

EXPLORING ROLE MODELS IN DISABILITY ADVOCACY

THE CASE OF THE YOUNG VOICES PROGRAMME IN ZAMBIA



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Disclaimer

This product is part of the author's academic graduation from the Master of Arts (Ma) in African Studies at Leiden University, the Netherlands. The findings and visions that are described in this product are therefore those of the author and not necessarily those of Leiden University.

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List of Acronyms

CHSZ	Cheshire Homes Society of Zambia
DPO	Disabled People Organisation
KPS	Kasenje Primary School
LCD	Leonard Cheshire Disability
MDGs	Millennium Development Goals
MGD	Munali Girls School
MOE	Ministry of Education
PWDs	Persons with Disabilities
SDGs	Sustainable Development Goals
TCS	Twatasha Community School
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UNDESA	United Nations Department of Economic and Social Affairs
UNZA	University of Zambia
SGDs	Sustainable Development Goals
YALIP	Young African Leader Initiative Programme
YV	Young Voices
ZAFOD	Zambia Federation of Disability Organisations
ZAMISE	Zambia Institute for Special Education
ZAPD	Zambia Agency for Persons with Disabilities

Abstract

Persons with disabilities (PWDs) are the biggest marginalised group in the world, especially within the context of the global South. Having a disability is linked to extreme poverty because of lacking social services, high medical costs and low employment rates. These challenges contribute to a low self-esteem among young persons with physical impairments. On top of that, societal prejudices and negatives stereotypes about PWDs only further deteriorate their situation. This thesis clarifies the potential that role models have in disability advocacy, something that has never been researched before. Field research in Zambia demonstrated that role models have the potential to (1) address the negative self-esteem of youth with disabilities, (2) stimulate their pro-active attitude, (3) strengthen their ability to speak out and (4) enhance group solidarity. These outcomes are realized through indirect engagement between role models and disabled youth (through observation) and direct engagement (through teaching and feedback).

Key Words

Disability, advocacy, role model, self-esteem, Zambia, awareness, youth, mentoring, capacity building.

“Like slavery and apartheid, poverty is not natural. It is man-made and it can be overcome and eradicated by the actions of human beings. Sometimes it falls on a generation to be great. YOU can be that great generation. Let your greatness blossom”.

- Nelson Mandela -

1. Introduction

§ 1. Advocacy for Disability in the Global South

According to research by the World Health Organisation, about one billion people worldwide live with some form of disability. Nearly 200 million of them experience considerable difficulties in functioning (WHO, 2011). Empirical evidence has shown that persons with disabilities (PWDs) in developing countries are at an disadvantage and experience high rates of poverty and social exclusion (Ghosh et al, 2015). PWDs are amongst the poorest of their society because poverty aggravates the challenges for children and families caused by society's reaction to disability (Gilligan, 2015). Already facing the high youth unemployment rates on the continent, the situation of PWDs gets further catalysed because of one or multiple disabilities. Social stigmas are powerful barriers that complicate participation and make PWDs suffer from exclusion (Frobisher et al, 2016). PWDs experience difficulties in accessing multiple sets of opportunities such as education, stable income, employment, housing, welfare or social insurance benefits, citizenship, civil rights, security, justice, mobility, social and political participation and information and communication (Ghosh et al, 2016).

This marginalisation of PWDs in the global South has its partial roots in stigmatising and stereotyping typically based on prejudices, a lack of knowledge and prevailing cultural beliefs (Potthof & Elbers, 2016). The wide spread belief exists that disability is caused by Satanism or witchcraft, creating social isolation and segregation which severely damage the lives of persons with disabilities. Because of these ideas, children with disabilities are hidden from the community or even killed at birth according to the *United Nations Department of Economic and Social Affairs* (UNDESA, 2017). These examples and frequent stigmas further intensify the prejudice that disability stands equal to inability. This results in exclusion of PWDs and this negatively affects their self-esteem, confidence and will to change their social position.

Nearly every country in the world has signed the *United Nations Convention on the Rights of People with Disabilities* (UNCRPD). This convention serves as an international set of regulations that should protect the rights of PWDs worldwide and serve as an umbrella model for national legislation. However, implementation of the UNCRPD is mostly unclear and so (inter)national legislation for PWDs remains insufficient. Disability has not been a main goal of the late *Millennium Development Goals* (MDGs) and it has only recently been enlisted as an explicit priority in the *Sustainable Development Goals* (SDGs). This marginalisation and lack of legislation has turned disability in a pressing and urgent problem because regulations in the SDGs do not take special needs into account. Extra costs for medical support and surgery are not insured by and cannot be afforded due to unemployment. This results in a decrease in social participation and eventually further stigmatisation. The lives of PWDs hereby run a risk of turning into a vicious circle, as seen in figure 1 by the British Department for International Development (2000). In this figure one can see that disability leads to poverty, making PWDs more vulnerable and more disabled through social exclusion. This especially occurs when members of vulnerable groups become disabled, which causes 'double discrimination' or intersectionality. This means that the vulnerability of PWDs becomes more problematic when they have another social identity, such as being a woman or a young person (Pal, 2011).



Figure 1: the disability-poverty cycle. Image by the DFID (2000).

§ 2. Advocacy, Role Models and Awareness Raising

Advocacy by civil society can help PWDs by finding ways that can influence both thinking and practice (Malinga & Gumbo, 2015). Advocacy can be described as “influencing the decisions, policies and practices of powerful decision-makers, to address underlying causes of poverty, bring justice and support good development” (Watson, 2015). In the case of disability advocacy, this is being done by drawing attention to disability marginalisation and by supporting change makers.

Although one might think that advocacy is only being done on behalf of PWDs, literature makes a distinction between advocacy *for*, *by* and *with* those who are affected by a situation (Watson, 2015). The advocating thus can be performed by external influencers, the marginalised people themselves or a combination respectively. Advocacy is closely linked to lobbying, but the main terminological difference is that lobbying is solely aimed for changing legal practices and does not handle the social, stigmatising thinking patterns in particular. Since the 1960s the creation of advocacy groups received a boost through more international recognition and eventually the signing of the UNCRPD, which is being seen as the most important result of advocacy for PWDs. Awareness raising and tackling stereotypes is therefore an important part of advocacy. It is not simply a matter of changing laws; in order to achieve social change, one also has to change the way people think about PWDs. Advocacy exists of both creating awareness and changing laws, policies and practices (Watson, 2015).

One way of awareness raising and empowerment for both PWDs and non-PWDs is by use of role models, who can serve as a way to influence PWDs in a positive way. Through this positive influence, they can oppose stereotypes. Role models can make PWDs more aware that disability does not stand equal to inability. Through social-emotional support a role model can inspire a person with a disability to achieve something that seems to be difficult or impossible for this person. Role models have the possibility to supplement or even redesign that person's state of mind, giving them a slight push in the right direction. By this way the PWD comes to a stage in which he/she is more able of standing up for his/her own rights, demands or preferences. They can because the morale of that person has been increased because they are able to compare to a success story of a person that serves as a role model (Lockwood & Kunda, 1997).

The potential of role models within the context of disability advocacy in the global South has hardly been researched. There has been research on role models, but only in a Western context. One result of Western role model research includes that role models become role models for each other and cause changes in attitudes and responsibilities of youth (MacCallum & Beltman, 2002). Another source suggests that sports related role model programmes have a demonstrable effect on the community (Payne et al, 2014). The importance of role models in the global South was identified by Frobisher et al (2016). This research stated that in Sierra Leone, girls with disabilities that participated in advocacy activities acted as role models for other girls with disabilities. However, the literature in which role models are researched is all based on Western programmes and it remains unclear whether key findings apply in vastly different contexts in the global South.

§ 3. Research Question

The goal of this research is to clarify the importance and potential of role models in disability advocacy in the global South. It takes place in the context of the disability advocacy project of *Breaking Down Barriers*. This is a research programme that uses academic research to build capacity for effective disability advocacy in Sierra Leone, Cameroon and Zambia. On behalf of *Breaking Down Barriers* a case study was conducted of a disability training programme by *Cheshire Homes Society of Zambia* (CHSZ). The training programme, called *Young Voices*, aimed for innovative advocacy activities for and by ± 300 young PWDs through training, group meetings and outreach programmes. This is done with the final goal to let young PWDs gain "the necessary skills and knowledge to adequately lobby and advocate for their rights" (Hamuhuma, 2016). Role models were expected to play an important role in *Young Voices*. The members that have been trained in grassroot groups can be seen as potential role models for other PWDs.

Taking the *Young Voices* programme as the starting-point, this study asks the following main research question: *how has the creation and strengthening of groups of disabled youth in the Young Voices programme in Zambia produced role model effects?*

The remainder of this thesis has 4 chapters. Chapter 2 explains the theoretical framework and academic sources that supported the research. The different methods that were used to collect data during the fieldwork is presented in the following chapter. In order to create an

image of disability stereotypes and legislation in the cultural context of Zambia, one chapter has been dedicated to this subject. The thesis will end with the results of the research based on the collected and analysed data.

2. Theoretical Framework

This chapter discusses the core terms of the research and the theories that support the research question. First there will be a more in depth explanation of what disability is and what awareness raising and advocacy have to do with it. Next there will be discussion on theoretical perspectives on role models. The final part of this chapter consists of sub-questions that together answer the main question.

§ 1. Disability

The term 'disability' is complex, widely definable and under constant change. The UNCRPD has described PWDs as "those who 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 other" (García Iriate, 2015). Because disability depends on interaction between individuals in a specific cultural context (Lewis Gargett et al, 2015) disability is far more than just a mental or physical inconvenience that decreases mobility. All members of a certain society are hereby indirectly involved in disability.

Apart from an approach in health and medical circumstances, there has been a shift in the last few decades to how disability is being observed. In the 1950s having an impairment was equalised with total disability in all circumstances (Brandt Jr. et al, 1997). Later, in the 1970s, a model was created that explained the development of a pathological deficiency into an impairment, which could lead to a limitation and eventually disability. This marks the transition of a pathological model into a social model "in which people are viewed as being disabled by society rather than their bodies" (WHO, 2011). It is, however, not a dichotomy; both the pathological and social model can be present and flow into each other. With the creation of this social model, the environmental barrier was highlighted for the first time. Although this was the start of involving environmental factors in disability studies, the 1970s concept of 'environment' mostly referred to activity limitations because of the social expectations of other individuals (Brandt Jr. et al, 1997). Besides, this 1970s model was not universally adopted and so the natural and urban environment remained an extra physical and mental hurdle. High transportation costs, elevated doorsteps and the absence of sign language interpreters are only a few examples of other environmental and communicational barriers that complicate or limit the physical and social mobility of PWDs in the global South. In figure 2 by Brandt Jr. et al (1997) an overview of this enabling-disabling process in relation to the environment has been explained schematically. The figure shows that PWDs are limited by their environment as soon as they want to start developing themselves (left). This is where the process of disability by society starts. This prevents the enabling process, which exists of both medical and environmental participation in society (right). As long as the social and environmental actors violate the sense of dignity and equality for PWDs, it is acknowledged that the human rights of PWDs are in need of protection to prevent on-going social exclusion.

