation is a process and in the process series of decisions and actions are directed to put a policy decision into effect. CBR was chosen as a model of solution to people with disabilities situation in the country. However, the international idea had to be translated to the local context in the country, considering the demand among people with disabilities. As mentioned before, the receiver of CBR can be seen as the transformer and transporter of the idea or policy (Johansson, 2002).

When an idea spreads to a new place, the idea often has no reference within the new context. To create meaning and establish references through social interpretation, the idea of CBR can become registered in a new context through the

process of localisation and by developing for the idea *a local past* (the meaning of an ideas origin), *a local present* (the ideas origin becomes less important and a translation takes place to the local context) and *a local future* (when the idea is put into a plan of action and becomes part of the long-term plans of a field and/or organisation) (Røvik, 2008). The spread of CBR to Uganda in the 1990s, implemented both voluntarily and governmentally, assumed that this idea rested upon the international definition of CBR from 1989 (Lang, 2011). The next definition came in 1994 (WHO, 1994), when CBR was already implemented in Uganda. In other words, the registration of CBR in Uganda was localised from international references and global trends, on its way to shaping a local identity (Czarniawska, 2005).

The aim of CBR in Uganda to “identify all forms of disabilities and provide the best rehabilitation services with full participation of the community” (Baryayebwa, 2002, p. 3) does not only follow the original international definition of CBR. It also contains a local understanding of the situation for people with disabilities in Uganda:

...actually they used our plan of action which we had prepared at that time in Uganda. (Apollo)

NAD’s use of the Ugandan plan of action for people with disabilities means that earlier approaches to rehabilitation are taken into account when packing the idea of CBR (cf. Czarniawska & Joerges, 1996; Røvik, 2008), providing references to a local history (past) (Røvik, 2008). A CDO describes this in the following statement:

We were reading CBR in comparison with institutional rehabilitation, which was there before. Looking at its challenges where people with disabilities were completely disowned by communities and the problems it caused to government and people with disabilities. (Bosco, CDO 2)

Despite the translation and creation of references to a local history, i.e. the people with disabilities’ situation and available services, the heavy emphasis on international history has not disappeared, especially when references to the local context and the idea’s local integration (present) are lost in a top-down manner of implementation. As noted earlier, the 1989 definition of CBR had a top-down approach focusing on transferring knowledge to people with disabilities. Jackline (CDO 3) describes it as follows:

We had a manual which we were following to implement that.
Yes, we used that manual to implement the programme.
(Jackline, CDO 3)

The idea of CBR consists of several manuals guiding the work with people with disabilities. The quotation somehow describes diffusion, a more copying of CBR in the context of Bushenyi. However, meanwhile diffusion seems to have taken place when carrying out CBR at local level, a translation of CBR to the Ugandan context took place in the beginning of the implementation process, when taking the scarce services for people with disabilities and their situation into consideration. Nevertheless, it seems like the manual do not still exists everywhere:

I don't have it here because when you are transferred from one sub-county to another, you are supposed to handover all the files or the programmes you are implementing but unfortunately this sub-county did not handover that manual. When I was trying to look for this file yesterday when you called me I found this file only, so the manual was not there in the cupboard. And this man, this officer who was implementing this programme by then, is now a deceased person so the one who succeeded him I don't know whether it was handed to him or not. (Jackline, CDO 3)

ten years after the implementation of CBR, it seems like the manual is not so important anymore. This can depend on the time frame of the pilot program, stopping after four years. So did also the evaluations of CBR. During the time frame, an evaluation was carried out quarterly, half yearly and yearly to see how far they have gone and how progressive CBR was. Today it looks differently:

The measurements now are not there except that when you plan your activities and integrate CBR in your activities you have to measure some of the achievements concerning rehabilitation, which is CBR. (Jackline, CDO 3)

This shows that the manual of CBR was used as guidance for action and was evaluated under a certain time frame. Thereafter CBR should be a part of the long-term plans for the field and/or organisations. Being used in such manner, gives according to Røvik (2008) the idea of CBR a local future. Thus there is a need to look more closely at how CBR was reembedded in practice in the chosen local area of Bushenyi.

Planning, arranging and acting

Implementation needs planning and arranging in order to embed CBR in the local context. The implementation process can be noticed in the various stages CBR was implemented in Bushenyi. The first stage was to choose and train 18 CDOs in Bushenyi. The nine-month training took place at Ruti Rehabilitation Centre in Mbarara, where CDOs earned certificates as planners and teachers of CBR. One of the interviewed CDOs describes the training:

Obviously before CBR I myself did not know about disability so they taught us what disability is all about, the major causes of disability, how we could prevent it, and how we could manage those who already are disabled. We also got information on referral systems where we could refer the cases that could not be handled at the grassroots. (Alex, CDO 1)

The quotation shows that (training) knowledge was an input in the project of CBR to create change for people with disabilities, whereby knowledge expressed through projects can change existing services. Johansson et al. (2000), however, say that the implementation of the project's result does not always happen when the project has ended; instead the training can be a mixture of studying and implementing various skills as in the CBR project in Bushenyi. When finishing the first course, a CDO says:

We came and did what we call registration of persons with disabilities and classification of types of disabilities we came across. (Bosco, CDO 2)

Another CDO describes how they received CBR and how they worked in practice:

We received it with much enthusiasm because we had not known that perhaps there are some people with disabilities down there. But when CBR came we had to go from home to home identifying the persons with disabilities. I think during that project cycle we almost knew each household in the sub-county which had a person with a disability. (Alex, CDO 1)

These statements show that CDOs were working according to the first part of the aim of CBR in Uganda "to identify all forms of disabilities" (Baryayebwa, 2002, p. 3). It also shows that the input of knowledge gave a result (output) which made it easier for them to identify families and children who needed assistance. When

visiting the homes, cases of people with disabilities were recorded in booklets with their name, and photos were taken. The booklets were used as checkpoints to measure success and challenges and to give recommendations for what should be done next. When going back for later studies, CDOs examined the cases to identify which interventions were needed for certain types of disability, which adjustments to do, whom to refer, and who to attend to at home. The CBR training the CDOs completed also included how to inform parents of the results found, whereby the second stage of CBR was implemented, including raise awareness among families of children with disabilities. Gloria, a parent of a child with a disability, gives an example of the help she received:

He was told that there is a disabled child in the home. The person who visited advised me to take my child to the hospital.
(Gloria)

With the knowledge gained from trainings, an output of awareness was experienced. According to Hill and Hupe (2009) it is good to search for behavioural output variables to avoid examining policies of goal-achievement (outcomes). During the meetings with families, the comments area of the booklet was filled with recommendations, such as surgery or a corner seat for a child with a disability. Bosco (CDO 2) mentioned that training materials, such as corner seats, parallel bars, climbing ladders, or old tyres fixed in the ground for children's exercise, were also designed when needed. This particular practice represents an idea from the WHO training manual (Asindua, 2002) and can be seen as an output from the knowledge the CDOs gained from the CBR project. At a later stage the adaptations and advice given to the families were evaluated and when progress was identified, a record was made. 36 parents were trained in CBR, 36 other parents were not trained but received services, and 47 children with disabilities were trained (Keibanda, 1995).

The third and final stage in the implementation of CBR, according to Bosco (CDO 2), was to raise awareness in the communities providing services to children with disabilities, including teachers, school children, and nurses. The awareness of families and the community reflects the second part of CBR's aim in Uganda, "to provide the best rehabilitation services with full participation of the community" (Baryayebwa, 2002, p. 3). It also relates to changes that took place in CBR during the 1980s and 90s, when more interventions related to education, prevention, social rehabilitation, and vocational training were found to be needed (Thomas & Thomas, 2002). These interventions gave CBR a more social approach that viewed the lives of people with disabilities holistically, rather than focusing narrowly on the medical aspect of "fixing" them to fit into the community.

Adequate resources

CBR as a project of change and development through generating knowledge, have been found giving outputs such as the possibility to identify the once in need, create awareness in families and the community as well as designing devices for people with disabilities. These outputs are the acts which put the policy of CBR into effect in Bushenyi, as Paudel (2009) mentioned earlier. However, when examining the implementation process of CBR in Uganda and Bushenyi it is found that another input, namely financial means, have especially influenced the implementation and maintenance of CBR. Both Paudel (2009) and Van Meter and Van Horn (1975) agrees that local capacity is critical to a policy's success. Receivers in an implementation process have to *be able* to implement the policy, according to Van Meter and Van Horn (1975).

When CBR was implemented in Uganda the funding for institutions serving people with disabilities was restricted. Networks providing resources to the institution received other directives and decreased funding or stopped it altogether, an unintended consequence of the shift from institutional to community services for people with disabilities. Jesca, a social worker who worked at such an institution during the introduction of CBR, express it in following way:

The approach was good but at one time it looked like it was killing the institution. I do not know if it was the understanding or the approach that . . . because networks worked into the institution towards people with disabilities, they were first at the institutions and then they moved to community, so the institutions tend to lay down because of the supply they were given to them. (Jesca)

An orthopedic officer employed at another institution for people with disabilities confirmed that resources to some institutions in Uganda were restricted when CBR entered, and one had to shut down. Once the networks, in the form of the government and/or NGOs, began to view CBR as the most effective way to provide rehabilitation for people with disabilities, fewer materials and other resources were provided to the institutions. Importantly, however, Baryayebwa's (2002) study comparing institutional rehabilitation and CBR showed that people with disabilities performed better and were more integrated into society as a result of the financial potential gained by developing skills at institutions. Thus, the two approaches are not mutually exclusive, especially given that age and the type of disability affect which kinds of services are needed.

With CBR viewed as the primary means of providing services to people with disabilities and with fewer funds going to institutions, one might expect that CBR

would be provided with the resources necessary for its success. However, the three CDOs interviewed at the local level give another view. While resources were readily available during the time frame of the CBR project from 1992 to 1998, they were reduced when it shifted to regular service activities. One of the CDOs in Bushenyi noted:

The participation of CBR had reduced a bit; we are just promoting participation of people with disabilities in decision making organs like Local Councils, encouraging parents to let all the people with disabilities to enjoy education, not the depth implementation like that time when it was getting heavy funding from abroad, from external donors. (Bosco, CDO 2)

External funders were important providers of funds to CBR activities, but the generous funding they provided initially was reduced with time. This dependency on donor support and funding has been noted earlier by Cannon (2000) and Tomasevski (1999). However, Bosco (CDO 2) also mentions the government's role in the provision of funds:

It is the government who paid our salaries. External funders were not paying us a house allowance; it was our government who paid us all that. But we were doing that service with help from people from outside, to subsidise the appliances like wheelchairs and training materials. So, it was a combined effort. (Bosco, CDO 2)

Despite this combined effort, the government has retreated from its role as a funder, leaving a much larger role for international NGOs (Jackson, 2010). This is especially evident when one considers the debt Uganda, like many other non-Western countries, has to the World Bank (Loomba, 2008; Tomasevski, 1999), with its neoliberal political influences. It is also evident when examining how the everyday work of the institutions that serve people with disabilities was affected by the funding to CBR during its programme time and maintenance. Jackline (CDO 3) observed that "if the programme was funded it could come back on the map because we have data and manpower, but funding is a problem". Two of the three interviewed CDOs describe this issue and how it affects their work:

I saw some changes because once the input reduces usually there are some changes. If you covered six parishes you might end up with going to two; where you have been going three times, you start going there once. (Bosco, CDO 2)

Today, okay, now when the funding stopped I would say our staff no longer reached down at the household level but there are some activities being done because . . . the CBR activities are also integrated in the plans at sub-county level so whenever funds are available they obviously have to go down and do activities at the grass roots. (Alex, CDO 1)

In addition to restricted funds limiting the ability to provide services at the local level, there is also uncertainty when the funds are available at the institutions serving people with disabilities. However, Bosco (CDO 2), says that when the CBR project came to an end the aim of the project had been achieved: people with disabilities were all allocated, those to be assisted were already assisted, and families that needed counselling and guidance were already helped. What was left was to monitor, register new cases, and raise awareness about what can cause disability. However, it seems difficult to maintain the work of CBR as well as bringing services to the ground when resources are scarce, as one CDO points out:

If at all we had enough resources, I would expect that we would extend the services to these people with disabilities because . . . now even our community development workers at sub-county level are not capable of reaching each person with a disability and that means that even the services are not wholly taken to them. If the government would solicit funding or set aside some fund specifically for people with disabilities, then I think our dream would be fulfilled. (Alex, CDO 1)

The government has been unable to continue implementing CBR practices effectively after the funding stopped, as Alex (CDO 1) also confirmed by noting that “the strategy which we were using was good; it was good only that we do not have enough resources to continue implementing it as it was designed”. Even though CBR is considered a cost-effective way of providing services to people with disabilities (Mpagi, 2001), supported by some interviewed CDOs and an initiator, it still consumes too many resources to enable it to continue in the same way. With restricted government financing it is even harder to maintain CBR, especially if resources may also disappear elsewhere. As Bosco (CDO 2) and Alex (CDO 1), two CDOs, and Innocent, an account assistant noted, the Ugandan government is trying its level best to fight corruption, which exists at both the national and local levels in Uganda (Steiner, 2006).

According to Bosco (CDO 2) no one has been judged guilty of misappropriating CBR funds, so he has no evidence to say that corruption exists. Another CDO also reported that no corruption exists, though she added:

Some contributed their money but they did not get the appliances they were in need of, so you find that they were somehow disappointed and at times they were called for trainings and what they expected was not what they got. At times they were given skills and maybe they hoped for much money but it was not like that. So they were somehow disappointed. (Jackline, CDO 3)

Corruption exists in form of parents of children with disabilities paying money without getting what they need in return. Similar incidents were reported at the local level by the parents of children with disabilities. Their accounts indicate that inequalities existed in the provision of CBR services, as some families, but not all, got what they expected and needed. Material or financial support was missing for all but one of the five parents interviewed, giving them a negative view of CBR. The exception was David, who held a very positive attitude towards CBR because of the benefits it provided to his son:

He was getting free books and pens and when he completed senior four he was taken over, he was given a scholarship. It should be recorded that the scholarship was from the government; it was because of CBR. It even gave me something, to go for courses and workshops outside the district, only as a parent. (David)

In David's case his expectations were fulfilled. This reveals another side of CBR, an experience different from that of the other parents in relation to material and financial support. This is remarkable because all the parents were living in the same sub-county. Such inequities can lead those who do not receive support to have a negative view of what CBR is meant to be and what it can do. It can also mean that corruption is involved, leading to some people receiving benefits that are denied to others. As Steiner (2006) has observed, even individual households are affected by this type of corruption, leading to negative attitudes towards CBR.

The input of financial means during the time of the project gave outputs, such as a support when raising awareness and allocating, assisting, counselling and guiding people with disabilities and their families. However, when the project stopped it was difficult to maintain the work of CBR as well as bringing services to the ground, whereby a correlation between time and financial resources can be

noticed. According to Johansson (2004) adequate resources are important local conditions which may benefit or hamper the implementation. Financial means was beneficial during the projects timeframe though giving receivers a low level of local capacity when trying to continue maintaining the project as it was planned, when ending. The knowledge and manpower is there as Jackline (CDO 3) expressed it, though the financial means is missing.

Motivation for participation in the project

Paudel (2009) and Van Meter and Van Horn (1975) agrees that *will* is another broad factor which is critical to a policy's success. Van Meter and Van Horn (ibid.) state that receivers in an implementation process have to have *the will* to implement a policy and according to Paudel (2009, p. 38) motivation or will "reflect the implementer's assessment of the value of a policy or the appropriateness of a strategy". A CDO express this in following statement:

By then it was very good but now it is a bit sliding back because even if you call people with disabilities for a meeting and you don't facilitate them with transport and allowance, and their situation of crawling coming this way, you find that it is difficult, you cannot get them. So people have developed high expectations getting money instead of knowledge and now the situation is going back like the other days when people were eager to hear what is required of them like getting knowledge and know how to handle their situation, but now they are after money not handling their situation and plan for it. (Jackline, CDO 3)

Though, CBR activities are included under other development activities today, it was noticed that CBR as a project is welcomed in Bushenyi again if financial means exists. The motivation among CDOs for a continuing CBR project can be related to what they gained from the project. Except the possibility to support people with disabilities with transport and allowance as the quotation shows, T-shirts, bags and office furniture was given. Whereby, CDOs can give the policy of CBR a high value (Paudel, 2009). However, the policy or project of CBR also created high expectations among people with disabilities, making them not to be responsible of their own lives. This can question the appropriateness of the project (Paudel, 2009) whereby further investigations is suggested. The high expectation can also create low motivation among people with disabilities to participate in CBR.

In the area of Bushenyi, with no nearby institutional rehabilitation centres for people with disabilities and where one of the pilot programmes for CBR was

established, a low level of participation among parents of children with disabilities occurred. The low level of participation may result from the top-down approach to implementation, which all of the parents described in different ways. Two parents, Amos and Fred, illustrate it as follows:

At first I thought that the expectation was like group formation so that we can learn and teach one another. (Amos)

By the time we looked at the service which was there, information and seminars were not matching with what we wanted so we had to look for our way out and continue helping our child. (Fred)

These quotations indicate a low level of participation due to a lack of involvement in CBR, giving rise to unfulfilled expectations and a lack of cooperation among individuals facing similar situations. It also illustrates that low participation results in the creation of services not desired by stakeholders (Messer & Townsley, 2003). When expectations are not fulfilled, low motivation can be a result. However, this does not mean the parents were not sensitised and did not attend meetings; they did, according to some of the parents interviewed. Nevertheless, the aim of CBR is full participation of the community (Baryayebwa, 2002), and in this case certainly the parents' participation could have been greater. The low participation may be a legacy of the first international definition of CBR, which creates a top-down approach by transferring knowledge to people with disabilities, instead of incorporating them as part of the planning (cf. Lang, 2011; Lysack & Kaufert, 1994). This also results in CBR's lack of reference to local actors—in this case; parents of children with disabilities—creating a low degree of local identity (cf. Røvik, 2008).

Thus the required bottom-up approach of CBR in Uganda was turned into an institutionalised top-down approach, due to the government's role in implementing CBR and the absence of NGOs working for people with disabilities within the particular area of Bushenyi. This top-down approach influenced also the low degree of participation among parents of children with disabilities and other actors, leaving CBR with a weak local identity. As a result, the idea of CBR is more affected by international and global history than by the local present and future (cf. Røvik, 2008).

Knowledge-based changing attitudes

Hill and Hupe (2009) suggest searching for behavioural output variables to avoid examining policies goal-achievement (outcomes), as mentioned before.

Except awareness, changed attitudes can be counted as an output due to the CBR project in Bushenyi. By receiving training and knowledge from CBR, not only CDOs attitudes changed as mentioned in the introduction. In general societal attitudes seemed to be challenged. Amos and David, two parents of children with disabilities, describe this change:

Like in churches, you may go to church as a person with disability and when seated you find that they are not minding about you like before when they said: I cannot sit with a person with a disability. (Amos)

There was a difference because there was like a programme. When you go to the hospital and you are carrying a child who was disabled you are quickly attended or if somebody comes in a wheelchair they were given first attention. So there was help. There was also attitude change in the hospital. (David)

These observations show how oppressive attitudes have been challenged and have changed in the community as a result of implementing a less paternalistic model of rehabilitation. This change is the result of the working process of CBR, through which CDOs were first trained to educate others in society. Thus it can be said that the government's top-down implementation of CBR has affected the community positively, encouraging professionals, parents, and community members to change their attitudes and behaviour towards people with disabilities. According to Fred, another parent of a child with disability, "there are some families of such thinking and they are still hiding their children". Benon, a teacher also describes the attitudes of other schools toward their school, which teaches children with disabilities:

Different institutions see us as if we cannot manage anything, our pupils, even when we join together they say leave those ones the deaf, they do not like our pupils because they are different. Yes, even they do not think we can win any game because we have those pupils. Like athletics, football, music, they consider us as if we cannot do anything. (Benon)

This quotation shows that oppressive attitudes still exist, indicating that CBR has not reached everywhere, and more awareness of the community is needed. It also demonstrates that the idea of CBR, which after its closure as a pilot programme was included in the regular services in Bushenyi, has not managed to

get a local future as wished for (Røvik, 2008). Another teacher, Ronald who teaches children with disabilities, describes this as well:

We normally hear of CBR, then there are some officers in charge of those programmes but they are not coming to the villages to see what is happening. When they are planning we request that these people should also involve us. They are at the district, they have motorcycles, you see them riding but they do not mind, maybe they are not interested. (Ronald)

Ronald's desire for increasing cooperation between different actors participating in the project is crucial for CBR to be institutionalised in Bushenyi, since the missing link of cooperation makes an obstacle to knowledge-based changing attitudes and thereby institutionalisation of a project (cf. Hargrove, 1975). Other reasons for CBR not to be institutionalised in the area includes a lack of funding from the government (Cannon, 2000), lack of nearby social services, the absence of NGOs working for people with disabilities, and low participation of people with disabilities in CBR. The need to liberate and empower people with disabilities is one motivation underlying the demand for a less paternalistic model of rehabilitation in Uganda. Changing attitudes in the community and among professionals is another one. The government's limited resources are a factor that has affected the demand for a new approach to rehabilitation. However, involving the community does not mean the government can relinquish its responsibility, especially when considering the socioeconomic situation of families of children with disabilities.

