

Disability is not Inability

A Case Study of Empowerment of Young Persons with Disabilities in Zambia

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Breaking down Barriers

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Dedication

I would like to dedicate this thesis to all the young persons with disabilities in Zambia for them to be respected for who they are, super humans.

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Abstract

People with disabilities (PWDs) are still amongst one of the most marginalized and excluded groups within societies globally. This study focuses on the empowerment of youth with disabilities, which is an under researched area in the literature. In particular, it examines the Young Voices program in Zambia which aimed to empower youth with disabilities. Theoretically, this study identifies two processes of empowerment, internal and external empowerment. Internal empowerment concerns the "power within" and "with" of people. External empowerment concerns the further process of empowerment in relation to the broader environment. The thesis asks the following research question: How has the Young Voices program contributed to the empowerment of young persons with disabilities? In order to answer this question qualitative research methods are utilized including participant observation, semi-structured interviews, focus groups and photovoice.

The thesis finds that the Young Voices program realized four outcomes relevant to empowerment: new relationships between young PWDs, new perspectives on disability, new confidence to speak out and new purpose. To a certain extent, these outcomes caused internal change in the young PWDs in terms of increased self-worth, increased self-confidence, rights awareness and commitment to the collective ("power within" and power with). Although the program significantly contributed to strengthening the internal empowerment of the young PwDs, the impact of the program in terms of external empowerment remained limited. The study found two limitations concerning the sustainability of the impact of the outreach activities and the ownership of the program. Additional underlying problems such as sustainable capacity and mobility constraints hamper the further process of external empowerment. Overall, the findings of this study question a key assumption in empowerment theory, namely that external empowerment automatically follows from internal empowerment.

Keywords: *persons with disabilities, youth, empowerment, power with, "power within"*

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List of Acronyms

CHSZ	Cheshire Homes Society of Zambia
(UN)CRPD	(United Nations) Convention of the Rights of People with Disabilities
CSO	Civil Society Organizations
CwD	Child with Disability
PwD	Person with Disability
WB	World Bank
WHO	World Health Organization
YV	Young Voices

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Chapter 1: Introduction

*“Having rights but no resources and no services available is a cruel joke”
- Rappaport (1981, 12)*

In this quote Julian Rappaport (1981), founding father of the theory about empowerment, shows how providing a proper set of rights can still be insufficient, especially for people most in need of addressing these rights. It concerns people who are often seen as a burden rather than an enrichment to society; people who are kept in poverty and therefore excluded from society because they are prevented from fully participating (Reynolds 2010). This cruel joke Rappaport is referring to resembles the everyday life of the most marginalized and most impoverished people of the world (Elbers 2015, 2), namely, people with disabilities (henceforth referred to as PwDs). Disability is a worldwide issue, especially in developing countries where PwDs including children, remain excluded from all kinds of basic services. In the Global South these people are at risk, because poverty and disability reinforce each other, which leads to exclusion and increased vulnerability (Ghosh et al 2016, 92).

The understanding of disability has changed over time, currently the so-called ‘social model’ based on UN Convention of People with Disabilities (CRPD) is used by most international agencies to specify the concept of disability. This model does not perceive disability as an individual problem, but it conceptualizes disability as arising from the interaction of a person’s functional status with their physical, cultural and policy environments (Burchardt 2004, 736). This way of thinking provides possibilities for people to gain control over their own lives by pursuing changes in their environment. This process of gaining control over one’s own life is called empowerment (Rapaport 1981, 12).

Although the popularity of empowerment is rising the past decades, almost no research has been done to the empowerment of youth with disabilities in the global South. Up to now research to empowerment has mainly focused on the economic domain, following the theory of scientists like Sen and Kabeer who underline economic empowerment as the essential underpinning of wider social and political empowerment. Although empowerment is a concept focusing on vulnerable groups in marginalized positions in general, the majority of research is conducted within the field of gender studies on the empowerment of women, both as individuals and as a collective marginalised group. This research provides new insights by

focusing on youth with disabilities, a group that is been under researched in the context of empowerment.

This research follows Eyben et al. (2008) who define empowerment as *“the ability to imagine one’s world differently and to realize this vision by changing power relations that have been keeping marginalized people in poverty* (Eyben et al. 2008, 5).” Empowerment is associated with people’s “power within” and “power with” being strengthened. “power within” enables people to have the courage to explore new things they never thought themselves to be capable of. “Power with” is created by working alongside others to claim their rights (Eyben et al. 2008, 5). “power within” and “power with” form the starting-point for individuals and collectives to work towards positive change. Such change can occur in various domains, referred to as social, economic, political and legal empowerment.

In order to stimulate and to start processes of empowerment for these specific groups, Civil Society Organisations (CSOs) can play an important role. The work of CSOs has been encouraged by international treaties, such as the Sustainable Development Goals and the ‘Leave No One Behind’ agenda, to raise awareness and make governmental policies and practices more inclusive for PwDs (Elbers 2015, 2). For CSOs in Zambia this is certainly the case, with regards to the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). CSOs have the ability to start dialogues with power holders, therefore, they hold the potential to be successful in putting rights of these people on the development agenda and increase accessibility of participation in society.

In order to research the processes of empowerment of young PwDs, I focused on the Young Voices program implemented by Cheshire Homes Society of Zambia (CHSZ). Young Voices is a good example of a project seeking to promote empowerment for youth with disabilities, in the age of 16 to 30 years old, using the CRPD as frame of reference. Goals of this program have been building capacities of the youth as ‘change agents’, enabling them to push for the implementation of the CRPD and improve human rights and living conditions of PwDs through empowerment. It makes it a good example, because even two years after the funding of the project has stopped, youth are still active as Young Voices. Although their activity is reduced because of lack of resources, the youth are still committed to the project and their group. It can be said that to certain extent empowerment has happened, which will be further analyzed in the findings of this thesis.

This research may contribute to the knowledge and literature on empowerment of youth with disabilities in the Global South by providing an answer to the following research question: **How has the Young Voices program contributed to the empowerment of youth with disabilities in Zambia?**

In order to answer this research question, the thesis is structured as follows: The thesis is divided into six chapters. The first chapter introduces the themes of the research focusing on the empowerment of youth with disabilities in Zambia. The second chapter presents the theoretical framework in which this research is embedded. This chapter sets out the evolution of thinking about disability according to different theoretical models. Followed by explaining the issue of disability in relation to poverty and exclusion. The final section sets out the concept of empowerment and its conditions based on the theory of Eyben et al (2008). The third chapter elaborates on the research design by discussing the different research methods used for data collection and analysis, research location and units of analysis. The chapter ends with an extensive methodological and ethical reflection. Chapter four describes how the participants of this research experience their disability in daily lives, with an emphasis on the challenges they face, which is relevant as it informs the backdrop of the next chapter. This following chapter, chapter five, analyzes the contribution of the Young Voices program to empowerment. This chapter in addition to chapter four are based on empirical data. The final chapter six concludes the thesis and provides recommendations and options for further research.

Chapter 2: Theoretical Framework

This chapter outlines the theoretical framework. First, this chapter describes the evolution of thinking about disability, focusing on how disability is perceived in society. Second, it discusses the relation between disability, poverty and exclusion. This section highlights the internalization of the stigmatized consequences of having a disability, which affects internal and external outcomes. This creates a situation in which empowerment can provide social change to improve one's life. In the final section of this chapter the concept of empowerment will be discussed and conceptualized. Together, these sections provide the theoretical framework that is used to interpret the data in the following chapters.

2.1 Understandings of Disability

This section explains the current way of thinking about disability which is relevant to understand how social thinking leads to the internalization these perspectives on disability. In order to understand the current way of thinking about disability, this section elaborates on the evolution of different understandings throughout time. Besides the evolution, also the tension between global and local understandings is discussed.

Although the current global discourse of disability lacks a universally agreed global definition of what constitutes disability¹, an international treaty named the CRPD aims to fill this gap and symbolizes a landmark in the history of disability rights (Iriarte 2016, 11). This international treaty provides a framework in the global understanding of disability. The CRPD describes 'persons with disabilities' as those "*[w]ho have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others* (as cited in Iriarte 2016, 11)." This description is widely acknowledged and implemented and represents a paradigm shift in thinking about disability (Lewis et al. 2015, 69). According to Iriarte

¹ The lack of a universally agreed global definition of what constitutes disability is problematic for the prevalence of disability to . In the case of Zambia, literature shows inconclusive statistics According to the National Census conducted in 2000, conducted by the Central Statistical Office Zambia, 2.7% of the Zambian population lives with a disability (Mtonga and Lungu 2017, 14; Nixon et al. 2014, 7). However, disability organizations (DPOs) argue that this prevalence is significantly underestimated and is in reality much higher. This statement is based on the fact that the Census makes use of a definition founded on the medical model (see Chapter 2) perceiving disability solely as an medical impairment rather than an activity limitation. Therefore, the definition is outdated and the prevalence provides incorrect information according to the DPOs (Mtonga and Lungu 2017, 14). Another study, conducted by SINTEF, about living conditions of persons with disabilities found prevalence rates in each province with an average national prevalence of 13.3% (Loeb et al. 2008, 38). In addition to this, the World Health Organization (WHO) conducted a research which shows even a higher prevalence of 15%. These calculations mean that approximately 2 million women and men live with a disability (Mtonga and Lungu 2017, 14).

(2016, 12), the description refers to the so-called 'social model' which is increasingly mentioned in the disability and development debate, and endorsed and channeled by numerous (international) development organizations, such as, the WHO and UNDP (Grech 2009, 773). The social model of disability breaks the direct connection between impairment and disability – referring to the social, environmental and attitudinal factors which in *interaction with* the impairment cause disability (Iriarte 2016, 12).

The acknowledgment of the social model represents an evolutionary step in thinking about disability, as it diverts from a previously dominant model, namely, the medical model. This model views all disabilities as a result of some physiological impairment due to damage or to a disease process (Llewellyn and Hogan 2000, 158). In this way, the model locates disability within people (Marks 1996, 85). The emphasis in this way of thinking is on changing the minority who cannot fit into mainstream society and adapt them rather than organising the environment in ways to make social life accessible for everyone (Marks 1996, 85). The adaptation process primarily consists of treatment and therapy in clinical terms. This model has been criticized by the disability movement consisting of activists and academics. They have argued that the approaches have failed to acknowledge the impact of the environment by mainly focusing on the defects of the functional body (Marks 1996, 86).

Environmental factors are included in the social model by conceptualizing disability as arising from the interaction of a person's functional status with their physical, cultural, and policy environments (Loeb et al. 2008, 34). In terms of interaction, disability can range from mild to severe, can be constant or episodic, and whether a person is considered to have a disability is dependent on their environment (Braithwaite and Mont 2009, 220). According to the social model, disability is not something that exists in the individual (Iriarte 2016, 17), but is the outcome of an oppressive relationship between people with impairments and the rest of society (Burchardt 2004, 736). According to Iriarte (2016, 17), the social model assumes that it is "*society that actually disables the person and generates the problems associated with disability.*" Since the social model breaks the direct link between impairment and disability, it politicizes disability as "*an expression of wider socio-economic, political and cultural formations of ... the exclusion of people with impairments* (Goodley 2007, 5; Grech 2009, 773)."

The social model tries to shift the focus towards social barriers while acknowledging that impairments can have psycho-emotional effects for disabled people (Iriarte 2016, 18).

Acknowledging that disability arises from the interaction of a person's functional status with their physical, cultural and policy environments creates a 'symbiotic' relationship, which, according to Kuyayama (2011, 167), requires the environment to minimize psychological, geographical, economic and cultural obstacles so that disability challenges are manageable. In his view, if society fails to be sensitive and responsive to the plight of children with disabilities, a situation will develop whereby these children remain the marginalized of the marginalized (Kuyayama 2011, 167). This highlights society's responsibility in managing the environment in order to stimulate development of PwDs and by this, the development of society as well.

Whereas the international understanding of disability, based on the CRPD, informs the work of international agencies, previous ways of thinking are not completely rejected and can still influence understanding of disability on a local level. Lewis et al. (2015, 69) point out that the lives of people with disabilities vary considerably depending on the country where they live. Besides the context of a country, also age, gender, socio-economic status and living in city or rural areas affect the lives of over 1 billion people with disability worldwide. According to Lewis et al. (2015, 69), individuals' experience of disability may largely be formed by cultural understandings of ability and disability. Many of these cultural views put most emphasis on physical competence, which results in the belief that PwDs are inferior (Campbell 2009 as cited in Lewis et al. 2015, 69). This belief arises from the perspective of the able-body as the 'normative' body, which functions as the comparison standard. In this way, it continues to regard PwDs as disadvantaged and maintains their discrimination around the world (Lewis et al. 2015, 69).

Many people in countries both North and South may not yet understand that disability is a product of a person-environment interaction (Lewis et al 2015, 71). Especially in the Global South, certain myths and cultural beliefs associate disability with misfortune or a bad spell and witchcraft. These beliefs result in discrimination of people with disabilities because disability is seen as a punishment from God or the ancestral spirits (Kuyayama 2011, 163). These spiritual perceptions of disability lead to stigma (Barg et al. 2010, 371). This results in isolation of the PwDs, since no one wants to be associated with sinners or victims of angered spirits and ancestors. Especially for children with disabilities this is detrimental for their development, since some parents turn away because of lack of knowledge. For example, the parents distance themselves from health care providers because they believe assistance can not eliminate the disability (Kuyayama 2011, 163).

The stigmatized perception of disability as inability leaves children with disabilities as ‘objects of pity’, which leads to compromises in their development of self-esteem and positive self-concept (Kuyayama 2011, 165). In line with this, Saetermoe et al. (2001, 699) argue that PwDs adjust their expectations of themselves downwards in order to cope with stigmatic responses. This results in a decreased self-esteem and self-confidence, which, in turn, affects their functioning. Saetermoe et al. (2001, 699) claim that this takes its toll in outcomes such as employment, income, college participation and physical activity (Saetermoe et al 2001, 699). This can lead to a feeling of powerlessness and marginalization, which creates the inferior position of PwDs in society.

It shows a vicious cycle in which shared beliefs and values of any culture, stimulating in- or exclusion, are adopted and internalized by individuals as part of their own value and belief system (Lewis et al. 2016, 76). This cycle doesn’t stop at individual level, because the individual systems all together contribute to and shape the cultural beliefs and values of the culture they are part of (Lewis et al. 2016, 76). It requires awareness of disability as a socially constructed concept that is context-specific.

2.2 Disability, Poverty and Exclusion

This section will explain how disability is related to poverty and exclusion, to create an understanding of the power relations that currently keep youth with disabilities in marginalized positions.

PwDs experience an inferior position characterized by marginalization and powerlessness. The experiences of PwDs in rural areas and urban slums across Africa, Asia and Latin America are often overlooked (Barnes and Sheldon 2010, 774). PwDs are more likely to experience poverty, poorer education and employment outcomes, restricted access to public life and denial of their most basic rights. Experience of these barriers varies across countries, social classes, gender, culture, ethnicity, and individual impairments (Iriarte 2016, 10). Literature shows that disability is pervaded by inequality that accompanied capitalist development the past decades, which incorporated the notion that disabled people are the ‘poorest of the poor’ in all societies (Barnes and Sheldon 2010, 772; Grech 2009, 771). Poverty experienced by such social groupings is rooted in structural inequalities and social processes.

