LUND UNIVERSITY
Faculty of Social Sciences

Major: Development Studies

Course: SIMV24

Crafting the Revolution – A Study on Intellectual

Disability and Well-Being in Socialist Cuba

Author: Susanna Lucas
Supervisor: Yahia Mahmoud

Abstract

This thesis focuses on the case of education and habilitation services in Cienfuegos, Havana, and Pinar del Rio to describe the well-being of persons with intellectual disability. The welfare of the target group is assessed through an ethnographic study of how actors from the societal sectors policy/service/household perceive that the well-being of individuals with intellectual disability is and can be achieved. These collected responses are analysed in this research study by applying the capability approach (CA). I found that how the intellectual disability categories mild/moderate/severe/profound are put into practice produces an unequal access to educational and habilitative services in Cuba. By applying the CA as a theoretical perspective, it was possible to discuss this unequal access in relation to the target groups' possibility to achieve their well-being. Based on the CA framework it can be argued that the persons who do not have the 'capability set' necessary to fulfil the 'beings' (being educated) are impoverished in the Cuban society. Some of the actors from the societal sectors policy/service/household did present solutions that were thought to increase the target groups' opportunities to welfare.

Key words: poverty, development, capability approach, intellectual disability, Cuba

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1. Introduction

A key issue at the moment is disability and the sustainable development goals (SDGs). Development and disability experts claim that the integration of disability matters within the development agenda is necessary in order to reduce poverty ("United Nations Enable 2," 2015). The SDGs have been defined within the post 2015 development agenda to continue with the process of poverty reduction. A version of the proposed SDGs "will be adopted by Member States at the Sustainable Development Summit in September 2015" ("Post-2015 Development Agenda," 2015). In preparation for this summit development and disability advocates are clarifying the importance of incorporating disability in all of the aspects of the SDG ("United Nations Enable 1," 2015).

Specifically, people with intellectual disability can be categorised as a vulnerable group in any society, and in countries with limited access to resources the societal provisions of education and habilitative services are likely to be constrained. These services attempt to increase the possibilities of well-being for a person with intellectual disabilities. Hence the absence or deficient quality of these services may impact the well-being conditions of people with intellectual disability (Mercadante et al., 2009).

Taking into account the generally high access to healthcare and education in the country, the case of Cuba can provide insights into the results of welfare that the education and habilitation services provide, in spite of Cuba's constrained economic situation (see appendix 3). This is relevant for international development in relation to the promotion of services that increase the participation and well-being of individuals with intellectual disability within developing countries. The intention of this research is to perform a descriptive study that can add to existing multidisciplinary literature on the subject. By looking at the well-being aspects as experienced by persons with intellectual disability in Cuba, I discovered that even if these services are provided in Cuba there are constraints in the range and accessibility of these. These constraints are related to difference in regional provision as well as degree of the disability.

2. Purpose and Research Question

The main aim of this study is to analyse the well-being of persons with intellectual disability in Cuba from the capability approach. More specifically to study the existence of societal measures to ensure the well-being of persons with intellectual disability and how these work in accordance with the realisation of valued functionings. This research attempts to contribute to the paucity of ethnographic studies on the subject on poverty and disability.

Research question: Based on the capability approach, how do actors within the societal sections policy/habilitation services/household perceive that the well-being of persons with intellectual disability is and can be achieved in the case of educational and habilitative services in Havana, Cienfuegos and Pinar del Rio (Cuba)?

3. Study Background
3.1 Disability Research within Development Studies

At the moment of writing, disability and development experts are participating in a meeting titled *Operationalizing the post-2015 development agenda for persons with disabilities* arranged by the United Nation bodies in Beirut. The purpose of the meeting is to formulate recommendations for procedures that the global community shall employ in the implementation of disability matters in the post-2015 agenda ("United Nations Enable 1," 2015). In the background description of the expert group meeting it is contended to be "impossible to genuinely achieve internationally agreed development goals without incorporating the rights, well-being and perspective of persons with disabilities in development efforts at all levels" (ibid). Mainstreaming disability in the development goals is claimed here to be a crucial factor for combating poverty.

A similar conclusion is reached in the United Nations (2011) publication *Disability and the Millennium Development Goals* the significant amount of disabled that experience multi-dimensional poverty indicates the importance of incorporating disability related issues in all of the development goals. Poverty is explained to be a consequence of the lack of access to services such as "education, employment, health care and the social and legal support systems" (Groce et al., 2011a, p. vii).

> The international development community is beginning to recognise that people with disabilities constitute among the poorest and most vulnerable of all groups, and thus must be a core issue in development policies and programmes. Yet the relationship between disability and poverty remains ill-defined and under-researched, with few studies providing robust and verifiable data that examine the intricacies of this relationship (Groce et al., 2011, p. 1493).

In this quote the scholars pinpoint that the global community have started to reach a shared awareness regarding the vulnerability that individuals with disability are subjected to by the circumstances related to the connection between poverty and disability. They also conclude that this correlation is not sufficiently investigated, meaning that there is a knowledge gap about these instances.

Correspondingly, Mercadante, et al (2009) stress that there is a gap in ethnographic knowledge, and conclude that there is a lack of research on intellectual disability in Latin

America and that this is negative for the function and quality of the services provided in the region. They write that:

> There is a need for studies that characterize the needs of people with intellectual disability specifically in Latin America, and future research in this area should emphasize how it can inform current and future policies and services for people with intellectual disability (Mercadante, et al, 2009, p. 469).

They argue that in the Latin American region, those responsible for policy design and service provision for ensuring the welfare of persons with intellectual disability do not have adequate knowledge of the specific needs intellectually disabled have. According to them further ethnographic research in Latin America with a focus on the specific needs of persons with intellectual disabilities can be useful in improving the policy making vis-à-vis habilitation services (ibid).

Yeo and Moore (2003) have written the article *Including Disabled People in Poverty Reduction Work: ''Nothing About Us, Without Us''* where they investigate the connection between poverty and disability. Dismissing disabled people to directly participate in development work and research, compromises this group's societal position and traps them into poverty. The following figure charts what they call the "vicious cycle of poverty and disability" (Yeo and Moore, 2003, p. 572).
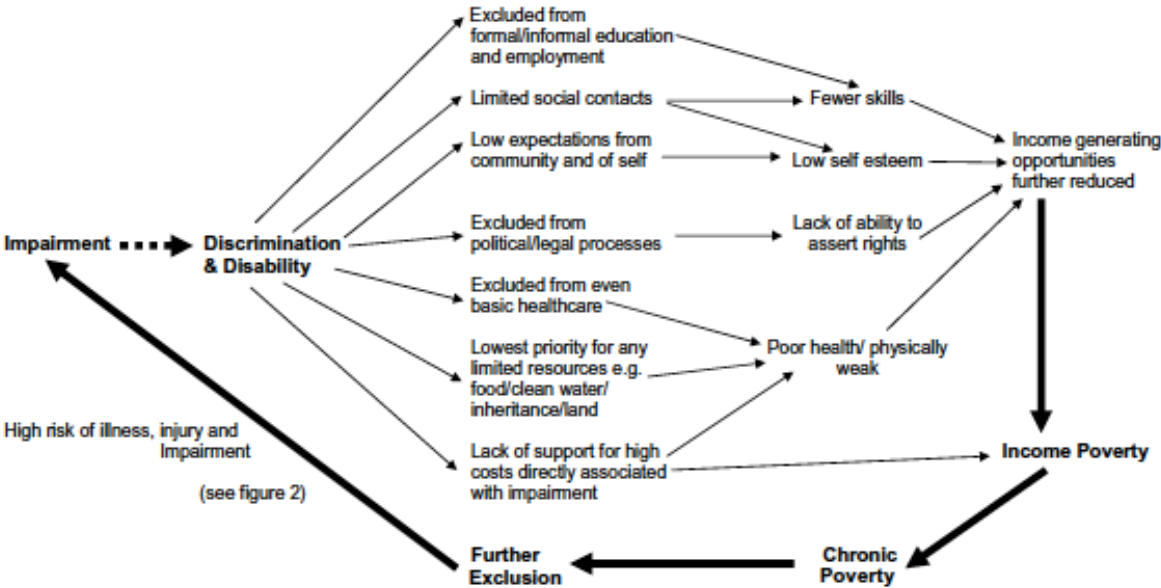