CBR Affecting Receivers Situation - Results

This section will highlight how CBR, as a change and development project, has affected the living conditions among children with disabilities and their parents in Bushenyi.

Endeavours for the improvement of children's living conditions

Since the Second World War, views regarding people with disabilities have started to change (Bille et al., 1999; Kerz et al., 1995). Their rights, along with the rights of people in other marginalised groups, have become an area of focus (Johnson, 2009), reflecting a growing awareness of the capabilities of persons with disabilities (UN, 1994). This has also led to the turn to a rights-based development approach (Grech, 2009) within international organisations promoting new ideas such as CBR. This is evident in CBR's aim of "enhancing the quality of life of disabled people by improving service delivery, by providing more equitable

opportunities and by promoting and protecting their human rights” (Lang, 2011, p. 3). As discussed earlier, the striving for a bottom-up approach by using CBR and Uganda’s institutionalisation of some laws and articles related to this approach have influenced human rights and the equalisation of opportunities for people with disabilities (UN, 1994). However, in Bushenyi people with disabilities face a continuing struggle for their rights, which a CDO describes as follows:

When I conceived the whole idea of CBR I looked at it as a way which would help the community themselves, help the people with disabilities at least in bringing them up; fighting for their rights which the parents were abusing, which the schools were abusing and even which the community were abusing. (Alex, CDO 1)

The need to achieve equal rights for people with disabilities was a focus when implementing CBR at the local level as well. The importance of changing contextual factors in the community was recognised as a necessary step to escaping a top-down medical model (Thomas & Thomas, 2002). This study found that parents of children with disabilities had acquired knowledge capital, based on experiences and skills, which the CBR services provided in practice. This knowledge capital also provides evidence of the changes that took place among parents of children with disabilities, which increased the rights of people with disabilities. As Fred, a parent explains:

So my feelings and effect was that the knowledge we were getting from the training was good, it was encouraging us and training us to handle, how to live with people with disabilities, that we should not hide them, it is not a curse. It strengthened me because it encouraged me to push him high in education, so I was encouraged. The knowledge and information I got changed me and it influenced my decisions on my child. (Fred)

This statement illustrates the changes that occurred due to the knowledge provided by CBR. All of the parents reported that they had gained knowledge and strength primarily as a result of their individual meetings with CDOs, although sometimes also as a result of community group meetings. Gloria appreciated the advice given to her by the service providers and emphasised the importance of the knowledge she gained, noting: “I was helped by being educated to have a positive attitude on my child”. She also points out that she was strengthened by seeing her child’s achievements and recognizing that her labour was not wasted.

Amos agrees and says that the programme brought parents and children together and educated parents that children with disabilities are like others. These parent comments show that CBR, implemented in a top-down manner, helped some parents in the programme become more aware of their children's rights and value. The services also changed the feelings some parents had towards their children with disabilities, providing another type of knowledge capital. As David and Gloria observe:

Before the CBR programme, I thought there could be no change of the child apart from eating to death. It changed me to love my disabled child like any other child, which is the biggest advantage I recognised in CBR. (David)

My child is my life, now even I have appetite to eat because my child is improving, I feel okay. It has changed; the love for the child is increasing. (Gloria)

Both David and Gloria express that knowledge from CBR changed their feelings, making them love their children more. David and Amos offer another example of the knowledge capital CBR has provided:

I felt that it was important and as a person with a disability, having a child with a disability, the knowledge they were giving was helping on how to take care of the child. I myself could also use the same knowledge to talk to some other parents having such children so that they do not leave them behind. (Amos)

We are still involved. After that I also advise other parents who have children with disabilities on how helpful it can be if their children are attended. (David)

The knowledge gained from CBR led the parents to attain skills that they could then use to inform and support other people in similar situations. Gloria mentions that she has shared the skills she learned even with others who are not disabled:

I used to be asked about the child but those who were asking how the child had been worked on, and I was sharing experiences with them, had no children with disabilities. (Gloria)

These comments demonstrate how information and knowledge gained from CBR may be shared with others, though David is the only parent interviewed who considered himself still involved in CBR. However, the other parents who are no longer involved in CBR still report sharing the knowledge they gained with others. David's continued involvement may result from the fact that he was the only parent interviewed who reported being satisfied with and appreciative of the services he received from CBR. The other parents appreciated the knowledge and awareness they gained, but were disappointed when their expectations were not met and when material needs were not provided. Gloria, for example, thought she would be helped after rehabilitating her daughter, but her expectations were not met because she did not receive any material support. Amos noted that he had only one expectation—to get school fees for his child—and this expectation was not met. Fred agreed, noting:

. . . but what was not okay; there were no material gains, the promises were not coming so expectations were not met. I am still not satisfied with what happened to my child. (Fred)

The parents' experiences indicate that the knowledge capital gained from CBR was not enough to meet the families' needs or to fight for their children's rights. A top-down implementation of CBR has made parents as well as the community more aware of the situation and the value of people with disabilities. However, contextual matters such as their socioeconomic situation and closeness to services, and their disappointment in not receiving the help they feel they most need, such as school fees and other material assistance, can be reasons for them to reject CBR. Rather than parents fighting for the rights of people with disabilities the fight often becomes, at the local level, a fight for needs. This shows that the needs of families and the aims of CBR, in practice, were not well matched, resulting in a low degree of participation by those whom the services are intended to serve.

Factors Influencing the Implementation Process

In this section, different factors which have influenced the implementation of CBR in Uganda are highlighted.

CBR as a new international idea in Uganda

Lang (2011) notes that it is crucial to examine the power dynamics and relationships behind implemented services. According to Apollo, an initiator of CBR, there was another motive for implementing CBR apart from understanding the situation of people with disabilities or recognising that existing services are not enough. He says that it "was the time the whole world had turned the attention

towards CBR". This shows not only that CBR was widespread and of great interest as a strategy of rehabilitation for people with disabilities, but also that CBR had become a superior idea and a trend to follow (Johansson, 2002), influenced by such strong initiators as the WHO and other UN organisations.

Nevertheless, it is not only international influences that can determine which trends will be followed. According to DiMaggio and Powell (1983), the state and professionals can also influence which trend will prevail. The role of the state as a trendsetter was noted by Apollo in the Ministry as well as by CDOs at local level when asked if they were ever hesitant about CBR:

I do not know if I ever got a chance to hesitate because this was a ministry policy. (Apollo)

I did not hesitate because when you are taking a job in government you accept to take all instructions. I was a civil servant; I have to carry out the responsibilities given out by my supervisors. (Bosco, CDO 2)

These quotations not only convey the difficulty of influencing one's method of working in a governmental job, but also indicate the government's role as a trendsetter with power over professionals in deciding which ideas to implement. According to Sandström (2008), power is also a way to make an idea take hold in the world, to make governments accept the implementation. The Ugandan government as a trendsetter for CBR is affected by hegemonic structures of dominance that WHO or other international organisations like NAD use to create global consensus around CBR, framing their international image, policy, and purpose (Stone & Maxwell, 2005). However, the initiator of CBR emphasises that the government in Uganda itself invited NAD to assist in the implementation of CBR:

They do not brag that they have a program here; they know the program belongs to the Uganda government for its self-sustainability in the future. But they came in to see it start . . . and actually they used our plan of action which we had prepared at that time in Uganda. (Apollo)

This statement illustrates the relationship between the external agency and the Ugandan government as well as the role of each in the implementation of CBR. As a former colonised country with existing post-colonial influences, Uganda's relationship to Western countries may be viewed as one of dependency in which the Western countries' ideas have become a legal procedure in the non-Western

country. The quotation also shows a tendency toward what Fanon (2008) referred to as a “move away from the inhuman voices of their respective ancestors so that a genuine communication can be born”.

With CBR as the second method of rehabilitation reaching Uganda (Baryayebwa, 2002; Claussen et al., 2005; Keibanda, 1995), and as a superior idea and trendsetter in the world, it can be argued that it was unavoidable that a non-Western country such as Uganda would implement a new strategy or model like CBR. In general knowledge, models, and strategies are transformed or copied from Western to non-Western countries (Kamali, 2006; Tomlinson, 1999). The trend of CBR was strong and seemingly unquestioned because it was implemented by the government, and also as a result of a lack of knowledge of different methods of rehabilitation.

Alex (CDO 1) working at the local level noted that the government had to inject reasonable amounts of money and resources into CBR because it was the best option available. However, he and Bosco (CDO 2) expressed a lack of knowledge about methods of rehabilitation other than institutional and CBR:

Another method than CBR? Like which one now? As I told you, CBR, to me, was the best approach. But obviously every approach has got its own advantages and disadvantages so if there was another approach we could also get some advantages from that approach and get the advantages from CBR approach, and then we combine and get something better. (Alex, CDO 1)

We are living in a changing world. If there is another methodology which can come in, so long as it improves the welfare of people with disabilities, it is okay. Before CBR we thought the institutions were a better solution, but when CBR came we found that institutions were causing other challenges to people with disabilities. They can work along with each other but not looking at it as the only approach to solve the problem. (Bosco, CDO 2)

These quotations show that knowledge of other rehabilitation methods was missing, which indicates that no other options were available at the time CBR was implemented, although several models exist (Marnetoft, 2000; Solomon, 1992). From this perspective, diffusion instead of translation has taken place, in which leaders copy an idea from Western countries that are presumed to have better ideas, and transfer it to an environment presumed to have poorer ideas (Czarniawska, 2005; Grape et al., 2006). A third CDO interviewed in Bushenyi

reinforces the idea that diffusion rather than translation of CBR has taken place in Uganda:

If we can get another funder or initiator who maybe can initiate a different method it would work, but for us we are still using the old one. (Jackline, CDO 3)

No continuing process of translation has taken place, as Grape et al. (2006) and Czarniawska (2005) observe. Instead, Jackline (CDO 3) points out that they are still using the same method as before and there is a sense of waiting for other methods to be presented by their funders. Others could come up with suitable rehabilitation methods, she notes, observing that “funders could come back and support these people. I think our society would feel very happy”. This also shows a relationship of dependency with funders of rehabilitation services, which two other CDOs state in similar ways:

The government role in CBR I think is okay because in the first incidence it is the government that solicited for support from abroad and it is the government that put up a policy of attending to challenges of people with disabilities. (Bosco, CDO 2)

Chances are open. Now when you come up with the report, I think you will give the government of Uganda a copy. So the government of Uganda can use that report to solicit for more funding, I think the ministry could use it to solicit for more funding from the government. (Alex, CDO 1)

The reliance on funders is shown when planning for CBR and a hierarchy can be noticed when addressing for funds. Funds must first be solicited from abroad, and only secondarily through the ministries advocating for funds from the government. This shows that searching for funds from different organisations within the country or abroad has become a widely accepted practice—this is how it works and how it should be done—instead of expecting funds to come directly from the government. This can be seen as evidence of a dependency relationship between non-Western and Western countries, created by the colonial time and to a large extent still imposed by the continuing post-colonial era.

Though CBR is proclaimed to be based on “traditional good practices” in non-Western countries (Hartley, 2001; Helander, 2007), Western structures nevertheless dominate and influence the implementation of CBR. Not only is CBR a trendsetting international idea, the new rehabilitation model in Uganda is also funded by NAD.

This and the government's role as trendsetter have influenced the implementation of CBR in Uganda, creating in many ways a top-down implementation approach. CBR implemented as a top-down approach may encounter difficulties when faced with a lack of resources and coordination.

CBR at the national and local level

According to Bosco (CDO 2) in Bushenyi, the implementation of CBR as a new rehabilitation approach was smooth because of its relation to the country's historical past:

It came at a time when the ground was levelled; you see, by 1990, 1991, and 1992, Uganda was in a transitional stage of people welcoming government programmes. We had come out of a regime that was not addressing community activities and people were accepting and welcoming all government programmes because they were looking at them as a way of helping communities, a way of solving problems. So CBR was not hesitated in any way. (Bosco, CDO 2)

As can be seen, Uganda's political unrest and an absence of social services (Nabuguzi, 1995) paved the way for an acceptance of government programmes of CBR. However, another historical element, related to colonial history and the idea of CBR travelling to the country, also influenced the implementation of CBR in Uganda (Erlingsdóttir, 1999). Apollo, an initiator of CBR and Joyce a physiotherapist working at an institution for people with disabilities during the time of CBR's entrance explained the travelling in following way:

In 1989 when I went to do my diploma, that was my first time. I was given a chance of doing a Post-diploma at East of London. (Apollo)

In 1990 I knew about CBR because a colleague we were working with is trained and starting off Community Based Rehabilitation Alliance. I just heard about it in 1989. They were going to do their study, the course in UK, a colleague of mine. But in 1990, that's when I got to know about CBR because Community Based Rehabilitation Alliance started. (Joyce)

These quotations show how knowledge related to CBR was transferred from England to Uganda. This is a common reality in the world order between non-Western and Western countries (Kamali, 2006; Tomlinson, 1999). It indicates that

CBR may have been easily transferred to Uganda due to the country's relationship to England, which is still influenced by the colonial past. This relationship has taken new forms (Lomba, 2008; Thörn et al., 1999), where not only knowledge but also an initiating of various NGOs gives Western countries a mandate to influence the process of implementation and create work opportunities for foreigners.

Social services for people with disabilities are provided by both the government and NGOs (Sengendo et al., 2000). According to the Ministry of Health (1999), the government sees NGOs as responsible for addressing disability issues due to the support provided by donors to NGOs and the government's limited resources (Bennet, 1990; Cannon, 2000; Manyire & Asingwire, 1998). Nevertheless, it was the government's recognition of the situation of people with disabilities in 1965, supplemented by many volunteer organisations (Sengendo et al., 2000), that paved the way for implementing CBR in Uganda. Still, it was not until the disability movement and the creation of a national organisation for people with disabilities, NUDIPU, in 1987 that the policy structures in Uganda started to be challenged (ILO, 2004).

Nevertheless, there were no specific disability laws or policies that supported the implementation of CBR in the beginning. According to NUDIPU (2004), the decentralisation reform that occurred in 1992 (Steiner, 2006) was designed to encourage the involvement of people with disabilities in Uganda, a principle CBR also embraces. When the implementation of CBR had been in progress for two years the UN document "The Standard Rules on Equalisation of Opportunities for Persons with Disabilities" (1994) was adopted, and in 1997 The Local Government Act, which provides for representation of people with disabilities at all levels of government, was adopted (Millward et al., 2005). The policy of Universal Primary Education (1997), which gives children with disability a priority for education in a family, has also contributed to the greater participation in society of people with disabilities (ILO, 2004; Millward et al., 2005).

The structural issues of decentralisation and laws have been found to correlate with the government's role in implementing CBR in Uganda, according to the CDOs from Bushenyi. One CDO says that the government is doing its work because it has organised structures from Local Council 1 up to the national level. Along the same lines, another CDO noted that the government is working well because it implemented CBR through the Ministries. With regard to the structure established by the government due to the decentralisation, two of the three CDOs argued that "the role of government is to design relevant policies and laws and . . . it has already done that". Such rules and laws provide a framework to be used for children with disabilities, as one CDO describes:

Rules have affected CBR positively because all Ugandan children have to be in school. The rule does not say that all children who are healthy and not disabled should be in school. No, it says all children should be in school, which means they are favoured by the law. All children should get equal treatment, boys or girls, they are all favoured. (Bosco, CDO 2)

All the CDOs are pleased about the government's role in CBR as a result of the decentralisation, laws, and policies it has established. Alex (CDO 1), also points out that it has favoured CBR by letting all children go to school, thereby integrating children with disabilities. However, many of the laws protecting people with disabilities were established after the implementation of CBR. This indicates that CBR, as a new approach to rehabilitation, has brought changes for people with disabilities in the country, alongside the work of NUDIPU (ILO, 2004). In other words, there do not seem to be any laws in Uganda that facilitated the implementation of CBR despite the fact that, as one CDO said, decentralisation, laws, and policies now support CBR.

However, although decentralised structures, laws, and policies have been put into place, this does not mean that all people or all children with disabilities have access to rehabilitation services. Such access depends largely on their socioeconomic situation as well as on how such services are managed.

Health and social services in Uganda are provided by the government, which uses national and international NGOs as resources when working with limited budgets. Thus these services are ultimately dependent on donor support and funding (Cannon, 2000; Tomasevski, 1999). This is evident in CBR's implementation in Uganda, where its funding was a concern of the government as well as of the external funder NAD (Baryayebwa, 2002; Claussen et al., 2005; Keibanda, 1995). Through this combined effort the institutional rehabilitation service was to change, bringing rehabilitation services closer to the stakeholders through a CBR approach (Hartley & Wirz, 2002).

However, participants in the study spoke of scattered service provision and an absence of NGOs working for people with disabilities in Bushenyi. Bosco (CDO 2), working in Bushenyi said that national NGOs have done much for people with disabilities, which is a strategy of the government. Two other CDOs gave their views of the role of NGOs in the district of Bushenyi:

So maybe we are still having problems with NGOs. We have so many NGOs which say they are offering services to people with disabilities, but which services we do not know, because they are not open to give us their work plan, to give us their budgets

and you know how much is going towards that section. (Alex, CDO 1)

NGOs, the ones I see they are not working on CBR, they are working on other programmes like savings, like those of adolescence, those of domestic violence, environment but those concerning CBR I have not come across any. (Jackline, CDO 3)

These quotations show that although a multitude of NGOs are working in the area, they concentrate on issues other than those of people with disabilities. As Alex (CDO 1) mentions, this can result from a lack of transparency and cooperation between institutions. Bosco (CDO 2), notes that few NGOs cover the whole district, indicating that services are not reaching everywhere. Jackline (CDO 3), express a sense of uncertainty about the NGOs working in the area, surviving through funds from international organisations and vanishing whenever interest and current need are not there. One parent describes the scattered services from NGOs as follows:

There was another NGO, which I cannot recall its name, which was registering children with disabilities to be taken for schooling but it also disappeared in space; I do not know what happened. (Fred)

Two other parents do not know anything about NGOs working for people with disabilities in Bushenyi, although one of them had heard of an NGO in Mbarara, one hour's drive away. Another parent mentioned that efforts from civil society have resulted in the establishment of two schools that people with disabilities can also use. According to Lavalette and Ferguson (2007), the civil society can be a concept of mobilisation to fight against inequalities in society. A public sphere could therefore increase associational and institutional collaboration between the state, concerned NGOs, and the families of children with disabilities based on communication (Calhoun, 1992; Edwards, 2004).

However, there is a risk that NGOs will undermine the state welfare service provision for people with disabilities as well (Lavalette & Ferguson, 2007). If this occurs and a bottom-up approach to services provided by NGOs is missing, there is a risk of giving parents of children with disabilities too much responsibility for the child's welfare, without taking into account their socioeconomic situation (Hoogeveen, 2005; Palme et al., 2003). To face some of the challenges provided by the implementation of CBR as a top-down approach, CBR must be given a local identity through reference to local authorities and other actors in the organisational field of disability in Bushenyi as well as a local understanding of

dimensions of interests (Røvik, 2008). Even though NGOs are important providers of social services in non-Western countries like Uganda for people in general (Eade & Pearce, 2000; Sengendo et al., 2000), and for people with disabilities in particular (Shakespeare, 1993), there is no direct sign of a bottom-up managing of CBR in Bushenyi. Instead a governmental top-down approach exists, based on the government's superior role and CBR's inability to shape a local identity.

In other words, factors, such as CBR being a trend to follow internationally and supported by the government and by international and national NGOs, influence the acceptance and the implementation of CBR at national and local level. One reason for the acceptance can be the colonial history of Uganda, where Western countries have been able to introduce terms and conditions which non-Western countries should follow (Wallerstein, 2005). On national level there is neither found any laws which favoured the first entrance of CBR in Uganda, instead it is found that CBR more or less paved the way for laws and directives which favour people with disabilities. Though many NGOs in the area, it seems like the responsibility given to them by the government to provide services to people with disabilities has not been fruitful. Instead, a lack of coordination and cooperation has affected the implementation of CBR and as Alex (CDO 1) mentioned before a lack of transparency between institutions can affect when NGOs are unwilling to share their work plan and budgets.