According to Braithwaite and Mont (2009, 230) disability and poverty are intricately linked as both a cause and consequence of each other. Although there is strong anecdotal evidence to suggest this relationship, literature shows that this relationship is not well-established, ill-defined and few estimates exist of the mutual impact (Braithwaite and Mont 2009; Groce et al. 2011, 1493). Groce et al. assign this to a number of distinct yet interrelated factors, namely, a lack of universally agreed global definition of disability, and a lack of statistical data regarding the socio-economic status of PwDs, particularly in the global South (Groce et al. 2011, 1493). Several studies address this issue and try to define this complex relationship according to multiple dimensions. For example, Groce et al. focus on two dimensions based on the accentuation of poverty by disability and the increasing impact of poverty on the livelihood of disability (Groce et al. 2011, 1496). They illustrate that it is increasingly clear that the links between disability and poverty are multidimensional in nature, and poverty cannot be understood solely in terms of deprivation of income (Groce et al. 2011, 1501).

Kuyayama (2011, 165) builds on this idea that poverty is more extensive than solely deprivation of income. In his research he argues that poverty is stressful to most families who are already stressed with challenges of raising children with disabilities. According to him, this stress is passed on to children with disabilities in a form of what appears to be general neglect of that child. The parents might be tended to give up all efforts to assist the children with disabilities because they cannot access the right resources. Kuyayama (2011, 165) underlines how unhealthy these attitudes of parents are for children who are already disadvantaged by their condition. This can also be seen as a form of social exclusion, which plays a crucial part in the disability-poverty cycle.

Gosh et al. (2016, 92) acknowledge this need to include social exclusion in their understanding of the complex relationships between disability and poverty. They argue that poverty and disability reinforce one another, leading to exclusion and increased vulnerability. To show this, they illustrate three pathways through which disability increases the vulnerability to poverty. The first involves the impact of disability on education and employment, consisting of inadequacies in education and employment limiting life chances, which can result in disparities that start in childhood. In terms of long term development, these disparities can persist throughout life and continue to have impact in adulthood (Gosh et al. 2016, 90). The second pathway comes from the high costs of living with disabilities in terms of direct costs, medication and treatment, and indirect costs, such as lost employment or working part-time (Gosh et al. 2016, 92). Thirdly, they state that poverty can cause disability, because living in impoverished circumstances exposes people to unhealthy and

unsafe environments which increase the likelihood that an individual will acquire a disability. These pathways underline the increased vulnerability to inequality and exclusion resulting from the inability to have the same options and opportunities as all other members of society (Groce et al. 2011; Gosh et al. 2016). Gosh et al. state that the conditions of all three pathways should be prevented in order to reduce social exclusion.

Literature shows that the marginalized position of people living in poor circumstances creates constraints to poverty reduction. Research by Banerjee and Duflo (2007, 150) states that low aspirations lead to low agency, which leads to a lack of investment, which keeps people poor. A process of internalizing the constraints develops, which causes a vicious cycle of the situation. According to Banerjee and Duflo, the behaviour of poor people is a reflection of their personal emotional experiences of lack of control over their environment. This can be crop loss due to unexpected weather or early and unexpected death owing to disease. In their research they call for the need to foster agency through development policy for the people to be able to take over control over their own lives and produce change (Banerjee and Duflo 2007, 151). In other words, empowerment is needed to produce social change in power relations that keep them in poverty. The upcoming section will set out the concept of empowerment and its processes.

2.3 Empowerment

The concept of empowerment is well known and widely used within different disciplines to deal with structural inequalities. It is a valuable concept to create an understanding of why and how certain groups are being excluded and how they aim to subtract from this marginalized position. This section will provide a brief history, review of current literature and conceptualisation of empowerment in this research.

2.3.1 A Brief History

In this paragraph, a brief history is provided of the development of the concept of empowerment in order to create a deeper understanding of the content of empowerment as a process.

The roots of empowerment can be traced back to the Marxist sociological ideals. However, the implementation and translation of empowerment as a process within society first appeared within the community psychology as a result of the work of an American social scientist Julian Rappaport in the late 70s, early 80s (1981). In his work, Rappaport presents

the theory of empowerment as an alternative to two opposing mechanisms, namely prevention and advocacy which dominate the field of social policy. Rappaport claims that prevention and advocacy are one-sided in the way that they focus solely on (resp.) needs *or* rights which affects the way these mechanisms provide solutions for societal issues. By one-sided he means paying attention to only one side of the truth and thus failing to take into account an equally compelling opposite (Rappaport 1981, 4). According to Rappaport both *needs* and *rights* should be taken into account; only acknowledging *needs* creates a dependency model and only recognizing *rights* creates an illusion of social responsibility. The illusion of this social responsibility is best questioned in following quote: “*what use is the right to treatment if treatment is neither available nor good (Rappaport 1981, 14).*” Empowerment provides a perspective of exploring both sides of needs and rights allows people to embrace reasoning that permits many different and contradictory answers to social problems, rather than a single narrow-minded solution.

Therefore, he views the concept of empowerment as a shift in thinking about how to deal with so-called “*social disasters*” as a society (Rappaport 1981, 15). In his view, empowerment is far more promising because it aims to enhance the possibilities for people to control their own lives. In order to take empowerment seriously, Rappaport (1981, 15) states that “*we will no longer be able to see people as simple children in need or as only citizens with rights, but rather as full human beings who have both rights and needs.*” In order to achieve this it is important to acknowledge that even people most incompetent and in need, require more rather control over their own lives by fostering control instead of ignoring. (Rappaport 1981, 15).

2.3.2 Review Empowerment Literature

The work of Rappaport created a starting point for the implementation of empowerment into other disciplines. Although implemented within different domains each with its own nuances and specific issues, empowerment is always characterized as an approach to deal with the marginalized groups within society. It is the societal values which determine these marginalized and minority groups and put them in a inferior position within the relationships in society (Rappaport 1981). In current literature, there seems to be a relatively strong emphasis on two domains of empowerment: economics and gender.

For instance, one specific form of empowerment became a dominant theme and characterizes the majority of the empowerment studies nowadays which is economic

empowerment. The concept of empowerment was introduced in the domain of development economics by Amartya Sen (Fox and Romero 2017, 4) on the basis of his capability approach theory. His theory claims that true development should be seen as a process which enlarged people's capabilities given their personal preferences. Sen argues that poor people in particular need to be involved in development policy to own the feeling of having contributed to the outcome. Pursuing this involvement requires empowerment (Fox and Romero 2017, 4). The introduction of economic empowerment created a tendency among other behavioral economists in the development field to explore empowerment in relation to economic decisions (Fox and Romero 2017, 6).

Based upon Sen's capability approach, scientist Naila Kabeer further developed economic empowerment as the essential underpinning of wider social and political empowerment of women, both as individuals and as collective marginalised group (Kabeer 2012, 7). In her research, she emphasizes the role of women which became a focus point for even more researchers. Kabeer defines empowerment as "*the processes through which women gained the capacity for exercising strategic forms of agency in relation to their own lives as well as in relation to the larger structures of constraint that positioned them as subordinate to men* (Kabeer 2012, 7)." Gender and economics literature primarily focuses on women's welfare and recognizes both the individual and communal aspects of empowerment. Kabeer understands empowerment as a process of change that transforms women's and girls' lives in four areas of power, namely, (1) "*power within*", (2) *power to*, (3) *power over*, and (4) *power with* (Perezniel and Taylor 2014, 236) and as a process that interacts with resources (pre-conditions), agency (process), and achievements (outcomes; Kabeer 1999). However, this perception of empowerment targets one particular group and leaves other marginalized groups untouched in the research to empowerment, which is a critical issue.

Little research has been done on the empowerment processes of (young) people with disabilities. They are a major group of people who constantly experience social exclusion, neglect of choice and are not recognized for their capabilities (Rappaport 1981, 12). This group of people is still viewed as divergent in a society in which the standard is based on being able-bodied, which causes a struggle between the aims of normalization and protection (Rappaport 1981, 12). For this group to experience actual contribution to outcomes in society, empowerment is crucial. This requires strengthening of power 'within' and 'with' (Eyben et al. 2008, 5) and social change in social, political and economic domain. Therefore, this research builds on the inclusive understanding of empowerment of Eyben et al. (2008).

The next paragraph will elaborate on the conceptualization of empowerment in terms of Eyben et al.'s understanding.

2.3.3 Conceptualising Empowerment

The idea of empowerment of Eyben et al. (2008) captures the freedom of choice and action, and also recognizes how power shapes imagination and by this the potential for achieving desired change (Eyben et al. 2008, 6). They define empowerment as a process that *“happens when individuals and organized groups are able to imagine their world differently and to realize that vision by changing the relations of power that have been keeping them in poverty (Eyben et al. 2008, 6).”* In this definition they narrowed down the conditions of empowerment to "power within" and "power with" in contrast with Kabeer (1999). They understand empowerment as a process which only occurs when both conditions - "power within" and "power with" - are met. This is in line with the idea of Fox and Romero that acting upon empowerment is only possible until self-esteem and self-confidence are recognized to imagine a different situation, because *“dreams by themselves do not constitute empowerment (Fox and Romero 2017, 4).”* In this way, empowerment - power 'within' and 'with' - generates collective action for reducing social inequality patterns and other conditions, which in turn contribute to further process of (external) empowerment (Eyben et al. 2008, 6).

"power within" enables people to have the courage to do things they never thought themselves to be capable of (Eyben et al. 2008, 5). This condition enables people to develop a sense of self-worth and self-knowledge which equips them to *“imagine their world differently and therefore act to change it (Eyben et al. 2008, 6).”* "Power with" is created from working along others to claim what is rightfully theirs (Eyben et al. 2008, 5). This condition of power is mostly organized collectively and relates to the components of communication and leadership. These two components create the ability for people to share their knowledge, educate others and critically reflect on other views. In other words, it enables people to realize their vision of imagination and to redefine their possibilities and act on them. "power within" and "power with" relate to internal processes within the affected people themselves, therefore, this research refers to these processes as internal empowerment. Eyben et al. (2008, 6) explain how internal empowerment constitute empowerment in social, economic and political domains. According to Eyben et al. these

conditions constitute empowerment in social, economic and political domains which is referred to as external empowerment.

In their understanding of empowerment, Eyben et al. view all three domains (social, economic and political) interconnected and equal to each other as pathways out of poverty, rather than preferring empowerment in one domain over the others. They also identified a fourth domain, legal empowerment, but they state that this domain is cross cutting the other three domains. The law is a contributory element to changing the ways things are done as well as to how people envisage themselves and are seen by others, enhancing their capacity to act and to bring about changes in their lives and those around them (Eyben et al. 2008, 6).

First of all, Eyben et al. (2008,8) describe social empowerment as taking steps to change society to a place in which people are respected and recognized on their own terms. This is extremely relevant for people living in poverty, because they are often spoken for and about by those who are not poor (Eyben et al. 2008, 9). Perhaps even more for PwDs, whose needs are often articulated by others instead of themselves. Power is operated through institutions and discourses, and determines the way people perceive themselves and how they choose to relate to others (Eyben et al. 2008, 8). People themselves are continuously, mostly unconsciously, reproducing these institutions and internalize a sense of lack of worth when they are treated less because of their physical features (Eyben et al. 2008, 8). This is where empowerment can process a change whereby people develop a sense of and capacity for agency, in other words, strengthening "power within" and "with". Social empowerment aims to improve the quality of their social relationships and to secure respect, dignity and freedom from violence, leading purposively or otherwise to changes in institutions and discourses maintaining certain stigma and keeping them in poverty (Eyben et al. 2008, 8).

Secondly, economic empowerment is the capacity of poor people to participate in, contribute to and benefit from growth processes on more humane terms, such as, recognizing the value of their contributions and negotiating a fairer distribution of the benefits of growth (Eyben et al. 2008, 9). Economic empowerment goes beyond the survival needs for people and enables people to recognize and exercise agency and choice, "power within" and "with". In this process, patterns of growth matter as much as the rate of growth, involving not only markets and private companies but also policies to increase peoples' access to markets (Eyben et al. 2008, 10). According to Eyben et al., inequalities matter to growth outcomes, particularly inequalities in the distribution of assets. They state that the higher the initial inequalities in the distribution of assets, such as education, land or capital, the less likely it is that a

particular growth path will lead to declines in poverty. In their study, Eyben et al. (2008, 11) provide several insights how economic empowerment can be facilitated, related to promotion of assets, social protection, “decent work” agenda, and voice and organization for economic citizenship.

At last, Eyben et al (2008) describe political empowerment in terms of representation in political institutions and foregrounding the least vocal. A way to facilitate political empowerment through "power within" and "with" is to mobilize the affected people around their rights, which helps to build their individual and collective political capabilities necessary to engage in policy negotiations (Eyben et al. 2008, 14). Political empowerment is a precondition for collective action of excluded groups to make their voices heard by reframing their relation to institutionalized power. This process enables people to think critically about their living conditions and possibilities, unlearn prior social conditioning and see things differently (Eyben et al. 2008, 15). In this process, central roles are assigned to civil society, the state and political parties in order to collaborate and achieve greater inclusion. However, the political actors are by themselves not necessarily sufficient because of the structures of power relations in society. Eyben et al. (2008, 17) suggest approaches such as mobilizing around new identities or deepening democracy concerned with sustaining more substantive citizen participation.

Chapter 3: Research Design

This chapter reflects on the research design of this thesis, outlining what methods are used and what choices were made and how this affected conducting the research. At first, the research questions will be set out. The second section elaborates on the research model which visualizes the levels of analysis in the research. In the third section, the research approach will be explained. Subsequently the influence of characteristics of the research location will be discussed. This is followed by the last paragraph concerning the methodology of the research. This paragraph discusses the research methods, methodological reflection, further limitations and ethical reflection.

3.1 Research Questions

The main purpose of this research is to develop an understanding of the processes of empowerment of youth with disabilities appeared throughout the implementation of the young voices project. Therefore, this research seeks to answer the following research question:

How has the Young Voices project contributed to the empowerment of youth with disabilities in Zambia?

Based on the theoretical chapter, this study uses the following sub-questions:

1. What activities were undertaken in the Young Voices program, where, when, and by whom?
2. How has the Young Voices program contributed to the "power within" of youth with disabilities?
3. How has the Young Voices program contributed to the 'power with' of youth with disabilities?
4. How did the 'Young Voices' use their power (within and with) to realize empowerment in different domains (economic, social, political)?

