

Honors Thesis

**Cross-Cultural Disability Advocacy: A Rhetorical/Discourse Analysis of NGO**

**Communication in South Africa and Ukraine**

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## **DISABILITY: A HISTORICALLY DENIGRATED SOCIAL CONSTRUCT**

In political and popular discourse, disability is a theme that is much abused and manipulated... People with disabilities thus become a commodity to be manipulated by powerful people and groups for their own gain. (Phillips, 2002).

Throughout history, discourses all over the world have framed disability as inherently negative and needing to be fixed or eliminated (Barnes & Mercer, 2003). People with disabilities have been pushed to the margins of society, facing socially constructed barriers that prevent full participation in many arenas of their lives (Oliver, 1990). Over time, activists began to fight for the rights of people with disabilities, leading movements to make physical spaces and social opportunities more accessible. The American disability rights movement pushed de-institutionalization and significant legislation that would protect individuals with disabilities from discrimination (Shapiro, 1993). In the UK, disability activists used similar approaches to integrate and include people with disabilities in educational and employment settings (Quinn, 2004). While notable gains have been made to improve the rights of people with disabilities around the world, they still remain more likely to be unemployed, uneducated, and often receive limited access to public benefits (Sminkey, 2011).

## **DISABILITY TODAY**

The World Health Organization and World Bank estimate that roughly 15% of people worldwide experience disability<sup>1</sup> (2013). According to United Nations Enable (2006), out of the entire

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<sup>1</sup> The term *disability* entails a wide range of definitions, particularly in various cultural contexts. For this research, I use the World Health Organization's definition of disability as an umbrella term "covering impairments, activity limitations, and participation restrictions." *Impairment* refers to structural or functional bodily differences; *activity limitation* refers to individual difficulties in executing a task, and *participation restriction* refers to issues accessing involvement in life situations (World Health Organization, n.d.).

population of people with disabilities, 80% live in non-OECD<sup>2</sup> countries. Further, out of about 200 countries in the world, only 45 have disability-specific laws such as anti-discrimination. The WHO and World Bank estimate that people with disabilities that do not receive treatment and health care ranges between 35-50% in OECD countries and 76-85% in non-OECD countries (2013). In OECD countries, the employment rate for people with disabilities is 44%, compared to 75% of their nondisabled counterparts.

These types of disability-related disparities provide a mere snapshot of the inequalities that result from societally constructed barriers, such as stigma and physical barriers. To contest these inequalities, people with disabilities and their allies have pushed paradigm shifts through contemporary social movements. All around the world, the goal has remained similar: reframe disability as a naturally occurring form of human difference instead of a problem associated with an individual. This paradigm shift is commonly referred to as the social model perspective.<sup>3</sup>

Disability rights movements everywhere have confronted the lasting legacies of oppression of people with disabilities. The historical oppression and subjugation of people with disabilities such as institutionalization and eugenics<sup>4</sup> may seem long gone, however there are

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<sup>2</sup> OECD versus non-OECD countries: OECD stands for the Organization for Economic Cooperation and Development, which is “a unique forum where the governments of 34 democracies with market economies work with each other, as well as with more than 70 non-member economies to promote economic growth, prosperity, and sustainable development” (USOECD.usmission.gov).

<sup>3</sup> The social model considers the environmental and systematic barriers that exist for people with disabilities in a world built predominantly for nondisabled people. Oliver argues that the social model “does not deny the problem of disability but locates it squarely within society.” Joseph Shapiro (1993) acknowledges that in spite of great gains made in the disability rights movement, people with disabilities still face barriers in acceptance as independent individuals without being “patronized, segregated or victimized in an antiquated social services system and a prejudiced society.”

<sup>4</sup> The Eugenics Movement takes root in 19<sup>th</sup> century biology, drawing from Darwinian concepts of evolution and defined by Galton as the belief and practice of improving the genetic quality of

echoes of these pasts today, many of which are being contested through disability activism and advocacy for rights.