Conclusion

This chapter has highlighted the implementation of CBR in Uganda in general and in the district of Bushenyi specifically. CBR was introduced by students who encountered the idea through their studies in England. Although the country was aiming for a bottom-up approach to rehabilitation, in practice CBR was launched as a government program with a top-down perspective and initiated by the government of Uganda with support from the NAD. The implementation process of the policy of CBR was managed and put into action in various stages. It was first translated to fit the local context in Uganda, taking people with disabilities situation into consideration. However, when reaching the local level of Bushenyi the policy was implemented according to the manual of CBR. It was implemented at the local level, first by training CDOs in Bushenyi, then by sensitising the families of children with disabilities, and finally by sensitising the communities from which the children with disabilities received services, such as teachers, nurses, and fellow school children. One conclusion of this study is that because CBR was initiated at national level and with a top-down approach, its purpose in Bushenyi did not arise from the realities or the needs of children with disabilities and their families. Instead, a general aim for Uganda was followed, giving CBR a weak identity in the local context.

It is found that CBR as a change and development project managed to influence and change the attitudes and behaviour of professionals, parents, and other community members towards people with disabilities in Bushenyi. CBR provided knowledge that strengthened the parents, changing their feelings for their children with disabilities and making them aware of their rights and value. This knowledge also led the parents to develop skills they could use to inform and support other people in similar situations. In this way, one could conclude that CBR with a top-down approach has affected the community positively. However, despite the knowledge and awareness they gained, all but one parent were discouraged when their expectations were not met and their material needs not provided for. Rather than parents fighting for the rights of people with disabilities their struggle became, at the local level, a fight for needs. This indicates a mismatch between the needs of families and the purpose of CBR, which may be due to a weak local identity and may result in a low degree of parents' participation.

This study identified some contextual factors that influenced the implementation of CBR in Uganda. Though some policy structures were challenged in the late 80s, no specific disability laws and policies supported the implementation of CBR. The structure of decentralisation in 1992 was seen by NUDIPU (2004) as a way to increase involvement of people with disabilities and their parents. However, the structure has not managed to implement CBR in Bushenyi as a bottom-up approach. Nevertheless, the government's recognition of the situation of people with disabilities, supplemented by the work of many volunteer organisations along with Uganda's political unrest and an absence of social services, paved the way for CBR's implementation.

The transfer of CBR to Uganda as well as its implementation in Bushenyi reflects a dependency relationship between Uganda and Western countries. The knowledge of CBR was transferred from England by students who later implemented the strategy, whereby a continuing postcolonial relation to England prevails. The promotion of CBR by the WHO and the UN made the adoption of this approach seem inevitable for a non-Western country such as Uganda. CBR was questioned neither by the government nor by CDOs at the local level, who lacked knowledge of other methods of rehabilitation. This indicates a copying, rather than a translation, of CBR from Western countries to Uganda in general and to the local level of Bushenyi in particular. This dependency relation is a legacy of the colonial past and can be seen as a contextual factor influencing the implementation of CBR in Uganda.

Finally, certain constraints and opportunities have affected CBRs continuity and institutionalisation in Uganda. Factors such as the availability of funds, level of participation of stakeholders, and a dependency on Western countries affects the continuity of its existence. The funding of CBR in Bushenyi allowed CDOs to

identify families that had a child with a disability and provided some opportunities for the parents of children with disabilities to meet one another. The end of funding has affected the continuity of CBR, restricting the ability of CDOs to continue working on behalf of people with disabilities. In addition, corruption can be an obstacle affecting CBR and interfering with its potential to be maintained as planned. This is especially harmful when parents pay for services that are never delivered, and when some parents are given benefits that others not.

With a lack of NGOs working for people with disabilities, a lack of cooperation between the government and NGOs, and severely restricted resources, parents' participation in CBR was found to be crucial for the maintenance of CBR in Bushenyi. However, the involvement of parents of children with disabilities was found to be low which may affect their motivation to attend CBR activities, giving CBR a weak local identity in its immediate environment. Thus CBR has not been institutionalised in Bushenyi as a bottom-up approach despite its good intentions. Rather, CBR has been institutionalised with a top-down approach, soliciting funds firstly from abroad and secondly from the government. CBR thus demonstrates a dependency on Western countries that represents a habitualised action that now seems to be institutionalised.

CHAPTER 6

THE IMPLEMENTATION OF CBR – SWEDEN

This section will highlight the spread of CBR to Sweden, i.e. how CBR was introduced and initiated, and why it was implemented. In this section quotations from four interviews with parents (Maria, Rickard, Moa and Viola) to children with disabilities are used to describe the living conditions of families to children with disabilities. Quotations from interviews with Malin a physiotherapist likewise the initiator and project leader of the CBR project and Johan a principal of education and training for people working with children with disabilities highlight the demand for a less paternalistic model of re/habilitation in Sweden. Both the professionals entered the CBR project in 1994.

Background

CBR was introduced in Sweden as a project between 1994 and 1998, with the name “CBR Fryksdalen”, financed by the county council with support from the National Board of Health and Welfare in Värmland (Hargö Granér, 1999). The initiator of CBR was a physiotherapist who was inspired by work in Gambia, where she recognised the value of CBR for children with disabilities.

When CBR was reembedded or turned over to local action (Erlingsdóttir, 1999) in Värmland, it was received by parents of children with disabilities. Parents were asked to participate in a group to improve their own and their child’s living condition. In 1994, 60 children in all enrolled in re/habilitation for children and youth in the northern district of Värmland, and their parents were invited. Eight parents joined from the beginning and approximately 30 parents joined in various activities during the time period of the project (Hargö Granér, 1999). The idea of involving the parents arose from what the initiator found during her practical work at the local level in Värmland. The parents were also the main implementers, with the initiator as project leader, deciding which steps to be taken in the project. The receiver of CBR can be seen as the transformer and transporter of the idea or policy, state Johansson (2002). According to several studies such receiving and spreading of the rehabilitation ideas demonstrates a bottom-up approach (Lang, 2011; Lipsky, 1980; Lysack & Kaufert, 1994; Thomas & Thomas, 2002).

However, the process of implementing CBR in Värmland also involved collaboration between the group of parents and various institutions working for the common good of children with disabilities, creating a public sphere and an organisational field of people working with disability (DiMaggio & Powell, 1983;

Jonsson, 2006; Lindqvist, 1998). As mentioned earlier, cooperation is important in implementing policy programs (Hjern & Porter, 1981; Sandström, 2008) and highly promoted in CBR (Kay & Dunleavy, 1996; Periquet, 1989; Thomas & Thomas, 2002). The collaboration, which formed the project, involved first cooperation between the parents and the Centre for Public Health Research in Karlstad, the capital of the county Värmland (Hargö Granér, 1999). A participation-based research strategy was used, making it easy for the parents to participate and see direct positive effects.

Other collaborating institutions, such as the re/habilitation centre in Karlstad as well as schools and social departments in the two municipalities implementing CBR, were also included. The collaboration shows the large number of government institutions involved in the implementation of CBR, a result of the Swedish government's principle of providing social services to its citizens (Swedish Industry, 2004). This demonstrates a top-down implementation and managing of re/habilitation services in Sweden where parents to children with disabilities easily become excluded (Lang, 2011; Lysack & Kaufert, 1994; Thomas & Thomas, 2002). Nevertheless, CBR as a strategy can be implemented in many ways in different countries as well as within a country (Asindua, 2002; Miles, 1996). As shown before, CBR was implemented in Sweden as a project with a timeframe from 1994 until 1998, and according to Johansson et al. (2000) projects has become a new form of implementing ideas and policies. A certain start and end point define a project; in this case a change and development project (Johansson et al., 2000), trying to change the living conditions of, and provide services to, children with disabilities and their parents in Värmland.

The living conditions of families to children with disabilities

The parents of children with disabilities may confront an overwhelming array of challenges. The parents interviewed for this study all live in a sparsely populated area of Värmland, far away (approximately 1 to 1½ hour) from its capital town, Karlstad, where the central re/habilitation centre for children and youth with disabilities is situated. All but one of the interviewed parents identified the distance to services their children need as a challenge. One parent expresses it in following way:

One day we went to Karlstad and the other day to Hagfors, then up to Torsby, perhaps something in Örebro and then it was the child care, school and counselors, it was like a single maze out of it all. (Viola)

The parents had to travel frequently, sometimes great distances, to reach the services needed for their children. How often they need to travel may depend on the child's disability, for as Maria points out, "some children could have up to 80 contacts." All of the parents emphasised how much organising all this travel and dealing with so many contacts affected their lives. Maria noted that it took a lot of time and a great deal of effort to keep up with all of these appointments. Moa, too, observes:

Then it is very difficult to see that any family that might work a lot as I do and have a disabled child and all I have to visit, I cannot see that I would have coped with it myself. (Moa)

Travelling to the offices of various professionals can also affect the family's financial situation. In addition to the cost of taking their children to various appointments, parents may also be restricted in their available working hours because of the time spent travelling. This point is emphasised by the work of some researchers who note that having a child with disabilities is often related to family financial strain (Hartley et al., 2004; Hooegeveen, 2005; Palme et al., 2003).

Moa's statement that she could never have coped with everything herself demonstrates the crucial role of support from other family members, relatives, and society. Some of the parents reported receiving greater support from relatives than others and some noted that their network of support was mostly linked to institutions concerning their child. The parents also identified the arrival of their child with a disability as a time of chaos in their lives. They recall the difficulty of coping with their situation at that time, which was complicated by a lack of support from various institutions involved with disability issues. As Maria explains:

We had to fight some but at that time we got good service from day care here; the manager helped us a bit. However, it was an uncomprehending administrator of the Law of Support and Service for Persons with Certain Functional Impairments, I can say. It is about ten years ago we struggle the most and there was no understanding or concern at all from social agencies or the administrator of the Law of Support and Service for Persons with Certain Functional Impairment; to me it seems to have grown. (Maria)

The parents faced difficulties in relation to re/habilitation institutions when trying to get help for their child. They encountered a lack of understanding and

knowledge from some professionals about the difficulties facing the families of children with disabilities. However, the level of knowledge among professionals seems to have improved over the years, perhaps because Swedish NGOs began to carry out social services to address needs that were not taken care of by the welfare state (Meeuwisse, 1999). One parent describes the issues he struggled with in trying to obtain needed services for his child:

There were no rights at that time, home help came. However, we were more supported by a physiotherapist here. We received good response by the re/habilitation. I have always had good contact with them. The Insurance Office is a necessary pain that never did any good. Insufficient knowledge, you had to search for everything yourself, and if not, you got a paper to read. No private contact. (Rickard)

Insufficient rights, inadequate support, and a lack of information are also evident in the comments of other parents who struggled to help their children. Viola states that it is “hard to know what you need; you are not really receptive when you're in the midst of it all”. Viola's words highlight the importance of providing services that are grounded in parents' own experiences of their situation. The lack of knowledge among authorities indicates that a top-down medical model of re/habilitation exists (Thomas & Thomas, 2002). Alongside the lack of knowledge, negative and even discriminatory attitudes may prevail. Maria explains the change she desires, as the parent of a child with disabilities:

Mainly to change society's view of disabled people in general. When I grew up this view was missing in the society. Yes, that my daughter would have a good life, her surroundings would accept her as she was and, well, that there would be resources and opportunities for her as for other children. (Maria)

Societies have dealt with people with disabilities based on their own cultural systems of belief, often labeling those with disabilities as “abnormal” (Kizito, 1993; Mackelprang & Salsgiver, 1996). This is one reason for the lack of opportunities and resources available to children with disabilities today.

Nevertheless, there may be another explanation for the lack of support and understanding among professionals, as Rickard mentioned. An increased neoliberal agenda, flourishing in the world, affects social finances (Hoogeveen, 2005; Palme et al., 2003) and thereby the resources available, as Maria mentions. Due to decentralisation, counties' and local authorities' responsibility for providing services has increased (Lilja et al., 2003) at the same time that professionals

working with service delivery are especially affected by regulated economics (Dominelli, 1999). This can be a reason for insufficient services during the implementation of CBR that seemed neither suitable for nor accessible to parents of children with disabilities.

According to Malin, the initiator of CBR, the financial situation was also a reason for implementing this approach. When she started to work in the sparsely populated region of Värmland she felt as if she were back in a non-Western country again. She notes:

First of all it felt like nothing had happen in the Swedish re/habilitation for five years, more than reaches the roof, i.e. the professional resources were not enough for the responsibility they had taken upon themselves. (Malin)

The initiator compares the provision of services to people with disabilities, and especially children with disabilities, in a sparsely populated area of Sweden with the situation in non-Western countries. In both settings the financial situation and lack of resources makes it impossible to fulfill the needs of children with disabilities. The parents faced a difficult reality because state, county, and local authorities were unable to shoulder their responsibility of providing for needs and guaranteeing the rights of children with disabilities with the existing model of re/habilitation.

The demand for a less paternalistic model of re/habilitation

This part presents some factors that lie behind the demand for a less paternalistic model of re/habilitation in Värmland. Re/habilitation in Sweden is controlled by the government and the municipalities governing employment and service provision (Dominelli, 1999). This presents a top-down approach in which the needs of children with disabilities and the voices of their parents can easily be overlooked (Thomas & Thomas, 2002), resulting in a paternalistic model of re/habilitation. This study found that the participants and their children did not receive enough support from various institutions. Malin, the initiator, noted that some items given to children with disabilities to help with re/habilitation went unused, they were found stored in barns, garages, and basements instead. She explains why these facilities were not used:

It is so easy to believe that they can try this support; maybe it helps, and then prescribes an aid. If you do not know about it or you do not follow it up as a therapist, then it is just there. Expensive, sometimes costing several thousand, and then you do not want to admit that the aid had no effect or that they

were just clumsy, unfriendly, and unpleasant to have indoors.
(Malin)

This view was also echoed by a professional working with special needs education:

Maybe it is a bit of a trap as well, to want to release something that actually does not change the situation fundamentally, but it is a little plaster on the wound. It was just this kind of activity we had, at first. We gave out training sets and toy sets and things like that. Farther in, I really do not think it was needed.
(Johan)

Failing to recognise the real needs of children with disabilities, the authorities provided inadequate substitutes instead. This suggests the importance of assessing what children with disabilities and their families genuinely need. It also demonstrates the need for a less paternalistic model of re/habilitation based on a user-led practice. However, although many NGOs and service providers have worked to make less paternalistic models a reality, they have found it hard to maintain the participation required for the model to succeed (Dorsner, 2004; Jönsson, 2010).

Malin, the initiator expressed another reason for needing a new, less paternalistic model:

There was a feeling that we at the re/habilitation had, those who could see and know, [that we] almost were taking the child away, interfering with the child in the integrated environment as a result of treatment, consultations and meetings, etcetera. The idea of integration was simply broken. (Malin)

This quote shows how re/habilitation professionals may exercise power over the parents, giving a sense that the professional is taking the child away from his or her parents. This dynamic may be one reason why the interviewed parents in Värmland felt a lack of understanding from the authorities and frequently expressed frustration and sadness in their interviews. Two parents, Moa and Richard, explain their responses to the professionals' expertise:

Sometimes as a parent, I could feel that, "Yes, yes, yes, you know, but now we do like this instead". They know best anyway so if you do not agree with them and do not have the same view, it is a slow system in re/habilitation, I think it is. I

myself would certainly be like that if I worked there, so I might not say anything. (Moa)

This is the response they get and this is no good answer to give people who have knowledge. Then they said goodbye and thank you directly. (Rickard)

Such dismissive attitudes towards the parents' knowledge of their children can lead to unmet needs. Moa has tried to offer professionals from various institutions suggestions on what her child needs, but without success. Maria has had similar experiences, but reports some success in obtaining services by fighting for them.

The demand for a less paternalistic model of re/habilitation in Värmland arose from the need for a user-led practice that better addressed the needs of children with disabilities and their families. In addition, such a model fostered collaboration between parents and professionals that increased communication and enhanced professionals' understanding of the parents' situation. In recognising the parents' expertise, this less paternalistic model returned the parents' power.

The Implementation Process

In this section, CBRs interaction with existing practices at local level in Sweden is analysed. So as well how it has been maintained in the new context. This analyse is based on interviews with the four parents and the two professionals mentioned in the introduction. However, six other interviews with professionals are also included under this section. Thomas and Samuel, two principals, one from each municipality, who joined the CBR project 1997; Anette and Linda, two LSS-administrators, one from each municipality, entering the project around 1995/1996; Ola, the head of social welfare service, who joined CBR 1995 and finally Rut, a social worker working as a counsellor at school, who saw herself being in the periphery of the CBR project since 1994.

Packing the idea of CBR

According to Hill and Hupe (2009) and several others (e.g. Buse, Mays & Walt, 2005; Lester & Goggin, 1998; Van Meter & Van Horn, 1975; Meyer & Goes, 1988) implementation is a process during which a range of decisions and actions are directed to put a policy decision into effect (Paudel, 2009). CBR was chosen as a model of solution for parents to children with disabilities situation in Värmland. However, the international idea of CBR had to be translated to the local context in Värmland, considering the demand among parents to children with disabilities.

When a model, policy or idea spreads to a new place, the idea often has no reference within the new context. To create meaning and establish references

through social interpretation, the idea of CBR can become registered in a new context through the process of localisation and by developing for the idea a local past, present, and future (Røvik, 2008). The spread of CBR to Värmland in the 1990s, rested upon the international definition of CBR from 1994, whereby the registration of CBR in Sweden was localised from international references and global trends, on its way to shaping a local identity. During the process of localising the CBR in Värmland, the living condition of children with disabilities and their parents was brought to light by Hargö Graner (1997, p. 140):

They are researching their own situation, maps needs, shortages, disabling factors, relationship to surroundings, their own and others' resources, propose solutions to change and initiate various actions.

This means that when packing the idea of CBR parents to children with disabilities' living conditions were taken into account (Czarniawska & Joerges, 1996; Røvik, 2008), providing references to a local history (past) (Røvik, 2008). As mentioned before, the receiver of CBR can be seen as the transporter and transformer of the policy or idea (Johansson, 2002). Because of the initiators (project leaders) translation of CBR and the creation of references to a local history where the parents were transformers and implementers, the idea of CBR was packed as a bottom-up strategy.

Nevertheless, the project was also between 1996 and 1998 followed by a management team consisting of responsible officials from Sunne and Torsby municipalities and parent representatives. The local Social Welfare Board was in charge of the project and the educator as co-manager. Members in the CBR project also regularly reported back to the local Social Welfare Board.

When packing the idea of CBR, no direct sign of using the manual of CBR is found. Instead, the idea of CBR was translated into a model for the local Swedish context, combining cooperation, knowledge production and to work and learn together (Hargö Granér, 1999). This shows that the idea of CBR was spread through translation rather than through unchangeable performances between actors (diffusion). According to Røvik (2008), for CBR to have a local future in Värmland it must become part of a long-term plan. This was the intention when CBR was scheduled to become part of the regular activities of the municipality, after the formal end of the project. The unit charged with carrying out the law of LSS was responsible for further development of CBR (Hargö Granér, 1999). Thus there is a need to look more closely at how CBR was reembedded in practice in the local area of Värmland.

Planning, arranging and acting

Implementation needs planning and arranging in embedding CBR in the local context. The implementation process can be noticed in the various steps CBR was implemented in Värmland. The first step was for the group of parents to explore their feelings about being the parent of a child with a disability. This step was especially noteworthy for the fathers in the group, as many of them had a chance to express their feelings for the first time. This process took about a year. Maria, one of the interviewed parents, explains this step in the process:

I think we met approximately once a week . . . then we only sat and talked to people about everyday problems, how it works and there were some lectures. The project leader sometimes invited the person in charge of the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), to tell what it is and which rights they have. Sometimes the head of the social department was invited as well. (Maria)

The parents met regularly in a research circle where they identified problems, why it was a problem and what to do about it. The meetings were taped and analysed by the parents and the project leader of CBR (Hargö Granér, 1999). By allowing parents to share their opinions and feelings with others, this first step also enabled them to gain knowledge from different actors through lectures. The lectures can thereby be viewed as an input in the project of CBR to change parents' and children's situation. A project can, according to Johansson et al. (2000), be separated from the permanent organisation with the aim to create new knowledge and to change existing services. Through this part of the process, parents concluded a second step that their children's grandparents were important to include, because they seemed to avoid talking about the difficulties of having a child with disabilities. The grandparents were then invited by the parents to participate in a conference. Various parents as well as an educated physiotherapist who herself had a child with disabilities gave lectures.