3.2 Research model

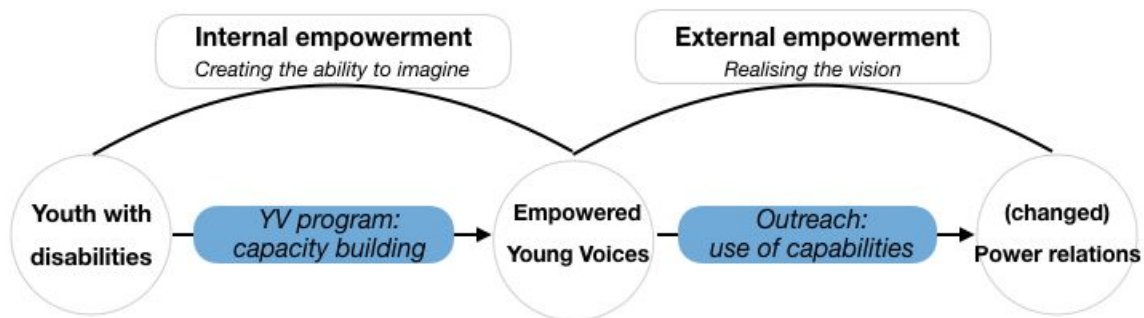


Figure 1: Research model (Lindsay Vogelzang)

The research model presented above clarifies the (sub-)dimensions of empowerment in relation to the research design. As is being visualized in the scheme, the process of empowerment is divided into two segments, namely, internal empowerment and external empowerment. The process of internal empowerment starts with youth with disabilities who participated in an intervention (the Young Voices Program) which may have had effects in terms of their internal empowerment. The Young Voices program focused on capacity building, such as gaining knowledge of self and rights and developing communication and leadership skills. Firstly, the research examines whether and how this capacity building enabled the youth with disabilities that participated in the program (the Young Voices) to imagine their world differently.

The second step in the research model focuses on the question whether and how the internal empowerment outcomes were put to practice in the external world. In other words it is about whether internal empowerment led to external empowerment thus resulting in changed power relations. How did the youth with disabilities use their newly acquired "power within" and power with to realize positive change in the social, economic and political domain? In the next chapters I will elaborate on the findings of both processes and the connection between the two segments.

3.3 Operationalisation of Concepts

The major concept underlying this research, empowerment, has been operationalised to show its application to this study (see Appendix A: Operationalisation Table). This was operationalised to help determine scope of study, relationships between concepts and the interview questions and during data analysis.

3.4 Research approach

This research is conducted within the framework of the research project ‘*Breaking down Barriers*’, initiated by the Liliane Foundation and African Studies Centre in Leiden. The research is conducted in three countries in Africa, namely, Sierra Leone, Cameroon and Zambia in collaboration with local partner organisations of Liliane Foundation. In Zambia this is Cheshire Homes Society of Zambia (see Photo 1). The research project aims to identify the success factors of advocacy for children with disabilities. Besides generating academic knowledge on disability advocacy, the research outputs are used to stimulate organizational learning on effective advocacy for PwDs (Elbers 2015, 1). This resulted in the selection of the Young Voices as case study, because this project aims to empower youth with disabilities by enabling them to become agents of change. This thesis focuses mainly on the processes of empowerment, which builds a foundation of knowledge for further research to focus on the contribution of advocacy on empowerment.



Photo 1: Made by author. Gate of Cheshire Homes Society of Zambia National Office, Strategic Partner Organisation of Liliane Foundation. 2018. Lusaka

Conducting research within an existing framework of a broader research project has several implications. Engaging in this project meant doing research in one of the selected countries. This affects the research in limiting the choice of destination, but also enriches the research in providing an existing network within the disability sector. Also, engaging in this project meant following certain pathways, such as working together with the assigned organisation (CHSZ in this case) and with the assigned local supervisor (dr. Thomas Mtonga of the University of Zambia). Such an arrangement has the potential to be beneficial and limiting at the same time, depending on the personalities of the people involved.

In terms of positive effects, it was very valuable to engage in an existing network as that of CHSZ because of the short time period of the research. Because of the openness of the CHSZ staff it was also possible to involve them as soundboard in terms of reflecting on research methods, approaching informants and going to events together. They were also helpful in terms of accommodation, administrative guidance with visa, and transportation. They provided help for arranging all practical resources which made it possible to reach the full potential of the research within nine weeks.

The local supervisor was also arranged by the Breaking down Barriers project, which means that he was selected with care by the coordinator of the research project (also the supervisor of this thesis) to make sure the local supervisor had enough understanding of disability issues in Zambia in terms of academic profession. The local supervisor supported me and a fellow student researcher (Master African Studies at Leiden University) who was also involved in the research project for the same period of time, consisting of two weekly meetings and feedback sessions on interim reports on the findings and process of the research.

3.5 Research Location and Units of Analysis

3.5.1 Research Location

Zambia is located in Southern region of the African continent. It is a land locked country and it shares borders with Tanzania, Democratic Republic of Congo, Malawi, Mozambique, Zimbabwe, Botswana, Namibia and Angola. This study was conducted mainly in Lusaka, the capital city of Zambia. Also, data was collected in Kafue, approximately 40 kilometers away from Lusaka. The reason to focus on Lusaka province, is because the Young Voices project

was implemented in these two locations during the year 2015-2016, when it received funding from the German Embassy. In Lusaka the Young Voices group was coordinated by the CHSZ staff and in Kafue the group was coordinated by a partner organization of CHSZ named Twatasha. Some characteristics of these locations affected my research in such a way that it is important to note.

First of all, Zambia (see Figure 2) is a very widespread country, which also holds true for her cities. The city of Lusaka is 412 square kilometres big². The surface in combination with poor infrastructure dating from the early 60's, before independence, add up to constant traffic jams. Because I did not have my own car I relied on taxis and colleagues, which created a certain dependance and limitation to the number of appointments I was able to make on any one day. In addition to this, using public transport in Zambia is time-consuming in itself. Public transport consists of minibuses which are mainly focused on being occupied to the full amount rather than driving the fastest and most efficient route. It could take up to a three hour drive to Kafue, which is only 40 kilometres. This limited my flexibility in terms of going to appointments in different places in the day, which means I would spent most of the day traveling to the different locations.



Figure 2: Map of Zambia, accessed on June 14, <http://ontheworldmap.com/zambia/>

²Google, accessed on June 14, https://www.google.nl/search?source=hp&ei=W3EtW5fJBsOTkwWk8KuwDQ&q=lusaka+size&oq=lusaka+size&gs_l=psy-ab.3..0i22i30k1i2.643.3822.0.4001.12.11.0.0.0.97.709.11.11.0...0...1c.1.64.psy-ab..1.11.708.0..0j35i39k1j0i67k1j0i131k1j0i10k1j0i203k1.0.11J_DXTktOM

Also the time of the year affected the accessibility of the locations, because it was rainy season during my stay. In Zambia rainy season is from December until March. This year (2018) December and January were particularly dry, which caused big floods in February and March. This caused some challenges concerning appointments. One day I was in Kafue in the Twatasha school building when it started raining heavily. This resulted in a delay in the appointments with two community leaders, because they couldn't move around since their only transport was by foot or by bike. These scenarios happened several times, which limited my efficiency in terms of planning more appointments in one day.

These previous points were influenced by the prevailing idea of time in Zambia, also referred to by the local people as "Zambian time". In short, this means that people are not experiencing the same strictness with time as we are used to in the Netherlands. Time is seen as an indication rather than a strict point in time to meet. This is reflected in the public transport system, which allows minibuses to depart once they are full not when it is departure time, but also in the compliance of making appointments. Making appointments is relatively easy, but showing up at the right time or at all seemed to be different from the perspective on time I am used to. This resulted in people not showing up without cancelling the meeting, or showing up an hour to two hours later. Because of my previous fieldwork experience in South Africa I could adapt relatively easily to this idea of time and aimed to confirm the appointment with the informants several times as a reminder before the meeting took place. After a personal invitation to the interview (by phone or in person), I texted a reminder the day before the meeting and called or texted them the morning of the meeting. This way I showed the appointment with them was of great meaning to me, but I also used it as an update to myself so I wouldn't wait until they showed up but could use my time productively until the moment they arrived.

This brings us to the ways of communication I used to keep in touch with my interviewees. In Zambia a phone call seemed to be the most accessible way of communication, because almost everyone owns a phone and calling is cheaper in terms of credits than texting. I think as a result of the Zambian openness/hospitality people are also able to speak with people on the phone whom they never met before and still be receptive. I noticed that texting is used less, only to confirm or to update people, but you often do not receive a response, only when necessary. This might be because of the costs. Lastly, I used email to communicate with mainly my colleagues and local supervisor when it concerned attachments or recaps of

meetings. I never used email with the members of YV, because the majority has no daily access to a computer.

In terms of research locations, I conducted interviews in different places. While making appointments for interviewing I always asked the interviewees where they wanted to meet, with exception of the two days I conducted interviews in one of the buildings of University of Zambia (UNZA). However, this was also proposed to the interviewees in order to give them the opportunity to reject this location. In the majority of interviews in Lusaka they wanted to meet at the CHSZ office and a couple of them I met at their homes. In Kafue, all of the interviewees wanted to meet at Twatasha. In all cases I ensured the privacy of the places to a certain extent, because it was not possible in all places to conduct the interview in a closed room without relatives, schoolmates or other people. In that case I discussed with the interviewee if they were okay with the circumstances of the interview, which they all were. I noticed that the different locations did not limit the interviewees per se in terms of being critical on the program in their responses. I believe that some of them in some cases felt limited to share personal experiences, but this also happened in closed settings without anyone else so this is not affected solely by the location factor.

3.5.2 Unit of Analysis and Sampling

The unit of analysis for this study was young persons with disabilities who participated in the Young Voices program. Therefore, the first contact with members of Young Voices I relied on CHSZ in relation to the Lusaka group and its partner organization Twatasha in case of the Kafue group. In case of the Lusaka group, after the first encounter with some youth, I requested a list of contacts of all the members who were and are still active as Young Voices (main criteria). In terms of sampling there was no specific method used since the number of the members [WE1] was relatively small. On the basis of this list of contacts I reached out to all the members. Out of all these contacts just the members who remained active responded. Contact details of members who are not active anymore seemed to be outdated. In Kafue it was more difficult to reach out to all the members by myself because not all of them owned a phone. Besides that, I only visited Kafue occasionally because of the distance. Therefore, the YV coordinator of Twatasha, the partner organization of CHSZ, recruited the participants and made sure they were reminded of appointments I made with them.

In addition to YV members I also conducted interviews with three other types of respondents: young PwDs who are not a member of YV (non-YV members), CHSZ staff,

community leaders and companies (see Appendix B: List of Participants). In case of the non-YV members I heavily relied on my local supervisor to get in contact with them. Their interviews provided perspective on whether or not the YV program influenced lives of young PwDs in comparison to the interviews with the members. This contributed to an overall understanding of the impact of YV on the lives of the members. The interview and focus group with CHSZ staff was valuable to verify certain findings. The interviews with the community leaders and companies were conducted in relation to the two outreach activities of the Young Voices. These interviews provided an idea of how the community and companies experienced these activities (triangulation). In case of the community leaders, they were contact through YV coordinator in Kafue, since the activity of distributing leaflets mainly took place there. In case of the companies I reached out to them on the basis of the results of the survey the YV members conducted.

3.6 Methodology

3.6.1 Data Collection Methods

This research is primarily based on in-depth interviews with youth with disabilities. Along with the interviews I made use of focus groups, photovoice and participant observation.

Participatory Observation

Since I spend a great deal of my time with the CHSZ staff and the Young Voices, a lot of complementary data arose from participatory observation in terms of informal conversations. Also visits to public events on national holidays such as Youth Day, fundraising for Zambian Charter for Women with Disabilities and the “Ring the Bell”-event. The first was a public holiday focused on youth, whereas the last two were mainly awareness raising events for women with disabilities as well as children with disabilities. The participatory observation was valuable for gaining a close and intimate familiarity with most of the participants, especially CHSZ staff and Young Voices members from both Kafue and Lusaka. This type of involvement with the participants led to complementary data from conversations, and also new participants whom I got to know via others. This method also gave me insight in other disability platforms which exists outside Young Voices. Moreover, an example of this is when a participant, a youth with a disability, which was not involved in the program sent me an invitation for an assembly for a new platform. When she sent me pictures of the event afterwards, a couple of the current Young Voices members also seemed to be involved in this platform which was never brought up before.

Since the YV members were currently not as active as they were in the year 2015-2016, because of lack of funding for 2018 and lack of further programming, this method was limited to the conversations and visiting the three public events (see Photo 2). The group didn't come together formally anymore for meetings or other activities. They did however, come together for the purpose of the research.



Photo 2: March at Ring the Bell event (Disability Awareness Raising event). 2018. Kafue

In-Depth Interviews

($n=29$) The main qualitative method to collect data was conducting in-depth interviews. These interviews were semi-structured and based on the interaction between the researcher and interviewer. Interviews in this research were guided by topic guides (See Appendix C: Topic Guides) designed according to the proposed designs developed by Arthur and Nazroo (2008). These topic guides distinguished different categories of topics and started with introductory topics for the interviewee to ease into the interview. In total 29 in-depth interviews were conducted (see Appendix B: List of Participants). After each interview I reflected on the topic guide to see if any adjustments were needed with regards to the sequence of the categories, content of the categories etcetera. The duration of each interview was approximately 1 hour, some of them 45 minutes and some of them 1,5 hours. In four

interviews a translator was needed. In two cases a translator capable of sign language was needed since the participants had a hearing impairment. In the other two cases the participants didn't speak English well enough to create mutual understanding, and for me not being able to speak Nyanja (the main local language in Lusaka Province) a translator was needed and provided as well. The interviews took place at different locations (see 3.4.1: Research Location). Always with the emphasis that people feel comfortable to speak out freely.

Focus Groups

(*n=3*) Focus groups are discussions within a small group moderated by a researcher and oriented to obtain information on a specific topic (Della Porta 2014, 291). In addition to individual interviews, focus groups provide an insight into how a group thinks about an issue, about the range of opinions and ideas, and the inconsistencies and variation that exists in a particular community in terms of beliefs and their experiences and practices (Elbers, 2015). In accordance with the focus group methods of Della Porta (2014) I organized three distinct focus groups for three distinct groups with the aim to create a safe space with people from the same background who already know each other to a certain extent. The groups consisted of the YV members of Kafue, the YV members of Lusaka (see Photo 3 and 4) and the CHSZ staff. The focus group of the YV members of Kafue was in the beginning of the fieldwork period and aimed on exploration. The duration of this focus group session was approximately 1,5 hours. The other two focus groups were organized towards the end of the fieldwork period with the idea to triangulate collected data from interviews and participant observation.

In order to structure the focus groups, I made use of the H-form method (Inglis 1999, 84). This method enables people to internalize the question and topics by sharing ideas about the weak and strong points of this certain topic. Using this method is quite extensive in terms of duration, therefore, it took at least 2,5 hours to finish four statements/questions with two staff members. With the YV members of Lusaka it took even longer because they were with six instead of two.



Photo 3 and 4: Participation of Young Voices members in Focus Group. 2018. Lusaka

Photovoice

($n=4$) Photovoice is a process by which people can identify, represent, and enhance their community through a specific photographic technique (Wang and Burris 1997). This method is used to (1) enable people to record and reflect their community, (2) to promote critical dialogue about community issues and (3) to reach policymakers (Wang and Burris 1997, 370). In this research the method was mainly used to provide for the first two goals. In total four youth with disabilities have participated. They received a digital camera for approximately three days. I say approximately, because due to transport issues I was not always able to meet with them exactly after three days. This photo project was conducted with informed consent from the participants and agreed on their responsibility for informing the third party that was included in some of the photos (mostly family or close friends). The data consists of the actual photos that have been taken but also the reflection interview afterwards. In these reflection interviews I used five of the same question (see Appendix D: Reflection Interview Photovoice), based on the theory of Wang and Burris (1997, 370) for every participant and every photo which focused on the photo, the relevance of what happens in the photo and what story it tells.