While extant research traces the accomplishments of many disability rights movements, they tend to focus on western cultures. In this research I explore how the rights of people with disabilities have changed in places that have not been center stage in disability movement discourse, Ukraine and South Africa. Ukraine and South Africa provide complex, dynamic examples due to the legacies of the Soviet regime and apartheid, respectively. I am interested the ways these shifts have affected disability rights and how these historical legacies are reflected in the experiences of people with disabilities today. I examine how disability advocacy efforts are framed and communicated through websites of nongovernmental groups that focus on disability advocacy<sup>5</sup>. After a literature review of disability rights in the historical/political context of the dissolution of the USSR and appeal of apartheid laws, I continue with a rhetorical/discourse analysis of the imagery and language on disability-focused nongovernmental groups' websites.

#### **DISABILITY ACROSS CULTURE AND IN THE MEDIA**

Definitions of disability and attitudes toward people with disabilities change substantially across cultures. Ingstad and Whyte (2007) say that, “cultural circumstances (such as assumptions about personhood) and social ones (such as the existence of disability institutions) shape the meaning of disability in different local worlds” (p. 1). In South Africa and Ukraine, a myriad of cultural assumptions were created from apartheid and the Union of Soviet Socialist Republics (USSR). Even with the appeal of apartheid laws and dissolution of the USSR, the transition in these

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the human population. The concept led to inhumane practices such as forced sterilization, abortion, marriage restriction, and genocide (Pfeiffer, 1994).

<sup>5</sup> In this research I define *advocacy* broadly as the active support for or by people with disabilities.

countries toward a post-Apartheid and Post-Soviet context reshaped certain cultural and social circumstances. In Ingstad and Whyte's cross-cultural analyses of disability, they outline their process as the following:

The basic approach is to start where people live, with their concerns and resources and the particular political ecology in which they are interacting. What is disabling for them there? We ask how relations with powerful institutions, organizations and media messages may affect their situations and their understandings of them. (p. 3).

Further, regarding media framing of disability, Parry (2009) says that, "throughout history, representations of bodily difference, mental illness, and intellectual and psychological disabilities have appeared in all the cultural products of all societies" (p 1). In particular, he points to the cultural product of media. Parry emphasizes the role of intersecting identities in the construction of disability in the media. While Parry's analysis refers to an American context, I find his approach applicable across that which Ingstad and Whyte call local worlds. Parry argues that, "representations [of disability] are framed by the intersection of racial stereotypes with ideas about the significance of disability," a concept that coincides with Ingstad and Whyte's concept of personhood. Those identities that are either prioritized or stigmatized, dominant or marginal, relate directly to the representation of disability in cultural products such as media. In this research, the representations of disability manifest in the cultural product of images generated by NGOs, reflecting that which is prioritized and stigmatized in Ukraine and South Africa.

### **RULING IN AND RULING OUT**

According to Hall (1997), "discourse governs the way that a topic can be meaningfully talked about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others" (p. 301). Hall writes that discourse *rules in* certain ways of

communicating about a topic, as well as *rules out* and limits ways of talking or conducting ourselves in relation to a topic. In this research I consider the ways political power shifts have worked to rule in and rule out certain ways of communicating about disability.

NGOs have had to respond to the unequal distribution of power created from the Soviet regime and apartheid, and the issues they currently include or exclude contribute to contemporary disability discourse in Ukraine and South Africa. In a similar vein, Schmidt (2008) writes that discourse goes beyond setting one set of actors' strategic interests and normative values. She says discourse operates to persuade others of the necessity and appropriateness of a given course of action (p. 10). This is particularly relevant in the context of disability advocacy, when the underlying message is often a call to action, i.e. NGOs commonly frame goals as humanitarian aspirations that community members ought to pursue in some capacity. I argue that the discourse communicated by NGOs *rules in* certain pieces of disability issues, excluding others by omission. Community members are persuaded to pursue those issues framed as priorities by NGOs, thus excluding the nuances of certain issues in disability, and sometimes excluding entire issues altogether.

#### **DISABILITY IN A POST-APARTHEID CONTEXT**

Examining contemporary forms of disability advocacy in South Africa requires consideration of the effects of apartheid. According to Lansdown (2002), the driving philosophy behind apartheid was to segregate and divide, thus “it is not possible to describe one South Africa” (p. 5). A Black child with a disability is often isolated or excluded in social realms due to her disability, which is then “compounded by the oppression experienced as a result of [her] race” (p. 5). Issues of class also intersect as children receive a lack of resources and care in rural, and largely Black areas. Lansdown writes that that rural children “are twice as likely to have

three or more disabilities than their urban counterparts” and that the highest national prevalence rates exist disproportionately in poorer provinces (p. 6).