After about two years, parents were ready for the third step, which was to engage various institutions involved in their child's daily life. Policymakers, managers, and officials of local planning were involved. During this step parents and professionals from various institutions also planned meetings, organised conferences, and held lectures in other municipalities. Rickard and Viola, two interviewed parents, describe this step:

In extension we traveled around and had some lectures. It was always that I took it from a father's perspective and his responsibilities, which was quite natural. (Rickard)

Then we organised courses and seminars for other parents. Each of us was out and talked about our experiences, we talked for staff and went, yes, constantly around and talked about this. In the end of the year 98 we told our life stories as parents of small children and we had invited the municipality, politicians at parliament. (Viola)

At a later stage, parents spread information and knowledge about their situation and thus about CBR to institutions at various levels of society. When parents felt ready, they contacted a newspaper about running a story depicting CBR activities. This reflects the purpose of CBR in Värmland, which highlights family involvement, self-determination, and influencing societal services (Hargö Graner, 1997). This also shows that the input of knowledge gave results (outputs); making parents' feelings and experiences known through activities such as lectures, courses, conferences and seminars.

In addition, the CBR project resulted in other actions as well. For example, a department called "Viljan" (The Will) was created by parents and a principal on a special school, focusing on specific support for children with severe disabilities who were in need of other stimulation beyond being in school. A DAMP (deficits in attention, motor control and perception) on call was also created to support parents of children with these disabilities at any time. (Note: These two activities are no longer in existence). Two parents of children with DAMP also wrote a book called *Happy Every Other Wednesday* (Boëthius & Rydlund, 1998). The book describes situations often faced by parents of children with DAMP. Additionally, a one-year, post-secondary vocational training program for assistance to children with disabilities was started in 1998. Today this training is a qualified vocational training.

Yet today, only the vocational training program seems to still exist in Värmland, despite the fact that when the project ended, CBR was spread by the initiator to Gothenburg, where she started a CBR learning centre for unemployed youth with financial support from the EU. It is notable that CBR was a new concept in Värmland, and perhaps in all of Sweden, not counting the spread of CBR to Gothenburg. However, theoretically the concept of CBR is not so new. Long before CBR was implemented in Värmland, Uppsala University offered a course in CBR aimed at teaching managers and implementers of CBR programs (Nganwa et al., 2003) who were working or planned to work in non-Western countries how to implement this strategy.

Adequate resources

CBR as a project of change and development through generating knowledge, have been found giving outputs such as making parents' feelings and experiences known through activities such as meetings, lectures, courses, conferences and seminars. These outputs are the acts which put the policy of CBR into effect in Värmland, as Paudel (2009) mentioned earlier. However, when examining the implementation process of CBR in Värmland it is found that another input, namely financial means, have especially influenced the implementation and maintenance of CBR. As Paudel (2009) as well as Van Meter and Van Horn (1975) puts it, local capacity is critical to a policy's success and receivers in an implementation process have to *be able* to implement the policy.

The financial circumstances that prevailed during and after the CBR project had an enormous impact on its implementation. As noted before, CBR was financed by the county council with support from the National Board of Health and Welfare in Värmland (Hargö Granér, 1999). Malin, the initiator, describes the process of applying for funding for CBR:

I had to apply through any institution which then was the re/habilitation. Thereafter, it was a political decision in the county that my application had to go to the National Board because there were many who sought money from the re/habilitation, support money to implement municipalisation. Yes, fortunately we got the money. (Malin)

Money was granted for the CBR project due to the municipalisation, which was part of the decentralisation taking place during the 1990s, not only in Sweden but worldwide (Akin et al., 2005; Burkitt & Whyman, 1994; Palme et al., 2002; Peat, 1997). This indicates an interest in a new way of providing services to parents and their children with disabilities, escaping a top-down approach to re/habilitation. Instead, a bottom-up approach was proposed that offered needed services while at the same time reducing costs, which CBR is proclaimed to do (Mpagi, 2001). Given the economic crises of the 1990s in Sweden, which affected the welfare of individuals and the welfare policy systems dramatically, this cost-cutting approach was critical (Bergmark & Palme, 2003; Bergmark et al., 2000; Palme et al., 2002).

The economic decline and its negative impact on the needs and rights of people with disabilities were noted in various ways by the parents. Moa describes a situation she faced:

We had a physical therapist that through the hospital was willing to help but the re/habilitation refused. Probably it cost money, and even the orthopedic doctor thought my daughter

needed it but anyway she did not get it. (Moa)

Restricted finances prevented Moa's daughter from getting the services that medical professionals recommended for her. Like the parents, the professionals also discussed the economic decline and highlighted the types of dilemmas it caused:

Sure, they could be mad at me because the money is not enough but they also had an understanding of my dilemma, because they knew I sat as a messenger. For it is a municipal policy, how much money you have. Of course it was me who was in charge of how the money was spent but sometimes I cannot touch the money; for example, when a child with special needs has to go to primary school or high school in Karlstad, it costs half a million. (Thomas)

Professionals can find themselves caught between parents and decisions made at higher levels in response to limited funding (Dominelli, 1999). Parents in turn could get angry about the lack of funding, but the implementation of CBR seemed to give the parents an understanding of the economic situation and of professionals' potential to influence and change things. As Moa describes:

No, I think most parents can say the same. Probably it will never do so for any parent, because there is no money for it. This is how it is. (Moa)

This pessimistic view of future services demonstrates how a lack of resources and an abundance of financial restrictions can make the focus on human rights and social justice fade away (Ferguson et al., 2005). For this reason, several authors recommend professional involvement at all levels in the service process, from the political to the individual, with diverse actors involved in issues concerning disability (Beaulaurier & Taylor, 2001; Dominelli, 2002; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006). Malin, the initiator of CBR, noted that something has to be done and that the LSS, which she leaned on, is so generous that it is not affordable:

There is much we could do better both for the individual and for the economy. It is a pity that it is so expensive so it is in jeopardy. (Malin)

This law, so important for the parents, will fade away if its work cannot be carried out in a different, more cost-effective way. One professional point out that he is convinced that money, the economy, and grants from the government can be influenced. Another professional gives an example of such influence when he notes that politicians became involved in CBR due to the large amount of money needed to reconstruct part of a school for children with special needs. They took the law of integration seriously, and he gave CBR credit for this:

Actually everything started with, it surely had happened anyway, but as CBR was, I think it hastened the development rather quickly. (Thomas)

CBR was a driving force that created rapid change when professionals and parents joined together politically to become effective agents of social change. However, there was still an obstacle, as one parent describes:

The project leader was employed and the one who drove and kept together everything, yes, was the united link. Of course when she was not there and when there was no money, instead it was voluntary. Then it becomes enormously heavier, because everyone has their regular jobs, parents and the ordinary day at home and then one is going to try, it went for a while. (Maria)

During CBR's project time, money was available to run the project and its activities. When the funding disappeared, the parents had to take on a heavy workload to continue running CBR voluntarily. Most of the professionals also participated without being paid for these activities. One professional stated:

I do not think we professionals got salary for this; it was just an opportunity for us to do our job in a different way. (Johan)

Some professionals saw this as an opportunity to learn, while others said it was part of their work and interest. However, there was also one professional who, like the parents, struggled to manage his daily workload alongside the CBR activities. This indicates that CBR can only be maintained in the way it was designed if sufficient funding exists, as one professional notes:

Actually I think CBR could be a forum anywhere in Sweden today. But it is all about money too, of course, a little bit, because it costs a dime. Though, one must have an enthusiastic project leader, who kicks it off. (Thomas)

CBR requires sufficient funding for its success, including enough money to pay someone to do the work on a daily basis. However, another professional mentions one more issue for continuing CBR services:

It probably has to do with the projects I have started; I have tried to include them as an integral part of the business. I have had various projects but not this one; this was dependent on money. (Samuel)

If CBR were integrated as a way of functioning in professionals' daily work—if it became a habitualised action, an institutionalised way of working—it would not be so dependent on finances and project leaders and would not risk vanishing when these no longer exist. According to Johansson (2004) adequate resources are important local conditions which may benefit or hamper the implementation. Financial capacity of the project was important during the entire project. The available funding made it possible to hire a project leader and to carry on activities which created awareness of the living conditions of children with disabilities and their parents. The importance of funding for the project created an awareness of the economic condition of the public sector, professionals, and NGOs working with children with disabilities. However, the financials came to an end and after a while a too heavy burden were placed on parents to continue with the CBR project.

Motivation for participation in the project

Paudel (2009) as well as Van Meter and Van Horn (1975) agrees that *willingness of participants* is another broad factor which is critical to a policy's success. They argue that receivers in an implementation process have to have *the will* to implement a policy. As Paudel (2009, p. 38) puts it, motivation or will "reflect the implementer's assessment of the value of a policy or the appropriateness of a strategy". Lang (2011) notices another issue which is critical to a policy's success, i.e. the relationship or the cooperation between different services provided to parents and their children. Cooperation and a good relationship are crucial to have the will to implement a policy, and can increase the motivation for participation in the project.

When CBR was transferred to Värmland by the initiator, as well project leader of CBR, the receiver was the parents to children with disabilities and later on their cooperation with professionals involved in their child's life situation. Though the cooperation, the majority of professionals and parents express a high reliance to the project leader during the project time, which Johan, a professional, and Viola, a parent, explains in following way:

No, I think I agreed upon everything I was asked, but since the project leader ran this wholeheartedly I relied a lot on her. (Johan)

The project leader was such a driving force, so strong and so impressive so all was just taken by storm. (Viola)

CBRs implementation in Värmland is highly depending on a single professional's strength and commitment. To lean on a professional, that according to DiMaggio and Powell (1983) has the possibility to determine which trends to follow in the society, can be a wise move. However, as mentioned earlier, in the long run it affects the possibility to maintain CBR which a professional express in following statement:

It was impossible to stand when the project leader disappeared. Maybe not immediately but gradually, and some moved. That it changes is also a fact and many times it has to restart when a new group gets involved. When the strongest individuals disappear, it can be worrisome to stay in business and so it was. (Thomas)

This shows that dependency on an enthusiast can make the project vulnerable and may lead to the dissolution of the project. However, there are other reasons which influence the continuation of a project. When the project ended it should enter under the work with LSS (the Act concerning Support and Service for Persons with Certain Functional Impairments) (Hargö Granér, 1999) in order to secure its continuation. An officer describes the possibilities of the continuing of CBR in following way:

Then it would survive without the project leader whereby we as officers plus the parents who were involved had a great responsibility. In the beginning, after the project ended, I thought of CBR and we went to some meetings but then it ran out of steam, those who were involved disappeared. I thought of CBR when I worked with networks in the individual plans but otherwise it vanished away. I felt quite lonely, I can say. Together with Sunne, we were many of us but then in Torsby I became alone. Unfortunately, I can say. (Anette)

CBR was hard to maintain as planned due to failure in cooperation as well as loneliness. It also indicate that a bottom-up approach of CBR do not mean sustainability if not getting a hold in existing services concentrating on disability issues. Whereby, a top-down approach of re/habilitation will be the dominating approach reaching parents to children with disabilities. However, all parents and professionals express that CBR could be suitable for Sweden:

They do not need to separate themselves so much, instead they can sit and talk about their worries and maybe find solutions. Sometimes it worked, and sometimes it was impossible but at least they know that you are in the same boat. Actually, I think CBR could be such a forum anywhere in Sweden today.
(Thomas)

Though many laws and policies are in place (Larsson, 2001; SOU, 2003; Swedish Institute, 2000), there is a need to implement them in relation to parents and their children's needs, whereby aspects within CBR can be of use as a way to get closer to the parents and create cooperation.

In examining the registration of CBR in the local context of Värmland, the idea of CBR had a high degree of local identity (Czarniawska, 2005; Røvik, 2008). Earlier re/habilitation solutions often did not match parents' needs, resulting in conflicts and frustration between professionals and parents (Røvik, 2008). In contrast, CBR obtained a local history by addressing local problems faced by parents of children with disabilities, for whom services were often not suitable and who were often forced to drive far distances to meet with authorities and obtain needed services.

The aim of CBR in Värmland was to obtain a local present, and indeed many local actors, especially parents, participated in CBR. Nevertheless, despite its high level of activity during the project time, CBR was not able to create a strong local future. When it comes to being part of long-term plans for the field and/or organisations that serve people with disabilities, a low degree of local future is found (Røvik, 2008). As Maria's and Viola's statements illustrate, CBR has not continued or reached many others:

Thus with individual plans, the person in charge of the LSS does not always know either, does not know how it should be done, so there is a huge ignorance in many municipalities still, that I want to say. (Maria)

Then this mother whom I spoke with said to me: "I have to hear a bit more about it, what is it? Can I ask for it from the person in charge of the LSS? "Yes, you can" I said. "It is her

responsibility". For that I told the person of charge of the LSS who was there. "Certainly it is your responsibility?" She agreed but was not so happy; it was troublesome. Then I met this mother again and she said that she has had her first plan and it was the best she has had. (Viola)

Despite its good intentions, the way the CBR project was implemented has at best fulfilled the needs of only a few in a certain area of Värmland. This shows that knowledge and cooperation are needed elsewhere as well. Especially as Violas statement shows, mothers of children with disabilities may not be aware of their rights of having an individual plan. According to many professionals who are not active in CBR anymore, it is the cooperation and knowledge that have been sustained after the end of CBR:

Yes, I have never forgotten. As soon as I read the word empowerment, I think of CBR! No, I will never forget it, the parents. It fits very well here. We try to have this thinking here a bit as well, that themselves shall choose and submit proposals, and make an individual choice themselves. Not intervene in their choice, which I think coincides well with the idea of CBR. (Linda)

Empowerment as a leading concept within CBR, were noticed among both professionals and parents as an outcome from the project. However, the empowerment was vulnerable since the project was at risk of coming to an end. Many professionals and parents interviewed expressed feelings of sadness due to the inability to sustain CBR. One professional observed a slowdown in the efforts at cooperation, leading to unfruitful meetings; the successful cooperation between professionals and parents had run its course and parents' participation did not continue. Malin, the initiator, offered an explanation for this phenomenon:

There is no professional who can compete with the knowledge parents have, especially if you combine their skills in groups like this, learning from each other, so it is a tremendous skill they possess. Of course no authorities are doing it. They don't even learn from each other because they have no way to work together. It is simply a culture that is missing, that we are not accustomed to, and that we must solve together. (Malin)

The strategy of working together to solve problems seems to be missing among authorities as well as between professionals and parents. Yet cooperation is

unquestionably important for a successful result, and necessary if the parents of children with disabilities are to be motivated to participate in service delivery. Such cooperation is also recommended by several authors working on behalf of the rights of oppressed and marginalised people (Beaulaurier & Taylor, 2001; Dominelli, 2002; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006).

Knowledge-based changing attitudes

Hill and Hupe (2009) suggest searching for behavioural output variables to avoid examining policies' goal-achievement (outcomes). Therefore the participants' changing attitudes can be counted as an output of the CBR project in Värmland. The results show that through adapting proper knowledge from participation in the CBR project in Värmland, professionals' and parents' attitudes have changed. Attitude change came after realising the reason behind the tense relationship between different participants in the work for improving children with disabilities' life situation. According to Åkerström and Nilsson (2004), it is not unusual for parents to have to fight for rights and services for their children with disabilities. Many professionals from various institutions confirmed the parents' reports of difficulties and the need to fight for their rights:

Parents of children with disabilities often experience a struggle, that they have to fight for their rights which they have the right to, and that "all professionals know exactly how it should be for our child and that is not how it is, it is we who know what we want". That was something one heard often, "it is we who have the knowledge about our children". (Anette)

This quote illustrates the clash between a medical and a social model of re/habilitation. The implementation of CBR introduced a new way of looking at these services. As some professionals state, parents may be frustrated, sad, and disappointed with the authorities' lack of understanding; a school principal laughs as he recalls, "we were many experts then". Johan, a principal of special education, noted that a power struggle takes place when roles are unclear. He and another principal viewed the parents as demanding:

Many were unsure about the Act Concerning Support and Service for Persons with Certain Functional Impairment and how it should be and these parents who were demanding. There was an attitude that they were troublesome. (Johan)

They had it in them, that it is a matter of fighting against the

authorities. (Thomas)

Despite these struggles, however, cooperation between parents and professionals eventually altered such views, as attitudes changed and collaborations were established. According to one principal, anger from the parents is now better understood and handled. Another headmaster noted that parents and professionals have learned to work together and that the parents are now seen as experts, with valuable knowledge of and experience with their children. However, the head of social welfare, with significant experience in national reform programs related to the situation of older people in the country (so-called Elderly Reform Act) and the LSS, said that when care was transferred to the municipality he did not know what the everyday lives of parents of disabled children looked like. A professional and a parent describe the changes that took place when CBR, as a less paternalistic social model of re/habilitation, arrived in Värmland:

Then I had a tremendous use of the response from these parents, parents who have been with children with disabilities. Yes, they may be perceived as aggressive because their needs were not met. If I had not had that experience, I think it would have been very hard. Now I could accept that they began, not shouting, but not be so pleasant. I could sit calm because I had had that knowledge, because they had talked about this, how they had met them here, they always met so much lack of wisdom. (Ola)

They should stop for a moment and listen to what we as parents have to say. We should do this together instead of you professional sit there and here we are as parents and we stand and scream at each other: "I should have this and I should have that" instead of sitting down together and finding a solution, what is best and how something good can come from it. (Viola)

These statements show that the meetings led to a more social model of re/habilitation, as participation, cooperation, and communication led to a better understanding of each actor's role in service provision. One principal said that things could be solved in five minutes because of open communication and confidentiality, which otherwise was almost impossible to achieve. A principal describes how this change affected him in his work:

The common meetings we had became of another character.

They became more constructive, we saw possibilities, what we can do together instead of having a power struggle over what we could contribute. (Johan)

Working together provided new perspectives and led to faster progress, supporting calls from several authors to collaborate in order to share experiences and knowledge (Beaulaurier & Taylor, 2001; Dominelli, 2002; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006) and to bring about social justice for marginalised and oppressed groups (Dominelli, 2002).

CBR Affecting Receivers Situation – Results

This section will highlight how CBR, as a change-oriented project, has affected the living conditions among children with disabilities and their parents in Värmland. This part is based on interviews with a group of parents to children with disabilities.

Endeavours for the improvement of children's living conditions

Since the Second World War, the rights of people with disabilities have increased (Bille et al., 1999; Johnson, 2009; Kerz et al., 1995). This has led to the use of more rights-based development approaches (Grech, 2009) by international organisations promoting ideas such as CBR. Though many laws and policies have been implemented to safeguard the rights of people with disabilities in Sweden, the aim of CBR in Värmland reflects that something was missing. Parents seemed to lack involvement in protecting the rights of their children with disabilities; thus the aim of CBR was to increase the family's self-determination and their participation in and influence on society's support and services for children with disabilities and their families (Hargö Granér, 1997). This shows that re/habilitation and other existing services with a top-down approach had not managed to fulfill certain important needs of children with disabilities and their families.

The introduction of CBR provided parents with knowledge capital that increased the rights of children with disabilities. The implementation of CBR has meant a provision of knowledge, awareness, and strength, which the interviewed parents have acquired through group meetings. Moa mentions that it was after many meetings that she began to see her own strength and to gain the determination not to give up. Rickard mentions that these meetings created very good contact among parents and that the experiences and knowledge they exchanged led him to dare to demand much more. Maria and Viola agree:

It has meant very much for me, I want to say that I have become stronger. I have got better information or I have got

information. Most of all I have been able to talk for my daughter which has been of use for her, that she has a parent, that there is someone who has managed to fight for her to get the resources that she somehow needs. (Maria)

But when you meet these people and other parents, because it is like you feel loneliest in the whole world: what will people say, are they talking behind your back? All these thoughts are there, but out of this you gain strength by meeting others, and others who meet you who are in exactly the same situation. (Viola)

These statements show that the knowledge the parents gained not only strengthened them, but also gave them skills in defending the rights of their child. "We did not even understand that the LSS is our right", says Maria. The strength gained can be seen in two ways. Moa and Viola express their emotions in their particular situation and note that CBR has made them stronger in their interactions with others. Meanwhile, Rickard and Maria have grown stronger in their ability to manage their life situations, expressing an increase in self-determination that was one of the original aims of CBR.