3.6.2 Data Analysis Methods

Labels and categories are used to organise and analyze qualitative data (Ritchie 2013, 203). The first step in data analysis was the identification of broader themes, such as internal and external empowerment. In the first round of coding I analyzed the data taking the dimensions into account of power 'within' and power 'with' and three domains of empowerment (see Appendix A: Operationalization Scheme). In the second round I specified

categorized the labels taken the indicators of the dimensions into account. In this round it became clear that additional labels were needed to identify elements of empowerment processes. For instance, among internal empowerment I generated new labels for self-confidence and self-worth and commitment. The second round I also used cross-sectional coding, which offers a systematic overview of the scope of the data to help making connections (Ritchie 2013, 203). This helped to analyze the outcomes of the interventions in relation to internal and external empowerment.

3.6.3 Methodological reflection

In order to understand the findings of this research and possible limitations it is important to reflect on the methodology. This evaluation is based on the alternative criteria to reflect on qualitative research elaborated by Bryman (377). This consists of two criteria: trustworthiness and authenticity which each are divided in sub-criteria. In terms of trustworthiness I will reflect on credibility, transferability, dependability and confirmability. In terms of authenticity, I will reflect on authenticity, fairness, ontological and educational authenticity.

Trustworthiness

Firstly, my research, in terms of credibility (aligns with internal validity and questions whether a realistic account is provided (Bryman 2016, 377)), aimed to give a realistic account of reality through triangulation of the data. I used focus groups to validate collected data from in-depth interviews by using the H-diagram method (see data collection methods). My strategy to spend a lot of time with my informants, mainly the YV members and the CHSZ staff, by visiting them at home, having phone calls and conversation helped to create a deeper understanding of their contexts. In this way, conversations were useful to ask more informal questions and to check some information I gained from other sources. Also, my local supervisor and I met every other week to discuss the methods used, sample of informants and preliminary findings so far. This constant reflection helped to be alert on creating a realistic account of reality in terms of credibility.

In terms of transferability (whether or not findings can be transferred to other contexts (Bryman 2016, 377)) the findings of this research could hold in other contexts. This thesis provides an explicit contextualisation (see Chapter 4) which can be used as a framework. This framework provides a tool of awareness which needs to be taken into account once the

findings are compared to other contexts. Findings concerning the contribution to internal and external empowerment could hold in other contexts, because it concerns elements which are not necessarily tied to the context. On the other hand, these findings come with a certain nuance, which means the focus on the young PwDs and the umbrella of the implementation of the UNCRPD. Findings related to the limitations of empowerment due to challenges of disability are particularly tied to the context, because disability issues arise from the interaction with the environment.

To ensure reliability (reflection of effect of subjectivity of the researcher(Bryman 2016, 377)) of this research it is important to maintain transparency about choices, methods and problems encountered during the research process. During fieldwork, I aimed to achieve this transparency by discussing all the choices in terms of methods, informants and issues encountered with my local supervisor and supervisor in the Netherlands as well during our two weekly skype meeting. By discussing these themes with three different actors I was constantly aware of the effect of my subjectivity in the research. This also comes back in terms of confirmability, which concerns the “objectivity” of the researcher to a certain extent. In my research I was completely aware of my subjective perspective. During my interviews and conversations with the informants with whom I developed a close relationship, some of the members and my CHSZ colleagues, I underlined this subjectivity. I did this so they would take this into account and be able to provide more context, more information, more stories to create a deeper understanding of the situation so I would not need to interpret gaps in knowledge or some connections. In turn, the loyalty to the CHSZ colleagues could have affected the research findings, by focusing on the positive outcomes rather than negatives. Also, I tried to validate all my preliminary findings with my close colleagues, since they were very open to all kinds of findings even if it was critical they were a great help for me in terms of keeping my objectivity to the highest extent possible.

Authenticity

In terms of wider social and political impact of this research the outcomes should be used as a toolkit as well as a foundation of achieving empowerment for the disability sector. Next to this the outcomes could be used by CHSZ to highlight the importance of their projects working with youth with disabilities in order to raise funds and awareness. In addition to this, it could be used by the organisation to strengthen their programs aiming to achieve empowerment with youngsters. Also, the outcomes could be used in interaction with government or other power holders to highlight the importance of empowerment and how

this can be achieved. However, the outcomes should not be used to lay all responsibility with the power holders since the process of internal empowerment can be achieved by themselves. Lastly, the research findings can be used to critically review the accessibility of resources in terms of funding and transportation for people with disabilities.

In order to be able to fully understand the perception of youth with disabilities in society it is important to fairly represent different viewpoints from different stakeholders within society. In this research, I include communal and corporate stakeholders but this could be more expanded on. Including more communal and corporate stakeholders would place the Young Voices project in a wider societal frame. However, because of a limited time frame, I was forced to narrow down the research focus to the contribution of Young Voices project to the lives of youth with disabilities. The informants that I did reach out to were sampled in different ways, mainly based on their availability. The YV members in Lusaka were recruited by myself, based on a list of their contact details I reached out to all of them. A number of them were out of reach, all the other were able to respond to my request. The YV members in Kafue and the community leaders were recruited by the coordinator of the YV project in Kafue, since they did not provide me any contact details of all the members I was dependent on who they invited to come over the first time. From that time on, I was able to make my own appointments with the informants. The organisations were approached by myself, based on the questionnaire and the quarterly report I knew what organisations were reached out to by the members. In terms of sampling it was difficult to ensure that all different groups were heard in the same number as others, because I depended on my own contacts and also on their availability and attainability.

In terms of ontological and educational authenticity (how the research contributed to the understanding of participants of the social setting and how they influenced others (Bryman 2016, 377)) this research has provided the opportunity for the informants to create a better understanding of their social milieu and of perspectives of other members of their social setting as well. At the end of my fieldwork period I organised a learning event to present the preliminary findings of the research. Different stakeholders were invited to this learning event to bring together different perspectives on the topic of disability empowerment. Although not everyone who was invited did attend, a number of 30 people were attending and exchanged thoughts and ideas with each other. Organising this learning event achieved these types of authenticity, because it created space for everybody to speak out and learn from each other, from people who they might not meet in usual circumstances.

3.6.4 Ethical reflection

During this research I was constantly aware of the ethical considerations which need to be taken into account when you are conducting research with and to people living in vulnerable circumstances. First of all, when I reached out to people who could be potential informants I started with introducing myself within the context of my research. I explained what my aim was of coming to Zambia and what the purpose of my research was. When this was clear I asked if they would be interested to help me with my research by letting me interviewing them, not on that particular moment but if it was ok to contact them for an interview later on. Of all my requests only one youngster wasn't interested.

In order to ensure their voluntary participation, I also emphasized during the research, in interviews as well as focus groups, that their participation was voluntary and they could choose freely to answer or not answer questions and to continue or to quit at any time. Introducing my research and my role as research was also part of the informed consent, but to ensure the informed consent I developed an informed consent form (see Appendix E: informed consent form) with an extensive explanation of the research for both interviews and photovoice. This form elaborated on the research objectives, the purpose of the research project my research is conducted within, how results were going to be processed, with which parties the results were shared and my contact details if they had any further questions after the interview. This form was signed by me as well as the informant. I noticed that the participants experienced the option to keep this form as comfortable, so they would be able to reread it at home.

In terms of safety in participation, I believe that this research did not ask for any necessary measures beside making sure their transportation was safe and it was safe for me to visit them at home in terms of environment and reaction of society on my visit. Often, we picked them up to make sure they arrived safely or my colleague brought me to the location of the informants. At the beginning of each interview, included in the informed consent form, I ensured the informants the confidentiality of the information provided in the interviews by anonymizing their names. At last, I paid a lot of attention to gaining trust of the informants. By adopting an open and interested mind I try to make the informats feel comfortable talking with me. Also, I emphasized that I wasn't working for Cheshire Homes and wasn't judging neither the program nor the members, but that I was specifically interested in them and their lives together with their involvement in Young Voices and other programs as well. I also

spend time with them outside the formal research activities through visiting them and chatting through phone. The most interesting thing was that this was a different process with all different informants, and I had to find out throughout the fieldwork what worked with whom. The one thing everyone had in common was that they appreciated if you paid attention to listen to them.

Chapter 4: Experiences of Disability

This chapter describes how the participants of this research experience their disability in their daily lives, with an emphasis on the challenges they face. Exploring these experiences and challenges is relevant as it informs the backdrop of the next chapter, which explores processes of internal and external empowerment within the Young Voices project. Three themes are highlighted which emerged as key from the interviews: employment and education, mobility and representation.

4.1 Employment and Education

The interviews demonstrate that the young respondents experience employment as a huge challenge. Employment often requires qualification obtained through higher education. However, attending higher education is not self-evident for every young person, in particular young PwDs. Interviewees explain that attending school can be quite challenging due to resources. Lynn, a young female with a leg impairment, explains that *“people who are disabled are also from poor families... So it is quite challenging to educate (Lynn. 2018. Interview by author. February 27).”* The costs for education, especially higher education, are often too high for the majority of (poor) families of PwDs. Therefore, some interviewees are dependable on sponsorships or bursaries in order to attend school. Unfortunately, sponsorships are not guaranteed which creates an uncertain process of attending school. Madeline finds herself in a situation in which she depends on external funding for her to go to school, but cannot accomplish this. *“Since 2015 I applied to go and study social work. Unfortunately, I did not have enough funds to go to school. Since then, I tried to look for sponsorship. I tried ZAPD... but then it turned out that they could not do anything to help me. I am still searching for people to sponsor me to school because I really want to go to school (Madeline. 2018. Interview by author. February 14).”*

Another situation in which a lack of financial resources in combination with the circumstances of disability hamper her school career is told by Angela: *“I have been to school and I completed in 2009, but I did not have good results. Because at the time I was supposed to write my exam I was in the hospital. I had an operation, which was why I did not go to school. So I told mom to take me back to school but it failed because of the situation in terms of money (Angela. 2018. Interview by author. February 15).”*

Besides financial resources, high results from middle school determine whether or not someone can attend higher education. In many cases this is problematic, since middle schools, which ones are affordable for poor families, offer low quality in terms of education which affects their results. This means that despite being educated you might not pass the exam. Emmanuel, an YV member in Kafue, elaborates on this: *“The issue is on the results because you see most of them the background they are coming from, the school they were attending was not very qualified... So, you find that even educating you are not given enough notes to pass the exam (Emmanuel. 2018. Interview by author. February 6).”* In his experience, good results of exams are key for a further school career. *“Most people who used to come from such schools and were disabled... were not getting good results and then at the University, they only want those who have qualified in terms of results. So you find that when you go to the University there are few disabled persons (Emmanuel. 2018. Interview by author. February 6).”* In their experience education is the foundation of employment, but attending school seems to be a challenge on itself. *“For them to get employment, it is even harder because one, you don’t have qualifications and you are also disabled “(Emmanuel. 2018. Interview by author. February 6).*

According to interviewees the right qualifications are crucial for getting a job. However, a number of participants living in Lusaka do have qualifications in terms of a certificate from higher education but are still unemployed. They undertake action to apply for jobs, but receive many rejections. Helen describes her experience of searching for a job: *“Irritating and frustrating. I have been here for more than one year hoping to find what I came here to do (Helen. 2018. Interview by author. March 7).”* She explains that she undertook initiative to visit companies personally to apply for a job, on herself but also together with Madeline. *“I have been to Zamtel... I have gone there personally to take my application but up to today there is nothing... There is some time we attended interviews with my friend Madeline at MTN call centre but because their offices were on second floor and the lift was not*

working, they could not take us. So despite us attending and passing interviews we were not picked (Helen. 2018. Interview by author. March 7)."

Several respondents feel that good qualifications are not sufficient if you are disabled. Out of her experience Helen concluded: *"Maybe they looked down on me like that I could not manage to do what they expect me to do. I think if they could give me a chance so I can prove to them, maybe then they could consider me than just by looking at me. People should not be judging me according to what they are seeing. I have been to school. (Helen. 2018. Interview by author. March 7)."* In addition to this experience, Madeline summarizes this feeling: *"They rather employ someone who is able bodied and who is naive, not having any knowledge, than employ a person who has the knowledge. However because of a disability, they tend to fire before they hire."*

According to the interviews, the main motivation for job searching is financial independence which would enable them to help the people that supported them so far. Lynn, living with her step mother shares her motivation: *"at least when I am employed I can be helping her [step mother] even financially, the house that we live in is not complete... So I have got big dreams about that (Lynn. 2018. Interview by author. February 27)."* Independence is a topic that seems to occupy the young participants. It mostly concerns them in relation to their mobility, which will be discussed in the next section.

4.2 Mobility



Photo 5: Helen. The steep at the entrance of her house. 2018. Photovoice method

“I was looking at the mat it was saying welcome. I was like what kind of welcoming is this where the wheelchair is not accessible. How well am I welcomed?.. It is not welcoming everyone... due to this stair instead of a slope when you are living with someone using a wheelchair (Helen. 2018. Interview by author. March 12).” With regards to the photos she took, Helen explains why she chose to capture this situation. *“When you say welcome make sure you accommodate everyone so that they really know that they are welcome to this place not finding it difficult.”* Helen experiences her own house as inaccessible which does not feel welcoming. With capturing this she wants to show that the inaccessibility already starts at her own house, a place that *“is not something that should stress me up (Helen. 2018. Interview by author. March 12).”* In relation to buildings and places that are accessible Helen feels that *“with Zambian structures that are few (Helen. 2018. Interview by author. March 12).”*

Halima, an older female with a disability, explains that majority of Zambian buildings date from the early 60’s. In this period of time disability was not recognized, therefore, not taken into account in social structures. *“I find that the environment has limited me a lot especially in terms of the physical structure. You find that a typical scenario in Zambia. Most of the infrastructure was built way before we got independence and slightly after we got independence. That was a time when disability rights were not even known. There was*

nothing like disability rights, disability awareness. So, people just built the infrastructure just to suit the able bodied people. So you find that there are a lot of stairways, no lifts. I think, in my own experience, it has inhibited me a lot (Halima. 2018. Interview by author. March 22)."

One may ask if this also accounts for new buildings which are being built. Allan, the consultant who facilitates trainings of Young Voices and is living with a disability himself, explains that it depends on the fact if they are built by order of international or national administration and organizations. A distinction can be made between national and international architecture, of which national architecture is experienced as inaccessible. *"Take for instance, these hotels like Intercontinental, they always have accessibility for the disabled... They come from Europe, South Africa. But let's go to our own: go to State House, Cabinet or to any government ministry, no accessibility... Nothing at all is provided at these government ministries, there is no car park, there is no accessibility. The doors are even narrow and they open going inside... From the government point of view, there is no policy³ (Allan. 2018. Interview by author. March 7)."*

The inaccessibility raises issues for the young PwDs who cannot enter buildings at all on their own. Consequently, they are dependent on help from others in terms of mobility. Helen explains how she depended on her friends for help to be able to attend class. *"The classrooms... turned out to be on the second, third and fourth floor. It was all stairs and no lifts... My friends used to help me out. They would lift the wheelchair depending to which class you are going (Helen. 2018. Interview by author. March 7)."* Another example is raised by Madeline in the following photo.

