

University of Montpellier
Faculty of Law and Political Science

European Master's Degree in Human Rights and
Democratisation

Academic Year 2015/2016

“Under our umbrella”

The evolution of disability rights through legal instruments and
increased civil society participation

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te quiero y me quedo corto
this thesis is dedicated to the most influential person in my life, my hero,
my mother

Abstract

This research thesis was focused on the evolution of disability policy, from the perspectives of International, regional and national (Zambia and France) legislations that have been put in place for their protection. The main goal through this study, was to observe if there has been increased representation of people with disabilities in decision making policies that affect their everyday lives. The research in this study was collected through research of publications dealing with the past a current movements of disability policy, to observe the changes that have occurred in legislation and civil society coordination. This study yielded many positive, but also limiting factors to issues concerning people with disabilities. In the positive scope, there are very tangible changes that have occurred in legislation, with the most important instrument contributing to this change being the United Nations Convention on the Rights of Persons with Disabilities. Also with increased legislation, there has been more civil society participation of people with disabilities. In a negative scope, there are groups of persons with disabilities whose issues are still put at the margin and who are still treated undignified, as is the case with people with intellectual and psychosocial disabilities.

Acronyms

ADA	Americans with Disabilities Act
APF	Association des Paralysés de France
CHA	Coordination Handicap Autonomie
CNCPH	Conseil national consultatif des personnes handicapées
COE	The Council of Europe
CJEU	Court of Justice of the European Union
CRPD	Convention on the Rights of Persons with Disabilities
CSO/CSOs	Civil Society Organization/Organizations
DPO/DPOs	Disable Persons Organization/Organizations
ECHR	European Convention of Human Rights
ECtHR	European Court of Human Rights
EU	The European Union
GIHP	Groupement pour l’insertion des personnes handicapées
HCt	High Court of Zambia
ILO	International Labor Organization
IMU	Independent Monitoring Unit
PWD/PWDs	Person with a disability/Persons with disabilities
CWD/CWDs	Child with a disability/ Children with disabilities
SWD/SWDs	Student with a disability/ Students with disabilities
WWD/WWDs	Woman with a disability/ Women with disabilities
UN	The United Nations
PCH	La prestation de compensation du handicap
PDA	Persons with Disabilities Act (Zambia)
MDA	Mental Disorders Act (Zambia)
MHUNZA	Mental Health Users Network of Zambia
UN	The United Nations
WHO	World Health Organization
ZAFOD	Zambian Federation of Disability Organizatins
ZAPD	Zambian Agency of Persons with Disabilities

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Introduction

Human Rights is a continually evolving concept that, although simple, carries many nuances and subsections throughout its ever-changing definitions. As we as humans are presented with new stimuli and experiences throughout our collective history, we become more aware of our environment and the role that it plays in our day to day interactions with our society. If we are to consider rights as stimuli, then as we become aware of our rights, we will in theory become more aware of our environment and the rights that are integral to our society. Although some rights may only affect a certain group, as a society it is important to recognize the rights of all members to truly harmonize our community. A society can not be considered just if it carries with it inequalities and, along with these inequalities, it does not guarantee people the ability or capacity to exercise their decision making based on the type of access that works for them¹. From this idea of equality, there are two important ideas that stem out of this statement, that of self-determination and its link with autonomy and accessibility.

One groups of rights that has continued to evolve, and is the subject of this study, is the rights of persons with disabilities. The definition and ideas of disabilities and their recognition has evolved throughout history, just as many other concepts have. Arguably, the ideas behind the people directly affected by disability have had a slow progression comparatively when observing the evolution of human rights. There has been a push in recent years from the international community for a universal definition and recognition of the rights of people with disabilities, most notably from the United Nations' Convention on the Rights of Persons with Disabilities (CRPD). Being disabled in society makes life artificially and avoidably complicated, artificial because the barriers that PWDs face are the product of a society that does not

¹ ZAFFRAN, Joel, *Accessibilité et Handicap*, p. 275

recognize the diversity of their community². It is also an avoidable complexity because the daily difficulties are products of unjustifiable absurdities, and PWDs are left as victims of individualism and unnecessary desires³. This is a harsh realization to ponder, as in theory we are apart of golden era for human rights and empathy. This realization is hauntingly indicative of how marginalized PWDs are in the community and that their disintegration is not due to their disabilities but rather from a society that has not taken the time to equally acknowledge their presence. Those who fit the molds of societies' "trends" determine the rights that will be respected, and even more so the concept of equality. With a growing active civil society PWDs are becoming agents of change by organizing and becoming more involved in the overall legislative processes concerning their rights. PWDs are living in a variety of unique environments, some with barriers that can make the realization of rights almost impossible. Although presented with many barriers, PWDs are becoming increasingly involved in their communities and claiming their effective role in the development process⁴.

I began to theorize on these topics through my professional experience abroad, which prompted me to the positive and negative aspects concerning the rights of PWDs. My work in this area has led me through the perspectives of advocacy, integration through education, civil society and community development. Beginning in Geneva, working in a project development role with Handicap International (HI)⁵, I truly became aware of the advocacy being promoted for PWDs out of the medico-legal sphere. This, as many first experiences are, was just an introduction to the reality behind the challenges of the environment for PWDs. HI, having no internal representatives with disabilities, is focused on promoting the rights of PWDs and raising awareness to the challenges of this group around the world; mostly in countries of development. Advocating from the external, I felt very positive towards

² ROJAS, Elisa, "*Libres et égaux sur le papier.*", p.67

³ *Id* 68.

⁴ Independent Living Institute, DRIEDGER, Diane, *Disabled People in International Development* available at <http://www.independentliving.org/docs1/dispeopleintldev1.html> (Last accessed 10.05.2016)

⁵ <http://www.handicap-international.org>

the movements happening in this sphere and many people appeared to be concerned for the rights of this marginalized group. Following my time at Handicap International, I worked at a public school in South Korea where I was able to observe how students with disabilities (SWDs) were integrated into the national public school system. SWDs participated and interacted most of the day with their peers at the school but also had separate lessons with a teacher specializing in education for SWDs, which focused on reinforcing and developing the knowledge from the lectures they attended with their other colleagues. All students at the school appeared well integrated and also very accepting of their colleagues with disabilities. More than just accepting, there was an atmosphere of normalization, which I attributed to the type of integration the public schools had in the region. This normalization was apparent in the daily interactions between SWD and SWoD. For the students, it appeared that there was a factor of solidarity between them and this was more important than the social differences that society placed on them. Another surprising observation that I noted, was that there was no fear associated in the students interactions with each other, which was contrary to my experience as a student in the United States. In the US there is a fear among youth of PWDs, which is mostly attributed to the lack of understanding and integration of SWDs in the school system. That being said, in general the SWDs were still seen as vulnerable and deficient by the teachers and elders in the community, and it was apparent that there was definitely more integration among peers than adults. In the sphere of development, I worked at the grassroots level in Lesotho, and it with this experience that I saw the reality of the current challenges faced by PWDs that affect their rights to autonomy and self-determination. Lesotho has a very harsh terrain and a majority of the population lives in rural areas. It was very difficult for PWDs in the local village where I was stationed, and after a few months I began to ask people about the underrepresentation of PWDs in the community. Many of the Basotho (people of Lesotho) in the community did not have a clear reason for the underrepresentation but some mentioned how the area was not accessible for some types of disabilities and also that mental disabilities were not always taken to account unless they were quite severe.

There was not a mention of what happened to those with severe mental disabilities, but from later observations and conversations it appeared that abandonment was one of the main issues. I began wondering about the challenges they faced, and through the aid of a local counterpart was able to start a support group for PWDs in the area. The first meeting included a diverse group of individuals from young, old, male, female and those with both physical and mental disabilities. Each person discussed their challenges in the community, which included subjects such as discrimination by local chiefs/ community members and accessibility (transport, education, employment opportunities). I'll never forget the gentleman that thanked me after the meeting because it made him aware of the other members of the community that were having similar issues as he was, giving a sense of solidarity. It was at this moment I truly realized actual length the rights of PWDs had reached and also the steps still required to reach effective integration and participation for this group.

As can be seen from above, people with disabilities face many challenges towards actual integration and these challenges are highly determined by the unique societies in which live. To gain an honest perspective on this matter, it is needed to start at the beginning. Observing, not only the evolution of rights, but also the definitions that have described PWDs in the past and surrounds them today, which are handicap and disable. The focus of this study is on the effects of globalization and changing disability legislation on the self-determination and autonomy of PWDs. The questions I posit are concerned on whether changing definitions of PWDs in international and national legislations have had positive outcomes for the inclusion and participation PWD; whether among these definitions there is a superior, "universal", definition that can be applicable to the diverse groups and situations of PWDs superseding all other definitions; whether increased globalization of legislation has or will increase the self-determination of PWDs (in rural and urban settings); and if PWDs are being effectively included in legislative and social changes recognizing them.

Part I: Origin of terms: from Invalid to Handicap

Concepts and terminology are constantly evolving to suit the world that has created them. These concepts usually begin at a much different place than where they end, and their meanings affect groups differently as they evolve. This idea is very indicative towards the origin of the term handicap, in which I look solely at the origin of the terms and not the historical presence of handicap persons. The term handicap, finds its origins in a much different domain than where it currently resides, which was in modern sports. Modern sports refer to the array of sports from the mid 19th and 20th centuries, which have been traced to Great Britain⁶. Handicap finds its origins from the adjoining of the words “hand in the cap”, which was originally a gambling game between three people and the items they forfeited⁷. In this game the role of “handicapper” was given to a person who would regulate the amount of money each player had to provide so that all objects gambled had equal value⁸. Looking at the debut of the term it was surrounded by the notion of equality. The *handicapper* was given the task of creating an equal starting ground, which gave all players the same opportunity. Handicap continued to be used in the sports sphere from horse racing, field athletics, and tennis. In these games, handicap rules were created to have a similar role as that of the handicapper⁹. The rules in essence gave preference to weaker players and created fair competition for the match. For example, in horse races the weight of the horse comparative to the saddle and the jokey were taken into account and In tennis weaker opponents were able to serve two times while their stronger ranked counterparts were only allotted one serve¹⁰. Without awareness these rules introduced principles of non-discrimination, integration and equality. Players of different abilities were not separated based on their talents but rather given the chance, on an equal basis, to compete with other members in their community. In

⁶ JØRN, Hansen, *The Origin of the Term Handicap in Games and Sports. History of a concept*, p.8

⁷ *Id*

⁸ *Id*

⁹ *Id*

¹⁰ *Id* pp 8-9

this sense, the term handicap was not surrounded by pity or exclusion but rather inclusion.

The literary association with PWDs, before eventually changing to handicap and disabled, was surrounded on the archaic term “invalid”¹¹. Invalid came from the Latin word *invalidus*, meaning weak or unsound, while its opposite *validus* (Valid) meant strong¹². As can be seen, the term surrounded the ideas of a lack of power, inadequateness, and a lack of clarity or common sense. Although utilized to describe other parts of society, invalid eventually found a destructive use in the descriptions of PWD. Being deemed unsound in our society is associated with the ideas of a lack of decision-making or autonomous power, as decisions that are deemed unsound are considered out of the realm of what is essential to being seen as an independent and sensible human being. Conceptually, our forces and strengths as individuals determine independence, but in reality our independence it is largely granted to us by our peers and other community members.

Along with invalid, the term crippled was utilized in association with PWDs and subjects surrounding their presence in the community. Where invalid depicted PWDs as weak and not of sound mind, the term cripple exacerbated the negative connotations of invalidity by depicting PWDs as individuals with limited mobility and who had limited chances of professional employment because of a deformity in their physical appearance¹³. Cripples were separated from the community because their physical appearance was deemed undesirable by society. Due to the negative connotations associated with their appearance, their success in the community would be met with limitations; the idea that one aspect of a person, because of society, determines their right to decision making and to equal opportunities. There was a differentiation between cripples and invalids by the nature of their disabilities, but the definitions of these terms were used interchangeably and at times that the lines between them were indistinguishable¹⁴.

¹¹ GURRIERI, John A, *Sacramental Validity: The Origins of Use of Vocabulary*, p30

¹² *Id*

¹³ JØRN, Hansen, *The Origin of the Term Handicap in Games and Sports. History of a concept*, p. 10

¹⁴ *Id*

The term invalid in conjunction with crippled were utilized for PWD up until the late 20th century and was even found in the names of organizations such as the *National Association of the Maimed and Crippled* (later changing its name in 1948)¹⁵. Gradually, around the 1980s, these terms began to be viewed as non-representative and following the *United Nations' proclamation of the International Year of Disabled Persons* in 1981, a change followed in the direction of the definition and views towards PWDs¹⁶. After 1981, the topic of disabilities moved from a viewpoint of pity and compassion to a movement that recognized that there needed to be more integration and equality of PWDs¹⁷. One group pitying another cannot form equality, true integration is found through respect. Through our differences as human beings, we all have inherent rights to lead our lives as we see fit and to be a part of an inclusive society.

Part II Defining “disability”: International, European and National

The evolution of the recognition and respect for handicap persons in society has highly been determined by the external actors found in decision making. At the national level, those individuals in society with decision-making capabilities are usually found in legislative positions and use their discretion in regards to consultancies. Some national governments incorporate different actors throughout their society and to guarantee that the laws concerning certain groups are centered on their protection and support, the government may incorporate council from civil society and non-governmental organizations. The decisions made at the national level only pertain to the particular nation that concludes said decision, and do not affect other nation's legislation. At the international level these policies are usually decided on by internationally recognized organizations and place obligations on states'

¹⁵ *Id*

¹⁶ *Id* pp10-11

¹⁷ *Id* p 11

government through ratification of international instruments. Once states' have ratified these instruments they have, in theory, adopted a universally shared perspective on the definition and policies that said documents concern. Regarding PWDs, four internationally recognized organizations have adopted provisions and definitions for this group that have become highly recognized and have even been included in certain national legislations. These four organizations are the United Nations (UN), the World Health Organization (WHO), the European Union (EU) and the Council of Europe (COE). This section will explore the international definitions included in the Declaration by the WHO, UN Declaration and Convention and the Charter of Fundamental Rights of the European Union as well as in the national definitions in legislations (past and current) of France and Zambia. These definitions will be compared within the documentation and also the evolution between the eras in which each instrument was introduced. Has the evolution of the definition in international and national spheres donned a positive effect in the legal and personal empowerment of PWD?

2.1 International Perspective: UN and WHO Definitions

Firstly, looking at the international definition of PWDs, we will observe the UN's definition from the 1975 declaration, the Classification of the WHO and finally the current Convention brought into force in 2006. The *1975 Declaration on the Rights of Disabled Persons* was one of the first international instruments of its era to look at the factors surrounding PWDs and the magnitude of their challenges and deficits according to the same fundamental rights of their fellow¹⁸. In this Declaration the definition of PWD is as follows

“means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency

¹⁸ BADEL, Maryse. *La loi pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées: un nouvel élan pour la prise en charge du handicap* p 27

congenital or not, in his or her physical or mental capabilities”¹⁹.

This definition, found in Article 1 of the Declaration, proposed a vision of PWDs as individuals who were not autonomous due to their disabilities. The “unable to ensure by himself or herself” paints a vulnerable picture of the individuals in this group and a need for them to be protected, externally. The definition also creates a separation between PWDs and “normal individuals”, which is indicative of the political climate for PWDs at the time; a climate where having capabilities out of the “normal” sphere that were considered undesirable. Although not the best model for a definition, it was a good introduction to the discussion on the inclusion of PWDs in society and their “right to respect for their inherent dignity”²⁰.