Parents have to fight for the rights and services their children need, and the knowledge shared in the CBR meetings helped these parents gain the necessary skills to advocate for their children's rights (cf. Åkerström & Nilsson, 2004). In this sense, though not in the long run, CBR delivered what it promised. This demonstrates that the parents' genuine need was something other than what was provided by existing forms of re/habilitation: They needed to be heard and to gain knowledge about their children's rights and their own rights as parents of children with disabilities. In this way their fight for needs became a fight for rights.

Factors Influencing the Implementation Process

In this section, different factors which have influenced the implementation of CBR in Sweden are highlighted. This section is based on interviews with both the parents and the professionals.

CBR as a new international idea in Sweden

According to Lang (2011) it is crucial to examine the power dynamics and relationships behind implemented services. The transfer of CBR to Värmland was an important knowledge given to the ones involved, though it was not implemented without resistance. This can depend on how CBR was accepted among authorities. For example, everyone was not pleased by the new re/habilitation concept coming up. The project leader faced hesitations among

people working at re/habilitation. The strategy was seen as a competition to existing ways of working rather than a complement. Johan, a principal involved in CBR and Malin, the initiator, describes it in following ways:

The management was hesitating for this way of working, it was something new and they had their own program and it was under consideration for a while and then finally, very clear though this fights, they decided that it probably was a good way of working. The only who were questioning it was the management of the county, the central function who sometimes added things which questioned the way of working. (Johan)

They are targeting different functions and therefore were this positional war of the best method totally meaningless. I knew that from the beginning but there were no one who understood what I was supposed to do. Though, the funny thing was that they at re/habilitation later saw what the difference was, so it was not a question of conflict. (Malin)

The transfer of CBR as a bottom-up approach brought hesitations and conflicts within re/habilitation. The initiator denies the conflict though it is shown in the words positioning war and fights. Other professionals and parents also describe a tense relationship with re/habilitation. According to Czarniawska (2005) resistance is something new ideas faces when entering in new contexts, something unavoidable which enriches the idea in its translation process. However, the conflicts arisen seemed to ebb out when an increased understanding of CBR and its way of working was gained. During the time of interviewing, one person working at re/habilitation in Värmland refused to be interviewed with the reason of not knowing much about CBR. Whereby, it seems like the way of communicating the new idea plays a vital role in its implementation process, because the person had worked hard for the Individual Service Program used within re/habilitation. Nevertheless, the hesitations and resistance from people may also come due to not understanding the idea of CBR and its origin. A parent and a professional describe it in following way:

Even then, after the first meeting I felt that this was so, well it was so big and so overwhelming, and I did not understand the thing correctly. The project leader was talking about CBR, the basic idea and that it takes a whole village to raise a child. She talked about Africa and I felt "what is this thing?" I was not

captured, what is she talking about? This was so huge and this we shall work with. (Viola)

It was the parents who had done research and the initiator who was the leader of it. I remember that very, I was very speechless. I think more people will remember. The fact that I knew so very little about this, well, first it was that it originated from Africa and it was very strange, I must say. (Ola)

These statements show that the knowledge of CBR in the beginning was overwhelming for some parents and professionals. The most noticeable with CBR seems to be that it comes from Africa. This can depend on the fact that not much strategies or models are transferred from non-Western to Western countries (Kamali, 2006; Tomlinson, 1999). However, it can also be a heritage from the colonial past, where the colonised "Others" are seen as pre-modern and irrational among other things (Rwomire, 2001). This can also be a reason for CBR mostly being taught in Sweden to be used in other countries, transferring Western thoughts to non-Western countries without exercising it themselves. It also shows that CBR in Sweden was not a trend to follow.

CBR at the national and local level

In Sweden, the government gives county councils and municipalities the main responsibility for the social welfare of people with disabilities (Lilja et al., 2003). However, NGOs also play a significant role in providing services and serve as a link between people with disabilities and their families on the one hand and various national authorities, the parliament, and the government on the other (HSO, 2011; Lilja et al., 2003; Swedish Institute, 2000). When CBR was implemented as a new way of addressing the situation of children with disabilities and their parents, several laws related to persons with disabilities were already established (Larsson, 2001; SOU, 2003; Swedish Institute, 2000). Thus the stage was set for implementing CBR in Sweden by existing laws and policies expressing the country's ambition of securing people's rights by legislation (Åberg, 1998; Ericsson, 1999).

However, one law in particular has played a significant role in advancing these rights. In 1994, the same year CBR was implemented in Värmland, the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) and the Act of Compensation for Assistance (LASS) came to force (Wolmesjö & Zanderin, 2009). According to the initiator of CBR in Sweden and the parents of children with disabilities involved in the project, the LSS supported CBR; or rather, CBR supported the law. The physiotherapist explains that she leaned on the Act in

the CBR project and especially in the individual plans, which received extra attention during the CBR meetings with their focus on network building.

Most of the professionals involved in the CBR project emphasised the importance of the individual plans within the LSS. Together, the professionals and parents developed an approach that went hand-in-hand with CBR. Anette, one of the professionals and Viola, a parent, express the importance of this work:

How a network can be planned for persons with disabilities I believe has been transferred from the CBR to individual plans.
(Anette)

Today I feel that it is CBR that has cleared the way for everything, such a very good base we have now, both care and the LSS. The platform I stand on today is because of that, absolutely. (Viola)

CBR has paved the way for providing more suitable services for parents and their children with disabilities. The idea of CBR was translated to fit into the law, and thus pure copying, diffusion, has not taken place. Instead, the individual plan was a collective creation of the professionals and parents involved in CBR (Czarniawska, 2005; Grape et al., 2006). This represents a civil society, a social sphere created mostly between parents and professionals, leaving the government out.

According to many of the interviewed professionals, the government was mainly involved in the implementation of CBR by supplying money. One professional says, "I do not think the state takes responsibility at all, but that is my personal opinion." Another explains how a government program doesn't always suit the people it intends to serve, and notes that the government had little involvement in this case, stating:

I think they could have an important role by sanctioning and encouraging this thinking. I think it is so with the state that they come with other packages that no one has asked for, some prohibitions, some pointers, and some rules. Some initiatives and new groupings, instead, might have been good. (Johan)

When it comes to the role of NGOs in providing services for people with disabilities, there is a lack of clarity among professionals. Only one viewed them as having a significant role in CBR; some did not mention them at all, and two others were not sure whether or not they were represented during meetings:

I do not know how they work. I cannot remember if there were associations attending during the meetings. (Rut)

No, I do not think so. We were invited to so many different meetings, so I do not know, I have forgotten. I firmly believe that it is good that they are involved because they if anyone have good knowledge of having a disability, regardless of what it is. (Anette)

The time from having been involved in CBR to being interview in this study may be one reason professionals failed to mention the NGOs' involvement. However, the parents also failed to mention NGOs as actors in CBR. Instead, some parents mentioned NGOs in relation to CBR's maintenance, noting that they were involved in other organisations related to disability issues. These other memberships, along with the overall life situation of children with disabilities and their parents, may explain why some families did not continue with CBR after the project ended. To sustain CBR was a heavy commitment, as Moa and Viola explain:

No! Yes, we are members of the National Association for Disabled Children and Adolescents and we are involved in the children's cancer association. Yes, the desire has been that it would continue, but what is difficult and what I feel myself in all this, I would almost not manage because I would have gone to different places and my husband had to ensure that our daughter had someone at home. At the same time we worked on all different places. (Moa)

It did a few years. We went out and left out pieces and informed at devices that CBR existed, that we exist in Sunne. But eventually you have just pushed, pushed, and pushed. You are a part of different unions and associations, and one is in a meeting here and a meeting there, finally you do not manage, you just have to focus on your own daily life and make sure it works. (Viola)

CBR continued for a while after the project ended; however, maintaining their participation became a burden for the parents due to their life situations. This indicates that CBR as a bottom-up approach has failed to become a part of existing re/habilitation practices, with their top-down approach. In other words, CBR has not been institutionalised or become a habitualised action, a way of working

(Berger & Luckmann, 1966; Czarniawska, 2005). CBR has enabled parents to have a say in their service delivery; however, with no backing from the government or other actors, there is a risk of providing welfare services for only a few (Lavalette & Ferguson, 2007) and a danger that the knowledge gained may vanish when the project ends. Maria voiced this concern:

About ten to fifteen years back we were on top in Sweden when it comes to having individual plans and we who applied and got it in the beginning when the CBR project started have continued with it. We see the value of it. However, among many employed at the municipality it is not working so well and that depends on lack of knowledge among the administrators, parents—I believe—and information. (Maria)

CBR cannot be sustained as a project in which only the government and NGOs are involved, changing ways of thinking and shifting the provision of disability services from a medical to a more social model of re/habilitation. Nevertheless, there is a risk of placing a burden on parents without considering their everyday socio-economic situation (Hoogeveen, 2005; Palme et al., 2003).

Conclusion

This chapter highlighted certain aspects of the implementation of CBR in Värmland, Sweden. CBR was introduced in Värmland with a bottom-up perspective, through a physiotherapist's engagement with and knowledge of CBR through her work in Gambia. In cooperation with parents of children with disabilities, she applied for and received funding from the county council with support from the National Board of Health and Welfare in Värmland, initiated CBR, and managed the CBR project.

The implementation process of CBR was managed and put into action in various stages in Värmland. It was implemented first with the parents at local level and second including grandparents. Later it included professionals involved in the children's lives, counting those working in schools and social departments in the two municipalities as well as at the re/habilitation centre in Karlstad, the county central service. The purpose of CBR in Värmland arose from the interviewed parents' realities of life, such as the need to travel long distances to rehabilitation services, limited economic means, and a lack of proper communication with the authorities. This gave CBR a strong identity within the local context. CBR provided parents and professionals with communication skills and knowledge of each other's situation. CBR also strengthened the parents' ability to manage their daily lives and helped them gain skills in advocating for the rights of their children. CBR

thus was able to compensate for the top-down strategy presented by the medical model of re/habilitation by fulfilling the parents' need to be understood and to gain knowledge of their rights. The struggle for needs thus became a struggle for rights.

This study also found some contextual factors that influenced the implementation of CBR in Sweden. A shortage of resources within the social welfare sector was one reason for the implementation of CBR's less paternalistic model of re/habilitation in Värmland. The decrease in funding may depend on a neoliberal agenda in the world, affecting the work of social workers as well as the services provided for children with disabilities and their parents. Sweden's longtime ambition of securing people's rights by legislation, especially through the LSS, was also found to have paved the way for CBR. The individual plan within the LSS, went hand-in-hand with CBR and was developed by parents and professionals together. The joint effort indicates that translation instead of diffusion of CBR took place. It was not pure copying, but rather a collective creation in a social sphere, a civil society consisting of professionals and parents.

It can also be concluded that the LSS contains components of CBR with a bottom-up perspective that have not been practiced before. Similar ways of working may be one reason why CBR has not taken hold in Sweden. Another conclusion is that the colonial past has influenced the implementation of CBR. As people learned about CBR, some were hesitant when they learned that the method came from Africa. This results from the fact that few strategies or models have been transferred from non-Western to Western countries. In addition, this skeptical response may be part of a heritage in which colonised "Others" are seen as pre-modern and irrational. This may be another reason why CBR has not become a widely used method in Sweden. Instead, it has mostly been taught for use in other countries, through a transfer of Western ideas to non-Western countries.

Finally, this study concludes that certain constraints and opportunities have affected CBR's continuity and institutionalisation in Sweden. Certain factors, such as access to funding, the availability of volunteers, and the stakeholders' responsibility for the CBR project affect its continued existence. The funding of CBR in Värmland presented opportunities to administer the project and enabled parents and professionals to meet and carry out activities such as lectures and conferences. However, CBR's success ended when it became part of the LSS, as the need for parents to work voluntarily made it impossible to maintain CBR. Sustaining CBR through volunteer work became too much of a burden for parents, who were at the same time responsible for carrying out all the other needs of the family.

Ultimately the success or failure of the CBR project depended on more than just funding. The project leader's enthusiasm was also seen as a driving force for the continuity of CBR in Värmland, as were the participation, good will, and interest of

parents and professionals. Although positive change took place and professionals incorporated a kind of bottom-up thinking in their ongoing work, the end of CBR and the difficulties in maintaining it show that CBR's bottom-up approach was unsuccessful in infiltrating the top-down medical model of re/habilitation. Thus, this study concludes that CBR has not been institutionalised and has not succeeded in becoming a habitualised action, a way to work within re/habilitation.

CHAPTER 7

COMPARISON AND DISCUSSION

In this chapter the results of the study will be summarised and compared in relation to the main objectives of the dissertation which is to examine how an international idea for social work practice, i.e. community based rehabilitation, is implemented in different structural and institutional contexts. CBR as a case are compared under headlines such as the introduction and implementation of CBR, contextual factors influencing the implementation of CBR as well as the possibilities of the continuation and institutionalisation of CBR in Uganda and Sweden. Further, the role of welfare state for implementation of CBR and the relevance of globalised international ideas for social work are discussed. Finally, this study's contribution to the field of social work, its limitations and recommendations for further research are discussed and presented.

The Introduction and Implementation of CBR

CBR has been introduced and implemented quite differently in Uganda and Sweden. In Uganda CBR was introduced in 1989 by Ugandan students who took diploma and master's courses at the Institute of Child Health at London University, England. The students spearheaded the birth of CBR courses in Uganda in 1990 by creating the NGO Community Based Rehabilitation Alliance. Ready to carry out the training, they implemented the first CBR programmes in 1992 through the government. CBR was planned, arranged and financed by the Government and the international Norwegian organisation for people with disabilities, NAD. Thereafter, one of the first pilot-programs was carried out at local level, as a project, in Bushenyi between 1992 and 1998. The reason for the introduction was a lack of services for people with disabilities, a need of attitude change and a need of a non-paternalistic model of rehabilitation.

In Sweden, on the other hand, CBR was introduced at local level in Värmland as a project between 1994 and 1998. CBR was planned and arranged by a physiotherapist who was inspired by work in Gambia as well as parents to children with disabilities, and financed by the county council with support from the National Board of Health and Welfare in Värmland. The reason for the introduction was the need for a user-led practice that better addressed the needs of children with disabilities and their families and a need of a non-paternalistic model of rehabilitation.

However, when creating change for children with disabilities and their parents through the development project, the idea of CBR was applied differently in the two countries. It can be concluded that the services from CBR was planned, arranged and carried out with a top-down perspective in Uganda, by the government, a foreign NGO and the Rehabilitation Office in the province of Bushenyi. With the intention to empower people with disabilities and to increase rehabilitation services, the diffusion of CBR instead of its translation took place because of a more copying of the idea from the existing original CBR Manuals, as well as using the national aim of CBR. In other words, CBR in Uganda depends on the standardisation of CBR, i.e. the content of the idea and how it was packed. This gave receivers of CBR such as community development officers (CDOs) less room for translating the idea accordingly to the local context. The reason for this packing can be found in the idea-producers strives for legitimacy. Professional expertise was evident both when it comes to who was planning and arranging the implementation of CBR in the country as well as who trained and carried out the implementation at the ground, especially when the parents to children with disabilities was not involved as such.

In Sweden, on the other hand, it can be concluded that a bottom-up perspective was used by a physiotherapist and parents to children with disabilities when implementing CBR in Värmland. The intention was to improve the parents of children with disabilities' influence on the institutionalised rehabilitation processes. The implementation process included emancipatory practices, translation rather than diffusion of CBR. This provided the physiotherapists and the parents a possibility to form and use the idea as they found best. In other words, CBR in Sweden did not depend on the standardisation of CBR. This also increased the ability of the receivers of CBR in Värmland to translate the idea in order to adjust it to the local needs of the parents. The engagement of professional expertise was lesser than in Uganda because of the parents' involvement in the implementation of CBR, giving the creator of the idea less legitimacy.

In both countries different steps were carried out in the implementation process at local level. In Uganda CDOs were first trained in CBR, who thereafter raised awareness among families to children with disabilities, registered persons with disabilities, and finally raised awareness in schools (classmates) and hospitals (nurses). In Sweden it started with the physiotherapist (project leader) and parents to children with disabilities, thereafter grandparents and later included social workers, municipal authorities and the county council. The reason for the two countries to carry out the implementation in different steps or processes can be concluded as a way to detect the children and their parents' need of assistance. However, the fact is that becoming aware of needs is not the same as fulfilling

them, or for that matter those using the services participating in decision-makings which concerns their living conditions.

In both countries however inputs, such as financials and training, has led to an important output which has created a change among children with disabilities and their parents. The project of CBR has given an output of knowledge in both Uganda and Sweden which created changed attitudes. The interviewed parents in Uganda started to love their children more and in Sweden parents and professionals started to understand each other's situation better, improving the communication to help the children. Increased knowledge also led to enlarged consciousness of the rights of children with disabilities. Both the interviewed CDOs and the parents in Uganda got more understanding of children/persons with disabilities' human value, i.e. that they are not less worthy than people without disabilities, that they are able. In Sweden on the other hand it led to that interviewed parents got skills to stand up for their children's situation.

The knowledge generated by the implementation of CBR also gave the parents in the two countries strength. The parents interviewed in Uganda was strengthened by the skills they gained to help their children. However, they also used the skills to help others in similar situations. In Sweden the interviewed parents gained strength to manage their daily life, resulting in fewer meetings with different professionals. It can be concluded that similarities were found in the output of the implementation process of CBR. The parents changed attitudes and behaviour, gained knowledge, strength and skills to manage their situation and professionals changed attitudes and improved their abilities to help the children with disabilities in the two countries.

Contextual Factors Influencing the Implementation of CBR

Even if changes have occurred in the two countries, contextual factors have been found influencing the implementation of CBR. In Uganda, it can be concluded that the government's recognition of the situation of people with disabilities, supplemented by the work of many volunteer organisations along with an absence of social services, paved the way for CBR's implementation. However, no specific disability laws and policies are found supporting the implementation of CBR. A continuous dependency relation to England because of CBRs introduction in Uganda and the promotion of CBR by the WHO and the UN makes the adoption of this approach seem inevitable for a non-Western country such as Uganda, more like a trend to follow. It can be concluded that legitimacy in form of expertise as well as influences from a colonial past and a post-colonial present is affecting the level of acceptance of CBR in Uganda where the idea seemed to be accepted as it was because of using the CBR Manual and because of the lack of other rehabilitation models available.

In Sweden, on the other hand, it can be concluded that a shortage of resources within the social welfare sector and Sweden's longtime ambition of securing people's rights by legislation, especially through the LSS, paved the way for CBRs implementation. The individual plan within the LSS, went hand-in-hand with CBR and was developed by parents and professionals together. The LSS also contains components of CBR with a bottom-up perspective that have not been practiced before. Similar ways of working may be one reason why CBR has not taken hold in Sweden. Another conclusion is that the colonial past has influenced the acceptance of CBR and thereby its implementation. Some receivers of CBR were hesitant because the idea originated from Africa. This results from the fact that few strategies or models have been transferred from non-Western to Western countries. In addition, this skeptical response may be part of a heritage in which colonised "Others" is seen as pre-modern and irrational. This may be another reason why CBR has not become a widely used method in Sweden. Instead, it has mostly been taught for use in other countries, through a transfer of Western ideas to non-Western countries.

In other words, it can be concluded that a countries' socioeconomic and political structures determine the implementation of an idea. The colonial and postcolonial history and position of a country which makes it either dependent of other countries and international organs or more independent influence its ability and possibilities of implementation of an idea, as well as its possibilities of defending the human values and rights of its citizens, including individuals with disabilities.

CBRs Chances of Continuity and Institutionalisation

In both Uganda and Sweden was the outcome of CBR not as expected after approximately ten years. CBR as a project and model disappeared when the funding came to an end, and after the end of the project CBR was to be involved in existing practices in both countries. In Uganda the services should enter under regular development programs at the sub-county, meanwhile in Sweden it was the LSS-administrator who was to coordinate CBR. However, this outcome has not been achieved because of several reasons. Limitations on the availability of funding affected the CBR in both countries, leaving a heavy burden on the CDOs in Uganda and parents in Sweden. This was mainly, due to the burden of voluntary work.

CBR did not institutionalise in the two countries involved in this study. The main reasons for the discontinuation of CBR in Uganda are the low level of participation of parents of children with disabilities in the project, on the one hand, and the shortage of resources on the other. In Sweden the existence of a strong

welfare state and institutionalised services to children with disabilities hindered the CBR's integration in the daily work of the professionals.