³ Policies regarding disability should derive from implementations of legal frameworks such as the CRPD. In 2010, Zambia ratified the Convention on the Rights of Persons with Disabilities (CRPD). Alongside this, Zambia domesticated the CRPD by developing and adopting the Persons with Disabilities Act in 2012 (also referred to as Disability Act) (Birtha 2013, 126). In line with the majority of government officials recognising disability as a cross-cutting issue (Mtonga and Lungu 2017, 14). Although this official recognition in terms of adopting and developing viewpoints and policies is most valuable, action on disability is required in the form of practical implementation and enforcement of these commitments (Nixon et al. 2014, 7). However, implementation of these frameworks faces challenges because Zambia does not have well-defined monitoring mechanisms to track the progress in the implementation of the CRPD. Alongside this, implementation remains a challenge in particular because of the absence of statutory instruments to operationalise the Disability Act (Mtonga and Lungu 2017, 14).



Photo 6: Madeline. Getting a helping hand by her sister at the entrance of their house. 2018. Photovoice method.

When asked to explain what the photo tells about her life she responds: *“It says that there are places that are accessible to me where I do not need a hand but with this one I need a hand... It is not always that I can find places which are accessible and it is very difficult for a place to change because of me. Like they cannot include other steps to meet my desire but rather leave it like that and give me a hand whenever I need it. It is rare to find places to change because there is a disabled person (Madeline. 2018. Interview by author. Marc 22).”* In her story Madeline (literally) shows the need for a helping hand in situations of inaccessibility.



Photo: William. Minibuses at Kalima Tower: Central Station for Minibuses. 2018. Photovoice method.

Alongside architecture of buildings, also the way to arrive at their destination is experienced as challenging in terms of public transport. Most of the interviewees move by public transport

if they have money to cover the costs. Public transport mainly consists of minibuses accommodating up to 20 people. William explains what he wanted to show with his photo: *“Transportation in Lusaka is quite a challenge and it is very pathetic especially for those on the wheelchairs. It is not really user friendly... so that is a big challenge as well* (William. 2018. Interview by author. March 20).” Interviewees mentioned being confronted with discrimination. ‘Not user friendly’ can refer to the extra costs that people in wheelchairs are forced to pay, which happens in the case of Helen: *“It is really costly for me for real, you can imagine if I have to use a minibus. I need to pay for two seats. Like how can a wheelchair be charged? So to avoid that I would want to use a taxi which is also costly* (Helen. 2018. Interview by author. March 7).”

In addition to this, the attitude of the conductor, driver or other travelers in the bus can be challenging as well. Their discriminatory attitudes can result in PwDs being rejected a seat. An example is the time Lynn and Madeline arrived two hours late for a research activity. When asked what the cause was of their delay they explained that they had to wait two buses⁴ until they were allowed to sit in the front. Madeline uses two artificial legs which she cannot bend. Therefore she cannot take place in the back and she needs to sit in the front of the minibus. When they arrived these seats were already occupied. She decided to ask the man in the front seat if he would be able to move in the back for her to be able to take the front seat. While asking this, the man turned his other cheek and ignored her (Madeline. 2018. Informal conversation with author. March 9). It reflects a situation in which her mobility depends on other people willing (or not) to help her. According to the interviews, respondents experience constant challenges in relation to their mobility.

4.3 Representation

In addition to the constant challenges of education, employment and mobility, many of the Young Voices in this study have a feeling that their voices are not heard. In their experience, there is no representation of PwDs to draw attention to their issues. *“We⁵ do not really have people who are leaders who can stress these issues [issues of health and education] to explain to the government that these are things that goes on with persons with disabilities* (Madeline. 2018. Interview by author. February 14).” Majority of the experiences related to representation is concerned with politics. The interviewees experience a lack of political

⁴ The minibuses depart once they are fully occupied. ‘Waiting two buses’ means to wait until two buses are fully occupied to depart.

⁵ With ‘we’ Madeline seems to refer to persons with disabilities as a group.

representation because there are no leaders or other power holders who share the same experience of having a disability, therefore, they cannot truly relate to disability issues.

“I tried to find out if there is a member of Parliament with a disability and I was told, there was one although he was just limping out of an road traffic accident... Follow me, honestly that did not make a lot of sense because that person did not go through the hardships that we are going through. Maybe that accident was a result of driving his personal car, meaning that the has not experienced the life of us (Madeline. 2018. Interview by author. February 14).”

In her story Madeline does not feel seriously represented by this member of Parliament because his impairment resulted of an event later in life. This means that the person did not experience disability throughout life, therefore, Madeline suggest that he cannot relate to the realistic challenges of living with a disability. A difference which she would support is the following situation: *“It can be different if a real person with a disability, especially those that have had it starting from when they were young. That person would really explain how it is to live with a disability, the real challenges starting from the family and everything (Madeline. 2018. Interview by author. February 14).”* Her story suggests that she does not feel disability issues are represented (in politics) until PwDs themselves can operate in representational roles, therefore, it makes them feel if no one is speaking out for their case. *“I have never seen any disabled person in Parliament. I think it is high time when one of the disabled people should go and speak out for us in Parliament (Joshua. 2018. Interview by author. March 5).”* In another example, an respondent shares this experience in relation to the political campaigns. *“I have been following the campaigns. When it is campaign period I have been following the manifestos of different candidates campaigning for the higher office. And I really hear little when it comes to improving the lives of persons with disabilities. When it comes to special education, I hear very little and this is why I really wanted ... an opportunity to build a personality⁶. I think I can be forwarding such questions to those people when they come for interviews, but I do my best I do call on different forums on different radio programs (Philip. 2018. Interview by author. February 15).”*

In their experiences, the youth do not feel represented by the current leaders, either in politics or media, because no PwD is involved. Therefore, they feel there is no one who speaks

⁶ In his interview, Philip expressed his ambition to become a radio DJ, also referred to as radio personality.

out, for and about the issues that continue to challenge their lives because they live with a disability. In their experience it is necessary to pay attention to these issues and bring it to the public audience, because they believe that the problem is in the lack of knowledge amongst others. *“It’s clear that most of these people they don’t understand special education and definitely it’s very much difficult to work on something that you don’t really understand. Yes and I think that is where the problem is (Philip. 2018. Interview by author. February 15).”* The problem in their understanding could be improved by *“educating other people cause they don’t know what it takes to have a disability living with a disability they don’t know. Because ... they really think that this person is now rendered useless or he/ she may not function well (Philip. 2018. Interview by author. February 15).”*

4.4 Conclusion

This chapter highlighted three domains which pose challenges for the young PwDs who participated in this research. First of all, education and employment raises challenges for these youngsters. Employment often requires qualifications obtained through higher education. The costs for education, especially higher education, are often too high for the majority of (poor) families of PwDs and sponsorships are not guaranteed which creates an uncertain process of attending school. If they do have the qualifications a job is not guaranteed. All members of Lusaka YV group are still unemployed despite their qualifications. In their experience, being qualified is not sufficient if you are disabled.

Second, in terms of mobility youth experiences constant challenges with regards to accessibility of buildings and public transport. Disability issues are often not taken into account in the architecture of buildings. Consequently, this raises issues for the young PwDs who cannot enter buildings at all, or need constant support of other people to gain access. In terms of transportation, public transport is often not accessible for PwDs. The main means of public transport consists of minibuses, and PwDs mentioned being confronted with discrimination, for instance being rejected a seat or charged double because of their wheelchair. In the experience of the young PwDs, architecture and public transport limit their mobility which makes them more dependent on others.

Finally, the respondents raise the issue of representation of PwDs. In their experience there are no leaders or other power holders who share the same experience of having a disability. Therefore, they feel they are not seriously represented because power holders cannot truly relate to their issues. This lack of representation maintains the lack of exposure of disability and lack of knowledge about disability issues.

Chapter 5: The Young Voices Programme and Empowerment

This chapter analyzes the contribution of the Young Voices program to empowerment. Therefore, this chapter will first introduce Cheshire Homes Society of Zambia, the initiator of the program. Second, this chapter discusses the Young Voices program and its activities. Third, this chapter identifies four outcomes of the interventions of the YV program. These outcomes include (1) new relations with other PwDs, (2) new perspectives on disability, (3) new confidence to speak out and (4) new sense of purpose. The subsequent discussion of these processes will illuminate in greater depth how the program contributed to empowerment including its limitations.

5.1 Cheshire Homes Society of Zambia

Cheshire Homes Society of Zambia (CHSZ) is responsible for the implementation of the Young Voices project 2015-2016. It is a non-governmental registered disability organization and a member of the Leonard Cheshire Disability Global Alliance, with its National Office situated in the capital city Lusaka. The organization aims to enable children and youth with disabilities to improve their quality of life and to advocate for reducing the barriers which hinder them. In order to accomplish this, CHSZ focuses on five core areas: health, education, inclusion, work and income (livelihoods), and child protection. CHSZ works with persons with disabilities throughout the country and implements activities through established so-called Cheshire Homes (also referred to as Cheshire Services) in partnership with different catholic congregations running the homes. The National Office for the Society was established in 1973 to help the nine Cheshire Homes in coordination, fundraising, supervising, monitoring, and evaluating in the implementation of services and activities. Alongside this, CHSZ collaborates with over 20 disability organizations (DPOs), also referred to as partner organizations, throughout the country to implement projects (CHSZ, 2015). Overall, the CHSZ functions as a secretariat for its local partner organizations that do implementation work.

In recent years, CHSZ has been supported by a range of international funders such as the European Union, Comic Relief, Credit Sussie, Vitol, Matep/USAID, International Committee of the Red Cross (ICRC), Lilianefonds (Netherlands) and Global fund (CHAZ) among others.

In its primary role as secretariat, the organization is run by four core staff members, consisting of an executive director, program officer, program coordinator and finance officer. The staff members are responsible for managing and assisting in the operation of the implementation of programs run by partners. The way CHSZ manages its resources is being monitored by the Board of Trustees⁷. The Board of Trustees is expected to offer an independent and objective opinion and provide mitigation measures in times of financial difficulty.

5.2 Young Voices Programme

5.2.1 Background

The implementation of the Young Voices project by CHSZ at the end of 2015 was based on a pilot project also called Young Voices that took place in 2009-2012. This was implemented by the Leonard Cheshire Global Disability Alliance and was conducted in approximately 20 countries in the Global South. The pilot project was funded by Garden Group Hotels, Leonard Cheshire Disability UK and the European Union (EU). In this pilot project in Zambia 150 young persons with disabilities were selected and divided into five groups in Lusaka, Kafue, Ndola, Solwezi and Livingstone. They participated to advocate for the ratification of the UNCRPD which became reality in 2010⁸ (CHSZ, 2015).

In 2015, CHSZ staff members felt the need to expand advocacy work amongst youth with disabilities; something which was insufficiently addressed by their implementing partner organizations (Halima. 2018. Interview by author. March 22). As such, they sought to restart the Young Voices program in Zambia.

The project was financially supported by the German Embassy for the duration of one year. The financial support was supposed to finance the program from the end of 2015 till the end of 2016. According to a staff member, they received the funding in the second quarter of 2016 which caused a delay in organizing activities. From the onset, the idea was to secure more funding during implementation to prolong the project; something that never materialized.

⁷ The Board of Trustees consist of volunteers, 14 members with diverse and rich professional backgrounds including finance, accounting, business administration, physiotherapy, legal among others.

⁸ For more information about the Young Voices in 2009-2012 see: <https://www.youtube.com/watch?v=2ok8wWQB77g>, accessed June 14 2018

The overall aim remained the same, which focused on enabling young persons with disabilities to become agents of change by speaking up for themselves and their rights and achieve social change. This time the actual implementation and domestication of the UNCRPD was central to the Young Voices, in which CHSZ expected them to play a part. The specific goals were to (1) build the capacity of young people with disabilities as change agents, (2) to enable them to push for the implementation of the CRPD in Zambia and (3) in general to improve human rights and living conditions for PwDs (CHSZ, 2016).

The project aimed to reach 300 young persons with disabilities directly through the strengthening and formation of four Young Voices groups. Two groups already existed as result of the previous project, both consisting of 34 people. The other two groups were planned to be formed as part of the project. The plan was to select and form these groups through Kabulonga Cheshire network and their DPO network (CHSZ, 2015). The reports and interviews show that two out of four groups were eventually realized, consisting of members of previous project and new members. In Lusaka, the members were recruited via Kabulonga Cheshire network and through the network of members themselves. In Kafue, the members were recruited through the network of Twatasha and by the YV coordinator of Kafue. The majority of the Young Voices members has a physical impairment, with the exception of a few members with a visual, hearing and intellectual impairment. What type of activities the members undertook during and after the implementation of Young Voices is explained in the next section.

5.2.2 Project-Activities

In the one year period in which the Young Voices program was implemented, the following core activities took place:

Monthly Meetings of the Young Voices

Meetings were facilitated by CHSZ⁹ to provide a forum for the Young Voices to interact freely with each other, share ideas and plan and strategize on lobby and advocacy aspects of the group. They were supposed to come together on monthly basis. Some meetings were

⁹ The meetings of the Young Voices in Kafue were facilitated by the partner organisation Twatasha, a community school and DPO.

cancelled because of a volatile situation at that time caused by the election period. It is unclear how many meetings took place exactly. According to the Quarterly Report two meetings took place. According to the members, however, this number was higher because the meetings continued after the official format of one year.

Capacity building trainings

CHSZ organised two three-day trainings for the Young Voices which were facilitated by a consultant who lives with a physical impairment and acts as a disability activist. The goal of these capacity building trainings was to equip young persons with disabilities with the necessary knowledge and skills to prepare them to take on future leadership roles in the DPOs, employment organizations and in the Young Voices project (CHSZ, 2016).

The first training took place from September 30 to October 2, 2016 in both Lusaka and Kafue and was joined by 46 youngsters in total. The youth were trained on leadership and fundraising issues including: leadership styles, leadership organisations, fundraising requirements, proposal writing and basics of financial management (CHSZ, 2016). The second training took place from November 30 to December 1, 2016 in Lusaka and was joined by 26 participants including representatives of DPOs and members of Young Voices. The training covered issues such as disability equality in which the emphasis is on the person rather than the disability. The models of disability were also discussed in terms of the traditional, medical, social and human rights model. In addition to this, the effect of language and use of concepts to describe disability and impairment were discussed. This was followed by discussing the national and international legal frameworks related to PwDs. At last, advocacy in relation to the Disability Act of 2012 was covered with an emphasis on in-depth understanding of its content. This training brought together partner organizations of CHSZ and the Young Voice members, also with the goal to formulate a clear position as to what needs to be addressed in terms of policy and practice to safeguard the proper implementation of the Disability Act.

Awareness Raising Meeting with Community Leaders¹⁰

This meeting was initiated by CHSZ. The aim of organizing this meeting was the sensitization of community leaders on pertinent disability issues in relation to the Disability Act of 2012. It was organised by the YV coordinator of the Kafue group who represented the Young Voices.