Figure 1. *Disability/poverty cycle.*

Figure 3.1 Disability and Poverty Cycle (Yeo and Moore, 2003, p. 572)

Yeo's and Moore's (2003) figure clarifies the manifold aspects of the overlap between the disability and development discourses. Limited access to societal services compromises the individual's prospect to be able to generate income, which exposes them to deeper exclusion and structural discrimination (ibid). Discrimination has a downgrading impact on a person's social status (Gonçalves Cavalcante and Goldson, 2009; Maulik and Darmstadt, 2007). How the unequal social position of people with disabilities is comprised depends on multiple factors that may vary from country to country (Groce et al., 2011).

Welfare services have an essential role in delivering habilitative services that enable intellectually disabled people to achieve high life quality (Mercadante et al., 2009; Salvador-Carulla et al., 2008). These services also help in shaping the cultural norms regarding intellectual disability towards increased knowledge and equality. Thus, the provision of habilitative services is significant for the enhancement of the well-being of people with intellectual disability (Santos-Zingale and McColl, 2006).

Participation is a central notion within the field of disability and speaks in favour of the right of disabled people to participate in society according the same conditions as others. It is also core in the main ambitions of the habilitation sector. Habilitative activities are often guided by the overall goal of working for increased participation of the disabled group into society. As a consequence, the notion of inclusion entails that measures and policies should consider participation as of pivotal importance. Development of functions is the central purpose of the habilitation services, to enable disabled persons to enhance their own capacities (Akhutina, 1997; Hauser-Cram et al., 2001). While participation works at the societal level, development of function concerns aspects at the individual level.

Yeo and Moore's figure (2003, p. 572) can be interpreted to indicate that the enhancement of abilities and self-esteem can break the poverty cycle since a person's employability becomes more likely with these two factors. Nonetheless, there are other ways to conceptualise poverty than measuring access and utilisation of income. According to Mikkelsen (1995) Amartya Sen conceptualises the notion of poverty as "the inability to fulfil fundamental needs" (Mikkelsen, 1995, p. 146), this view has triggered a discussion within the development doctrine regarding human basic needs. From Sen's (2001) perspective the primary task when

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evaluating an individual's or group's poverty level is to determine what their basic needs are and based on these to further investigate the possibility that they have to satisfy them. In many cases it might be restricted access to monetary resources that impedes a person in satisfying his/her needs but it can also be depend on other factors. This assessment can be perform by applying the capability approach (CA), which will be further discussed in the theoretical framework.

3.2 Contemporary Historical Background

Since 1959, when a group of rebels led by Fidel Castro overthrew the US-supported Fulgencio Batista's regime, the political system in Cuba is that of a one-party system where the power is maintained by the communist party, 'Partido Comunista de Cuba' (PCC) (Utrikesdepartementet, 2012). The historical events of the late 1950s, known as the Cuban revolution, are still today celebrated by the propaganda and the ubiquitous concept of *la revolución* permeates the public sphere and political discourse. The political climate is distinguished by the restrictions of freedom of speech, press, and association. The distribution of anti-revolutionary messages can result in severe legal consequences (ibid).

The economic situation in Cuba today is of great complexity. The country has two official currencies since 1993, the year when the government decided to allow use of the U.S. dollar. This decision was motivated by the need to attract harder currency, mainly from tourism[1]. Cuba was hit in the 1990s by a severe economic crisis caused by the collapse of the Soviet Union, and the repercussions for the population were tangible. *El período especial*, which this crisis is often called, began in 1991, peaked in 1994 and was characterised "by severe and widespread shortages. Clothes, hygienic products, electricity, transportation, shoes, water medicine, paper and, above all, food, were scarce" (Padrón Hernández, 2012, p. 26).

The economic recovery finally began in the late 1990s thanks to a series of reforms that allowed joint ventures, cooperatives and even private enterprises. In 2006 Fidel Castro turned over power to his brother Raul who continued to reform the socialist economy allowing a number of deregulations and opening some sectors of the market to private actors. Finally, the

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[1] Lundgren (2011) describes how the U.S dollar was later substituted in 2004 by the Cuban convertible peso, CUC, which today has hard currency value and is much more desired than the Cuban pesos (CUP), also called *Moneda Nacional*. However, "the absolute majority of people receive their salaries in Cuban Pesos. Some products, such as cooking oil, hygiene products and clothing, are difficult to come by in Cuban pesos and must be purchased in CUC" (Lundgren, 2011, p. 35).

conciliation process between US and Cuba[2], which began in December 2014, was embraced with enthusiasm by the population who awaits a normalisation of relations between Cuba and the rest of the world and the lifting of US embargo[3] against the country.

The social security system in Cuba includes economical benefits, rationing quota of consumption goods and a majority of Cubans' housing is free of cost (Mesa-Lago, 2013, pp. 15–16). These benefits are a way to guarantee a minimum fulfilment of basics in spite of the meagre job-wages.[4] Despite these governmental efforts to deal with deprivation, income inequality persists. Mesa-Lago writes that "Poverty is higher among retirees, female heads of household and single mothers, Afro-Cubans, migrants from the less-developed eastern provinces, residents of slums, and those who lack access to foreign currency" (Mesa-Lago, 2013, p. 16). Cubans can obtain hard currency Cuban convertible peso (CUC) through two main sources: remittances and directly working with tourists. Lundberg highlights that the access to these income sources is not equally distributed within society, and that some groups have a more privileged position then others. (Lundgren, 2011, pp. 34–35).

Cuba's welfare state is built upon the principle of social justice that inspired the Cuban revolutionary movement. In the wake of the reformist period that aimed at cancelling the huge social inequalities that existed in the pre-revolutionary Cuba, free healthcare and education were introduced[5]. Cuban healthcare together with education system are the two real successes of the revolution and the country is often ranked amongst the first when looking at health and education indicators ("Human Development Index," 2015)(For cross-country comparisons on economic and developmental indicators see appendix 3). A concrete example of this governmental strategy is the international recognition that the country receives thanks to the effort of its healthcare workers that help around the world (Huish, 2014).