In addition apartheid’s influence on the stigma attached to disability, Lansdown also points out that some causes of disability originated within the apartheid regime. For working-class Blacks, wages were often paid in part by wine. As a result, many children were born with FAS, Fetal Alcohol Syndrome. The world incidence of FAS is estimated around 0.4%, while studies in Western Cape, South Africa show rates of 5%, the highest in the world. Further, conditions of the apartheid laws such as “inadequate nutrition, unhygienic living conditions, overcrowding, exposure to pesticide poisoning, accidents and violence also contributes to high levels of disability” (pp. 6-7).

The appeal of apartheid is said to have sparked many political changes and commitments in the interests of people with disabilities, but the process is slow and amidst the successes are many shortcomings and challenges that have yet to be confronted. For instance, while many NGOs have formed to bring more services to specific groups of people with disabilities (especially deaf communities and people with physical impairments), Lansdown says most of them focus exclusively on adult issues. The support for children is lacking, particularly in educational settings. Integrated National Disability Strategy (1997) estimates that 99% of people with disabilities are unemployed, which reflects a lack of support in the educational settings. Initiatives and governmental interests have adopted issues of disability rights; however, Lansdown writes that, “there remains a view that NGOs are often consulted but not heard” (p. 34). A closer look at the imagery and language on NGOs websites are consistent with the claims that most of the focus is on adult issues (especially deafness, blindness, and physical impairment) and that governing bodies are slow to respond to NGOs’ requests for policy change.

## DISABILITY IN A POST-USSR CONTEXT

In an ethnographic study, Sarah D. Phillips interviews people with various disabilities who lived through the Soviet regime and its disbanding. One man who uses a wheelchair told Phillips that the Soviet regime pursued a policy of compensation in which people with disabilities were given a label, the Russian and Ukrainian word for *invalid*. With this label came “a pension, and a license to do nothing” (p. 1). This categorization rendered people with disabilities invisible and their needs were neither considered nor met. A medicalized model of care eventually dominated what efforts were made to rehabilitate individuals with disability, particularly during the post-USSR period of industrialization when people with disabilities were increasingly expected to join the work force and placed in unaccommodating and unsafe situations (Rasell & IArskai-Smirnova, 2014).

Phillips (2009) writes that the Ukrainian disability rights movement includes hundreds of NGOs and some state structures, and is “one of the most dynamic yet understudied post-Soviet social movements” (p. 4). According to Phillips’ ethnographic project on disability, today there are nearly 18,000 charitable and civic organizations in Ukraine, of which about 900 focus on disability issues. Among this select 900, 38 coalitions have formed to address disability issues as well. Phillips writes that while the NGOs have made many gains in raising awareness about disability rights, providing services, lobbying efforts, and pushing for funding opportunities, these successes exist primarily on a small-scale, community level.

On a systemic level, certain legislation has been enacted to protect people with disabilities’ right to education, employment, and physical accessibility since the collapse of the Soviet Union. According to Phillips, improvements in infrastructure and social opportunities “are accompanied by a range of injustices that compel many people with disabilities in Ukraine to

feel as if they live in a parallel world where their rights to full citizenship in the new Ukrainian state are circumscribed” (p. 6). Phillips also writes that the perceptions of NGOs are overwhelmingly negative. “Those outside the NGO sphere may be suspicious of the motives of NGO activists; one disability rights activists said that most of his disabled acquaintances distance themselves from NGOs” because they worry that NGOs seem more concerned with self-fulfilling ulterior motives than seeking social change. This creates a disinterest in NGO activism among youth. Phillips writes that NGO activists are typically middle-aged representatives of the last Soviet generation. These patterns are reflected in the discourses created by Ukrainian NGOs through the language and imagery maintained in their web presence.