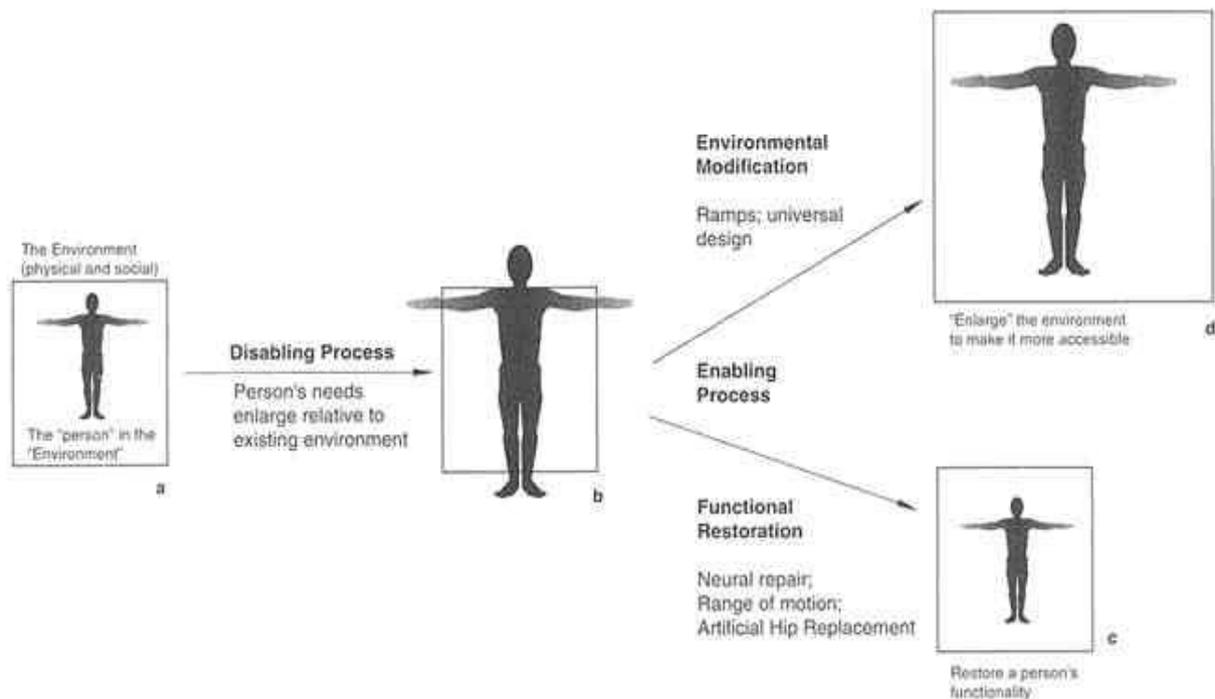


Figure 2: the enabling-disabling process. Image by Brandt Jr. et al (1997).

Not only is there a link between disability and social exclusion, but also between disability and poverty. As explained by Hoogeveen (2005) PWDs in Uganda are more likely to end up in situations of poverty because of a limited access to food, healthcare and education. Reduced capabilities in term of employment and/or work also play a part in their increased chance of ending up in poverty. In the case of Uganda, PWDs have less consumption per capita and higher poverty rates than able-bodied Ugandans. In addition to Hoogeveen's findings, Imrie (1996) speaks about "apartheid by design" in which he points to certain areas and institutions that have an inaccessible design which excludes PWDs from using them. These areas include medical facilities, places of employment and public locations that do not supply Braille, sign language or services for persons with hearing impairments. Because of high transportation costs for PWDs in developing countries, it is already difficult to visit these institutions at all. Having little to no access to these important institutions, may it be in terms of transportation or architecture, result in lower degrees of education, health and income and thus cause or exaggerate poverty for PWDs. According to a research on SDGs and disability by the Zambia Federation of Disability Organisations (ZAFOD) in 2017, 93% of PWDs in Zambia live in poverty. This means that 1 in 8 Zambian nationals is a PWD living in poverty, which results in the conclusion that there is at least a correlation between disability and (extreme) poverty in the context of Zambia.

Disability does not only affect the material welfare of PWDs, but also their wellbeing. Many members of different societies have a negative or stereotypical set of beliefs on disability, denigrate PWDs in their surroundings and even harass them because they have an ignorant attitude towards disability (Chondoka & Machila, 2011). When this happens on a frequent basis and at different levels, this will eventually affect the self-esteem of PWDs. When others tell them from their early childhood onwards that they are just a burden for their family, that

they are not able to achieve anything in their lives or that they will never be a part of the community, these PWDs will eventually start to believe what other say about them. This especially counts when these sets of believes come from family and friends, which are among the most powerful influencers of the PWD's concept of self (Voigt, 2009). What happens then is that their self-esteem drops and hereby the motivation to change the attitude of others is decreasing.

The lower level of self-esteem and confidence by community ignorance about disability has different psychological effects on PWDs. Although they differ per person, the mind-set of a PWD maximises the negative events and the comparisons they between themselves and able-bodied persons become unrealistic (Voigt, 2009). These unrealistic comparisons also result in unrealistic goals they set for themselves. When they do not reach these goals, the negative mindset becomes even more negative than it was before. What happens next is an overgeneralisation of their own failing and a lack of self-appreciation according to Voigt (2009).

§ 2. Advocacy and Awareness Raising

The previously mentioned UNCRPD has incorporated eight general principles that can lead to improved living conditions of PWDs. As explained by Mittler (2015) these general principles aim for respect for dignity, non-discrimination and both participation and inclusion. Also the treaty implicates acceptance of PWDs, equal (gender) opportunities, accessibility and respect for the evolving capacities of children with disabilities. These principles are more likely to be maintained when PWDs, social institutions and policy makers become more aware of the existence of the UNCRPD as well as of the medical, social and environmental consequences of disability marginalisation. This is when awareness raising, as also emphasized in Article 8 of the UNCRPD, and advocacy come into the picture.

Advocacy is being described as “practical use of knowledge for purposes of social change (...) by directing this at decision makers” (Malinga & Gumbo, 2015). When the voice of a group or an individual is not heard by decision makers, advocacy can act as a tool to draw attention to or raise awareness for a certain underexposed social matter. Figure 3 by Elbers (2018) identifies four different but interlinked types of advocacy, based on two characteristics: (1) *goals of advocacy* (horizontal axis), and (2) *target groups* (vertical axis). The Young Voices programme can be viewed as belonging to the upper left quadrant.



Figure 3: the disability advocacy model. Personal publication by Elbers (2018).

Although the term ‘advocacy’ might suggest that marginalised groups are dependent or submissive, one has to realise that advocacy is not always solely being plead on behalf them. It also does not mean that marginalised groups are merely listeners in the advocacy debate. Advocacy is not only being done *for* marginalized groups *by* external organisations, although this form of advocacy is effective in situations where the affected community experiences fear, time pressure or distance. In order to strengthen voices and by this way contribute to a more inclusive and sustainable system, advocacy can also be carried out *with* marginalized groups. A collaborative way, in which the role of the advocacy organisation is to play a part in the capacity building and community support (Watson, 2015). The third and final form of advocacy is advocacy *by* the affected group (also known as *self-advocacy*) in which the role of the advocacy organisation is limited to supporting the affected group.

Despite that there is said that advocacy and political activity can have an effect on challenging societal stigmas and creating policy outcomes, knowledge on the factors shaping the effectiveness of advocacy remains insufficient (Almog-Bar & Schmid, 2014). This especially holds up to disability advocacy in the global South. A few recent studies have shown that disability advocacy can make a difference, although many aspects remain poorly understood. For example, Frobisher et al (2016) found that empowerment advocacy in Sierra Leone has led to situations in which girls with disabilities in the position to interact strong and dignified in their community. In Cameroon, Potthof & Elbers (2016) found out that advocacy organisations were able to convince the government to start a pilot on inclusive education.

Overall, advocacy can not only lead to institutional change in laws and practices, but it also fights frequent stereotypes and stigmatisation by power holders that causes marginalisation. Maybe even more important, advocacy can contribute to a much needed sense of dignity, inclusivity and self-awareness for marginalised minorities that strengthens both their confidence and aspirations (DFID, 2000). Since awareness raising is the starting point for marginalised groups in becoming inspired and motivated to come up for their own rights (Gilligan, 2015) this thesis focuses on the issue of awareness raising, and more specifically, role models.

§ 3. Role Models

A role model is “an individual who inspires through personal contact and observability [and] can personify behaviours that build self-esteem, most rooted in relationship” (MacCallum & Beltman, 2002). As displayed in figure 4, certain exemplary features of a person can result in certain role model effects. For example, when a person is hard working and hereby inspiring to others, this can be seen as a role model feature. Mere exposure to role models is expected to have less impact than a situation in which there is personal contact with role models. It is assumed that exposure to a role model is the first step towards the final effect, which is confidence gaining and an increased self-esteem. In between features and effects, there are processes that explain how role models realise certain effects. In this research there is a focus on all three aspects (see figure 4) although the main research question is primarily about the process.

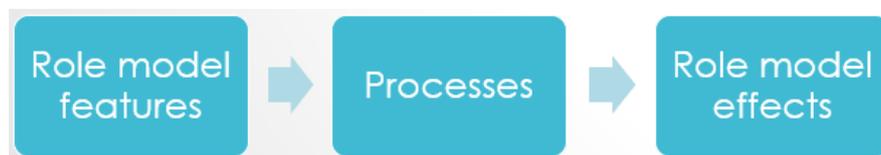


Figure 4: role model features can lead to role model effects through certain processes.

Who can be a role model? There is an enormous variety of (non-)fictional characters or people that can be considered a role model. An athlete that turns into a celebrity by its performances (Payne et al, 2014) a religious prophet that serves as a good example for its followers or a parent that makes his/her baby mimic behaviour can all be seen as role models. They are seen as an example for others and worthy of imitation, mostly through personal contact and stimulation (Acedo et al, 2011). A role model can be in the same socio-economic position as the admirer, but can also be on a different hierarchic step of the social ladder. Role modelling is, as a matter of fact, not merely restricted to individual beings. Homogeneous subcultures or groups that pursue a specific dream are possible of changing or strengthening the frame of reference of (potential) members. Needless to say, not every member of such a group is a role model, but both their members as well as outsiders may see certain individuals as role models. In this sense, everyone has the potential to become a role model.

Differences in how role models are both created and received may depend on the cultural context, though. In many cultures gender (Techbridge, 2013), age, tribe or race may play a role in the acceptance or rejection of role models. For example, in some cultures women will less likely be seen as role models by men because of gender differences, while in other cultures a village elder is a role model just because of his/her respected age. What is important to highlight is that a role model is not similar to a *mentor*. The differences between the two are that role models do not need long term, personal contact to reach desired effects and that the actions of a mentor are deliberate, which does not count for a role model (Payne et al, 2014). Since every role model acts differently and has a different elaboration on the mindset of the potential admirer, one distinguishes four types of prototypes. *Classical heroes* have a

high cultural and historic value that is famous on a national scale (e.g. Gengis Khan). *New heroes* represent the ones that have been underrepresented and hereby claimed their spot in history books (e.g. Nelson Mandela). *Moral exemplars* (or *quiet hero's*) gain their respect through courage like joining the military or protesting against whale hunting. The final prototype is the *role model* itself (MacCallum & Beltman, 2002).

Role models need to possess certain features or characteristics in order to become inspirational or admirable for others. Admiration is, however, a very personal emotion that changes from person to person. What might be seen as exemplary for one PWD, can be seen as a negative attitude from another PWD's point of view. Apart from unaffected factors such as age, gender or ethnicity (Zirkel, 2002) there are several other features that can define an influential person as a role model. These characteristics can be naturally intertwined within the personality or taught externally, for example through teaching (Elzubeir, 2001). To this extent it is important that the role model has the *commitment* to serve its community (Price-Mitchell, 2011). If there is no sense of passion or a lack of morale to be a role model, the role model process will strand. A role model is known to possess a *positive* attitude and a *clear set of values* that can be seen as inspirational. This is considered as one of the most important features since many PWDs do not experience many positivity in their situation and do not experience attitudes that can be imitated and eventually internalised. What is finally needed to become a role model is the *ability to overcome obstacles* (Price-Mitchell, 2011). Especially if the role model is a person where others can identify with, it is important to express perseverance that resulted in a success story.