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[2] See Council on Foreign Relations' web site for further information about the history of the difficult relations between US and Cuba("Council on Foreign Relations," 2015.).

[3] In 1962, the "Kennedy administration imposed a complete economic embargo on Cuba, restricting travel and trade. The embargo has devastating consequences for Cuba, whose economic infrastructure greatly depends on trade with the United States. The embargo results in a loss of approximately $1.126 trillion over the next fifty years, according to Cuban government estimates" ("Council on Foreign Relations," 2015.).

[4] "In 2010, 52.6% of the population's total monetary income came from salaries, 12.5% from private-farmers earnings, 4.5% from the non-agricultural private sector (the self-employed, etc.), 3.5% from cooperatives revenues, and 26.9% from other income. The latter is an unspecified high percentage that likely includes remittances from abroad. The monthly average pension in 2010 was 245 CUP, 54% of the State average salary. The salary scale was very narrow: the highest pay (550 CUP in mining) and the lowest pay (366 CUP incommerce, restaurants, and hotels)"(Mesa-Lago, 2013, p. 17).

[5] Pardón Hernández (2012) adds that "Efforts were also made to universalize access to cultural capital: a huge literacy campaign aimed at the whole population, free education, possibilities for workers to study and undergo specialized training, campaigns to make people formalize their unions by marriage, subsidies of cultural products (entry-fees to museums as well as tickets to the cinema, concerts and ballet) are examples of just some of these efforts"(Padrón Hernández, 2012, p. 45).

3.3 Intellectual Disability in Cuba

In 2001-2003 an extensive, state-run nation-wide study was carried out in Cuba with the objective of investigating the population with intellectual disability. The study showed that 21 percent of the persons with intellectual disability who were not diagnosed with mental retardation prior to the study could be diagnosed as a result of the screening. The disability that these individuals have was discovered due to the extensive outreach of the investigation at the household and community levels. In the study it was found that 20.8 percent of the 140 489 persons with intellectual disability in Cuba 2001-2003, lived in a home that was in poor condition and 15.4 percent lived in a home that was in critical condition. It is not specified whether the conditions measured involve the social environment or the state of the housing/building. The results also presented that 3.3 percent were permanently bedridden, though the reason is not specified. (Cobas Ruíz, etal, 2010).

In Cuba, persons with intellectual disability are diagnosed according to the concept of *retraso mental,* which translates to mental retardation (MR) in English. MR is divided into four categories of increasing intensity as given in the table: ligero = mild, moderado = moderate, severo = severe, and profondo = profound. For the individual, the specific MR category will determine what welfare services are made available for him/her. A person's incorporation or exclusion from services is based on the following understanding of people's capabilities within the MR categories:

- Those within the category mild MR are perceived to have the potential of completing the 9th grade in special education, able to be prepared for employment, and to reach social and occupational inclusion in society.

- An individual with moderate MR is presumed to be able to complete special education's 6th grade, and to be able to participate in employment preparation, and to reach social and occupational inclusion in society with support.

- The severe MR category indicates that a person can have the ability to adapt, and individuals are able learn basic work skills and, under favourable conditions, are able to reach social and occupational inclusion in society.

- A person with profound MR is assumed to potentially be able to verbally communicate. They are expected to be reliant on others for their daily activities, and it is the household and community actors who can provide favourable conditions for their development (ibid).

These MR categories will be further explored in the empirical and discussion chapter. In Cuba there are juridical instruments that regulate the sectors controlling health, education, employment, social security, leisure and spare time, accessibility, technical appliances, and security and health in the workplace. In a brochure published by the ministry of work and social security in 2007 the laws and resolutions are compiled within these areas. The human rights of persons with disabilities is claimed to be central for the Cuban state, which strives for equal opportunities for all (Ministerio de Trabajo y Seguridad Social, 2007).

3.4 Definition of Central Concepts

Participation is a central notion in this study and is a concept with various meanings. Mikkelsen (1995) writes that participation is commonly operated either "as an end in itself or as a means to development" (Mikkelsen, 1995, p. 63). In this study the target group's participation in the service activities is important for their welfare; the individuals' participation in these sites are in that sense seen as an end in itself. At the same time societal participation is claimed to be a main goal for the individuals to achieve through the education and habilitation services, and a means for their development towards improved well-being conditions. When it come to participation as an end the definition that participation entails an "involvement in people's development of themselves, their lives, their environment." (ibid p. 62) can be suitable to proceed from.

Disability is a concept that is based both on the individuals' impairment and social context. The World Health Organisation (WHO)(2015) defines disability as "reflecting the interaction between features of a person's body and features of the society in which he or she lives" ("Disabilities World Health Organisation," 2015). Moreover intellectual disability is defined by WHO as:

> a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development ("Definition: intellectual disability," 2015).

4. Theoretical Framework

In accordance with the goals and the expectations of my research I decided to use the Capability Approach (CA) as a main theoretical line of thought to analyse the multiple societal features of the 'Cuban model'. It is argued that CA provides a deep and defining way to examine poverty and welfare related aspects.

4.1 The Capability Approach

Within the capability approach (CA), evaluations of quality of life are conducted by first exploring which 'beings' and 'doings' (being well-nourished, being transported) are valued by the concerned individual or group. These beings and doings are named 'functionings' (being well-nourished, being transported). Subsequently, an assessment is made of the factual opportunities the concerned people have to achieve these valued beings and doings. The functionings that people have the possibility to choose are termed 'capabilities' (Ibrahim and Tiwari, 2014; Robeyns, Ingrid, 2011). Taken together, functionings and capabilities serve as a base to interpret people's living conditions and comprehensive welfare (Nussbaum and Sen, 1993).

The CA initially articulated by Amartya Sen (1993) is a fundamental theoretical perspective within disability studies and versions of CA are also commonly used as a welfare measure (Human Development Index) in the international development configuration (Burchardt, 2004; Robeyns, Ingrid, 2011). The selection of this framework for the present study is based on CA's relevance within the two fields (disability & development) that are principal to this study. A shared scholarly conclusion of the contribution of CA is that it is constructed to obtain well-being in a dynamic fashion that goes beyond static welfare and disability models, and thus is more potent in capturing the target group's or individual's actual living circumstances (Burchardt, 2004; Kuklys, 2005). This argument is based in the following position: if looking at what factors people value as central for their well-being and by taking into account what possibilities they have to realise these factors, the obtained information can provide an adequate comprehension of deprivation the way it is experienced (Saith, 2007).

Some scholars have pointed out that CA is rather difficult to operationalise since it relies on subjective estimations making the approach complex to apply (Sen, Amartya, 2005; Sugden, Robert, 1993). Nonetheless, since the 2000s the approach has been frequently used by social scientists, resulting in elaborative studies that have generated empirically based conclusions. A significant proportion of these studies use quantitative measures to chart and compare

objective and subjective well-being (Brandolini and D'Alessio, 1998; Kuklys, 2005; Qizilbash and Clark, 2005). Some studies that operationalise CA using a qualitative direction have also produced noteworthy findings giving an indication that CA can be fruitful within qualitative research where people's life stories and perceptions can be obtained more in depth (Ibrahim and Tiwari, 2014, pp. 12-15; Watts and Ridley, 2007). Correspondingly, the small-scale scope of this study and its concentration on the interpersonal perceptions of actors, to directly capture the subjective features, reduces the difficulty of operationalizing the CA (Robeyns, 2006, p. 354).