¹⁰ Also referred to as Stakeholder meeting

Eventually, it took place in July 2016 in Kafue in relation to the YV group in Kafue. A total of 20 community leaders participated, including councilors, government heads of departments, NGOs, and churches. In the meeting five issues were discussed concerning disability: health, education, accessibility, employment and social amenities.

According to interviews and quarterly report, a result of the meeting was the inclusion of PwDs in the Farmer Input Support Program. This is a government program in which resources are distributed among vulnerable farmers such as fertilizer and maize, to support their farming. According to interviews a similar meeting was conducted which was said to result in the inclusion of PwDs in another government program as well, the Social Cash Transfer Program. This program supports vulnerable people with monthly financial support so they can buy basic food.

Field Visits to Companies

The members of YV Lusaka and CHSZ staff initiated field visits to companies to raise awareness on disability issues and conduct a survey. The questionnaire was about the Disability Act (article 37) concerning the tax rebate¹¹ for companies who employed PwDs and was developed by CHSZ staff. They also aimed to establish how many companies have employed PwDs¹² and how employers understand reasonable accommodation in the working place for PwDs. Lastly they tried to find out whether employers are aware of the tax rebate that applies with the employment of PwDs. The Young Voices visited 22 companies, including NGOs, hotels and lodges, mobile companies, shopping malls and banks.

The survey revealed that most employers especially those charged with the responsibility of recruitment are not aware of the Disability Act. Three companies were identified with awareness of the Disability Act and who have employed PwDs. This activity was supposed to lead to next course of action focusing on reaching out to the media to raise awareness about Disability Act (article 37), but this reportedly did not happen due to lack of resources.

¹¹ This is a policy focused on the promotion of employment for Persons with Disabilities. The tax rebate allows companies to claim a reduction on their tax payment when they employed a PwD.

¹² Only 3 out of 22 companies

Production and Translation of Campaign Materials

Campaign materials were produced in order to raise awareness on disability issues and increase the visibility of the Young Voices. These materials were used during meetings (with the stakeholders) such as the awareness raising meetings with community leaders, capacity building trainings (with the DPOs) and field visits (to the community). The original aim as stated in the proposal was to hand out campaign materials, especially leaflets¹³, to the PwDs in the community to provide them with information about their rights (CHSZ, 2016). Therefore, the leaflets were translated into local languages and also in braille.¹⁴

¹³ The leaflets contained an introduction to the CRPD

¹⁴ 1000 leaflets were translated into local languages and 42 leaflets were translated into braille.

5.3 Processes of Internal Change

This section elaborates on outcomes of the interventions of the Young Voices program. Four outcomes are identified: new relations between young PwDs, new perspectives on disability, new confidence to speak out and a new sense of purpose. The section will demonstrate that these outcomes are all in the conceptual domain of ‘internal empowerment’. Overall, it shows that the young PwDs have started to recognize and to a certain extent exercise their agency.

5.3.1 New Relations between Young PwDs

Since their childhood, the Young Voices are confronted with challenges in relation to their disability which have shaped their self-perception and self-worth. This subsection examines how developing new relations with other young persons with disabilities, as a result of the YV program, contributed to a new self-perception.

While the interviews with Young Voices members highlighted individual experiences and views, they also made clear that many experiences are similar. Growing up being the only one different from the rest in your family and/or community is often an experience that marks the beginning of lives of many young person’s born with an impairment. It starts in the family situation in which children with disabilities are often hidden from the outside world by their parents. Even if they are not hidden from the outside world, the family situation is the first confrontation with other people without disabilities. This can directly affect the development of the self-worth of young PwDs, the way how they think and feel about themselves. For instance, Sepo, a young female and Young Voices member who suffered from polio and uses a wheelchair, was confronted with her disability because of the birth of her younger (able-bodied) sister. Before Sepo herself could walk and talk, her baby sister was already able to communicate and to move around in ways Sepo never could. In addition to this, her mother used to cry when she thought of what happened to Sepo and her step father used to insult her because she could not do anything (Sepo. 2018. Interview by author. February 5). Considering this is her family situation from a very young age, it seems to create a sense of insecurity and uncertainty throughout her young life: *“I just think about my life, what will happen to me and my family. Because every time my mother and father are just crying because of me. So maybe one day they can say go away and I have nowhere to go to (Sepo. 2018. Interview by author. February 5).”*

In another case, Helen explains how her experience at the University affected the way she thought about herself. When she was younger, Helen went to a special school and visited the Kabulonga Cheshire Homes, which meant that she was surrounded by other children with disabilities. Once she continued her studies at the University of Copperbelt she found herself in a place where she was the only one facing the challenges of having a disability. With a slight sense of disbelief she asks the rhetorical question: *“Can you imagine I was the only disabled there (Helen. 2018. Interview by author. March 7)?”* For three years she struggled with the (in)accessibility of the University. Since she was the only one facing these challenges it made her question herself. *“I had this self-pity for myself. Like how have I found myself here? How am I going to manage? And because of that sometimes my grade could even go down. I would miss classes (Helen. 2018. Interview by author. March 7).”* Her story shows how facing the challenges of living with a disability in isolation at that point determined the way she thought about herself. These examples provide an insight into the creation of self-worth underpinned by the feelings of insecurity caused by their disability. This self-worth is strongly shaped by the lack of opportunities to compare or share their situation with others, simply because they were the only one with a disability.

The relatively simple act of bringing young PwDs together already had an effect on the way in which these youth looked at themselves. During the Young Voices meetings, the members came together and shared ideas and thoughts on how to put themselves out there in terms of advocacy and lobby (see 5.2.2 Activities (interventions)). By working alongside each other the meetings facilitated a deeper connection among the members. For instance, William, the chairperson of YV in Lusaka, explains how he experienced joining the group. *“After I became a member, I think it really changed me because it gave me a different perspective of how things are done ... It gave me an opportunity to connect with a lot of youths who are disabled and with good qualifications and who are able to contribute and participate fully in the society (William. 2018. Interview by author. March 20).”* The setting of the YV group enabled the members to feel connected, which reduced their feelings of isolation. They were provided the opportunity to learn how others perceived similar challenges and situations. The meetings were experienced as *“learning new things from the other disabled people and interacting with them (Lynn. 2018. Interview by author. February 27).”* Findings suggest that engaging in new relationships through the meetings contributes to a new self-perception. For instance, Emmanuel, who came to learn that people are just the same. *“The meetings we have been having here it gave me the idea and the knowledge that we are*

just the same except that the person is older or younger than me. So, you just have to respect but you have to speak what you are there for (Emmanuel. 2018. Interview by author. February 6).”

Bringing the PwDs together offered opportunities to build new relationships which enabled them to collect and compare different experiences on living with a disabilities. Sharing their experiences reduced their feelings of isolation and insecurity which increased their sense of self-worth. A sense of self-worth reflects how the young PwDs think about themselves. An increased self-worth is crucial to develop "power within" (Eyben et al. 2008, 6). In addition to this, findings suggest that the relationships go beyond the goal of group formation. It reflects a deeper emotional attachment. *“I enjoy being with my fellow disabled persons... I feel like they are family when I am with them* (Yolan. 2018. Interview by author. March 9).” This attachment, the strong connection with the group and each other created a foundation to undertake action as a group, in other words their power with (Eyben et al. 2008, 5)

5.3.2 New Perspectives on Disability

A recurring topic in the life stories told by the Young Voices is that they are often seen as ‘the problem’. As such, it is not surprising that many of them have come to internalize this idea to a certain extent. In the YV trainings, however, they were introduced to different ways of understanding disability, with an emphasis on the social model. The core idea of this model is that it is the environment which makes people disabled (Braithwaite and Mont 2009, 220). Several interviewees expressed they found this perspective a liberating eye opener.

By discussing the social model the members learned to view their limitations as arising from their environment, not necessarily from within themselves. Halima, CHSZ staff member living with a disability herself, explains what was taught during the training. *“A disability is something that has made someone to have certain limitations in doing certain things. Those limitations may not necessarily arise out of their own disability. There are other factors that come in like the environment which play a very big role. It inhabits a person with a disability in doing some of the things that they can achieve. If the environment is not enabling enough especially in terms of accessibility that can be one of them* (Halima. 2018. Interview by author. March 22).” The members learned in relation to the social model that *“disability is not inability* (Helen. 2018. Interview by author. March 7)”, which is a much commonly used quote amongst the members. It suggests that the members internalized the

perspective which emphasizes the role of the environment in the creation of limitations rather than their impairment.

In addition to the understandings of disability, the capacity building training informed the youth about disability rights legislation. In particular the CRPD and Disability Act 2012 were discussed. Although interviews with the young PwDs highlighted individual experiences, they also made clear that for many young PwDs the training was their first encounter with the notion of having rights. For instance Lynn, she indicates that without the YV program *“I would not have known much of the things that I know now such as the rights, the human rights for disabled people (Lynn. 2018. Interview by author. February 15).”* Another member, William was introduced to these disability rights frameworks for the first time. *“I think for me personally I would say, that was the first time I was given a copy of UN convention and that was the first time I had to go through it on the Disability Act. So it is an eye opener for me.”*

Findings suggest that providing the youth of information about rights created a new perspective based on awareness of rights. *“At least now I am able to know that if I go to a public place, I don’t have to queuing for staffs or maybe if I go to health Government institution we don’t need to pay and the like because I never knew such (William. 2018. Interview by author. March 20).”* Madeline also shows a new awareness of rights when she is asked if she was aware of these rights before the program. *“I would say not really, I was thinking that I have the right like any other person such as the right to education or the right to live... But I did not know that there is a tax rebate. I didn't even know that my guardian or my parents can benefit (Madeline. 2018. Interview by author. February 14).”* The rights awareness provided the youth to understand their disability from a new perspective. A perspective in which they have the possibility to address these rights. Such a perspective is the starting-point of exercising agency, which is a key component of (internal) empowerment.

Findings suggest that rights awareness is crucial for them to be confident enough to claim their rights. *“They [persons with disabilities] do not really know whether their rights have been infringed or not. But if they become aware, they become confident and know where to get their rights from (William. 2018. Interview by author. March 20).”*

The new perspectives developed as a result of the trainings and the subsequent discussion about it in the groups, are crucial for the "power within" and "with" of the young PwDs. In terms of "power within", the social model created an awareness that (environmental) barriers influence their experience of disability, which means that change is possible. This enables them to imagine their world differently. The new perspectives enabled them to undertake action as a collective to address their rights based on their rights awareness, which strengthened their power with.

5.3.3 New Confidence to Speak Out

The study found that young PwDs often refrain from speaking out due to a negative self-image, shyness and a lack of knowledge. This section elaborates on the contribution of the YV program to a new confidence to speak out.

First of all, the program implemented activities in order to obtain and train communication skills. For instance, the capacity building training about advocacy and lobby enabled the youth with communication skills and also *"public speaking skills was one of them (Joshua. 2018. Interview by author. March 5)."* The training enabled youth to obtain communication skills in order to develop themselves as leaders. *"it was a training where they told us to say a leader is someone who must come openly and speak to the people and someone who should have answers to every question (Joshua. 2018. Interview by author. March 5)."* Alongside the capacity building training, these skills were strengthened by applying them in other activities such as the field visits to companies and the monthly meetings. *"Going to the organizations and meeting new people really taught me a lot, talking to people like I do not know, yes (Lynn. 2018. Interview by author. February 15)."*

"Well through the workshops that we would have, as young voice members and through the meetings that we would have because young members and mostly through the survey we did (William. 2018. Interview by author. March 20)."

Findings suggest that obtaining communication skills contributed to overcoming shyness. According to their stories, they were not comfortable with talking to (strange) people or speaking out in public. Their experiences suggest that the trainings improved their skills to such an extent that it made them feel confident enough to talk to people freely. For instance Joshua, he explains that at first he *"was shy to come out to talk to people but with this*

advocacy training from Young Voices I am now used to that (Joshua. 2018. Interview by author. March 5).” A similar experience is expressed by Lynn who describes herself as a quiet person. When asked what skills she obtained from the training she responded: *“Skills like talking to people freely since I grew up as a quiet person* (Lynn. 2018. Interview by author. February 15).”

Findings suggest that they developed a new confidence to speak out resulting from the activities of YV. This is also shown in their activities in which they are confident enough to advocate and speak out in public (see photo 7).



Photo 7: Made by author. Madeline speaking in public during fundraising event of *Zambian Charter for Women with disabilities*. 2018

“I think after the program, I have varsity knowledge about the disability movement. I mean, I am able to articulate issues more confidently and I have more knowledge in whatever I would want to talk about, yes. Because previously I really didn’t know much, but now at least I am able to advocate for like any issue and maybe like employment accessibility, going on tours and performing tasks that maybe. I have the knowledge and skills to do that I would say (William. 2018. Interview by author. March 20).” In addition to this, William elaborates how he sometimes receives invitations to attend public events from partner organisations of CHSZ. When asked if he accepts these invitations he answers: *“Very much, I do because it provides an opportunity to like voice out my options and share my experiences* (William. 2018. Interview by author. March 20).” Another member who applies his communication skills in public is Joshua. *“I use it as I make news*

¹⁵ ... *I know which words to use and the kind of speech to say* (Joshua. 2018. Interview by author. March 5).” Their experiences show that the new confidence encourages them to speak out, for, and about themselves and their rights creating an audience for disability issues. In this way, it contributes to their "power within", which consists of the courage of people to act on their vision to realize change. The new confidence to speak out also contributes to their power with, because their acts of speaking in public marks the beginning of their advocacy work.

5.3.4 New Sense of Purpose

Although the funding stopped at the end of 2016, the study found that the members still show engagement to speak out for disability issues. They This section shows how the YV program inspired several youth to become disability activists themselves. As such, it gave them a new sense of purpose.

Findings suggests that the activities inspired the members to stand up for disability rights. For instance by enabling them to inform and train others. Allan, the consultant who facilitated the training, indicates how the training provided capabilities for the participants to train peers as well. *“Most of these things [trainings] are made in such a way that ... we train someone and we tell them to go and train their fellows because we are bringing everyone under one roof. So my training is more like train of trainers. We train you; you train your friends that is how it goes* (Allan. 2018. Interview by author. March 7).”

Several persons explained that they started to see themselves as advocates. This gave them a new purpose, namely, a purpose of speaking out for disability issues in order to help other PwDs as well. It shows a sense of solidarity which engages them with their purpose. *“I see myself as an advocate in the sense that I joined the Young Voices. If I hear anything that is going on like maybe is benefitting persons with disabilities. I would go and tell my friends that there is this program or maybe there are sponsors who are buying walking aids and I would involve my friends* (Madeline. 2018. Interview by author. February 14).” This resonates with her view of the program: *“The Young Voices is all about helping other people. Like the Young Voices speaks out not only to their benefit but to the benefit of others as well.”* In addition to this, William expressed his mission of advocating for PwDs. *“I want*

¹⁵ Joshua refers to the news he shares on his social media to advocate for disability issues.

every person with a disability to be seen [that is why] for me my advice has always been to step out of the shadows (William. 2018. March 20)."