A lack of cooperation can also be seen as a hindrance of CBRs continuance and institutionalisation. Hargrove's (1975) express this as the "missing link". In Uganda, there were a "missing link" between the government and NGOs in Bushenyi when it comes to provide rehabilitation to children with disabilities as well as low participation of parents to children with disabilities in the services provided by the CBR project. In Sweden, the interaction between professionals and parents to children with disabilities improved by implementation of CBR. However, the discontinuation of CBR created a heavy burden for parents to children with disabilities because of a large amount of voluntary work. The LSS-administrator integrating CBR in existing practices felt also alone in her work when the interaction did not continuing in the same way as before. Successful outcomes may be expected when there are close links between different actors in the process of implementation. The missing links leads to the lack of successful outcomes and discontinuation of the CBR (cf. Pressman & Wildavsky, 1984).

Another reason for the failure of institutionalisation of the CBR projects in Uganda and Sweden is the high level of dependency of the projects to external actors. In the province of Bushenyi in Uganda, CBR was highly dependent on foreign aid to keep it alive and implemented, and, in the province of Värmland in Sweden the project was dependent on an enthusiastic and dedicated project manager. For CBR to be institutionalised the government should put more efforts to make CBR a nation-wide program led by the government. However, although CBR has not been institutionalised, a new understanding and awareness has been reached in the countries which can affect different authorities working with and for children with disabilities. However, when the people who have gained this knowledge disappear from the field of disability, the risk is that the knowledge also disappears if not institutionalised in the organisation.

The ability to maintain the CBR in both countries can be summarised by the financial resources available as well as the need of cooperation between authorities and between authorities and parents to children with disabilities and their caregivers, as well as with civil activists and civil society organs. Civil society plays a major role in both countries, albeit in different ways, when it comes to the survival of the CBR and creating a better rehabilitation for children with disabilities. It can be concluded that CBR as a project with enough finances, trainings and evaluations gave positive outputs though did not get any foothold in the existing service i.e. was not institutionalised in any of the countries. This shows that despite many valuable ideas, it is difficult to create lasting institutional change through projects (cf. Hasenfeld, 1983; 1992; Lewin, 1996; Sahlin, 1996).

The Welfare State and its Role and Function for CBR

During the recent decades' neoliberal reorganisation of the welfare states in many Western countries makes the states reducing their welfare services to citizens and as a result civil society organisations increasingly play a prominent role in service delivery to citizens (Burkett & McDonald, 2005; Ferguson et al., 2005; Martin & Schumann, 1997).

When looking at the two countries' implementation of CBR one might believe that the development in the Uganda and Sweden goes in different directions, i.e. Uganda mainly has reverted to the state for provision of rehabilitation services, while Sweden turned to civil society. This is a misleading conclusion. The existence of the strong rights of people with disabilities and still the existence of one of the world's strongest welfare states in Sweden make the efforts of civil society agents much more fruitful than Uganda. With a rather weak judicial system and welfare state in Uganda, people with disabilities are faced with greater difficulties and challenges in their struggle for social justice. When CBR as a project came to an end in Sweden, people with disabilities were still able to lean on the laws and rights already in place, such as free transportation services, free education, disability allowance and relief-services for families with children with disabilities. Consequently, the lack of such benefits and services in Uganda makes CBR much more important for people with disabilities and their families in Uganda than in Sweden.

Nevertheless, the Swedish strong welfare state and strong laws intended to guarantee the welfare of people with disability do not mean that the required services for children with disabilities are completely provided. The recent decades' changes in the Swedish official policies and the government's political adjustment to the global neoliberal ideology and policies have led to the retreat of the welfare state from its traditional responsibilities, which harm people with disabilities among others. In such circumstances, civil society agents try to compensate for the retreat of the welfare state and find new ways to promote rehabilitation. The project of CBR in Sweden was one of such attempts in order to increase the engagement of parents of children with disabilities in the process of rehabilitation. However, the attempts came to a halt shortly after the CBR project ended because of a dependency relation to key persons and a heavy work load on parents to children with disability.

However, the "bottom-up" project of CBR in Sweden intended to force the authorities to take the experience and knowledge of parents to children with disabilities seriously, while in Uganda the "top-down" project of CBR intended in the first place to engage parents and families to children with disabilities in the

rehabilitation process. Based on the strong rights and legal entitlements of people with disabilities in Sweden, the economic positions of parents did not play an important role for the quality of the services received by children with disabilities. But, in Uganda the parents' economic deprivation was a great hindrance for children with disabilities to receive suitable services and to participate in the project. In the process of providing appropriate services, it is crucial to consider the the socioeconomic and political context in which such services are provided and implementers should examine the power dynamics and relationships that underpin this service provisions (cf. Lang, 2011).

The global triumph of neoliberal ideology and the withdrawal of the state from its traditional role for providing welfare to citizens have increased the role of NGO's for providing welfare to people, as mentioned earlier. However, too much reliance on civil society with empowerment as a political strategy can undermine the responsibility of the welfare state (Wright Nielsen, 2009) and deteriorate the living conditions of people in need of continuous and guaranteed help. Besides, the dependency of NGOs on the foreign donors in Uganda or on governmental and some civil donors in Sweden make social work projects, such as CBR, very vulnerable. This study shows that even in Sweden the implementation of CBR has been created a heavy burden for parents to children with disabilities because of a large amount of voluntary work. Whereby an overreliance on civil society can advance the neoliberal agenda and undermine the state's responsibility for providing health and welfare services to people.

Globalised International Ideas and Social Work

In an increasing globalised world, many ideas, policies and concepts in social work are spread to and implemented in different structural and institutional contexts to provide proper welfare services to citizens and increase social justice. However, one can question the usefulness of the ideas and policies implemented through projects, especially when research show that ideas used to improve social welfare services has a hard time to reach the users and create change (see Dorsner, 2004; Hasenfeld, 1983: 1992; Helander, 2007; Jönsson, 2010; Lewin, 1996; Sahlin, 1996).

A question to ask is then if ideas, such as CBR, is just a trend or has the possibility to become institutionalised and form permanent organisations? When looking at the results after more than ten years since the projects ended, one might say that the CBR has been a trend and hard to institutionalise. Another question to be asked is why CBR, which has been implemented in so many countries, seems to be difficult to integrate in such countries' welfare policies? World Health Organisation as a producer and advocate of the idea of CBR continues to defend such projects in different countries even if authors still request more research

concerning its appropriateness (Hartley, 2001; Jackson & Mupedziswa, 1988; Mitchell, 1999).

Unlike Sweden, the Ugandan government has involved CBR at national level. Uganda's status as a former colony bearing many burden of its colonial past in a postcolonial world with less socio-economic opportunities and a dependence on foreign and national NGOs, can make the country more eager to use CBR than Sweden, which has greater socio-economic opportunities to provide social welfare for people/children with disabilities. Especially, when institutions try to establish an international image (Stone & Maxwell, 2005), legitimise external organisations or to obtain external resources (Johansson, 2000).

In comparison with Uganda, one can say that Sweden is freer to use or not to use the standard of CBR, which WHO created. Standards are a type of rules that are optional and it is in the recipients' own interest to follow them (Johansson, 2006) when for example promoting new approaches to rehabilitation. This can be one reason why it has been difficult to integrate CBR in the respective countries' existing practices. A weak interest in a new idea can according to some researches be a hindrance for successful implementation (Guldbrandsson, 2007; Pressman & Wildavsky, 1984). As mentioned before, it was noticed a larger acceptance and interest of CBR in Uganda than in Sweden because of the ideas origin.

Nevertheless, international ideas of social work, such as CBR, can make a difference for those in need of services for the improvement of their life situation. This is true at least as long as there are funding, cooperation and a continually examination of power structures affecting the implementation. Though, there exist huge challenges for an idea and the results from a project to be established and institutionalised in a country.

Neither in Uganda nor in Sweden CBR became the responsibility of the state and institutionalised in the normal functions of the welfare state. Even though funding would continue to exist, the projects would not be used of or help all children with disabilities. In Uganda all districts did not receive CBR and in Sweden only three municipalities, two in the province of Värmland and a unit in the city of Gothenburg, used the model. This means that CBR as an idea with important aspects of empowerment and emancipation practices was restricted to few children with disabilities and their parents. Rather than CBR being implemented as a government program in the whole country, at all levels, with close cooperation with users, it spontaneously occurs as limited projects in some areas. This provides the opportunity of better rehabilitation to some people but not to everybody.

A decline in the state-provided health and welfare services for all can take place when much emphasis is put on the civil society (Lavalette & Ferguson, 2007). Social workers are encouraged to engage in the sphere of civil society i.e. the

family, state and voluntary activities to improve understanding through cooperation so the social welfare services as far as possible will satisfy the people using them (Beaulaurier & Taylor, 2001; Dominelli, 2002; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Sewpaul, 2006). However, to engage in civil society requires an understanding of each other's limits and strengths, as well as a fruitful communication beyond professional borders. Especially, if an idea or policy is to be implemented through projects and be useful not only for a few in need of the service.

The gains of an idea or policy, as CBR, to be spread within a country involve available resources to evaluate and implement successes of the project in the mother organisation. Resources in form of financials and manpower are needed to make the idea or policy to take hold in existing services. For example, the state can provide social workers broader opportunities to examine already existing working methods in relation to the new idea. This conclusion is drawn from the fact that CBR in Sweden shaped and supported the law of LSS. This also shows that changes do occur, however, the changes may not be as fast as desired and above all do not reach everywhere they are needed, which disproves the usefulness of international ideas implemented through projects.

However, social work is a socio-political field including many contentious ideas, ideologies, policies and vested interests. Promoting social justice needs therefore social workers' engagements in both individual and structural levels including political engagements. Changing existing welfare services requires engagement in political decision-makings, cooperation, and a critical examination of structural and institutional arrangements, in order to include successful projects in the daily functions and duties of the welfare state of every country. This will prevent an international idea for social work to not only be a temporary trend to follow, but also an established working method for helping people in need of proper services.

The Study's Contribution to the Field of Social Work

This study has examined how an international idea for social work practice, as community based rehabilitation, is implemented in different structural and institutional contexts. To do so the introduction, translation, implementation and institutionalisation of CBR in Bushenyi, Uganda, and in Värmland, Sweden, has been in focus. The theoretical tools of travelling of an idea and its translation and implementation have been used to understand if and how the idea of CBR has managed to change the situation for children with disabilities and their parents in Uganda and Sweden. Finally, the comparative approach of CBR in the two countries has served as a way for the study to enter an international arena where

knowledge of how an idea can be used differently in two countries in order to improve the living conditions of children with disabilities and their parents.

However, it is not mere implementation of an idea as a project which is central to social work, but if the project started to change the situation for children with disabilities and their parents in Uganda and Sweden and become permanent and created a new way of practice. This study shows how difficult it is to monitor development through projects in both non-Western and Western countries. To institutionalise CBR, in Bushenyi, Uganda, it is necessary to develop a CBR model rooted in local needs and with the influence of people with disabilities and their caregivers. To do the same in Värmland, Sweden, it is important for CBR project to recognise and include the parents' knowledge in the practical rehabilitation work and to integrate the knowledge from CBR in existing practices of the strong welfare state.

There is also a need to take a closer look at the idea's origin, global history and the power structures that influence the successful implementation of an idea in a new context. Otherwise a CBR project can lead to the scarce resources for social workers, low participation level among users, heavy work burden, and unfulfilled expectations and unexpected outcomes. In other words, it is not only restricted finances which determine the success of CBR and social workers' struggle for social justice. It also depends on how the idea is translated and used, how rooted the idea becomes and which perception the government, NGOs and professionals have of the users. Whereby, social workers have an important task to engage different actors in a project's activities, to inspire cooperation, to critically examine itself and their perceptions and power position, the underlying values of their work as well as power structures influencing the practices of social work in general. The struggle for social justice for marginalised and oppressed groups requires social workers' engagement locally, nationally and globally (Beaulaurier & Taylor, 2001; Dominelli, 2002; Mackelprang & Salsgiver, 1996; Stainton et al., 2010; Swepaul, 2006).

It requires also engagement in political decision-makings influencing the structural and institutional arrangements which influences the organisation of social work and the resources allocated to help people in need of services. It is important to consider that the NGOs can never compensate for the responsibilities of the state to provide necessary services to the citizens, including to people with disabilities. The recent globalisation of the neoliberal ideology and policies have led to the retreat of the welfare state in Western countries and legitimises non-responsibility of non-Western countries' states to not develop sustainable welfare states.

Finally, after examining two countries' implementation of an international idea such as CBR, limitations of the study is considered. New studies can be carried out

engaging a broader perspective including representatives from different disability organisations and broader economical issues. However, the main focus of this study was the relationship between parents to children with disabilities and those actors who were working close to them. Other areas of research are not only how an idea are implemented in a project because it is shown that changes do occur. Rather there is an urge to examine how gains from development projects really are institutionalised in the practical work of existing organisations, and how existing institutions can cooperate with each other and with the target group to provide suitable services.

REFERENCES

- Adams, R., Dominelli, L., & Payne, M. (Eds.) (2002). *Critical practice in social work*. Basingstoke: Palgrave.
- Aitken, C., & Walker, J. (1987). Care of disabled people in the community. *International Disability Studies*, 9(2), 55-59.
- Akin, J., Hutchinson, P., & Strumpf, K. (2005). Decentralisation and Government Provision of Public Goods: The Public Health Sector in Uganda. *The Journal of Development Studies*, 41(8), 1417-1443.
- Alexander, J. C. (1997). The Paradoxes of Civil Society. *International Sociology*, 12(2), 115-133.
- Alexander, J. C. (1998). *Real civil societies: dilemmas of institutionalisation*. London, Thousand Oaks, New Delhi: Sage Publications.
- Altbach, P. G., & Kelly, G. P. (Eds.) (1984). *Education and the colonial experience*. New Brunswick, New Jersey: Transaction Books.
- Amstel, H., Dyke, T., & Crocker, J. (1993). Would people with disability in the highlands benefit from community-based rehabilitation program? *Papua and New Guinea medical journal*, 36(4), 316-319.
- Asindua, S. (2002). What is CBR in the African Context? In: Hartley, S. (Eds.) *CBR: A Participatory Strategy in Africa*. Kampala, Uganda; London, UK: The Centre for International Child Health.
- Baolin, C., & Huang, G. (1999). Primary health care and community-based rehabilitation in the People's Republic of China. *Disability and Rehabilitation*, 21(10-11), 479-483.
- Baryayebwa, H. (2002). *Comparative study of Community Based and Institutional Based Rehabilitation of persons with disabilities in Mbarara district*. Kampala, Uganda: Department of Social Work and Social Administration, Makerere University.
- Beaulaurier, R. L., & Taylor, S. H. (2001). Social Work Practice with People with Disabilities in the Era of Disability rights. *Social Work in Health care*, 32(4), 67-91.
- Bennett, R. J. (Eds.) (1990). *Decentralization, local governments and markets: towards a post-welfare agenda*. Oxford: Clarendon.
- Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: a treatise in the sociology of knowledge*. London: Allen Lane Penguin.
- Bergmark, Å., & Palme, J. (2003). Welfare and the unemployment crisis: Sweden in the 1990s. *International Journal of Social Welfare*, 12(2), 108-122.

- Bergmark, Å., Thorslund, M., & Lindberg, E. (2000). Beyond benevolence – solidarity and welfare state transition in Sweden. *International Journal of Social Welfare*, 9(4), 238-249.
- Bille, B., Andersson, H., & Olow, I. (Red.) (1992). *Barnhabilitering vid rörelsehinder*. Stockholm: Almqvist & Wiksell.
- Bille, B., Olow, I., & Annerén, G. (red.) (1999). *Barnhabilitering vid rörelsehinder och andra neurologiskt betingade funktionshinder*. Stockholm: Liber.
- Bitarabeho, J. (2003). *Curbing Corruption and Promoting Transparency in Local Governments. The Experience of Bushenyi District, Uganda*. Washington DC: World Bank Institute.
- Black, T., Namwadda, R., Mugambe, J., Walugembe, E., & Esanu, C. (1999). Educational growth in Uganda. *International Journal of Educational Development*, 19, 111-126.
- Blennberger, E. (2005). *Etik i socialpolitik och socialt arbete*. Lund: Studentlitteratur.
- Blomberg, J. (1998). *Myter om projekt*. Stockholm: Nerenius & Santérus.
- Boëthius, G., & Rydlund, C. (1998). *Lycklig varannan onsdag – DAMP mammor berättar*. Stockholm: Cura, Studentlitteratur AB.
- Boyce, W., & Johnston, C. (1998). Collaboration in community based rehabilitation agencies. *International Journal of Rehabilitation Research*, 21(1), 1-11.
- Boyce, W., Johnston, C., Thomas, M., Enns, H., Naidu, D. M., & Tjandrakusuma, H. (1997). Pathways to scaling-up in community based rehabilitation agencies. *International Journal of Rehabilitation Research*, 20(4), 381-392.
- Broberg, R. (1973). *Så formades tryggheten: socialförsäkringens historia 1946-1972*. Stockholm: Försäkringskassaförbundet.
- Burkett, I., & McDonald, C. (2005). Working in a different space: linking social work and social development. In: Ferguson, I., Lavalette, M., & Whitmore, E. (Eds.). *Globalisation, global justice and social work*. London: Routledge.
- Burkitt, B., & Whyman, P. (1994). *Public sector reform in Sweden: competition or participation*. UK; USA: The Political Quarterly Publishing Co. Ltd. Blackwell Publisher.
- Burnell, P. J., & Randall, V. (Eds.) (2008). *Politics in the developing world*. Oxford: Oxford University Press.
- Buse, K., Mays, N., & Walt, G. (2005). *Making Health Policy*. Berkshire: Open University Press/McGraw-Hill Education.
- Calhoun, C. J. (Eds.) (1992). *Habermas and the public sphere*. Cambridge.: MIT Press.

- Callon, M. (1986). Some elements of sociology of translation: Domestication of the scallops and the fishermen of St Brieuç's Bay. In: Law, J. (Eds.) *Power, Action, and Belief: A New Sociology of Knowledge?* London: Routledge & Kegan Paul.
- Cannon, C. (2000). NGOs and the State: a case-study from Uganda. In: Eade, D., & Pearce, J. (Eds.). *Development, NGOs, and civil society: selected essays from Development in practice*. Oxford: Oxfam GB/Oxfam International.
- Chatterjee, N. (2001). Every solution has a problem. *Disability & Rehabilitation*, 23(1), 30-35.
- Chermark, G. D. (1990). A global perspective on disability: a review of efforts to increase access and advance social integration for disabled persons. *International Disability Studies*, 12(3), 123-127.
- Clark, A. K. (1987). Community-based rehabilitation in England. *International Disability Studies*, 9(1), 18-21.
- Classon, S. (1988). *Kampen för tryggheten: en dokumentation*. Stockholm: Landsorganisationen.
- Claussen, J., Kandyomunda, B., & Jareg, P. (2005). *Evaluation of the Community Based Rehabilitation Programme in Uganda*. Oslo, Stockholm, Copenhagen: Nordic Consulting Group.
- Cochrane, A., Clarke, J., & Gewirtz, S. (Eds.) (2001). *Comparing welfare states*. London: Sage in association with the Open University.
- Cohen, J. L., & Arato, A. (1992). *Civil society and political theory*. Cambridge: MIT Press.
- Coleridge, P. (1993). *Disability, Liberation and Development*. UK, Ireland: Oxfam publications.
- Comaroff, J. L., & Comaroff, J. (Eds.) (1999). *Civil society and the political imagination in Africa: critical perspectives*. Chicago: University of Chicago Press.
- Connell, R. (2007). *Southern theory: the global dynamics of knowledge in social science*. Cambridge: Polity.
- Czarniawska, B., & Joerges, B. (1996). Travels of ideas. In: Czarniawska, B., & Sevón, G. (Eds.). *Translating organisational change*. Berlin: de Gruyter.
- Czarniawska, B., & Sevón, G. (Eds.) (1996). *Translating organisational change*. Berlin: de Gruyter.
- Czarniawska, B. (2005). *En teori om organisering*. Lund: Studentlitteratur.
- Davidson, B. (1992). *The Black man's burden: Africa and the curse of the nation-state*. New York: Times Books.
- Davis, S. (2006). *Rehabilitation: the use of theories and models in practice*. Edinburgh: Elsevier Churchill Livingstone.