Robeyns (2006) writes that CA "is not a theory that can *explain* poverty, inequality or well-being; instead, it provides concepts and a framework that can help to *conceptualize* and *evaluate* these phenomena" (ibid, p. 353). The objective of CA to contemplate and estimate welfare, as clarified in this quote, has a descriptive character that fits well with my ambition to describe the welfare of persons with intellectual disability living in Cuba. This has been done by obtaining certain beings that the target group has reason to value and by evaluating the opportunities that they have to fulfil these functionings.

At best, the functionality set should be determined by the people themselves and include those beings and doings they themselves value as relevant for their welfare based on the present circumstances (Watts and Ridley, 2007). Nonetheless, a decision has been made in this research to include the functionality set that the caregivers, service personnel and policy makers indicate as relevant for the target group. Furthermore, the functionality is determined by how a commodity is utilised by the person in question depending on the features of both the consumed product or service and the conversion factors e.g. individual traits (physical and intellectual impairment, age), as well as social (norms, welfare system) and environmental aspects (locational distance, buildings) (Kuklys, 2005, pp. 10–12; Saith, 2007, pp. 56–57). For instance, in order to achieve the functioning/being (well-rested) it may be necessary to attain the commodity (shelter) that has the characteristics (safe)(comfortable)(Saith, 2007, pp. 56–57).

The capabilities in this study will be connected to the possible functioning set available for persons with intellectual disability. The establishment of capabilities is done by charting the available and unavailable choices of the relevant functionality set (Watts and Ridley, 2007). The following example illustrates the chain of a capability set: school material (commodity) provides information (characteristics) and reliant on a person's age and his/her access to the

school system and buildings (conversion factors: individual, social, environmental) he/she can be educated or not educated (capability set) (Kuklys, 2005, p. 12). Hence the functioning in this example is being educated and the capability set refers to the functionings that can be selected depending on the conversion factors and available commodities.

Finally, the capability set has the purpose of adding the dimension of analysis of the available life choices. A person's capability set ought to describe his or her quality of life, as opposed to solely evaluating existing resources or what the individual or group wants to be or do without considering if these indeed are fulfilled (Saith, 2007). The extent to which intellectually disabled are able to realise being cognitively and socially stimulated and how this may impact their well-being will be analysed below in the discussion chapter.

4.2 Disability and Autonomy

In the process of narrowing down the CA in this study, the concept 'autonomy' emerged as relevant in the case of habilitation services for the intellectually disabled. Interestingly, autonomy also functions as a corresponding theme between disability and capability theory. A shared view is that domains of autonomy are considered significant for a disabled person's contentment. When there is room for self-sovereignty, despite or in conjunction with cognitive limitations, an individual can increase his/her participation and, as a result, increase well-being.

Doyal's and Gough's (1991) work builds on the interconnection between autonomy and well-being. Their theory is based on a presumption of a shared principal goal: "participation in some form of life without serious arbitrary limitations"(Gough, 2004, p. 292). This goal is argued to be achieved relative to people's range of 'personal autonomy' and 'physical survival'. They claim that these two notions constitute our basic human needs. Personal autonomy is assessed by the components 'mental health', 'understanding' and 'having opportunities' (Saith, 2007, p. 62). With regards to 'understanding', Doyal and Gough (1991) assert that cognitive disability has hindering implications vis-à-vis the ability to comprehend the world and to reason about encountered circumstances leading to difficulties in reaching the fundamental goal of social participation (Doyal and Gough, 1991, pp. 60–61, 181–184). To explain how participation is important Doyal and Gough use the concept 'critical autonomy'. Which according to them "entails the capacity to compare cultural rules, to reflect upon the rules of one's own culture, to work with others to change them" (Doyal and Gough, 1991, p. 187). The outcome of participation rooted in critical autonomy is making political

policy adjusted to peoples needs.

The relation of autonomy to disability is further established as follows: "Liberation from disability is about having choices, not about living life in conformity to some pre-defined notion of normality" (Burchardt, 2004, p. 742). Burchardt (2004) reaches this conclusion drawing on the centrality that 'autonomy' has within the disability movement's general claims. Here the importance of options is stressed, yet she questions the idea about normality as being differentiated from disability. This can be seen as a reaction against the ground that Doyal and Gough's (1991) thought builds on, that the disability/impairment itself (due to constrained functioning) is what hinders the attainment of participation (Doyal and Gough, 1991, pp. 60-61). Similar to Doyal and Gough's definition of 'autonomy', Burchardt defines the concept as the "opportunity to formulate and pursue a plan of life" (Burchardt, 2004, p. 742). However, she makes a distinction between autonomy and 'independence', "the opportunity to choose your own living arrangements" (ibid).

The presence of an ambiguity can be detected in how 'autonomy' is brought up within the CA's internal discussion of basic needs in relation to disability. Nussbaum (2000) maintains the position that the premises for a valuable and decent life are dependent on a person's capability to understand and control their own life. Burchardt (2004) argues that Nussbaum's (2000) line of thought "risks classifying some people with cognitive impairments as incapable of having a good life" (Burchardt, 2004, p. 744). Baylies (2002) shares this criticism and argues that Nussbaum (1995) postulate in her work 'Human capabilities, female human beings' is deeply problematic:

> because basic capabilities include living a long and healthy life, and are so closely linked to body and cognitive functions […] potentially rendering individuals with some impairments conceptually not quite human in a similar way that many societies have done for centuries (Baylies, 2002, pp. 733–734).

What Baylies identifies as faulty in Nussbaum's (1995) making a benchmark of basic human needs, is that these are made dependent on human value, which is conceptualised through people's capacities. In the case of persons with cognitive disability, their incapacity to reason and remember may impact their level of consideration as human beings in what Nussbaum suggests is her ambition to set a standard for minimum fulfilment of basic needs (ibid). Nussbaum argues that in the case of "extreme absence of ability to engage in practical reasoning" (Nussbaum, 1995, p. 82) that a person does not lead a life that can be accurately

defined as human, she continues by saying that "certain severely damaged infants are not human ever, even if born from two human parents" (ibid).

Furthermore, Gough (2003) makes a comparison between his and Doyal's framework of basic needs with Nussbaum's, saying that "bodily integrity and practical reason are closely related to our two basic needs of health and autonomy" (Gough, 2003, p. 14). According to these scholars, the need for 'autonomy' versus 'practical reason' is of fundamental importance for people's welfare. Their approach shares an actor-oriented view of situating people's comprehension of their circumstances as triggers for their act of changing things for the better. Gough (2004) argues that "Humans, distinct from other species, also exhibit autonomy of agency – the capacity to make informed choices about what should be done and how to go about doing it" (Gough, 2004, p. 292). Positioning the ends of 'autonomy' as being beneficial is not what Burchardt (2004) and Baylies (2002) seem to oppose, instead they criticise the normative values of which abilities make us human beings.