Several members act on their new advocacy mission by raising awareness in their environment. William claims to be committed to inform others: *"Yes, definitely I do that on my personal level... Mostly on social media like Facebook because I have a page where I do such on Facebook. Even through just personal discussions."* When asked what kind of responses he gets on his actions he replies: *"I think there are having been positive responses to my view I have seen people to not really have information out there. Mostly in education they really lack knowledge and information towards that. And also I have also tried to engage parents with children with disabilities especially those who like feel shy to look after their children in their homes (William. 2018. Interview by author. March 20)."* In terms of employment, Madeline continued to visit companies after conducting the field visits with Young Voices. *"So, that was the exercise [visiting companies and conducting questionnaires] we had under the Young Voices. But still, I have tried to use that knowledge, when I meet other HRs... When I go to companies to meet the human resource officers, I try to explain to them about the tax rebate."* On the question what impact she thinks her actions have, she responds: *"The help did not really like come out even for the NGOs that we visited at that particular time. But maybe it will because many of them did not have the idea of tax rebate like they all acted so ignorant (Madeline. 2018. Interview by author. February 14)."*

Their actions, together with their voluntary involvement, solidarity and long term commitment in awareness raising show a sense of duty of being the voice of the voiceless. They feel they are given an opportunity to speak out for themselves but also for others and the duty to utilize this opportunity. *"So it has kind of given me an opportunity to speak to them [other PwDs] and make them understand that not really the difference wages... It has also given me an opportunity not only to speak for my own needs as an adult who has a disability but also given me a sense of responsibility or duty ... to speak for the others and also be the voice of the voiceless (Francis. 2018. Interview by author. February 16)."*

5.4 From Internal to External Empowerment?

While the Young Voices program has made a significant contribution to the domain of internal empowerment ("power within" and "with"), its contribution in the field of external empowerment (changing societal power relations) has been limited. The Young Voices program did feature two major events in which the disabled youth tried to influence their broader environment: (1) the field visits to the companies and (2) the distribution of campaign material (mainly leaflets) in the community. This study found that these two events suffered from two important limitations.

First, they were both one-off activities from which a sustainable and systemic change in power relations is probably not realistic to expect. The reports and interviews show an absence of follow up events of both the outreach activities, reportedly due to the absence of funds (Halima. 2018. Interview by author. March 22). Second, the ownership of these activities essentially remained with CSHZ. CSHZ-staff explained that, due to the short time frame in which the project operated, they had to make the key decisions. In other words, the events were organized for and to some extent with the youth, but not by them.

This is not to say that these activities were meaningless as the interviews clearly show that they in fact further contributed to the internal empowerment of the Young Voices. It marked the beginning of publicly operating on their advocacy work for the young PwDs. In relation to the four outcomes discussed in the previous section the events contributed in several ways. For example, the field visits to companies were conducted in smaller groups which gave them concrete experience to work alongside each other to undertake action as a collective. Furthermore, in their outreach activities they were able to apply their knowledge and practice their skills. Also, the lack of knowledge of companies and within the communities which they experienced during their outreach activities contributed to their sense of purpose to commit even more to their mission to raise awareness for disability issues.

Reflecting upon the theory of Eyben et al (2008) on the basis of this case study, it is clear that the connection between internal and external empowerment is not as clear-cut and self-evident as hypothesized. Empowerment theory assumes that after people build their internal power ('within' and 'with'), they will use their new 'powers' externally to create change in different domains (political, social, economical). The findings of this study

question the 'automatic' causal relation between internal and external empowerment. Two barriers surfaced during the research.

First, it is clear that advocacy requires substantial capacity and expertise. While real progress has been made with internal empowerment, it is highly questionable whether the limited number of trainings in the program were sufficient to develop real advocacy skills. In addition to this, for many members it was their first encounter with disability rights and advocacy in general. This raises the question what can be reasonably expected from these trainings. Second, the findings suggest that collective action is problematic for PwDs due to the (financial) problems they face with transport. As discussed in Chapter 4, PwDs experience many barriers in terms of mobility, transport and accessibility. A significant share of the project resources was spent on covering transport costs for the members, and transport issues limited the number of group meetings. Overall, it seems that transport issues create an extra barrier for PwDs to engage in collective action.

5.5 Conclusion

In conclusion, this chapter distinguishes four outcomes which positively contributed to the "power within" and "with" of the young people with disabilities (PwDs) in the Young Voices program. First, new relationships were build with other young PwDs. Second, the members internalized new perspectives on disability. Third, the young PwDs gained new confidence to speak out. And lastly, the program contributed to developing a new sense of purpose.

Although the program significantly contributed to strengthening the internal empowerment of the young PwDs, the impact of the program in terms of external empowerment remained limited. The two events within the program that targeted the environment (the field visits to the companies and the distribution of campaign material in the community) were one-off activities that were not owned by the youth. The study also found that advocacy requires substantial capacity and expertise which cannot realistically be expected from a limited number of trainings. Furthermore, it is clear that collective action for PwDs is particularly problematic due to transport challenges.

Chapter 6: Conclusion

6.1 Introduction

Disability is a worldwide issue, especially in developing countries where People with Disabilities (PwDs) including children, remain excluded from all kinds of basic services. In the Global South, these people are at risk, because poverty and disability reinforce one another, which leads to exclusion and increased vulnerability (Ghosh et al 2016, 92).

The global understanding of disability currently follows the so-called 'social model' based on UN Convention of People with Disabilities (CRPD). This model does not perceive disability as an individual problem, but it conceptualizes disability as arising from the interaction of a person's functional status with their physical, cultural and policy environments (Burchardt 2004, 736). This way of thinking provides possibilities for people to gain control over their own lives by pursuing changes in their environment.

Empowerment is a concept which is used to examine the (lack of) emancipation of vulnerable and marginalized groups. Eyben et al (2008, 5) define empowerment as the ability to imagine one's world differently and to realize this vision by changing power relations that have been keeping marginalized people in poverty. As of yet, few studies have used the concept of empowerment to study the emancipation of people with disabilities in the Global South. This thesis addresses this gap in the literature.

The processes of empowerment of PwDs in this research are studied in relation to the case study of Young Voices program which is implemented by Cheshire Homes Society of Zambia, a Lusaka based NGO. This organization aims to enable children and youth with disabilities to improve their quality of life and advocates for reducing the barriers which hinder them. In line with their main aim, they implemented the project of Young Voices which focused on enabling young persons with disabilities to become agents of change. The program mobilized young people with disabilities to engage them in activities such as monthly meetings, capacity building trainings, field visits to companies, and distributing campaign materials.

This research asks the following main research question: **How has the Young Voices program contributed to the empowerment of youth with disabilities in Zambia?**

6.2 Internal and External Empowerment Outcomes

This study identified four outcomes which positively contributed to the "power within" (self-awareness and self-confidence) and with (ability to mobilize and work collectively) of the PwDs that participated in the Young Voices program. First, new relationships were built with other young PwDs. The program brought PwDs together which offered opportunities to build new relationships and enabled them to collect and compare different experiences on living with a disability. Sharing their experiences reduces their feelings of isolation and insecurity and increased their sense of self-worth. Second, the members internalized new perspectives on disability. The trainings within the Young Voices Program created the awareness that disability is not only an individual problem but is also created by the broader environment. This also means that change is possible by changing the environment. Furthermore, the youth learned about disability legislation and their rights. Both are crucial for taking action to challenge one's current situation. Third, the young PwDs gained new confidence to speak out for and defend their rights. This was achieved through the trainings, and by practicing in public events. Overall, the youth gained new courage to act on their vision to realize change. At last, the Young Voices Program provided inspiration to several youth to become disability activists themselves. In that sense it gave them a sense of purpose which is speaking out on behalf of their peers whose voices are not heard.

Although the program significantly contributed to strengthening the internal empowerment of the young PwDs, the impact of the program in terms of external empowerment remained limited. Two events were conducted by the young PwDs to influence companies and their community. This study found that these two events suffered from two important limitations. First, they were both one-off activities from which a sustainable and systemic change in power relations is probably not realistic to expect. Second, the ownership of these activities essentially remained with CSHZ which meant that the events were organized for and to some extent with the youth, but not by them. However, the activities were of significant value for strengthening internal empowerment of the young PwDs by marking the beginning of their advocacy work in public. They enabled the young PwDs to undertake collective action, apply their knowledge and practice their skills. It also strengthened their commitment to raising awareness when they experienced the lack of knowledge amongst companies and within the community.

The findings of this study question the ‘automatic’ causal relation between internal and external empowerment as hypothesized by empowerment theory (Eyben et al, 2008). Two underlying issues surfaced during the research. First, it is clear that advocacy requires substantial capacity and expertise. While real progress has been made with internal empowerment, it is highly questionable whether the limited number of trainings in the program were sufficient to develop real advocacy skills. In addition to this, for many members it was their first encounter with disability rights and advocacy in general. This raises the question what can be reasonably expected from these trainings. Second, the findings suggest that collective action is problematic for PwDs due to the (financial) problems they face with transport. As discussed in Chapter 4, PwDs experience many barriers in terms of mobility, transport and accessibility. A significant share of the project resources was spent on covering transport costs for the members, and transport issues limited the number of group meetings. Overall, it seems that transport issues create an extra barrier for PwDs to engage in collective action.

6.3 Recommendations

Following the findings of this study several recommendations can be made which are relevant for future interventions aiming to empower youth with disabilities. These recommendations arise from the positive experiences and the critical reflections of the impact of the interventions. Based on the positive experiences three recommendations can be made which all contribute to the internal empowerment of PwDs:

1. Ensure group mobilization by bringing PwDs together. The impact of physically bringing the members together should not be underestimated. The study found that this resulted in new relationships which were of significant importance for internal empowerment.
2. Take understandings on disability and disability rights into serious consideration. It enables the members to take on new perspectives on disability and increases their rights awareness. This contributes to their self confidence which is a major gain in the lives of youth who are constantly facing challenges and discrimination resulting from their disability.
3. Invest in the development of communication and advocacy skills. Obtaining communication and advocacy skills enables youth to speak out, for, and about themselves and their rights. It strengthens their commitment to their mission to improve disability to help others.

Based on the critical reflections three additional recommendations can be made:

1. Ensure that programs aiming to empowerment PwDs adopt a long term perspective. Such a perspective is crucial given the deep rootedness of the structures that marginalized PwDs.
2. Second, ensure ownership of PwDs in the empowerment interventions. The very notion of empowerment is based on the idea of people can control their own life and claiming their own life.
3. Take into account that PwDs face additional mobility issues. This study found that mobility issues limit the ability to operate as a collective and pursue change.

6.4 Future Research

In terms of future research, this study found that the assumption that internal empowerment automatically results in external empowerment is questionable. This study identified several factors impeding the realization of external empowerment. The issue of transport is particularly interesting because this seems uniquely associated with the specific characteristics of PwDs. Therefore, future studies could further clarify the conditions under which internal empowerment results in external empowerment.

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Appendixes

Appendix A: Operationalization table

Appendix B: List of Participants

Appendix C: Topic Guides

Appendix D: Reflection Interview Questions Photovoice

Appendix E: Informed Consent Forms

Appendix A: Operationalization Table

Concept	Dimension	Indicators	Questions in study: How has CHSZ managed to ...
(Internal) Empowerment	Power within	Knowledge of self	Help youth to gain knowledge of their own interests, preferences, strengths, needs, and attributes of one's disability?
			Inform youth about their social position?
			Help the youth identifying the details of their disability?
			Learn the youth about disability terminology?
		Learn the youth to judge the impact of their disability on performance?	
		Knowledge of rights	Inform youth about their rights as citizen?
	Inform youth about their rights an individual with a disability?		
	Enable youth to recognize when their rights have been violated?		
	Ability to imagine	Enable youth to find ways to redress violations?	
		Enable youth to redefine their possibilities?	
		Learn youth to imagine their world differently?	
		Enable youth to speak out these imaginations?	
	Power with	Communication	Enable youth to speak about and for themselves?
			Learn youth to communicate in groups and meetings?
			Provide youth with communication skills?
			Learn youth to communicate about feelings, needs, and desires?
Leadership		Enable youth with the ability to say no?	
		Provide youth of leadership instruction?	
		Inform youth about the roles and dynamics of a group?	
		Enable youth to function in a group	
Enable youth to perform their duty as a team member?			
Enable youth with information about political processes			

Concept	Domain	Indicators	Questions in study: How, and to what extent, have the empowered Young Voices managed to ...
(External) Empowerment	Social empowerment	Participation in society	Increase accessibility of participation in society for themselves?
			Increase accessibility of participation for other youth?
		Social aspirations	Change their view about future possibilities?
			Change other young people's view about future possibilities?
		Social institutions	Inform other youth about the norms and customs that limit mobility of PWDs?
			Try to include the narrative of youth into these norms and customs?
		Social relations	Improve the quality of their social relationships?
			Secure respect, dignity and freedom from violence in their social relationships?
			Enable other youth to secure respect, dignity and freedom from violence in their social relationships?
			Speak up to discrimination they experience?
	Enable other youth to speak up to discrimination?		
	Convince companies to hire youth?		
	Economic empowerment	Market participation	Increase accessibility of participation in the market for themselves?
			Increase accessibility of participation for other youth?
			Stimulate other youth to participate in the market?
			Provide themselves of an income in formal sector?
		Economic aspirations	Change their view about economic possibilities?
			Inform others about economic possibilities for youth?
		Economic institutions	Change other young people's view about economic possibilities?
			Inform other youth about social protection services?
Political empowerment	Political participation	Increase accessibility of social protection for youth?	
		Increase accessibility of participation in politics for themselves?	
		Increase accessibility of participation in politics for other youth?	
		Engage in decision making processes?	
Engage in policy negotiations?			