Following the definition of the UN, the World Health Organization (WHO) introduced a document in 1980 titled the *International Classification of Impairment, Disabilities, and Handicaps*²¹. This document was created as a tool that classifies types of disabilities, delving into the consequences associated with each type of disability and (most importantly) discussed the interaction of PWDs and their environment²². In this document, disabilities and handicaps are used as comprehensive terms that acknowledged not only the disabilities and the limitations but also the effects these disabilities have on a person’s capacity to fulfill daily activities²³. By presenting and defining the challenges that PWDs face with their basic activities, it also raised awareness towards the realization of their rights. If accessibility was limited in their internal spheres, how were PWDs expected to succeed in an external environment that was not inclusive in regards to accessibility and did not account for the everyday challenges that PWDs face. There is also a defining entry concerning the idea of handicap, which is as follows:

“The structure of handicap classification is radically different....the items are not

¹⁹ Declaration on the Rights of disabled persons 1975

²⁰ *Id*

²¹ WHO, “*International Classification of Impairments, Disabilities and Handicaps*”, p1

²² *Id*

²³ RICH, Robert F., ERB Christopher T., RICH Rebecca A., *Critical legal and Policy Issues for People with Disabilities*”, p. 5

*classified according to individuals or their attributes but rather according to the circumstances in which people with disabilities are likely to find themselves, circumstances that can be expected to place such individuals at a disadvantage to their peers when viewed from the norms of society”*²⁴

This is a very compelling statement as it takes into account the challenges that are presented in each type of environment for each individual and their unique disability, which is considered in the classification of each handicap in this document. The definition also addresses that society contains norms that are discriminatory to certain members in the society. The handicap classification from the WHO can be considered more of a system based on circumstances that PWD find themselves in, rather than a classification based solely on their disability. The fact that their handicaps are not what put them at a disadvantage but rather the pressures exerted on them from their own physical and social environment²⁵. The current definition of PWDs by the WHO describes disability in a unique way and is as follows:

*“Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions...Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers”*²⁶

This unique definition places the duties for realization of rights for PWDs in the hands of society by mentioning that the environmental and social barriers must be removed from the society for PWDs to overcome the difficulties they face. In this way we observe that the disability is not the handicap but it is the non-inclusive environment that creates the obstacles towards the disability. This idea creates a positive view for the full inclusion of those with disabilities in society based on the

²⁴ WHO, *International Classification of Impairments, Disabilities and Handicaps*”, p.4

²⁵ *Id*

²⁶ WHO, *Disabilities*

fact that there is no invalidity because of their disabilities and that physiological impairments should not impair their human rights. An important term to point out from the definition is the idea of disability as an “umbrella” description. Disability in itself does not describe the diverse groups of people that can be found under this *umbrella*. Most recently, in 2011, the WHO released a summary report on disabilities discussing issues for and recommendations for PWDs with consideration of the implementation of the CRPD. One of the most compelling parts of the summary from this report is the mention of Disability as a part of the human condition²⁷. Basically permanent disability will be something that almost every human being will have to face in life, especially the elderly²⁸. Considering this factor, it is even more important that all people advocate for a more accessible environment, as in one way or another we will all be under this *umbrella* one day. Along with accessibility, there must be an environment of respect and dignity in which all persons are able fully and equally enjoy their human rights.

Thirty years later after the UN Declaration, in 2006, the *UN Convention on the Rights of People with Disabilities* was created and introduced new concepts in the definitions and challenges that were concerning this marginalized group. This instrument was created due to the lack of power that international law had in challenging national laws that were not inclusive of PWDs²⁹. According to Article 1 of the Convention, PWDs:

*“Include 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”*³⁰.

This definition has major improvements from its pre-millennial predecessor. One of the major changes is the mention of how PWDs interact with their

²⁷ WHO, *Disability Summary 2011*, p.7

²⁸ *Id*

²⁹ BIRTHA Magdolna, *Nothing about CRPD Monitoring with US: A Case Study on the Involvement of the Disability Movement in Policy-Making Zambia*, p116

³⁰ UNCRPD Article 1 “Purpose”

environment, using the strategic wording of “barriers”. In this definition it is not the disabilities that hinder the full participation of individuals in society, but rather the environment and community that the individual is a part of. This interplay with the environment advances the idea of how rights are realized by creating a universal definition in the socio-political approach that is culturally relative. It, in a brief description, acknowledges that people have different challenges from the “various barriers” in their society and these barriers affect their decision-making roles in society. So although a handicap person in France and in Zambia have the same fundamental rights, the way their environments are equipped will determine if they are able to exercise these rights equally. Their environments, in respect of their right to dignity, must be accessible to guarantee that their rights can be exercised. Another important point raised in this definition is that of equality, and equality on the level of *all others* in society. By acknowledging that the barriers for PWDs are environmental and are not due to their identity, there is an awareness that their participation can improve once their society removes the barriers that limit them from achieving and realizing their full potential. The most important shift to be noted from this definition and Convention is that it moves from the medical viewpoint of PWD, which was surrounded on the idea of PWD as only beneficiaries, to a viewpoint of equality and respect³¹.

Looking at the evolution of the definitions of PWDs since 1975, it is interesting to see that in a relatively “short” time, in a legal sense, the concepts of disability and those persons living in a disabling society has changed exponentially. What was happening in the international sphere that lead towards current rights based/agents of change approach towards disability? Six years after the proclamation of the 1975 CRPD, the UN declared 1981 as the International Year of Disabled People that ignited a turning point in the disabled people’s movement³². This year was marked by more civil society presence of PWDs and improved efforts by states in coordination with its citizen with disabilities. The evolution that followed this

³¹ BIRTHA Magdolna, *Nothing about CRPD Monitoring with US: A Case Study on the Involvement of the Disability Movement in Policy-Making Zambia*” p116

³² SHAH, Sonali; Priestley, Mark. “*Disability and Social Change*”. p 8

would eventually change the way PWDs were viewed in society, and the considerations of what the term disability meant. After the proclamation of the International Year of DP, the UN followed its proclamation and recommended for the Advisory Committee for the International Year of DP³³ with the World Programme Action Concerning Disabled Persons (WPA)³⁴. One draw back of the WPA, mostly due to the definition in its time, was the explicit mention of prevention of disability and rehabilitation. During this time, disabilities were still associated with the person and the idea of prevention or rehabilitation (although important) perpetuated the idea of invalidity. On a positive note, the WPA focused on equality and the full participation of disabled persons within society. The WPA recognized the monumental success in 1981 and used this document to proclaim United Nations Decade of Disabled Persons. This length of period, from 1983 to 1992, was meant to give governments and organizations ample time to implement the recommendations that were included in the WPA³⁵. During the Decade of DP, the General Assembly created a framework to improve inclusion of PWDs in society known as the Development in Field of Disability and the a set of Principles for the Protection of Persons with Mental Illness, which described fundamental freedoms and rights for this subgroup³⁶. Following the Decade of DP, the General Assembly adopted the “UN Standard Rules of Equalization of Opportunities for Persons with Disabilities”, which was created as a moral compass for governments in their policy making and incorporation of PWD³⁷. Most notably from this document, is the definition of equality concerning opportunities for PWDs, which describes equality as availability. Availability in the sense that all individuals should have the same access to resources and through this access, equal participation will flourish. In this regard, PWDs should receive the required support to access mediums in society such as health, education

³³ *World Programme Action Concerning Disabled Persons 1982*

³⁴ DEGNER, Theresia, *International Disability Law-A New Legal Subject on the Rise: The Interregional Expert' Meeting in Hong Kong*, p 188

³⁵ *United Nations Decade of Disabled Persons*

³⁶ *Id*

³⁷ *UN Standard Rules of Equalization of Opportunities for Persons with Disabilities*

and employment³⁸. The UN was highly active in this period and, from a personal perspective, this hyper-activity had effect on the rest of the world concerning the rights of PWDs. This is not to say that the UN was sole actor igniting the changes that followed the Decade of DP, but rather that they gave a platform for the recognition of the rights of PWDs. Following and around the Decade of DP, the 1990s were said to be the influential decade concerning disability legislation as more than twenty countries created laws surrounding disability discrimination³⁹; among them the United States is said to be one of the most influential pioneers⁴⁰. It is important to discuss the 1990 US enacted the Americans with Disabilities Act (ADA) because it, for its time, presented a comprehensive approach to disability rights in the country. The importance of this document from an international perspective is due to the involvement of United States in the drafting and advising process of the CRPD, lending aid to the Committee using the history and experience of the ADA⁴¹. The ADA clearly states the environmental barriers that society has put in place, creating the handicap for PWDs in society, which is an essential principle of the CRPD⁴².

2.2 Regional: European Perspective

2.2a The EU perspective

The Charter of the Fundamental Rights of the European Union was introduced in 2000 (legally binding in 2009) with the idea that there must be principles that could be agreed as common legislation within the Union, principles that were not

³⁸ DEGNER, Theresia, *International Disability Law-A New Legal Subject on the Rise: The Interregional Expert' Meeting in Hong Kong*, p 189

³⁹ *Id* pp 183-184

⁴⁰ WALKER, Kevin, “*Comparing American Disability Laws to the Convention of the Rights of People with Disabilities with Respect to Post Secondary Education for Persons with Intellectual disabilities*”, pp115-116

⁴¹ *Id*

⁴² ADA, Section 12012§2,3 “*section 12101 mentions how the historical and current perspectives of society have affected the way in which PWDs are seen and that this discrimination persist in “critical areas such as employment, housing, public accommodation, education, transportation, communication, recreation, institutionalization, health services, voting and access to public services. This section also makes a particular mention in the structural design of the society, which not only limit but also discriminate against the capacity of PWDs”*

based on the economic purposes of the Union's construction⁴³. Observing the Charter, its "definition" for PWD is not a clearly stated as those of the documents by the UN and the WHO. Article 26 on the "Integration of persons with disabilities" of the Charter is as follows:

*"The Union recognises and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community"*⁴⁴

How does the Union recognize PWDs to whom this respect for autonomy is given? Does Article 26 create a clear definition for the beneficiaries? The EU recognized, in its Communication on the *2010-2020 disability strategy*, that the definition of disability in the EU has many variations and its uses have many connotations in the political and legal sphere⁴⁵. The lack of a concrete definition in Article 26 can be critiqued, as it takes away from the idea of the unification that the Charter symbolizes. The plethora of definitions of disability from each Member State has been said to be a major obstacle is the common application of national decisions concerning the disabled community⁴⁶. Without a standard definition for the Union, the Charter is essentially dependent on the viewpoints of each Member States' national legislation⁴⁷ and in this regard what would be the purpose of Article 26 in the Charter, as it would not change the beneficiaries in the eyes of each State. For example, if one state defined PWDs as those persons with long term and short terms impairments while another defined PWDs as those persons having only long-term impairments, there would be inherent inequality under the Union's beneficiaries in similar categories. This lack of definition was resolved through the two definitions proposed by the Court of Justice for the European Union (CJEU) interpretation in the

⁴³ HELIN, Laufer Gencaga, *The Past, Present and Future of the EU Charter of Fundamental Rights: A Prediction*, p. 163

⁴⁴ EU Charter of Fundamental Rights and Freedoms Art 26

⁴⁵ PEERS, Steve; HERVET, Tamara; KENNER, Jeff; WARD, Angela, *The EU Charter of Fundamental Rights: A Commentary*, p 734

⁴⁶ *Id*

⁴⁷ *Id*

cases of *Chacon Navas v Eurest Colectividades SA*⁴⁸ and *HK Danmark v Dansk Almennyttigt*⁴⁹. In the July 2006 *Chacon Navas* case the Court found it needed to clearly state a uniform definition regarding disability to create an equal application of the law concerning PWDs and to differentiate disability from a medical illness⁵⁰. The Courts' definition, inspired by the WHO International Classification, was as follows:

*“Disability must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of person concerned in professional life”*⁵¹

The interpretation of the Court in defining disability followed a medical approach, which looks at the “defects” as the limiting factor for the person’s full participation in society rather than the direct of the role of the environment in the realization of rights. The Court further looked towards distinguishing sickness and disability by the inclusion of the provision that said disability must have a probability of an extended duration⁵². This provision faced high critique because of the vagueness of its representation in explaining duration⁵³, which is understandable because there is not a definitive coordinate when assessing the duration of a disability. It can also be critiqued against the CRPD’s viewpoint of disability as an evolving concept, in the sense that the environment (society) ultimately decides the duration of said disability. In the April 2013 *HK Danmark* Case, almost seven years after *Chacon*, the Court would adopt the social model in interpreting what disability meant in the EU. This case concerned the capacity of employees in the workplace, in contrast with the differentiation between sickness and disability of the *Chacon* case. In the *HK Danmark* case the Court interpreted disability as follows:

⁴⁸ ECJ ,11 Jul 2006 *Chacon Navas v Eurest Colectividades SA*, Case C013/05,EU:C:2006:456

⁴⁹ ECJ, 11 April 2013, *HK Danmark*, Case C-335 and 337/11, EU: C: 2013: 222

⁵⁰ PEERS, Steve; HERVEY, Tamara; KENNER, Jeff; WARD, Angela, *The Charter of the Fundamental Rights: A commentary*, p734

⁵¹ ECJ ,11 Jul 2006 *Chacon Navas v Eurest Colectividades SA*, Case C013/05,EU:C:2006:456

⁵² *Id*

⁵³ CABRELLI, David, *Employment Law and Context: Text and Materials*, p 457

*“disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”*⁵⁴.

This definition is a huge leap in the concept of PWDs, especially when comparing with the definition proposed in *Chacon* only a few years prior. In this interpretation the Court recognizes the effect that the environment plays on the person, which affect the way PWDs are able to interact, on an equal basis, with their society. This monumental change in the view of disability in the EU between these two cases is mostly (if not completely) attributed to the EU’s accession to the CRPD in 2010, a definition uniting the EU with the UN Convention. An interesting thing to consider, in terms of the evolution of disability for the EU, is the outcomes of the *European Year of Person with Disabilities* (EYPD) and the *Equal Opportunities for People with Disabilities: European Action Plan* (EUAP). These were both enacted with as a way of mainstreaming disability issues for PWDs in the EU⁵⁵. What is interesting is that these two initiatives were geared in the human rights/social model towards disability but were not effective enough in regards to the interpretation of the CJEU in the *Chacon* case. If these Acts were actual meant towards addressing issues for PWD, why didn’t the CJEU continue these ideas in practical matters of the Court. This fact and the *HK definition* give the weight to the CRPD its influence the EU.

2.2 (b) COE Perspective

Further surrounding the evolution in Europe, it is important to mention the Council of Europe (COE), which is revered as one of the first international organizations to acknowledge the rights of PWDs⁵⁶. In 2006, a few months before the UN adoption of the CRPD, the Council of Europe proposed a “*Europe Action Plan*”,

⁵⁴ §3 ECJ, 11 April 2013, *HK Danmark*, Case C-335 and 337/11, EU: C: 2013: 222

⁵⁵ *European Year of Person with Disabilities & Equal Opportunities for People with Disabilities: European Action Plan*

⁵⁶ HENDRIKS, Aart; DEGENER, Thereisa, *Evolution of a European Perspective on Disability Legislation* p356

with the aim of improvement of the quality of life and Participation of PWDs in Europe from 2006-2015⁵⁷. Although not proposing its own definition, the Plan identifies a “paradigm shift from patient to citizen” and cites that PWDs are no longer perceived as persons requiring care but rather individuals whose full participation awaits the removal of barriers in society⁵⁸. The presentation of this Plan a few months before the UN adoption of the CRPD is not of pure chance, the COE specifically mentions the developments occurring at the time in drafting on the UN Convention in their plan⁵⁹. Considering the primary goal on full participation and the action points⁶⁰, it appears that the COE was preparing for the CRPD and creating an internal strategy that would follow closely to the UN’s concept of disability. This could also explain why the ECtHR has utilized the CRPD for interpretation of the ECHR, which will be presented later in the discussion of the influence of the CRPD.

2.3 National perspectives: France and Zambia

The purpose of the above international and regional documents and definitions is to provide a definition and protection for PWDs that is inclusive and provides an extra layer for appeal when their national laws do not protect or include them. The goal behind these documents is, not only to raise awareness, but to create an internationally recognized definition for PWDs that will be respected by all in the hopes of creating equal rights for all those who are experiencing barriers from their environment barriers and discrimination on the basis of their disabilities. These documents have evolved over time to consider the multitude of challenges that are present for PWD in the quest for equality. If national laws can follow these international documents, through actual implementation, the equal Rights of PWDs at the level of their peers may one day be a universal reality.

⁵⁷ COE, “*Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe*”

⁵⁸ *Id* Section 2.2, *Paradigm Shift from Patient to Citizen*

⁵⁹ *Id* Section 2.4, *Human Rights Framework*

⁶⁰ *Id* Section 1.3, *Key Action Lines*, Few key Examples: Participation in political an public life, Information and Communication, Education, Research and Development, Awareness raising

Continuing with the purpose of this study I am observing the definitions of PWDs in French and Zambian legislations and evaluating the evolution of the definitions alongside their international counterparts. Firstly we will take a look at the definitions from the two main legislations in France and following this analysis look at the Zambian legislation.

2.3 (a) French evolution

The representations of disabilities in French legislation can be found as early as 1924, in regards to the respect in employment⁶¹. In view of the circumstances of WWII, the law was solely focused on disabled veterans and their rights to fair treatment at work, although it did not deal with remedies concerning discrimination⁶². Thirty three years later, in 1957, a law that covered those recognized as handicap was put into force through the plights of handicap civilians in the post-war WWII French society and was one of the first laws to introduce a quota scheme into employment⁶³. These legislative instruments did not address the other plethora of rights for PWDs that were being overlooked in society. It seemed to be born out of the new disabled community during the post-war era but did not account for those whose disabilities were not physical. The first “comprehensive” look at handicap rights in France comes from the 1975 75-53 Act “*en faveur des personnes handicapées*” and made the access to all fundamental rights a national obligation⁶⁴. This was the first shift in the national legislation to consider all those in the community that were under the sphere of handicap, although it had its limitations. During the years leading and surrounding the law of 1975, the term handicap was surrounded along the idea of deficiencies and terms such infirm and invalid to describe the people under the categories of handicap⁶⁵. This law also did not propose its own definition for disabilities or handicap persons, but rather followed the previous definitions proposed by the special

⁶¹ BESNER, Eric A, *Employment for Disabled Individuals: What can France Learn from the Americans with Disabilities Act*, p.401

⁶² *Id*

⁶³ *Id* 401-402

⁶⁴ ZAFFRAN, Joel, *Accessibilité et Handicap*, p.16

⁶⁵ *Id*. p.50

Commissions CDES and COTOREP⁶⁶. These two Commissions were looking at disabilities from the medical perspectives, which defined handicap solely under the categories of those injured due to work, crippled or “simple minded”⁶⁷. These categories are extremely limiting, derogative and do not encompass the full range of identities that are within the handicap community. The perspective that branches from this stem is that of pity and charity towards those “crippled” and “simple-minded” individuals within society, which have deficits that place them on a lower level than the “others” in the community. This law was also more concerned with benefits and the disabled persons organizations present and not at all about strategies for integration that would allow PWDs to participate effectively in society⁶⁸. The 2005-102 Act “*pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées*” would change the daily lives of many PWD in a positive way, as it introduced the important concept of compensation⁶⁹. This law focused on the accessibility as an important pillar for the autonomy and participation of PWDs⁷⁰. In the 2005 Act the definition of handicap persons was as follows:

“constitue un handicap, au sens de la présente loi, toute limitation d’activité ou restriction de participation à la vie en société subie dans son environnement par une personne en raison d’une altération substantielle, durable ou définitive d’une ou plusieurs fonctions physiques, sensorielles, mentales, cognitives ou psychiques, d’un polyhandicap ou d’un trouble de santé invalidant”⁷¹.

This law created its own definition regarding who among the population in

⁶⁶ include link to texts that proposes the definitions proposed by the medical perspective of these two commissions at the time. CDES and COTOREP later consolidated into the MDPH

⁶⁷ MAISSONEUVE, Catherine. *La Loi Handicap et les collectives territoriales* p. 13

⁶⁸ *Id*

⁶⁹ *Droit du handicap et procédures: Guide Juridique et Pratique pour Connaitre et Defendre ses Droits* p.5

⁷⁰ MAISSONEUVE, Catherine. *La Loi Handicap et les collectives territoriales* p. 13

⁷¹ *Id* p.13 “Constitutes a handicap, in view of the present law, all limitation of activity or restriction of the participation to social life in their in environment from a substantial change in a person, long lasting or definitive of one or more physical, sensory, mental, cognitive or physical functions of a disability or health problem”

France were to be considered and the biggest improvement in this law is that there was in fact, finally, a legal definition of PWDs in France. The definition proposed by the present law considered handicap persons as those individuals who were restricted from participating in their environment. The restrictions experienced by PWDs are attributed, in this definition, to substantial changes in their physiological functions. Although the Law of 2005 was centered on the idea of accessibility, the legal definition appears to place the limiting factor on the disability without considering the environmental factors. In the UN and WHO definitions of handicap and disabled persons, there are explicit mentions of the environment's role in the accessibility of PWD and create the idea of equality through an equally accessible environment. Comparing between the three, the French law utilizes the outdated idea of disabilities and does not consider the role of society in the realization of equality. It is also interesting to note that the 2005 law drew inspiration from WHO's definition in 2011, because their definitions focus on two distinct areas; France on the disability and the WHO on the environment⁷². The current public opinion in France has advanced into a more reactive state, with thirty percent of the population finding themselves handicap due to barriers found in the environment⁷³. This increase in public activity can be attributed to the high percentage of individuals that find themselves in inaccessible situations because of the barriers in their environment that do not allow them to accede certain aspects of life. With such a high percentage of persons experiencing this barrier, advocates for the matter start to increase by the other people in the community associated with said individuals on a daily basis (such as family, friends co-workers). Those associated also become more aware as they, from a third person perspective, experience how limiting society can be on the basis certain characteristics of an individual. In France (and many other countries), the subject of disability was often only viewed from a private perspective for those who were affected by these barriers but these issues have increasingly been brought to the

⁷² *Id*

⁷³ LARROUY, Muriel in ZAFFRAN, Joel. *Accessibilite et Handicap* p 50.

public's attention through actions from associations and civil society⁷⁴. Hopefully through increased interactions and cooperation throughout all facets of society there can continue to be a positive increase in the accessibility for PWDs. From a communication in 2012 posted by the guardian, many steps have been taken in the right directions since the law of 2005 has been introduced. There has been more visibility and acceptance of PWDs in France in areas such as employment and cinema⁷⁵. One representative of handicap.fr by the name of Bissadron noted that (in regards to the film *Les Intouchables*) that attitudes are changing in France towards disability, which was once a topic that many people in the country wanted to remain hidden⁷⁶. The evolution of the definition for PWDs in France through legislation continues to bring this marginalized group to the forefront, and is slowly removing the barriers that the environment has exerted on them for many years. From war wounded and simple minded to active participants in society, these evolutions hold promise for the future of disability integration in France.

2.3(b) *Zambian evolution*

Comparatively with France, Zambian legislation on the Rights of PWDs has quite an early history concerning representation for PWDs in the community. Following the achieved independence the first Handicap Persons Act was brought into Force in 1968, which created the Zambian Council for Handicap Persons⁷⁷. This Act contained within it a definition for PWD, or term used in the Act “the handicapped”, that is as follows:

“means those persons of defect mind, senses, or body, congenital or acquired, are unable to take part in normal education, occupation and recreation or require special assistance and training to enable them to take part in normal education,

⁷⁴ *Id*

⁷⁵ The Guardian, WILLISHER, Kim, *France turns corner on disabilities-but austerity threatens further progress*

⁷⁶ *Id*

⁷⁷ CHIPULU, Protasio, *“Living with Cerebral Palsy: A Parent Guide to Managing Cerebral Palsy”*, pp 63-64

occupation... ”⁷⁸

This definition essentially defines PWDs without any aspect of consideration of their environment. Under this Act, those considered handicap, which is not clearly defined, were seen to have deficiencies that did not allow them to participate with the “normal” society. The definition also did not provide a clear view of what truly constituted a deficiency, only that the deficiencies were present, PWD were in this regard not considered normal members of society because they required special treatment and services to be considered as “normal” in society. A positive look at the above definition is that it identified the environment as a barrier for PWDs, although in the definition the environment was “normal” and the individuals were the abnormal part of the society. Following this Act, much later, the Persons with Disabilities Act came into force in 1996 to establish the *Zambian Agency for Persons with Disabilities*⁷⁹. This act created a definition for both “disability” and “person with disability”, which is as follows:

“disability means any restriction resulting from an impairment or inability to perform any activity in the manner or within the range considered normal for a human being, and would or would not entail the use of supportive or therapeutic devices..”

“person with disability means a person with a physical, mental or sensory disability including visual, hearing or speech functional disability”

Initially the improvement can be seen in the clear definition of what disability is and the types of disabilities that individuals in this category may experience. There is also a substantial change from the use of deficiency to that of impairment, changing the idea of a disability from a lack in something to a barrier towards an individual. Although improved from the 1968, the definition in this bill still looks at

⁷⁸ Cornell University. “Zambia: Chapter 551: *The Handicapped Persons Act*” under Interpretations

⁷⁹ Zambia “The Persons with Disabilities Act 1996” Part 2 *Interpretations*

PWDs in a negative view by considering characteristics of their physiology as abnormal from the status quo. It also looks at the disability as the limiting factor and does not consider the way that the environment creates barriers in the way it interacts with disabilities. The Act to repeal the 1996 law was enacted in 2012 under the title The Persons with Disabilities Act 2012. The Act of 2012 exponentially builds on its 1996 predecessor and also defines disability and person with disability as follows:

“disability means a permanent physical, mental, intellectual or sensory impairment that alone, or in a combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in society on an equal basis with others”

“person with disability means a person with a permanent physical, mental, intellectual or sensory impairment which, in interaction with various barriers may hinder that person to fully and effectively participate in society on an equal basis with others”⁸⁰

The above definitions show the advancement in perceptions of PWD in the national legislation. The 2012 PDA looked at the perspective of how the environment affects individuals, and how the interaction between environment and disability creates barriers for some PWDs. The perspective has moved from that of pity and deficits to the actual challenges for PWDs. The definition also includes the society as a whole, as they are included in this environment that benefits some and excludes others. Following the view of the disabling environment, there is finally a mention on equality, and equality on the basis of society. This definition is the shift toward viewing those with disabilities at an equal level and supporting their inclusion into society. The definition goes further in the inclusion of the concept of effective participation, showing raised awareness to the hard fact that PWDs are hindered from exercising their maximum talents because of the environment. Defining and

⁸⁰ Zambia *The Persons with Disabilities Act 2012*

acknowledging this fault in society, suggest that the legislation is concerned with the future inclusiveness of PWDs and in maximizing their potential in society.

Purposefully, I did not include the Mental Disorders Act of 1951 in this section but is still an active instrument that concerns a particular group under this umbrella. This highly derogatory Act will be presented later to discuss challenges still facing people with intellectual disabilities in Zambia.

Observing the definitions proposed by the two national instruments, along side the changes in between the texts, we can apply the same logic proposed in the international sphere concerning the influence on evolution definitions of disability internally. Applying the phenomena in history presented above in the international arena, it gives some reasons behind the change, but what was happening internally within France and Zambia that could be indicative reasons behind changes in their national legislation concerning the rights of PWDs. It is also interesting to note that France, unlike Zambia, has not updated its legislation since the EU's accession to the CRPD in 2010.

France's disability legislation dates back as early as the 1920s, with a focus uniquely on disabled veterans⁸¹. The law at the time was based on providing equal employment opportunities for those veterans and started small civil movements towards more realization of the employment rights of PWDs outside the sphere of combat⁸². Fast forward to the time of increased change, the law of 1975 introduced the quota system towards employers and was aimed at ensuring PWDs "the autonomy of which they are capable"⁸³. After 1975, the following 30 years would see a rise in legislation and civil society coordination concerning the different challenges that PWDs face in their daily lives. The 1975 Act did not pass smoothly and was met with critiques from civil society organizations, such as "le Comite de Lutte des

⁸¹BESNER, Eric A. *Employment Legislation for Disabled Individuals: What France can learn from the Americans with Disabilities Act* p. 400

⁸² *Id* pp. 401-402

⁸³ *Id* 402

Handicapés”, who believed that the Act lacked human rights objectives⁸⁴. These disability movements fought for the recognition of PWDs and argued against the concept of national solidarity, feeling politically misunderstood by the country⁸⁵. This misunderstanding can be easily understood when considering the definition that the law proposed, and echoed the need for change to the disability community. The evolution of concerning the disabilities would follow through the 1980’s in France with the claims concerning accessibility by associations and slogans such as “s’il n’y a pas de solution, il n’y a pas de problème”⁸⁶. These early movements strongly focused on the equal access and political acknowledgment of PWDs and the challenges they faced in the struggle for effective participation. Arguably, the most important move coming out of era is the 1987 Act concerning the rights of workers with disabilities. This law was in response to the unemployment rate for PWDs, who by the mid eighties represented a very low portion of the labor market⁸⁷. From this Act came the quota system for employers to bridge the large unemployment percentage PWDs. Although it focused on issues of participation for PWDs, it lacked issues regarding equality⁸⁸ and issues for those with disabilities that highly limited their accessibility to many jobs at the time. The 1990’s would provide vehicles of change in France that would diversify the ways in which handicap or disability would be viewed in society. A strong movement of activism arrived in to Europe in 1993, manifesting into the autonomous living promoting federation of *Le Groupement Française des Personnes Handicapées* (GFPH)⁸⁹. Around France the movement in disability movement was blossoming and culminating with two very important European entities, the European Disability forum (EDF) and the European Network for Independent Living (ENIL)⁹⁰. EDF, a very important movement in terms of disability in the European region, has

⁸⁴ LARROUY Muriel, in ZAFFRAN,Joel, *Accessibilité et Handicap*, p. 56

⁸⁵ GARDIEN, Eve, *L’émergence en France des mouvements de pairs-représentants*, p.99

⁸⁶ LARROUY, Muriel, in ZAFFRAN, *Accessibilité et Handicap* p. 58 “If there is a solution, there isn’t a problem”

⁸⁷ BESNET, Eric A, *Employment Legislation for Disabled Individuals: What France can learn from the Americans with Disabilities Act*, p 402

⁸⁸ *Id* 401

⁸⁹ GARDIEN, Eve. *L’émergence en France des mouvements de pairs-représentants* p.102

⁹⁰ *Id* p.101

been attributed to the evolution of NGOs in France like GFPH⁹¹. Back in France a number of Acts concerning disability were issued in the nineties and focused on accessibility, integration and non discrimination of PWD⁹². Following the start of the new millennium in France, which can also be thought of as a new millennium for disability politics in the country, two new DPOs were created. They are the Collective of Handicap Democrats (CDH) and the very influential Handicap and Autonomy Coordination (CHA), which engage in activities such as respect of law for citizens and public policy that concern PWD and their participation⁹³. A few years prior to 2005, a couple of Acts were initiated based on health and the quality of specialized institutions in France. Out of these, the 2002-2 Act is very notable in the creation of a system of monitoring for social and medico-social institutions and the national assessment agency (ANESM) that evaluates and the quality of these institutions⁹⁴. These were some of the more notable events occurring in the law and social action that can be attributed to the culmination of the 2005 Act, which is still evolving today and is increasingly heading towards a human rights based approach on the rights of PWDs. A very controversial case also took place during this time period and had a highly influential effect on the disability policy. The *Perruche Case* was based on a complaint by a mother who had given birth to a CWD, citing negligence from the physician who had committed an error in her medical tests⁹⁵. The mother stated she would have terminated the pregnancy, if she had known about the risk of her condition and the effects it would have on her child⁹⁶. The Supreme Court sided with the Perruche family⁹⁷, which was raised a moral question on the Right to life. Is it ethical to terminate a pregnancy solely on the basis of a disability? The impactful

⁹¹ BARRAL, Catherine; ROUSSEL, Pascale; SANCHEZ Jesus, ANED, *Country Report on the implementation of policies supporting the independent living for disabled persons*, p.9

⁹² *Id* p.4 1990 Act 90-602 protection against discrimination due to disability, 1991 Accessibility Act 91-663 housing, work places and equipment for accessibility of DP, 1999 Handicol: Promotion of individual plans and provisions for school integration increase access to education for CWD

⁹³ *Id*

⁹⁴ *Id* p 4, also website for ANESM showing current status

http://www.anesm.sante.gouv.fr/spip.php?page=article&id_article=108

⁹⁵ MANAOUIL, C, GIGNON, M, JARDE, O, *10 years of Controversy, Twists and Turns in the Perruche Wrongful Claim: Compensation for Child Born with a Disability in France*, p 663

⁹⁶ *Id* 664

⁹⁷ *Id*

after effects from the case came from the 2002 Patient's *Rights and Quality Care Act*, which created the idea of the Right to Compensation in France for a disability⁹⁸. This idea honors the value of life but also addressed the barriers that PWDs may face due to financial and social burdens. Although coming from a derogatory history, the right to compensation was an achievement towards models for effective participation of PWDs by identifying their barriers in society

In Zambia the evolution towards the current definition can be attributed to a variety of actors from the civil and international sphere. Commencing from the period of 1996 PDA, the highly effective *Zambian Agency for People with Disabilities (ZAPD)* was created and represents a number of different DPOs in Zambia. The ZAPD has functioned as an intermediary force between the government and civil society, and has also allotted a fund for the advancement of employment for PWDs⁹⁹. Also improved upon by the law is the *Zambian Federation of Disability Organizations (ZAFOD)*, which organizes a large group of DPOs throughout the country and has increasingly become a driving force throughout the country through assessment reports¹⁰⁰, legislative actions¹⁰¹ and monitoring¹⁰² towards the many issues plaguing PWD in the country. Different policies concerning issues of disabilities following the 1996 Act towards the current 2012 act, and addressed issues as integration of SWD, labor laws and capacity building¹⁰³. There were definitely movements on the ground aiding to recognition of PWDs in Zambia, but the biggest contributor to the legislative changes in definition is the CRPD, Which Zambia ratified in 2010. The UN Convention could arguably be said to be the foundation for the current Act, and can be seen through the Act in the wording of the Articles. From

⁹⁸ *Id* 665

⁹⁹ ILO, *Zambia Country Profile: Promoting the Employability of People with Disabilities through Effective Legislation (Southern Africa)*, p. 5

¹⁰⁰ *Id* p. 4

¹⁰¹ *No. 2011/HP/0818 Sela Brotheton v the Electoral Commission High Ct. ZA 2011* Court's decisions will be discussed further in this paper, Violations found against the Commission

¹⁰² BIRTHA, Magdolna. "Nothing about CRPD Monitoring without Us: A case Study on the Involvement of the Disability Movement in Policy Making in Zambia". p.127

¹⁰³ BANDA, Natasha; KAKALUKA, Likando. "*Zambia*". pp 274-275

this present Act the social model of disability has, almost, prevailed in the direction of policies on PWDs in the country. Although the definition has evolved an important factor to consider is the presence the Mental Health Disorders Act (MHA)¹⁰⁴, which is still a part of Zambian legislation for PWDs and retains a highly discriminatory definition and view of people with intellectual and psychosocial disabilities. In this regard, although a positive change in some aspects of how disability is viewed in Zambia, there is still a limit towards how the government views certain disabilities.

The social model appears to be making headway throughout the international and national sphere of the rights concerning PWDs, changing the frame of what is considered a disability. The definitions of disability in international law and national law are evolving and, following the CRPD, are dynamic in the creation of an increasingly equally accessible environment for the realization of fundamental rights for PWDs. Through the elaboration of the definition in legislative actions and text, it is important to observe who, among the population identifying as being in a disabling situation, are the beneficiaries from this new socio-economic definition.

Part III Beneficiaries

Observing the national, international and regional instruments, the beneficiaries of these rights are identified through specific articles within the instruments. The realization of the rights for the beneficiaries in an international context is highly determined by the interpretation of the Articles in jurisprudence. Interpretations of the law can have positive, but also negative effects for PWDs and the diverse subgroups that are also a part of their community and vary depending on the environment in which they are interpreted. In this following section, we will observe how these instruments identify their beneficiaries and case law supporting the access that PWDs have to these benefits.

¹⁰⁴ *Id* p274 Mental Health Disorders Act, 1951

3.1 Beneficiaries in International & Regional Instruments:

3.1 (a) UN CRPD

Beginning with the CRPD the beneficiaries are first and foremost the PWDs, and mentions the benefits aimed in a general sense in Article 1 of the Conventions stating

“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”

According to this article it can be said that those considered as PWD in the Convention (definition of PWD in previous section) benefit from the protection and promotion that is put in place to facilitate the realization of their rights and freedoms. Article 3 of the Convention further details the general principles of the Convention, which outline the inherent benefits and are as follows:

“-Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons
-Non-discrimination
-Full and effective participation and inclusion in society;
-Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
-Equality of opportunity;
-Accessibility;
-Equality between men and women;
-Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities”¹⁰⁵

The principles in Article 3 and statement in Article 1, allude to PWDs’

¹⁰⁵ UN Convention on the Rights of Persons with Disabilities Article 3

benefits of respect, accessibility, and equality. Although the content of this instrument can be generally applied to those falling under the definition of PWDs, there are also minority groups and third party organizations that are also considered beneficiaries and are given specific mention throughout the convention and will be discussed further in this section. Firstly, looking at the general beneficiaries, we can turn to examples in case law to discuss how PWDs benefit from specific articles in the CRPD. In 2014 case of *Mr F v Austria*, the applicant found consolation from his benefits within the CRPD¹⁰⁶. Without a remedy in the national jurisdiction, the applicant chose to find appeal in with the Committee on the Rights of Persons with Disabilities¹⁰⁷. Mr F's case against the Austrian government was concerned with the lack of implementation complete accessibility of public transportation on an equal basis of others in society. The story surrounding the applicant concerned his daily activities, which were facilitated by audio systems at each tram stop that reproduced the written digital information on the screen that alerted passengers to changes in schedules. Being visually impaired, the applicant found these audio systems extremely useful in informing him of any changes to scheduled planning on his daily route. In 2011 the tram lines was extended but not equipped with these audio systems, which hindered the applicant's equal accessibility to information that was available for public use. Mr F argued that the State violated its obligations in the Convention and the Committee found the State had violated Articles 5(2) and 9(2) [points f and h], requiring states to proceed with the following:

*“prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds”*¹⁰⁸

“Promote other appropriate forms of assistance and support to persons with

¹⁰⁶ No. 21/2014 *Mr F v Austria* CRPD/C/D/21/2014 Court ruling in favor of the applicant in Austria's violation of Articles 5 and 9 on the CRPD because of its lack to implement technology for the equal accessibility to all groups in the community

¹⁰⁷ OHCHR: Competence of Committee recognized by States party to the Convention and the Optional Protocol of the CRPD

¹⁰⁸ UN Convention on Rights of Persons with Disabilities Article 5(2)

*disabilities to ensure their access to information*¹⁰⁹”

*“Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.”*¹¹⁰

Firstly looking at Article 5, the committee agreed with the applicant that the State’s lack of effective legal remedy, in this case not implementing equally accessible information, was in violation as monetary compensation was not an adequate solution to the problem that could affect others in the community if not remedied. Continuing with the two subsections in Article 9, the Committee noted that the State had violated its obligations to ensuring access of information by not implementing design strategies that considered the accessibility of all community members. This case is a good example of the effectiveness for legal remedy for the beneficiaries in the Convention, which on a general level include all those considered as PWD in the Convention. To note for further discussion, the recommendations (remedies) by the Committee in this case addressed not only applicant, but also all those like Mr. F that could face challenges with an environment that is limiting and inconsiderate of its members’ unique capabilities. Apart from the general frame of PWDs, The CRPD also lists specific beneficiaries, which can be considered as subgroups under the general classification of PWD. These beneficiaries are noted as being part of other vulnerable groups and in addition to a disabling environment, can create a heavily discriminatory atmosphere that make realizations of rights very difficult. Concerning these sub-groups the CRPD mentions Children with Disabilities (CWDs), Women with Disabilities (WWDs), PWDs in emergency situations and Organizations concerned with disability. In respect for CWDs, and their capacities and identities, Article 7 of the Convention addresses discusses this groups as beneficiaries by requiring States party to the treaty to:

¹⁰⁹ *Id* Article 9(2) f

¹¹⁰ *Id* Article 9(2) h

“(2) take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.”¹¹¹

“(3) ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right”¹¹²

CWDs thus benefit on the obligations of the state in creating an environment in which they may effectively participate in and the equal value of their opinions. Article 7 also discusses the fact that these children must be provided assistance to effectively participate, and children’s assistance could be interpreted depending on the situation; as will be presented later in a decision adopted by the ECtHR concerning child’s parents.

Along with the special provision for children, the CRPD also benefits women with disabilities and recognizes the challenges they face on a daily basis by the double discrimination that they face in their environment and, similarly to Article 7, in Article 6 obliges states to:

“take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”¹¹³

Women have historically been placed on the margin of society, so one can imagine how the presence of a disability would further create discrimination for their development. WWD are not on the equal consideration in society as their male counterparts, and can experience a further discrimination in participation determining on how society and culture interprets their role. For an example, I interpret the cultural context I observed in Lesotho to the Articles above. In Lesotho women are given the role of home-makers, and many parents told me that if they only had

¹¹¹ 2006 UN Convention on the Rights of Persons with Disabilities Article 7(1)

¹¹² *Id* 7(2)

¹¹³ *Id* Article 6

resources for one child to go to school and had to choose between their son or daughter, they would send their son to school. When I asked why, many of the parents noted that it is very important that their daughters learn to be efficient home makers for their future roles as wives and mothers. In terms of disability in Lesotho, from my experience with PWDs in rural villages, they are largely not considered highly by the community, and there are very few efforts made in any type of inclusion for their effective participation. If you couple the vulnerabilities of and imagine yourself as girl with a disability in this context (woman, child and PWD) the importance of specifically mentioning these sub groups separately as beneficiaries is of extreme importance and needs to be acknowledge.

Organizations are also listed as beneficiaries, specifically organizations that represent PWD. Under Article 4(3) *General Obligation*, States are obliged to a particular cooperation as seen below:

“States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

This Article creates the benefits of legislative decision-making ability for those organizations that are focused on the policies concerning PWD. This is an important provision because it obliges states to interact with CSOs and creates more accountability and diversity for those in decision-making roles.

Lastly it is important to mention Article 11 of the Convention, especially in light of the current state of humanitarian affairs across the globe. This Article protects those persons who are considered “in situations of risk or emergencies”. Article 11 recognizes that PWD are living in countries that are going through international crisis, natural or man-made, and through that recognition it obliges states to take:

“all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian

emergencies and the occurrence of natural disasters.”¹¹⁴

With the various conflict and crisis happening on a daily basis, the extreme challenges that these events place for PWDs are placed on the back-burner and could largely be attributed to the plethora of challenges that are experienced in remedying situations for persons affected by these crises. Although challenging, their needs to be stronger efforts in considerations of PWDs in these situations and planning for the challenges they will experience in these situations.

The uniqueness of the UN Convention in addressing the many diverse groups that may find themselves in a disabling situation, aids addressing the types of beneficiaries who also be living in doubly discriminating environments; such as woman and children. This addresses the fact that even within a group that is experiencing discrimination in their community, there are other sub groups experiencing further inequality from the window in which society chooses to place them.

3.1 (b) The Charter

The Charter of Fundamental Rights for the EU is not directly targeted at PWDs, but according to the Charter all persons are considered equal and the Article 21 and 26 cite PWDs as beneficiaries of non-discrimination and measures ensuring integration¹¹⁵. The Charter does not refer to the unique groups under the broad umbrella of disability and, as mentioned above, the generalization of the definition has been critiqued before for leaving a large margin of interpretation to the legislation of the Member States¹¹⁶. Due to the highly vague nature of the Charter, it is difficult to simply mention the sub groups that are also considered as beneficiaries without observing the case law that reinforces the Charter and through resolutions helps adopt more uniformity in application of the Articles within the EU. As cited above the *HK*

¹¹⁴ *Id* Article 11

¹¹⁵ Charter of Fundamental Rights of the European Union

¹¹⁶ cited from The Charter

case helped determine the approach to definition of disability in the EU and was an important milestone to the concept of universalism that the Charter seeks to reaffirm within the Union. An important case that created the more clarity and expansion of the beneficiaries of Article 21 and 26 of the Charter is *Coleman v Attridge Law & Steve Law*¹¹⁷. Coleman's case is interesting because it called into question whether a third party related to a PWDs could be considered a beneficiary of the rights guaranteed to those PWDs. Ms Coleman is a mother that had been working as a legal secretary but due to her son's condition she began taking the role of his primary caretaker. Her complaint towards the Court was that she faced discrimination at work for requesting time off to take charge of some of her child's needs, especially when compared to other colleagues who had children without disabilities. Considering the goal of an enabling environment, these third party affiliates should be considered in legislation surrounding PWDs as they are aiding in the realization of the rights for certain groups of PWDs by creating this enabling environment. The Court (CJEU) sided with Ms Coleman, interpreting Articles within the Directive 2000/78¹¹⁸ in a way that the discrimination of an individual that affects the primary care-taker of PWDs is also in violation of that person being cared for. This was not only an important step in the ideas of beneficiaries of rights in legislation but also monumental step for the EU in promoting an enabling environment for PWDs. If care-takers are also protected under the law, this creates better accountability and legal remedy for PWDs. States must be accountable for the actions they take that could be discriminatory and affect PWDs. In the case of Coleman, the mother losing her job would greatly impact the life of her son, hindering the way his accessibility to his environment. This being said, the specific beneficiaries in the Charter are hard to single out from the general sphere of PWDs, as the Charter does not go into great debt regarding what exactly entails the rights of PWDs. This interpretation, in regards of the Charter, must be found in the jurisprudence.

¹¹⁷ ECJ, 17 July 2008, *Coleman v Attridge Law and Steve Law*, C-306/06 ,EU:C: 2008: 415

¹¹⁸ Article 1 and 2 from Directive 2000/78

3.2 National beneficiaries: Zambia and France

3.2 (a) Zambia PDA 2012

On the national level, the legislation sometimes follows the trend of the international documents. Looking at the current Zambian PDA 2012, there are parallels that are indicative of the inspiration it draws from the CRPD. In Zambian Act the beneficiaries are identified in the beginning of the Act which describes the document's function as follows:

“continue the existence of the Zambia Agency for Persons with Disabilities and define it's function and powers; promote the participation of persons with disabilities with equal opportunities in...”¹¹⁹

In the opening sentences of this Act the beneficiaries are listed as the Zambian Agency and PWDs. Firstly, looking at the most important beneficiaries of this Act, the benefits for PWDs are summarized quite well in the guiding Principles of Part II stating:

“(a) respect for inherent dignity of PWDs, their autonomy-focusing on the freedom to make one's own choices and independence of persons

(b) non-discrimination

(c) recognition as persons before the law

(d) respect for physical and mental integrity

(e) independent living

(f) full and effective participation and inclusion in society

(g) respect for difference and acceptance of persons with disabilities as a part of human diversity and humanity

(h) equality of opportunity

(i) accessibility

(j) gender equality

¹¹⁹ The Persons with Disabilities Act, 2012 “Entitled”

(k) respect for evolving capacities of children with disabilities

(l) respect for the preservation of the identity of children with disabilities”¹²⁰

Looking at the last three Principles included in *J*, *K* and *L* it can also be observed that vulnerable subgroups that are recognized as part of the community of PWDs. *J* mentions the benefits of gender equality for PWDs, putting attention gender and recognizes that gender perspectives create disparities between certain groups of PWDs. Furthering the gender perspective Part IV of the Act, titled “Strategic Planning for Persons with Disabilities” highlights two gender specific directives, which are as follows:

“(b) The mainstreaming of gender into the policies, programmes and activities relating to the equalisation of opportunities for, and integration of, persons with disabilities”¹²¹

“(c) that women with disabilities have equal opportunities to participate in all aspects of life and to ensure the full development, advancement and empowerment of women with disabilities”¹²²

These two directives are important, especially considering the social context in Zambia for women¹²³ who are and are not disabled. In this way the legislation acknowledges the double discriminating climate that exists for women with disabilities and that they must benefit from the same rights as men with and without disabilities to ensure the realizations of their potentials in society. Observing the last two points on letters *K* and *L* in the guiding principles, there is focus on the rights of children with disabilities. Respect for capacity and preservation of identity are important highlights as children without disabilities are often viewed with a lack of sensibility in decision making, and this perception is exacerbated for CWDs. For this reason children are often considered a vulnerable group and have other legislative

¹²⁰ PDA 2012 Part II Section 4, *Principles of Rights of Persons with Disabilities*,

¹²¹ *Id* Part IV, *Strategic Planning for Persons with Disabilities*, Section 21 part (b)

¹²² *Id* Section 21 part (c)

¹²³ MACHINA, Henry. *Women’s Land Rights in Zambia: Policy, Provisions, Legal Framework and constraints” p 2*

texts concerning their specific rights and the realizations of those rights¹²⁴. Within the Act there are multiple mentions to the benefits and rights reserved for CWDs but the general encompassing provision for their benefits is explain in the following provision:

*“(h) children with disabilities enjoy all human rights and freedoms on an equal basis with other children and have equal opportunities and equal access to education, health care, sports, recreation and all other services in the community”*¹²⁵

Similarly, to the reasoning above concerning gender, children without disabilities deal with many challenges in the daily lives, which become further challenging when being tackled by a disabling environment. It is very important that these two groups have special provisions acknowledging their challenges because they will face other more challenges in realization of their rights than an adult male who is in the part of the same group. Interestingly enough this Act has reference to other beneficiaries that do not fall in the typical window of association with disabilities:

*“(g)Children with disabilities and their parents, guardians, and custodians are provided with information about services available and that early interventions such as early stimulation and education shall be provided to such children as early as possible in order to prevent development of disabilities”*¹²⁶

*“(1) The Government shall grant a person who employs a person with a disability a tax rebate of the taxable income in respect of each person with disability employed and shall be prescribed in relevant legislation”*¹²⁷

“(2)The Government shall grant special incentives[...] to business organisations that

¹²⁴ UN Convention on the Rights of the Child

¹²⁵ *Part IV, Strategic Planning for Persons with Disabilities*, part 21 (h)

¹²⁶ *Id* (g)

¹²⁷ “*Division 4 Employment and Social Protection*” under Part V of the Act no. 37 provision 1

employ persons with disabilities”¹²⁸

*“(4) An employer who improves or modifies facilities or avails special services in order to provide reasonable accommodation for employees with disabilities shall be entitled to a tax rebate as prescribed by relevant legislation”*¹²⁹

Beginning with the provision mentioned in g, outside of those directly affected by the disability, those closely related to a CWDs are beneficiaries from the State’s promise to early intervention and proper information regarding disabilities. It is interesting to note that this text highlights “early intervention” and “prevention of development of disabilities” can be seen a violating the right to life of PWD¹³⁰, as early intervention based on prevention could entail the right to abort the child based solely on the fact of their disability. The following three provisions in 1, 2, and 4 highlight the third party beneficiaries concerning disability rights and are very positive initiatives by the State in promoting the presence of PWD in employment. By providing incentives to employers to hire PWDs, the State is showing its concern for the presence and effective participation of PWDs in the community. Although this may not be the most humanistic approach, as employers are in a sense being bribed by the State, it is still a strong step forward into ways of incorporating and integrating PWDs and enabling the environment for the effective participation. Although disability legislation creates benefits for PWDs, the realization of these benefits is subject to effective interpretation of the law. That being said, it the types of beneficiaries identified in the PDA does create a forum for the diverse groups under the umbrella of disability.

3.2 (b) France loi 2005-102

As the other legislative texts mentioned above, the beneficiaries in the French

¹²⁸ *Id* provision 2

¹²⁹ *Id* provision 4

¹³⁰ Perrache case cited earlier: concerning mother who sued doctor for not alerting her that child would be born with disability and not giving her the chance to have an abortion, but doctor’s only fault was allowing the baby to be born

“Loi n° 2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées” are first and foremost persons who are considered disabled who are French citizens or legally reside in France¹³¹. As mentioned in the previous section that observed the definitions of PWD, France’s most current law on disabilities still uses some of the the archaic medical model for its reference to disability¹³². The Act also makes a specific reference to tertiary beneficiaries, which include family members and those closely associated with PWDs¹³³, recognizing the importance of the family unit in the protection and realization. To provide adequate support for PWD, those close to them need to be properly prepared and also supported by the government for their efforts in aiding the advancement of the law. A strong highlight early into the Act is the mention of situations of premature childbirth, where mothers benefit from a protection for their time of leave in order to properly benefit from proper education on the matter for the return home¹³⁴. The article follows is as follows

“Lorsque l'accouchement intervient plus de six semaines avant la date prévue et exige l'hospitalisation postnatale de l'enfant, la période de suspension du contrat de travail prévue aux alinéas précédents est prolongée du nombre de jours courant entre la date effective de la naissance et la date prévue, afin de permettre à la salariée de participer, chaque fois que possible, aux soins dispensés à son enfant et de bénéficier d'actions d'éducation à la santé préparant le retour à domicile”¹³⁵

This is an very innovative approach to disability protection, and respects the notion of the disabling situation not disable persons, as working mothers who give

¹³¹ Loi 2005-102 Titre 1 Art 2

¹³² mentioned in part one of this work, instead of looking at the environment as the disabling factor, it is the persons disability that hinders their participation in society.

¹³³ Loi 2005-102 Titre 1 Art 2§3, “Chaptire 3 Maison departementales de personnes handicapée”s Art 64

¹³⁴ Loi 2005-102 Article 10

¹³⁵ *Id* “When childbirth is occurs six weeks before the expected due date and requires hospitalization of the child, the period of suspension of work contract expected is prolonged for the number of days between the actual date of birth and the expected date, in the end it allows the worker to participate, each time that is possible, to care available to their child and benefit from the health education in preparation of the return to their home” Art 10

birth to a premature infant will face an unexpected situation that will require immediate modifications in their lives. This Article is highly innovative and also promotes equal rights in a gender specific perspective. Students with disabilities (SWDs) are also listed as beneficiaries of specific for adaptable spaces and equal distribution¹³⁶. Interestingly enough, there is a distinction made people elderly persons and PWDs in the Act and creates a unique space for them as beneficiaries in the law. An example of this come from Article 50 which is as follows:

“De contribuer au financement de l'accompagnement de la perte d'autonomie des personnes âgées et des personnes handicapées”¹³⁷

The specific reference to elderly, takes note that advancing age may put someone in a handicap situation, which will require a new type of support to help them achieve the same level of autonomy that they are used to. I mentioned above how the Act mentions the rights of those close to the PWDs, this is further built upon giving rights to persons who are coined as legal representatives. The following excerpt for Article 67 gives an insight into a type of benefit legal representatives have:

“personne handicapée ou son représentant légal a droit à une information sur les garanties que lui reconnaît le présent article”¹³⁸

Basically, third parties are also respected legally concerning the information of PWDs if they are legally tied to the individual through representation (families, friends, other legally appointed individual). The 2005 Act also has a list of beneficiaries that are centered around the topic of employees with disabilities and those close to them that are a part of this process, continued from the previous law of

¹³⁶ Loi 2005-102 Accessibility Articles 19, 20, 21, 22

¹³⁷ *Id* Art 56§1 “Financially contribute to the accompaniment of the loss of autonomy of elderly and persons with disabilities”

also mentioned in Art 57 §3(2), Art 58 §1, Art 58 §2

¹³⁸ *Id* Art 67§2(e) “Persons with disabilities or their legal representatives have a Right to information on the guarantees that are recognized by this article”

1987¹³⁹ We have mentioned generally PWDs benefit from all the provisions existing in the document, but in the frame of employment the law also recognizes tertiary members and through these members creates accountability for the participation in employment PWDs. Extending the 1987 Act¹⁴⁰, Article 27 of the current law recognizes the rights of employment rights of PWDs, but also recognizes a unique group of beneficiaries to this provision. These unique members includes widows and orphans of war and also the wives whose husbands have been confined to an institutions after returning from war¹⁴¹. This provision is a bit outdated, and has a large gender bias, but it does in interpreted manner recognize the right to family life.

Part IV Words in Action: Influence of Legislation

With notable goals of the CRPD, such as evolving definitions and increased autonomy of individuals, being included within legislation at the international and national level, it appears that there is a trend towards harmonization/globalization of the disability concept and the rights that are guaranteed to this large minority. People with disabilities around the world are living in a variety of contexts, and therefore it is difficult for their rights to be understood and effectively addressed similarly. Estimating that 80% of PWDs are living in developing countries¹⁴² an important topic to consider is whether international and national disability are having an ACTUAL influence on the rights of PWD. If there is an effective influence, which, if any has a stronger legislative influence? Following the influence in legislation, we must consider the effective participation of PWDs in the society, as mandated by the UN Convention¹⁴³, are PWDs gaining more visibility in society as agents of change? Finally, the most important question, and is a concept that can be argued, is on the

¹³⁹ Loi n 87-517 1987 *en faveur de l'emploi des travailleurs handicapé*

¹⁴⁰ DARES *La loi d'obligation d'emploi des traigilleur handicapé p 2*

¹⁴¹ BESNER, Eric A. "Employment Legislation for Disabled Individuals: What France can learn from the Americans with Disabilities Act", p.401

¹⁴² BIRTHA, Magdolna, *Nothing About Us Without us: A Case Study on the Involvement of the Disability Movement in Policy Making Zambia*, p 116.

¹⁴³ UNCRPD Art 33

harmonization or universality in the law concerning PWDs; is there or can there be a universal recognition of the Rights of this group?

4.1 International influence

The International Court system has aided in remedying situations for individuals or groups who have not been able to find an effective remedy in their national justice system. At the International level, most notably, the Committee for the Rights of Persons with disabilities¹⁴⁴ is an important source for active jurisprudence involving the CRPD and its implementation and interpretation. The Committee has judicial competence from those states that formally recognize its powers, through the Optional Protocol that followed the UN CRPD¹⁴⁵. Furthering the Committee's competence in interpretation, other international regional Courts, such as the European Court of Human Rights (ECtHR) and the Court of Justice of the European Union (CJEU), have used the CRPD to interpret and aid in the support of legislative decisions concerning PWDs. International cases that have led to disability reform in the international sphere will be presented in the following subsections, highlighting the influence that the CRPD has exercised in the international arena. A few of these cases were discussed above, in regards to beneficiaries, and will not be heavily discussed in the following sections.

4.1(a) Decisions from the Committee

As mentioned above the Committee has gained effective legislative decision-making power after the Optional Protocol (OP) to the Convention was brought into force. The Committee has the ability to consider complaints raised by individuals

¹⁴⁴ Article establishing this committee in the convention and optional protocol, which gives the Committee legislative competence for those countries who are party to the protocol (Article 1 of the Protocol), interesting to note that not all states that have ratified the treaty, have ratified the Optional protocol

¹⁴⁵ Optional Protocol to the CRPD 2007

against the State due to this recognized legal competence, but the effectiveness of their decision-making abilities is dependent on the countries that have ratified the OP¹⁴⁶. The Committee has proved to be a final resource for those individuals who have not received proper or effective remedies from their national governments, and facing continued discrimination from their community. The 2010 case of *HM v Sweden* surrounded the theme of the Right to live a life of quality, not a life¹⁴⁷. In the case, the applicant was refused a building grant for her property as it went against the building codes set in place by city planners. This was not simply a case of remodeling, the applicant required this addition to her home to aid in her recovery following recommendations by doctors who concluded that the addition to her home was essential for her condition to improve. In regards to this case the Committee found Sweden in violation of Articles 5 (paragraph 1 and 3), 19 (b), 25 and 26 of the CRPD¹⁴⁸. The effectiveness of the CRPD in resolving specific concerns that impact PWDs are found within the Articles that were found in violation; especially Articles 19, 25 and 26. Article 19 of the Convention is based on integration and independence, with *section b*, noted by the Committee, stating the following

*“Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”*¹⁴⁹

This section directly addresses the author’s situation, in stating the importance of accessibility to services leading to further inclusion in society. The applicant was bound to her home, as the environment did not support the safety of her health. Considering the situation, the State (party to the CRPD) clearly had an obligation to grant the author’s request that would give her the accessibility to proper treatment

¹⁴⁶ OHCHR UN Committee CRPD’s competence

¹⁴⁷ No. 3/ 2011 *HM v Sweden* CRPD/C/7/D/3/2011

¹⁴⁸ CRPD Art 5 equality, Article 19 Right to , Article 25 Right to, Article 26

¹⁴⁹ CRPD Art 19(b)

that would lead to further participation of the applicant in society. Article 25 places an obligation on states to recognize and provide proper health services for PWDs and is as follows:

“the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for person with disabilities to health services...”¹⁵⁰

From the above, the state is clearly at fault and has acted in a very discriminatory matter. The State argued that their decision was according to national law, but if that was the case it could be said the law is discriminatory, not considering the challenges that the applicant would face daily because due to the law. A State, acting in the interest of the “many”, without regarding individual situations will discriminates others and creates inequality and exclusion. Lastly, Article 26 creates a comprehensive plan and obligation to States to promote independence of PWD and states that

“States Parties shall organize, strengthen, and extend comprehensive habilitation and rehabilitation services and programmes, particularly in areas of health, employment”¹⁵¹

The government’s concern in the case should have been focused on the realization of the applicant’s rights. The extension to the author’s home would have provided a possibility for rehabilitation, ease and inclusiveness, and should have been considered outside of the perspectives of the law. A dynamic point to note from the case is the extent the resolution goes in remedying the applicant’s situation. The Committee resolution mandated the State to prevent further violations of this manner, a remedy that not only concerns the applicant but all members in the community that are, and could be affected by discrimination by the national law on this subject.

¹⁵⁰ *Id* Art 25

¹⁵¹ *Id* Art 26 (1)

The Committee has currently concluded on a seven admissible cases since, and including, *HM v Sweden*¹⁵². The Committee is playing an active role as an influential interpreter, monitor and promoter of the CRPD but, that being said, there are still over twenty cases still pending for review. Considering the global attention and recognition of the UN Convention and the Committee, the number of cases will most likely increase as the CRPD become more prevalent in international law. Will the Committee be able to rise in the event of universality of the CRRP?

4.1(b) Decisions of Court of Justice of the European Union (CJEU)

The European Union acceded to the CRPD in 2010 and in a short time, the influences of the Convention have started to come into play in the legislative actions of the CJEU. Although introduced earlier in this study, concerning the European perspective, I want to further discuss the *HK Danmark* case to highlight the influence of the CRPD and the debut of a possible trend towards harmonization between the CRPD and EU law on disabilities. The CJEU's elaboration of the judgment in the *HK Danmark* case particularly cited the UN CRPD's Preamble, recognizing "that disability is an evolving concept", Article one on the definition¹⁵³ and Article 2 that concerns "reasonable accommodation". The applicants in this case were experiencing a disabling environment due to a sickness, and the CJEU re-evaluated the concept of disability in this case. The Court thus affirmed that since *Chacon Navas*¹⁵⁴, the CRPD had been ratified by the Union and further consideration of the case was required to honor the principles in the Preamble of the Convention. In that regard, The CJEU moved from the medical definition in *Chacon's* case, to a social model respecting the CRPD. The ruling was very important and indicated the EU's willingness to adhere to

¹⁵²Concluded cases available at ohchr.org

¹⁵³CRPD Article 1 "those who have long term physical, mental, intellectual or sensory impairment which in interaction with various barrier may hinder the full and effective participation in society on an equal basis of other"

¹⁵⁴ECJ, 11 Jul 2006 *Chacon Navas v Euresit Colectuvidades SA*, Case C013/05, EU:C:2006:456 First definition of disability for the CJEU

implementing the Convention in its legislative activities, decisions that affect other Member States. Most recently, in 2014, the CJEU has interpreted disability in a unique case of *Kaltoft v Municipality of Billund*¹⁵⁵. In the case the applicant, Kaltoft, had been terminated from his job, which the Municipality reasoned by the current decline in market of the applicant's career. As the only employee to be dismissed and observing events leading up to his dismissal¹⁵⁶, the applicant brought his complaint to the Court as he believed his termination was solely based his obesity. The CJEU was now faced with the whether obesity could fall under the frame protection from discrimination due to disability. It must be highlighted the monumental meaning of the fact that the Court was considering the situation surrounding the applicant's termination and how his obesity played alongside the environment. The Court was in fact positing on whether obesity *in this situation* could constitute a disability; honoring the "evolving concept of disability". It is important to note that this case followed the important decision of the Court during the HK Danmark, which asserted the Court's position on disability and the Convention. The CJEU, through the resolutions in these two cases, has rapidly shown its commitment and respect to the foundations of the CRPD, which could become the basis for disability law for the CJEU.

The EU's accession to the Convention is a historical event¹⁵⁷ and observing the above cases, it appears that the future of disability law in the EU is heading in a social model that follows the principles of the CRPD. The influence of the Convention is dependent upon the interpretation by the Court but, although interpretive, the CJEU is bound to respecting the principles of the Convention concerning cases of disability. In a semi-direct manner, the CRPD is shaping legislation concerning PWD throughout the Member States of the EU.

¹⁵⁵ ECJ, 18 Dec 2014, *Kaltoft v the Municipality of Billund*, C-354/13 EU:C:2014:2463

¹⁵⁶ Applicant was visited by officials from the municipality who were "inquiring" about his weight

¹⁵⁷ CLIFFORD, Jarlath, *The UN Disability Convention and its Impact on European Equality Law*, p11 "On 23 December 2010, The European Union ratified the United Nations Convention on the Rights of Persons with Disabilities, it is the first time in history that the EU has become a party to an international human rights treaty"

4.1(c) Decisions from European Court of Human Rights (ECtHR)

Since the CRPD's entry into force in the legal arena, its effects have come full circle in interpreting and creating standards in the international and regional courts¹⁵⁸. The ECtHR has utilized the CRPD more efficiently than the CJEU, uniting the principles found in the European Convention of Human Rights (ECHR) and the CRPD¹⁵⁹. The movement of the ECtHR reaffirms the commitment of COE to its Action Plan on the promotion of disability rights. The ECtHR has decided on numerous cases and, as will be discussed in this section, has benefitted from the CRPD in its interpretation of Articles in the ECHR for decisions concerning PWDs. An important case decided by the ECtHR concerning disability and the window of consideration, is that of *Glor v Switzerland*. This case surrounded a Swiss national who was suffering from diabetes and medically declared unfit for, compulsory, military service by a military doctor¹⁶⁰. The applicant's case was brought before the ECtHR due to the fact that he was required to pay an exemption tax¹⁶¹, although declared unfit for service by a military doctor previously¹⁶². The applicant's felt that he should not be obligated to pay an exemption tax for something he was willing to do but hindered from due to the interpretation of his status by the community. The main idea surrounding this case was whether the State's requirement imposed on the applicant was discriminatory of his disability. The ECtHR made an important

¹⁵⁸ *Id* p 19

¹⁵⁹ *Id* p. 20

¹⁶⁰ No.13444/04. *Glor v Switzerland* Eur. Ct. H.R. 2009 Court's Decision: ECtHR sided with the applicant finding a violation of Article 7 and Article 14 of the ECHR, and obliged the Swiss government

¹⁶¹ No.13444/04. *Glor v Switzerland* explained that in Switzerland Swiss men who did suffer from a major degree of disability exceeding a degree 40% had to pay a tax in order to be exempted from their military service, found under Article 59 of the Federal Constitution concerning Military, which in part 3 is as follows: "All men of Swiss nationality who do not do military service or substitute civilian service shall pay a tax".

¹⁶² No.13444/04. *Glor v Switzerland*, explained that in Switzerland Swiss men who did suffer from a major degree of disability exceeding a degree 40% had to pay a tax in order to be exempted from their military service, found under Article 59 of the Federal Constitution concerning Military, which in part 3 is as follows: "All men of Swiss nationality who do not do military service or substitute civilian service shall pay a tax".

statement observing the fact that there is a “European and worldwide consensus on the need to protect people with disabilities from discriminatory treatment”, and this consensus could be attributed to the CRPD and its global acceptance through ratification¹⁶³. This would be the first time the ECtHR mentioned the UN Convention as a base for a “universal” view on the perspectives surrounding PWDs¹⁶⁴. This is an important part of the UN Convention’s history as it shows the movement of the CRPD towards document of force could be utilized for universal application in the sphere of disability rights and legal remedies. It is equally important to note that the ECtHR (due to the circumstances of the case) viewed diabetes under the window of disability and discussed the concept of reasonable accommodation¹⁶⁵, which follow the CRPD’s idea of disability as an “evolving concept” and the importance of an environment that is accommodating¹⁶⁶. Not long after their decision in *Glor*, the ECtHR used the support of the CRPD again in interpreting the disability concept in the case of *Alajos Kiss v Hungary*. In this case, the applicant presented his case to the ECtHR because barred from voting following a medical diagnosis that put him under partial-guardianship¹⁶⁷. The applicant felt that his condition did not warrant his exclusion from political participation and cited that there was no remedy for the current issue in the Hungarian Constitution. The ECtHR considered the Articles 1, 12, and 29 of the CRPD for interpretation, as Hungary had ratified the UN Convention¹⁶⁸. Articles 12 and 29 of the CRPD are highly relevant in this case and concern both legal capacity and the right to vote, and (without much interpretation) place a clear obligation of the State to protect the right to vote for PWDs¹⁶⁹.

¹⁶³ 166 Countries are party to the UNCRPD

¹⁶⁴ STAVERT, Jill, *Glor v Switzerland: Article 14 ECHR, Disability and Non Discrimination*, p143

¹⁶⁵ CLIFFORD, Jarlath, *The UN Disability Convention and its Impact on European Equality Law*. p 20

¹⁶⁶ Article 2 CRPD “Reasonable Accommodation”

¹⁶⁷ No. 38832/06. *Alajos Kiss v Hungary*. Eur. Ct. H.R. 2010: In Hungary under Article 70(5) of the Constitution, individuals are not able to participate in election automatically if they are placed under guardianship. Resolution from the ECtHR: Court was in favor of the applicant and cited that a blanket ban on voting rights can not be placed on an individual without individual assessment. Violation of Article 3 of Protocol 1 of the ECHR “Right to free elections”

¹⁶⁸ Hungary ratified UN CRPD in 2007

¹⁶⁹ UN CRPD Article 12(3) “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”
29(a) Ensure that persons with disabilities can effectively and fully participate in political and public

They also help build on the standard in Article 3 of Protocol 1, expanding upon the idea of free elections in the disability perspective. This is an important case to consider because it brings in the question of legal capacity, and what (if any) rights can be subject to suspension if an individual is determined to be “lacking” a certain decision-making capability. The concept of individual assessment brought up by the ECtHR in this case, is an important step to recognizing that legal capacity must be taken on an individual basis, as it will vary from between persons and their interactions with the unique environments in which they live in. This is also a question of autonomy, which is a controversial topic concerning persons with intellectual disabilities in a legal and social setting. The ECtHR addressed this idea in the *Stanev v Bulgaria case*, where the applicant had been kept in a mental care facility against his will, having no access to his funds during his time at the facility¹⁷⁰. The applicant presented his case before the ECtHR as he believed that he had been deprived from his right to liberty due to the facility’s physical location coupled with inaccessibility to his identifying documents and money, which created a barrier to his ability to exercise his autonomy. Concerning the CRPD the ECtHR referenced Articles 12 and 14 of the Convention, 12 referenced before in the *Alajos Kiss case*¹⁷¹ and 14 that obliges States to respect the right of liberty¹⁷². Article 14 also discusses that if denial of liberty occurs for the individual, reasonable accommodation must be taken into account¹⁷³. Considering the fact that the applicant did not want to be kept at that facility his right to liberty was violated and also his ability to make decisions regarding his own wishes. It should also be noted that in the case, the applicant’s guardian had no relationship to him and, upon making the decision to place the

life on the equal basis of other...including the right and opportunity of persons with disabilities to vote and be elected...

¹⁷⁰ No. 36760/06. *Stanev v Bulgaria*. Eur. Ct. H.R. 2012 Resolution The Court sided with the applicant finding a violation in Articles, 3 (conjunction with Article 13), 5(§1,4,5), and 6§1. The ECtHR considered that there was not an effective remedy with the national Constitution for the applicant to be reevaluated or to have an effective judicial review.

¹⁷¹ CRPD, Article 12 concerning *Equal recognition before the law*” particularly in *Alajos Kiss v Hungary case* the ECtHR looked at section 2 of this Article that discussed the enjoyment of legal capacity

¹⁷² CRPD, *Liberty and Security of Person* Art 14(1) [a &b]

¹⁷³ *Id* 14(2)

applicant in said facility, had never met the applicant. Although the actions taken by the guardian were not developed further in the case, they represent one of the negative examples that the CRPD is trying to amend on the concept of guardianship that still teeters on the cliff with support versus control¹⁷⁴. The ECtHR missed an opportunity to address this fault but this case was still very effective in the acknowledgment of the legal capacity of people having mental disabilities¹⁷⁵, a group that still does not receive adequate respect for their rights to autonomy¹⁷⁶. The ECtHR also sought support from the UN Convention for interpretation of the discrimination of the applicant in *Kiyutin v Russia case*¹⁷⁷. The applicant brought his complaint before the ECtHR due to his denial of a residence permit by the Federal Migration Office, due solely to his HIV positive status¹⁷⁸. Not only was this action highly discriminating to applicant but also affected his personal life, as he had married and had a child with a Russian national a few years prior to the case. Under relevant international instruments Articles 5(2), 8(1b) and 23(1) of the UN CRPD were mentioned to aid the interpretation of ECHR towards the particularities of this case¹⁷⁹ and obliges State Parties to prohibit discrimination, recognize autonomy on liberty of movement and respect for family¹⁸⁰. Considering the specifics of this case, the sections from the Articles above were extremely relevant to the case, and echo the Articles from the ECHR that were found in violation by the Court¹⁸¹. The ECtHR noted that the applicant was eligible for receiving a residence permit due to his

¹⁷⁴ UN CRPD, Supported decision making models---include reading of this

¹⁷⁵ ACUNA, Erik, *Institutionalization of People with Mental Disabilities: Comparative Analysis between its treatment under the Inter-American and European System of Human Rights*, p. 81

¹⁷⁶ *Id* Abstract p 72

¹⁷⁷ No. 2007/10. *Kiyutin v Russia*. Eur. Ct. H.R. 2011. Court decision: Violation of Art

¹⁷⁸ In Russian Foreign Nationals Act 7(1)(13) there is a restriction on issuance of a residence permit for those foreign nationals who are unable to show that they are HIV negative and the refusal also specified that the applicant had to leave the country within three days.

¹⁷⁹ UNCRPD Art 5 “Equality and non-discrimination”, Art 18 “Liberty of movement and nationality”, Art 23 “Respect for home and family”

¹⁸⁰ UNCRPD Art 5(1) “2. prohibit all discrimination on the basis of disability”, Art8(1) (b)are not deprived, on the basis of disability, ...to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement”, Article 23(1) “take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships on an equal basis to others”

¹⁸¹ ECHR Article 8 “Right to respect of private and family life”, Article 14 “Non Discrimination

marital and parental status and that the only limiting his successful application for his permit was his HIV status. Also noted in the court, was an international consensus that discrimination on the basis of an individuals HIV status is not justified¹⁸². In terms of the exchange between illness and disability, the ECtHR had already discussed this possibility in the case of *Glor v Switzerland* that was presented earlier. Building on previous case law and the “international consensus” on disability that the CtHR had noted earlier in *Glor*, the applicant’s HIV status could easily be seen as a disabling factor that lead to discriminatory acts against him that affected his rights within the CRPD and ECHR. This case shows the continued interpretation of the ECtHR that is inline with the UN Convention’s notion of disability as an “evolving concept” and re-enforces the influence that the CRPD has concerning the interpretation of the ECHR. The ECtHR has continued to use the CRPD for interpretation in jurisprudence, in cases such as, *Haas v Switzerland*¹⁸³ and *Jasinskis v Latvia*¹⁸⁴. Most recently the ECtHR has interpreted the CRPD in *Çam v Turkey*¹⁸⁵ and *Guberina v Croatia*¹⁸⁶. It is important to highlight the case of *Guberina v Croatia* as it discusses the idea of disability rights for those persons indirectly affected by a disability. This case was brought to the ECtHR by the parent of a child with a disability who had chosen to leave his apartment due to the inaccessibility of the building for his child. The applicant applied to a tax exemption after purchasing a

¹⁸² ECtHR mentions in the communication that there is an international consensus that expert and international organisation consensus is that there is no justification in the restriction of travel for HIV positive persons. Also third party noted that in the joint report “Disability & HIV Policy Brief” of 2009, the UNOHCHR, WHO and UN AIDS on the applicability of HIV

¹⁸³ No. 31322/07. *Haas v Switzerland* Eur. Ct. H.R. 2011

¹⁸⁴ No. 45744/08. *Jasinskis v Latvia*. Eur. Ct. H.R. 2010

¹⁸⁵ No. 51500/08. *Çam v Turkey*. Eur. Ct. H.R. 2016 Court’s decision: the Court recognized that the unaccommodating environment of the academy did not warrant an exclusion from the community. It is important to note that although the Court found a violation in this case¹⁸⁵, the remedy awarded by the case is not effective at all and does not consider the community of PWDs. The Court in this case decided to provide monetary compensation for the applicant, but this (in my opinion) provides a limited application and durability in the realization of the Rights of other PWDs that could be affected by this type of discrimination currently and in the future.

¹⁸⁶ No. 23682/13. *Guberina v Croatia*. Eur. Ct. H.R. 2016 Court’s decision: Siding with applicant, The CtHR found a violation of Article 14 “non discrimination” in conjunction with Article 1 of Protocol No 1 of the ECHR and ordered compensation of pecuniary damages

new property, under the Real Property Tax Act¹⁸⁷, citing that the conditions in his previous home made it impossible to take his child out of the house¹⁸⁸. The applicant's request was denied because domestic authorities came to the conclusion that his previous apartment met the needs of his family, an analysis that did not take into account the inaccessibility the applicant's son faced daily and would continue to face if the family remained in the same property. The ECtHR cited Articles 2, 3, 4, 5, 7, 9, 19, 20, and 28 of the UN Convention¹⁸⁹ for interpretation in the case, and mentioned the practice of the Committee of the CRPD along with the above Articles¹⁹⁰. Addressing the specifics of this case provisions interpreted from Articles 7, 9, 19, 20, 29 are highly relevant and echo the notions of the rights of CWD, accessibility, integration, freedom of movement and right to a quality life¹⁹¹. Observing the sections of the Articles within the UN Convention that were utilized by the ECtHR, it is apparent the need of the CRPD for interpretation concerning the

¹⁸⁷ ECtHR: section 11(9) Tax exemption for a person who was buying a flat or house in order to remedy their housing needs, and they did not have a

¹⁸⁸ ECtHR: Applicant's son is in a wheelchair and family was previously living on the third floor, which the applicant said made it impossible to meet his son's needs and prompted him to purchase the new property.

¹⁸⁹ Art 2 "Definitions", Art 3 "General Principles", Art 4 "General obligations", Art 5 "Equality and Non Discrimination", Art 7 "Children with Disabilities", Art 9 "Accessibility", Art 19 "Living Independently and being included in the community", Article 20 "Personal mobility", Article 29 "Adequate living standards and social protection

¹⁹⁰ Practice of UN Committee, noted "1. Accessibility is a precondition for persons with disabilities to live independently and participate fully and equally in society. Without accesspersons with disabilities would not have equal opportunities for participation in their respective societies" and "29. It is helpful to mainstream accessibility standards that prescribe various areas that have to be accessible.....Persons with disabilities who have been denied access.....should have an effective legal remedies at their disposal. When defining accessibility standards, State parties have to take into account the diversity of persons with disabilities in provision of accessibility...."

¹⁹¹ UNCRPD Art 7 (1) & (2) "1. take all necessary measures to ensure the full enjoyment by children with disabilities for this which immediately followed the entry into force of the treaty and of all human rights and fundamental freedoms....2. In all actions concerning Children with disabilities, the best interests of the child shall be a primary consideration", Art 9(1) "1. Take appropriate measures to ensure to persons with disabilities access on an equal basis as others... These measures, which shall include the identification and elimination of obstacles and barriers to accessibility", Art 19 (a)&(b) "(a) Persons with disabilities have the opportunity to choose their place of residence...and are not obliged to live in a particular living arrangement (b) persons with disabilities have access....to community support services...to prevent isolation and segregation from the community", Art 20 "ensure personal mobility with the greatest possible independence for persons with disabilities, Art 29 "recognize an the right of persons with disabilities to an adequate standard of living of themselves and their families, including adequate food, clothing and housing and continuous improvement of living conditions and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability"

multitude of specific factors concerning PWDs. It is clear that the national government's decision was in violation of the standards in the CRPD and was highly discriminatory towards the applicant's son. More than just discriminatory, the decision made against the applicant at the national level did not take into account the applicant's son and the difficulties that he would face by remaining in the previous location. As the main guardian, the applicant was acting in a matter that created a more enabling environment for his son to have higher accessibility to his community, and the State should have taken this under consideration during their judicial proceedings and conclusions. The ECtHR also noted this negligence of the national courts to take into account the particular situation the applicant was in, and passing judgment without consideration.

The ECtHR has sought the interpretation from the CRPD in multiple cases concerning PWDs and through previous jurisprudence, specifically those mentioned above, it seems that they are moving inline with the ideas of accessibility and evolution that are key principles within the UN Convention. The ECtHR has also acknowledge practices communicated by the Committee, giving weight to this body, that continues to grow in force with continued ratification of the Optional Protocol to the CRPD. Although having less jurisprudence concerning the CRPD, the CJEU also seems to be giving weight to the CRPD through legislative decisions since it formal accession to the UN Convention. One way in which the CJEU meets its own barriers is in the interpretation of legal capacity, as it has no competence (or little) to decided on this matter¹⁹². This could be the reasoning for the lack of cases decided by the CJEU in this area, as legal capacity has been left to the determination of Member States. Although there is a positive influence from the UN Convention, the sustainable remedies proposed by the ECtHR are lacking the same effectiveness as the Committee. There needs to be a push towards more effective remedies that are not solely monetary and do not require all PWDs to bring their cases before a decision

¹⁹² Fundamental Rights Agency, *Legal Capacity of Persons with Disabilities and Persons with Mental Health problems*, p.7

making body, but rather oblige states to change their discriminating environment once and for all.

4.2 National Influence

The influence of international and regional law surrounding the entry into force of the UN CRPD (with the Optional Protocol), has definitely gained a tangible force through its short legal lifetime. If the UN Conventions continue on the same trend of events, its influence will revolutionize the concept of disability and legislation regarding PWDs. With that being said, is this influence solely attributed to the CRPD or is there a similar effect at the national level? For this discussion on national legislative influence of disability policies we will look at Zambia and France. These two countries actively have disability specific legislation.

4.2 (a) Zambia

Zambia enacted its most current disability legislation in 2012, known as the Persons with Disabilities Act (PDA) that immediately followed its ratification of the CRPD¹⁹³. The PDA has many similarities with the UN Convention, honoring the respect for the rights based model that is shrouded throughout the CRP¹⁹⁴. Although the PDA finds the majority of inspiration from the CRPD, it has been critiqued as it does not fully domesticate the UN Convention¹⁹⁵. The influence of the PDA can be in its continuation of the *Zambian Agency for Persons with Disabilities*¹⁹⁶, which is the national recognized body that helps coordinate the government with promotion and implementation of activities for PWDs and is an important body that creates a

¹⁹³ In Zambia for international treaties to have legislative importance they must be domesticated following communication in *No. 2008/AHLR/259 Attorney General v Roy Clark ZaSC 2008* “In applying and construing *Zambian Statutes*, courts of law can take into account international instruments to which Zambia is a signatory. However these instruments are only of persuasive value, unless they are domesticated by law”

¹⁹⁴ CHILEMBA, Enoch Macdonnel. “Disability Rights and Emerging Disability Legislation in Selected African Jurisdictions”. p 299

¹⁹⁵ BANDA, Natasha. KALALUKA, Likando, *Country profile: Zambia*, p 271

¹⁹⁶ PAD 2012 Part III *Zambian Agency of People with Disabilities continued with this Act*

link between the civil society and the government¹⁹⁷. It is also given legislative power to bring complaints before the courts and have, under the powers in the previous Act, brought issues before the High Court concerning discrimination against PWDs¹⁹⁸. Aside from this continuation, the affects of this new legislation can mostly be associated with the empowerment of DPOs, which will be discussed later in this paper, who have seen the national interpretation of the CRPD as a moment for them to become more active to insight change in the country's advancement of disability policy. This is the influence that creates change, although not directly from the government, it shows a trend for the State towards real democratic relations; the effective and important exchange between the government and the people that it represents. Recently, a Special Rapporteur from the UN who visited Zambia noted that if the government can prioritize the legal framework already in place Zambia could “become a disability champion in the African region”¹⁹⁹. Obviously the legal framework is already in place nationally, but it is up to the government to turn the text into a reality; a reality that could be an example and extend disability rights and politics around the whole continent.

4.2(b) France

The influence of French disability law can be seen in the creation and increased interaction of different consultative a monitory bodies that are concerned with the effectiveness of the national plan concerning PWDs towards social inclusion. Following the evolution of the definition of disability in the current 2005 law, came the advancement and interpretation on the issues of accessibility and compensation

¹⁹⁷ BIRTHA, Magdolna , *Nothing about CRPD Monitoring Without US: A case study on the involvement of the disability movement in policy making in Zambia*, p 127

¹⁹⁸ *No. 2011/HP/0818 Sela Brotheton v the Electoral Commission* (Secretary of ZAPD and suing with the capacity given to her by the State) v the Electoral Commission of Zambia. Resolution: High Court sided with the applicant sighting that there was discrimination against PWD by the Electoral Commission and ordered a remedy be put in place for increased accessibility of the polling stations during the for the *next election* proceedings

¹⁹⁹ *Zambia has the potential to become a disability champion in the African region*, 28 Apr 2016

for PWD in France²⁰⁰, and it is these two themes that have dominated the politics concerning PWDs in France and where the 2005 law has produced the most effective influence. Under the framework for compensation, the departmental houses for PWD were created (MDPH), following 2005 Act/law, to provide an individualized plan of action of compensation from PWD and their families²⁰¹. This type of compensation was revolutionary for France as it put in place a system that was based on the principle that PWD would decide compensation plan unique to their needs²⁰². The individualized disability compensation plan (PCH) is created with a representative from the MPDH along with the PWD (and/or family member) and can be used for a variety of aids, such as human/animal assistance, technical aids, home adaptations and transport²⁰³. This consultation and planning service has pushed the autonomy of PWDs and put them at the forefront of decision that concern their daily needs for facilitation of their accessibility in society. This revolutionary idea is based on the idea that autonomy for PWDs is determinant on the financial resources the individual has available to be effectively integrated in society and achieve what is possible²⁰⁴. The implementation of new compensation plan has raised the average monthly compensation available reportedly from 2007 to 2008 the number of people receiving PCH, giving up the old model from the previous disability law²⁰⁵. Uniquely, Compensation benefits are on average a bit higher for university students with disabilities, in consideration of their needs, and do not factor the student's parent's income²⁰⁶. Ultimately though, this creates a unique approach to the distribution of unique financial needs of and with PWDs that can be tailored to their specific needs, with the goals of greater inclusion in society. Accessibility being another key concept

²⁰⁰ BARRAL, Catherine, ROUSSEL, Pascale, SANCHEZ, Jesus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people* p 2

²⁰¹ *Id* p 13

²⁰² BADEL, Maryse, *La loi pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées: un nouvel élan pour la prise en charge du handicap*, p. 28

²⁰³ BARRAL, Catherine, ROUSSEL, Pascale, SANCHEZ, Jesus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people*, p. 16

²⁰⁴ BADEL, Maryse, *La loi pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées: un nouvel élan pour la prise en charge du handicap*, p. 29

²⁰⁵ BARRAL, Catherine, ROUSSEL, Pascale, SANCHEZ, Jesus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people*, p. 16

²⁰⁶ *Id* p. 20

of the 2005 Act, a very ambitious goal was set in place after its entry into force. The idea being that by the 2015 all public spaces, existing and those following the Act, would be completely accessible²⁰⁷. Unfortunately the report that followed this decade's dream revealed that, only thirty-percent of the target areas had been reached²⁰⁸. Although not a complete success, it has shows the movements that have been made since the 2005 and the continued strive for the principles of the law. An important step raised in the report was the interest of the government in protecting the law. During this decade the State and Constitutional Council annulled three Acts that were proposing a delay on the 2015 mark, and although they had not reached the intended goal, the protection of the principles and promises for the decade helped achieved the strides that are in place today²⁰⁹. The actions taken by the state do show a commitment to the goal and spirit of the law and if more force is put behind all relevant actors, the influence of this legislation can be expedited/ A strong positive outcome within the report was in the sector of the Minister of Culture, which noted success in accessibility of publications and television as well as increased participation of PWD in artistic education²¹⁰. The government also asked for feedback concerning the report for different organizations, including actors in DPOs which I think is important for tackling the issues that still plague the effective implementation of the disability law.

It appears that France, through restructuring the legislation with organized units and creating target points on disability issues, has found a way to advance and build upon the diverse points of issues affecting the inclusion of PWDs and those in their care circle. Although not having updated their legislation since ratification of the CRPD, France is acting in the spirit of the principles of the CRPD and moving forward with the advancement of disability rights through consultation of the actors

²⁰⁷ “*La France face au défi de l’accessibilité: de la nécessaire adaptation de la loi du 11 février 2005*” p. 14 –interestingly accessibility to information was also included in this plan, BARRAL, Catherine, ROUSSEL, Pascale, SANCHEZ, Jesus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people*, p. 5

²⁰⁸ “*La France face au défi de l’accessibilité: de la nécessaire adaptation de la loi du 11 février 2005*”

p. 1

²⁰⁹ *Id* p. 17

²¹⁰ *Id*

concerned. Though advancing, there are still issues that are not being discussed effectively, such as persons with intellectual disabilities. The 2015 report lacks any reports on persons with intellectual disabilities, or any moves towards changing legislation that deprives them of autonomy²¹¹. In 2011, the ECtHR found France in violation of not providing adequate medical attention to a prisoner having physical and mental health issues²¹², denying her dignity and dismissing her mental health as an act. Most recently, Human Rights Watch (HRW) released a report concerning the number of people with psychosocial disabilities in French prisons without adequate treatment or attention²¹³. This echoes the issues that are still concerning autonomy for this subgroup and the need for further development of the law that respects the dignity of all PWDs.

4.3 “Nothing about us, without us” Agents of Change: A Real Paradigm shift?

“Nothing about us, without us” has become the slogan for the disability movement and echoes Article 33 of the CRPD, which calls for State Parties to include civil society in the process of its legislative evolutions concerning. Disregarding the various legislative texts that promote the goals of Article 33 of the CRPD²¹⁴, the most important area to consider is if PWD are effectively part of the decisions that directly concern them and the group that society places them in with the term “disabled”. In terms of efficacy, I am concerned with the presence of PWDs in decision-making and legislative processes and not solely the fact legislation or jurisprudence concerning PWD has increased. Remaining on topic with this paper, I will discuss the increase in presence of DPOs and CSOs in France, Zambia, and the international sphere.

²¹¹ BARRAL, Catherine, ROUSSEL, Pascale, SANCHEZ, Jesus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people*, p. 13

²¹² No. 36435/07. *Raffray Taddei v France*. Eur. Ct. H.R. 2010 Court’s decision: The ECtHR finds a violation of Article 3 of the Convention

²¹³ HRW article “*Double Punishment: Inadequate Conditions for Prisoners with Psychosocial Disabilities in France*”

²¹⁴ UNCRPD Art 33, principles: “*Protect, promote, and monitor*”

4.3 (a) *Zambian Agents of Change*

In Zambia, the concept of disability is evolving and there are still problems associated with accessibility and resources available, which are pinnacle to sustainable development. The WHO reported, in 2011, that fifteen percent of the population in Zambia are living with a disability, with most of this percentage being concentrated in rural areas²¹⁵ Although barriers are still present, PWD are pushing through and demanding to be heard and to be part of the decisions that concern their autonomy and independence. There are strong DPOs present within Zambia and most of them are under the representation of the *Zambian Federation of Disabled Persons (ZAFOD)*²¹⁶, which main activities are in advocacy, education and support²¹⁷. ZAFOD has legally been recognized as the “umbrella” organization since the 1996 PAD Act²¹⁸ and has put idle words into action. A good example of their efficacy comes from the case cited earlier of *Sela Brotherton v the Electoral Commission of Zambia*²¹⁹, which was brought to the High Court by ZAFOD. The applicants, who visited the site, noted that the Electoral Commission failed to secure legislative changes that would guarantee the effective participation of PWDs during the electoral process in Zambia. This information was made available by a report released a year prior by ZAFOD who concluded the inaccessible inaccessibility of the polling

²¹⁵ ILO “*Inclusion of People with Disabilities in Zambia*” 2013 p 1

²¹⁶ ZAFOD created in 1985, officially registered in 1995

²¹⁷ ILO “*Inclusion of People with Disabilities in Zambia*” 2013 p?. ZAFOD represents DPOs such as *Zambian Association of Disabled Women, Zambian Association of the Deaf, Zambian National Association of the Hearing Impaired, Zambian National Association of the Partially Sighted, Zambian National Association of the Physically Handicapped, Zambian Association of Children and Adults with Learning Disabilities, Zambian Association of Parents with Disabilities, Mental Health Users Network of Zambia (MHUNZA)*

²¹⁸ ZAFOD “Background information”

²¹⁹ *No. 2011/HP/0818 Sela Brotherton v the Electoral Commission High Ct. Za 2011*

Court’s decision: High Court of Zambia concluded that under Section 19 of the PAD 1996 “discrimination means (a) treating a person with a disability less favorably from a person without a disability” and noted that the Commission was acting unfavorably towards applicant. The HCt ruled that, in the next election, the Electoral Commission must erect temporary ramps, ensure polling booths are located on the ground floor of buildings, and include a tactile ballot guide for voters who are blind

stations to PWDs²²⁰, made available to the Electoral Commission with recommendations. The Commission did not follow through with any of the recommendations, and proceeded with the preparations of the polls. This case is very interesting in the fact that ZAFOD effectively brought a complaint before the High Court on behalf of the request of the civil society. PWDs in Zambia are challenging the government to recognize their rights to effective participation in society and taking their complaints towards judicial remedies. It is also equally important to note that there was a report done by the DPOs a year prior to this case, which echoes Article 33 of the UNCRPD in the push for PWDs in the part of the monitoring process. PWDs in Zambia are not only taking a passive role and solely monitoring their discrimination, but are actively in the forefront of the follow through and promotion of their rights. In terms of this case an example of executive participation comes from Mr Wamundila Waliuya²²¹, who at the time of the case was the Human Rights manager of ZAFOD. Mr. Waliuya was an important witness in the interpretation of the communications that had been done between ZAFOD and the Electoral Commission prior, highlighting the fact that problems were identified (as early as 2006) but there had been no changes implemented in accessibility of the polls for PWDs to effectively participate in the voting process. Although the remedies proposed were granted by the HCt, the judge noted that trying to remedy the polling stations for the current elections would be “damaging” to the nation and therefore mandated the remedies be done in time for the next election. This judgment ended with a double edge sword, it basically acknowledges a violation but places the interest of the many over the other interest. How can a violation be considered democratic? In specifically mentioning this provision in the remedy, the Court

²²⁰ *No. 2011/HP/0818 Sela Brotheton v the Electoral Commission High Court* Audit of stations showed that they were inaccessible to PWDs, mostly concerning those blind and wheel chair bound. The registration officers at the polling stations also did not have any knowledge of sign language and many PWDs were made to stand in lines with no access to bathrooms, which the ZAFOD noted as a highly demotivating factor

²²¹ Currently is the Disability Inclusion Specialist for Plan International Zambia (linkedin, disability rights watch), previous Human Rights Manager for ZAFOD, according to Disability Rights Watch he has been working with DPOs for many years and is also a trainer and activist on the UNCRPD <http://disabilityrightswatch.net/about-us/board/> Global Disability Watch posted a short biography of him noting he is a person with a visual impairment <http://globaldisability.org/our-team/wamfl>

acknowledges that the current election will not be followed through democratically as it will not represent the will of ALL citizens. It also echoes the importance of an accessible society, without access the most fundamental of rights cannot be realized. Along with this representation in the legal systems, DPOs in Zambia are engaging in activities of monitoring to make sure government is maintaining the principles upheld within the PAD and the CRPD. After Zambia ratified the CRPD they were obligated to have a board that would monitor the implementation of the UN Convention²²². The solution created by the Zambian government was not considered effective by DPOs in the country and so, instead of waiting for action, they created their own monitoring board, known as the Independent Monitoring Unit (IMU)²²³. The IMU was initiated by ZAFOD in 2011, and its main focus was to assist with the domestication of the CRPD into the national legislation²²⁴. Due to the circumstances surrounding its birth, the Zambian government did not formally recognize IMU and due to continued miscommunications there has not been coordination between this group and the Human Rights Commission of Zambia, even though it is listed as part of the IMU body²²⁵. Although not coordinating well with the HRC, the IMU is composed of a multiple stakeholders in disability politics of Zambia and includes (in the spirit of Art 33 CRPD) government, international and civil actors²²⁶. This initiative taken by the civil society, particularly DPOs is inspiring and disheartening at the same time. An inspiration in the fact that it shows the power of civil society in the response to a government that is not effectively engaging the issues of its citizens. This is also disheartening as it shows problems that can occur during the democratization process, which can derail a movement if external solutions are not found. The IMU, not being recognized formally by the national government, had to search for funding externally to help with the monitoring process²²⁷. This is not inline with what the UN Convention is trying to promote, and does not show an effective change. The

²²² UNCPRD Art 33

²²³ “Zambia Persons with Disabilities” African Disability Yearbook 2013 pp 127,129

²²⁴ *Id* 127

²²⁵ *Id* pp 127, 129

²²⁶ *Id* 127-includes ZAPD,

²²⁷ *Id* p 127

advancement of disability cannot occur if the group who is directly affected is the only interested party, it must be a collected effort from a government that supports the autonomy of its citizens. The inspiring initiative taken to achieve the IMU echoes the unresponsiveness of government to the people, which is a problem for sustainable change and is damaging to the concept of democracy.

A lingering problem in Zambia, discussed earlier in this essay, is the Mental Disorders Act of Zambia. The MDA, brought into force in 1951, remains key legislative document in the country concerning those with intellectual or psychosocial disabilities although it has been critiqued due to the terminology used to describe PWD, such as imbecile and lunatics²²⁸. The MDA gives authority to police officers and magistrates who “believe” that a person is of “unsound mind” or “defective” to arrest or put in detention²²⁹. The language and ideas proposed by those provisions of the MDA are frightening as they put the autonomy and liberty of an individual at the interpretation of how others interpret them. This Act strongly goes, wholeheartedly, against the spirit and goals of the CRPD and of human rights in general. Under ZAFOD there is one DPO dealing representing the rights and interest of individuals with mental disabilities, and is known as the Mental Health Users Network of Zambia (MHUNZA)²³⁰. In 2014 MHUNZA, along with the Mental Disability Advocacy Center (MDAC), released a report known as “Human Rights and Mental Health in Zambia”²³¹. The document includes accounts from over 100 people with intellectual or psychosocial disabilities and their families²³², and after findings of continued systemic violations against people with mental health disabilities (even after the Zambia’s ratification of the CRPD) MHUNZA, MDAC and ZAFOD presented a list of recommendations aimed at remedying the issues surrounding this marginalized

²²⁸ BANDA, Natasha. KALALUKA, Likando, *Country profile: Zambia*, pp. 272-273

²²⁹ *Id* 273 Section 8 and 9 of the Mental Disorders Act

²³⁰ *Id* p. 277

²³¹ Available at <http://www.mdac.org/en/zambia>

²³² MDAC & MHUNZA, “Human Rights and Mental Health in Zambia: Recommendations for Action” p 1

subgroup, most notably among these is the need for a new legislation on the derogatory and condescending Mental Disorders Act²³³.

There is a powerful push for change within the community of PWDs that is leading to more recognition within government and the movement in Zambia echoes the importance of advocacy and representation of PWDs by their peers that is a quintessential part of Article 33 of the CRPD. DPOs are even taking the initiative outside of the capital and into rural villages throughout Zambia, raising awareness to disability rights through education on the CRPD and providing copies of the document in different accessible formats²³⁴. Speaking from my experience in Lesotho, this initiative of human rights is very important to advancing the rights of PWDs. Considering that most PWDs are living in developing countries, if there is not a push to educate those in rural areas with limited access to information, disability politics will remain in a narrow window; a window that will only affect those privileged enough to be presented with the information. The disability movement in Zambia seems to be heading in the right direction and hopefully the government and the civil society can work together to maximize the potential of the framework that is already in place.

4.3(b) France: Agents of Change

The current disability law in France²³⁵, was created through the collaboration of the government and CSOs following the controversial Perruche ruling and this law, although created before the presentation and entry into force of the CRPD, respects many of the fundamental principles of the UN Convention and drastically changed the definition from the limiting disability law of 1975²³⁶. DPOs have been present in disability politics since 1975 and have been actively part of the creation on

²³³ *Id* p 3

²³⁴ BIRTHA, Magdolna, *Nothing about CRPD Monitoring without Us: A case Study on the Involvement of the Disability Movement in Policy Making in Zambia*, p 133

²³⁵ Loi 2005-102

²³⁶ MAISSONEUVE Catherine, *La loi de handicap et les collectives territoriales*, p. 13: 1975 d'orientation en faveur des personnes handicapées concerned mostly disability institutions, not their participation in society

specialized institutions, which are still managed by the DPOs involved in their creation²³⁷. Growing with the changing definition is the presence of PWDs as agents of change. Following the 2005-102 Act different consultative and monitoring bodies were created that are geared towards the effectiveness of the law and the support towards the realization of the Rights of PWDs.

The most prominent DPO in France is the National Advisory Council of Persons with Disabilities (CNCPH), which is the main organization that works with the national government towards advancement of disability legislation²³⁸. The CNCPH is most notably attributed to the development of the current policy in France, especially the unique PCH benefit program that was discussed above in the national influence²³⁹. The PCH most likely achieved its success due to the government's involvement of the CNCPH in consultation and drafting of the process of this policy. The CNCPH issues a report every three years on the compliance of certain organs with the policies that surround the 2005-102 Act. The most recent report was issued in October of 2015 and that evaluated projects throughout France and gave recommendations on whether the perspective respects disability rights²⁴⁰. A very important concern was communicated through this report on the MDPH and its effectiveness. The report noted that some organizations were not content with the system of compensation, problems of needs and response and a reform of processes and departments such as the MDPH²⁴¹. Along with CNCPH, there are a many of DPOs invested in advancement and inclusion of PWDs in France. Among those Coordination Handicap Autonomie (CHA), Association des Paralysés en France, and Groupement pour l'insertion des personnes Handicapées (GIHP) are some of the DPOs challenging large issues for PWDs and demanding the recognition of the government. CHA's was able to mobilize a strike, targeting the issue of problems

²³⁷ BARRAL, Catherine, ROUSSEL Pascale, SANCHEZ, Jésus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people*, p. 4

²³⁸“*La France face au défi de l'accessibilité: de la nécessaire adaptation de la loi du 11 février 2005*” p.20 CNCPH is composed of disabled persons

²³⁹ Id

²⁴⁰ CNCPH October Report 2015 available at http://social-sante.gouv.fr/IMG/pdf/avis_cncph_de_sept-dec_2015.pdf

²⁴¹ Id pp 4-5 discussed “Zero sans solution” report

with compensation for those PWDs who are highly dependent on assistance in their daily activities, resulting in the PCH benefits increasing coverage expenses for personal assistance²⁴². GIHP provides accessibility support in the community and has most notably created three apartment buildings able to accommodate over sixty students with disabilities in three different cities²⁴³. The APF has a very exciting campaign for the 2017 elections called *AGIR2017*, which creates a forum for ALL citizens (not just PWDs) to vote for proposals and make suggestions to them that APF will raise towards the candidates in the next election²⁴⁴. The defining line of this campaign, where real change occurs, is “*agir ensemble*” or act together. The true strength of a community is its ability to work together for a change, rather than in the separate groups constructed by society. APF has vocalized its dissatisfaction with the current implementation of the law²⁴⁵ and is looking for a change or penalty of the 2005 Act²⁴⁶. The disability movement in France is active and PWDs are exercising pressures on the State to further effectively implement the 2005 Act. There does appear to be a growing dissatisfaction with legislation and the strategies proposed over the last ten years, coupled with the fact that France has had disability specific legislation forty years, which could lead to another movement for legislative change for more effective and inclusive policies.

France and Zambia have very prominent disability movements, which are being headed by PWDs who are focused on creating an inclusive environment. Although each country has separate disability issues in their respective environments, both countries are together in the fact that their societies still have faults with accessibility and recognition issues that PWDs face in their fight for self-determination.

²⁴² BARRAL, Catherine, ROUSSEL Pascale, SANCHEZ, Jésus, *France: ANED Country Report on the Implementation of Policies supporting independent living for disabled people* p 9

²⁴³ GIHP webpage under “Nos actions pour l’autonomie”

²⁴⁴ APF webpage under “Campagnes”

²⁴⁵ *La France face au défi de l’accessibilité: de la nécessaire adaptation de la loi du 11 février 2005*, p.

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²⁴⁶ *Id* p.56

4.4 A trend towards Harmonization?

Between the international, regional and national legislative instruments presented above and the evolution of the concept of disability and the persons concerned, it is important to think of the goals behind these movements and efforts in federal and civil activities. Has the legal and social concept of disability become more universal? Regarding the harmony in the increasing global community, that is very difficult to ascertain. The social construct of disability and PWDs has many strides towards a universal human rights design, as the diverse contexts and cultures that PWDs are a part of determine how they are perceived. Observing some of the changes happening through the legal discourse, international law is providing the platform for this universal definition. The CRPD is increasingly being referenced in the European courts, using a (almost) globalized definition of disability to build the framework on the socio-economic rights of this group. Nationally, from the observations of France and Zambia, the effect of the CRPD can be felt through the initiative of the civil societies, who are holding their governments accountable and pushing legislation from the paper and into action. Although not completely harmonious, there does seem to be fundamental rights for PWDs that are being harmonized under the law, in the areas of accessibility, adequate living and autonomy. Legally speaking, it appears that the European community is taking the initiative towards harmonization of the CRPD regionally, which could be a step towards a universal model. Hopefully this trend towards harmonization will continue, reinforcing the principles of CRPD that have a impactful influence revolutionize disability rights all around the world.

V Limitations, recommendations and conclusions

Have the rights of PWDs evolved? The answer is no because their, or better our, rights have always existed but with a slight problem of recognition. The disability rights movement lacked a comprehensive approach in its early stages, which left many fundamental rights out of scope of application. Since the Declaration

by the UN, it seems as though the recognition for the rights of PWD in society has rapidly evolved the way disability and those affected are able to exercise their most fundamental rights right; self determination. PWDs, at the national level, are becoming agents of change and bringing out the effectiveness of existing (previously dormant) legislation. The foundation of a democratic society is built on the will of the people, and PWDs are exercising their new found opportunities that a creating greater inclusion for them in society. The entry into force of the UN CRPD has, in my opinion, revolutionized the politics on disability in the short time since its adoption by the UN General Assembly. The velocity of its evolution, has to do with the combined and inclusive approach to disability legislation that is occurring now. PWDs are being consulted at the national and international level, which is creating greater visibility. Not only are they being consulted, but actively voicing their critiques on previous and existing legislation, and igniting a change. If we take the case of Zambia, the CRPD gave disability actors in the country a platform. These DPOs and CSOs rapidly hopped onto that platform and through new opportunities have been included in legislative decisions and remedies for the issues that were collecting dust. The Optional Protocol of the Convention is also creating a new space for legal remedies with the recognized competence of the Committee of the CRPD to address individual complaints that address violations on the principles of the Convention. The Committee is beginning to give another voice and concluding jurisprudence that has effective remedies for the entire community. The accession of the EU to the CRPD is a defining moment that appears to be in the process of harmonizing the politics governing EU law. With further interpretation of the CRPD by EtCHR, this harmonization could come full circle for the European region if the EU and COE maintain the “evolving concept” of disability in their actions. Although there are tangible positive changes happening for disability rights, the legal and social applications still have factors that are limiting the real potential for change.

5.1 Limitations

From my experience and the observations before and throughout this study, there are definitely “real world” limits to adequate recognition of the rights of PWDs and the effectiveness of their participation. Firstly, the scope of disability rights from the courts and the Committee shows a potential problem with accessibility to information. In a regional perspective most of the disability cases decided by the ECtHR have been raised from countries in the COE with higher economic resources (Sweden, Denmark, The United Kingdom, and Switzerland), which usually correlates to better access to information. Internationally, observing cases decided by and pending with the Committee of the CRPD, only five out of the thirty-two cases are outside of the European region²⁴⁷. This also could be indicative of a lack of transparency in developing countries, where the majority of the population lives in areas with limited daily communication technologies. In Zambia, ZAFOD has coordinated an effort to educate rural community members on the existence and powers of the CRPD and the principle of the document. This is a great initiative, but it should not be left solely to the DPOs to implement the Convention, as was the case with the creation of the IMU. Following this lack in accessibility, another factor that is limiting are the remedies designated in the courts. While the ECtHR has been very effective in interpreting the CRPD, the remedies and decisions issued by the courts are monetary. Monetary compensation is important but if the problem in the environment is not remedied, and there is no monitoring in place to ensure a change, the problem of inaccessibility will persist. Therefore negating the spirit of the Convention and the dynamic disability movement. This raises questions of those democratizing states and their progressive interest, which may allow violations to continue in the name of development. The most important issue regarding PWDs currently is the recognition of the right to autonomy of people with intellectual and psychosocial disabilities. They are still largely being kept at the margin of society, with laws that allow for their liberties to be taken away, such as the cases of the *Taddei* and *Stanev* cases. There are still hurdles that must be passed for globalized

²⁴⁷ OHCHR

recognition, but there is a movement in place. If the limits on this movement can be addressed, the future of politics and participation of PWDs is very promising considering the strides that have been made in the last forty years, and more importantly, since the entry into force of the CRPD and the Optional Protocol.

5. 2 Recommendations

In light on some of the issues, a few recommendations would be in the frames of education, legal capacity, and effective remedies. In the area of education, I allude more towards those societies living without daily access to communication technology. Through combined initiatives by DPOs, local government and the Committee of the CRPD towards increased human rights education and training on the CRPD in rural areas of developing countries, there can be more awareness on the legal remedies and obligations of the state to protect the rights of PWDs. Not only education on remedies but also in fundamental human rights being shared by all²⁴⁸. Concerning legal capacity, there needs to be a legal model in place that respects the autonomy of the individual. Article 12 of the CRPD addresses *Supported Decision Making (SDM)*, a model of guardianship that respects the decision-making abilities of the person under guardianship²⁴⁹. It is an exchange that promotes autonomous rights and participation in the community. In terms of remedies, there need to more effective remedies, similar to those concluded by the UN Committee, that take into account the situation and how it can be remedied. Money is not compensation for continued discrimination.

In theory, with the current course of disability rights these recommendations may not be a far off reality. The international community needs to come together to support the development of this movement; especially in countries were resources

²⁴⁸ . In Lesotho, I taught a course on human rights and it was amazing to see some of the rights that were still quite taboo or not discussed in the community. The lack presentation of the issues, keep them hidden in the community

²⁴⁹ CARNEY, Terry, BEAUPERT, Fleur, *Challenges in advancing CRPD Supported Decision Making*” p.179

impede the effective implementation and growth of disability policy. There have been large strides for PWDs and they are increasingly a part of the legislative decisions that concern their community. The growing human rights modeled definition and recognition of disability rights is empowering PWDs to claim their rights. A claim that is needed for their effective participation, accessibility and autonomy in “our” increasingly globalize world.

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