Autonomy is continuously found as a central dimension for persons with intellectual disability. Hammell (2015) reaches the conclusion that, based on reflections of persons with disabilities, 'autonomy' is one of the main areas of relevance for realisation of their participation. This gives an indication of the importance for the disabled to have a range of autonomy, or plausibly that when a social milieu is confronted with disability, that the question of autonomy is brought to the surface. In 2009, Nussbaum pinpoints that in the case of persons with cognitive disabilities, rights-based theories are brought to a head because the needs of these persons are commonly overlooked. She brings up several suggestions for how their will and choices may be attended to, such as through guardianship (Nussbaum, 2009). This indicates Nussbaum's (2009) recognition of the limitations intellectual disability may pose in relation to making autonomous decisions, as well as suggesting possible solutions to address these. Still, in this article Nussbaum does not attempt to revise her theoretical framework on basic needs towards being encompassing for this group.

In sum, the importance of people's autonomy becomes perhaps even more concrete when addressing the well-being of persons with intellectual disability. The boundaries for what persons are capable of reflecting on and deciding for themselves become pertinent to identify when considering the life people with intellectual disabilities lead.

5. Methodology and Material Collection and Analysis

This is a cross-sectional case study in which data collection and analysis were performed using qualitative methods. A discourse analysis was conducted in the initial research stage, in which I analysed the development discourse by focusing on matters relating to disability, and the disability discourse through matters relating to poverty. In this way it was possible for me to limit the scope of the research and select the appropriate theory, case, and context to study. While in Cuba I held interviews with relevant actors and conducted participant observations at the education and habilitation service sites as the main data collecting methods. The collected material was subsequently analysed by using the method of grounded theory to code the material to find significant concepts and interconnections between these. In the empirical presentation of the work I chose to interweave individual case portrayals into the text to concretise the description of how the respondents from the societal sections policy/service/household perceive how well-being is or can be achieved (Mikkelsen, 1995, p. 45).

5.1 Field Preparations

After choosing to investigate welfare from the aspect of intellectual disability, appropriate methodologies and cases were reviewed. The cross-sectional methodology was selected with regards to the two-month timeframe during which the fieldwork was carried out; the data was collected at one period of time (Shanahan, 2010). After consulting the previous research literature, the role of habilitative services was highlighted as being central for the well-being of the sample group, this motivated the decision to focus on the habilitation services as the case of the study. Habilitation services are multi-disciplinary as well as cross-sectional in their arrangement, which also affirms the suitability of this combination of case and methodology. (Later on I added educational services in adaption with the field).

With regards to generalizability, the study does not cover all the habilitative and educational services in Cuba, nor is the aim to describe the setting at the province level in general terms. It is rather a study based on collected material from seven education and habilitation locations in three provinces as well as observations made in the public and private spheres in Cuba. Hence, the material is connected to conditions at the national level as well as some information regarding more local circumstances.

Narrowing the research down to the case of habilitation services in Cuba was motivated by the fact that the Cuban context can be significant for the realm of development. The case of

Cuba can be argued to be particular. On the one hand, material and monetary resources constrained in the country, while on the other, the quality of and access to welfare services is high (see tables in appendix 3). Even if it is an exceptional case, the circumstances in Cuba can provide significant information about poverty dimensions in a developing country especially because the relatively well-developed welfare sectors indicate beneficial conditions for persons with intellectual disability despite the national economical constrictions. To clarify, the objective of this study is not to make generalised conclusions derived from the description of this cross-sectional case study. It is rather to contribute with a description of the circumstances in this specific case that can be interpreted as relevant for other developing regions (O'Reilly, 2009, pp. 82–88).

I had the possibility to do a brief preparative study of the habilitative service provision in Sweden. Interviews where held with policy makers and personnel working with habilitation. One interview that was of particular use during the fieldwork was the one held with a person working at 'För barn unga och vuxna med utvecklingsstörning' (FUB) the Swedish interest organisation for persons with intellectual disability. She gave me insight into how an interest organisation works on practical and conceptual levels to guarantee the well-being of their target group. This was shown to be a highly relevant matter in the Cuban context, it was the lack of this kind of interest group that according to several of the informants revealed the importance of the existence of one. The purpose of a pre-study in Sweden was to learn about habilitation services and disability matters in general, a comparison between the two welfare systems (Swedish, Cuban) was never intended.

Parallel to these interviews I conducted a text analysis on previous research in development studies and disability studies to detect the overbridging points between the two(Bernard, 2011). In the text analysis I found the capability approach (CA) to be present in both the literature treating poverty definition and measures as well as in disability studies. The relevance that this approach has in both of these fields can be shown in for instance Kuklys (2005) work where she studies relative poverty as experienced by people with disabilities.

After locating this useful theoretical framework I turned to literature with research that operationalises the CA measures in the fields of both disability and development in order to construct a research model to employ in the field. Being that this study is qualitative I was

specifically inspired by pervious research using similar methods (Hall, 2014; Horrell et al., 2015; Watts and Ridley, 2007). Quantitative studies were also examined in order to see how these operationalise the CA, in order to probe how the determination of functionings and capabilities can be undertaken (Brandolini and D'Alessio, 1998; Kuklys, 2005; Robeyns, 2006; Saith, 2007). When writing the interview template I reformulated the CA questions that Burchardt (2004) had formulated in her article, these were later used as my main interview questions (see appendix 2)(Burchardt, 2004, p. 741). These questions aimed to explore the respondents' perception regarding if the target group in relation to others are limited in realising the functioning that they value, in what way such limitations are experienced, and what can be changed to ease these limitations.

In accordance with the cross-sectional methodology I attempted to include a wide-ranging set of informants and habilitation sights in the sample selection. Fortunately I was able to collaborate with Havana University for this study and travelled to Cuba on a student visa, which made it possible for me to visit services that are provided by the state. Yet, I also contacted non-governmental organisations (NGOs), and other actors who are not state employees. As this is a small-scale case study, I chose to use a non-probability sampling method by strategically selecting informants from different sections of educational and habilitation, state-run services and services managed by community and NGOs to widen the range of the included perspectives (Bernard, 2011, p. 143). The validity in the study was thought to expand by including actors from different societal positions (Bernard, 2011, p. 108). Non-governmental actors were thought to be less prone to withhold information since they are not as bound to a loyal position as state employees might be. At the same time, state employees are knowledgeable about the services since they are the primary service providers in Cuba. This variety of actors was sought to increase is the probability of obtaining information regarding the actual circumstances that should be captured in accordance with the aim of the study. Hence, to some extent the validity criteria ought to have been achieved in this research by triangulating perspectives of the selected informants (Mikkelsen, 1995, p. 209; Teorell and Svensson, 2007, pp. 55–59). Initially the focus was only on the adolescent age group, but the target group was widened during the fieldwork to include all ages. This decision was made in light of the fact that the habilitative locations accessed in the field had participants of all ages.