Appendix B: List of Participants

Nr.	Date	Name	Age	Sex	Type of Informant	Type of method	Location
1	05.02	Nyamwali	29	Female	Member YV Kafue	Interview`	Twatasha
2	06.02	Derick, Twig, Ruth, Miseal, Deborah, Gift	X		Members YV Kafue	Focusgroup	Twatasha
3	06.02	Emmanuel	20	Male	Member YV Kafue	Interview	Twatasha
4	06.02	Elida	30	Female	Member YV Kafue	Interview	Twatasha
5	06.02	Malindi	X	Female	Member YV Kafue	Interview	Twatasha
6	13.02	George	32	Male	Member YV Kafue	Interview	Twatasha
7	13.02	Sepo		Female	Member YV Kafue	Interview	Twatasha
8	14.02	Madeline	26	Female	Member YV Lusaka	Interview	Own house
9	15.02	Angela	x	Female	Non-YV with a disability	Interview	University of Zambia
10	15.02	Philip	24	Male	Non-YV with a visual impairment	Interview	University of Zambia
11	15.02	Temwani	25	Female	Non-YV with a disability	Interview	University of Zambia
12	15.02	Jennifer	26	Female	Non-YV with a disability	Interview	University of Zambia
13	16.02	Francis	32	Male	Member YV Lusaka	Interview	National Office CHSZ
14	23.02	Royd	27	Male	Inactive member YV Lusaka	Interview	National Office CHSZ
15	26.02	Alice & Mulubwa	20, 22	Both female	Non-YV with a hearing impairment	Interview	Mulani Girls School
16	27.02	Lynn	24	Female	Member YV Lusaka	Interview	University of Zambia
17	27.02	Salma	19	Female	Non-YV with a visual impairment	Interview	University of Zambia
18	02.03	Mr. Banda	45	Male	Community leader Kafue	Interview	Twatasha
19	02.03	Mrs. Kwanga	x	Female	Community leader Kafue	Interview	Twatasha
20	05.03	Joshua	26	Male	Member YV Lusaka	Interview	Own house - Mtendere
21	06.03	Noah	28	Male	Projectmanager Plan International	Interview	Regional office Plan International
22	07.03	Helen	25	Female	YV member Lusaka	Interview	Own house - Woodlands
23	07.03	Towela	18	Female	Member YV Lusaka	Interview	National Office CHSZ
24	08.03	Allan	x	Male	Consultant Trainings YV	Interview	Office of consultant
25	09.03	Yolan	22	Female	YV member Lusaka	Interview	National Office CHSZ
26	09.03	Viena, Janet, Carol, Stanislavia, Temba, lan	X		YV members Lusaka	Focusgroup	National Office CHSZ
27	12.03	Helen	25	Female	YV member Lusaka	Photovoice discussion	Own house - Woodlands

28	13.03	Leonard, Halima	X	Male, Female	Staff	Focusgroup	National Office CHSZ
29	14.03	Sonkwe	28	Male	HR manager Pick n Pay	Interview	Head office Pick N Pay
30	19.03	Lynn	22	Female	YV member Lusaka	Photovoice	University of Zambia
31	20.03	William	26	Male	YV chairperson Lusaka	Interview	National Office CHSZ
32	22.03	Halima	X	Female	Project manager Young Voices	Interview	National Office CHSZ
33	22.03	Madeline	26	Female	YV member Lusaka	Photovoice	National Office CHSZ
34	21.03	Suria	x	Female	Councilor Kafue	Interview	Twatasha
35	28.03	William	26	Male	YV chairperson Lusaka	Photovoice	Cresta Golfview

Appendix C: Topic Guides

This Appendix contains six topic guides for the semi-structured interviews with all informants categorized as follows:

1. Young Voices members
2. CHSZ staff
3. Non-Young Voices members
4. Companies
5. Community Leaders
6. Consultant

1: Topic Guide Interview Young Voice Member (Active)

OBJECTIVES

- To gather information about the Young Voices activities
- To gather reflections on their experience(s) of Young Voices
- To understand the challenges they face as YWDs
- To examine the contribution of the Young Voices program on their knowledge of self, knowledge of rights, communication and leadership
- To examine the changes in power relations in terms of social, political, economic and legal empowerment

INTRODUCTION

- Introduce University of Amsterdam and Breaking Down Barriers; confidentiality; timing

1 PRESENT CIRCUMSTANCES

- Nature of current housing status
- Summary of current activity (work/education/other) s

2 LIFE HISTORY

- Childhood and family background
- School life/education/work
- Friendships and further relationships

3 DISABILITY

- Meaning of disability
- Type of disability
- Challenges of disability
- Impact of their disability on performance/daily lives
 - Being a girl and having a disability, is this interrelated with each other? Example?
- Differences between different disabilities?

4 YOUNG VOICES PROGRAM

- Enrolment in Young Voices program
- What is the focus of the program?
 - How achieving this?
- Describe activities (meetings, trainings, public events)
- Trainings?
 - Why valuable? What was most valuable?
 - Example
- Field visits to companies?
 - Why valuable? What was most valuable? Example
 - How effective were these visits?
- What skills did they obtain? Example?
- Group dynamics
 - What are the roles of team members?
 - Effect of being a group rather than individual?
- How would your life be different without YV program?
- Collaboration with other organisations? DPOs/NGOs?

5 EXTERNAL EFFECT

- Participation society
 - Can you participate in everything you like?
 - Reactions of society on disability
 - How about other young PWDs? Same struggle?
 - How do you reach other PWDs? Example
- Employment
 - Career possibilities for young PWDs?
 - How are Young Voices trying to improve this? Example?
 - Convince corporate companies to hire PWDs?
 - Tax rebate
- Politics
 - Governments perspective on disability?
 - PWDs involved in decision making processes? Example
 - Is politics a topic you talk about with others?
 - How to create political will for implementation rights PWDs? YV contribution?

6 FUTURE / ENDING

- What changes would you like to see in your community
- What changes would you like to see in YV?
- How would you realise these changes? What is needed?
- What goals should Young Voices achieve in future?

2: Topic Guide Interview Staff Member

OBJECTIVES

- To gather reflections on the contribution of CHSZ on empowering youth
- To gather reflections on the contribution of Young Voices on their environment

INTRODUCTION

- Introduce University of Amsterdam and Breaking Down Barriers; confidentiality; timing

1 PRESENT CIRCUMSTANCES

- Name and Age
- Current activity (work)

2 DISABILITY

- Meaning of disability
- Own experience with disability
- Challenges of disability

3 IMPLEMENTATION OF PROGRAM

- Design of the program
- Objectives program
- What did CHSZ do to realize this change?
- Strong points YV program
- Weaker points YV program

4 YOUNG VOICES

- Current status of program
- Outcomes program (social domain, economic domain, political domain, legal domain)
 - What did CHSZ do to realize this change?
 - What did YV do to realize change?

5 FUTURE / ENDING

- What follow up is needed for this group? Disability advocacy in general?
- What goals should Young Voices achieve in future? What needs to be changed?

3: Topic Guide Interview Non-Young Voice Member

OBJECTIVES

- To gather reflections on their experiences as YWDs
- To understand the challenges they face as YWDs
- To gather information on their experiences of disability advocacy
- To examine their level of knowledge of self, knowledge of rights, communication and leadership
- To examine their ability to realise changes in power relations in terms of social, political, economic, and legal empowerment.

INTRODUCTION

- Introduce University of Amsterdam and Breaking Down Barriers; confidentiality; timing

1 PRESENT CIRCUMSTANCES

- Nature of current housing status
- Summary of current activity (work/education/other)

2 LIFE HISTORY

- Childhood and family background
- School life/education/work
- What like to do in free time?

3 DISABILITY

- Meaning of disability
- Type of disability
- Challenges of disability? Example
- Impact of their disability on daily lives
 - Being a girl and having a disability, how is this interrelated with each other?
Example
- Differences between different disabilities?

4 INTERNAL EMPOWERMENT

- Experience groups
 - Joining clubs/groups/platforms?
 - Experience with working in groups?
 - Examples
 - Connection with other PWDs?
 - Aware of DPOs and NGOs?
- Sharing experiences of disability
- Rights of PWDs
- Imagine life differently
 - What is needed to realize

5 EXTERNAL EMPOWERMENT

- Participation society
 - Can you participate in everything you want?
 - Reactions of society on disability
 - How about other young PWDs? Same struggle?
 - Do you try to find a solution together with other PWDs?
- Employment
 - Career possibilities for young PWDs?
 - How can this be improved? Example
 - How can you contribute to this improvement?
 - Tax rebate
- Politics
 - Government perspectives on disability? Local politics?
 - PWDs involved in decision making? Example
 - Is politics a topic you talk about with others?
 - How to create political will for integration of PWDs?

6 FUTURE / ENDING

- What changes would you like to see in your community
- What changes would you like to see in YV?
- How would you realise these changes? What is needed?
- What goals should Young Voices achieve in future?

4: Topic Guide Interview Companies

OBJECTIVES

- To gather reflections on the employment of PWDs
- To gather information about their policies of employing PWDs
- To examine realised changes in economic power relations since the implementation of YV project

INTRODUCTION

- Introduce University of Amsterdam and Breaking Down Barriers; confidentiality; timing

1 PRESENT CIRCUMSTANCES

- Name and Age
- Company (departments)
- Role in the company

2 DISABILITY

- Meaning of disability
- Challenges of disability
- Company's perspective on disability

3 YOUNG VOICES

- Perspective on Young Voices
 - Activities Young Voices?
 - Similar YV projects
 - How is YV being useful? Example?
- Field Visits and Survey
 - Experience of Field Visit end of September 2016
 - Collaboration with other DPOs or NGOs?
 - How handling issue of disability?

4 EMPLOYMENT

- Participation employment sector
 - Reaction community on disability?
 - Accessibility of participation in community? Example?
 - PWDs involved in committees or projects?
- Employment
 - Career possibilities PWDs?
 - Accessibility in company for PWDs?
 - How convince companies to employ PWDs? What would make you employ PWDs?
 - YV contribution?
 - Disability Act; Tax rebate

5 FUTURE / ENDING

- What changes would you like to see in your community?
- What goals should Young Voices achieve in future? What needs to be changed?

5: Topic Guide Interview Community Leaders

OBJECTIVES

- To gather reflections on their experiences with disability
- To gather information about the community's perspective on young PWDs
- To examine realised changes in power relations since the implementation of YV project according to the community
-

INTRODUCTION

- Introduce University of Amsterdam and Breaking Down Barriers; confidentiality; timing

1 PRESENT CIRCUMSTANCES

- Name and Age
- Nature of current housing status
- Summary of current activity

2 COMMUNITY

- Role in community
- Description of community
- Committees

3 DISABILITY

- Meaning of disability
- Challenges of disability
- Disability in daily life

4 YOUNG VOICES

- Perspective on Young Voices
 - How was the Young Voices practiced in the community?
 - Activities Young Voices?
 - How is YV being useful? Example?
 - What other things can be done to achieve YV goals?
- Stakeholder meetings
 - Frequency?
 - In what way valuable? Example
 - Collaboration with other DPOs or NGOs?
 - Convinced to handle the issue?

5 IMPACT COMMUNITY

- Participation society
 - Reaction community on disability?
 - Accessibility of participation in community? Example?
 - PWDs involved in committees or projects?
- Employment
 - Career possibilities PWDs
 - Subsidies for projects but not for PWD projects?
 - How can young PWDs speak up for their rights?
 - How can community speak up for the rights of PWDs?
 - YV contribution?

- Local politics
 - Describe local politics in community
 - Involvement of PWDs in decision making processes?
 - YV contribution?

6 FUTURE / ENDING

- What changes would you like to see in your community?
- What goals should Young Voices achieve in future? What needs to be changed?

6: Topic Guide Interview Consultant

OBJECTIVES

- To gather reflections on training the Young Voices
- To gather information about the content of the trainings
- To examine realised changes as a result of the trainings

INTRODUCTION

- Introduce University of Amsterdam and Breaking Down Barriers; confidentiality; timing

1 PRESENT CIRCUMSTANCES

- Name and Age
- Current activity (work)
- Meaning of trainings
- Experience of training (especially PWDs)

2 DISABILITY

- Meaning of disability
- Challenges of disability
- Consultant perspective on disability
- Motivation of giving training to PWD

3 TRAINING (USE TRAINING MATERIAL)

- Describe different trainings
- Objectives of trainings
- Process of developing trainings
- Why these topics to PWDs?
- Achieved goals of the training?
- Expectations of the trainings?

4 FOLLOW UP/OUTCOMES

- Results of the training
 - In terms of activities Young Voices
- How are skills from training being used in daily life?

5 FUTURE / ENDING

- What follow up is needed for this group? Disability advocacy in general?
- What goals should Young Voices achieve in future? What needs to be changed?

Appendix D: Reflection Interview Questions Photovoice

After the photovoice activity the photos were discussed in a reflection interview. The following questions were asked in relation to each photo:

1. Can you describe what is on the picture?
2. What is happening in the picture?
3. Why did you take a picture of it?
4. What does the picture tell about your life?
5. How can this picture provide opportunities to improve your life?

Appendix E:

Consent Form

CONSENT FORM TO PARTICIPATE IN RESEARCH	
Full Name of Researcher: LINDSAY VOGELZANG	
Full Name of Participant: _____	
Occupation/Relationship to Young Voices: _____	
Date and Time of Interview: _____	
Location of Interview: _____	
For participants under the age of 30 only: Date of Birth: _____ Age: _____ <i>(For participants under the age of 18, the participant's parent or guardian must also complete a consent form)</i>	
Hello, my name is Lindsay Vogelzang and I am a student based in the Netherlands.	
The objective of my research today is to conduct interviews and focus groups as part of a research project investigating the advocacy strategies of Cheshire Homes of Society Zambia, specifically their advocacy strategies of the Young Voices project.	
This interview is part of a research project in which various other people will be involved, including staff, young people, community leaders and NGOs. Following this research, the findings will be analysed and presented in the form of a Master's thesis at the University of Amsterdam in Amsterdam.	
The results from the study will be shared with Cheshire Homes of Society Zambia with the intention of helping to develop their capacity for more effective advocacy strategies. The findings will also be shared with the African Studies Centre Leiden and Liliane Foundation, as part of their co-operative project, <i>Breaking down Barriers to Inclusion – Building Capacity for Lobby and Advocacy for Children With Disabilities</i> , to help build their knowledge of the conditions for successful advocacy to improve the conditions for children with disabilities worldwide.	
I would very much appreciate your participation in this research, since your knowledge and opinions about the <i>Young Voices project</i> are very important. The discussion will cover topics related to the advocacy strategies and impact on your life, and I expect it to take no longer than one hour.	
Please remember that participation in this interview or focus group is voluntary. This means that you can choose not to answer any question or all of the questions. You are free to stop and leave the interview at any time, without giving any explanation. Your identity will be protected in this study, and unless I seek your prior written approval, your name will not be made public. For purposes of validity, the discussion will be recorded, but you can tell me to stop recording at any time.	
Do you have any questions that you would like to ask me?	
If you have any questions in the future, or if you would like to discuss any concerns, my contact details are: Phone (Airtel): +260 0978394629 Email (Personal): vogelzang.lindsay@gmail.com Phone (Netherlands): +31 631628006 Email (Academic): lindsayvogelzang@student.uva.nl	
I, _____, have read or been explained this form and any questions have been answered to my satisfaction. I agree to participate in the research: YES <input type="checkbox"/> NO <input type="checkbox"/>	
Signature of Participant: _____	Date: _____
I, the researcher, have explained to the participant in the language that he/she understands the procedures to be followed in this research and the risks and benefits involved. He/she has agreed participate in the research.	
Signature of Researcher: _____	Date: _____

Consent Form Photovoice

Photography Consent Form

In February-March 2018, you took part in the research of Lindsay Vogelzang's Masters project, taking photographs to explore 'What it means to be a young person with a disability in Zambia'.

Your role as the creator of these photographs will be made explicit and centralised, and all the activities of Voice4Thought are exclusively for non-profitmaking purposes. These photographs and the stories of the creators and the subjects will be presented in an attempt to show people how young people with disabilities experience life in Sierra Leone.

For the creators of these photographs:

By signing this form,

- I allow my photographs to be displayed with Voice4Thought.
- I agree to be named as the creator of the photographs I took, and for information about myself to be made public.
- I allow my photographs and/or my image to be published in documents involved with Lindsay Vogelzang's master thesis.
- I allow my photographs and/or my image to be published in promotional materials on different platforms including Facebook.

For individuals whose identifiable image appears in these photographs:

By signing this form,

- I allow the photograph containing my image to be used in the activities described above.
- I understand that my name will never be made public.
- I allow my story, as described by the photo's creator, to be made public.
- I allow my photographs and/or my image to be published in documents involved with Lindsay Vogelzang's master thesis.
- I allow the photo of myself to be published in promotional materials on different platforms including Facebook.

In cases where the subject in the photo is a dependent, their guardian must provide consent.

YES

NO

Name:

Date of Birth:

Age:

Telephone number:

Signature: Date: