

Disability, Living Conditions and Quality of Life

*The case of the Municipality of Anapoima in
rural Colombia*

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THESIS SUMMARY

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May 2015

Submitted as a part of the Master of Philosophy Degree in
International Community Health

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Data Collection: September 15 - December 1, 2013

Funding: This study was funded in part by a grant from the Ivar Helles Foundation.

ACKNOWLEDGEMENTS

This master thesis would not have been possible without the help and support of numerous people, to whom I am and will always be very grateful.

To my parents and relatives in Colombia: there are no words to express my gratitude for their unconditional love and support, and for providing the necessary lodging.

To my wife: for her kind and warm encouragement, for her help with translations, and for her positive critique.

To my supervisors: I am extremely grateful to Prof. Arne Henning Eide and Gunnar Aksel Bjune. I wish to further thank Prof. Arne Eide for his thoughtful guidance, exceptional support, patience, and dedication, and to Prof. Gunnar Aksel Bjune for his expertise, constructive criticism and advice, and his stimulating insights.

To all the participants who willingly decided to take part in this study.

To my research assistant, Irma Mahecha: for facilitating the data collection, for her motorcycle rides to treacherous and at times remote locations, and for her guiding skills during the fieldwork.

To the personnel at Anapoima's City Hall: for welcoming me with open arms. Special thanks to Luz Maria Vargas and Nayibe Vargas at the Social Development Office, for their kindness and enthusiastic support.

To Nidia Constanza Piñeros and the Seeds of Hope Foundation - FUSES: for sharing with me her experiences in working with disabilities in Anapoima, and for her sincere assistance.

To the diligent assistance provided by the Research Division at El Bosque University in Bogotá: my profound appreciation goes to Dr. Miguel Otero Cadena and to Maria Helena Alarcón Ovalle, for their outstanding support and thoughtfulness towards this study.

To Sibel Volkan: for kindly allowing me to use the WHOQOL-BREF questionnaire on behalf of WHO.

To the Ivar Helles Foundation: for their financial support to the project.

To my fellow classmates: for their friendship, good will and support throughout the master studies.

And last but not least, to Ragnhild Beyrer (now retired), Line Løw and Terese Eriksen: for their friendliness, willingness to help, and for always being available when needed.

PREFACE

This thesis is being submitted as part of a Master of Philosophy degree in International Community Health at the University of Oslo. The current submission follows the second option, among the forms for delivering the master thesis, accepted as highlighted on the “4th semester, spring 2014” guidelines, under *Requirements of the Master Thesis* section, from the Department of Community Medicine: **One article submitted to an international peer reviewed journal + a summary**. Hence, results and discussion of findings are not included.

The thesis begins with an abstract of the manuscript that was submitted for publication to the **Scandinavian Journal of Disability Research** on February 2015. This is followed by the introduction that explains the topic’s importance, as well as background, and what is already known about the topic from scientific literature. Other sections include the rationale for the study, the research question and the objectives.

In the methodology section, a brief methodological consideration is presented along with detailed materials and methods.

At the end, a list of cited references, pertinent appendices and a copy of the submitted paper concludes this thesis.

ABBREVIATIONS / ACRONYMOUS

BCODP:	British Council of Organizations of Disabled People
CBR:	Community-Based Rehabilitation
CRPD:	Convention on the Rights of Persons with Disabilities
DANE:	National Administrative Department of Statistics – Colombia. (Spanish: <i>Departamento Administrativo Nacional de Estadística</i>)
DPI:	Disabled Peoples International
ECLAC:	Economic Commission for Latin America and the Caribbean
ICIDH:	International Classification of Impairments, Disabilities and Handicaps
IDB:	Inter-American Development Bank
IDRM:	International Disability Rights Monitor
ICF:	International Classification of Functioning, Disability and Health
ILO:	International Labour Organization
GNP:	Gross National Product
NCD:	Non-communicable Diseases
OAS:	Organization of American States
PAHO:	Pan American Health Organization (Spanish: <i>Organización Panamericana de la Salud – OPS</i>)
QOL:	Quality of Life
SES:	Socioeconomic status
SPSS:	Statistical Package for Social Sciences
UN:	United Nations
UNDP:	United Nations Development Programme
UNESCO:	United Nations Educational, Scientific and Cultural Organization

UNFPA: United Nations Population Fund
UNICEF: United Nations Children's Fund
UNSD: United Nations Statistics Division
WG: Washington Group
WHO: World Health Organization

ABSTRACT

Disability, Living Conditions and Quality of Life

The case of the Municipality of Anapoima in rural Colombia

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The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes that individuals with disabilities have the same rights to freedom, respect, equality and dignity as everyone else. How this is perceived by individuals with disability themselves may be a good indicator on implementation of the CRDP. This article analyses the relationship between disabilities, living conditions and quality of life of people living in rural areas in Colombia, as well as the impact of disability on their living conditions. Using data collected through household surveys, comparisons were made between individuals with and without disabilities, as well as between households with and without a disabled family member. The survey consisted of three questionnaires: one on living conditions, another on quality of life and a third on disability. These pre-existing and validated questionnaires, which had been used in some sub-Saharan countries, were adapted to the Colombian context. Even though the Socioeconomic Status indicator (Material Possessions Scale) ranked higher among the cases than among the controls, persons with disabilities and their families showed a considerable lower quality of life than the control group. This suggests the negative impact that disability exerts on quality of life.

Keywords: disability; living conditions; quality of life; survey; Colombia

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1 INTRODUCTION

1.1 Importance of the topic

According to WHO, a world population of over one billion experience some form of disability. This corresponds to about 15% of the planet's population. Disability is becoming a significant matter; its prevalence is increasing, and this is a cause for concern (WB-WHO, 2011). Throughout the world, the number of ageing people is increasing, as well as their lifespan. An ageing population, in turn, gives rise to a higher risk of disability. Additionally, in the coming years, more and more elders from all over the world will have suffered from disabilities as a result of non-communicable diseases, like diabetes, cancer and heart disease (NIH-WHO, 2011).

In general, people with disabilities have difficulty reaching education goals, are marked by economic deprivation, have more significant health issues, and are less involved in all aspects of society, compared to people without disabilities. This is the result of the numerous obstacles that people with disabilities encounter when they try to access a different array of services like education, health care, transportation and employment. These difficulties are even more notorious in low- and middle- income countries of the world (WB-WHO, 2011).

In the last decade the term disability has been gaining more ground within the human rights framework. However, greater awareness of disability issues as well as additional documentation with scientific information on disability, are much needed. While disability deserves enhanced policy attention and resources in public health and international development, there are still enormous gaps when it comes to evidence about disability, especially in low- and middle-income countries of the world (Bickenbach, 2011). There is a need to not only narrow the gap, but also to create awareness and to help achieve a more equalitarian environment for people with disabilities in all aspects of life – from getting access to education, transportation and health care, to being a participative member in the labor market and in a variety of social and cultural activities.

1.2 Background

The Convention on the Rights of Persons with Disabilities (CRDP) was adopted by resolution on December 13th, 2006 during the sixty-first session of the General Assembly. The Convention was open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of March 30th, 2007. As of January 2015, the Convention has been signed and ratified by 151 states. Through the signing of the convention's content, governments have demonstrated their goodwill to improving the rights of individuals with disabilities, as well as their commitment with the world and their citizens. Colombia signed the Convention on March 30th, 2007, and ratified it on May 10th, 2011 (UN, 2014). The states that have signed and ratified the Convention, are now required to promote, protect, and ensure total and equal enjoyment of human rights and fundamental freedoms by all persons with disabilities, as well as to promote respect for their inherent dignity.

The Convention brings hope mainly to over 1 billion people living with disabilities all over the world; the majority of them, about four fifths, live in developing countries. According to the latest available data, the Economic Commission for Latin America and the Caribbean (ECLAC) has estimated that at least 66 million people in Latin America and the Caribbean (LAC) are living with at least one type of disability. These figures represent 12.3% of the total regional population (ECLAC, 2012). The empirical support for this estimate is however weak in many low- and middle- income countries in the region. This is because methods of data collection across the Americas vary greatly. Most countries report disability prevalence rates well under 10%, while in cases like Chile, the prevalence rate varies from 2.2% to 5.3% and even up to 21.7%, depending on the survey and/or the methodology used. These figures are based on reports from censuses or surveys from UNSD, as shown in Figure 1 (UN, 2003; IDRM, 2004; ECLAC, 2012).

The majority of the countries in the Americas continue to use different impairment-based definitions of disability in at least some part of their legislation. Colombia has already begun using, in very recent disability policies and disability assessment systems, a definition of disability based on the International Classification of Functioning (ICF). As a result there are conflicting definitions between national legislations, which exert a direct impact on how disability is measured (IDRM, 2004).

Figure 1 compares the population-weighted average prevalence of disability for 33 countries in Latin America, gathered from multiple sources like censuses and surveys (ECLAC, 2012) (WB-WHO, 2011).

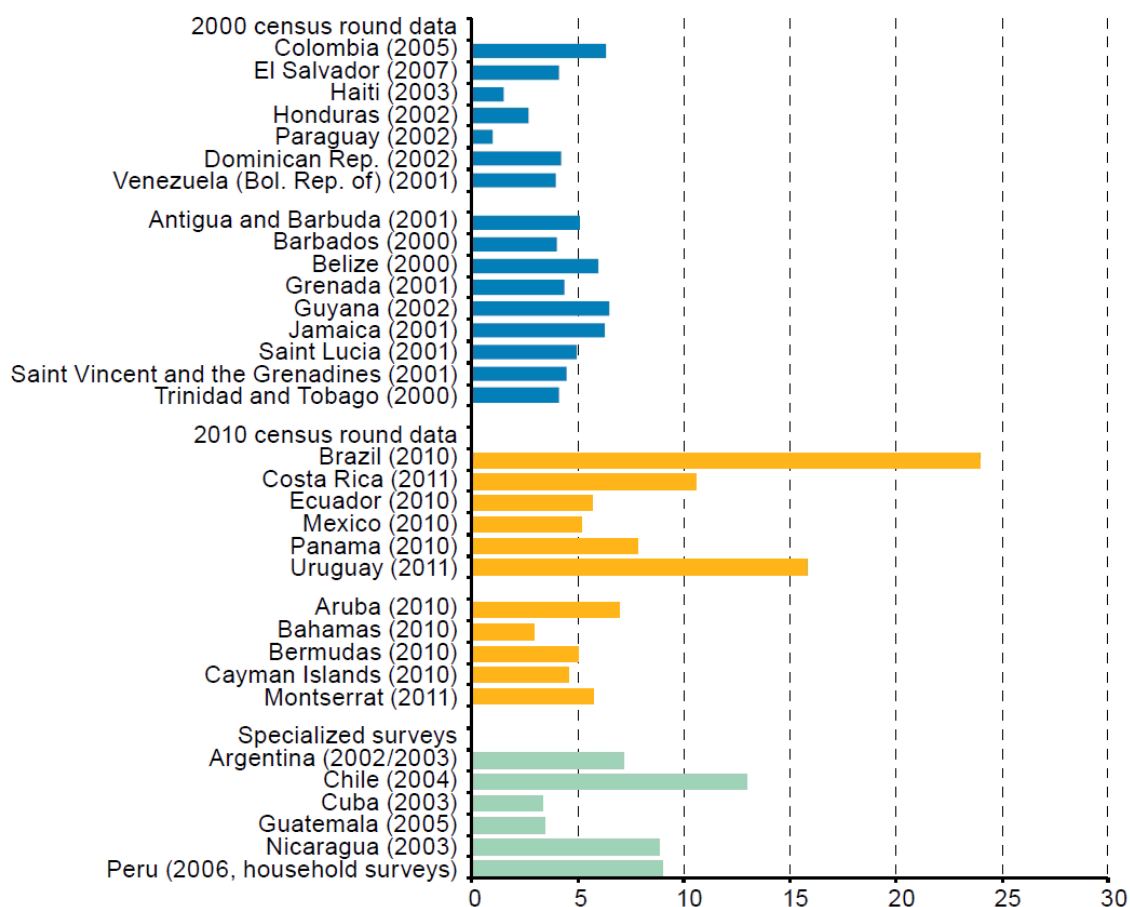


Fig 1: Prevalence of disability - Country variations within Latin America. (Source: ECLAC, 2012)

When it comes to the economic circumstances in both, low-income and high income nations in the region, there are considerable contrasts, as well as a wide range / diversity in the predominance of disability. Trinidad and Tobago, Bahamas, Aruba, Cayman Islands and Bermuda, are some of the nations found under the high-income category. Nations such as Antigua and Barbuda, Argentina, Barbados, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, Grenada, Jamaica, Mexico, Panama, Peru, Saint Lucia, Saint Vincent and the Grenadines, Uruguay, and Venezuela, fall under the upper-middle-income category. Belize, El Salvador, Guatemala, Guyana, Honduras, Nicaragua, Monserrat, and

Paraguay, are placed under the lower-middle-income category. The only nation found under the low-income nation is Haiti.

Regrettably, in Latin America, individuals with disabilities continue to endure a susceptible and relegated position; this, in spite of the economic circumstances of any given nation. Even though several conventions and agreements were signed in recent times, susceptibility and relegation live on and significantly affect individuals living with disabilities in the region.

The inability to identify disability rights as human rights, as well as the unwillingness of politicians to take action, have resulted in the absence of wide-ranging policies and laws that facilitate individuals with disabilities to have access to equal chances, in terms of education, employment and protection of their civil rights. The sense of humanity and value of individuals with disability has been reduced in worth by the failure of society to classify disability as a human right.

1.3 Agreements, conventions, and organizations

Over the last decades, not only the number of papers that have been written about disability has increased, but also the number of agreements and conventions that have been signed in order to bring necessary attention to the issue. This in turn has given rise to international standards regarding disabled people and their rights. Some of the agreements and conventions that have had the greatest impact in Latin America are listed below (Contreras et al., 2006):

- 1948: The Universal Declaration of Human Rights was adopted by the United Nations General Assembly
- 1980: The World Health Organization develops the ‘Community-Based Rehabilitation’ (CBR).
- 1981: The UN declares this year the ‘Disability International Year’
- 1982: The UN subscribes the ‘World Programme of Action Concerning Disabled Persons’
- 1982: The UN proclaims the period 1983-1992 the ‘United Nations Decade of Disabled Persons’

- 1993: The UN General Assembly adopts the ‘Standard Rules on the Equalization of Opportunities for Persons with Disabilities’
- 1999: The Organization of American States (OAS) signs the ‘Inter-American Convention on the Elimination of all forms of Discrimination against Persons with Disabilities’
- 2004: The heads of state of Spain, Portugal and the Latin-American Countries declare this year the ‘Ibero-american People with Disability Year’

Additionally, an increasing number of international organizations have become involved and more active members in the defence of this cause in the region (Contreras et al., 2006). Among them:

The Pan American Health Organization (PAHO) has taken a number of measures regarding the Disability issue. Through the *Noncommunicable Diseases & Disabilities Unit*, PAHO not only coordinates and implements technical cooperation activities to strengthen capacities of Member States, in order to adequately respond to the burden of NCDs and disabilities; PAHO also participates in the related global agenda on NCDs for the Americas. Its work is directed toward human resources training, mainly on aspects related to rehabilitation and disability prevention. This organization has also stimulated technical cooperation between different countries.

The World Health Organization (WHO) in partnership with other UN agencies, collaborating centres and nongovernmental organizations initiated and developed *Community Based Rehabilitation* (CBR) following the Declaration of Alma-Ata in 1978. The declaration focuses on enhancing the quality of life for people with disabilities and their families; meeting basic needs; and ensuring inclusion and participation. CBR is a multi-sectorial strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR has been implemented with the support of PAHO in many countries, including LAC countries, over the last decades. Since the 90's ILO, UNESCO and WHO have been working together to establish programs related to CBR, and to facilitate both coordination and cooperation for its application.

The International Labour Organization (ILO) has developed programmes to promote the creation of dignifying jobs for men and women with disabilities. The ILO’s Disability Programme promotes equality of opportunity and treatment for persons with disabilities in

vocational rehabilitation, training and employment, while the ILO Code of Practice on Managing Disability in the Workplace was finalized and unanimously adopted in 2001. Both, the Programme and the Code of Practice, help to promote employment opportunities for people with disabilities and to overcome obstacles that might arise and interfere with the inclusion of people with disabilities in the labour market.

The United Nations Children's Fund (UNICEF), has been watching over the fulfilment of the 'International Convention of Children's Rights'. UNICEF has also been developing strategies to include children with disabilities into their programmes. Disability is one of the issues they cover with the aim to attain global development of children.

The United Nations Educational, Scientific and Cultural Organization (UNESCO) has been taking care of Special Education, designing policies and laws, training teachers, and giving financial support. They designed the framework for the 'World Declaration on Education for All' (1990).

The World Bank (WB) has been directing its attention over the sustainable development of nations. In the context of inclusive development, the *Advisory Service on Disability and Development*, was created on 2000. This office directs its efforts towards people with disabilities and the conditions of exclusion they have to face, especially in developing countries.

The Inter-American Development Bank (IDB) has been working in two areas: (a) Urban Development, with emphasis to access to public transportation; and (b) Social Development, with focus in poverty and exclusion of people with disability, improvement of statistical analysis system and data collection, and market labour insertion of people with disability.

The above mentioned list of agreements, conventions, and organizations shows the multilateral effort that has been made, which is still taking place, in order to create political awareness and to call the attention to the problematic of disability and human rights in Latin America.

1.4 Situation of people with disabilities in Colombia

A study that used comparable data from 14 developing countries found not only that people with disabilities tended to be less well off in terms of education, employment, living

conditions, consumption and health, but also that, on average, households with disabilities also report spending a higher fraction of their expenditure on health care (Mitra et al., 2011).

Disability is an important cause and consequence of poverty. "About 82% of disabled people in LAC live in poverty, which in most cases also affects family members", reads the World Bank's Fact Sheet named: "Disability in Latin America and the Caribbean". This shows that disabled people tend to experience widespread exclusion from the social, economic and political life of the community, whether due to active stigmatization or due to the neglect of their needs in the design of policies, programs and facilities.

Even though recent progress in internal rules and regulations show a more social approach based on human rights, it is clear that in Colombia, the way in which disability is addressed is still largely influenced by the medical rehabilitation approach. In practice, there is still a close relationship between the concepts of disease and disability. Therefore the programs and actions that have been implemented throughout the country are based on this relationship. Such programs and actions are still intended to bring the disabled individual into conformity with the concept of "normality", rather than being aimed to developing and implementing a set of specific adaptations to the environment, so that people with disabilities can be fully included and have genuine participation in society. This explains why most of the resources are intended to provide health and rehabilitation services and evidences the gap between the perception of the government and the reality of the population living with a disability (Colombia Report, 2014).

Colombia is an upper middle income country that has a relatively high GDP per capita income of US\$7,826 (UN, 2013). Nevertheless, over 30% of the country's population live below the national poverty line (WB, 2013). According to the United Nations Population Fund, on 2014, Colombia had a calculated total population of 48.9 million people (UNFPA, 2014). With the World Report on Disability estimate in mind, the number of people with some kind of disability amounts to more than 7 million (WB-WHO, 2011). With the purpose of increasing health coverage for its population, a universal health insurance scheme was introduced in 1993. Prior to the introduction of the mandatory social health insurance, just over 20% of Colombians had health insurance. Likewise, access to and use of health care was low, and around 60% of those who reported an illness did not seek assistance from a health facility due to the costs associated with the service. The introduction of subsidized health insurance had as a result a broadening in health coverage for the poorest of the population which may, in turn,

benefit people with disabilities. Figures from 2008, showed that not only over 85% of the population was insured at the time, but also that access to and use of health care had increased for the general population, especially among the poor (Glassman et al., 2009).

Additionally, data about the situation of people with disabilities in Colombia is sparse. The 2005 general census revealed a disability prevalence of 6.4%, up from just 1.8% from the previous census of 1993 (DANE, 2005). In most cases, figures obtained by census in relation to the population with disabilities represent only the more severe or permanent disabilities. Censuses are usually tools that look for the presence of disabilities by the use of one or just a few relevant questions in most cases. Consequently, the results show an average between 2% and 5% of total national population (OPS, 2012). For the specific case of the Municipality of Anapoima – located 87 km south-east from Bogotá – in terms of permanent disability alone, the 2005 census revealed a prevalence of 9% for women and of 9.5% for men, which is around 45% higher than the average in the country (DANE, 2005). The 2005 census in Colombia estimated the prevalence of disability based in the answer to a YES/NO questionnaire included in question 39, which contains 9 items (Fig 2).

Does [the respondent] have permanent limitations for: (basic)	YES	NO
1. Mobility or walk?	<input type="checkbox"/>	<input type="checkbox"/>
2. Move his/her arms or hands?	<input type="checkbox"/>	<input type="checkbox"/>
3. See, despite using contact lenses or glasses?	<input type="checkbox"/>	<input type="checkbox"/>
4. Hear, even with hearing aids?	<input type="checkbox"/>	<input type="checkbox"/>
5. Speech	<input type="checkbox"/>	<input type="checkbox"/>
6. Understand or learn?	<input type="checkbox"/>	<input type="checkbox"/>
7. Maintain relationships with others due to mental or emotional problems?	<input type="checkbox"/>	<input type="checkbox"/>
8. Bathe, dress, feed himself/herself?	<input type="checkbox"/>	<input type="checkbox"/>
9. Other permanent limitation?	<input type="checkbox"/>	<input type="checkbox"/>

Fig. 2: Extracted from the Colombian General Census of 2005 (Question 39)

Even though the focus of these 9 items is *limitations*, they still include most of the domains covered by the WG6. In addition, one item includes *limitations in maintaining personal or social relationships*. This shows the sensible intention of going beyond a pure set of items on impairments or limitations. Yet, the measuring disability questions on the 2005 Census, came short of the improved WG6's extent.

1.5 Literature Review

This thesis puts forward Disability, Quality of Life and Living Conditions as the three fundamental notions of this study. My perception of these concepts has evolved in synchrony with few noteworthy changes occurred over the last few years. The approach to understanding these concepts may not only differ, but also lead to drawing diverse conclusions. Furthermore, the fact that every socio-cultural context will perceive and apply these notions differently should be noted (Whyte and Ingstad, 1998). The significance of the concepts, in terms of design, evaluation and results interpretation of the study as a whole, asks for further elucidations.

1.5.1 Quality of life

In 1948, the World Health Organization (WHO) included the definition of health in its constitution as being "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 2006). Since then, it has become progressively evident that a proper instrument capable of accurately measuring health, and the effects of health care, is much needed — an instrument that would not only measure the frequency and severity of the diseases, but also assess the improvement of quality of life, in relation to health care. Just as there are adequate means for measuring the incidence and seriousness of diseases, there should also be suitable ways of gauging the wellbeing and quality of life of individuals.

Based on the impact that evaluations on quality of life have on the lives of people, as well as the probability of circumstantial discrepancies from one location to another, in 1991, the World Health Organization, acknowledged the need for a quality of life instrument that, while being analogous, would extend across international borders and bridge the differences between cultures. It was maintained that this instrument should include both people's idiosyncratic perception of happiness, in relation to their lives and situations, as well as an explanation of circumstantial personal factors (WHO, 1996). A number of talks with collaborators from all over the world took place, and the following definition for Quality of Life was born as a result: "an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1996). Subsequently, WHO teamed up with 15 collaborating

centres located worldwide, and brought into existence two instruments for measuring quality of life: WHOQOL-100 and WHOQOL-BREF, which add up to existing instruments that endeavour to grasp people's intricate life situations. These instruments not only grant the possibility of comparing results between various nations and their inhabitants, but can also be used in diverse ethnical contexts (Warren and Manderson, 2013).

The WHOQOL instruments have, among others, two important strengths:

- a) The WHOQOL instruments were meant to be used across cultures. In fact, they offer the possibility of comparing results between cultures. The WHOQOL-100 was created worldwide in 15 field centres concomitantly. Using data from the WHOQOL-100's field-trial version, a condensed 26-item version was produced thereafter, and it was called the WHOQOL-BREF. At present, the WHOQOL can be accessed in over 20 different languages, and their availability in other languages is in progress.
- b) The primary focus of the WHOQOL instruments is the way in which people are perceived. By concentrating on how individuals view their personal wellbeing, the WHOQOL instruments offer a fresh outlook on illness.

There are many other frequently used instruments for measuring quality of life; the Medical Outcomes Study Short Form-36 (SF-36) (Ware and Sherbourne 1992), the EuroQOL (Nord 1991; Brooks 1996), and the Quality of Well-Being Scale (QWB-SA) (Kaplan et al., 1998) are among them. However, these instruments do not measure quality of life per se. Instead of gauging quality of life, these instruments are used to determine the diverse facets of diseases, the effect that conditions exert on people, and the wellbeing of individuals (Warren and Manderson, 2013).

1.5.2 Living conditions

There has been an increased and progressive interest in the study of living conditions of people with disabilities over the last few decades. The profound implications that these types of studies have on the scientific and political arenas, explains this growing interest. The initiative of performing general surveys about peoples' living conditions emerged in the Nordic countries; Scandinavia was one of the first world regions that implemented this tradition. Even though there were multiple reasons for employing this specific practice, the

influence of two important factors cannot be overlooked. One of these factors is the social indicators movement, and the other, the growing attention generated by the study of social problems and disadvantaged groups (Tøssebro and Kittelsaa, 2004).

The social indicators movement saw the light during the 1960s. It is presumed that it was Raymond Bauer who first defined 'social indicators,' and so he did in the following manner, "statistics, statistical series, and all other forms of evidence that enable us to assess where we stand and are going with respect to our values and goals" (Bauer, 1966).

The Social Research Institute in Copenhagen, Denmark, brought to completion two investigations that could be regarded as pioneer in the field of living conditions. The studies targeted vulnerable social groups, and were performed in the beginning of the 60's. One study, carried out by Andersen in 1964, dealt with individuals with physical challenges, and the other with individuals of advanced age.

Initially, the notions of standard of living or living conditions had a somewhat restricted economic and material connotation. Nonetheless, these notions evolved and turned into an increased interest on human potential, and on the way in which individuals use such potential. This goes in line with the conceptual development of the ICF. In developed nations, the economic and material indicators perform a significant role in the continuing practice of carrying out studies on living conditions. Even so, research reveals that material belongings no longer delineate the standard of living of a person like it did in the past. Rather, the standard of living is determined by the aptitude to make smart choices and influence the direction and path of life as a result. Further investigations on standard of living have shown an increased interest on these types of questions. The intention behind these queries is to evaluate both, the extent of productive and creative work that will shape people's future, as well as the scale of their participation in decisions involving the economy, politics and the social order (UNDP, 1997).

In general, investigations on living conditions use comparison as a method of study. Hence, the objective is to pinpoint a number of individuals collectively, who present conclusive attributes, and to determine if there are methodical dissimilarities in living conditions. Geographical location, age, gender, as well as the central purpose of this paper, –that is, individuals with disabilities in contrast with people without disabilities– is what delineates the collective subgroups under consideration.

A number of investigations have demonstrated somewhat few contrasts among individuals with and without disabilities. These conclusions may perhaps be unanticipated. When it comes to improving the laws and constitutions in accordance with expectations of the public, which aim to enhance the condition of individuals with disabilities, these findings may well be disconcerting, especially for those who use the collected information to plead on their behalf. The eager anticipation that investigations on individuals with disabilities will provide evidence of poor living conditions, and as a result furnish a foundation for taking actions, is often the case. Theoretically, such eager anticipation is considered inconsequential by both the investigators, and the study as a whole. Nevertheless, it may possibly generate a situation of uneasiness that is not invariably manageable (Eriksen and Næss, 2004).

The few contrasts among individuals with and without disabilities have to do with a logic based on essence and procedures. It has been observed that as soon as the concept of disability is broadened so as to include individuals with minor impairments, the tendency to overlook documenting poor living conditions is likely to happen, when such a wide concept is put into practice. The high figures employed to support actions designed to attain a purpose by the use of political power (that is, the evidence of elevated levels of individuals with disabilities), can be weakened by the very same statistic, which is incongruous. This is due to the fact that when the relative amount of people with impairments rises, the number of their non-disabled counterparts tends to become smaller. The underreporting of inadequate living conditions has also been pointed out.

Health, education, income, work, family status and housing, are the tangible factors subject to variation, to which, as a rule, the concept *living conditions* makes reference. Nevertheless, other factors such as recreation and social networks, as well as relationships are also taken into consideration. Both concepts –*living conditions* and *quality of life*– are closely related, however. Quality of life, for instance, tends to be used in several manners. For academics and for the general population, it has to do with the subjective nature of the individual's existence, with the way in which his/her emotions are dealt with, and with how his/her circumstances are lived through. Also regarded as psychological wellbeing, quality of life specifically relates to an individual's positive and negative, evaluative and emotional processes of perception, understanding and remembrance of life events.

It is not surprising to find *quality of life* indicators included in living conditions studies or surveys. Likewise, it is not uncommon to come across people with disabilities, more precisely

individuals with severe and lasting impairments, who state having either a pleasant or an exceptional quality of life, and being content with their lives. From the perspective of outsiders, however, the life that these individuals endure may appear to be far from desirable. *The disability paradox* is a descriptive concept that acknowledges and illustrates the high rating of quality of life found among individuals with disabilities (Bowling et al., 2007). The concept places emphasis on the significance that impairment has when personally lived through; it delineates not only the self, the surrounding circumstances and social interactions, but also how the world is perceived. This is notably different when compared to individuals who have not gone through such experiences. Individuals with disabilities have had to put up with pronounced prejudice in relation to behaviors and suppositions of the community and of health care providers. Consequently, the disability paradox comes in two forms. On the first type, individuals with disabilities state having day-to-day activities severely circumscribed. They also report finding it difficult to perform their social functions, and having to endure constant prejudice. Despite all of these obstacles, they express having a pleasant or exceptional quality of life. On the second type, however, seen from the perspective of the community, practitioners and of other health professionals, the quality of life of individuals with disabilities is dissatisfactory, even though more than half of these individuals state having an exceptional or pleasant quality of life (Albrecht and Devlieger, 1999).

1.5.3 Disability

The World Health Assembly approved the International Classification of Functioning, Disability and Health, along with the *ICF* acronym, on the 22nd of May 2001. It took nine years of revisions at a global scale, all managed by the World Health Organization, until the ICF was sanctioned. It was in the 1970's that the classification was initially shaped and later published for trial purposes. The name given by WHO at the time was: International Classification of Impairments, Disabilities, and Handicaps, or ICIDH (WHO, 1993). Back then, the ICIDH set up the fundamental structure that allowed categorizing different disability and functioning health elements in an integrative manner. As of 1980, the ICIDH became the instrument for categorizing the significance of illnesses, including injuries and other lesions, and the repercussions that disorders in general had in people's lives (WHO, 1993). It has been voiced with uneasiness, however, that the ICIDH fails to convey, in a clear manner, the role that social and physical surroundings have in relation to the handicap process. It has also been

alleged that the ICIDH might have promoted a more medicalized approach to disablement. Disablement here is understood as impairment, disability, and handicap altogether. The ICIDH had been mainly used for explaining the life situation of people with disability on diverse locations. A more direct application of the ICIDH allowed evaluating people's care during the diagnostic process and a course of treatment. It also permitted to analyze the results of treatments, gather information, and evaluate people's fitness for work. Statisticians in disability studies, made at a local, national and regional scale, as well as policy-makers, demographers, epidemiologists, and health planners from both, industrialized and emerging countries, made use of the ICIDH's fundamental structure in an effective way. When it comes to the policy and theoretical levels, not only the perception of disabilities as a whole and of individuals with disabilities, but also the role that social and physical surroundings have in relation to the handicap process, has changed thanks to the application of the ICIDH. The response to these concepts on the part of individuals, organizations and governments, in terms of policy, planning, and administration, has also been partially transformed by the ICIDH.

The ICIDH was thereafter revised by WHO, on account of a report presented by United Nations Commission on Human Rights, on the Forty-third Session on Human Rights and Disability. The report drove WHO to take the role that social and physical surroundings have in relation to the handicap process into thorough consideration. Among the suggested changes that were deserving of attention was that the handicap description needed to encompass the interplay between disabilities and impairments, and social and physical surroundings, as the circumstances that individuals find themselves facing as a result of this interaction. Not only was the description of handicap dealt with during the revision process of the ICIDH (which took place in 1993); the revised version received a new name as well. ICIDH-2 was the name by which the new version was known by 1996 (Bickensack et al., 1999). The function, actions and interrelationships of environmental influences were also clarified, as they play an important part in the definition and shaping of the various features tackled by the revised ICIDH. The need for a comprehensive expression that would amalgamate a wide range of experiences associated with the terms handicap, disability and impairment, became evident. Although not accepted unanimously, this is how the term "disablement" was set forth and shown on the reprint of the ICIDH made in 1993 (WHO, 1993). The previously used concepts of "disability", "handicap" and "impairment" were not only substituted, but their meaning was also broadened so as to embrace constructive events. In 2001, these three concepts were supplanted by two essential lists that were published in the Final Draft of the ICIDH-2,

namely: *Body Functions and Structures*, and *Activities and Participation* (WHO, 2001a). Within a short time, the classification's name of ICIDH-2 changed and came to be called ICF (WHO, 2001b).

The close link between the structure and design of people's external physical conditions, the perception of the population in relation to disablement, and the restrictions that individuals with disabilities face, were better portrayed by the new description of disability. The terminology has experienced a shift lately, as well as a rising disposition towards considering the complexity of disability and the different elements and factors that shape the concept. An array of elements found on personal and collective levels comprise such process. The UN implemented the Convention on Rights of People with Disabilities (CRPD), in 2006. A definition for disability was then established, as follows:

“Persons with disabilities 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 others” (UN, 2006).

The prospect of chronic disabilities in populations that begin to grow older has seen a substantial rise. This and the progressive ageing of people have led disability into becoming a growing concern of public interest (Harwood et al., 2003). Time and again disabilities tend to remain invisible to the general public sight. This is why the level of disability is presumed to be much higher than the majority thinks. The reason for this is that people with disabilities are often confined to a house or institution. While some other individuals live with disabilities, particularly cognitive, which may be invisible or not obvious to those who are not part of their inner circle.

The way that an individual experiences disability is influenced by various elements. Similarly, controversy has emerged over the concept of 'disabilities' that has been known by and large, due to its vague undertone (Waidmann & Manton, 1998). The reason for this is that the term disability spans over a variety of cognitive and physical conditions that cannot be easily classified into a frame of reference. Whenever an effort is made to determine either the attributes or the number of people with disabilities a large disparity comes into light. This happens because there isn't a common frame of reference. Mayhew has asserted that there is significant variation in the official and unofficial rough calculations of the number of

individuals with disabilities. And this is why making comparisons becomes problematic at times (Mayhew, 2003).

1.5.3.1 Models of disability

Disability has come to be explored from different perspectives by an emerging academic field called Disability Studies. This discipline looks at and hypothesizes about aspects that delineate disability, such as cultural, economic, social and political factors. A number of debates through which the different models about disability are discussed are being carried out by academicians, advocates, the disability rights movement and by physicians. Being a set of mutually supportive beliefs, the models depict disability in a particular manner. They also show how the social order can approach disability. Thanks to the Models of Disability, which are fundamental instruments for outlining impairment, governments and societies are able to formulate strategies that have the aim to respond to the needs of individuals with disabilities. Time and again, the picture of day-to-day life presented by the Models of Disability has been regarded as dubious, because they are considered to lack elements and open-mindedness. The absence of thorough management for taking actions has also been alleged. It cannot be denied however that the Models of Disability, as a frame of reference, has been helping to better understand not only the problematic of disability but also the mindset of individuals who are developing and implementing the Models (Amponsah-Bediako, 2013).

After all, the Models of Disability have been formulated by no other than people (usually people without disabilities) who keep other people in mind (people with disabilities). Impressions, inclinations and discrimination are some of the predispositions looked at by the models, as well as how these affect individuals with disabilities. The right to approach services, jobs, goods, economic leverage, and bureaucratic influence, based on what societies restrict or put at the disposal of people with disabilities, become exposed by the Models.

Two intrinsic principles sway the Models. One principle perceives individuals with disabilities as being contingent upon society. This perception may lead to prejudice, isolation and condescendence. Individuals with disabilities are seen by the second principle as customers of what society has to offer. This viewpoint prompts to enablement, power to choose, integration, and human rights equality (Amponsah-Bediako, 2013).

The actions taken to find a solution to a problem is determined by the mental outlook from which the problem is observed. There are several models of disability. Few models worth mentioning due to the influence that they have exerted are: Medical model, Social model, Bio-psychosocial model, Nagi model, Charity/tragedy model, Expert/professional model, Right-based model, Religious/moral model, Economic model, Tragedy/Charity model, Customer/empowering model, and Rehabilitation model (Amponsah-Bediako, 2013; MDRC, 2013 Mitra, 2006).

A number of disability academicians acknowledge that there isn't a single model that is able to fully elucidate disability – David Pfeiffer (2001) indicated. He added that every disability model may provide a practical outlook of disability in a given framework. When it comes to a person's self-identity, disability in general is one of his/her many focal components, and not the only distinctive feature of the individual (Smart and Smart, 2006). Looking upon the Models as an array of absolute alternatives, some of which might be regarded as superior, and others as fitting for outplacng previous options, wouldn't be applicable. As the Models are shaped and gain recognition, the transformation of social perception towards disability, as well as the status of such perception, persist and evolve. Any societal changes bring about adjustments to the Models. This is the reason why a number of models that can be operated ought to be created. Additional models will not only grant individuals with disabilities access to the same adequate and balanced rights as all other fellow humans, but they will also empower them. (Amponsah-Bediako, 2013; MDRC, 2013). Progress has been made not only in medicine and technology but also in the manner in which the world is viewed. Likewise, the way in which disability, as an innate component of people's lives is perceived, has also evolved. (Smart and Smart, 2006).

1.5.3.1.1 Medical Model of Disability

Mental or physical limitations are the cause for disability, the Medical Model maintains. For this model, there is no connection between disability and the social or topographical settings. This Medical Model has often been labeled as the Functional-Limitation or Biological-Inferiority Model.

Upon substantial input provided by medical doctors, the World Health Organization came up with the following definitions (WHO 1980):

- "Impairment: any loss or abnormality of psychological or anatomical structure or function.
- Disability: any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being.
- Handicap: any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual."

By looking at these definitions one cannot help to empathize with the stigma that expressions such as "lack of" or "abnormality" may evoke in individuals with disabilities.

For the Medical Model the disability problem begins with a specific individual with impairments, and presumes that the focus for finding solutions must be placed on the individual (Brisenden, 1986; Lightfoot 2004). Economic influences, as well as a weak commercial climate, are both taken into consideration by a more refined outline of the model, which has perceived that these factors will affect job opportunities for an individual with disabilities in a negative way. Be that as it may, this polished form of the model looks for solutions focusing on the individual. The individual receives help for transcending personal impairments, so that s/he may be able to deal with a stumbling job market.

Finding a cure, as supposed by the Medical Model, is the first action to be taken. WHO describes this assumption as, "making disabled people more normal." Since people with disabilities may neither get better by therapeutic treatments, nor are they axiomatically ill, the postulate is doomed to failure. Granting imperative assistance to relieve a disabled person who 'cannot be cured', as well as putting up with 'abnormality' seems to hardly be the way out. Rehabilitation regimes, the supply of equipment and aids, training for a specific vocation with the purpose of finding a job, and financial plans for maintaining a certain income level, make up the assortment of options to which policy makers are restricted (Sullivan, 2011).

The conception of the disability policy has been overshadowed by the Medical model, for many years now. The remedial elements of the Medical model, which may relieve or heal individuals with disability who experience mental and physical conditions, should not be rebuffed. Nonetheless, seen from the standpoint of people with disabilities, the model does not provide a practical outlook (Bury, 2001). Firstly, the notion of "abnormal" would be reproved by the majority. To make matters worse, the model enforces a condescending approach to dealing with problems. In spite of the underlying positive intention, the approach focuses on "care", and offers an excuse for isolating and institutionalizing in the end. As a

result, people with disabilities find their likelihood to choose freely, and the expansion of their potential, restrained.

The mindset of employers is negatively influenced by existing preconceptions that the Model promotes. When a condition is perceived as ‘medical’, by this very fact, a disabled individual will be susceptible to poor health, and leave of absence because of illness. Similarly, his/her health is expected to decline, which will therefore lead to not being as productive as his/her co-workers.

The role of the priest as the person entrusted with guarding the healing process and values of society was outplaced by scientists and doctors, inasmuch as the scientific and medical scholarship developed extensively, particularly in the late 19th and early 20th century (Bury, 2001). Time became an absolute physical reality, and labor and production turned into commodities. Global aspects of work that are important to a person's job satisfaction, as well as lucrateness, begun to dictate the value of humans. Furthermore, both lives and styles of living became determined by automatic and impersonal practices, and by establishments of the sovereign state. Defining moments were overruled by the status of the person's consciousness, individuality took the place of universality, and unexplained events took over rationality. Having a masculine, white, juvenile, and capable-of-performing body became the standard for 'normality', and any disparity to this standard became ranked as of lower status. Consequently, the concept of difference was reformulated to become the commanding control that differed from the norm.

The everyday life of individuals with physical impairments was hence greatly affected by occurrences that took place at around that time. Their future became circumscribed to a prediction of the course of their disease, and their lives were brought down to a nothing more than a medical label. This point of view turned individuals with disabilities into a societal group that had to be physically pulled out from the ‘physically abled’ standard that was evolving in the metropolitan social order. It was around that time that the term ‘disability’ emerged, thus, gradually replacing offensive ones such as lame and cripple (Jewson, 2009; Altman, 2001).

Institutions were founded when a specific cluster of individuals started to be regarded as non-capable and non-productive. There were two main reasons behind the establishment of these institutions: to be the placement of individuals with disabilities, so that family members could

carry out their job duties; and to be the venue where individuals with disabilities could be trained, with the purpose of enabling them to become fruitful components of society.

But then again, the social theories derived from evolutionism, as well as the application of, or belief in, the scientific method, were given progressive priority in the modern era. This gave rise to a switch of roles on the part of special institutions; they changed from being instruments of reform into becoming instruments of custody; the individuals labeled as ‘sub-normal’ found themselves at the mercy of social control and constrained by institutional segregation. This is how institutions turned into agents that promoted the idea that individuals with disability were not to be accepted as fully human by the wider society, turning them into what is known as ‘socially dead’. Affirmed on the idea of misfortune, hardship and powerless habituation, and under the assumption of having a scientific status, the notion of care for individuals with disability was removed from political influence, was made technical, and was given a professional character.

In the Western world, the notion of disability was viewed as a personal affliction mainly discussed in medical and scientific speeches, during the post-industrial and post-enlightenment era specifically. As a result, the notion of ‘disability’ metamorphosed into an attribute or peculiarity of an ‘unfitted’ individual – a notion that can be observed impartially and that is unbiased in its capacity. This model asseverates that it is the person who has a problem, not the society. Assisting the individual to cope with such a problem, with acquiring adequate skills, and through rehabilitation, is the aim of various interventions (Brisenden, 1986). Contemporary Western medicine portrays the body as an object that can be controlled, however. Therefore, the individuals who are unable to control their bodies are regarded as unsuccessful or disappointing (Sullivan, 2011).

More recently, as of the early 1970’s specifically, thanks to the influence of the strongest and long lasting integration theories in severe disabilities in the world — the normalization principles — the place of a concept treated on a case-by-case basis has changed from institutions managed by the state, to community based settings (Hoeman, 1992). However, the medical sector still views disability as of being firmly in support of the economy. Time and again, an individual’s ability and competence is computed as inability and incompetence. This will dictate whether a person is eligible for benefits and monetary aid, and to use resources made available to cases like his/hers. The intricacy of disability is reduced to restrictions and

limitations by an economic viewpoint, which questions whether individuals with ‘abnormalities’ can be capable of producing or of receiving education.

The charity discourse continues to prevail due to the fact that proper material resources are not being made available. Individuals who need assistance are portrayed as objects of commiseration, as perpetually dependent, just as children are, and as people experiencing a dreadful life. Compassion and philanthropy are the pillars upon which the charity discourse, as well as the early Christian communities, was built. The aim is to meet the needs of the less fortunate by offering to the ‘privileged’ members of society the opportunity to carry out noble deeds of charity and benevolence in favor of individuals who show a clear need for help (Clapton and Fitzgerald, 1997).

In the 19th Century, just as modern medicine started to expand, and the role of medical practitioner reached new heights, the Medical Model emerged. Based on the idea that the origin of various disabilities is medical, those who were placed under the direction of the medical profession counted on seeing improvements. For the Medical Model, disability and all its related complications are regarded as being part of the person. Put differently, based on this model’s view, problems disappear when the person is "cured". Furthermore, while being excluded from a society that neither is accountable for, nor has made room for them, individuals with disabilities are seen as strangers on hold to be ameliorated (Bury, 2001).

The Medical Model perceives individuals with disabilities as sick people. This criterion releases them from day-to-day societal duties such as: finding work, handling family obligations, pursuing education goals, and so forth. For the sake of getting better, they are also supposed to place themselves on the hands of the medical community. This is why many issues found on disability policies are considered to be health issues. Likewise, when it comes to policy making the main authority has been placed on medical practitioners (Sullivan, 2011).

At present, the organizational form that better reflects the impact that the Medical Model has had on public policy in relation to disability is the Social Security system. To this organizational form, the definition of disability is made apparent through the incapability to perform a job. This view is in agreement with deeming individuals with disabilities as having the role of sick people. This poses a huge dilemma for individuals with disabilities who wish to work. Losing their disability status may lead to no longer being eligible for receiving Personal Assistance Services (for personal and home care), not having access to public

benefits or losing their health care coverage—all this because they simply had the initiative to work.

Disability being represented as a disease, regarded as an object, put into a category and particularized, are some of the fundamental characteristics of the Biomedical Model, which rely on methods for diagnosing and systematic grouping employed by the health occupations. Organizations such as the American Psychiatric Association (2012), and the World Health Organization (1980, 2001a), as well as several academicians, have expressed their support of the model. Additionally, when compared with evaluations of other models, the health occupations' methods for diagnosing are thought to be the most impartial, regulated, trustworthy and unbiased from the moral perspective.

1.5.3.1.2 Social Model of Disability

For the Social Model, the obstacles that stand in the way of disability are institutional and physical in nature, and are marked by a characteristic cultural, social or attitudinal behavior. These obstacles impede that individuals with impairments enjoy maximal fellowship in society (Oliver, 1990). In the Constitution of Disabled Peoples' International (DPI), this view is concisely expressed. The DPI makes a differentiation and elucidates the terms disability and handicap as follows:

"Whereas disability has too long been viewed as a problem of the individual and not the relationship between an individual and his/her environment, it is necessary to distinguish between:

- Disability is the functional limitation within the individual caused by physical, mental, or sensory impairment, and
- Handicap is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers." (DPI, 1993)

The principle that makes up the Social Model, emanated from the American civil rights movement. The British Council of Organizations of Disabled People and the Voluntary Organisations for AntiDiscrimination Legislation (VOADL) – currently known as Rights Now – which demanded the power of making free choices unrestrained by external channels,

stood behind it. Then as well, in the United Kingdom preeminent thought leaders such as Bert Massie and Dr. Steven Duckworth have supported the model publicly. For the founding of the late Commission for Disabled People, as well as for The Local Government Management Board, the Social Model has had profound influence and has been a source of inspiration and admiration.

The Minority-Group Model of Disability it is also another name by which the model is known. From a socio-political perspective, the model maintains that disability results from society's inability to adapt in order to adequately respond to the hopes and needs of a disabled outnumbered group (Hughes and Paterson, 1997). Unquestionably, should the issue be found in both the social order and the surroundings, these must then be adapted. If a wheelchair user cannot access a building, the building entrance must then be redesigned. Some examples are already found in England and in Japan, where an existing set of stairs retracts to reveal a lift, which helps the wheelchair user go up and down the staircase, thus making the building fully accessible.

The UK backs the argument up to such extent that those inhabitants who are short-sighted are not placed under the category of disable. Visual aids and eye-examinations are either available free of charge or are within people's financial means. Individuals with this impairment are thus empowered to take active part in community life without segregation. In contrast, individuals with the same impairment living in a nonindustrialized nation, would experience stern disability, since they may not have access to eye-care. Each and every social order would regard the incapacity to read and therefore to learn and assemble information as a harsh impairment.

The Social Model strongly suggests that the lives of people with disabilities would improve if the obstacles that stand in the way, which are institutional and physical in nature, and marked by a characteristic cultural or social behavior, were to be removed. In this way, individuals with disabilities will have equal opportunities as their fellow humans, on an impartial and fair basis (Swain et al., 2004).

Under the Social Model, the responsibility is placed on the social order rather than on the person. There lies the weight of the Model. While the Medical Model employs diagnostic tools to generate levels of disability, and takes for granted that the requirements and aptitudes in individuals with matching impairments are alike, the Social Model concentrates its attention on what the person requires. In addition, it provides solutions that are not only

beneficial, but which have been successfully applied in some industrialized countries such as the United States, Canada and Australia.

Even so, two objections have come against the Model. Number one, as the age of community members increases, so does the number of individuals with impairments. The adjustment on the part of society that this implies becomes more difficult. Number two has to do with the conceptualization of the Model. Committed experts who work in charities and rehabilitation institutions in particular, find the Model's ideas not easy to grasp (UNFPA, 2012). However, such mental outlook calls for a change of attitude on the part of these experts. Their function shouldn't be pure cure-or-care-oriented. Their role should rather be that of assisting individuals with disabilities to take charge of their lives.

The way in which previous models had affected the lives of people with impairments was the causal factor for the disabled community to mobilize and to formulate the Social Model. At the time, the social order was the causal agent of disability, the Social Model maintains. Neither a particular person with disabilities, nor the repercussion of his/her limiting condition, which might be unavoidable, can be attributed to being the basis for disability to exist. Obstacles that are institutional and physical in nature, and marked by a characteristic behavior, not only have resulted in discrimination in current society, but have also played a major role in the emergence of disability. Both the conception and the way to deal with societal organization need to undergo a transformation, for discrimination to be eradicated (Corker and Shakespeare, 2002).

For the Social Model, individuals with disability are considered part of the collectivity, the surroundings and the economy. It is the obstacles that keep any person with disabilities from actively participating in society, not the person per se. There are still obstacles that are essential for the development of the individual, ranging from basic services, like education and health, to transportation and housing. Another obstacle is the adverse way in which individuals with disabilities have been portrayed in the mass communication industry.

Eradicating obstacles is the main objective of the Social Model. Doing so not only allows individuals with disabilities to have equal opportunities as their fellow humans, but also to choose the way they wish to live their lives. It would not be appropriate to regard a wheelchair user as disabled in a location where s/he has total access to transportation, and to constructions and their amenities, just as individuals without impairments do.

The legislation on the right of people to be treated equally, or anti-discriminatory law, has been strongly influenced by the Social Model of disability, which has transformed the way in which disability is looked upon. A subsequent evaluation carried out by a handful of scholars and individuals with disabilities since 1992, revealed that the time to take a step ahead this elemental frame of reference had arrived (French, 1993; Crow, 1996). Furthermore, in his book “Disability Rights and Wrongs” (2006), Shakespeare states that the social model requires revision or further expansion, and elucidates why. Referred by him as *the unchanging social model*, he goes on to assert that the model should act in response to the constant shifting of the state of affairs. In this respect, neither the model’s supporting principles, nor the objectives of the disability movement, should be modified. Individuals without disability have more choices and more adaptability than their disabled counterparts, he expressed. This means that when the circumstances between the two are correlated, neither balance, nor fairness exists. Feeling handicapped by their bodies, many individuals may still experience limitations and find it difficult to take part in societal activities, even if they were to live in an ideal environment containing no barriers.

1.5.3.1.3 Bio-psychosocial Model of Disability

The combination of the Medical and Social Models gave rise to the Bio-psychosocial Model. By including aspects of each, this model avoids narrowing the concept of disability and all its components to a single aspect. This model forms concepts based on broader viewpoints of impairment – concepts that denote the interplay between a person’s inherent characteristics and his/her communal and tangible situation. (Bickensack et al., 1999).

The Bio-psychosocial Model was the holistic proposition presented by George Engel (1913-1999), in place of the widespread biomedical model – a model that, since the half of the 20th century, had a predominating influence over modern societies. The scientific/experimental clinical method was in need of the Bio-psychosocial Model. This is why its contribution was noteworthy. In order to comprehend the pain that a patient endures and respond appropriately, while offering him/her a sense of sympathy, physicians must take the different aspects of illness seriously, namely the social, biological and psychological aspects. This is what Engel sustained (Engel, 1977). He developed his model over 35 years ago. Science was undergoing a gradual change at the time. It went from a concerted effort based on investigation, expertise, and reductionism, to assuming an interdisciplinary form and relating more to the context.

Incidentally, reductionism here is understood as an attempt to explain all biological processes by the same rationale that chemists and physicists use to make sense of inanimate matter. George Engel devised the Biopsychosocial Model based on the premise that the human experience was interactive, and dynamic –an occurrence where the body and mind sway each other, and is therefore twofold (Borrell-Carrió et al., 2004).

Under this model, disability is perceived as a reciprocal process connecting the state of health of an individual and the setting where s/he resides. The Biopsychosocial Model is in favor of both, the Social and Medical Models, and finds them not only suitable but also complimentary; however, it argues that each of them lack elements that may explain the intricate essence of human wellness.

The goal of this proposal is to take the focal point over and above the person and devote its efforts to concerns that act upon one another. This, in order to influence the person's capacity to perform in the society, as well as to uphold his/her level of health and prosperity to the maximum extent possible. The amendments to the description of disability carried out by the WHO, go in line with the Biopsychosocial Model. The Model acknowledges that disability frequently occurs as a result of physical damage or poor health, and does not overlook the strong influence that problems involving emotional states, environment, and biology exert upon welfare, health and performance in the social order. A critical review of the Model has insinuated that what delineates the Biopsychosocial Model's conception is the condition that causes disablement –neither the individual, nor the firsthand knowledge that an individual with disabilities endures (Lutz and Bowers, 2007).

ICF was built upon the Biopsychosocial Model. It combines the Social and Medical Models and, in a simplified manner, offers a logical interpretation of the collective, particular and biological prospects concerning health. This leads to a broader understanding of disability and the disablement process (WHO, 2002) (Fig 3). Nevertheless, those who formulated the ICF, have highlighted that there might be other conceivable representations. They stated that, “any diagram would be insufficient and could be prone to misrepresentation because of the complexities of interactions in a multidimensional model.” (WHO, 2001b)

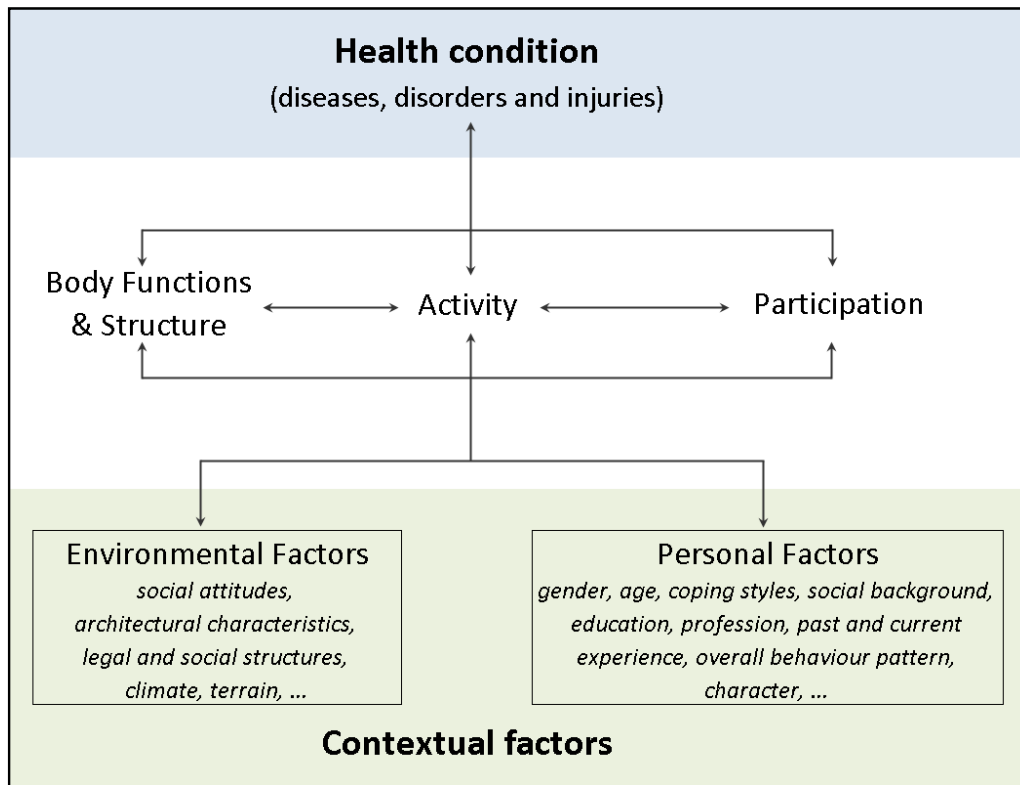


Fig 3: Adapted diagram of the representation of the biopsychosocial model of disability.
 Source: WHO, 2001b

From the time of its commencement, the contribution of disabled individuals and of institutions of persons with impairments was advantageous to the process of reformulation of the ICF. Noteworthy efforts towards the reformulation process were made specifically by Disabled Peoples' International, which are reflected in the final version of the ICF (WHO, 2001b).

1.6 Rationale of the study

The quality of life of people with disabilities has been widely studied in developed countries. The progressive improvement in various population health indicators observed in low- and middle-income countries, has made perfectly clear that the attention must now shift, and focus on, improving the quality of life of the most disadvantaged and marginalized groups, among which individuals with disabilities are found.

With the purpose of promoting the objectives and principles of the CRPD, it becomes essential to know to what extent the experience of being disabled has a direct impact on quality of life.

In unindustrialized nations, services such as health and social welfare, as well as the levels of development are largely insufficient. This has given rise to a continued poor quality of life among disabled individuals. There is an overall consensus about the need for more research on how, and to what degree, disabilities affect the quality of life of the concerned population. The information gathered through the study would allow putting together policies that strive for the betterment of the quality of life of individuals with disabilities.

Life is difficult enough for people without disabilities in rural areas of Colombia, let alone for individuals with disabilities, who face the absence of surroundings adapted for them. Not only are individuals with disabilities usually not considered an integral part of society, but their access to education, employment, rehabilitation and medical care is less likely to happen for them in such areas. Social exclusion has become far-reaching for individuals with disabilities, and adequate subsidies or special benefits are not yet being provided by the social welfare system. Consequently, discrimination, violence, insensitivity, and even pity, are some of the problems that most people with disabilities often experience. The medical model of disability, which predominates, portrays disabled people as "inferior, dependent and of little or no value to society." This is based on the model's inclination to "blame the victim". This segregation not only hinders the possibility of devising solutions, but creates confusion. The approach has undergone changes for the better. Nonetheless, many significant changes are still pending – changes that may pave the way for people with disabilities to integrate into modern society in an inclusive way.

1.7 Research question

To what extent is the quality of life of an individual affected by (the condition of) being disabled in the context of the Municipality of Anapoima, in rural Colombia?

Is there any relationship between disability, living conditions and quality of life in the same context?

1.8 Objectives

To study the impact that being a person with a disability has on the quality of life in the Municipality of Anapoima, in rural Colombia.

To analyze the relationship between disability, living conditions and quality of life.

To compare the quality of life and living conditions of people with disabilities against those of people without disabilities

2 DESIGN AND METHODS

2.1. Study area

Data included in the present study was collected from the municipality of Anapoima (Fig 4). The municipality covers an area of 124.2 km² (48.0 sq. mi), and is located in the south west of the Department of Cundinamarca, 87 km (54 mi) from Bogotá, the capital of Colombia. The average annual temperature is 26 °C (79 °F), and it has a total population of 11,337 residing in 3,637 households. Many of these households are inhabited by extended families. Around 30% of the Municipality's population live below the national poverty line, which is about the national average. Most people in this area are members of the Catholic Church, and, based on the 2005 census by DANE, their main occupation is farming (DANE, 2005). While results from this municipality may not be as readily generalizable as results from a large-scale cluster sample, data obtained from this municipality is likely to be valid and reflects what is actually happening in the selected location. The Municipality of Anapoima was chosen because, in terms of permanent disability alone, the 2005 census revealed a prevalence of 9% for women and of 9.5% for men, which is around 45% higher than the average in the country (DANE, 2005).

Anapoima is served by a small health care facility that counts with two physicians (general practitioners), and a dentist, based in the town of Anapoima. There are also two health posts established in the small towns of San Antonio and La Paz. Even though the town of Anapoima is centrally located in the municipality, geographic conditions and a limited

transportation network makes it sometimes difficult for people living in the peripheries to readily reach the health care facilities. The closest referral establishment is a second-level hospital situated about 16 km (10 mi) away, in northeast direction. Based on costs and easiness of transportation, whenever needed, residents who live in the municipality's outskirts choose to go to hospitals located in neighboring municipalities such as Viota. They do this despite the fact that, due to administrative reasons and service coverage, they should resort to the health posts located in their corresponding municipality, i.e., the town of Anapoima.

Por ley, las personas con discapacidad tienen derecho a recibir el subsidio gubernamental por discapacidad. A pesar de que la mayoría de las personas con discapacidad en Anapoima tienen derecho a recibir dicho, solo algunas tienen acceso al mismo. El monto del subsidio asciende a U\$35, sin embargo, el número de personas que pueden beneficiarse de éste, para nada generoso subsidio, es limitado.

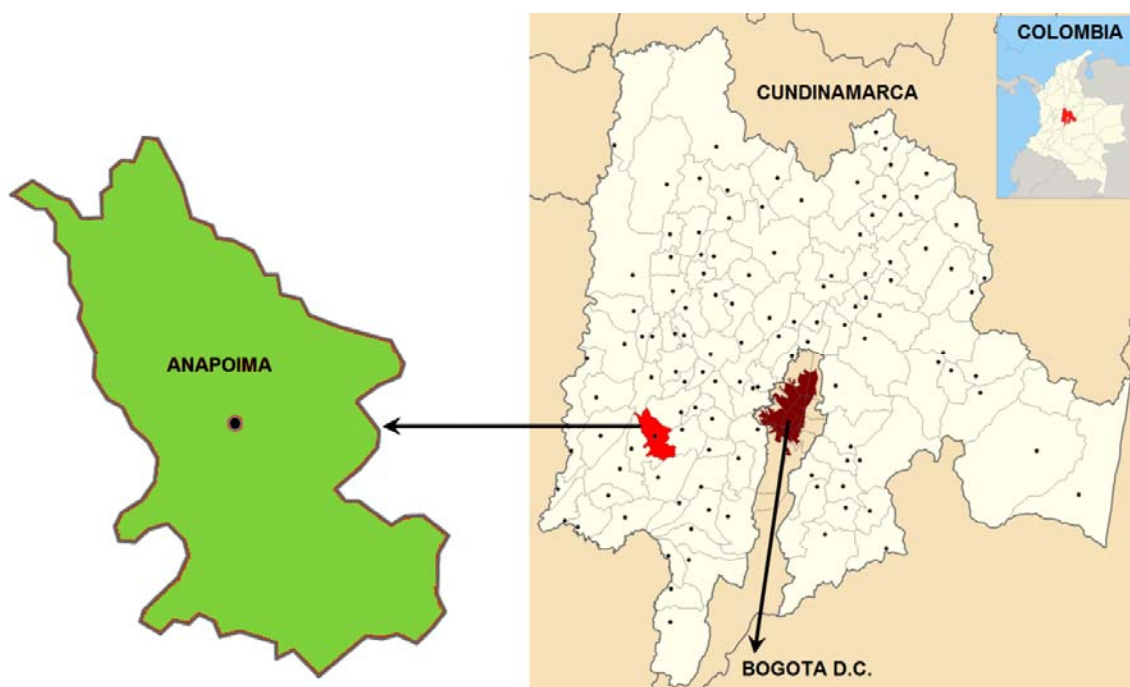


Fig 4: Location of the Municipality of Anapoima in relation to Bogotá D.C, to the Department of Cundinamarca, and Colombia. **Source:** World Wide Web - Wikipedia

By law, all individuals with disabilities have the right to receive a governmental disability subsidy. In spite of the regulation, due to economic restrictions, not all of Anapoima's residents with disabilities have access to the subsidy. The local government has set the

subsidy to U\$35, in order to benefit a larger number of people, they argue. That amount is very low when compared to the cost of living in Colombia. Due to growing demand, the waiting period that some individuals endure in order to be granted the disability subsidy can range from months to years. In some cases, the lack of sufficient resources lead local authorities to decide, arbitrarily, to withdraw the subsidy from one beneficiary and grant it to another who has been waiting to receive it. The authorities justify this action by assuming that former disabled beneficiaries should be content with the charitable donations they seldom receive from the local church, which consists of simply non-perishable foods, and not financial assistance. In addition to the government disability subsidy and the help from the church, a local NGO, namely, Seeds of Hope Foundation (FUSES), often carries out campaigns in favor of the population with disability. While this study was being carried out, a number of mattresses were delivered to underprivileged households that had a disabled family member. Sadly, a lack of coordination of resources aimed at bringing help to the population with disabilities was clearly perceived.

Overall, Anapoima reflects the reality observed not only in several municipalities but also across cities of Colombia, and in Latin America as a whole. For example, a set of stairs needs to be walked up in order to reach the main entrance of Anapoima's City Hall, not to mention that just a few buildings offer proper access to persons with disabilities. The sidewalks are not wheelchair friendly either, and in some cases the height of the sidewalks is significantly taller than / larger than the street level. When it comes to public transportation, vehicles are not adapted for the disabled. As a result, the possibility of persons with impairments to get in and out of a bus, for instance, depends on the driver's willingness to lend a helping hand.

2.2. Study design and methods

This descriptive cross-sectional and case-control study includes a sample of 202 participants, 101 cases (individuals with disabilities) and 101 controls (individuals without disabilities). This type of observational study was considered to be the most appropriate for the data collection process and the forthcoming data analyses in order to answer the research question. In this manner, this case-control study is designed to help determine to what extent the presence of disability has an impact on quality of life of people living in the rural area of the Municipality of Anapoima. Participants were asked to answer a comprehensive survey through a one-on-one interview. The survey consisted of three questionnaires: one on living

conditions, another on quality of life and a third on disability. These pre-existing and validated questionnaires, which had been used in some sub-Saharan countries (Eide et al., 2011), were adapted to the Colombian context. Within the questionnaires, the WHOQOL-BREF instrument was included. The 26 items that comprise the WHOQOL-BREF instrument measure the following broad domains: physical health, psychological health, social relationships, and environment. The WHOQOL-BREF was chosen as instrument to measure the quality of life because it has been shown that is a sound, cross-culturally valid assessment of QOL. The WHO granted the necessary permission to use the Spanish version of the WHOQOL-BREF questionnaire on this study.

The limiting and restricting elements affecting activity, and in turn the ability to participate in society, which delineates what is understood as disability within a theoretical framework (illustrated in Figure 3), is what forms the basis for this investigation. The use of the Washington Group Short Set of Questions on Disability (WG6) during the screening process makes this evident. Bearing this in mind, and given that the *disability* vocable relates to or is connected with a perception based on identity and impairment, *disability* is considered a challenging concept. Due to the fact that disability is a generally established term, and considering that there isn't a new, more functional and simpler term in the field yet, it is however employed all through this text as a descriptive concept.

The researcher conducted the fieldwork over two and a half months. Collection of quality data on a sensitive issue, such as disability, requires time and cultural sensitivity on the part of the researcher, and trust on the part of the respondents. To develop a good rapport with the villagers, the researcher stayed in the villages being studied during the whole data-collection period, i.e. from September to December 2013. The selected research assistant was a member of the community and a former health worker who was acquainted with a large group of persons with disabilities in different areas of the municipality. She was one of the key figures who facilitated locating not only cases and controls, but who also helped the author with the data collection process by carrying out 82 interviews from a total of 202. When completed, all questionnaires were thoroughly inspected by the principal investigator.

The study population included all people who were the usual residents of the Municipality at the time of the study, excluding institutionalised and homeless people. The survey above-mentioned was carried house-to-house in the Municipality.

Analyzing the relationships between quality of life, living conditions and disability, and as result obtaining an overall picture of the situation in Anapoima as a whole, was the main requirement of the study sample. A census would have been too expensive and time consuming given the available resources. However, it is widely known that sample surveys whose design and methodologies are well developed and executed can produce estimates that can be very close to those that would have been obtained, had a census been conducted. Hence, the survey was carried out on a sample basis.

Taking into consideration the resources and time available, it was calculated that a sample of 100 persons with disabilities would be adequate to provide estimates of acceptable precision at the municipal level. Using the 'snowball sampling technique', also known as 'chain sampling', or 'referral sampling', persons with disabilities were identified, until a case group of at least 100 people was singled out. In other words, being a non-probability sampling method, through the 'snowball sampling technique', interviewees are prompted to recommend other potential participants. Due to the selection method, the sample is subject to bias and may cause the upsurge of associations between sets of data within the study, which are not relevant to the overall population. This fact does not pose a problem to this study, because the main purpose is to analyze the relationships between quality of life, living conditions and disability, and this does not call for a strictly representative sample. In fact, the 'snowball sampling technique' has significant advantages over other sampling methods, such as: the possibility to get through people who are not easily reachable; it is inexpensive, straightforward and produces optimum results for the expenditure; it does not require lengthy planning; and calls for less humans resources. The usage of the 'snowball sampling technique' poses, in contrast, some drawbacks. The sampling technique cannot be easily controlled by the researcher; the level of how well or how accurately the population is reflected upon the sample is not assured: and, as mentioned earlier, sampling bias is highly plausible (Faugier and Sargeant, 1997).

When it came to selecting the control group, the controls were matched to cases based on location. Matching was intended to reduce confounding due to the size of the sample. Thus, controls had to fulfill the following requirements: (1) be the closest home in relation to the house inhabited by a person with disability; (2) not have disabled family members; and (3) agree to participate voluntarily. After identifying the household closest to a case, a screening procedure, based on questions about activity limitations, was carried out to ensure that no

individuals with disabilities resided in that dwelling. Lastly, after obtaining the informed consent the interview was carried out.

2.2.1. Questionnaires

Bringing together two types of traditional research –investigations on living conditions and disability studies– was the underlying intention of the blueprint that was employed on this paper. Disability studies is a descriptive concept herein comprehended as a wide and measurable range of diverse investigations, which have brought awareness about the state of affairs of individuals with impairments.

It has been advised by the Guidelines and Principles for the Development of Disability Statistics issued by the United Nations Statistics Division (UNSD, 2001), that disability is determined within the conceptual frame of reference of the ICF (WHO, 2001b). Using the theoretical frame of reference of ICF offers notions that have become a standard. Similarly, its wording helps to compare data at a larger scale, thus reaching nationwide and intercontinental settings. In doing so, ICF allows the information to become increasingly suitable to a broad range of users.

For this specific case study, first, a house-to-house survey was carried out in the municipality using a screening questionnaire that had the objective of identifying disabled people based on the Washington Group Short Set of Questions on Disability or WG6 (WG, 2010). Second, a complete questionnaire –consisting of mainly closed-ended questions– designed to collect information on disability, and to prompt about the way in which disability affected their lives was used. The respondent was either the disabled person or his/her caregiver. Disabled people who were children or who had substantial problems with communication were not directly interviewed. Third, a simplified version of the complete questionnaire was answered by the closest neighbour (controls). The overall case study plan granted the opportunity to compare the situation of individuals with disabilities, and of the household in which they lived; against the non-disabled and the families where no members with impairments were found. The questionnaires were all developed in English, and subsequently translated into Spanish.

The topics contained in the generic questionnaire were as follows:

- Demography and disease burden
- Education and literacy

- Economic activities of household members
- Reproductive health of females aged 12 to 49 years
- Household amenities and housing conditions
- Household access to facilities
- Household asset ownership
- Household income and its main source
- Household food production
- Health and general well-being
- Knowledge of HIV/AIDS, malaria, tuberculosis and diabetes

Furthermore, the subject matters included in the in-depth Disability Questionnaire were as follows:

- Activity limitations and participation restrictions
- Environmental factors
- Awareness, need and receipt of services
- Education and employment/income
- Assistive devices and technology
- Accessibility in the home and surroundings
- Inclusion in family and social life

People without disabilities were given a *Control questionnaire* – a condensed version of the *Disability questionnaire* answered by individuals with impairments.

In view of their intrinsic inapplicable nature, not all the questions were asked to the study participants, however. Only respondents with disability who were over 12 years of age were prompted on the impact of employment. Individuals with impairments who were over 10 years of age, as well as individuals who did not have serious communication barriers, were asked questions concerning *reasons for emotional problems, changes in community activities, and changes in social attitudes*.

The household screening questionnaire was the instrument used for detecting disability. The questionnaire was a translation of the Short Set of Questions on Disability, namely 6 questions or WG6, contained in the Washington Group on Disability Statistics (WG, 2010). The WG6 is based on the ICF.

2.2.2. Screening and Data collection

Both the researcher and the research assistant traveled together and collected data within a pre-determined geographical area in the municipality. Whether as a detached action or plainly associated with the collection of information, the screening process was performed in one operation. Any persons who answered having "a lot of difficulty" with the content of at least one question, or "some difficulty" in two or more of the WG6 questions of the household screening questionnaire, were regarded as being disabled. The differentiation between kinds of impairment and seriousness of disability was based on the posterior assessment of the replies to the 6 questions.

Face to face and questionnaire-based interviews were conducted with the person in charge of the household or the most senior person present. If the disabled person was not available, was too young or unable to comprehend the questionnaire, a suitable proxy was asked to respond on his/her behalf. There were 40 proxies in total.

In addition, upon completion of the data collection, the author of the project took on the task of organizing the data entry, as well as the cleaning of data files for analyses.

2.3. Ethical Considerations

Before starting the data collection, ethical clearance was obtained from both, the Norwegian Regional Ethics Committee (REK) South-East Region, and in Colombia by the Institutional Committee of Ethics in Investigations of "El Bosque" University (see appendix).

While the Norwegian Regional Ethics Committee (REK) South-East Region, had no ethical objections to the design of the study, the Institutional Committee of Ethics in Investigations of "El Bosque" University, noted that the Informed Consent should make participants more clearly aware that the purpose of the study was to gather information about disabilities,

quality of life and living conditions only, rather than taking actions and promoting solutions, which would be out of the scope of the research. As a result, the Informed Consent was adjusted and deemed approved, accordingly.

With disability being a sensitive topic and the study population considered vulnerable, ethical considerations were highly emphasised, and the choice of individuals to participate willingly, was given precedence.

Written informed consent forms were read, explained and handed to the adult participants, or to the parent/guardian in the case of a participant being a minor or a person without the ability to comprehend it. Participation was voluntary and interviewees were free to end or withdraw from answering the questionnaire at any time with no negative consequences. All information about the participants, like name and other unique characteristics that could identify them, were handled in a confidential manner. Participants were given the option to skip questions that they felt reluctant to answer. Furthermore, in accordance with the declaration of Helsinki, all personal information, as well as the mental integrity of the participants, was kept private and confidential (WMA, 2013).

Another important ethical consideration to be made in relation to the study was anonymity. The name and other unique characteristics of the participants in the response forms were encoded by the investigator, and could be decoded by him only, whenever necessary. Put differently, no names were included in the data file used for analyses. Each participant was given a unique identity number, and personal identification details were placed separately. All the response forms were stored by the researcher at his place of residence during the data collection period. Later, all the response sheets and consent forms were carried back to Norway in a hand luggage, upon study completion. Upon completion of data entry, all the original questionnaires were shredded.

The research project was implemented in accordance with current operative laws, regulations and guidelines that apply in both Norway and Colombia. In this way, by means of the current principles that were established based on guidelines known globally, namely: autonomy, non-maleficance, beneficence, and justice; all ethical considerations were duly observed (Brody, 1998; Beauchamp and Childres, 2001).

3 DISCUSSION AND CONCLUDING REMARKS

The study demonstrates the inequality between people with disabilities and their non-disabled counterparts. This finding represents a step forward in relation to the amelioration of living conditions and the endorsement of human rights, in favor of people with disability. The study puts forward favorable circumstances for encouraging advocacy, establishing precedence, identifying future consequences and setting forth policies, all of which would not only allow overseeing the situation, but also expanding the understanding of and among the individuals with disability and the general population.

The study helps to expand the existing database of knowledge concerning the problematic of disabled individuals in underdeveloped nations, and in Latin America in particular. Sequentially, making comparisons among nations and throughout the region may become feasible thanks to the local database, which may in turn be a medium for capacity development and for partaking of experiences. In this way, the situation of individuals with disabilities might see significant improvement. Eventually, this study may serve as a stepping stone for implementing the Convention on the Rights of Disabled People (UN, 2006), which has been signed by 80% and ratified by all nations in the region.

In addition, the study is meant to be used as a tool by those involved in the formulation of policies, as well as the medical sector, government bodies and other national institutions that are responsible for the disability problematic; that is, those who are in charge of bringing disability into the mainstream of conventional life throughout diverse fields, on a local and national, and even regional scale. Reasonably, a long-lasting and ongoing conversation about the effective way to use the study findings – so that changes that benefit the disabled at diverse levels of the social order are actually implemented – should take place between pertinent authorities, disability institutions and the disability movement.

When measuring living conditions, two key indicators take the central role – education and employment. The disadvantages experienced by individuals with disability are clearly revealed through these indicators. Either knowledge shortfall or discrimination is deemed to be the reason for the discrepancies in alphabetization and formal learning, but there might be other causative factors.

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Region: REK sør-øst	Saksbehandler: Claus Henning Thorsen	Telefon: 22845515	Vår dato: 11.09.2013	Vår referanse: 2013/1278/REK sør-øst C
			Deres dato: 25.06.2013	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

J. Fernando Arango R.
Fredrik Holsts hus

2013/1278 Disability, Living Conditions and Quality of Life

Forskningsansvarlig: Universitetet i Oslo
Prosjektleder: J. Fernando Arango R.

Description

Despite progress at the legislative level, it has been little improvement in Colombia when it comes to effectively promote inclusion for people with disabilities as well as to eliminate discrimination based on disability. A responsible and homogenous data collection process – focused on Living Conditions and Quality of Life – could assist in sensitizing the society and pertaining authorities even more. This could result in an improvement of the situation being faced by the population with disabilities. The rural area of Anapoima has an incidence of permanent severe disability of 9% (2005 Census) compared to 6% nationally. This study will examine if quality of life, participation and perceived quality of the environment of community-dwelling adults differ according to the absence or presence of disability. The general and primary objective is to identify the differences in life conditions and quality of life among individuals with and without disabilities in the rural area of Anapoima.

Ethical considerations

The Committee has reviewed the project application on the basis of the current laws and regulations in Norway for Medical Research Projects originating from Norwegian Research Institutes.

The Committee has no ethical objections to the design of the study. The project is based on a questionnaire, and the aim of the study is to map out differences in quality of life among people with and without disabilities.

Based on the information provided in the application, the Committee assumes that the project is approved by a Local Health Research Ethics Committee in Colombia, in accordance with Colombia's National Code of Health Research Ethics, before the commencement of the study.

Participant information sheet

The information sheet contains the most important elements. The Committee has noticed that a form for illiterate participants has also been included, thus the Committee assumes that the form will be filled in before they are included in the study.

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff

MEMBERS

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MSc. PhD.
Expert in Research Methodology

Bogota, 2nd of September of 2013

Doctor José Fernando Arango R.
International Community Health MPhil programme
Universidad El Bosque

Research Project: Disability, Living Conditions and Quality of Life: The case of the Municipality of Anapoima – Colombia

We hereby inform that during the regular meeting that took place on the 27th of August of 2013, Act No. 011-2013, the Institutional Committee of Ethics in Investigations, revised and discussed the referenced project and the recommendation below was made.

- ✓ The study is considered to be feasible, in terms of proposal and methodology, being its aim to identify the severity and types of disability affecting the rural population of Anapoima. In this regard, the population should be made aware of this objective. The purpose of raising people's consciousness, and promoting solutions before the incumbent authorities would be the step to follow, and will not depend exclusively on the person carrying out the study. Rather, solutions would depend largely on public authorities and on those in the private sector who choose to collaborate. In other words, the study seeks to identify problems and to propose strategies in order to solve them. However, this neither implies that actions will be taken in the short term, nor that those carrying out the study would implement them. In short, the study's pledge is not to solve the problems but rather point them out and raise awareness before the society and before those who possess the means to grant solutions.
- ✓ For the reasons above explained, the last question on page 10 of the research project shown on the Informed Consent form should be either modified or adjusted.

The research project is thereby deemed approved once the adjustment is made.

Best regards,

(signature and El Bosque University seal)

NADIA YADIRA CASTAÑEDA GARCIA
Institutional Committee of Ethics in Investigations, President

Copy to: Dr. MIGUEL OTERO CADENA
Research Division, Director

Ismael Jose Collazos Ortiz
Official Translator and Interpreter
Ministry of Foreign Affairs of Colombia
Resolution # 00083, October 30, 2009
Ministry of Justice of Colombia


ISMAEL J. COLLAZOS
RES. 00083



MIEMBROS

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ABELARDO LEAL HERNÁNDEZ
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Abogado

OSCAR RODRÍGUEZ AGUIRRE
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Experto en Metodología de la
Investigación

Bogotá, 2 de septiembre de 2013

Doctor
José Fernando Arango R.
Máster en Filosofía
Salud Comunitaria Internacional
Medicina Comunitaria
Universidad El Bosque
Ciudad

Protocolo: "Discapacidad, Condiciones y Calidad de Vida. El caso del área rural de San Antonio, Vereda del Municipio de Anapoima – Colombia."

Respetado Doctor Arango:

Estamos informando que el Comité Institucional de Ética en Investigaciones, en la sesión ordinaria del 27 de agosto de 2013, Acta No.011-2013, revisó y discutió el proyecto de referencia y se hicieron las siguientes recomendaciones:

- ✓ El estudio es viable, tanto en su propuesta como en su metodología, y está encaminado a identificar los grados y clases de discapacidad que padece la población rural de Anapoima. De esta forma, es importante aclarar a la población que ése es su objetivo inmediato, y que el propósito de concientizar a las personas sobre este hecho y de promover ante las autoridades pertinentes soluciones al mismo, es un paso posterior, que no depende exclusivamente de quien realiza el estudio, sino en mayor medida de las autoridades públicas como del sector privado que se quiera sumar a esta labor. En otras palabras, el estudio busca identificar problemas, y proponer estrategias para solucionarlos, pero ello no indica que se vaya a llevar a cabo en el corto plazo ni que pueda ser ejecutado por los realizadores del estudio. En este sentido, es importante aclarar que el compromiso del estudio no es solucionar estos problemas, sino señalarlos, y crear consciencia de los mismos en la sociedad y en quienes tienen los medios para darles solución.

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Bogotá, D.C., Colombia



- ✓ Al respecto, se debe modificar o ajustar la pregunta contenida en el formulario de Consentimiento Informado, incluido en la página 10 del protocolo.

El protocolo queda aprobado con los mencionados cambios.

Reciba un cordial saludo.

Nadia Yadira Castañeda G.

NADIA YADIRA CASTAÑEDA GARCÍA

Presidenta

Comité Institucional de Ética en Investigaciones



copia: **Dr. MIGUEL OTERO CADENA**
Director División de Investigaciones

Ofelia M.

2.

Informed Consent – Study Research: Disability, Quality of Life and Living Conditions

I volunteer to participate in a research project conducted by Dr. Jose Fernando Arango Restrepo. I understand that the project is designed to gather information about disabilities, quality of life and living conditions. I will be one of approximately 200 people being interviewed for this research.

1. My participation in this project is voluntary. I understand that I will not be paid for my participation. I may withdraw and stop participating at any time without penalty. If I decline to participate or withdraw from the study, no one will be informed about it.

2. I understand that most interviewees may find the discussion interesting and thought-provoking. If, however, I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.

3. Participation involves being interviewed by the researcher. The interview will last approximately 45-60 minutes. I am aware and agree with the fact that notes will be taken during the interview.

4. I understand that the researcher will not identify me by name in any report using information obtained from this interview, and that my confidentiality as a participant in this study will remain private. Subsequent uses of records and data will be subject to standard data use policies, which protect the anonymity of individuals and institutions.

5. No one from my community will neither be present at the interview, nor will they have access to draft notes or transcripts. This precaution will prevent my individual comments from having any negative repercussions.

6. I understand that this research study has been reviewed and approved by El Bosque University, and by the Norwegian Regional Committees for Medical and Health Research Ethics.

7. I have read and understood the particulars provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

8. I have been given a copy of this consent form.

_____ Name of Interviewee or Guardian	_____ Signature of Interviewee or Guardian	_____ Date (dd/mm/yy)
_____ Name of Interviewer	_____ Signature of Interviewer	_____ Date (dd/mm/yy)

☒ RESEARCH TEAM CONTACT INFORMATION: Fernando Arango - Tel. 315 8532274

☒ ETHICAL COMMITTEE CONTACT INFORMATION: Nadia Yadira Castañeda García Tel. 648 9000

Consentimiento Informado - Investigación: Discapacidad, Condiciones y Calidad de Vida en Anapoima

Me ofrezco como voluntario para participar en un proyecto de investigación dirigido por el Dr. Fernando Arango. Entiendo que el proyecto está diseñado para recoger información sobre discapacidad, calidad y condiciones de vida. Yo seré uno de aproximadamente 200 personas que están siendo entrevistadas para esta investigación.

1. Mi participación en este proyecto es de carácter voluntario. Entiendo que no voy a ser pagado por mi participación. Me puedo retirar y dejar de participar en cualquier momento sin penalización. Si me niego a participar o me retiro del estudio, no se le dirá a nadie.
2. Entiendo que la mayoría de los entrevistados pueden encontrar interesante el tema y los lleve a la reflexión. Si, sin embargo, me siento incómodo de alguna manera durante la entrevista, tengo el derecho a negarme a responder cualquier pregunta o incluso para poner fin a la entrevista.
3. La participación implica ser entrevistado por el investigador. La entrevista tendrá una duración aproximada de 45-60 minutos. Soy consciente y acepto que se tomen notas durante la entrevista.
4. Entiendo que el investigador no dará a conocer mi nombre en ningún informe ni en referencia a la información obtenida durante la entrevista, y que mi secreto como participante en este estudio queden bien protegido. Usos posteriores de los registros y los datos estarán sujetos a las políticas y normativas de uso de datos que protegen el anonimato tanto de las personas como de las instituciones.
5. Nadie de la comunidad que no esté previamente autorizado por mí estará presente en la entrevista, ni tendrá acceso a las notas tomadas ni a transcripciones posteriores. Esta precaución evitará que mis opiniones o comentarios expresados generen una repercusión negativa.
6. Entiendo que este trabajo de investigación ha sido revisado y aprobado tanto por la Universidad El Bosque como por El Comité Regional de Ética de Noruega que regula los trabajos de Investigación Médica y de la Salud.
7. Yo he leído y entiendo la explicación dada. Todas mis preguntas han sido contestadas a satisfacción y, en consecuencia, acepto voluntariamente participar en este estudio.
8. Se me ha entregado una copia de este formulario de consentimiento.

_____ Nombre del entrevistado o acudiente	_____ Firma del entrevistado o acudiente	_____ Fecha (dd/mm/aa)
_____ Nombre del entrevistador	_____ Firma del entrevistador	_____ Fecha (dd/mm/aa)

☒ INFORMACIÓN DE CONTACTO DEL GRUPO DE INVESTIGACIÓN: Fernando Arango Tel. 315 8532274

☒ INFORMACIÓN DE CONTACTO DEL COMITÉ DE ÉTICA: Nadia Yadira Castañeda García Tel. 648 9000

Screening Questionnaire

Household Number	Head of Household (name)	As a result of a health problem (physical, mental or emotional), does anyone in your household have any degree of difficulty to...?					Is there any person with a disability in your household? 1 = Yes 2 = No
		...seeing, in spite of using eyeglasses? 0 = No difficulty	...hearing, even if hearing aids are used? 1 = Moderate difficulty	...walking, going up the stairs? 2 = Great difficulty	...remembering or concentrating? 3 = Unable to do it	...personal care, e.g., showering/bathing, dressing or eating/drinking? 3 = Unable to do it	

Formato de identificación de hogares

Hogar número	Jefe del hogar (nombre)	Debido a un problema de salud (físico, mental o emocional), ¿alguien en su hogar tiene algún grado de dificultad...?					¿Hay alguna persona con discapacidad en su hogar? 1 = sí 2 = no
		... para ver, a pesar de usar lentes o gafas? 0 = ninguna dificultad	... para oír, incluso si utiliza aparatos especiales? 1 = alguna dificultad	... para caminar o subir escaleras? 2 = mucha dificultad	... con el autocuidado: bañarse, vestirse o alimentarse por sí mismo? 3 = incapaz de hacerlo	... para comunicarse, entender o ser entendido por los demás?	

Disability, Living Conditions and Quality of Life The case of the Municipality of Anapoima in rural Colombia

J. Fernando Arango R.^a, Arne Henning Eide^b, Gunnar Aksel Bjune^c

^a *International Community Health Master Program, Institute of Health and Society, University of Oslo, Norway;* ^b *SINTEF Health Research, Oslo, Norway;* ^c *University of Oslo, Department of Community Medicine, Institute of Health and Society, Oslo, Norway*

Acknowledgement

This study was funded in part by a grant from the Ivar Helles foundation.

Abstract

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes that individuals with disabilities have the same rights to freedom, respect, equality and dignity as everyone else. How this is perceived by individuals with disability themselves may be a good indicator on implementation of the CRDP. This article analyses the relationship between disabilities, living conditions and quality of life of people living in rural areas in Colombia, as well as the impact of disability on their living conditions. Using data collected through household surveys, comparisons were made between individuals with and without disabilities, as well as between households with and without a disabled family member. The survey consisted of three questionnaires: one on living conditions, another on quality of life and a third on disability. These pre-existing and validated questionnaires, which had been used in some sub-Saharan countries, were adapted to the Colombian context. Even though the Socioeconomic Status indicator (Material Possessions Scale) ranked higher among the cases than among the controls, persons with disabilities and their families showed a considerable lower quality of life than the control group. This suggests the negative impact that disability exerts on quality of life.

Keywords: disability; living conditions; quality of life; survey; Colombia

Introduction

As of January 2015, the Convention on the Rights of Persons with Disabilities (CRPD) has been signed and ratified for 151 states (UN, 2015). Ratification implies that states are required to promote, protect, and ensure total and equal enjoyment of human rights by persons with disabilities. One important principle of the CRPD states that persons with disabilities and their family members should receive the necessary protection and assistance in order to obtain full and equal enjoyment of the benefits outlined in the Convention (UN, 2006). This principle is directly related to the quality of life of individuals with disabilities and their families. With the purpose of promoting actions to safeguard this principle, it is important to know to what extent the experience of being disabled has a direct impact on quality of life. This paper is based on data from a recent household survey from the Municipality of Anapoima in rural Colombia. The aim is to study the impact that being disabled has on quality of life by analyzing the relationship between disability, living conditions and quality of life in this particular context.

Context

Latin America and Colombia

The World Health Organization (WHO) estimates that around 15 % of individuals in any population are disabled (WHO and The World Bank, 2011). The empirical support for this estimate is however weak in many low- and middle- income countries. Methods of data collection across the Americas vary greatly. Most countries report disability prevalence rates well under 10%, while in cases like Chile, the prevalence rate varies from 2.2% to 5.3% and even up to 21.7%, depending on the survey and the methodology used. These figures are based on reports from censuses or surveys (UN, 2003) (International Disability Rights Monitor, 2004).

The majority of the countries in the Americas continue to use different impairment-based definitions of disability in at least some part of their legislation. Colombia has already begun using, in recent disability policies, a definition of disability based on the International Classification of Functioning (ICF). As a result there are conflicting definitions among national legislations, which directly impacts on how disability is measured (International Disability Rights Monitor, 2004). In addition, there is limited high quality data on disability in Latin American countries in general, especially data that could be used for comparisons across countries and regions (The World Bank, 2011). Disability statistics in Latin American countries has thus been mostly composed of highly diverse impairment prevalence figures. It

can be inferred that prevalence itself does not generate enough concern. The overall low levels of development and inadequate health and social welfare services have contributed to the persistence of poor quality of life among the disabled people in these countries. The need for data that can describe, analyze and compare the situation among individuals with disabilities is therefore evident.

According to the United Nations Population Fund, on 2014, Colombia had a calculated total population of 48.9 million people (UNFPA, 2014). With the World Report on Disability estimate in mind, the number of people with some kind of disability amounts to more than 7 million (WB and WHO, 2011). With the purpose of increasing health coverage for its population, a universal health insurance scheme was introduced in 1993. Prior to the introduction of the mandatory social health insurance, just over 20% of Colombians had health insurance, and access to and use of health care was low and around 60% of those who reported an illness did not seek assistance from a health facility due to the costs associated with the service. Figures from 2008 showed that not only was over 85% of the population insured at the time, but also that access to and use of health care had increased for the general population, especially among the poor (Glassman, Escobar, Giuffrida, & Giedion, 2009).

Nevertheless, data about the situation of people with disabilities in Colombia is sparse. The 2005 general census revealed a disability prevalence of 6.4%, up from just 1.8% from the previous census of 1993. For the specific case of the Municipality of Anapoima – located 87 km south-east from Bogotá – in terms of permanent disability alone, the 2005 census revealed a prevalence of 9% for women and of 9.5% for men, which is around 45% higher than the average in the country.

Quality of life (QOL) and Living Conditions

Ever since the term ‘Quality of life’ started to appear in the literature several decades ago, the concept has been difficult to define. It involves many subjective and personal variables as well as scientific elements within the social and cultural context. There is a tendency to easily make a causal connection between good health and good quality of life; while, on the other hand, poor health, disease, and disability are usually associated with poor quality of life (Warren & Manderson, 2013). According to Veenhoven (Veenhoven, 1996), in the first half of the twentieth century the concept of QOL was associated with the Gross National Product (GNP), while after the 1960’s, it was associated with broader indicators that incorporated a social aspect to the term.

At the beginning of the 90's, WHO acknowledged the lack of a medium that was able to compare quality of life internationally. Following some debate and discussions a definition was issued: "*Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns* (WHO, 1996)." Soon after, studies about QOL among people living with disability started to rely, to a great extent, on quantitative means. Quantitative instruments have been used widely and are valuable tools that help us understand the relationship between a health condition or a disability and the well-being of an individual, at a physical, mental, emotional and social level (Warren & Manderson, 2013). Particularly, quantitative instruments have proved to be an important mean in the process of comprehending the impact that health conditions or disablement have upon people's well-being, physical functioning, mental and emotional health, and social participation. However, there is controversy around the capability of some QOL instruments, and whether they actually measure quality of life – controversy that has grown in part due to the lack of consensus over the definition of QOL, and to some degree, of the use of other terms such as "happiness", "satisfaction" and "well-being", to designate QOL (Taillefer, Dupuis, Roberge, & LeMay, 2003) (Mandzuk & McMillan, 2005).

Most of QOL instruments assume that injury, disease, deficiency, problem or need of a person is what is relevant, without taking into consideration other potentially compensatory factors. Consequently, a person cannot be disabled and healthy simultaneously; nor, in theory, can a person with a physical condition claim a positive life quality. And yet, people with chronically limiting conditions often report a positive life quality (Koch, 2000). Accordingly, QOL instruments are sometimes constructed assuming that context plays a limited, if any, role in shaping people's perceptions of QOL, and that people report on such measures in the same way, regardless of cultural settings or environment (Warren & Manderson, 2013).

Nevertheless, research in some sub-Saharan countries (Eide et al., 2011) has shown a pattern which reflects that people with disabilities perform far worse than people without disabilities on several living conditions indicators – a pattern that has also been reported in studies carried out in industrialized countries (Newman, 2003). The concept of living conditions is relevant when analyzing QOL because it comprises indicators that are expected to influence QOL. Thus, controlling these factors becomes necessary in order to find the unique contribution that disability has on QOL.

The notion of 'living conditions' has developed and transformed from an economic and materialistic point of view to a concept that encompasses the human capabilities and how

individuals can make the most of their potential abilities (Eide et al., 2011). In industrialized countries, economic and material indicators usually play an important role on surveys of living conditions. A great advantage of doing research on living conditions based on an economic and materialistic point of view is that it allows comparison between groups, and helps monitor development over time. However, socioeconomic status alone is not necessarily the main concern in the living conditions of an individual. Availability and accessibility to basic services and human rights, the freedom to choose and to affect the course of his/her own life, working conditions, the degree of social integration, health and education, whether people are particularly fragile economically or physically, are all important parts of the equation as well (UNDP, 1997). The concept of "living condition" thus embraces a range of factors that may have an impact on how individuals perceive their quality of life, as defined by WHO (WHO, 1996).

Disability

Since the early 1970s, an important change in society's understanding of disability has taken place. It has been a transformation from an individual and medical perspective («the medical model») into a structural and social perspective («the social model») (Raiter, 2008) (Oliver, 1990). The latter model explains disablement as the result of any behavior or barrier which prevents people with impairments from taking integral part in the life of society. The social model does not wish to deny the existence of impairments and physiological differences - far from it; rather, it addresses them without attaching value judgments such as 'normality', and shifts the emphasis towards those aspects of our surroundings that can be changed (Swain, French, Barnes, & Thomas, 2004) (Hughes and Patterson, 1997) (The Disability Research Unit - School of Sociology & Social Policy - University of Leeds, 1996).

Later, the need for an approach that took into account the different aspects of disability became evident (Shakespeare, 2006). That is how another model called a «bio-psychosocial model» emerged. This model offers a viable balance between the medical and social models, which is shown in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). Gradually, the human rights of individuals with disabilities have been added to national and international initiatives. An example of this is the approval of the CRPD in 2006 (UN, 2006). As a result, much of the focus is now on both the individual and the structural/social environments, and on how this might reduce or enhance an individual's level of activity and social participation.

This research project compares people with disability against their non-disabled counterparts, taking certain Living Conditions and Quality of Life indicators as reference; this, with the purpose of finding the answer to the following question: To what extent does disability impact the quality of life of individuals with disability in the context of Anapoima, in rural Colombia?

Methods

The Survey Questionnaire

The survey was designed based on validated research instruments that were used in African countries (Eide et al., 2011) upon which the survey was adapted and combined. In the end, three questionnaires made up the survey: one questionnaire on living conditions, another on quality of life and a third on disability. In addition, a household screening questionnaire was used to identify households with members with disabilities as well as the controls. The household screening questionnaire was a translation of the Washington Group on Disability Statistics' 6 questions (Washington Group on Disability Statistics, 2010), which, is in turn based on the ICF.

Measures

Quality of Life

The instrument employed for the purpose of collecting data on quality of life was the WHOQOL-BREF, an abbreviated version of the WHOQOL-100, which covers the following broad domains: physical health, psychological health, social relationships, and environment in a total of 26 questions with five ordered possible response levels (Likert scale). The WHOQOL-BREF leads to a quality of life profile. Domain scores are scaled in a positive direction and the mean score of items within each domain (raw score) is used to calculate the domain score. Each domain score is first transformed into a 4-20 scale (which facilitates making comparisons with WHOQOL-100), and then transformed into a 0-100 scale (WHO, 1996).

Disability

Disability was operationalized by means of the Short Set of Questions on Disability (Washington Group on Disability Statistics, 2010). The questions on activity limitations concerned different activity domains, and the respondents were asked to indicate whether they had any problems in performing different activities, as follows: seeing, hearing, walking,

remembering, personal care and communicating. The 6 questions had four possible answers: No - no difficulty (0), Yes – some difficulty (1), Yes – a lot of difficulty (2) and Cannot do at all (3). A person who answered ‘a lot of difficulty’ to 2 or more questions, or ‘cannot do at all’ to at least one question was considered to be a person with disability.

Living conditions

Three common living conditions indicators, namely, socioeconomic status (SES), education (formal primary education specifically) and income, were used. These indicators were chosen because they allow for making comparisons between groups. The respondents were asked to state whether they had 23 different household items or commodities in their household; each affirmative answer added a point on the corresponding scale. Respondents were also asked if they attend or had attended formal primary education and about their last monthly income.

Ethical considerations

The study was approved both, in Norway, by the Regional Committees for Medical and Health Research Ethics (REC), reference number 2013/1278/REK sør-øst C, and in Colombia, by the Institutional Committee of Ethics in Investigations of El Bosque University.

Sampling and data collection

The descriptive, cross-sectional and case-control methodological design chosen was deemed to be the most appropriate for the data collection process and the forthcoming data analyses in order to answer the present research question.

The selected research assistant was a member of the community and a former health worker who was acquainted with a large group of persons with disabilities in different areas of the municipality. She was one of the key figures that facilitated locating not only cases and controls, but also helped the author with the data collection process by carrying out 82 interviews from a total of 202.

Using the ‘snowball sampling technique’, also known as ‘chain sampling’, or ‘referral sampling’, other persons with disabilities were identified, until a case group of at least 100 people was singled out.

Face to face and questionnaire-based interviews were conducted with the person in charge of the household or the most senior person present. If the disabled person was not available, was too young or unable to comprehend the questionnaire, a suitable proxy was asked to respond on his/her behalf. There were 40 proxies in total.

When it came to selecting the control group, the controls were matched to cases based on location. Matching was intended to reduce confounding due to the size of the sample. Thus, controls had to fulfill the following requirements: (1) be the closest home in relation to the house inhabited by a person with disability; (2) not have disabled family members; and (3) agree to participate voluntarily. After identifying the household closest to a case, a screening procedure, based on questions about activity limitations, was carried out to ensure that no individuals with disabilities resided in that dwelling. Lastly, after obtaining the informed consent the interview was carried out.

A total of 202 households were included in the study; half of them had at least one member with disability. All questionnaires were checked by the author of the project.

Handling of data and analyses

The computer software SPSS (release 22.0) was used by the author for data entry and for data analysis. Data entry to the program was performed right after completion of the data collection. The variables were assessed using univariate, bivariate and multivariate analysis. The significance of observed associations and/or differences between variables was tested using Student's *t*-test and the X^2 statistic (Pearson's X^2) where appropriate. A difference was considered to be statistically significant at $p < 0.05$. Bivariate regressions on quality of life by each of the chosen predictors were conducted, and finally a regression analyses including all predictors that were associated with quality of life in the bivariate regressions.

Results

Demographics

The sample consisted of 101 individuals with disability (cases), and 101 individuals without disability (controls). Of these, 79 (39.1%) were males and 123 (60.9%) were females. Gender distribution differed between case and controls, with 68.4% and 31.6% males respectively. This observed difference was statistically significant ($X^2 = 14.483$, $df = 1$, $p < 0.01$) (Table 1). On average, the age of the case group was higher than the average age of the control group, while the mean age for males in the total sample was higher than that for females (Table 1).

Table 1 - Demographics (Condition groups and gender by age)

	N	Mean	95% C.I.	Std. Error of Mean	Std. Deviation	Range	Min.	Max.
Case group	101	54.15	48.40 - 59.87	2.90	29.10	88	4	92
Control group	101	48.31	44.88 - 51.73	1.73	17.35	64	16	80
Males	79	52.28	46.54 - 58.02	2.88	25.62	86	5	91
Females	123	50.55	46.43 - 54.68	2.08	23.11	88	4	92

Both the case and the control group showed a normal distribution in regards to age. The observed mean difference in age between the groups is not statistically significant ($t = 1.73$, $df = 200$, $p > 0.05$). In the same way, the number of members per household showed a normal distribution for cases and controls. Even though the average number of members per household was higher for the cases (3.63) than for the controls (3.34), the observed mean difference between the groups was not statistically significant ($t = 1.15$, $df = 200$, $p > 0.05$) (Table 2).

Table 2 - Summary table

		N	Mean	Mean difference	t-test for Equality of Means	
					t	p-value
Age	Case group	101	54.15	5.84	1.73	0.09
	Control group	101	48.31			
Activity Limitations Score - WG6	Case group	101	6.11	5.33	19.59	0.00
	Control group	101	0.78			
Material possessions scale	Case group	101	11.42	1.95	4.38	0.00
	Control group	101	9.47			
Income	Case group	44	2.00	-0.57	-2.85	0.01
	Control group	85	2.56			
QoL - Total Score	Case group	73	74.39	-15.91	-8.26	0.00
	Control group	96	90.29			

Activity limitations

The six questions referring to the six activity domains were subject to a scale analyses that produced Cronbach's Alpha value of .72, which is sufficient to construct a scale on Activity Limitations. The six questions were added together and a new variable was created (Activity Limitations Score - WG6), yielding the following scale properties: Range: 0-13, Mean: 3.45, Standard deviation: 3.29). The mean difference between cases and controls is statistically significant (Table 2).

Socioeconomic Status (SES) indicator: Material Possessions Scale

Respondents were asked to state whether they had 23 different household items or commodities in their household. The results show that the case group scores higher in 18 out of 23 items evaluated. The difference is statistically significant for 9 of the items when analyzed by the Pearson Chi-Square test (Table 3).

There were, in general, higher percentages of possession of household items among the case group than among the control group. Only four items had higher percentages among the controls in comparison with the cases: Cellular phone, Gas/electric stove, Sofa, and Motorcycle. The items with larger percent difference were Poultry (42.6%), Radio (36.6%), and Iron (25.7%). Both the top and the bottom of the list for the two groups were occupied by about the same items: the top four positions for the case group were Bed(s), Cellular phone, Chairs and Television, while for the control group it was Gas/electric stove the item that ranked higher, instead of Chairs. The positions at the bottom were occupied by Microwave oven, Own vehicle, and Landline telephone in the two groups.

A scale analysis was performed, yielding a Cronbach's Alpha value of 0.71, which is sufficient to construct a scale on Material Possessions. The answers to the 23 questions were added together and a new variable was created (Material Possessions Scale), yielding the following scale properties: Range: 1-19, Mean: 10.44, and Standard deviation: 3.31. It was observed that households with a disabled family member had, on average, more possessions (mean 11.42), than households without a disabled family member did (mean 9.47). The mean difference between cases and controls was 1.95, which is statistically significant ($t = 4.38$, $df = 200$, $p < 0.01$).

Table 3 - Household items

	CASE GROUP			CONTROL GROUP			Chi-Square Tests	
	Responses		Percent of cases	Responses		Percent of cases	Pearson's χ^2	p-value
	N	Percent		N	Percent			
Radio	75	6.5%	74.3%	33	2.9%	32.7%	34.40	0.00
Television	92	8.0%	91.1%	92	8.0%	91.1%	0.23	0.63
Sound device	35	3.0%	34.7%	33	2.9%	32.7%	0.04	0.84
DVD/VHS player	36	3.1%	35.6%	23	2.0%	22.8%	3.87	0.05
Cellular phone	96	8.3%	95.0%	97	8.4%	96.0%	0.12	0.73
Landline telephone	2	0.2%	2.0%	0	0.0%	0.0%	2.00	0.16
Iron	70	6.1%	69.3%	49	4.2%	48.5%	8.14	0.00
Electric fan	32	2.8%	31.7%	21	1.8%	20.8%	2.81	0.09
Gas/electric stove	83	7.2%	82.2%	92	8.0%	91.1%	5.28	0.02
Wood stove	54	4.7%	53.5%	40	3.5%	39.6%	3.42	0.06
Fridge	85	7.4%	84.2%	79	6.9%	78.2%	0.64	0.42
Microwave oven	8	0.7%	7.9%	1	0.1%	1.0%	5.56	0.02
Washing machine	33	2.9%	32.7%	22	1.9%	21.8%	2.74	0.10
Sofa	20	1.7%	19.8%	26	2.3%	25.7%	1.18	0.28
Table	88	7.6%	87.1%	84	7.3%	83.2%	0.22	0.64
Chairs	93	8.1%	92.1%	87	7.5%	86.1%	0.98	0.32
Bed(s)	101	8.8%	100.0%	101	8.8%	100.0%	-	-
PC or tablet	22	1.9%	21.8%	10	0.9%	9.9%	5.08	0.02
Cable or satellite TV	21	1.8%	20.8%	10	0.9%	9.9%	4.36	0.04
Poultry	56	4.9%	55.4%	13	1.1%	12.9%	39.61	0.00
Bicycle	27	2.3%	26.7%	15	1.3%	14.9%	4.04	0.04
Motorcycle	16	1.4%	15.8%	25	2.2%	24.8%	2.72	0.10
Own vehicle	8	0.7%	7.9%	5	0.4%	5.0%	0.68	0.41
Total	1153	100.0%		958	100.0%			

Education

Only 62.6% of those pertaining to the case group attended formal primary education, compared with 89.9% of those pertaining to the control group. The difference was statistically significant when analyzed using the Pearson's χ^2 (value: 20.34, df = 1, p< 0.01). The Phi coefficient (0.32) shows that the strength of the association is moderate. Compared to persons with disabilities, controls were significantly more likely to ever attend primary education (41.1% and 58.9% respectively).

Income (personal)

The question on personal income was answered by only 44% of the cases, and by 85% of the controls. There were 5 possible answers, in a scale from 1 to 5: (1) Does not get salary, (2) Up

to COL\$250.000 (\leq US\$120), (3) COL\$251.000-600.000 (US\$120-290), (4) COL\$600.000-1.000.000 (US\$290-485), and (5) Over COL\$1.000.000 (\geq US\$485).

The control group had, in general, higher personal income than the case group. In the scale from 1 to 5 it was observed that the mean personal income among the cases was lower (2.0) compared to controls (2.56). The mean difference was -0.57 ($t = -2.85$, $df = 127$, $p < 0.01$), which is statistically significant.

Quality of Life

Owing to missing values, the number of cases included in the assessment was reduced to 73, and the number of controls was reduced to 96. According to the WHOQOL-BREF's user guide, "Mean substitutions are recommended for Domain 1 (Physical Health) and Domain 4 (Environment) if no more than one item is coded missing". If more than 2 answers are missing from Domains 1 (Physical), or 4 (Environmental), or if at least one item is missing from Domain 2 (Psychological), or 3 (Social Relationships), it is advisable not to estimate the corresponding domain score for that particular individual.

The QOL total score was calculated adding up the four domains, and it was found to be higher for the controls. The mean difference between cases and controls is statistically significant ($p < 0.01$) (Table 4).

Assessment by domains

Physical Health Domain. The 7 items that measure the Physical domain were subject to a scale analyses. The reliability coefficient for the Physical domain was .86, as measured by Cronbach's Alpha, which shows a reasonable high level of reliability.

A new variable was created by adding the 7 items together, yielding the following scale properties: Range: 9-34, Mean: 23.15, Standard deviation: 5.96. The Physical domain score was found to be lower for the cases. The mean difference is statistically significant.

Psychological Domain. The 6 items that composed the Psychological domain were subject to a scale analyses. The reliability coefficient for the psychological domain was .77, as measured by Cronbach's Alpha, which shows an acceptable level of reliability.

The 6 items were added together in order to create the new variable, yielding the following scale properties: Range: 9-29, Mean: 20.87, Standard deviation: 4.38. The Psychological domain score was found to be higher for the controls. The mean difference is statistically significant.

Table 4 - Quality of Life and its domains

<i>Domains</i>		N	Mean	Mean difference	t-test for Equality of Means	
					t	p-value
Physical Health (raw score)	Case group	73	18.59	-8.03	-11.10	0.00
	Control group	96	26.61			
Psychological (raw score)	Case group	73	18.51	-4.16	-6.52	0.00
	Control group	96	22.67			
Social Relations (raw score)	Case group	73	8.83	-1.73	-5.22	0.00
	Control group	96	10.56			
Environmental (raw score)	Case group	73	25.63	-1.50	-2.16	0.03
	Control group	96	27.13			
QoL - Total Score (raw score)	Case group	73	74.39	-15.91	-8.26	0.00
	Control group	96	90.29			

Social Relations Domain. It contains only 3 items that were subject to a scale analyses. The reliability coefficient for the Social relations domain was .59, as measured by Cronbach's Alpha, which shows a rather low level of reliability.

To construct the scale Social relations domain, the 3 items were added together and a new variable was created, yielding the following scale properties: Range: 4-15, Mean: 9.81, Standard deviation: 2.29. The Social domain score was found to be lower for the cases. The mean difference is again statistically significant.

Environmental Domain. Its 8 items were subject to a scale analyses. The reliability coefficient for the Environmental domain was .64, as measured by Cronbach's Alpha, which shows an acceptable level of reliability.

The scale Environmental domain was created next. The 8 items were added together and a new variable was created, yielding the following scale properties: Range: 14-39, Mean: 26.48, Standard deviation: 4.53. The Environmental domain score was found to be higher for the controls. The mean difference is statistically significant.

Regression analysis

A linear regression analysis was performed for Quality of Life (Total Raw Score) in relation to the following five predictors together: Activity Limitations, Age, Education, Material Possessions, and Gender, as well as for Quality of Life (Total Raw Score), and each predictor individually (Table 5).

About 36.8% of the total variance in QOL (Total Raw Score) can be explained by the combination of the five predictors. When the predictors are analyzed one by one, about 33.8% of the total variability in QOL (Total Score) can be explained by the Activity Limitations Score (WG6) alone, followed by Age with about 23.8%. The other predictors were not statistically significant when analyzed combined or individually.

Preliminary analysis showed that there were no violations in the assumptions of normality, linearity, or homoscedasticity when the analysis was conducted to evaluate if QOL can be predicted by the level of Activity Limitations. There is significant evidence to conclude that there is a strong, negative association between the Activity Limitations Score ($M = 2.95$, $SD = 2.94$) and QOL (Total Raw Score) ($M = 83.42$, $SD = 14.41$) $r(168) = -.59$, $p < .01$. Higher levels of Activity Limitations are associated with lower levels of Quality of Life. When the analysis was conducted to evaluate if QOL can be predicted by Age, preliminary analysis showed that there were no violations in the assumptions of normality, linearity, or homoscedasticity. There is also significant evidence to conclude that there is a strong, negative association between Age ($M = 55.82$, $SD = 21.85$) and QOL (Total Raw Score) ($M = 83.42$, $SD = 14.41$) $r(168) = -.49$, $p < .01$. Old age is associated with lower levels of Quality of Life. For the other three predictors, Gender, Education, and Material Possessions there is no significant relationship and QOL cannot be predicted by any of these three predictors.

A linear regression analysis was performed also for the four domains that compose the QOL Total Score. About 50.0% of the total variability in the Physical Health Domain can be explained by the five predictors combined. For the Psychological Domain it is about 28%, and for the Social Relations Domain it is about 20.4%. Only 3.7% of the total variability in the Environmental Domain can be explain by the five predictors combined. For the Physical Health, Psychological and Social Relations Domains, Age, and Activity Limitations Score were the statistically significant variables; whereas for the Environmental Domain, Gender, and Activity Limitations Scores were the statistically significant variables (Table 5).

Table 5 – Regression analysis

Dependent variable	Predictors	Adjusted R Square	p-value	p-value <i>(for each predictor)</i>
<u>Bivariate correlation</u> Quality of Life (Total Raw Score)	Activity Limitations Score - WG6	0.338	0.00	0.00
	Age	0.238	0.00	0.00
	Education	0.009	0.12	0.12
	Material possessions	0.002	0.26	0.26
	Gender	0.001	0.27	0.27
<u>Multivariate correlation</u> Quality of Life (Total Raw Score)	Activity Limitations Score - WG6			0.00
	Age			0.00
	Education	0.368	0.00	0.68
	Material possessions			0.45
	Gender			0.30
Physical Health domain (Total Raw Score)	Activity Limitations Score - WG6			0.00
	Age			0.00
	Education	0.500	0.00	0.53
	Material possessions			0.26
	Gender			0.97
Psychological domain (Total Raw Score)	Activity Limitations Score - WG6			0.00
	Age			0.00
	Education	0.280	0.00	0.62
	Material possessions			0.83
	Gender			0.35
Social Relations domain (Total Raw Score)	Activity Limitations Score - WG6			0.00
	Age			0.00
	Education	0.204	0.00	0.66
	Material possessions			0.78
	Gender			0.51
Environmental domain (Total Raw Score)	Activity Limitations Score - WG6			0.01
	Age			0.82
	Education	0.037	0.05	0.49
	Material possessions			0.48
	Gender			0.04

Discussion

One of the major findings of this survey is a pattern that reflects the following: on two living conditions indicators (Education and Income), and in all of the Quality of Life domains, people with disabilities and their families perform far worse than individuals without

disabilities. This finding is in accord with research carried out in industrialized nations and in some sub-Saharan countries (Eide et al., 2011) (Newman, 2003). The overall regression model explains almost 40% of the variation in Quality of Life in the sample, with disability being the major predictor followed by Age. This strongly indicates that disability in this context affects Quality of Life, especially when it comes to the Physical Health domain. The relevance of Age as a predictor can be seen as a consequence of the limitation caused by diseases or injuries that add up as time goes by.

An expected negative association between being disabled and Socioeconomic Status, measured by means of a possession scale, was not found. On the contrary, the higher SES measured by the Material Possession Scale for households with disabled members may be explained by means of the help and support that these individuals receive in general by close family members. Such help and support represents material elements in some cases, but in others it is provided by means of care, which is not offered by the health care system.

When it came to explaining the variability of the four domains of Quality of Life, a pattern was noticed through the model. Such pattern showed that disability (Activity Limitations) and Age explained, consistently, the variation in the dependent variables when analyzed in conjunction with Gender, Education, and Material Possession. The Physical Health, Psychological and Social Relations domains in particular were the domains in which the variables combined explained the variability to a large extent. The exception to this pattern was the Environmental domain, where Gender, not Age, was the significant variable along with Activity Limitations.

Many people were reluctant to report income, especially within the cases. This may be due to factors like fluctuating and/or unstable income caused by seasonal labor, unfavorable working conditions or other factors. Even though it was difficult to obtain suitable data on household or individual income the observed difference in mean personal income between the two groups was significant. This refers to an individual measure – i.e. the income of the individual with or without disability – while the SES indicator refers to a household measure. This shows that households with disabled members compensate their low income with a comparatively larger amount of material possessions than his/her non-disabled counterparts.

On the research results presented in this paper both terms “quality of life” and “living conditions” were used because they complement each other. While living conditions generally refers to a set of material variables, quality of life relates to more immaterial aspects of life like feelings, emotions or experiences surrounding one’s existence. It was then examined whether “quality of life” and “living conditions” were influenced by the presence or absence

of disability. Taking into account that material and traditional living conditions indicators are usually considered to be of limited value to describe the life situation of a group of people, it was decided to couple them with "classical" indicators of quality of life. This approach not only shed light on the understanding of the situation, it also helped comparing groups, and it may as well facilitate making comparisons over time.

Limitations

One of the main limitations was restricted time and resources. Due to the size of the sample in the study, it was not possible to ensure a representative distribution of the population of Anapoima as a whole. This reduced the scope for generalizing the findings.

Furthermore, bias due to a sample error may have occurred. Having chosen to use a voluntary sample posed the risk of involuntarily over-representing individuals with strong opinions.

Conclusion

The importance of not only disability but also age as contributing factors to explain variation in Quality of Life opens a wide range of opportunities for research and new challenges for policy-makers. This was made evident in a publication released in 2014 by the Economic Commission for Latin America and the Caribbean (ECLAC), which shows how over the last 20 years the adult population of Colombia has doubled due to an increased life expectancy and lower birth rates (ECLAC, 2014). The United Nations Population Fund (UNFPA) Aging Report estimated in 2012 that the Colombian population over 60 years of age would triple between 2012 and 2050 (UNFPA, 2012). To address the needs of both, the disabled and the aging population, a re-evaluation of policies in regards to pension, healthcare, welfare, and savings programs of the most vulnerable members of the Colombian society, like the elderly and the disabled, is deemed to be necessary.

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