5.2 Data Collection – Interviews, Observations

The fieldwork was carried out during a time-period of nine weeks from 27th January until 29th March 2015. I spent most of the time in Havana and visited schools and habilitative locations in different parts of the city. Additionally, I travelled to Pinar del Rio and Cienfuegos to visit community projects in these less populated provinces. I visited the following sites: two NGO offices, two households, two special schools for pupils with intellectual disability, an institution, three project locations, a house of culture, a telecommunications office, a carpenter workshop, and local buses in Havana. At these locations I observed and interacted with many different actors with the constant purpose of investigating the current and possible well-being circumstances of persons with intellectual disability in the Cuban culture.

When conducting ethnographic research in Cuba the political and economic conditions must be taken into account. When communicating with people these aspects are of central importance because people living in Cuba constantly reflect on where the limits for societal criticism are drawn. In order to determine what a critical position is, a negotiation emerges concerning the character of the revolution. This becomes especially prominent in the conversations about political and social matters in Cuba. On the one hand, *la revolucìon* (the socialist system) is perfectly constituted: a final and static product. On the other, the revolution is dynamic and evenly reshaped by the Cuban citizens, the pillars of the socialist society. In the latter version there is space for reflection about problematic issues and ways of dealing with these without having a critical position against the political structure of the country.

At the policy level three persons were interviewed: two persons working at the ministry of education and the director at an institution. At the service level actors from the following professions were interviewed: psychologists, defectologists[6], physical educators[7], teachers, programme coordinators, school principals, psycho-pedagogues, workshop instructors, a

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[6] The term defectology is currently used in some countries (Cuba) to refer to the study and habilitation of disability. In the introduction of the book *Vygotsky's Legacy : A Foundation for Research and Practice* the authors refer to defectology as the "study of disabilities"(Gredler and Shields, 2008). Knox and Stevens (1993) write that "The word *defectology*, which may sound harsh to Western ears, is the current soviet term for the discipline which studies the handicapped, their development, teacher training and methods" (Knox and Stevens, 1993, p. 1). In Russia the defectologist role entails according to Broekaert et al (2000) "to evaluate the characteristics of the mental and social development of a child with handicap, his/her health abilities and possible ways of treatment development of a child with a handicap" (Broekaert et al., 2000, pp. 64–65).

[7] In Cuba the profession physical educator is connected to the science " Cultura Física y Deportes" (Physical and Sports Education, own translation) at the university of Havana this direction is a part of the faculty of medical science.

carpenter and an institution sub-director. I met persons with intellectual disability and their family members in conjunction with activities arranged at the community projects and at the habilitation service centres and school buildings. All together I held 33 informant interviews and 3 background interviews in Cuba (see appendix 1).

The interviews were semi-structured in that I was prepared with a set of questions and asked some of these in fitting with how the interview situation proceeded. My attempt was to create an atmosphere similar to a normal conversation rather then asking all of the prepared questions. Mikkelsen (1995) writes that "In-depth and open-ended interviews attempt to reduce the non-sampling errors by paying close attention to putting the person at ease […] eliciting longer answers from the person to ensure that the researcher understands what is being said" (Mikkelsen, 1995, p. 205). This was what I was striving for in the interview situations. I followed the conversation trajectory that the informant took and tried at some points to direct the conversation towards the relevant themes of the research (Bernard, 2011, pp. 160–161).

My Spanish language skills enabled me to communicate on a basic level at first and with a gradually growing ability throughout the study. The language barrier did have a negative impact on the conversation flow in the interview situations. The patience of my interview subjects was proven when my language ability faltered. I decided to not use an interpreter for the interviews, because even if I did not always express myself perfectly I did understand what the informants were saying. Using an interpreter could have compromised the quality of the material collected, as it would have generated a more distant conversation climate (Mikkelsen, 1995, p. 207).

Many of the participant observations occurred at the sights where I held the interviews. Most of these situations were planned with the gatekeepers (Bernard, 2011). I was well received at the schools and habilitation service sites and had the possibility to spend entire days of observing the service activities. At these visits my role as an observer was obvious, such as when I was welcomed to a school by a group of pupils performing a song only for me and the principal. On other occasions I took a more participatory role, dancing together with project participants (ibid. pp. 256–257). The fact that I went to a completely new context to conduct the fieldwork, the whole nine-week stay was a sort of participant observation to deepen my understanding of the Cuban culture. I had a constant focus on disability matters when in Cuba

and that enabled me to adapt in situations that spontaneously became a participant observation, which happened in one of the observations included in the empirical chapter.

One problem with the data collection method interview was that it was not possible to record all of the interviews and this may have impacted the balance of the material. I took more detailed notes during the interviews that were not recorded and rewrote these directly afterwards; nevertheless these notes are not as specific as the recordings. This may have created an imbalance in the stage of data analysis of the material.

5.3 Data synthesis, analysis

I used grounded theory in the data analysis more specifically a type of open coding method to interpret the material. A first step in analysing the data was to distinguish patterns of concepts in the interview material by reading through the interview notes and listening to the interview recordings (Goulding, 2002, pp. 74–76). From these patterns seven themes where extracted as the main focus in the results section. Three of these themes were incorporated in the remaining four themes: "educable or ineducable', 'occupation after the school years', 'security and overprotection', and 'interest group for people with intellectual disabilities'. The inter-relations between the themes were the focus on well-being and ways to achieve this. The interviews were categorised by number during this procedure and noted beneath the relevant theme category. Finally, the interview and observation data was once again analysed and sorted in a more detailed manner under the four themes. I found that autonomy was perceived to be an important aspect in the ethnographic study, which developed the theoretical stance.

5.4 Ethical considerations

With regards to the political system in Cuba as it is described above the ethical considerations were given significant attention throughout the research process. In the planning stage I adjusted the purpose and scope of the study to avoid having a critical ingression to the research context. In the procedure of gaining access to the field my research intention had to be presented in an honest and explicit way. I thoroughly explained the purpose and character of the research so that all the gatekeepers and informants that I encountered in the field were able to verify their informed consent (Davies, 2002, pp. 46–51). Due to the delicate political context in Cuba I decided to keep all of the sites and persons confidential, a majority of the informants in the study was informed of this feature.

Davies (2002) writes that in order to guarantee that the respondents give their informed consent to participate in the study the researcher must "explain as fully as possible, and in

terms meaningful to participants, what the research is about" (Davies, 2002, p. 46). She highlights the importance of making sure that the participants are aware of what consequences can come with their involvement as respondents in the research (ibid, p. 47). Considering that this field study was my first visit to Cuba, I can not say that it was possible for me to fully be aware of the possible consequences of the informants to participate in the research study, and let alone inform the relevant actors about these. Nevertheless, I did communicate with persons with central positions within the Cuban welfare system. In accordance with their affirmation of my intentions and direction of the study I felt assured that the thesis would not be perceived as being provocative or trigger negative reactions that in turn could result in negatively affecting the interview respondents. This was part of why I found it important that every person included as well as the specific service locations be anonymous. The respondents are mentioned in the text by referring to their professional title, relation to the targets group individuals or in some instances with a pseudonym. Also, when referring to the cases that are included in the empirical and discussion chapter the persons are given pseudonyms.