What comes next are the processes that function as the bridge between features and effects. After the stimulation has taken place by the role model, it is up to a mentor to further guide and coach this person. There are roughly three processes that form the chain between role model features and role model effects. In order for coaching to be successful, a mentor first needs to be *worthy of imitation* (MacCallum & Beltman, 2002). This means that the features of the mentor need to be exemplary so that others will mimic his/her thoughts or actions. Through these imitation-worthy features a PWD can possibly be *inspired* if he/she starts to believe that a similar success can be equalled (Lockwood, 1997). The imitation of inspirational role model features can finally lead to an *alternative vision of the future* because personal circumstances are more likely to change (Potthof & Elbers, 2016). An alternative future is then possible to further instigate the previously mentioned inspiration and motivation for a PWD.

Now that we know what critical features are of role models and how these produce positive effects, it is important to look at the effects that role models can have. Sometimes the role model is aware of the (unwanted) effect that it has on its admirer(s), but this is not always the case. Role models can cause the admirer to become motivated or inspired to change its own personal behaviour, mentality or attitude towards a certain situation. However, according to Lockwood & Kunda (1997) it is assumed that influential people such as superstars can also have a demoralizing effect under certain circumstances. In this context, the conception that role models merely have positive effects is questioned. One positive effect that has been associated with role modelling includes exposure to a *success story* or *alternative future* (MacCallum & Beltman, 2002). This can next raise the *awareness* among PWDs. Through the

role model they gain the knowledge that they have possibilities or opportunities to fully participate in their community. The awareness of this alternative future may have the effect of *stimulating confidence* (Rossi, 2015). When a role model inspires a PWD because of his/her success story, this might have a positive effect on the confidence of that person. What comes next is the *setting of achievement-oriented goals* (Zirkel, 2002). Many PWDs have the tendency to think steps ahead and set personal goals that are not feasible due to the social barriers that they face. By sharing personal experiences role models can stimulate the PWD to make smaller steps towards his/her final goal. These smaller goals give a higher chance of experiencing success, which can further increase motivation and self-esteem to reach their final goals.

§ 4. Role Model Programmes

As role models can have positive effects, programmes have been designed that strategically use role models to reach certain effects. In the broadest sense, a role model programme is any kind of programme that deliberately uses role models to realise effects (MacCallum & Beltman, 2002). In a more narrow definition, for a programme to become a role model programme it should contain individuals whom young people experience as important, inspirational and/or supportive. Multiple possibilities exist in the diverse range of role model programmes. Examples of these programmes include guest speakers, workshops by consults, drop-in centres and long term mentoring programmes. After all, role model programmes differ in their intensity and intentions (MacCallum & Beltman, 2002). Role model programmes vary considerably and can have different aims. While one role model programme might focus on stimulation of general education accessibility, the other programme concentrates on resilience training and other forms of personal development.

When examining the literature on role model programmes in more detail, it is clear that conceptual clarity is an issue. This is due researchers using different definitions of role models and related concepts such as 'mentor' and 'awareness'. Despite the lack of conceptual clarity, most studies do find that role model programmes can produce a range of positive effects. For example, a role model programme for people suffering from cancer pains resulted in immediate, significant improvement in attitudes and knowledge after the programme (Janjan et al, 1994). Another role model programme for girls in technical studies claimed that role models in the programme were better prepared and had more meaningful interactions with participants (Techbridge, 2014). Research on role model programmes dealing with disability issues, including those in the global South, is currently non-existing.

A multitude of theoretical assumptions exist about how role models work in relation to the amount of interaction, role model types and role model programmes. MacCallum & Beltman (2002) identify four theoretical perspectives on role model programmes (see figure 5).

Perspective:	Programme Focus:	Role Model Type:	Interaction Intensity:	Example:
Sociological	Exposure to alternatives or success stories	Successful people that have faced similar challenging circumstances	Limited	Imaging of a successful marginalized person without feedback possibilities
Social Cognitive	Observational learning including feedback	Non-traditional adults	Some	Programmes that tend to develop specific skills
Sociocultural	Individuals construct meaning for themselves through interaction with others	Teachers, adults, peers	Extended	Experienced one guide and support the less experienced ones
Humanist	Caring relationship	Parents, adults, peers, mentors	Extensive	Long term mentoring by an experienced person for a unexperienced person

Figure 5: perspectives on role model programmes (MacCallum & Beltman, 2002).

In the *sociological* perspective, the degree of interaction is limited and participants will merely be exposed to speeches, interviews or forms of audio-visual (social) media. Medal ceremonies at the Paralympic Games broadcasted by mass media can be named as an example of this framework, in which athletes or other media personalities serve as role models. When there is a bit more interaction between the role model and the participant in the shape of a (famous) guest speaker, this is known as the *social cognitive* perspective. Interaction between the role model and the participant in the programme is possible, but still not very intensive. This becomes more extended in the *sociocultural* perspective. One-time interactive workshops, clinics and shelters led by professional caretakers for a long term effect and hereby have a different approach than the previous perspectives. Youth group programmes use series of mentoring workshops in which also peers, parents and other adults are involved. With individual support, this *humanist* perspective tends to create a sustainable personal relationship with the participant. Overall, the table shows that role model programmes differ in terms of who the role models are, how these role models are supposed to produce positive effects and what the degree of interaction is between role models and target groups.

What needs to be taken into account is that these four perspectives can overlap one another. Moreover, they are based on experiences with programmes that took place in a Western context. This raises the question whether (elements of) the above framework are also applicable in non-Western contexts and Zambia in particular.

§ 5. Sub-questions

Based on the above, the following sub-questions have been formulated:

- 1. What have been the goals, activities and results of the Young Voices programme in Zambia?*
- 2. What have been the characteristics of the role models in the Young Voices Programme?*
- 3. How, through what processes, did these role models produce effects?*
- 4. What have been the role model effects of the Young Voices programme?*

3. Methodology

This chapter focuses on the research methods that were used to collect data about role models in CHSZ's YV programme. The first section briefly discusses issues of data collection and analysis. This is followed by sections about the research conditions and the interviewees. The chapter will end with a section about possible limitations that might have affected the outcomes of this thesis research.

§ 1. Data Collection

In order to answer the four sub-questions and eventually the main question, a qualitative case study has been performed on the Young Voices (YV) programme in Lusaka, Zambia for a total of twelve weeks. The data collection took place between 12 February and 30 March 2018. A qualitative study was thought to be the most effective for this topic, since the actual case deals with members of a marginalised group that were expected to have some intense, personal and sensitive stories to share (Potthof & Elbers, 2016). Also the number of informants was expected to be too small for a quantitative research.

The desk research mostly took place at the national office of CHSZ in Lusaka. Most research data has been collected in an informal setting both inside and outside office hours. Informal small talk and participating observation with staff members have been used to gather data. Field notes have been taken during informal meetings, if possible from a participatory point of view. The YV programme started in October 2016 after a pilot programme that took place from 2009 until 2012. This means that the research took place in an advanced stage of the programme. Necessary information about the situation between October 2016 and the present was consulted through desk research of CHSZ's documentation, which was provided by a local research supervisor and the programme manager of CHSZ. The research focused on the YV groups in Lusaka and Kafue and field data collection took place in the two respective towns with YV members and relevant stakeholders.

Data was collected from the informants by semi-structured interviews and focus groups, because the nature and level of structure of these methods are generally seen as flexible and responsive (Arthur & Nazroo, 2008). Since this research was expected to be exploratory and designed to discover emotional development of PWDs, these unstructured methods were seen as the most effective methods for data collection. The strength of this method is that the objective is not only to answer the predetermined questions, but also to start discussions between the participants (Della Porta, 2015). By this way they present their own view, but also hear the experiences of others (Finch & Lewis, 2008).

Respondents were divided into five groups: YV members, potential role models within YV, YV staff members, PWDs that were not involved in YV and non-disabled stakeholders that were not involved in YV either. Each interview or focus group was based on a semi-structured interview guide, one for every specific target group. This semi-structure was chosen to make the interviews less formal and by this way invite the informant to come up with more information. Also it was thought to be a useful methods because it directs the respondent to topics that are related to the study (Della Porta, 2015). Their answers are also the most likely to understand the sense that actors give to their actions.

The 5 different interview guides have been revised and supplemented several times as the research progressed. These adaptations came in the shape of revising certain questions and adding or removing certain elements that were considered missing or unnecessary. After an introduction, the interview guides started with opening topics, since this eases participants and gives information that can be important in a later context (Arthur & Nazroo, 2008). Because of the personal and potentially emotional nature of the topics, it was also seen as an opening that showed respect for and interest in the situations of the participants (Legard et al, 2003). Next were actual questions about characteristics of role model, their own role model(s) and the effects of this role model(s) on themselves. This was all done in everyday language and ended with a positive note about future perspectives, points of improvement or words of advice.

In addition to the interview guides, an interview consent form was handed out to each informant before the start of each interview. In this form it was explained what the interview was about, what the informant could expect and what his/her rights were. If an informant had a visual impairment or turned out to be illiterate, the form was read aloud to him/her by the researcher or interpreter. In case photographs were requested, a similar photo consent form was used to ask permission.

Data has been collected from a total amount of 21 respondents. The data collection existed of 19 interviews and one focus group session with 2 PWDs. This focus group session, as well as 8/19 interviews, took place together with fellow researcher Lindsay Vogelzang, whom was also collecting data on behalf of Breaking Down Barriers. This has been done to increase time efficiency, to profit from each other's data and to make additional notes while the other person was focusing on the informant. However, each researcher only asked the questions that he/she designed him/herself. The length of each interview differed between 20 minutes and 1,5 hours depending on the answers of the informant. The interviews and focus groups with the fellow researcher took longer than the one-on-one interviews.

During all interviews a digital voice recorder was used to record the answers of the informers. All interviews were analysed by listening back the interviews at a later moment. This was done to discover new information or to elucidate specific replies that were previously unclear. After finishing the interviews, the audio files have been transcribed by Zambian contacts that have not been involved in the YV programme or CHSZ whatsoever. Other consulted sources have been analysed by desk research and field notes. Names of informants have been anonymised by creating fictional first- and surnames for each informant. The real names of the informants are known by the researcher(s) only.

§ 2. Environment and Conditions

Some of the interviews in Lusaka took place at the national office of CHSZ. This is the location where YV members, YV staff and some potential role models were interviewed at. This location was chosen because it was the workspace of the researcher and because the environment is friendly for PWDs in terms of accessibility. A few interviews were taken in a closed office room, others were taken in an office room where also the programme co-ordinator was working. The environment was quiet and had little to no distractions that could

affect the answers of the informants. The major downside of this location is that these informants had to come to the office of the organisation that supports them. This might have led to socially desirable answers because they were afraid to criticise CHSZ. The thought behind this fear is that critique could possibly lead to a stop of CHSZ's individual support. Although most interviews took place without physical proximity of YV staff members, there is an eventuality that the location might have affected data validity for these interviewees.

Two PWDs outside the YV programme were interviewed in a focus group simultaneously at Munalu Girls School (MGS) which had a special unit for students with hearing impairments. This focus group was done together with the fellow researcher. The downsides of simultaneous interviewing were that it was more challenging to focus on one informant and that parroting was more likely to occur. However, the positive side was that the two informants were in the position to complement each other's answers. This interview came about with translations performed by a sign language interpreter, whom translated back to English. Some terms and questions turned out to be difficult to translate into sign language and vice versa. That was why some questions needed to be simplified or re-asked in order to create mutual understanding between the informants and the researchers. The interviews were taken in an empty classroom where distractions were limited. It was also considered to be a safe environment for the informants to talk, since the researchers were the visiting party and environment that was familiar to the informants.

Another two interviews took place at the respective homes of two informants. These informants were facing a transportation barrier due to their disabilities. Transportation to the national office of CHSZ was too expensive and time consuming for them. That is why the researcher proposed to meet in their own private surroundings. The side effect of this decision was that the researcher could also see the situation in which the PWD was living, which created some significant context. Also the informant was possibly more at ease because the environment was familiar to him/her, which could have prevented distorted answers because of nerves or tension. Both interviews took place in the living room, which made it an informal setting in which the informant had no expected environmental speech restrictions.