### **READING THE IMAGES**

Drawing from 20 NGOs<sup>6</sup>, I browsed each organization’s images and text accompanying those images. For Ukrainian websites, I used Google Translate to convert the text to English. For Ukrainian NGOs and South African I pulled 50 images including photos and text screenshots, totaling 100 images overall. I archived these images for later review and reading. Drawing from the concepts in the literature review on representation of disability in mediated discourses as well as power dynamics in discourse, I conducted a close reading of the images and language from the various websites. My analysis follows.

The pivotal historical moments in South Africa (appeal of apartheid laws) and Ukraine (dissolution of USSR) mark shifts in power that reorganized and redistributed power and

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<sup>6</sup> To identify NGOs in South Africa and Ukraine that focus on advancing the rights of people with disabilities, I conducted a search both within the library database and Google. Ukrainian websites were more difficult to locate, so I consulted the work of Sarah Phillips on Ukrainian NGOs to locate lists of groups that focus on issues in disability. I used Google Translate to translate the Ukrainian webpages into English; it should be noted that the translations do not come out with full clarity and at times certain pages were not able to be translated. Overall, I drew images from 10 NGOs from Ukraine, and 10 from South Africa.

privilege in complex ways. It should be acknowledged that NGOs in particular have made a great deal of progress in bringing disability issues to the attention of powerful governing bodies. However, in both countries, the legacies of apartheid and the Soviet regime are prevalent within the discourse mediated by NGOs online communication. The discourse communicated by NGOs, as Hall (1997) would call it, *rules in* certain pieces of disability issues, excluding or *ruling out* others by omission.

### **READING THE IMAGES: UKRAINIAN NGOS**

In Ukraine, the first theme I noticed among NGO imagery was a tendency to focus on accessibility issues. Figure 1 (see Image Archive) depicts two images, that of a Ukrainian man using a wheelchair on public streets, and an image of a damaged curbside nearby with no curb cut. The photo of the curb is taken up close, suggesting the difficulty an individual using a wheelchair would have getting safely onto or off of the sidewalk. Images and missions related to accessibility are prevalent across NGO sites. While it is indicative of positive progress toward a more physically accessible Ukraine, it should be noted that this majority emphasis on people with physical impairment naturally excludes people with cognitive or developmental differences. Out of the 10 Ukrainian NGOs that I browsed, I saw no inclusion of people with cognitive difference. The primary population depicted was wheelchair users, and some websites depicted visual impairment as well as dwarfism.

Another theme across images from NGOs in Ukraine was one of employment. I read this pattern as a reflection of the post-USSR prioritization of employment. While the value on employment directly after USSR was associated with the industrialization of the country, today employment seems to be framed as a source of economic security, empowerment, and stability. Various NGOs feature images of people with disabilities in jobs (see Figures 2, 3). This is

positive for the association the images make between employment and disability. However, in all the images of people with disabilities in workplaces, I did not find any images of people with cognitive disabilities. This rules in the gaining of economic opportunities by people with mobile impairments, and not those with intellectual differences. This perpetuates the idea that the only people with disabilities that should be valued as contributing members of society are those in wheelchairs or with prostheses.

The final pattern I found in the imagery of Ukrainian NGOs was evidence of Phillips' finding that the leaders of disability NGOs tend to be older, from the Soviet generation. By featuring this homogenous demographic of leadership on the sites, it likely makes youth with disabilities less motivated to have agency in the NGO sphere. As a consequence, the voices of youth with disabilities are not heard and their diverse perspectives are not incorporated in the disability rights movement at large. The only place I located images of young people with disabilities was on spotlight features of Paralympic champions (see Figures 4, 5). This contributes to the "super crip" model<sup>7</sup>, perpetuating the tendency to assume that people with disabilities achieving great physical feats are more valued by their communities than others.

