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Manuela Espejo Solidarity Mission: When Success Meets Rurality

Has the Manuela Espejo Solidarity Mission Enhanced the Lives of Physically Disabled People in Rural Ecuador?
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ABSTRACT

The following is a critical analysis of the Manuela Espejo Solidarity Mission (MESM) and in how far it enhances the lives of physically disabled people in rural Ecuador. An overview of the debate on models of disability and an account of physical disability in rural areas in the Global South sets the ground for the discussion. From a Sustainable Livelihoods (SLA) and Capabilities Approach (CA) point of view, this research reveals that although comprehensive and regionally admired, the MESM lacks considering the rural context as a social determinant. Therefore, this analysis reveals the implications of overlooking rurality and concludes that the MESM enhances the lives of physically disabled people in rural Ecuador to an extent. Further research needs to be done in the area of rural physical disability. Moreover, the policy implications of this research are the importance of adapting MESM to the rural context in different levels (or capital assets), including disabled people in rural development policy and further fostering social and political capital.

Key words: rural context, physical disability, MESM, Capabilities, Sustainable Livelihoods
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1: INTRODUCTION

Disability has historically been a source of discrimination, however, in recent decades policy responses have changed as the result of ongoing debate, introducing notions of inclusion and the recognition of particular rights for disabled people (Rimmerman, 2013). As perceptions of disability transformed, so did policy responses which included a diversity of views or models of disability (ibid). Moreover, the increase and shift of policy responses attended an increasingly evident reality for policy makers: the fact that 15% of the world’s population lives with some type of disability, making disabled people the world’s largest minority (United Nations Enable, 2014). Such is even more relevant for the Global South where 80% of disabled people reside, many of which live in rural areas (ibid). Moreover, 75% of the world’s poor live in rural areas, where socio-economic exclusion is high and access to services is generally low (World Bank, 2008). Therefore, the situation for disabled people in rural areas is particularly because cycles of poverty and disability reinforce each other (Seeley, 2001).

Currently, despite the attempts to integrate human rights and social inclusion in new debates around disability policies, the notion of normalising disabled individuals persists as policies seek to adapt disabled people to ‘mainstream’ society (Mike Oliver, 1986; Rimmerman, 2013). It is in this context that the Manuela Espejo Solidarity Mission (MESM) emerges and presents the opportunity to study, from a theoretical standpoint, its conception and application in rural Ecuador. Attempting to alleviate the issues of poverty and social exclusion affecting disabled people, the MESM bloomed as a south-south cooperation program resulting from an Ecuadorean-Cuban partnership and has now become a regional point of reference (José & Monje, 2013)

This dissertation will explore the situation of physically disabled people in rural Ecuador in the light of the MESM. The aim is to expose the complexity of improving the lives of people who are not only excluded for being impaired but also for belonging to ethnic minorities, being poor and for residing in the rural areas. That is because there is often a correlation

---

1 See Appendix 1 for “A note on terminology”
2 In Spanish, Misión Solidaria Manuela Espejo.
between ethnicity, poverty and disability and this may hinder the goal of policies such as the MESM to ameliorate the lives of disabled people (Elwan, 1999).

Therefore, despite the MESM being regarded positively at the international level, it must be analysed thoroughly in order to find out how it enhances the lives of disabled people in the rural areas in particular. Ultimately, the contribution of this research is to bring light to the importance of the characteristics of the rural context and that these should be considered in disability policies.

1.1 Research question

The question to address this topic more specifically is: **In how far does the MESM enhance the lives of people with physical disabilities in rural Ecuador?** It is important to note that the term ‘physical disability’ is understood in this research as mobility impairments only – which differ from blindness, deafness or mental impairments. In rural Ecuador almost half of the total number of disabled people have physical impairments of different kinds (INEC, 2010). This group is diverse and includes many different mobility impairments, yet physically disabled people have a common problem in the rural context; the notion of personhood in rural areas depends on being physically able (Grech, 2008).

In sum, the research question sets the ground for discussing the extent to, and ways in which, the lives of physically disabled people in rural areas are enhanced by the MESM. In order to answer the question, it is necessary to use a conceptual framework that allows operationalising the idea of ‘life enhancement’. With that purpose, the Sustainable Livelihoods Approach (SLA) and the Capabilities Approach (CA) will be used as part of this framing as explained next.

1.2 Methodology

The research for this paper consists of a literature review on models of disability as well as on SLA and the CA applied to disabilities in the rural context. Moreover, the following secondary sources from institutions that stem from different sectors of society are used in order to consider multiple viewpoints: Ecuadorean National Policy Reports from the Technical Secretary for Disabilities (SETEDIS) and the National Statistical Office (INEC),
United Nations Human Rights (UNHR) reports by the Committee on the Rights of Persons with Disabilities (CRPD), United Nations Enable publications and information from the civil society Ombudsman organisation (Defensoria del Pueblo).

In addition, this analysis uses quantitative information of disabled people in rural Ecuador which was collected during the biopsychosocial census performed in the first stage of the MESM’s. The main limitations of this research’s methodology are the lack of access to primary qualitative information. This would have been useful to map the perception that disabled people have of their lives, unveiling their daily difficulties in rural areas.

1.3 Structure

In the next chapter, the literature review explores the contested definitions of disabilities and the difficulties of rural life for disabled people in the Global South. Thus leading to the discussion of the conceptual framework - consisting of the SLA as well as the CA - that is later used to analyse in how far the MESM enhances the lives of disabled people in rural Ecuador. The third chapter explores the case study in depth looking at the overall context of disability in Ecuador and consequently, explaining the design and relevance of the MESM. Lastly, in this section, the case of rural beneficiaries of MESM is explored based on secondary data. The fourth chapter presents the discussion and policy implications of the MESM case study under the framework of the SLA and CA. The last chapter has concluding remarks.
2 LITERATURE REVIEW

This section presents a debate of the conceptualisation of disability which is essential for understanding disability policy. The first part presents an overview of the difficulties and characteristics of the lives of physically disabled persons in rural contexts in different places of the Global South. This is done as a form of background to this research given that no literature on disability in the Ecuadorean rural context was found. The second part provides an overview of the different models of disability. The third part examines the contributions that the CA provides to the study of disability. The fourth part presents the SLA as a framework to understand the rural context. Lastly, this literature review brings together a conceptual framework through which the lives of physically disabled people in rural areas will be assessed under the MESM.

2.1 Physical Disability in the Rural Context

Rural contexts are not identical across the world, but they tend to present common dynamics which are reported in the literature and are worth mentioning (Charroalde & Fernandez, 2006). When looking at physical disability in the rural context, different factors such as: ethnicity, poverty and rurality need to be considered. Such factors contribute to further exclusion of physically disabled people and in order to understand the linkages between these factors it is important to draw attention to the significant relationship between poverty and disability. According to (Seeley, 2001), when looking at disabilities in rural India, the cycles of poverty and disability do not have a causal relationship but rather one of mutual reinforcement. In other words, poverty conditions create disability and this leads to further impoverishment. (Grech, 2008) claims that rural areas in Latin-American countries, like in Guatemala, are characterised by a historic exclusion of indigenous populations which results in poverty that in many cases leads to disability.

In terms of mobility, (Charroalde & Fernandez, 2006) argue that, due to the inaccessible environment in rural areas, a person with acute mobility impairment cannot access medical centres for treatment, let alone visit other places in the community or reach their workplace with a wheelchair. According to (Van Rooy et al., 2012), in the case in rural Namibia, rural
settings often lack paved roads, distances are long and there is limited public transportation. Moreover, seasonality affects mobility of people with physical impairments during rainy season; for example, the use of wheelchair and crutches becomes more difficult. This is problematic because the possibility to move freely is essential for integrating in community activities, reaching medical centres and in the best cases workplaces. In addition, the rural context does not only complicate the access that physically disabled people have to valuable aspects of their lives, but also makes service and assistance delivery more challenging, as it can be difficult to reach physically disabled people.

With regards to medical facilities in rural areas, authors find that there are often shortages of treatment infrastructure and specialists as well as low frequency in the services for therapies (Charroalde & Fernandez, 2006; Charroalde & Fernandez, 2006; Grech, 2008; Van Rooy et al., 2012). In terms of access to education, according to the (DFID, 2000: 1) “disability limits access to education and employment, and leads to economic and social exclusion. Poor people with disabilities are caught in a vicious cycle of poverty and disability, each being a cause and consequence of each other”. Consequently, the phenomenon of rural-urban migration of disabled people arises, leaving the lives of those in rural areas unresolved (Kothari, 2002).

Along with the issue of poverty and limited access to basic services, the notion of ethnicity plays an important role explaining the causes of poverty and social exclusion of physically disabled people in rural areas. Namibia and Guatemala are interesting examples where similar exclusion dynamics are drawn by the line of ethnicity and culture. In the case of Guatemala, (Grech, 2008) illustrates how belonging to an ethnic minority results in further social exclusion and thus intergenerational poverty. Similarly, argues that in Namibia, language is a barrier between healthcare providers and rural ethnic groups where a hierarchy is set and influences their interaction. Such attitudes and lack of opportunities due to ethnic and cultural characteristics of rural people add on to the increasing discrimination of disabled people. To sum up, the structural difficulties that rural contexts place on physically disabled people are different and should be considered differently than in urban contexts as (Charroalde & Fernandez, 2006) suggests.
2.2 Models of Disability

In order to understand the impact and effect of a social policy on disability, it is essential to understand the models used to define the concept and their political and social implications. The definition of disability sets the ground for understanding the interactions and power relations between disabled people and the wider society; including policy makers and the welfare system. Here four major models of disability are considered: the medical, social, cultural and human rights models. The overview of the models will contribute to the analysis of the MESM.

The medical model emerged during the 18th century and establishes that disabilities are directly linked with impairments and illnesses (Rimmerman, 2013). Drawn from a positivist approach, diagnosis simplified the process of service delivery but also promoted exclusion and discrimination against disabled people. According to this model, impairments represent suffering and thus the solution is to restore and ‘treat’ in order to achieve a better functioning that is closer to ‘the normal’ (Thomas, 2004). The model justifies administering medical treatment to alleviate chronic pain, easing the lives of disabled people (M. Oliver & Barnes, 2012). The policy implications of this model are that normality should be achieved through individual adjustment to society (Rimmerman, 2013). Such approach does not consider, however, that society can or should adapt to the lives of disabled people (ibid).

In response to the medical model, the social model by Vie Kinfelstein, Paul Hunt and Michael Oliver emerged during the 1970s in the light of the British Disabilities movement (Rimmerman, 2013). Initially established through the manifesto of the Union of Impaired Against Segregation (UPIAS), the model criticises the objectification of people under the medical model and proposes to look at the social dimensions of disability. It makes a clear distinction between the notions of impairment and disability. It does not assume that they represent the same, impairment is the injury, illness or condition whereas disability is the limitation of opportunities to take part in society (Northern Officer Group, 2010). Thus, the model proposes that disabled people are ‘disabled’ by society (M. Oliver & Barnes, 2012). Thus, disabilities are not based on impairments but on the limitations that the social context poses on people with impairments. Unfortunately placing the social aspect as a cause of
disability, can neglect disabled people’s wellbeing in terms of health which demanded for a
more balanced model. In that context, the WHO introduced the International Classification
of Functioning, Disability and Health (ICF) (see Appendix 1) that considers both the social
and medical aspects that affect the lives of disabled people (WHO, 2002). Therefore leading
to the biopsychosocial model that is used internationally and has been adopted for policy design
by many countries, Ecuador included.

The cultural model brought up the question of ‘normalcy’, integrating the value of everyone’s
perspectives as it defines disability as stigmatisation (Shakespeare & Watson, 2002). Meaning
that it defines disability as something most members of society experience; for example
LGBT groups or ethnic minorities. The model does not consider disability as a problem to
be solved but rather as an add-on to social diversity (Üstün et al., 2001). The value of this
model for policy making is that it advocates for the creation of pride and cultural
representation allowing disabled people to have a voice in policy making for disability
(Rimmerman, 2013; Shakespeare & Watson, 2002).

Lastly, the Human Rights Model of disability is predominantly represented in the UN
Convention for Rights of Persons With Disabilities, effective since 2008, as an international
treaty to protect the rights of disabled people (Stein, 2007). Furthermore, the model serves as
a mechanism to justify and demand policies that protect and enhance the right to health,
education, employment, political and public life and freedom of expression, among others
(United Nations, 2008).

All things considered, the importance of defining disabilities is essential to gear policies that
target particular objectives. As Oliver & Barnes (2012) argue, definitions are important
because if disabled people are seen as victims social policies will aim to compensate their
tragedy. On the contrary, if disabled people are seen as socially oppressed social policies will
aim to alleviate oppression.

2.3 The Capabilities Approach and Disabilities

The CA suggests an alternative definition of disability that also serves as a framework for
analysing policies on disability. This approach considers disability in a more comprehensive
way than the models discussed previously and acknowledges that disability is a dynamic process, as will be explained in this section. The CA is the model that sets the working definition of disability for this study and, in addition, will set the framework to discuss whether and in how far the MESM enhances the lives of disabled people in rural areas.

The approach proposes that the enhancement of people’s lives is based on whether capabilities can become functionings. The difference between these two concepts is that a capability (e.g. a wheelchair) is the means or opportunity to achieve a functioning, whereas a functioning (e.g. transporting oneself with a wheelchair) is the end or achievement, the actual ‘being’ and ‘doing’ of an individual. Therefore, according to the CA, wellbeing (or, for the purpose of this research, life enhancement) is reached when functionings are achieved. (Mitra, 2006; Qizilbash, 2006; Sen, 1999)

Mitra (2006), systematised the CA and its understanding of wellbeing into a framework for analysing disability policies (see Figure 2.1). Under such framework, disability is conceived as the deprivation of capabilities and functionings on the basis of impairment (S. Mitra, 2006; Sophie Mitra, 2011). Defining disability according to the CA is useful because it helps to differentiate between potential and actual disability which stem from the difference between the ‘capability’ and the ‘functioning’ concept. Simply put, (1) a potential disability corresponds to the deprivation of a capability, it is “a reduction in the range of practical opportunities; and (2) an actual disability corresponds to the deprivation of a functioning, it is “a reduction in the valuable doings and beings of the person” (Sophie Mitra, 2011:11). The concept of ‘practical opportunity’ is a key element of this framework. It suggests that if policies provide individuals with capabilities that are not practical (i.e. useful) it is unlikely that functionings will be achieved. Meaning that policies that attempt to enhance the lives of disabled people must aim to solve not only the potential but also the actual disability that individuals face. For example, providing a wheelchair (opportunity) without considering its contextual usefulness (practicality) does not lead to the achievement of greater mobility (functioning). Here, this person will suffer from an actual disability; namely, having a wheelchair that is useless in the rural context. Hence, if the opportunities provided by disability policies are not practical (i.e. do not consider contextual usefulness), the lives of disabled people cannot be enhanced. Important to note is that this process of achieving a functioning is not only determined by whether practical opportunities are provided but also by people’s choice on
whether to transform them into functionings or not. Practicality of the opportunity is important for this case in particular, but considerations of choice, are beyond the boundaries of this research.

![Figure 2.1. Capabilities Approach for Disability explained.](Author’s adaptation of (S. Mitra, 2006)](#)

### 2.4 The Sustainable Livelihoods Approach

The SLA is a framework that is mostly used in academia to understand rural people’s lives. It is a tool to analyse the extent to and the process by which people have access to resources (Seeley, 2001). The SLA usually serves researchers to understand how poor people make a livelihood for themselves and for their family amidst hardship. However, IFAD (n.d.)
suggests using the SLA with flexibility, as it often requires modifications depending on the circumstances. That is because the SLA is not supposed to be a model that includes all aspects of the lives of people, instead its use and purpose is to ‘stimulate thought and analysis’. According to (IFAD, n.d.) the SLA is appropriate for examining how policies affect livelihoods. In this case, the purpose of using the SLA is to assess, from a theoretical standpoint, how the MESM enhances the lives of disabled people in rural areas. In order to understand how the SLA can support such assessment, the basic aspects of the SLA must be reviewed first.

The SLA stipulates that a ‘livelihood’ is the means to make a living, which results from the access and combination of six3 types of assets; human, political, physical, natural, financial and social (Hall & Midgley, 2006). A ‘sustainable livelihood’ is achieved when such access and combination of assets allows individuals to overcome a context that generates vulnerability. Hence, a sustainable livelihood ensures overcoming vulnerability and, by doing so, generates wellbeing (IFAD, n.d.). Thereby, in the terms used in this research, a sustainable livelihood ensures life enhancement. In practical terms this means that the life of a physically disabled individual in the rural areas is enhanced when he/she can access and make use of resources in a way that the rural context does not represent vulnerability. The importance of policy here is that the access to assets is determined by the interplay, between the context in which people live and the policies that may influence their access to livelihood assets. This interaction between the livelihood assets and policy, context and access is displayed in Figure 2.2 below. (Conway, Moser, Norton, & Farrington, 2002).

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3 The original SLA consists of five livelihood assets but Baumann & Sinha (2001) suggest including political capital.
According to Grech (2008), the six livelihood assets in the context of disability are explained as follow:

*Financial capital* is directly linked to income possession and can be understood from a supply and demand side. In terms of supply of financial opportunities, disabled people face difficulties in three levels: 1) achieving employment 2) having accessible workplaces 3) coping with discriminatory attitudes. Similarly, from a demand side physically disabled people have difficulties: 1) infrastructure (e.g. ramps) is costly for employers 2) impairment-related pain and difficulties might make working difficult at times 3) there are limited incentive structures for self-employed physically disabled people in rural areas as industry.
Human capital is often hindered or triggered by health and education and encompasses the capacity to work. In the case of physically disabled people, the achievement of human capital may hindered by limited rehabilitation centres and a lack of accessible schools, mistrust in doctors, or stigmatisation.

Natural capital represents the land and livestock possessions of rural families that in cases where disabilities are present may be sold to cover high medical and transportation costs.

Physical capital represents the physical infrastructure that in the case of physically disabled people plays an important role in providing the mobility opportunities necessary for them to be included in economic and social activities.

Social capital consists of the social relations of trust and networks derived from rural community contexts. Networks and relations are tighter when poverty and exclusion conditions unite rural people as a community that is facing similar issues. However, disabled people may be excluded from these networks due to stigmatisation.

Political capital entails the capacity which rural communities have to organise and defend their livelihoods. This capital is found in the literature as an addition to the original five capital assets (Baumann & Sinha, 2001; Hall & Midgley, 2006). This form of capital may be inexistent for physically disabled people who are barely recognised within their communities.

2.5 Towards a Conceptual Framework

This section explains how combining the CA and SLA results in a comprehensive conceptual framework to tackle the leading research question. Figure 2.3 below shows how the SLA and the CA meet. The access to livelihood assets, the disability policy and the personal characteristics of disabled people (e.g. impairment) determine an individual’s capabilities; the opportunities that a person has. These, in turn, are transformed into
functionings depending on whether such opportunities are practical.\textsuperscript{4} Note that all of the interactive process occurs within a rural context.

The combination of the SLA and the CA provide the conceptual framework that is needed to theoretically analyse whether a disability policy such as the MESM enhances the lives of people; in this case physically disabled people living in rural areas. The way in which it supports such analysis is by assessing ‘life enhancement’ which, theoretically, is assured if a policy (1) provides livelihood assets for individuals to overcome vulnerability (caused by impairment and by the characteristics of the rural context) and (2) whether these opportunities are ‘practical’ and lead to functionings.

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\caption{Conceptual Framework 3: CASE STUDY}
\end{figure}

\textsuperscript{4} The transformation of capabilities into functionings also depends on agency but, as it has already been discussed, including this is not part of this research. The reason for excluding agency is because it is not possible to include choice due to the lack of evidence.
The following section examines the context of disability in Ecuador along with the specific action of the MESM and its impact particularly on rural beneficiaries. The data analysed in this section is mostly comprised of national reports and statistics on the rural population of disabled people. The term ‘rural’ encompasses areas where population is dispersed and does not exceed 5000 inhabitants (SIISE, 2014).

### 3.1 Context of Disabilities in Ecuador

The history of disabilities in Ecuador is characterised by exclusion and abandonment (El Hoy, 2011). Between the 1940s and 1960s, the Ecuadorean government promoted special schools in major cities and created the first Law for Blind People, which became a pioneer in the region. The 70s were followed by major progress in the policy and treatment of disabled people, essentially due to the economic oil boom that meant increased welfare budget. Between the 1970s and 1990s the model of policy-making for disabled people shifted from a medical focus (based on the Ministry of Health) to a more social one (in the Ministry of Social Welfare) with the creation of organisations such as CONADIS which approached disability welfare holistically (covering health, education, social protection and labour integration). Subsequently, the institutionalisation of NGOs and federations flourished during the 1990s in a context of national economic crisis where the public budget for disabled people shrunk. As a result of improvements made in the 90s, in 2001 Ecuador was awarded the Franklin Delano Roosevelt prize by the UN, reflecting the efforts of ´de jure´ progress for disabled people in Ecuador. The award is focused on the country’s legal and institutional framework but not on indicators of wellbeing. Prior to this, Ecuador signed the UN Petition for the Convention of People With Disabilities in 2006 and in 2008 joined the Convention (UN, 2008). In parallel, in 2007 Lenin Moreno, the first and only Vice-president with a physical disability, established disability policies as a topic of national interest (SETEDIS, 2013). His mandate paved the way to the introduction of a nation-wide project that ´makes disabled people more visible´. Consequently, the MESM, starting in 2009, became a regional point of reference (CONADIS, 2013; José & Monje, 2013; SETEDIS, 2013).
The legal framework in which MESM is taking place is the Ecuadorean Constitution of 2008, Organic Act of Disabilities and the UN Convention on the Rights of Persons with Disabilities. Recently, the UN Committee on the Rights of Persons with Disabilities (CRPD) released its latest report and list of issues gives further explanations in terms of how the Current Act of Disabilities\(^5\) is being implemented, especially for disabled women, indigenous and afro-Ecuadorian children (UN, 2014). The Ecuadorean government reported major institutional and legal progress in the support and inclusion of women, children in education and rural people in medical system (ibid). Overall, according to the government, the disability policy and its legal framework is inclusive and attempts to cover most aspects of life of a disabled person (Ecuadorean National Government, 2014). This, however, does not include much information about the treatment of disabled people in the rural context.

3.2 Manuela Espejo Solidarity Mission

The MESM emerges in the context of the government's interest in 'good living'\(^6\) and investment in social policy to reach historically excluded fractions of Ecuadorean society (SENPLADES, 2013). It was established in 2009 as the result of a south-south cooperation scheme between Ecuador, Cuba and Venezuela. The MESM consists of three phases: 1) identification and diagnosis, 2) response and 3) integration. The objective of the programme is to reach all disabled people in Ecuador providing them with services and programmes that enhance their quality of life (José & Monje, 2013).

The first phase of diagnosis and identification happened from 2009 until 2011, where more than 1.2 million families with disabled members, in both rural and urban Ecuador were studied (SETEDIS, 2013). The later phase in 2011 consisted of providing technical assistances to those who were in chronic situations and faced high levels of poverty and vulnerability (ibid). Afterwards since 2013, along with the continuation of technical assistance and diagnosis, the MESM started its last phase of inclusion. This phase has an emphasis on labour and educational inclusion. Since then, the MESM has exponentially gained momentum in the region. Experts on disability issues and policy-makers from  

\(^5\) Código Orgánico de Discapacidades in Spanish
\(^6\) Ideological backbone of development planning policies which proposes a notion of well being based on traditional indigenous values. SENPLADES, 2013
Colombia, Peru, Paraguay, Guatemala and Uruguay seek Ecuadorean assistance and expertise on policies for disabled people. Moreover, in 2014 Uruguay launched its disability programme "Uruguay sin Fronteras" based on the Ecuadorean model (El Telegrafo, 2014).

The MESM has an extensive agenda that attempts to use the data from the initial phase of identification to provide emergency assistance and implement long-term policies for disability. As can be seen in Graph 1, the initial phase of MESM focused its efforts on identifying the existence and needs of disabled people as well as diagnosis their medical condition Source: (SETEDIS, 2013).

![Figure 3.1: Phases of the Manuela Espejo Solidarity Mission](image)

Source: (SETEDIS, 2013)

The initial phase of identification and diagnosis represented great logistical efforts as it aimed to map the situation of disabled people in Ecuador in a holistic manner. After a year of conducting a biopsychosocial study, the MESM collected data to geographically map the presence of disabled people (SETEDIS, 2013). The diagnosis phase resulted in the examination of approximately 300 thousand disabled people and concluded that the
prevalence rate was 2.08% (SIME, 2013). It is important to note that as Stone (1997) argues, numbers are powerful symbols in policy and should be carefully interpreted. Such numbers derive from the definition of whether somebody is disabled (Barnes, 2011). Therefore it is important to understand the impact of defining disabilities when assessing people with impairments. In the case of MESM, the Ecuadorean government has opted for a model that considers defining disability under the ICF, leading to a programme that follows the biopsychosocial model (SIME, 2013)

The following phases, response and inclusion, built on the preceding ones and have been essential for the improvements in the everyday lives of physically disabled people. These phases established projects that are ongoing until 2017 and are essentially social protection measures for families with disabled members. The response phase includes the provision of technical assistance such as wheelchairs and crutches for improving the living conditions of physically disabled people as well as medical and physiotherapeutic assistance to approximately 520 thousand people (SETEDIS, 2013). This phase also included the initiation of a housing project in cooperation with the Ministry of Housing. The programme consists of providing fully-equipped accessible housing for physically disabled people to improve not only their lives but also the quality of life of their families, which usually lack economic resources (MIDUVI, 2014). By 2013, approximately 11 400 houses have been provided and almost 8 000 houses have been equipped with beds, fridges and other utilities to improve the quality of life of poor disabled people and their families (MIDUVI, 2014). Moreover the response phase also included the provision of orthoses and prostheses through mobile units who reach people living in remote areas, as well as the creation of three factories to produce such prostheses and orthoses (SETEDIS, 2013). Lastly, as a response to the economic vulnerability found during the biopsychosocial study, MESM initiated a conditional cash transfer (CCT) scheme -Joaquin Gallegos Lara Programme (JGLP). The JGLP consists of a $240 monthly transfer that currently has almost 20,000 beneficiaries (ibid). It is conditioned to individuals who qualify as disabled according to the earlier mentioned ICF scheme proved by an official disability ID. (CONADIS, 2013; SETEDIS, 2013).

The last phase of the MESM is the inclusion of disabled people in different aspects of Ecuadorean society between 2013 and 2017. Such inclusion goes in line with the second
‘Buen Vivir National Development Plan’, where the rights of disabled people are further discussed (SENPLADES, 2013). This phase aims to create an inclusive educational system where opportunities are equally distributed among disabled and non-disabled students. The policy is under the scope of the Ministry of Education and is in its early stages of implementation. Similarly, the labour inclusion policy in coordination with the Ministry of Labour, has imposed a 4% quota of disabled workers for all companies in Ecuador. The sanctions are harsh for employers and have managed to include 73,000 people with disabilities in the labour market. Moreover, the labour inclusion initiative included funding for 189 entrepreneurship projects like local bakeries or handcraft businesses. Additionally, there are efforts to create integrated response services that work with the early detection and prevention schemes for sensory impairments; hearing and seeing as well as mental impairments through the Neonatal Screening programme. Such integrated services aim to continuously provide technical assistances across the country. Furthermore, the inclusion phase comes with a universal accessibility scheme to improve the infrastructure in public space, particularly in urban contexts. Lastly, the efforts of inclusion are mirrored by an intersectoral coordination through SETEDIS, which was created in May 2013 as the Secretariat that coordinates all aspects of the MESM.

In sum, the MESM is the backbone of disability policy in Ecuador and has been holistically designed. In practice, coordination between ministries and institutions presents one of the biggest challenges which so far are being managed through SETEDIS. Overall, despite its complexity, MESM has enhanced the lives of disabled people in Ecuador to an extent. Not only by providing mechanisms of social protection in cases of extreme vulnerability, but also in terms of social inclusion. However, when looking at the rural context, the MESM has not fully adapted, and this brings with it several difficulties that are explored below. (SETEDIS, 2013)

### 3.3 Rural beneficiaries

When looking at disability policies the rural context matters because it presents significantly different living conditions than the urban setting. The Ecuadorean rural context shows

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7 Fine up to ten minimum wages; this is $3 400  (Art. 42 Num. 33 Work Code, (Legal and Codification Commission, 2013)
higher degrees of vulnerability, poverty and exclusion (Bird et al., 2002; Jara, 2013a). The economically poorest live in rural areas where access to basic services is still scarce (Jara, 2013b). In the case of Ecuador, 32% of the population live in rural areas that contain 34% of the country’s disabled people (SIME, 2013; World Bank, 2012). From this total of disabled people in the rural areas, the majority, 37% have some type of mobility impairment (SETEDIS, 2013). Furthermore, agriculture is the main economic activity in rural Ecuador which is characterised by hard manual labour and predominantly necessitates high degrees of physical activity (Jara, 2013b). Hence, mobility in the Ecuadorean rural context is necessary for labour, hence as earlier discussed, it perceived a determinant of personhood (Grech, 2008).

Additionally, despite the latest progress in terms of social development in Ecuador, the attention given to the rural context is still a weak point in the development agenda of the country (Sánchez, 2013). The MESM’s response and inclusion phases are designed without considering the rural context. Thus creating inequality between rural and urban beneficiaries. This will be further unveiled in the following discussion chapter.
4: DISCUSSION AND POLICY IMPLICATIONS

This section explores the theory presented in chapter two, applied to the case study of the MESM. The SLA and the CA provide a definition to discuss in how far the MESM enhances the lives of physically disabled people in rural Ecuador. The conceptual framework suggests that ‘life enhancement’ is present if the policy (1) provides livelihood assets for individuals to overcome vulnerability (caused by impairment and social barriers, and by the characteristics of the rural context) and (2) if the opportunities that the policy provides are ‘practical’ and lead to functionings. Therefore, in the first part this chapter merges the structure of capital assets provided by SLA and includes the CA perspective on each one of them. Thus, this discussion covers the different aspects of the MESM in detail with the CA and gives an overall view of how the sustainable livelihoods are created, or not. In this way, the overall framework (SLA and CA) points to the importance of the rural context that is discussed in the later section of this chapter.

4.1 The MESM from a Capabilities and Sustainable Livelihoods perspective

The following section analyses how the MESM policy provides livelihood assets. Table 4.1 summarises the policy responses of the MESM that have been organised according to the six capital assets proposed by the SLA in order to see the extent to which the program addresses all forms of capital; that is if MESM creates sustainable livelihoods and enhances disabled people’s lives. Additionally, the CA’s notion of ‘practical opportunity’ will be integrated in the analysis of each capital. This is helpful to understand the areas of rural life tackled by MESM and visualises the conceptually weak aspects of the policy.
<table>
<thead>
<tr>
<th>Sustainable Livelihoods Approach</th>
<th>Policy response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial Capital</td>
<td>Joaquin Gallegos Lara Conditional Cash Transfer</td>
</tr>
<tr>
<td>Human Capital</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Scholarship programme</td>
</tr>
<tr>
<td>Health</td>
<td>Ortheses &amp; Prostheses (delivery with 3 units and creation of 3 factories to produce them)</td>
</tr>
<tr>
<td></td>
<td>Inclusive schools system</td>
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<tr>
<td></td>
<td>Creation and equipment of medical centres</td>
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<td></td>
<td>Information system INFOSEDIS</td>
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<tr>
<td>Early detection</td>
<td>Early hearing and visual detection</td>
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<tr>
<td></td>
<td>Neonatal Screening programme</td>
</tr>
<tr>
<td>Labour</td>
<td>Labour Inclusion (73,000 PWD)</td>
</tr>
<tr>
<td></td>
<td>Entrepreneurship projects (189 funded)</td>
</tr>
<tr>
<td>Natural Capital</td>
<td>Houses</td>
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<tr>
<td></td>
<td>Equipping Houses</td>
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<tr>
<td>Physical Capital</td>
<td>Universal Accessibility</td>
</tr>
<tr>
<td>Social Capital</td>
<td>Inclusive Sports (e.g. Bici Inclusiva)</td>
</tr>
<tr>
<td></td>
<td>Artistic (theatre, painting) workshops for kids with and without disabilities</td>
</tr>
<tr>
<td>Political Capital</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Table 4.1 MESM Policy Responses According to SLA
Source: Author’s own elaboration based on (CONADIS, 2013; José & Monje, 2013; MIDUVI, 2014; SETEDIS, 2013; SIME, 2013)

4.1.1 Financial Capital

In terms of financial capital, the two main policy responses are the JGLP cash transfer scheme as well as inclusive labour policy.

Cash transfer

The JGLP cash transfer programme serves as a social protection mechanism for covering high medical and transportation costs of physically disabled people, especially in rural areas.
where the highest vulnerability and poverty rates exists. The JGLP is therefore helpful and not only provides financial security but also elevates the status of disabled family members within their families. They are no longer seen as a burden but as financial contributors to the household economy. Moreover, the cash transfers are tied to a condition that aims at securing its use for the needs of the disabled people (SETEDIS, 2013). This however, may negatively affect the individual’s right to decide on how to spend the money as it assigns a third party as the administrator of the cash transfer. In sum, an increase in financial capital may increase the acceptance of physically disabled members in the family but it may not contribute to their empowerment.

From the point of view of the CA, the JGLP provides an opportunity or capability that is not practical for disabled people in the rural areas in the sense that it does not assure their control over the cash transfer. This is the result of a rationale that considers all disabled people as the same group. For instance, the policy as it is more practical for mentally disabled people who may not have the intellectual capacity to administer it. This is not the case for physically disabled people. Thus, the JGLP only addresses a potential disability by providing a capability (i.e. cash transfer), but fails to consider the actual disability (i.e. administering their own cash transfer); which limits their functioning. Thus, the financial situation of disabled people may remain unsolved, given that they are provided financial resources yet they are not able to administer them.

**Labour**

Also, within the concept of financial capital labour play an important role. In this aspect, the MESM attempts to aggressively increase the numbers of disabled people in the labour market and this is reflected in the 73,000 of them who are currently working (SETEDIS, 2014). The efforts in introducing this part of the population into the labour market is evidenced by a 4% quota posed on all medium and big business (ibid). It is important to mention that such policy has mostly benefited disabled people in urban areas where most of the industry is located. The quota cannot be as advantageous for those in rural areas where most work is based on demanding physical activities related to agricultural production. In addition, the entrepreneurship support policy within the MESM that, by the end of 2013, had funded 189 projects presents an opportunity for disabled people in rural areas to work in a non-labour intensive job (ibid).
From the CA viewpoint, the inclusion of disabled people in the labour market does serve as a social inclusion mechanism that empowers physically disabled people; this may not always be the case. This means that from the CA viewpoint, physically disabled people are not provided with a practical opportunity, as a quota for disabled employees does not consider the difficulties to find a job in a physically demanding job market. In contrast, supporting entrepreneurial projects may enhance the lives of physically disabled people in the rural areas as it tackles an actual disability (i.e. not having jobs that they can perform).

4.1.2 Human Capital

In terms of human capital, the MESM has focused its efforts in the areas of education and health in order to increase the opportunities to eventually integrate disabled people effectively into the labour market. The question is how much this policy can really benefit disabled people in rural areas?

**Education**

The current transformation of the educational system towards an inclusive one focuses on teachers and school infrastructure; however, such policy does not consider transportation difficulties especially posed by rural environments. In this way, the opportunities for mobility of disabled students in rural areas needed to attend school are hindered by the quality of transport service. Consequently, the chances for a rural physically disabled student to have access to higher education are even lower. This is a problem not only for disabled students but also in general an issue of limited educational opportunities in rural areas. The example of education elucidates the fact that the efforts of the MESM can be enlarged by including disabled people in rural development policies and projects; which in this case means considering the needs of physically disabled people when building rural infrastructure.

Seen from a CA perspective, although inclusive education creates opportunities for physically disabled people, in the rural context these opportunities are limited. Such limitation is set by the lack of acknowledgement of the practical barriers to opportunity; how useful is an inclusive school if physically disabled students are not able to reach the school? Thus, inclusive education in the rural context should address not only the potential disability
(i.e. not having an inclusive school) but also the actual disability (i.e. not being able to get to the inclusive school).

**Health**

With regards to the case of health policies for physically disabled people, it is evident that there is a general rural disadvantage in terms of equipment, personnel and accessibility. The MESM extensively covered rural areas when identifying disabled people and providing technical assistance, yet the challenge of continuous health care remains. It is extremely difficult for people in rural areas to have access to medical and physiotherapy treatments regularly (Ecuadorean National Government, 2014). Moreover, doctors in rural areas are mostly medicine students with limited knowledge and experience to adequately treat disabled patients (ibid). On the positive side, the wellbeing of physically disabled individuals has been enhanced in the first stage with medical and technical assistance, where disabled people received wheelchairs and other material and in a later phase with the provision of orthotics and prosthetics (SETEDIS, 2014).

In light of the CA, the health aspect of MESM in rural areas has not addressed a potential disability (i.e. not having proper continuous medical attention), let alone addressing actual disability (i.e. not overcoming everyday pain due to impairments). On the other hand, the provision of technical assistance, orthotics and prosthetics has enhanced the lives of physically disabled individuals by tackling an actual disability (i.e. not being able to move to a larger degree). Overall, the health aspect of the human capital partially provides an enhanced life for physically disabled individuals in rural areas.

**4.1.3 Natural Capital**

The main contribution of MESM in terms of natural capital is the housing programme that provides accessible housing for families with members who are disabled. Additionally, the housing programme includes equipping houses as a measure of social protection for disabled people living in conditions of extreme poverty and exclusion. Housing has been provided by the MIDUVI, which is also the Ministry for Urban Planning, thus leaving considerations of the rural setting aside.
In the light of the CA, the housing programme can enhance the lives of rural disabled people as it addresses an actual disability (i.e. not living in appropriate housing facilities due to poverty cycles). This however is the case if houses are functional can be useful in the rural context. Information of this was not available; yet considering rural functionality is paramount.

### 4.1.4 Physical Capital

In terms of physical capital the project for Universal Inclusion focuses on the creation of accessible spaces but only in urban areas. Although most disabled people live in cities, the mobility limitations in rural areas are profound and difficult to solve because they require substantial investments that exceed the budget of the MESM or local authorities.

From a CA perspective, the lack of physical capital is a result of not considering mobility as an actual disability in the rural context. This hinders any action to improve infrastructure for physically disabled people in rural areas. Therefore, if universal access characteristics were integrated into rural development policies and planning, the lives of physically disabled people could be enhanced.

### 4.1.5 Social Capital

In terms of social capital, physically disabled individuals have limited capacity to belong to their immediate community particularly due to the lack of infrastructure to mobilise to visit family or friends or get to work. Thus, due to this lack of inclusive infrastructure, physically disabled people are hardly visible and therefore less accepted in their communities. A lack of exposure or visibility feeds others prejudice towards people with physical impairments (McKercher et al, 2003). In this aspect, although the MESM has created inclusive sport practices such as inclusive cycling or artistic and cultural activities, these are mostly carried out in urban areas (El Comercio, 2014; SETEDIS, 2014)

The lack of inclusive infrastructure and limited mobility affects the social capital of physically disabled people in rural areas to a greater extent than in the urban context. Moreover, when sporting, cultural and artistic activities are focused in urban areas inequality between people
in urban and rural contexts is created. From a CA standpoint this means that the policy does not enhance the lives of physically disabled individuals in the rural areas as it does not address the actual disability (the fact that these people are particularly socially excluded and lack social capital).

4.1.6 Political Capital

Last, but not least, with regards to political capital the MESM has no single policy response that can encourage and foster the political participation and representation of physically disabled people in rural areas. Partly due to the lack of physical capital - and consequently social capital - and despite the rights included in the Ecuadorian constitution to improve the lives of physically disabled people, there are no groups of disabled people in the country that are politically active (Andrade, 2012).

Political capital is essential as it could provide a basis for the MESM to be sustain itself across time. The fact that the MESM was initiated due to the political will of a single individual, Lenin Moreno the Ecuadorean vice-president, demonstrates that political participation and voice matter for effectively transforming ideas of change into action. Moreover, according to the cultural model of disability, political capital is fundamental for achieving social cohesion, for strengthening self-esteem and fostering a sense of pride; all of which lead to enhance disabled people’s lives.

From a CA standpoint, the relevance of fostering and enabling political capital is that it provides a practical capability. As discussed earlier, physically disabled people could advocate for their rights and enhance their pride and self esteem. This could be done by accomplishing the functioning of being politically engaged in their own movement. Such engagement, could then translate into the creation of new capabilities - or opportunities - that are more ‘practical’, as they would be thought by disabled people themselves. However, in this case there is no policy response of the MESM that addresses political capital.

After a thorough analysis of all the components of the MESM, based on the livelihood assets (i.e. capitals) proposed by the SLA and analysing them through the lens of the CA, it has
become evident that, although comprehensive, the MESM enhances the lives of physically disabled people in rural areas to a limited extent. Overall, disabled people are provided with sets of opportunities that are partially practical - and therefore only partially useful - in the rural context. It has been explained how not all capabilities provided by the MESM are equally life enhancing. That is because the MESM proposes changes for the lives of disabled people in general but it does not explicitly consider the special characteristics of the rural areas (i.e. vulnerability context). Furthermore, some policy responses only address potential and not actual disability of individuals.

Following the logic of the SLA the above mentioned finding is confirmed; the access to livelihood assets that the MESM provides for physically disabled people in the rural areas does not result in a combination of capitals that represent a ‘sustainable’ livelihood. Drawing from the conceptual framework, the lack of a sustainable livelihood means a lack of capacity to overcome the difficulties posed by the rural context. Hence, the fact that the MESM does not provide political capital and only limited social and physical and that it does not differentiate the rural context on policy responses, results in only a partial enhancement of the lives of physically disabled people in rural areas.
5. CONCLUSION

This research concludes that the situation of physically disabled people in rural Ecuador has been partly enhanced by the MESM, however there is room for improvement. The aspects of political, social and physical capital are still unattended by the policy. This is mostly because the MESM is designed and geared towards an urban setting, leaving aside the specific needs of disability in the rural context. The implications of an unattended rural context are the deepening of inequalities that already exist between rural and urban disabled people. Therefore, although the MESM has become a reference point in the region, work still needs to be done in terms of social inclusion. Such inclusion, should not only be based on the premises of poverty conditions but also on the fact that rurality may be a deterring factor for enhancing the lives of physically disabled people. In other words, although MESM has incrementally enhanced the lives of disabled people in general, some benefits do not reach individuals in the rural areas.

The question of in how far is the MESM enhanced the lives of physically disabled people in rural Ecuador has been answered with the aid of a comprehensive conceptual framework that combines the SLA and CA. Such framework helped to map and understand that life enhancement is comprises achieving a sustainable livelihood and also receiving opportunities that are practical, or context specific. In this sense, the conceptual framework not only points out the weaknesses of the MESM as is now, but also reveals the potential strengths that considering a SLA and a CA may provide when designing disability policies for the rural context.

Adopting a social policy outlook helps to see why enhancing the lives of physically disabled rural individuals is important. It challenges the MESM approach to act upon disabled people in the sense that its social determinants for policy are not only poverty but also rurality. Moreover, this research sheds light on a particularly vulnerable social group, physically disabled people in rural Ecuador, claiming that their needs have to be considered in relation to their context. This is because they are a particularly vulnerable disadvantaged group that is often overseen by policies due to the remoteness or limited numerical significance; such is the case of MESM. All in all, physically impaired individuals are differently 'disabled' by the rural context than by the urban.
The limitations of this research are mainly that the conceptual framework used for this analysis could not include the aspect of ‘choice’ from the CA perspective. This was due to the limited availability of primary sources, especially of qualitative data that could reveal the choices made in a rural life context in further detail. Also, a shortcoming for this research is that few scholars have focused on physical disability in the rural context. This was a limitation in terms of providing an already existent conceptual framework to analyse the MESM. This however, was an opportunity to propose the SLA and CA as a combined framework to analyse disability in the rural context. Thus, the academic implications of this work are that it contributes to the limited literature on physical disabilities in the rural context from a social policy perspective.

The main policy implication of this research is that the rural context matters when aiming to enhance the lives of physically disabled people in rural areas. The MESM’s biopsychosocial approach does not distinguish the rural from the urban context. Therefore the ‘social aspect’ of the MESM only considers poverty and age as social determinants that define the lives and environment of disabled people. The implications of considering rural and urban disabled people as a homogenous group have been discussed throughout this research and it has been established that this has major consequences in creating inequality amongst physically disabled people. In other words, rurality must be included in the design and implementation of the different policy responses of the MESM. In addition, there needs to be more emphasis on processes of transforming capabilities into functionings to ponder the impact of the policy. Therefore, more research needs to be done in the feasibility and importance of adapting MESM to rural areas. In such case resource distribution should not represent a further expenditure for MESM because a more focused and tailor-made policy should include rural development policy and institutions to assist and integrate disabled people technically and also financially.

By the end of 2013, the MESM has improved considerably the lives of disabled people in general. There is an institutional framework like SETEDIS that coordinates the work across different institutions and provides a better service that was inexistent and unimaginable before 2009. This however, can be improved especially in rural areas thus based on the findings of this analysis three main areas of action are identified:
• **Re-framing the MESM**: considering the difficulties that rural context poses, the MESM should consider its medical, educational, housing and financial services delivery differently in rural areas. The policy programmes should be understood based on the existing rural vulnerability characteristics.

• **Including disabled people in rural development strategies**: the limits of MESM, for example in designing and building infrastructure for physically disabled people, should be part of a broader rural development policy. Therefore, including physically disabled people in rural policy not only will provide them with a more life-enhancing infrastructure, but will also represent an inclusion and recognition as members of their rural communities. Thus, stimulating their social and political capital.

• **Include social and political capital in the MESM agenda**: as evidenced in this research, the already limited programmes to enhance social capital do not reach the rural areas. As sports and cultural events take place in urban areas, physically disabled people in rural areas remain invisible to their communities. Thus the inclusion of rural areas in fostering social and political capital is essential for creating self-esteem and pride in physically disabled people. Hence enhancing their lives.

This research calls attention to the issues of physically disabled people in *rural* Ecuador as beneficiaries of an ambitious policy; the MESM. The findings and discussion open new opportunities for researchers and policy makers to focus on rural life. Overall, further research should consider physical disabilities in the rural context from a policy perspective.
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APPENDIX

Appendix 1

A note on terminology:

In accordance with the social model of disability formulated by UK disability activists Vic Finkelstein, Paul Hunt and Michael Oliver, this research uses the term 'disabled people', since it views 'disability' as a social phenomenon and a form of discrimination and social exclusion that is unnecessarily imposed on people on the basis of them having an impairment.

In the US-American civil rights tradition and the language of international human rights law, the term 'persons with disabilities' implies that the disability is a minority characteristic of the individual, and that the person is mentioned before the disability.

However, this research follows the line of thought which stipulates that people are disabled by social and physical barriers in the society that surrounds them, and not by their bodies.

Therefore, in an equal, accessible society free from discrimination and exclusion, people with impairments would still exist, but they would not be disabled people anymore.

Appendix 2

![Diagram of Health condition, Body Functions & Structure, Activity, Participation, Environmental Factors, Personal Factors, Contextual Factors](image)

Source: (World Health Organisation, 2002)