In Kafue, all of the interviews took place at Twatasha Community School (TCS), a disabled people organisation (DPO) that is a partner of CHSZ. This is where the active members of YV in Kafue came together because most of their trainings also took place here. Also the director of TCS was the co-ordinator of the YV group in Kafue. Since most of the school buildings were fairly noisy and rich on distractions, the interviews at this location took place near the neighbouring boarding school which was more quiet. During one of these interviews there was assistance of an interpreter since the informant's level of English proficiency was insufficient.

One interview in Kafue took place at Kasenje Primary School (KPS) because the informant, an employee of the Ministry of Education (MOE) worked there. This interview took place in a quiet classroom far away from the rooms where classes took place, so there was no chance of being disturbed.

§ 3. Interviewees

The primary group that was interviewed were the *members of YV* in Lusaka and Kafue. Not all of the YV members in these two groups were that active though, mostly because of high transportation costs that prevented them from participating in trainings and meetings. That is why a total of 5 active and more mobile YV members have been invited by CHSZ and all of them agreed with participation in this research. This is possible to have resulted in a bias, because these members already had a higher potential than other members of YV. Four of the informants had a physical disability, one of them had both a physical and an intellectual disability. This intellectual disability of this person had to do with a deficient memory and slow responsiveness. In case a response was not very clear or very extended, the answer of this informant was summarised aloud and confirmed or denied by the informant. There were 3 women and 2 men in this group and since women are considered to be more vulnerable than men it would be interesting to see if there were gender differences in who is considered a role model. For example, it is possible that female PWDs benefit more from female role model than from male ones. Vice versa it could also be that men are less likely to see female PWDs as a role model due to the Zambian cultural context. The objective of these interviews were to find out if role models were present in the YV programme and if so, what kind of role model effects were present.

Each interview started with an introduction to the research. In this introduction the reason for the interview and the estimated duration were explained. Also it was clarified that false answers do not exist and that the interview was on a voluntary basis. Questions could be skipped if the informant was not comfortable about them and it was explained that the name of the informant would be anonymised. Unless the informant had any remaining questions, he/she was asked to introduce him/herself to get to know a little bit more about his/her background. After this informal introduction, a further explanation of the person's disability was requested to get a better view on the barriers that the informant was facing. Following was a question about how the informant got involved in YV and a general question about what characteristics a person must have to become an 'example' for others. The term 'role model' was left out deliberately because this term is more significant than just the term 'example for others' and could have influenced the informant's answer. Next there was asked which person the informant saw as good example for him/herself and why. In this question it had to become more clear what characteristics a role model has, so the following question was about the effects of this person on the informant. If it was not clear what the role model's gender or age was, this was asked after the informant's response. Also the intensity of the contact between the informant and it's role model was questioned if this did not became immediately clear. The closing questions of the interview involved personal future expectations, points of improvement for YV and advice to other PWDs in dealing with the negative stereotypes about disability.

In addition to the interviews with members of YV, a total of 5 persons that were seen by CHSZ as (*potential*) *role models* for PWDs have been approached to participate in this research. Three of them were active members of YV that have been participating in fellowships that were organised by CHSZ. These three members were suggested by CHSZ because they were

said to be both active and influential for other PWDs. The other two potential role models were engaged through the local supervisor Mr. Thomas Mtonga, a lecturer at the University of Zambia (UNZA). One other role model was engaged through the YV group in Kafue, where this person was the group's co-ordinator. Three of the informants were older than 30 years old and thus it was interesting to see if these people were more likely to be a role model because of their age. Interestingly, all of the potential role models that were interviewed were men. This rose the suggestion that men are more likely to be seen as role models in the Zambian cultural context, although it could also have been a co-incidence.

The interviews with potential role models had two objectives. Not only the effects of role models were explored, but also to what extent the YV programme helped to create an environment in which these informants were shaped into role models for other PWDs. The substantive questions about role models were preceded by the same explanation of the interview itself and introduction question used for the regular YV members described in the previous paragraph. The first substantive question was about how the person had become a 'leader', as CHSZ calls the influential YV members. Next it was asked how the informant learned to act as an 'example for others', in order to research the creation and strengthening of role models in the YV programme. The next question was similar to one of the questions to the YV members: who inspires the informant to be a 'leader' and why? In other terms: who is the role model of the potential role model and what are its effects? Again the age, gender and contact intensity were discussed. Just like in the interviews with YV members, the interviews were closed with questions about the future perspective, points of improvement for YV and words of advice to other PWDs.

Not only PWDs within the YV programme have been approached for this research, but also two *people that do not have a disability* and whom are not involved in the YV programme. First an interview was held in Kafue with a person who is both a primary education teacher and an employee of the Ministry of Education (MOE). She was encountered during a monitoring session by the MOE at Twatasha Community School (TCS) where the interviews in Kafue took place. As an employee of the MOE she was expected to have useful details to share about disability in Zambian education as well as access to MOE data that could be used in the research. The interview took place several weeks after the first meeting in Kafue. The other person in this group of interviewees was the senior rehabilitation officer at ZAPD. He was first met during a meeting at the ZAPD office and later agreed to participate in the research. He was through to be an significant informant because of his position and because he is working at a DPO as a person without a disability. The objective of these two interviews was to discover what kind of role models persons without a disability in Zambia have. Both of the informants worked with PWDs, but they did not have a disability themselves.

At the start of the research, two *YV staff members* were interviewed. These staff members were the programme co-ordinator of YV and the programme manager of CHSZ. The objective of these interviews was to discover the goals, activities and results of the YV programme and to clarify to what extent there has been creation and strengthening of role models in the programme. These people were asked to participate because they have initiated the YV programme and have been involved in the development and execution of the programme. To

discover more about the practical execution of advocacy trainings in YV, the programme coordinator was interviewed and asked about the people that played a leading role in the trainings and thus could be seen as a potential role model for the YV members. The other informant was the programme manager and intended director of CHSZ, an inspired person that has been involved in the YV programme in both a theoretical and practical way. Next there was asked to this person about the content and goals of advocacy trainings for YV members, role model creation during these trainings and the mentoring aspect that was discovered by analysing the work of Rossi (2015). This was asked to get to know if this mentoring aspect was still present. Both of the informants also have been asked about their own role models and what kind of effects these role models have on them in general. Because one of these informants had a disability, it was interesting to see if there was a difference in role models and role model effects between a staff member with a disability and without a disability. Finally the staff members were asked about future expectations and points of improvement for the YV programme.

§ 4. Learning Event

After the interviews were held between 12 February and 23 March 2018, the preliminary findings of the research were presented to and discussed by a wide range of stakeholders during a one day learning event at a hotel in Lusaka on 30 March 2018. On this day several YV members and staff of CHSZ were present, as well as partner organisations of CHSZ, lecturers of UNZA, the Dutch and Zambian research supervisors, local media, fellow disability researchers and a graphic designer that made an infographic of the presentation. After the presentation of the preliminary findings, a central question was discussed. The question that was discussed was about how role models can be used in disability advocacy. This was discussed in an informal didactic approach known as 'World Café'. The power of this didactic method is that it provides a large-scale discussion that draws on the wide range of answers given by the participants (Carson, 2011). To make this work, the participants were divided into 5 groups. Each group was appointed one 'table host' in advance by the organisation. This person was responsible for leading the group discussion and writing down the findings, opinions and feedback of the session on a poster. After the discussion ended, these table hosts remained seated and the regular participants switched tables to start a discussion in a new group setting. This was done to get as many information as possible from the participants; group composition was expected to influence the outcomes, so this was why there were two sessions in two different group compositions. Next the table host informed the new group about the findings of the group that (s)he hosted previously. After the second session ended, the final findings were presented by each table host to all participants on the basis of the poster. During the presentation of the group session results, the graphic artist drew a infographic about the outcomes and feedback. After these presentations, there was space to comment on both the outcomes of the sessions and the learning event as a whole. The infographic that has been made during this event can be found in the appendixes (p. 47, 48).

The phases, objectives and time course of the research have been schematically shown in figure 6.

Phase:	Content:	Method:	Location:	Time span:	Informants:
1	<ul style="list-style-type: none"> • Reading disability literature • Creating consent forms and interview guides • Analysing CHSZ data. 	<ul style="list-style-type: none"> • Desk research 	<ul style="list-style-type: none"> • CHSZ National Office, Lusaka. 	January 2018	-
2	<ul style="list-style-type: none"> • Interviews YV staff 	<ul style="list-style-type: none"> • Semi-structured interview 	<ul style="list-style-type: none"> • CHSZ National Office, Lusaka. 	February 2018	2
3	<ul style="list-style-type: none"> • Interviews YV members Kafue 	<ul style="list-style-type: none"> • Semi-structured interview 	<ul style="list-style-type: none"> • Twatasha Community School, Kafue. 	February 2018	3
5	<ul style="list-style-type: none"> • Interviews potential role models 	<ul style="list-style-type: none"> • Semi-structured interview 	<ul style="list-style-type: none"> • CHSZ National Office, Lusaka • Home location • Twatasha Community School, Kafue • Munali Girl's School, Lusaka 	February & March 2018	5
6	<ul style="list-style-type: none"> • Interviews YV members Lusaka 	<ul style="list-style-type: none"> • Semi-structured interview 	<ul style="list-style-type: none"> • UNZA • Home location 	February & March 2018	2
7	<ul style="list-style-type: none"> • Interviews non-PWDs 	<ul style="list-style-type: none"> • Semi-structured interview 	<ul style="list-style-type: none"> • Kasenje Primary School, Kafue • CHSZ National Office, Lusaka 	March 2018	2
8	<ul style="list-style-type: none"> • Preliminary findings 	<ul style="list-style-type: none"> • Analysing interview recordings • Reading interview summaries • Field notes • Connections • Conclusions 	<ul style="list-style-type: none"> • CHSZ National Office, Lusaka. 	March 2018	-
9	<ul style="list-style-type: none"> • Learning event 	<ul style="list-style-type: none"> • Presentation • World Café 	<ul style="list-style-type: none"> • Cresta Golf View Hotel, Lusaka. 	March 2018	-

Figure 6: overview of the research phases.

§ 5. Possible Limitations

CHSZ was the gatekeeper during this research since the organisation (co-)provided housing, contacts, local supervision and informants. The downside of this position was that the researcher depended on the organisation that was being researched. Also the relationship between the researcher and the organisation was very personal. To this extent the relationship with CHSZ was not neutral and this might have affected the research results. Also in terms of interviewing informants, the CHSZ national office was not a neutral environment. Criticising CHSZ could have been difficult for informants if the interviews took place at the national office in Lusaka, since the organising people were in the direct surroundings. To prevent them from hearing critique, the informants could have remained silent about his/her actual opinion because they did not want to disappoint the ones that helped them in the YV programme. Since some of the informants also criticised CHSZ during the interviews, this is unlikely to have been the case, though.

Another limitation was a cholera outbreak in Lusaka that took place during the stay of the researcher. Although cholera outbreaks are fairly frequent during the rainy season, this year's outbreak was more severe. This made the Zambian government decide to close down infections spots like schools and markets. Since most of the interviews took place at educational institutions, it was not possible to start interviewing PWDs for the first 3 weeks of the researcher's stay. This caused a lot of time pressure that might have affected the quality of the interview guides and the interviews themselves. For this reason the amount of interviewed PWDs was also lower than initially intended.

The Ma in African Studies includes an internship that is related to the research topic of the student. This is why a 6 weeks internship on inclusive education was to be done alongside the data collection for this research. The downside of this internship is that it happened often that information flows intermingled, causing confusion about which data belonged to which part of the studies. As far as possible this was prevented by first finishing the internship in order to give full attention to the research in the second half of the stay.

Finally the background of the researcher was not academic and that is why the research skills of the researcher were somewhat limited. This was experienced as challenging during the creation of interview guides and the data collection since methodological knowledge was lacking. To address this issue, literature about methodology was read and the work of the fellow researcher Lindsay Vogelzang was observed and sometimes imitated. The visit of the Dutch supervisor to Zambia was experienced as fruitful since his insights created a clearer guideline to analyse data and write the eventual thesis.

4. The Context of Disability in Zambia

To gain a better understanding of the social, cultural, legal and environmental circumstances for PWDs in Zambia this chapter explores the cultural and legal context in which disability stereotyping in Zambia takes place. The first part of this chapter exists of an exploration of disability prevalence in Zambia, followed by a paragraph about disability legislation in Zambia. Next there will be an explanation about disability in the context of Zambian culture and what effects this has on the accessibility of PWDs in the country.

§ 1. The Prevalence of Disability

The republic of Zambia has about 16 million inhabitants (Central Intelligence Agency, 2017) of which 2 million people live with one or multiple disabilities (Banda & Kalaluka, 2014). According to official statistics by Banda & Kalaluka (2014) about 2,4% of the Zambian population is a woman living with one or multiple disabilities. This comes to about 40.000 women. For children, this amount has been set to 1,6% or 32.000 children with disabilities. However, it is expected that the official rates are way higher because many PWDs are not registered because they are hidden from society. What is a problem in general is that clear statistics on disability in Zambia are missing.

Disabilities in Zambia come in many different shapes and earnestness. First there are visual disabilities, which expands from the necessity to wear glasses to complete blindness. Although the reasons for blindness vary, a paper by Dang (2015) stated that measles damage the eye and may result in a loss of sight or even complete blindness. It is expected that these rates have dropped since the introduction of large scale vaccination programmes in later decades. Hearing impairments, like visual impairments, have multiple causes in the Zambian context. One specific group that is known to deal with hearing difficulties or complete deafness are miners. This is because they are or have been exposed to drilling sounds, rock blasting and other continuous noise (Obiako, 1979). About 27,000 children have hearing loss or no hearing at all, making them the 3rd biggest group of children with disabilities in Zambia (Ministry of Education, 2008). One of the most frequent physical disabilities in Zambia is cerebral palsy, which causes paralysis, speech problems and motion difficulties. Many of these disabilities are related to the presence of malaria in Zambia, since the malaria parasite affects the foetal brain development causing physical, hearing or speech disabilities (Manyike et al, 2015). The final disability group is people with an intellectual disability. They are seen as one of the most vulnerable disability groups because their learning capacities are low; many of them are not expected to make any progression in e.g. education. That is why programmes aim for reducing stereotypes about people with intellectual disabilities by integrating them into mainstream schools (Nabuzoka & Rønning, 1997).

§ 2. Disability in Zambian Culture

The ignoring, neglecting and abandoning of PWDs is historically not linked to specific (sub)cultures; behind disability marginalisation in every culture there are complicated practical and psychological factors that play a role in disability stereotyping (Cheshire Homes Society of Zambia, 2018). However, to understand the root causes of discrimination of PWDs

in Zambia it is important to look at the cultural context in which the marginalisation of PWDs takes place.

What causes this fear and shame are misconceptions concerning the causes of disabilities (UNDESA, 2017). Disability cause stereotypes based on both fear and discomfort (Coleman et al, 2014) which are hereby transmitted to the PWDs themselves and eventually the community. The movements and/or behaviour of PWDs, depending on the kind of disability, can be unpredictable, unexpected or unknown to others. Moreover, they can create a sense of helplessness and embarrassment among bystanders. The sense of fear is further strengthened by the belief that disability and its unexpected movements are caused by Satanism, sinning, a bad omen or a curse by a supernatural being. It is said that because of this viewpoint the subconsciousness of people is still filled with negative attitudes towards PWDs (Simui & Mtonga, 2014).

Disability in Zambia is known to be a cross-cutting issue that becomes more pressing when a PWD is also part of another vulnerable groups. Being a part of multiple vulnerable social identities is known as intersectionality, as also explained by Pal (2011). Woman suffering from a disability are disadvantaged by their gender because there is no equal treatment between men and women. There is speculated that parents tend to shield a female PWD more than male PWDs, offering them less chances to interact with other community members in comparison with their male counterparts. This protective attitude of female PWDs results in lower degrees of independence and social acceptance and an increase of poverty. Other examples of intersectional vulnerability include PWDs that are infected with HIV, children with disabilities and geographically subordinated PWDs.

§ 3. Accessibility

Despite economic progress over the past few years, poverty in Zambia still manifests itself in the shape of high living costs and undersized opportunities to access the job market, healthcare, education and other social services (Chondoka & Machila, 2011). However, there is no clear interpretation of these government policies. Although a “special focus” in the social protection programme is on disability and disability “will also need to be addressed” in health investments, there are no hands-on appointments, promises or measures present in the Seventh National Development Plan (2017). Therefore it is questionable if the healthcare progress in Zambia mentioned in this document also refers to disability morbidity and policy.

In the Disability Act (2012) there is a clear section considering access to healthcare for PWDs. Part V, Division 2 of this act states that PWDs will be provided with the same equal range, quality and standard of health services as able bodied persons. Besides, these (free) services by professional health workers are said to be close to the community and based on a non-discriminatory principle (Disability Act, 2012). However, the practical execution of these policies are lacking. Situations of poverty and unemployment which many Zambian PWDs are in results in unaffordable medical costs that cannot be paid by own personal contributions. Especially for PWDs living in rural areas, high transportation costs obstruct them from getting specialised medical care.

When it comes to education, Zambia's first Education Act dates from 1966, two years after independence. This act stated that "the Minister may (...) make regulations (...) providing for (...) the exclusion of pupils from school on the grounds of health" (Laws of the Republic of Zambia, 1995). Although there was no policy for enrolment of PWDs in education, the national enrolment application form included a field in which the parent is asked for "physical handicaps or serious illness" of their child. The existence of this field suggests that children with disabilities were not rejected from education in advance. After the 1990 Education For All conference in Thailand, Zambia adopted a global framework that offers deadlines that are linked to the MDGs. However, the implementation of the Education For All principle was lacking and this resulted in a continuation of disability exclusion in terms of education access. The provision for education for PWDs was further highlighted in the 2011 Education Act. The emphasis in this act was on education for students with special education needs and the monitoring of special education institutions. Also in the 2012 Disability Act intends about education for PWDs are being mentioned. Inclusive education at all levels is said to be provided through environmental adaptations, individualised support and alternative learning adaptation such as Braille and teachers skilled in sign language. Despite the fact that Zambia has experienced positive progression in both health and education" (ZAFOD & CHSZ, n.d.).

The physical impairments of PWDs also affect their possibilities to enter the job market or start working on a career. Negative stereotypes among most employers keep them from hiring PWDs in jobs that they are able to do. Since the 1990s Zambia has experienced a high unemployment rate and this mostly affects women, youth and PWDs (Shamenda, 2012). Since the focus of the Zambian economy is on raw products and the entrepreneurial culture is considered low, it is hard for PWDs to qualify for many forms of physical labour. Despite the existence of employment policies specified towards youth and gender, national employment policies for PWDs are absent and PWDs remain in a marginalised position when it comes to professional opportunities.

5. Role Models in Zambia: the Young Voices Programme

This chapter presents the main research findings. In the next paragraphs there will be an explanation of the researched YV programme by CHSZ. The sections examine the Young Voices programme through the lens of role models. It seeks to clarify the importance of role models in this programme and whether, and how, they produced any kind of positive effects.

§ 1. Cheshire Homes Society of Zambia and the Young Voices Programme

The *Cheshire Homes Society of Zambia* (CHSZ) was founded in 1973 and is part of the international organisation of *Leonard Cheshire Disability* (LCD). The goal of this non-governmental organisation is to improve the quality of life for children and youth with disabilities. CHSZ campaigns for the removal of social, environmental and physical barriers that prevent a full participation of disabled youth in local communities. The work of CHSZ exists of five core functions including education, health, inclusion, work/income and child protection. As a member of the global alliance of LCD it runs nine locations, so called Cheshire Homes, in Zambia. In some cases these Cheshire Homes are being managed by catholic congregations, supported by volunteers. In these Cheshire Homes young PWDs receive support such as vocational training, education, rehabilitation and livelihood support. The national office of CHSZ is located in Lusaka and hosts a programme manager/director, a programme co-ordinator and a financial manager. The financial substantiation is supported by the European Union and donor organisations including the German embassy and a Dutch disability NGO. CHSZ co-operates with other disabled people organisations (DPOs) throughout Zambia. Other parties that are involved with the work of CHSZ are the Ministry of Education (MOE), Zambia Agency for Persons with Disabilities (ZAPD), and the Zambia Federation of Disability Organisations (ZAFOD).

The YV programme was created to make young PWDs advocate for the rights of other PWDs that have no voice and by this way create quality leadership (interview YV co-ordinator Aron Mwape, 28-02-2018). After the pilot project (2009-2012) 5 YV groups of about 30 PWDs were created in the districts of Lusaka, Kafue, Ndola, Livingstone and Solwezi in 2015. The Lusaka group existed of both PWDs and able-bodied youngsters (interview YV programme manager Alex Hachilala, 12-02-2018). These able-bodied members were e.g. DJs, musicians or producers that already had a stage to advocate for the rights of PWDs. The activities of the groups existed of leadership trainings, trainings on disability rights and trainings on advocacy. This was done to prepare them for participating in campaigns and the attending of meetings. This has been financially supported through contributions of the German embassy. Please note that this research did not focus on the pilot project.

YV's most recent and active project (2015-2016) and the focus of the current research existed of two grassroots groups; one in Lusaka and one in Kafue, each existing of about 30 young PWDs in the age range of 16 to 25 years old. The YV groups also contained members that participated in the pilot version (2009-2012). This pilot version was held in multiple countries in which Leonard Cheshire Disability (LCD) is active. These two Zambian groups are the only ones that have been involved in this research. The two groups received 3 days of trainings on leadership skills, speech skills, human rights and advocating (Hamuhuma, 2016) spread over

multiple months in order to strengthen the members as a group and to co-ordinate themselves (interview YV programme manager Alex Hachilala, 12-02-2018). The trainings were used as a way of preparation for advocacy focused meetings with companies (Lusaka group) and wider communities (Kafue group). The trainings consisted of workshops and were facilitated by external consultants that had a wide knowledge on advocacy issues. One of the consultants was a PWD himself and with his knowledge and skills, CHSZ tended to inspire the members of YV to become role models themselves. Workshops further consisted of drama, roleplay and presentations. Topics of the trainings included advocacy, the difference between advocacy and lobbying, policy implementation and information about the different barriers that PWDs experience. According to the interview with YV programme co-ordinator Jacqueline Tembo (12-02-2018) all the YV members were present during these trainings. Finally, there has been a regional meeting organised by CHSZ for multiple southern African countries. This is where the YV co-ordinator of the Kafue group, Aron Mwape, was trained to motivate and inspire the YV members of that group.

YV groups also (tended to) come together during (inter)national events and activities. During these events they explained the barriers that they face and what they themselves and others should do to remove those barriers. This was expressed in the shape of drama, music and poetry. Apart from events organised by CHSZ or external organisations, YV members also (tended to) meet among themselves without intervention of CHSZ. However, this was challenging because transportation was difficult for many members. Travel costs for PWDs were very high and prevented YV members from seeing each other on a regular basis. CHSZ stimulated the groups to meet on a monthly basis, though, and asked members to inform the organisation about what their plans were. By this way, CHSZ gave members room to come up with own ideas for advocacy strategies. The Lusaka and Kafue group were the most active groups and so they were the groups that came up with the most ideas. It appears that not all of the groups were this active. This inactivity is mostly related to mobility issues and high transportation costs for PWDs. However, members of the other groups did keep in touch through social media.

§ 2. Activities by the Groups of Young Voices

Although the goals and trainings of the two Young Voices groups were similar, they operated independently from each other and thus they had handled a different strategy. According to interviews with members of both groups, the focus of the Lusaka group was on employment of PWDs, while the Kafue group aimed for awareness raising within the community (interview YV member Paul Luwawa, 13-02-2018). These ideas were initiated by the members of YV themselves.

The Lusaka group organised meeting with potential employers and informed them about a tax rebate for companies that hire PWDs, hereby stimulating these companies to hire PWDs. The group carried out a survey at these companies and found out that they had very little knowledge about disability issues (interview YV role model Edgar Nyirongo, 05-03-2018) and were unaware of the existence of the UNCRPD. In talking to company representatives, the Young Voices informed them of the tax rebate for employing PWDs (interview YV programme manager Alex Hachilala, 12-02-2018). However, this strategy was considered quite ambitious

and the strategy was expected to have a higher impact than in reality. One of the members of the Lusaka group explained that he learned public speaking skills and currently uses this for his advocacy work (interview YV role model Edgar Nyirongo, 05-03-2018).

The Kafue group paid visits to the community, and more specifically, to parents of PWDs. During these visits, members of YV tried to raise awareness amongst parents of children with disabilities about the importance not to hide their children from both education and the community itself. These visits were accompanied by members of Twatasha Community School, which is a disabled people organisation (DPO) existing of parents of CWDs. The initiative of these meetings was taken by the YV members themselves, though. The co-ordinator experienced his task as a challenge, because the members did not know how to represent the voiceless and because of mobility, financial and motivation issues that hindered the planning of YV meetings (interview YV co-ordinator Aron Mwape, 28-02-2018). Mr. Mwape hereby insisted that the environment was not accessible for the YV members and because of expensive public transport for PWDs. Also because of their low self-esteem, the motivation for them to come together was not very high. For the above reasons, the members did not succeed in getting all the YV members together anymore after the programme ended.

The members of YV not only initiated own activities, but also participated in activities organised by CHSZ. One of the 3 day training that was organised by CHSZ focused solely on leadership skills. Members of YV were seen as the future leaders of Zambia that inspire young PWDs from a younger generation (interview YV programme manager Alex Hachilala, 12-02-2018). The information about what characteristics and skills a leader must have, had been shared with the members. This is why in their respective interviews the YV staff members expected that role models would stand up after this training. Depending on the context, CHSZ believed that all the YV members have the potential to be role models because they have received the leadership training and have acquired skills to present themselves (interview YV role model Edgar Nyirongo, 05-02-2018). Especially “reaching out” to other PWDs is potentially productive for the involvement of other DPOs (interview YV member Jacob Zgambo, 28-02-2018).

After the training, some members of both groups appeared in local radio broadcasts to advocate for the rights of PWDs. Or like one of the YV members explained: “Without talking to [other PWDs] they learn from your action” (interview YV member Moira Jumbo, 27-02-2018). The leadership training was described as the *mentoring part* of the entire training process by YV programme manager Alex Hachilala (12-02-2018). This is because it prepared the YV members to advocate without interference of CHSZ. The mentoring aspect matches with the description of MacCallum & Beltman (2002) that a role model differs from a long term mentor in terms of the increased intensity of personal contact and higher involvement. The mentorship was organised by both CHSZ and the YV members themselves. Mentoring was an addition to the leadership training; it was not a separate element. The YV members that did a fellowship hereby became mentors for the PWDs that had no voice and became an example for others (interview YV member Moira Jumbo, 27-02-2018). In Kafue, the mentoring aspect was realised in co-operation with Twatasha Community School, a DPO that offers inclusive education for both PWDs and able-bodied students. After one of the trainings by

CHSZ the co-ordinator of YV in Kafue became a mentor for the YV members, which is closely linked to a role model.

YV programme co-ordinator Jacqueline Tembo (12-02-2018) stated in an interview that the YV trainings were first of all based on capacity, confidence building, attitudes and behaviour. This was because some of the members were initially shy and could not speak for others. After the training, she stated, they were more able to articulate and their self-confidence had increased. However, one can raise questions about what can realistically be expected in terms of long term impact after a one day training. YV programme manager Alex Hachilala (12-02-2018) explained that it was also the goal of CHSZ to let the members discover their assertiveness and their own potentials in terms of what they were able to do. This was confirmed by YV member Franklin Nakazwe (16-02-2018) who stated that he became an example for others because of the way he handled 'setbacks' through his positive attitude. This positive attitude is related to the confidence building that was part of the YV trainings.

Each of the groups had its own chairperson and its own leadership strategies. The people that played a critical or leading role in the trainings, and hereby served as an example for others, were also the YV members themselves. This was done to create full commitment and passion in order to become inspiring for other PWDs. Among the YV members, leaders stood up after the first training in the shape of chosen chairpersons. During this training, CHSZ staff started a group discussion between PWDs and able-bodied participants. These able-bodied participants were invited to promote the aspect of inclusion and interaction (interview YV programme manager Alex Hachilala, 12-02-2018). In each group a chairperson was chosen in a democratic process. For example, the chairperson for the Kafue group had the task to take challenges, needs and other information to the co-ordinator. Also during drama sessions that were part of the training, YV members gave certain roles to each other, creating interaction between the members that did a fellowship and the others. The gathering of the YV group in Kafue was sometimes supervised by a member of the Zambia Agency for Persons with Disabilities (ZAPD) to check the YV agenda. It was also co-ordinated by the director of Twatasha Community School, who was also seen as a role model by one of the YV members because of his motivational attitude towards the YV members. This person had the task to make sure that there were meetings and activities between YV members.

Furthermore, the YV staff lobbied and advocated for a place for three YV members in so called international *fellowship programmes* and a scientific congress or *symposium*. The selected members have participated in the Young African Leader Initiative Programme (YALIP) in South Africa, the Nelson Mandela Fellowship in the United States and a symposium at the Dutch organisation of *Bond Ouders met Spastische Kinderen* (BOSK) in the Netherlands. These fellowships existed of international meetings including presentations, discussions or workshops to gain new skills about disability advocacy. This was done to let them acquire the skills that were necessary to "be the champions" (interview YV programme co-ordinator Jacqueline Tembo, 12-02-2018) in disability rights when they came back to Zambia from the fellowship they did abroad. The YV members that did a fellowship programme have made the most progression in becoming role models for other members of YV. They were also expected to inspire others and hereby become role models for other PWDs.

§ 3. Role Models and Role Model Features

The interviews with members of YV showed that role models played an important role in the programme. Two types of role models were identified in the project: (1) YV staff working for CSHZ and (2) the YV members themselves.

First, some of the YV staff members were experienced as exemplary and motivating. In the Kafue group, YV co-ordinator Aron Mwape was seen as a “friend, a father and grandfather” of one of the YV members. “When he’s not there, I cannot participate fully. When he is there, everything is fine” (interview YV member Paul Luwawa, 13-02-2018). This co-ordinator motivated the YV member by offering help if the member would not marry soon. From this example there can be stated that the role model feature of this YV co-ordinator was his involvement with the programme. Also for Lushomo Makondo, one of the staff members was inspirational for her. She explained that YV programme manager Alex Hachilala was her role model, because he was involved with PWDs although he did not have a disability himself (interview YV member Lushomo Makondo, 14-03-2018). This involvement was above all special because as a YV staff member, Alex Hachilala had a certain status that made him inspirational. As for YV co-ordinator and role model Aron Mwape, his own role model was also involved with YV. He attended YV workshops with the former director of CHSZ. This person turned out to be the one that changed Aron’s negative attitude towards PWDs. The knowledge of disability that this role model had was seen as an important feature by the co-ordinator. He explained that he was ignorant about disability before the YV workshops, but that he became committed and learned the skills that he needed to become a role model for the YV members (interview YV co-ordinator Aron Mwape, 28-02-2018).

The second type of role models that was discovered in the data collection were the YV members themselves. This especially counted for the YV members that participated in the fellowships. One of the fellowship trainees and founding members of YV, Franklin Nakazwe, participated in the Nelson Mandela Fellowship in the United States and at the BOSK (*Bond Ouders Met Spastische Kinderen*) symposium in the Netherlands. This was realised through CHSZ. Franklin’s experiences and enterprising attitude inspired another YV member, Edgar Nyirongo, who also applied for the same fellowship in the United States after he became motivated for disability advocacy through YV in 2015. When he came back, him was offered a platform to proclaim the gaps between the disability situation and governmental response in the United States and Zambia. Hereby he was able to become a role model for counsellors and other NGOs because he was more able to express and expose himself after the YV trainings. With other words, the exemplary feature gained by this YV member was his ability to speak out.

Participating in the YV programme contributed to becoming a leader for other members, as he said. His ability to speak out made him active on social media in proclaiming his message to his followers and friends, receiving a lot of positive feedback from other PWDs. These positive experiences made his attitude more active, witnessing the home visits he paid and the radio shows about disability that he hosted. This was the result of his ability to see what was possible, the feeling that he could become successful. Fellow YV member Moira Jumbo took inspiration from another member, Edgar Nyirongo. He was inspiring because his disability

did not seem to affect him and because he was advocating independently without CHSZ support. The charisma of YV role model Moira Jumbo motivated her to study hard, to finish her course and to be independent (interview YV member Moira Jumbo, 27-02-2018). It became clear that CHSZ did not yet get the chance to physically bring together the YV members that did a fellowship programme with the other YV members. This was due to a lack of resources. It was a future plan to bring the fellowship trainees and the other YV members together in order to share information, skills and knowledge. This was said to be important because these 'leaders' were equalised with role models (interview YV programme manager Alex Hachilala, 12-02-2018).

For one member in the Kafue group, it was already motivating enough to just meet other PWDs in the YV group (interview YV member Natasha Chipasha, 13-02-2018). Natasha also explained that her role model was another member of that YV group, Paul Luwawa. The interpreter explained that these two members encouraged one another and talked on the phone every day. By this way, these PWDs were involved with each other and became role models just because they have been brought together as a group in the YV programme. The will by these role models to assist others was mentioned as an exemplary feature by the YV members. These role models have been supportive for the YV members and were willing to invest time and effort in them.

Briefly summarised, this study identified the following features of role models. First, several of the role models had considerable knowledge related to issues of disability. This knowledge varied from knowledge about different disabilities to accessibility issues and legislation. When a person is charismatic, he or she was more likely to be experienced as a role model as well. When the appearance of a person was confident, eloquent and approachable, members of YV were more likely to look up to this person. Especially when a charismatic person was also able to speak out there was a higher chance of being experienced as a role model. Another feature that was experienced as exemplary was an entrepreneurial and pro-active attitude. This was derived from the fact that many interviewed YV members found it important that their role model was educated and/or employed. Involvement of a person in the situation of a member was also considered to be a very important feature in role modelling, since this gave the members a sense of empathy by other. Finally, the staff members of YV did not only have knowledge about disability, but also a certain societal status that made an impression on some of the YV members. This was related to the function they fulfilled at the YV programme or CHSZ respectively.

§ 4. Role Model Effects

After analysing the semi-structured interviews and informal conversations with the staff and members of YV, four different positive role model outcomes and underlying mechanisms were discovered. Regarding the outcomes, the research shows that role models can (1) address the negative self-esteem of youth with disabilities, (2) stimulate their pro-active attitude, (3) strengthen their ability to speak out and (4) enhance group solidarity. This study found that these outcomes are realized through indirect engagement between role models and disabled youth (through observation) and direct engagement (through teaching and feedback).

First, inspired by the success stories of and experiences with role models in the YV programme, YV members to a certain extent have revised their negative view on PWDs and as such themselves. Through observation of both the staff members and the YV members that did a fellowship, they learned that also PWDs can become successful people with a certain status. With other words, YV members gained self-esteem because they became able to imagine an alternative future for themselves through indirect contact with both role model groups. This was the case for example for member Edgar Nyirongo, who discovered his capabilities in speaking out after the fellowship and YV trainings.

Furthermore, by being in direct contact with YV staff and other PWDs within the programme, the members revised their own negative self-image. Throughout their lives they always learned that they themselves were to blame for their own situation and the misery it has caused. The role models from the CSHZ taught them that it is the environment that makes them disabled instead of thinking that the marginalisation was their own fault. After her participation in YV, member Moira Jumbo told that she wanted to see changes in her environment, for example in the way houses in Zambia were built (interview YV member Moira Jumbo, 27-02-2018). It is very likely that this statement was influenced by a YV staff member, since disability by the environment was one of the topics in the YV trainings.

The second outcome is that role models in the project seem to have contributed to YV members adopting a more pro-active attitude. Through observation of the YV members that did an overseas fellowship, they are more able to believe that they can make something of their own lives. The fellowship trainees motivated the other YV members to take responsibility for their own lives and those of others. This responsibility was felt by fellowship trainee Franklin Nakazwe, who stated that after meeting another fellowship trainee, he felt a sense of responsibility that he needed to become “an active participant in creating positive change” (interview YV member Franklin Nakazwe, 16-02-2018).

A pro-active attitude was also stimulated by the role models who made an effort to motivate and encourage YV members to change their own lives and those of others. This encouraging occurred partly informally, but also during the formal trainings, for example on entrepreneurship, that were part of the YV programme (interview YV member Jacob Zgambo, 28-02-2018).

Third, from the role models YV members learned how to speak out regarding certain issues. By observing the role models speaking out in public, YV members learned out to speak out for themselves and also for other PWDs that have no voice. This aspect of the YV trainings was

highlighted in the interview with Natasha Chipasha, one of the YV members in Kafue. She stated that she met with other YV members every month in which they talked about the hiding of other disabled youth and about health issues (interview Natasha Chipasha, 13-02-2018).

Speaking out in public was also something that the YV members learned from direct interaction with the role models. In another example, public speaking was one of the skills that YV member Edgar Nyirongo obtained through the trainings in the YV programme. He explained that after the programme's trainings, he learned which words to use and what kind of speech strategy is fitting in a certain case (interview YV member Edgar Nyirongo, 05-02-2018). Another member stated that through the YV programme, he was able to articulate disability issues more confidently and that his knowledge on the disability movement had increased (interview YV member Walter Kaunda, 20-03-2018). This can be seen as the direct role model effect as a result of being in contact with the YV staff.

Fourth, the role models in the Young Voices project contributed to a sense of group solidarity. The mere presence of role models fighting for a joint cause (disability rights) gave YV members a sense of belonging, of feeling part of being part of a collective. For many of the youth who used to live a quite isolated life, this reduced their feelings of loneliness. One direct role model effect includes that the members have been taught by role models how important it is to work together in disability advocacy. These effects were most noticeable in the Kafue group. For example, two of the group's members, Paul Luwawa and Natasha Chipasha, became closer connected to each other throughout the YV programme because of the solidary feelings they shared. The decreased feeling of loneliness was based on the previously described relationship between Paul Luwawa and YV co-ordinator Aron Mwape, who have known each other since 2015. The offer of help from the co-ordinator to assist this YV member made the co-ordinator feel like a parent (interview YV member Paul Luwawa, 13-02-2018).

Conclusion

This thesis sought to clarify the potential of role models in disability advocacy by researching a case study of a disability advocacy programme at *Cheshire Homes Society of Zambia (CHSZ)*. The programme, called *Young Voices (YV)* organised advocacy trainings for about 300 young PWDs in Zambia. The members of YV were hereby seen as potential role models for other PWDs. The main question in this research was *how role models in the Young Voices programme created positive effects for the participating youth with disabilities*.

For the members of the YV programme, role models were experienced as important in becoming inspired and motivated to become agents of change. Generally speaking, the members have experienced two kinds of role models. First the *staff members of YV* have been experienced as inspirational because they supported the members, both emotionally and through trainings, and decreased their feelings of loneliness. This counted for both the staff members of CHSZ and the YV co-ordinator for the Kafue group. Then there were the *members of YV themselves*. Their positive mindset, ability to express and expose and the acceptance of their disability were features that turned people into role models. They were able to show other members what was possible, that PWDs are also able to become successful. It became clear that several of the members were inspired and motivated by being in a group because they were brought together with other PWDs in the YV programme. For example, two members of the Kafue group had frequent contact with each other and hereby encouraged each other simply because of the feeling that someone else was investing time and/or energy in them.

This study demonstrated that role models in the field of disability advocacy can produce four kinds of positive effects. Especially the staff members of YV made the YV members *revise their negative view of PWDs (including themselves) and gain self-esteem*. By observing their role models YV learned that PWDs can become capable people of status and power. Furthermore, the role models from CHSZ contributed to a more positive self-image by teaching the YV members that it is the environment which makes people disabled (instead of the idea that they themselves are to be blamed). Second, YV members have become more *pro-active* by observing that role models can make something out of their own lives and those of others and by being motivated through role models, giving them the courage to take action and change their lives and those lives of others. Next, the YV members have learned to *speak out* by observing the skills and features of role models in the YV programme and being taught by these role models how to speak out. Finally, the YV programme stimulated an *improved group solidarity and a reduced feeling of loneliness*. This was created by putting YV members and potential role models together and by role models teaching YV members the importance of co-operation.

The consulted theories on role models were mostly based on Western programmes and as such it was initially unclear whether these theories would hold up in Zambia. This study shows, however, that the theories proved quite suitable and useful to study role models (features and effects) in the Zambian context. Particularly the theory on role model programmes by MacCallum & Beltman (2002) proved helpful. This theory explains that role models are persons who are committed, positive, worthy of imitation and committed to the things that

they do. This corresponds to the role model features described by the YV members, whom included being *passionate* (committed) *educated* and *employed* (worthy of imitation) and *able to accept their situation* (positive). The theoretical framework that has been used to support this research has thus been valuable in answering the main research question.

What this research adds to the existing range of role model theories is that role models have the potential to change the negative self-esteem that many PWDs in the global South have. If role models also have this positive effect on other marginalised groups, their inspiration and motivation can be used as an advocacy strategy in other capacity building programmes. This research has also confirmed that role model effects in the global South are largely in line with theories consulted in the literature, which was based on Western programmes and sources. This is something that has never been researched before. However, this research has been performed on a small scale and only on one disability advocacy programme. It would be interesting to see if the discovered role model processes as displayed in figure 7 (p. 39) also count for other advocacy programmes and in other cultural contexts. Finally, this research clarified the potential of role models for the improving of the negative self-esteem of PWDs. It has not been researched if and how role models can also have a positive effect on the negative stereotypes and prejudices by other societal stakeholders and policy makers (see figure 3 on p. 13). Further research on role models is needed to clarify the potential of role models with disabilities on lacking disability policies in the global South.

Literature

- Acedo, C., Opertti, R., Brady, J. & Duncombe, L. (2011). *Interregional and Regional Perspectives on Inclusive Education: Follow-up of the 48th Session of the International Conference on Education*. Geneva: UNESCO.
- Almog-Bar, M. & Schmid, H. (2014). *Advocacy Activities of Nonprofit Human Service Organizations: A Critical Overview*. London: Sage Publishing.
- Artur, S. & Nazroo, J. (2008). *Designing Fieldwork Strategies and Materials*. In *Qualitative Research Practice: a Guide for Social Science Students and Researchers*. Los Angeles: Sage Publications.
- Banda, N. & Kalaluka, L. (2014). *African Disability Rights Yearbook*. Pretoria: Pretoria University Law Press.
- Brandt Jr., E.N. & Pope, A.M. (1997). *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*. Washington D.C.: National Academy Press.
- British Department for International Development (2000). *Disability, Poverty and Development*. London: British Department for International Development.
- Carson, L. (2011). *Designing a Public Conversation Using the World Café Method*. In *Social Alternatives, Volume 30, No. 1*.
- Central Intelligence Agency (2017). *The World Factbook*. Consulted from [here](#).
- Cheshire Homes Society of Zambia (2018). *Inclusive Education: the Zambian Situation*. Lusaka: Cheshire Homes Society of Zambia.
- Chondoka, Y. & Machila, M. (2011). *Education for All Assessment Report*. Lusaka: Zambia National Education Coalition.
- Coleman, J., Brunell, A. & Haugen, I. (2014). *Multiple Forms of Prejudice: How Gender and Disability Stereotypes Influence Judgments of Disabled Women and Men*. New York: Springer Science+Business Media.
- Dang, S. (2015). *Six Ways Measles Can Affect the Eyes*. San Francisco: American Academy of Ophthalmology.
- Della Porta, D. (2015). *Focus Groups*. In *Methodological Practices in Social Movement Research*. Oxford: Oxford University Press.
- Della Porta, D. (2015). *In-Depth Interviews*. In *Methodological Practices in Social Movement Research*. Oxford: Oxford University Press.
- Department for International Development (2000). *Disability, Poverty and Development*. East Kilbride: Department for International Development.
- Elbers, W. (2015). *Breaking Down Barriers to Exclusion – a Research Design Paper*. Leiden: African Studies Centre.
- Elzubeir, M. (2001). *Identifying Characteristics that Students, Interns and Residents Look For in Their Role Models*. In *Medical Education, Volume 35, Issue 3*.

- Finch, H. & Lewis, L. (2008). *Focus Groups*. In *Qualitative Research Practice: a Guide for Social Science Students and Researchers*. Los Angeles: Sage Publications.
- Food and Agriculture Organization of the United Nations (n.d.). *Social Cash Transfers Help Break Poverty Cycle and Foster Productivity in Zambia*. Rome: Food and Agriculture Organization of the United Nations.
- Frobisher, E., Elbers, W. & Ibrahim, A. (2016). *Can Participation Enhance Outcomes?* Leiden: African Studies Centre.
- García Iriarte, E. (2015). *Models of Disability*. London: Palgrave Macmillan.
- Ghosh, S., Dababnah, S., Parish, S. & Igdalsky, L. (2015). *Disability, Social Exclusion and Poverty*. London: Palgrave Macmillan.
- Gilligan, R. (2015). *Children's Rights and Disability*. London: Palgrave Macmillan.
- Hamuhuma, M. (2016). *Quarterly Report on the Young Voices Disability Rights Advocacy and Campaign Project July to September 2016*. Lusaka: Cheshire Homes Society of Zambia.
- Hoogeveen, J.G. (2005). *Measuring Welfare for Small but Vulnerable Groups: Poverty and Disability in Uganda*. *Journal of African Economics*, Volume 14, Number 4.
- Imrie, R. (1996). *Disability and the City: International Perspectives*. London: Chapman.
- Janjan, N.A., Martin, C.G., Payne, R., Dahl, J.L., Weissman, D.E. & Stratton Hill, C. (1994). *Teaching Cancer Pain Management: Durability of Educational Effects of a Role Model Programme*. Alexandria: American Society of Clinical Oncology.
- Laws of the Republic of Zambia 1995 Edition, Volume 10, Chapter 134, Part VI, Regulation 32:b.v.
- Legard, R., Keegan, J. & Ward, K. (2003). *In-Depth Interviews*. In *Qualitative Research Practice*. Los Angeles: Sage Publications.
- Lewis Gargett, A., Barton, R., Llewellyn, G., Tsaputra, A., Soc, S.K.Z. & Tawake, S. (2015). *Global Cultures and Understanding of Disability*. London: Palgrave Macmillan.
- Lockwood, P. & Kunda, Z. (1997). *Superstars and Me: Predicting the Impact of Role Models on the Self*. Washington D.C.: American Psychological Association.
- MacCallum, J. & Beltman, S. (2002). *Role Models for Young People – What Makes an Effective Role Model Program?* Hobart: Australian Clearinghouse for Youth Studies.
- Malinga, J. & Gumbo, T. (2015). *Advocacy and Lobbying: The Road Map from Charity to Human Rights*. London: Palgrave Macmillan.
- Manyike, P.C., Okike, C., Onyire, N.B., Chinawa, J.M. & Austin-Abu, J.U. (2015). *Cerebral Malaria Complicated by Blindness, Deafness and Extrapyrmidal Tract Manifestation*. In *The Annals of Medical and Health Sciences Research, July-August; 5 (4)*.
- Ministry of Education: Republic of Zambia (2008). *2008 Educational Statistical Bulletin*. Lusaka: Ministry of Education.
- Ministry of National Development Planning (2017). *Seventh National Development Plan*. Lusaka: Ministry of National Development Planning.

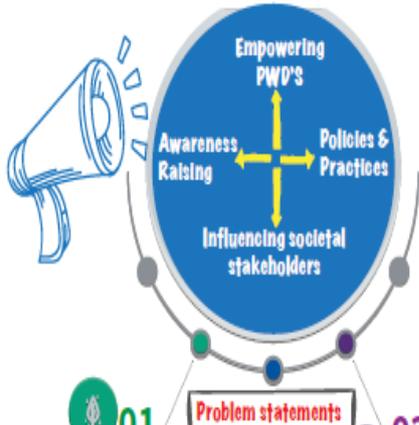
- Mittler, P. (2015). *The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift*. London: Palgrave Macmillan.
- Nabuzoka, D. & Rønning, J. (1997). *Social Acceptance of Children with Intellectual Disabilities in an Integrated School Setting in Zambia: a Pilot Study*. In *International Journal of Disability, Development and Education*, Vol. 44, No.2.
- National Assembly of Zambia (2012). *The Persons with Disabilities Act, 2012*. Lusaka: National Assembly of Zambia.
- Obiako, M. (1979). *Deafness and the Mining Industry in Zambia*. In *East African Medical Journal*, Vol, 56, No. 9.
- Pal, G. (2011). *Disability, Intersectionality and Deprivation: an Excluded Agenda*. Los Angeles: Sage Publications.
- Payne, W., Reynolds, M., Brown, S. & Fleming, A. (2014). *Sports Role Models and Their Impact on Participation in Physical Activity: a Literature Overview*. Ballarat: University of Ballarat.
- Potthof, S. & Elbers, W. (2016). *Which Organisational Resources Matter?* Leiden: African Studies Centre.
- Price-Mitchell, M. (2011). *What is a Role Model? Five Qualities that Matter to Youth*. Consulted from *Roots of Action* on 10-06-2018.
- Rossi, G. (2015). *Proposal on Young Voices Disability Rights Advocacy 2015*. Lusaka: Cheshire Homes Society of Zambia.
- Shamenda, F. (2012). *Employment Creation Policies and Strategies in Zambia, Prospects, Challenges and Future Outlook*. Lusaka: Ministry of Information, Broadcasting and Labour.
- Simui, F. & Mtonga, T. (2014). *The Situational Analysis of Inclusive Education in Zambia*. Lusaka: University of Zambia.
- Techbridge (2014). *Creating Connections with Role Models: the Power of Collaboration*. Oakland: Techbridge.
- Techbridge (2013). *Working Together: Role Models and Girl Scouts*. Oakland: Techbridge.
- United Nations Department of Economic and Social Affairs & Division for Social Policy Development (2017). *Toolkit on Disability for Africa: Culture, Beliefs, and Disability*. New York: United Nations Department of Economic and Social Affairs.
- United Nations General Assembly (2007). *Convention on the Rights of Persons with Disabilities*. New York: United Nations.
- Voigt, R.J. (2009). *Who Me? Self-Esteem for People with Disabilities*. Arlington: Brainline.org.
- Watson, J. (2015). *Advocacy Toolkit*. Teddington: Tearfund.
- World Health Organisation (2011). *World Report on Disability*. Geneva: World Health Organisation.
- Zambia Federation of Disability Organisations (2017). *Report on Inclusion and Participation of Persons with Disabilities in the Planning, Adoption and Adaptation, Domestication and Implementation, Monitoring and Evaluation of the Sustainable Development Goals in Zambia*. Lusaka: Zambia Federation of Disability Organisations.

Zambia Federation of Disability Organisations & Leonard Cheshire Disability (n.d.). *Disability Inclusion and the Sustainable Development Goals: Zambia Country Brief*. Lusaka: Zambia Federation of Disability Organisations & Leonard Cheshire Disability.

Zirkel, S. (2002). *Is There a Place for Me? Role Models and Academic Identity among White Students and Students of Color*. Oakland: Saybrook Graduate School & Research Centre.

Appendix 1

Preliminary Findings: Rik Jongeneel, Ma African Studies
2017-2018



- 01** - PWDs are largest marginalised group.
- Disability linked to (extreme) poverty.
- Exclusion - stigmatisation & lack of (effective) policies.
- PWD's, & youth, - negative self-esteem.
- 02** - Role models 'disability is not inability'.
- Role model = "skills to inspire", to create self-esteem & make listeners reflect on themselves, "worthy of imitation".
- Little knowledge on role models in disability advocacy.
- 03** - Goal research: clarify importance of role models in disability advocacy.
- Young Voices programme in Lusaka and Kafue, Zambia.

ROLE MODELS IN DISABILITY ADVOCACY THE CASE OF THE YOUNG VOICES PROGRAMME

- How did the young voices programme enable young PWDs to become role models for others?
- Trainings
 - Staff inspiring members
 - Members inspiring other members
 - Mentoring
 - Fellowship programmes
 - Drama

- Imagine alternative future
- Gain courage
- Learn desirable behavior
- Increased self esteem
- pro-active attitude
- New skills



what are role model features

1. Being independent
2. Being educated
3. Able to accept situation
4. Be passionate
5. To assist others

The young voices programme

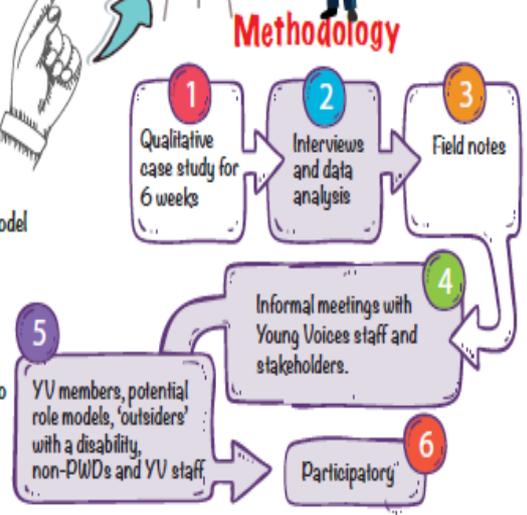
- 1/1**
- Goals:**
1. Advocate for disability rights
 2. Disability awareness
 3. Improved self-esteem
 4. Law implementation
- Activities:**
1. Trainings (knowledge on disability rights, advocacy skills, leadership and media skills).
 2. Group formation & facilitation.
- 1/2**
- Pilot (2009-2012) followed by programme (2015-2016).
 - Funding by German embassy.
 - Lusaka group: meeting with potential employers - tax rebate.
 - Kafue group: visits community to convince parents of PWDs not to hide their children.



Who is a Role model?



1. What makes somebody a role model for young PWDs?
2. How do role models positively influence young PWDs?
3. How did the Young Voices programme enable young PWDs to become role models for others?

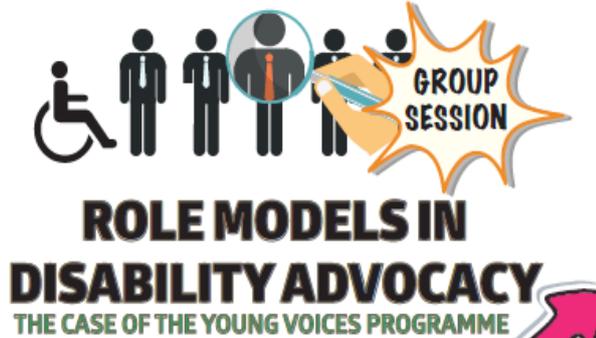
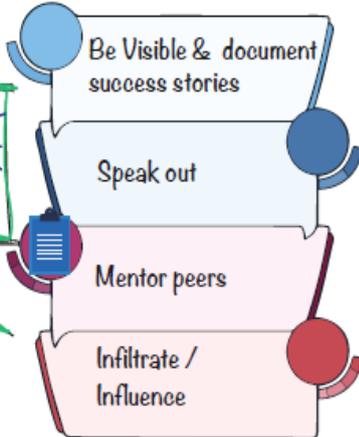


Appendix 1: preliminary findings of the research. Presented at the Disability World Café learning event on 30 March 2018 in Lusaka, Zambia.

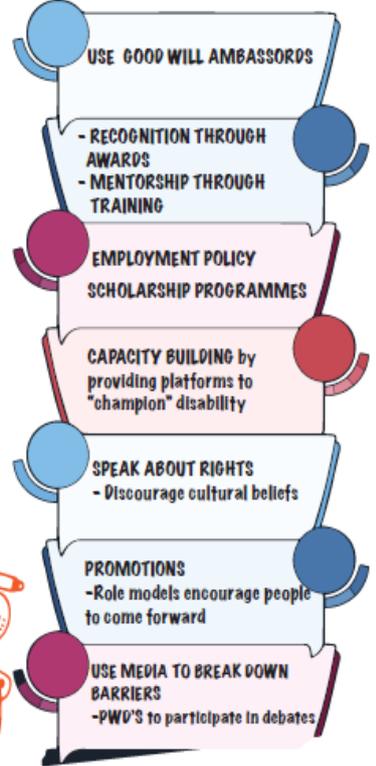
Appendix 2

WORLD CAFE APPROACH

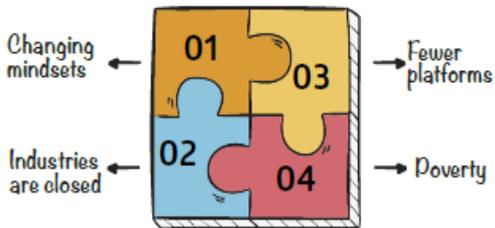
ROLE MODELLING



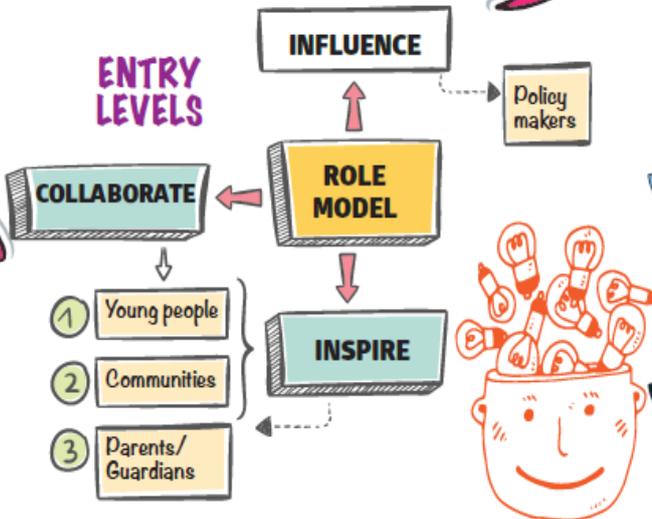
WAY FORWARD



CHALLENGES



ENTRY LEVELS



Appendix 2: outcomes of the World Café discussions. Presented at the Disability World Café learning event on 30 March 2018 in Lusaka, Zambia.