Equally, in order to achieve scientific validity and reliability in the ethnographic description it has also been important to avoid censuring or overlooking circumstances that might be politically sensitive. The vulnerability that can be experienced by persons with intellectual disability in society is a delicate matter. In the process of coding and analysing the data I have reflected particularly on ethical concerns of this sort when describing the real life circumstances of persons with intellectual disability in Cuba. Referring back to the political climate in Cuba, in the conception of the dynamic character of the revolution there seems to be some space for problematizing and discussing improvement, at least among internal actors.

6 Empirical Findings

The purpose of this chapter is to give a clear account of the perception that relevant members of the Cuban society have about the quality of life of people with intellectual disabilities. The perspectives presented in this empirical summary contrast with each other at some points (who can learn), yet correspond on some matters (the importance of inclusion).

The empirical material is divided into four chapters. The first chapter, 'educable or ineducable', presents the actors' perception on the intellectual disability categories in connection to the target groups' abilities to learn in relation to their special needs. The sub-chapter 'occupation after the school years' focuses on what occupations exist for persons with intellectual disability and how the respondents consider the importance of being occupied. In the part on 'security and overprotection' well-being is related to the balance of being secure and overprotected and how this equilibrium is considered essential for a person's quality of life. The final section 'association for people with intellectual disability' deals with some aspects of the decentralised Cuban system and reveals how some of the respondents argued that a specific association for persons with intellectual disability would be beneficial for the improvement of relevant policy application.

In the field study I was continuously discovering and charting what educational and habilitative services exists in the Cuban welfare system and to whom they were provided. In the diagram below I have compiled the information that was given to me during the fieldwork about the structure of a central part of the Cuban social security services available for Cuban residents with intellectual disability. Most of these service locations were visited and the actors presented in this chapter are to some extent connected to these services.

A Part of the Structure of Education and Habilitation Services in Cuba
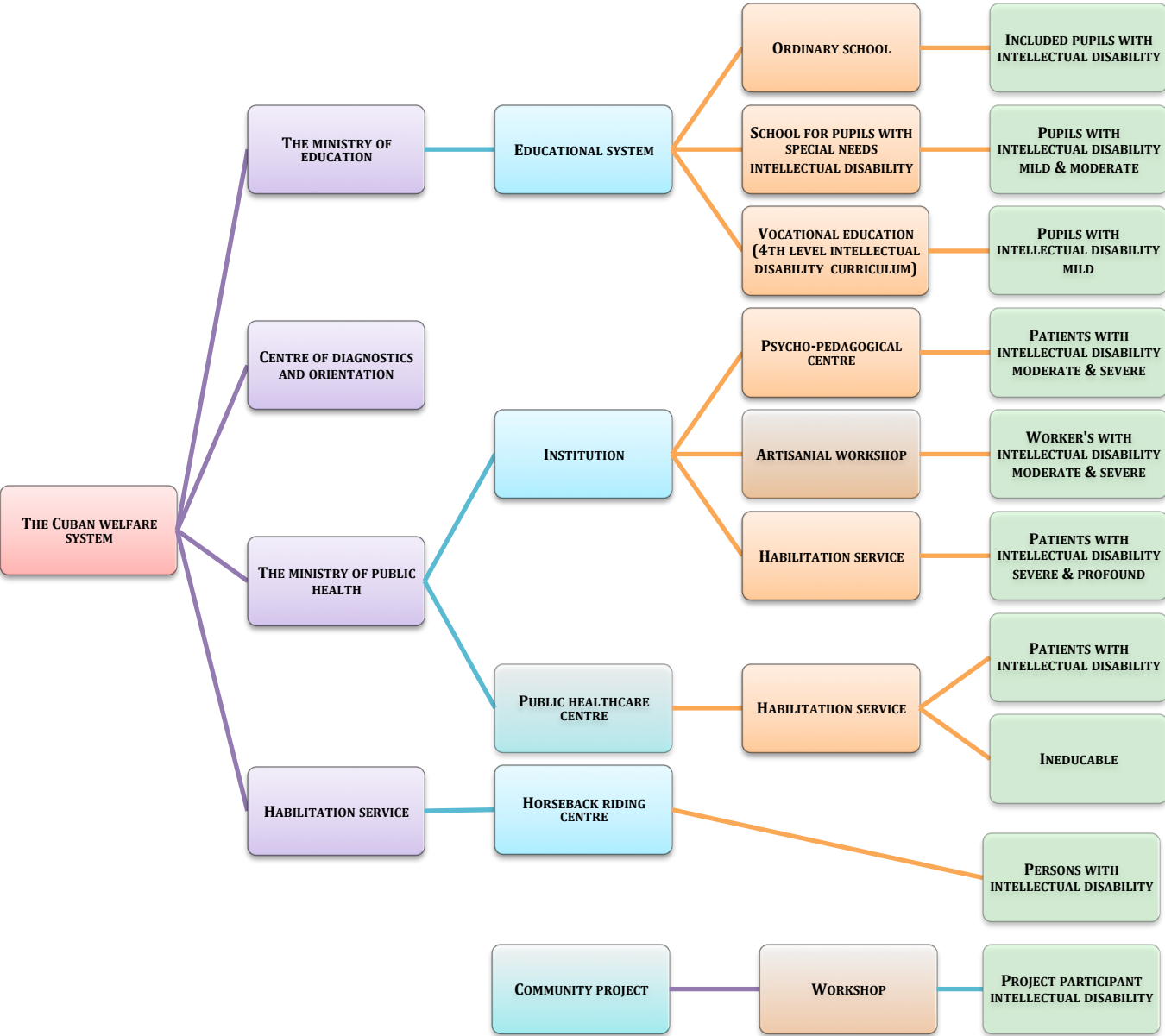
Figure 6 Education and Habilitation Services in Cuba

6.1 Educable or Ineducable

This section refers to the division made between children who are enrolled in the school system and the children who instead are a part of the activities provided by the public healthcare system. I was told that Cuban policy dictates that children are categorised as being educable or ineducable, a decision that is made by the centre of diagnostics and orientation (CDO) based on results of multidisciplinary investigations. This decision has a profound effect on the life of the child with intellectual disability. When a child is categorised as ineducable he or she will not be enrolled in a school or at the psycho-pedagogical centres. The

child will then be at home in the care of family members and in some cases be living at an institution.

In one of the first interviews carried out in the study, two programme coordinators problematized the category ineducable. They emphasised the negative impact that this categorisation had on the well-being of the child at hand. According to them, these children often diagnosed with severe or profound mental retardation (MR) have learning capabilities that with rather small measures can be developed, and through this development of functions their quality of life increases. The measures were related to the development of physical-motor and cognitive abilities that they in a programme format had worked with the family members to perform together with the programme participants. The results had been that these children developed functions that neither the family members nor others first presumed could be achieved. This served as a basis for their conclusion: being identified as educable will stimulate and improve measures to develop practical and cognitive abilities. Concurrently, one of the programme coordinators reasoned that the categorisation ineducable holds back tangible procedures and actions to stimulate their factual abilities, which as a consequence disadvantages their well-being.