- Dempsey, I. (1995). The enabling practices scale: The development of an assessment instrument for disability services. *Australia & New Zealand Journal of Developmental Disabilities*, 20(1), 67-73.
- DENIVA (2006). *Civil Society in Uganda: At the Crossroads?* DENIVA: Development Network of Indigenous Voluntary Associations.
- Denk, T. (2002). *Komparativ metod: förståelse genom jämförelse*, Lund: Studentlitteratur.
- DiMaggio, P. J., & Powell, W. W. (1983). The Iron Cage Revisited: Institutional Isomorphism and Collective Rationality in Organisational Fields. *American Sociological Review*, 48(2), 147-160.
- Dixon, J. (red.) (1987). *Social welfare in Africa*. London: Croom Helm.
- Dogan, M., & Pelassy, D. (1990). *How to compare nations: strategies in comparative politics*. Chatham, New Jersey: Chatham House.
- Dominelli, L. (1999). Neo-liberalism, social exclusion and welfare clients in a global economy. *International Journal of Social Welfare*, 8(1), 14-22.
- Dominelli, L. (2002). *Anti-oppressive social work theory and practice*. New York: Palgrave Macmillan.
- Dorsner, C. (2004). Social Exclusion and Participation in Community Development Projects: Evidence from Senegal. *Social Policy & Administration*, 38(4), 366-382.
- Dyer, R. (1997). *White: essays on race and culture*. London: Routledge.
- Eade, D., & Pearce, J. (2000). *Development, NGOs, and civil society: selected essays from Development in practice*. Oxford: Oxfam publications.
- Edebalk, P. G. (1996). *Välfärdsstaten träder fram: svensk socialförsäkring 1884-1955*. Lund: Arkiv.
- Edebalk, P. G. (2000). Emergence of a Welfare State - Social Insurance in Sweden in the 1910s. *Journal of Social Policy*, 29(4), 537-551.
- Edwards, M. (2004). *Civil society*. Cambridge: Polity.
- Eldar, R. (2000). Integrated institution – community rehabilitation in developing countries: a proposal. *Disability and Rehabilitation*, 22(6), 266-274.
- Eliassi, B. (2010). *A stranger in my homeland: the politics of belonging among young people with Kurdish backgrounds in Sweden*. Diss. Sundsvall: Mid Sweden University. Available at Internet: <http://urn.kb.se/resolve?urn=urn:nbn:se:miun:diva-11903>.
- Elliott, D. S., & Mihalic, S. (2004). Issues in disseminating and replicating effective prevention programs. *Prevention Science*, 5(1), 47-52.
- Engwall, M. (1995). *Jakten på det effektiva projektet*. Stockholm: Nerenius & Santerus.

- Ericsson, K. (1999). *Establishing CBR for persons with mental retardation: a task for the Sweileh integration project in Amman*. Uppsala, Sweden: Department of Education, Uppsala University.
- Eriksson Baaz, M. (2002). *The white wo/man's burden in the age of partnership: a postcolonial reading of identity in development aid*. Diss. Gothenburg: University.
- Eriksson Baaz, M. (2005). *The paternalism of partnership: a postcolonial reading of identity in development aid*. New York; London: Zed Books.
- Erlingsdóttir, G. (1999). *Förförande idéer: kvalitetssäkring i hälso- och sjukvården*. Diss. Lund: University.
- Escorpizo, R., Reneman, M. F., Ekholm, J., Fritz, J., Krupa, T., Marnetoft, S-U., Maroun, C. E., Rodriguez Guzman, J., Suzuki, Y., Stucki, G., & Chan, C. C. H. (2011). A Conceptual Definition of Vocational Rehabilitation Based on the ICF: Building a Shared Global Model. *Journal of Occupation Rehabilitation*, 21(2), 126-133.
- Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*, Princeton, New Jersey: Princeton University Press.
- Estes, R. J. (1988). *Trends in world social development: the social progress of nations, 1970-1987*. New York, London: Praeger.
- Esteva, G., & Prakash, M. S. (1994). From Global to Local Thinking. *The Ecologist*, 24(5), 162-163.
- Ewald, J., & Närman, A. (2001). *Göteborg University in Africa = Africa at Göteborg University*. Göteborg: Centre for Africa Studies, Univ.
- Fanon, F. (2008). *Black skin, white masks*. New York: Grove Press.
- Ferguson, I. (2004). Neoliberalism, the Third Way and Social Work: the UK Experience. *Social Work & Society*, 2(1), 1-9.
- Ferguson, I., Lavalette, M., & Mooney, G. (2002). *Rethinking welfare a critical perspective*. London: SAGE.
- Ferguson, I., Lavalette, M., & Whitmore, E. (Eds.) (2005). *Globalisation, global justice and social work*. London: Routledge.
- Finkelstein, (1999). Extended Review: Doing Disability Research. *Disability and Society*, 14(6), 859-878.
- Finkenflügel, H. (2004). *Empowered to Differ*. Amsterdam: Free University.
- Finkenflügel, H., Wolffers, I., & Huijsman, R. (2005). The evidence base for community-based rehabilitation: a literature review. *International Journal of Rehabilitation Research*, 28(3), 187-201.

- Finnstam, J., Grimby, G., & Rashid, S. (1989). Use of the WHO Classification in Assessing the Prevalence of Diseases, Impairments and Handicaps in Punjab Province, Pakistan. *World Health Statist*, 42(3), 157-160.
- Finnstam, J., Grimby, G., Nelson, G., & Rashid, S. (1988). Evaluation of community-based rehabilitation in Punjab, Pakistan: I: Use of the WHO manual, "training disabled people in the community". *International disability Studies*, 10(2), 54-58.
- Fixen, D. L., Blase, K. A., Naom, S. F., & Wallace, F. (2010). Core Implementation Components. *Research on Social Work Practice*, 19(5), 531-540.
- Flick, U. (2007). *Designing qualitative research*. Thousand Oaks, Calif.: Sage Publications.
- Forssell, A., & Jansson, D. (2000). *Idéer som fångslar*. Malmö: Liber Ekonomi.
- Foucault, M. (1984). In interview with Paul Rabinow and Hubert Dreyfus. In: Rabinow, P. *The Foucault Reader*. Harmondsworth: Penguin.
- Fredrickson, G. M. (2000). *The comparative imagination: on the history of racism, nationalism, and social movements*. Berkeley, California: University of California Press.
- Freeman, E. A. (1997). Community-based rehabilitation of the person with a severe brain injury. *Brain Injury*, 11(2), 143-153.
- Gerdner, A., Bodin, L., & Söderfeldt, B. (1988). *Behandling som hjälp till självhjälp: Minnesota-modellen tillämpad på ett svenskt LVM-hem, Runnagården: bakgrundsfaktorer och resultat*. Örebro: Örebro läns landsting.
- Gibbs, G. (2007). *Analyzing Qualitative Data*. Los Angeles: SAGE Publications.
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Cambridge: Polity Press.
- Golola, M. L. (2001). *Decentralisation, Local Bureaucracies and Service Delivery in Uganda*. Discussion Paper No. 2001/115. United Nations University, WIDER.
- Gough, I. (1999). *Welfare regimes: On adapting the framework to developing countries*. Bath, UK: Institute for international policy analysis.
- Gould, A. (2001). *Developments in Swedish social policy: resisting Dionysus*. Basingstoke: Palgrave.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Grape, O., Blom, B., & Johansson, R. (Red.) (2006). *Organisation och omvärld: nyinstitutionell analys av människobehandlande organisationer*. Lund: Studentlitteratur.

- Gray, M., & Allegritti, I. (2002). Cross-cultural practice and the indigenisation of African social work. *Social Work/Maatskaplike Werk*, 38(4), 324-336.
- Grech, S. (2009). Disability, poverty and development: critical reflections on the majority world debate. *Disability & Society*, 24(6), 771-784.
- Gregory, R. J. (2001). Community based service delivery: power and pathology: or, social rehabilitation is still a 'Commie plot'. *Disability and Rehabilitation*, 23(1), 22-25.
- Grimby, G., & Smedby, B. (2001). ICF approved as the successor of ICIDH. *Journal of Rehabilitation Medicine*, 33(5), 193-194.
- Grimby, G., Finnstam, J., Nelson, G., & Rashid, S. (1988). Evaluation of community-based rehabilitation in Punjab, Pakistan: II: The prevalence of diseases, impairments, and handicaps. *International Disability Studies*, 10(2), 59-60.
- Guldbrandsson, K. (2007). *Från nyhet till vardagsnytta. Om implementeringens mödosamma konst*. Statens Folkhälsoinstitut: Elanders.
- Hai, T. T., & Chuong, T. V. (1999). Vietnam and activities of community-based rehabilitation. *Disability and Rehabilitation*, 21(10-11), 474-478.
- Hargö Granér, S. (1997). CBR – Från Vanmakt till vardagsmakt. In: Forsberg, E., & Starrin, B. *Frigörande kraft: empowerment som modell i skola, omsorg och arbetsliv*. Stockholm: Gothia.
- Hargö Granér, S. (1999). Från vanmakt till vardagsmakt: Community Based Rehabilitation i ett välfärdsperspektiv. *Socialmedicinsk tidskrift*, 1, 21-29.
- Hargrove, E. C. (1975). *The Missing Link: The Study of the Implementation of Social Policy*. Washington, DC: Urban institute.
- Hartley, S. (2001). Commentary on 'community based service delivery in rehabilitation: the promise and the paradox' by Kendall, Buys and Lerner. *Disability & Rehabilitation*, 23(1), 26-29.
- Hartley, S., & Wirz, S. L. (2002). Development of a 'communication disability model' and its implication on service delivery in low-income countries. *Social Science & Medicine*, 54(10), 1543-1557.
- Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2004). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health & Development*, 31(2), 167-180.
- Hasenfeld, Y. (1983). *Human Service Organisations*. Englewood Cliffs: Prentice Hall.
- Hasenfeld, Y. (1992). *Human Services as Complex Organisations*. Newbury Park: Sage.
- Hearn, J. (1999). *Foreign aid, democratisation and civil society in Africa: a study of South Africa, Ghana and Uganda*. Discussion Paper 368. Brighton: Institute of Development Studies.

- Hedlund, M. (2004). *Shaping Justice: Defining the disability benefit category in Swedish social policy*. Lund: Department of Sociology, Lund University.
- Helander, E. (1993). *Prejudice and dignity: an introduction to community-based rehabilitation*. 2. ed. New York: United Nations Development Programme.
- Helander, E. (2004). *CBR is not a medical system*. www.fru.se/artikel.asp?artkelID=10 (2006-02-25).
- Helander, E. (2007). The Origins of Community-Based Rehabilitation. *Asia Pacific Disability Rehabilitation Journal*, 18(2), 3-32.
- Helander, E., Mendis, P., & Nelson, G. (1983). *Training disabled people in the community: a manual on community-based rehabilitation for developing countries*. Geneva: WHO.
- Helander, E., Mendis, P., Nelson, G., & Goerdts, A. (1989). *Training in the Community for People with Disabilities*. Geneva: WHO.
- Hill, M., & Hupe, P. (2005). *Implementing Public Policy: Governance in Theory and in Practice*. London: Sage.
- Hill, M., & Hupe, P. (2009). *Implementing Public Policy. An introduction to the study of operational governance*. Los Angeles; London: SAGE.
- Hjern, B., & Porter, D. O. (1981). Implementation structures: a new unit of administrative analysis. *Organisation Studies*, 2(3), 211-227.
- Hofstede, G. (1984). *Culture's Consequences: International Differences in Work-Related Values*. London: SAGE Publications.
- Hokenstad, M. C., Khinduka, S. K., & Midgley, J. (Eds.) (1992). *Profiles in international social work*. Washington D. C.: NASW Press.
- Holmberg, Å. (1994). *Världen bortom västerlandet. 2, Den svenska omvärldsbilden under mellankrigstiden*. Göteborg: Kungl. Vetenskaps- och vitterhets-samhället.
- Hoogeveen, J. G. (2005). Measuring Welfare for Small but Vulnerable Groups: Poverty and Disability in Uganda. *Journal of African Economies*, 14(4), 603–631.
- Hough, G. W. (1975). *Technology diffusion*. Mt. Airy, MD: Lomond Books.
- HSO (2011). *Handikappförbunden*. <http://www.hso.se/vi-ar-handikappforbunden/In-English/> (2011-04-01).
- Hugemark, A., & Roman, C. (2007). Diversity and Divisions in the Swedish Disability Movement: Disability, Gender, and Social Justice. *Scandinavian Journal of Disability Research*, 9(1), 26-45.
- ILO (2004). *Uganda Country Profile. Employment of People with Disabilities: The Impact of Legislation (East Africa)*. Geneva: International Labour Office.

- Ingstad, B. (1990). *The Myth of the Hidden Disabled. A study of Community-Based Rehabilitation in Botswana*. Norway: University of Oslo. Department of Community Medicine, Section for Medical Anthropology.
- Inthirat, T. R. S., & Thonglith, S. (1999). Community-based rehabilitation in the Lao People's Democratic Republic. *Disability and Rehabilitation*, 21(10-11), 469-473.
- Jackson, B., (2010). At the origins of neo-liberalism: The free economy and the strong state, 1930 – 1947. *The Historical Journal*, 53(1), 129-151.
- Jackson, H., & Mupedziswa, R. (1988). Disability and Rehabilitation: Beliefs and Attitudes Among Rural Disabled People in a Community Based Rehabilitation Scheme in Zimbabwe. *Journal of Social Development in Africa*, 3(1), 21-30.
- Jelsma, J. M., Cortes-Meldrum, D., Moyo, A., & Powell, G. (1995). The Children's Rehabilitation Unit, Harare, Zimbabwe: an Integrated Model of Rehabilitation. *Pediatric Physical Therapy*, 7(3), 140-142.
- Johansson, R. (2002). *Nyinstitutionalismen inom organisationsanalysen: en skolbildnings uppkomst, spridning och utveckling*. Lund: Studentlitteratur.
- Johansson, S. (2004). *Implementering av BBIC-projektet i socialtjänstens organisationer*. Socialstyrelsen, Stockholm: KopieCenter.
- Johansson, S. (2010). Implementing evidence-based practices and programmes in the human services: lessons from research in public administration. *European Journal of Social Work*, 13(1), 109-125.
- Johansson, S., Löfström, M., & Ohlsson, Ö. (2000). *Projekt som förändringsstrategi*. Göteborg: Elanders Graphic Systems AB.
- Johnson, K. (2009). Disabling discourses and enabling practices in disability politics. In: Allan, J., Briskman, L., & Pease, B. (Eds.). *Critical social work: theories and practices for a socially just world*. Crows Nest, N.S.W.: Allen & Unwin.
- Joint Position Paper (1994). *Community-Based Rehabilitation: For and with People with Disabilities*. International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation and the World Health Organisation.
- Joint Position Paper (2002). *Community Based Rehabilitation (CBR): With and for people with disabilities*. International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, United Nations Children's and the World Health Organisation.
- Joint Position Paper (2004). *CBR: A Strategy for Rehabilitation, Equalisation of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities*.

- Switzerland: International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation and the World Health Organisation.
- Jönsson, J. H. (2010). Beyond empowerment: Changing local communities. *International Social Work*, 53(3), 393-406.
- Jonsson, K. (2006). Idéspidning och kunskapskultur. In: Grape, O., Blom, B., & Johansson, R. (Red.) *Organisation och omvärld: nyinstitutionell analys av mänsikobehandlande organisationer*. Lund: Studentlitteratur.
- Kallio, V. (1982). *Medical and social problems of the disabled*. Euro Reports and Studies 73. Regional office for Europe, Copenhagen: WHO.
- Kamali, M. (2001). Civil society and Islam: a sociological perspective. *European Journal of Sociology*, 42(3), 457-482.
- Kamali, M. (2006). *Multiple modernities, civil society and Islam: the case of Iran and Turkey*. Liverpool: Liverpool University Press.
- Kamali, M. (2008). *Racial Discrimination: Institutional Patterns and Politics*. New York: Routledge.
- Kangere, M. (2003). *Development in Disability: The Ugandan Experience*. A paper presented at an expert meeting for Inclusion of Disability in Dutch Development Co-operation Policy and Practice. Kampala, Uganda: COMBRA – The Community Based Rehabilitation Alliance.
- Karna, G. N. (2001). *Disability studies in India*. New Delhi: Gyan Publishing House.
- Kasza, G. J. (2002). The Illusion of Welfare Regimes. *Journal of Social Policy*, 31(2), 271-287.
- Kay, E., & Dunleavy, K. (1996). Community-Based Rehabilitation: An International Model. *Pediatric Physical Therapy*, 8(3), 117-121.
- Keibanda, K. (1995). *The operation of Community Based Rehabilitation (CBR) programme in Bushenyi District: The case of Igara County*. Bachelor of Arts degree in Social Work and Social Administration, Kampala, Uganda: Makerere University.
- Kendall, E., Buys, N., & Larner, J. (2000). Community-based Service Delivery in Rehabilitation: The Promise and the Paradox. *Disability and Rehabilitation*, 22(10), 435-445.
- Kendall, E., Muenchberger, H., & Catalano, T. (2009). The move towards community-based rehabilitation in industrialized countries: Are we equipped for the challenge? *Disability and Rehabilitation*, 31(26), 2164-2173.
- Kerz, J., Werner, M., & Wesser, E. (1995). *Vad vet vi om rehabilitering?: svensk rehabiliteringsforskning 1980-1993*. Lund: Bokbox.

- Kiberu, C. N., & Karyeiya, B. (2007-2012). *Bushenyi District Strategic Plan for Orphans and Other Vulnerable Children*. Uganda: Bushenyi District Local Government.
- Kivelä, S - L. (1985). Problems in Intervention and Evaluation. *Scandinavian Journal of Primary Health Care*, 3(3), 137-140.
- Kizito, E. (1993). *The Educational Newsletter of the Uganda National Institute of Special Education*. Uganda: UNISE.
- Lagerkvist, B. (1992). Rehabilitation in practice. Community-based rehabilitation – outcome for the disabled in the Philippines and Zimbabwe. *Disability and Rehabilitation*, 14(1), 44-50.
- Lane, J-E. (1987). Implementation, accountability and trust. *European Journal of Political Research*, 15(5), 527-546.
- Lang, R. (2011). Community-based rehabilitation and health professional practice: developmental opportunities and challenges in the global North and South. *Disability and Rehabilitation*, 33(2), 165-173.
- Langtree, I. (2011). *World Facts and Statistics on Disabilities and Disability Issues*. Disabled World: <http://www.disabled-world.com/disability/statistics/> (2011-03-24).
- Larsson, M. (2001). *Organiserande av stöd och service till barn med funktionshinder: Om projektnät, språkliga förpackningar och institutionella paradoxer*. Institutionen för psykologi, Lunds Universitet, Lund: KFS AB.
- Latour, B. (1986). The Power of Association. In: Law, J. (Eds.) *Power, Action, and Belief: A New Sociology of Knowledge?* London: Routledge & Kegan Paul.
- Lavalette, M., & Ferguson, I. (2007). Democratic language and neo-liberal practice: The problem with civil society. *International Social Work*, 50(4), 447-459.
- Lester, J. P., & Goggin, M. L. (1998). Back to the future: the rediscovery of implementation studies. *Policy Currents*, 8(3): 1-9.
- Levin, C. (1996). Misslyckade projekt och framgångsrika organisationer. In: Sahlin, I. (Red.), *Projektets paradoxer*. Lund: Studentlitteratur.
- Liamputtong, P. (2007). *Researching the vulnerable: a guide to sensitive research methods*. London: Sage.
- Lightfoot, E. (2004). Community-based rehabilitation — a rapidly growing method for supporting people with disabilities. *International Social Work*, 47(4), 455-468.
- Lilja, M., Månsson, I., Jahlenius, L., & Sacco-Peterson, M. (2003). Disability policy in Sweden: Policies concerning assistive technology and home modification services. *Journal of Disability Policy Studies*, 14(3), 130-135.