### **READING THE IMAGES: SOUTH AFRICAN NGOS**

The web presence of NGOs focusing on support for people with disabilities seemed much stronger when I searched for South African groups than Ukrainian groups, although it may be due to the issue with translating between English and Ukrainian. I find that the imagery and language on South African NGO sites tends to prioritize the issues of adults, especially those experiencing mobility impairments, blindness, and/or deafness (see Figures 6, 7). Figure 6 shows

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<sup>7</sup> Parry (2009) describes 'super crip' as a common trope in mediated disability representation, in which someone with a disability is revered for having excelled in physical or intellectual challenges. Super crips are "presented as extraordinary examples of those who have succeeded despite their disability" (p. 775).

a woman receiving training in adaptive technology for people with visual impairment, while Figure 7 shows a group of blind individuals receiving hands-on assistance to use canes. These images incorporate an aspect of care through physical touch; in both, a nondisabled individual is assisting a visually impaired person through individualized attention. This creates the notion that people with visual impairment can access resources that entail caring and individualized support. The text on these sites is important in particular for people with visual impairment that cannot access the images but may use a screen reading device that reads the text aloud for them. Figure 6 is accompanied by text that describes a list of classes offered to help visually impaired, deaf, or deaf-blind adults to “empower themselves by obtaining academic training and, ultimately economic freedom and independence” through education and employment (Blind Institute SA). People with visual and/or hearing impairment that access these messages are encouraged to access educational and employment opportunities as a vehicle for autonomy and economic stability.

Among the South African groups’ images, there was clearly more inclusion of cognitive disability and mental health. In Figure 8, a woman is depicted next to a caption that reads, “I have a successful career, two gorgeous children, and schizophrenia” (South Africa Federation for Mental Health). This imagery and language seeks to normalize mental illness by listing the woman’s positive possessions alongside schizophrenia. It communicates that people with mental illness are capable of leading what many would deem a normal, successful life. The inclusion of intellectual disability and even mental health is a valuable characteristic of these NGOs’ web communication. This works against isolating or stigmatizing messages about cognitive and psychiatric disorders.

In addition to looking at what is present in the images, I remained conscious of what is absent. Children are less present in the images, particularly Black children. I found very few images of Black children, especially Black children with intellectual disabilities. Some groups did comment on how underserved rural areas are, and fewer commented on the exclusion of children with cognitive delays. This type of erasure and under-depiction rules out the issues of Black children with cognitive disabilities. I read this as evidence of the legacy of apartheid, the tendency to exclude rural, predominantly Black areas (see Figures 9, 10).

### **THEMES ACROSS IMAGES**

It is evident that in both Ukraine and South Africa, the priorities of disability-related NGOs reflect historical power dynamics, ruling in some aspects of disability issues and ruling out others. South African NGOs seem to rule in a focus on bringing services to people experiencing deafness, blindness, and physical impairment. Ukrainian NGOs rule in a focus on physical impairment, as well as a focus on employment. In doing so, the South African and Ukrainian NGO discourses rule out people with intellectual disabilities and youth. Youth are rarely found on the boards of NGOs in Ukraine, and youth are an underserved population in the disability rights movement in South Africa. This is not to say that the advocacy work being done by the existing NGOs is not valuable. On the contrary, the push toward a self-advocating social model of disability has brought voices of people with disabilities to the forefront within some of these NGOs. However, certain groups are commonly excluded in NGO discourse, and I believe this is linked to apartheid and the Soviet regime. That is, much of what we find included and excluded in disability issues on the NGOs sites reflect the political work that resulted from apartheid and the Soviet regime. Reflecting on this may be a first step toward making gains in policy and perceptions related to disability in these countries.

Certain limitations exist within my analysis. Foremost, the breadth of the scope taken on in the consideration of entire countries poses some issues. It is difficult to draw claims about entire countries, especially two with such complex histories. It may be useful in future work to look more closely at particular NGOs or smaller geographic areas within South Africa and Ukraine, to make analyses that are more inclusive of the nuanced narratives existing within these contexts.

I also experienced issues translating information from the Ukrainian websites. At times the translator function did not work (possibly because of formatting on Ukrainian websites). Even when the translator successfully changed the page to English, it is possible that the initial intent of certain phrases is lost after translation. In the future, a similar study may incorporate Ukrainian people with disabilities in analyzing the rhetoric of language on NGO websites. There is a lack of narratives created by people with disabilities in Ukraine other than the work of Sarah D. Phillips. Thus, conducting a similar ethnographic method (interviewing people with disabilities) would be a positive way to involve people with disabilities in the disability rights discourse.

Finally, I suggest that the existing NGOs implement a more reflective discourse that engages with the post-apartheid and post-USSR contexts. I suggest reframing missions and goals to address the needs of people with disabilities that have been multiply disadvantaged as a result of the legacies of apartheid laws and the Soviet regime. With this type of infrastructural change, imagery would hopefully adapt over time to depict more children, people with cognitive disabilities, and youth involvement in disability leadership. When these groups become commonly depicted on NGO websites, this will be evidence of a paradigm shift toward a discourse that ‘rules in’ the empowerment of people with disabilities that have been commonly excluded from the discourse.

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## IMAGE ARCHIVE



Для інвалідів-візочників поїздка у місто дає насили.

У Полтаві дуже мало місць, де інваліди-візочники можуть комфортно і без перешкод пересуватися містом. Бордюри в кілька разів перевищують допустимі норми, величезна кількість магазинів, аптек і всіх установ без пандусів. Також сюди можна додати горбями лежить тротуарну плитку і розбиті тротуари.



Ось така Полтава для полтавських інвалідів на візках.

Figure 1. Image Source: VPoltave. URL: <<http://vpoltave.info/read/novost/id/200195961/Poltava-s-prepyatstviyami-dlya-invalidov-kolyasochnikov>>

# New Jobs for People with Disabilities



**RUSLAN KURLKO IS VERY ENTHUSIASTIC ABOUT HIS NEW JOB**

Figure 2 Image Source: NADU Ukraine. URL: <http://www.ua.undp.org/content/ukraine/en/home/ourwork/povertyreduction/successtories/jl-jk-11/>



Figure 3. Image source "National Assembly of Disabled of Ukraine" NADU Photo Gallery



Figure 4: Image Source NADU Ukraine Photo Gallery



Figure 5: Image Source NADU Ukraine Photo Gallery



Figure 6. Image source: <http://www.blind-institute.org.za/what-we-offer/adult-training/>



Figure 7. Image Source <http://www.sancb.org.za/>

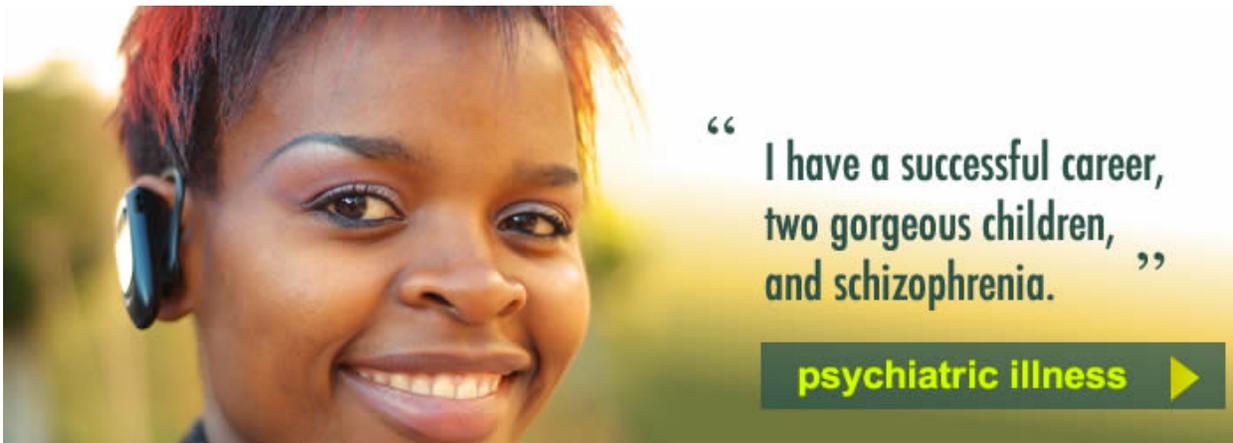


Figure 8 Image source <http://www.safmh.org.za/>



**"A South Africa accessible to all"**

To be an effective and efficient democratic national assembly of all disabled persons, which mobilises us to advocate for our rights, for the attainment of

Figure 9: Image source DPSA, Disabled People South Africa front page scrolling images



Figure 10: Image source DPSA Front Page scrolling images