- Lindblad, B-M. (2006). *Att vara förälder till barn med funktionsnedsättning: erfarenheter av stöd och av att vara professionell stödjare*. Umeå: Print & Media.
- Lindqvist, R. (1998). Gränser mellan organisationer: exemplet arbetslivsinriktad rehabilitering. In: Lindqvist, R. (Red.) *Organisation och välfärdsstat*. Lund: Studentlitteratur.
- Lindqvist, R., & Hetzler, A. (Red.) (2004). *Rehabilitering och välfärdsolitik*. Lund: Studentlitteratur.
- Lipsky, M. (1980). *Street Level Bureaucrazy*. New York: Sage.
- Loomba, A. (2008). *Kolonialism/Postkolonialism: en introduktion till ett forskningsfält*. Stockholm: Tankekraft.
- Lorenz, W. (2002). *Socialt arbete i ett föränderligt Europa*. Uddevalla: Daidalos AB, MediaPrint.
- Lundgren-Lindquist, B., & Nordholm, L. (1993). Community-based rehabilitation – a survey of disabled in a village in Botswana. *Disability and Rehabilitation*, 15(2), 83-89.
- Lundqvist, Å., Davies, K., & Mulinari, D. (Red.) (2005). *Att utmana vetandets gränser*. Malmö: Liber
- Lysack, C., & Kaufert, J. (1994). Comparing the Origins and Ideologies of the Independent Living Movement and Community Based Rehabilitation. *International Journal of Rehabilitation Research*, 17, 231-240.
- Mackelprang, R. W., & Salsgiver, R. O. (1996). People with Disabilities and Social Work: Historical and Contemporary Issues. *Social Work*, 41(1), 7-14.
- Macqueen, N. (2007). *Colonialism*. Harlow: Longman.
- Macrae, J., Zwi, A. B., & Gilson, L. (1996). A Triple Burden for Health Sector Reform: "Post"-conflict Rehabilitation in Uganda. *Social Science Medicine*, 42(7), 1095-1108.
- Manyire, H., & Asingwire, N. (1998). The State of Dynamics of Social Policy Practice and Research in Uganda. *Journal of Social Development in Africa*, 13(2), 75-83.
- Marnetoft, S - U. (2000). *Vocational rehabilitation of unemployed sick-listed people in a Swedish rural area: an individual-level study based on social insurance data*. Diss. Stockholm: Karolinska institutet.
- Martin, H-P., & Schumann, H. (1997). *Globaliseringsfällan: angreppet på demokrati och välfärd*. Eslöv: B. Östlings bokförlag.
- Matland, R. E. (1995). Synthesizing the implementation literature: the ambiguity conflict model of policy implementation. *Journal of Public Administration Research and Theory*, 5(2), 145-174.

- Mazmanian, D. A., & Sabatier, P. A. (1983). *Implementation and public policy*. Glenview, IL: Scott Foresman Reissued 1989, University Press of America.
- Meeuwisse, A. (1999). *Debatten om välfärdsstaten och det civila samhället*. Sköndals Institute Working Papers NR 11, Ersta Sköndal University College. Stockholm: Erlanders Gotab.
- Messer, N., & Townsley, P. (2003). *Local institutions and livelihoods: Guidelines for analysis*. Rome: Rural Development Division, Food and Agriculture Organisation of the United Nations.
- Meyer, A. D., & Goes, J. B. (1988). Organisational Assimilation of Innovations: A Multi-Level Contextual Analysis. *Academy of Management Journal*, 31(4), 897-923.
- Meyer, J., & Rowan, B. (1977). Institutionalised Organisations: Formal Structures as Myth and Ceremony. *American Journal of Sociology*, 83(2), 340-363.
- Midgley, J. (1997). *Social welfare in global context*. Thousands Oaks, London, New Delhi: Sage Publications.
- Miles, M. (1993). Different ways of community-based rehabilitation. *Tropical and Geographical Medicine*, 45(5), 238-41.
- Miles, M. (2004). CBR in Africa - Between Evidence and Ideology. *Disability World*, June-August (24), 1-12.
- Miles, S. (1996). Engaging with the Disability Rights Movement: The experience of community-based rehabilitation in southern Africa. *Disability & Society*, 11(4), 501-517.
- Millward, H., Ojwang, V. P., Carter, J. A., & Hartley, S. (2005). International guidelines and the inclusion of disabled people. The Ugandan story. *Disability & Society*, 20(2), 153-167.
- Ministry of Education and Sports (1999). *The Uganda experience of Universal Primary Education (UPE)*. Kampala, Uganda: Ministry of Education and Sports.
- Ministry of Gender, Labour and Social Development (2002). *National Community Based Rehabilitation Strategic Plan 2002/03 – 2006/07*. Kampala, Uganda: Ministry of Gender, Labour and Social Development.
- Ministry of Health (1997). *Making a difference for people with disabilities: Learn more about Disability and Rehabilitation*. Kampala, Uganda: Ministry of Health, Disability and Rehabilitation Section.
- Ministry of Health (1999). *Essential Services for rehabilitative Health Care for persons with disabilities in the District*. Kampala, Uganda: Ministry of Health.

- Miron, G. (1994). *Special needs education in Nicaragua: a study of the prevalence of children with disabilities in primary schools and the factors affecting their successful participation*. Diss. Stockholm: University.
- Mitchell, R. (1999). Community-based rehabilitation: the generalized model. *Disability and Rehabilitation*, 21, 522-528.
- Mitchell, R. A., Zhuo, D., & Watts, G. H. (1989). Emerging patterns of disability distribution in developing countries. *International Disability Studies*, 11(4), 145-148.
- Mitchell, R. A., Zhuo, D., Lu, Y., & Watts, G. (1993). Community-Based Rehabilitation: does it change community attitudes towards people with disability? *Disability and Rehabilitation*, 15(4), 179-183.
- Mmatli, T. (2008). Political activism as a social work strategy in Africa. *International Social Work*, 51(3), 297-310.
- Mohanty, C. T. (2006). *Feminism utan gränser: avkoloniserad teori, praktiserad solidaritet*. Stockholm: Tankekraft.
- Momm, W., & König, A. (1989). Community integration for disabled people. A new approach to their vocational training and employment. *International Labour Review*, 128(4), 497-509.
- Montan, K. (1988). *Från partiellt arbetsför till funktionshindrad: rehabilitering och handikappomsorg under perioden 1945-1985*. Bromma: Svenska centralkommittén för rehabilitering (SVCR).
- Mpagi, J. S. (2001). Government's role in CBR. In: Hartley, S. (Eds.) *CBR: A participatory strategy in Africa*. Kampala, Uganda; London, UK: The Centre for International Child Health.
- Mwansa, L-K. J. (2010). Challenges facing social work education in Africa. *International Social Work*, 53(1), 129-136.
- Nabuguzi, E. (1995). Popular Initiatives in Service Provision in Uganda. In: Semboja, J., & Therkildsen, O. (Eds.). *Service Provision under Stress in East Africa: State, NGOs and People's Organisations in Kenya, Tanzania & Uganda*. UK: Long House Publishing Services.
- Nganwa, A., Mirembe, J., & Kisanji, J. (2003). *An Evaluation of CBR Training Programmes in Uganda*. Kampala, Uganda: CAN Consulting Report.
- Nilsen, P. (2010). *Implementering: teori och tillämpning inom hälso - & sjukvård*. Lund: Studentlitteratur.
- NUDIPU (2004). *Local Government Budgeting Process for People with Disabilities*. Uganda: National Union of Disabled Persons of Uganda.

- Nuffield Council on Bioethics (2002). *The ethics of research related to healthcare in developing countries*. London: Nuffield Council on Bioethics.
- Ojwang, V. P., & Hartley, S. (2002). Community Based Rehabilitation Training in Uganda: an Overview. In: Hartley, S. (Eds.) *CBR: A Participatory Strategy in Africa*. Kampala, Uganda; London, UK: The Centre for International Child Health.
- Okunzi, S. (2004). Dying for economic growth? Evidence of a flawed economic policy in Uganda. *Lancet*, 364(9445), 1632-1637.
- Oloka-Onyango, J. (2000). Poverty, Human Rights and the Quest for Sustainable Human Development in Structurally-Adjusted Uganda. *Netherlands Quarterly of Human Rights*, 18(1), 23-44.
- Palme, J., Bergmark, Å., Bäckman, O., Estrada, F., Fritzell, J., Lundberg, O., Sjöberg, O., & Szebehely, M. (2002). Welfare trends in Sweden: balancing the books for the 1990s. *Journal of European Social Policy*, 12(4), 329-346.
- Palme, J., Bergmark, Å., Bäckman, O., Estrada, F., Fritzell, J., Lundberg, O., Sjöberg, O., Somestad, L., & Szebehely, M. (2003). *A welfare balance sheet for the 1990s: final report of the Swedish Welfare Commission*. Umeå: Epidemiology, Dept. of Public Health and Clinical Medicine.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods*. 3. ed. London: SAGE
- Paudel, N. R. (2009). A Critical Account of Policy Implementation Theories: status and Reconsideration. *Nepalese Journal of Public Policy and Governance*, XXV(2), 36-54.
- Payne, M. (2002). *Modern teoribildning i socialt arbete*. Stockholm: Natur och kultur.
- Pease, B. (2010). *Undoing privilege: unearned advantage in a divided world*. London: Zed.
- Pease, B., & Fook, J. (Eds.) (1999). *Transforming social work practice: postmodern critical perspectives*. London: Routledge.
- Peat, M. (1997). *Community based rehabilitation*. London: W. B. Saunders.
- Periquet, A. O. (1989). Community-based rehabilitation in the Philippines. *International Disability Studies*, 11(2), 95-96.
- Pollard, N., & Sakellariou, D. (2008). Operationalizing community participation in community-based rehabilitation: Exploring the factors. *Disability and Rehabilitation*, 30(1), 62-70.
- Pollock, G. (2001). Civil Society Theory and Euro-Nationalism. *Studies in Social and Political Thoughts*, 4, 31-56.
- Powell, W., & DiMaggio, P. (1991). *The new institutionalism in organisational analysis*. Chicago: University of Chicago Press.

- Pressman, J., & Wildavsky, A. (1984). *Implementation: How great expectations in Washington are dashed in Oakland*. California and England: University of California Press.
- PUL (1998) Personuppgiftslag. <http://www.notisum.se/rnp/SLS/lag/19980204.HTM>, Svensk författningssamling, Riksdagen.
- Putnam, M., Sherraden, M., Edwards, K., Porterfield, S., Wittenburg, D., Holden, K., & Welch Saleeby, P. (2005). Building Financial Bridges to Economic Development and Community Integration. *Journal of Social Work in Disability & Rehabilitation*, 4(3), 61-86.
- Qvarsell, R., & Torell, U. (2001). *Humanistisk hälsoforskning: en forskningsöversikt*. Lund: Studentlitteratur.
- Ran, C., Wen, S., Yonghe, W., & Honglu, M. (1992). A glimpse of community-based rehabilitation in China. *Disability and Rehabilitation*, 14(2), 103-107.
- Rattansi, A. (1997). Postcolonialism and its discontents. *Economy and Society*, 26(4), 480-500.
- Regionfakta (2010). Värmlands län – fakta och perspektiv. [http://www.regionfakta.com/Varmlands-lan/Befolkning-och-hushall/befolkning/Befolkningsutveckling-1805-2005/\(2010-11-29\)](http://www.regionfakta.com/Varmlands-lan/Befolkning-och-hushall/befolkning/Befolkningsutveckling-1805-2005/(2010-11-29)).
- Rothstein, B. (1998). *Just Institutions Matter: The Moral and Political Logic of the Universal Welfare State*. Cambridge: Cambridge University press.
- Røvik, K. A. (2008). *Managementsamhället: trender och idéer på 2000-talet*. Malmö: Liber.
- Rowley, J., & Gibbs, P. (2008). From learning organisation to practically wise organisation. *The Learning Organisation*, 15(5), 356-372.
- Rwomire, A. (Eds.) (2001). *Social problems in Africa: new visions*. Westport: Praeger.
- Rwomire, A., & Raditlhokwa, L. (1996). Social Work in Africa: Issues and Challenges. *Journal of Social Development in Africa*, 11(2), 5-19.
- Sahlin, I. (1996). *Projektets paradoxer*. Lund: Studentlitteratur.
- Said, E. W. (1978). *Orientalism*. New York: Pantheon Books.
- Said, E. W. (1983). *The world, the text, and the critic*. Cambridge: Harvard University Press.
- Said, E. W. (1993). *Culture and imperialism*. London: Chatto & Windus.
- Sandelowski, M. (2000). Focus on Research Methods Whatever Happened to Qualitative Description? *Research in Nursing & Health*, 23(4), 334-340.
- Sandström, A. (2008). *Policy Networks: The relation between structure and performance*. Diss. Luleå: Luleå University of Technology; Department of Business Administration and Social Sciences.

- Schön, D. (1983). *The Reflective Practitioner. How Professionals Think in Action*. New York: Basic Books.
- Seligman, M., & Darling, R. B. (2007). *Ordinary families, special children: a systems approach to childhood disability*. New York: Guilford Press.
- Sengendo, J., Nambi, J., Kanya, S., Wabulya, P., Kyadondo, D., & Kanya, M. (2000). *National Survey of Children and Adolescents with Disabilities*. Kampala: Uganda: United Nations Children's Fund.
- Sewpaul, V. (2006). The Global-Local Dialect: Challenges for African Scholarship and Social Work in a Post-Colonial World. *British Journal of Social Work*, 36, 419-434.
- Shakespeare, T. (1993). Disabled People's Self-organisation: a new social movement? *Disability, Handicap and Society*, 8(3), 249-264.
- Sjögren, O. (1996). *ISP - Individualiserade Serviceprogram, del 1 Modellen*. Stockholm: ISP Norden.
- Smith, L. (2008). South African social work education: Critical imperatives for social change in the post-apartheid and post-colonial context. *International Social Work*, 51(3), 371-383.
- Socialdepartementet (2000). *Från patient till medborgare – en nationell handlingsplan för handikappolitiken*. (Regeringens proposition 1999/2000:79). Stockholm: Regeringskansliet.
- Socialstyrelsen (2004). *Handikappomsorg: Lägesrapport 2004*. Stockholm.
- Solomon, P. (1992). The Efficacy of Case Management Services for Severely Mentally Disabled Clients. *Community Mental Health Journal*, 28(3), 163-180.
- SOU (1958). *Socialförsäkring och rehabilitering: betänkande av särskilt tillkallade utredningsmän*. Statens offentliga utredningar 1958:17. Stockholm: Socialdepartementet.
- SOU (2003). *Att samla och sprida kunskap om skadlig inverkan och framgångsrik rehabilitering: slutbetänkande från Utredningen om handläggning av arbetsskador*. Statens offentliga utredningar. Stockholm: Socialdepartementet.
- Spivak, G. C. (1990). *The post-colonial critic: interviews, strategies, dialogues*. New York: Routledge.
- Stainton, T., Chenoweth, L., & Bigby, C. (2010). Social Work and Disability: An Uneasy Relationship. *Australian Social Work*, 63(1), 1-3.
- Steiner, S. (2006). *Decentralisation in Uganda: Exploring the Constraints for Poverty Reduction*. GIGA Research Programme: Transformation in the Process of Globalisation. German Institute of Global and Area Studies, GIGA Working Papers, No 31.

- Stone, D., & Maxwell, S. (Eds.) (2005). *Global knowledge networks and international development: bridges across boundaries*. New York: Routledge.
- Stone, E. (1999). *Disability and Development: Learning from action and research on disability in the majority world*. University at Leeds: The Disability Press.
- Strier, R., Surkis, T., & Brian, D. (2008). Neo-liberalism: Bottom-up counter-narratives. *International Social Work*, 51(4), 493-508.
- Stuelz, A. (1999). Community-based rehabilitation in Lao – comparison of needs and services. *Disability and Rehabilitation*, 21(10-11), 508-514.
- Sundell, K. (2002). *Familjerådslag i Sverige. Socialtjänstens fortsatta insatser till barn och föräldrar*. Stockholm: Forsknings- och Utvecklingsenheten, Stockholms stad. Rapport Nr 2002:3.
- Svedberg, L. (2005). Det civila samhället och välfärden: ideologiska önskedrömmar och sociala realiteter. In: Amnå, E. (Eds.) *Civilsamhället: några forskningsfrågor*. Södertälje: Gidlunds förlag.
- Swärd, H., Edebalk, P. G., & Wadensjö, E. (2013). *Vägar till välfärd – idéer, inspiratörer, kontroverser, perspektiv*. Spanien: Liber AB.
- Swedish Institute (2000). *Disability Policies in Sweden*. Sweden: Swedish Institute.
- Swedish Industry (2004). *The Service Sector in Sweden*. Sweden: Swedish Institute.
- The Swedish Research Council (2002). *Forskningsetiska principer inom humanistisk-samhällsvetenskaplig forskning*. Vetenskapsrådet: Elanders Gotab.
- Thomas, M., & Thomas, M. J. (2002). Some Controversies in Community Based Rehabilitation. In: Hartley, S. (Eds.) *CBR: A participatory strategy in Africa*. Kampala, Uganda; London, UK: The Centre for International Child Health.
- Thörn, H., Eriksson, C., & Eriksson Baaz, M. (Eds.) (1999). *Globaliseringens kulturer: den postkoloniala paradoxen, rasismen och det mångkulturella samhället*. Nora: Nya Doxa.
- Tiberondwa, A. K. (1998). *Missionary teachers as agents of colonialism in Uganda: a study of their activities in Uganda, 1877-1925*. Kampala: Fountain Publishers.
- Tomasevski, K. (1999). *Economic, Social and Cultural Rights*. United Nations Commission on Human Rights.
- Tomlinson, J. (1999). *Globalization and culture*. Cambridge: Polity Press in association with Blackwell.
- Turmusani, M., Vreede, A., & Wirz, S. L. (2002). Some ethical issues in community-based rehabilitation initiatives in developing countries. *Disability and Rehabilitation*, 24(10), 558-564.

- UBOS (2006). *The 2002 Uganda Population and Housing Census: Households Characteristics*. Kampala, Uganda: Uganda Bureau of Statistics.
- UBOS (2010). *Statistical Abstract*. Uganda: Uganda Bureau of Statistics.
- UN (1994). *The standard rules on the equalization of opportunities for persons with disabilities*. New York: United Nation.
- UNCST (2007). *National guidelines for research involving humans as research participants*. Kampala, Uganda: Uganda National Council for Science and Technology.
- UNDP (2011). *Human Developments Reports*. http://hdr.undp.org/en/media/HDR_2010_EN_Readers_reprint.pdf (2011-03-29).
- UNESCO (1994). *The Salamanca Statement and Framework of Action on Special Needs Education*. Salamanca, Spain: United Nations Educational, Scientific and Cultural Organisation.
- Van Meter, D., & Van Horn, C. (1975). The Policy Implementation Process: a Conceptual Framework. *Administration and Society*, 6(4), 445-488.
- Vanneste, G. (2004). Current Status of CBR in Africa: A review. *Journal for Disability and International Development*, 15(1), 11-17.
- Wallerstein, I. (2003). *The decline of American power: the U.S. in a chaotic world*. New York: New Press.
- Wallerstein, I. (2005). *Världssystemanalysen: en introduktion*. Stockholm: Tankekraft.
- Whaites, A. (2000). Let's get civil society straight: NGOs, the state, and political theory. In: Eade, D., & Pearce, J. (Eds.) (2000). *Development, NGOs, and civil society: selected essays from Development in practice*. Oxford: Oxfam publications.
- WHO (1981). *Disability Prevention and rehabilitation*. Geneva: World Health Organisation Technical Report Series 668.
- WHO (1996). *Health Care Systems in Transition, Sweden*. Copenhagen: World Health Organisation.
- WHO (2003). *International Consultation to Review Community-Based Rehabilitation (CBR)*. Helsinki, Finland: World Health Organisation, United Nations Organisations, Non-Governmental Organisations and the Disabled People's Organisations.
- WHO (2007). *Working for health: an introduction to the World Health Organisation*. Switzerland.
- WHO (2011). *World Report on Disability*. Malta: World Health Organisation, The World Bank.

- WHO (2011). Global Health Observatory Data Repository. <http://apps.who.int/ghodata/?vid=20300&theme=country> (2011-03-29).
- Wolmesjö, M., & Zanderin, L. (Red.) (2009). *LSS: regelsystem, implementering och realitet*. Lund: Studentlitteratur.
- World Bank (2011). The World Bank. <http://web.worldbank.org/>, (2011-03-29).
- Wright Nielsen, T. (2009). *Viljen til at frigøre. En undersøgelse af empowerment i praksis*. Diss. Lund: Mediatryck, Lunds Universitet.
- Åberg, J. (1998). Rehabiliteringsteori och rehabiliteringsprinciper under åttio- och nittitalen. In: AGRA-utredningen (1998). *Arbetsgivarens rehabiliteringsansvar: betänkande*. Stockholm: Fritzes offentliga publikationer.
- Åkerström, B., & Nilsson, I. (2004). *Samhällsstödet till barn och ungdomar med funktionshinder och deras föräldrar i Jämtlands län*. Östersund: FoU-Jämt, Mitthögskolan.