During the study the label ineducable was not exhaustively unravelled. I rather sporadically came across this category and conceptions about it. For instance in week five in the field, I visited a horseback riding therapy centre and the defectologist told me that Isabel, one of the participants who is 13 years old, is categorised as ineducable, meaning that she spent most of her days in the private sphere of the household. While being told this, I was showing them some pictures on my camera and Isabel leaned closer in order to see the pictures. Based on my observation Isabel seemed to be both cognitively and socially attentive which made me wonder how this person could be diagnosed as ineducable. I continued to ask different specialists about this diagnosis. A director at an organisation said that all children have the right to be educated. When asked about children diagnosed as ineducable, he answered they have access to other forms of activities such as the ones performed at the psycho-pedagogical centres.

A main perspective on education in this chapter concerns the ability to learn and develop skills of multiple ranges and that is precisely what all the schools and habilitative activities are concerned with accomplishing. Hence being educable is for the target group extended

from mainly focusing on cognitive abilities towards including social, physical-motor, and linguistic abilities. This conclusion is based on how the majority of the interview respondents (at all the three societal levels: policy/service/household) reflected about the learning capacity of persons with intellectual disability. In the case of Isabel, being categorised as ineducable limits what services she can attend and as a consequence her development of abilities.

6.1.1 Reading and Writing Skills

The perception of what the concept educable entails in the Cuban culture seemed to vary depending on the actor and his/her area. At the institution in Havana the woman responsible for the psycho-pedagogical centre talked about the difference between the children who are enrolled there and at the special schools. She came to the conclusion that the children participating at the centre usually do not have the ability to learn how to read and write which the pupils at the special school do. She suggested this as a reason that the centre participants are not integrated in the educational system. Nonetheless, during the interview with Alvaro who is enrolled at the centre, he proudly demonstrated his writing and reading abilities, showing that some participant at the psycho-pedagogical centre actually do learn how to read and write.

Yet, at the two special schools for intellectually disabled in Havana both principals made clear that not all of their pupils learn how to read and write. According to them, the education is adapted to the pupil's special needs and abilities to a great extent. Domestic science is one of the scheduled classes designated to develop the children's practical abilities such as getting dressed and making a bed, abilities that favour their autonomy and are meant to prepare them for living a independent life. Both principals at the special schools said that the education they provide includes stimulating the children's cognitive, social, physical-motor and linguistic abilities even if they do not necessarily master the skill of reading and writing after completing the school years.

I found it interesting that the two different service-provision locations, the first being a part of the educational-sector and the second the health care-sector, were difficult to differentiate between. At both locations the services work with children with special needs (due to their intellectual disability) where they used similar methods in the daily-activities in order to develop the children's competences. And even if mastering the skill of reading and writing was claimed as the differentiating factor, it does not function as a clear dividing line for understanding whether a person can be educated at school or at the psycho-pedagogical

centre.

Nevertheless, on an individual basis belonging to the educational or healthcare system does have drastic consequences for a person's development and life choice opportunities. Services provided either by the ministry of public health or the ministry of education fundamentally comprise different aspects of their development. At the psycho-pedagogical centre the pedagogical aspects such as cognitive abilities and knowledge-based learning are not their primary concern. Meaning that even if the defectologists in practice do work with developing Alvaro's cognitive learning, his opportunities for being educated are more limited than if he was a part of the school system where the pedagogical teachers and methods ought to more explicitly emphasise his cognitive learning development. He would in that case have the possibility to reach higher educational levels. However, as will be explained in the following sub-section, the secondary school level would still be out of range.

6.1.2 Educational Levels

In the interview with the institution's director she spoke about educational levels and the fact that children should be in the environment where they have the most favourable conditions to develop their functions. She argued that it is not the element of segregation (being enrolled in an institution rather than a special school) that is negative for persons diagnosed with MR. It is rather the values that we in society associate to the participants that create this damaging impact. Elite schools directed towards sports or high intelligence performance are examples she brought up to underline her argument: it is the value associated to the pupils rather than the segregation that is problematic. According to her, children enrolled at the psycho-pedagogical centre are in an environment designed to promote their development to their fullest potential. Although, in Yeo's and Moore's (2003) figure of the disability and poverty cycle, exclusion from formal education is one of the factors that leads to poverty, due to the privation of development of skills that excludes them from income generating employment (Yeo and Moore, 2003, p. 572).

A coordinator for a programme focusing on increasing the educational quality for the included pupils (children with special needs in ordinary schools) told me about Rafael who has Down's syndrome. He started his education in an ordinary school and after a couple of years his parents felt pressured by the teachers to enrol him in a special school, which they did. Subsequently, they decided to change back to the ordinary school because he showed a tendency towards regression in his development and had started to lose abilities, which they

ascribed to his attending the special school.

At the moment of writing, Rafael is about to finish the primary level so the programme coordinator is investigating if it is possible for a pupil diagnosed with MR to continue to study at secondary school level at an ordinary school or if it is not possible by law. The answer that the special school principals provided me with is that in the current educational system it is not possible for a person with MR to study at the secondary school level: children diagnosed with MR have a completely different curriculum from that level. Thus, a child's learning abilities in correlation to educational level, as shown through Rafael's case, is not based on an assessment of individual capabilities: even if he could perform at secondary school level, regulations prevent him from doing so.

6.1.3 Everybody can Learn

A shared perspective encountered at all of the different educational and habilitative sites was that the target group they worked with is made up of capable, intelligent individuals. The director of the institution claims that everyone has the ability to learn and that this is a fundamental principle in the programmes that they have created and followed in the habilitative services. Subsequently, the director explained that she was referring to persons with severe MR when highlighting the learning capability of every person. This may imply that the group with profound MR are not included in the group that has an ability to learn. The sub-director told me that the persons diagnosed with profound MR do not participate at the psycho-pedagogical centre and that they are located in another part of the institution. According to her, persons with profound MR have other activities where they are physically, cognitively and socially stimulated.

I have visited the institution on six occasions, but the building where the persons with profound MR spend their days was never shown to me. This may be because the institutions declared ambition (director, sub-director) is to present their patients as being as competent as possible. My own conclusion is that the patients with profound MR may not conform to what they wish to display as being capable. For instance, when they have an external visit (which happens on a regular basis) the handicraft workers usually perform an act such as singing a song or giving a dance performance. On several occasions these artistic performances are also what people refer to when talking about the patients at this specific institution: 'Hacen cosas maravillosas' (They do marvellous things, own translation).

There seems to be a tendency in Cuba towards emphasising the abilities that the persons with intellectual disability have. During the interviews at the habilitative service level, a vast majority explicitly emphasised the strong capacity held by their target group. On some occasions these capacities were emphasised in comparison to the incapacity of other people. For instance, a mother said that she did not want her daughter Monica to participate in the activities provided by the institution because the participants there are 'vegetables'. This mother reasoned the same way that Rafael's parents did, suggesting that her child's abilities would be negatively affected by the inabilities of others in her surrounding. As an alternative, Monica's parents decided to engage in a community project so that she would have a meaningful occupation after she had graduated from school.

Even if the capacity of persons with intellectual disability was underlined, the absence or deficiency in services provided was brought up as having a negative impact on their development of cognitive and social skills. The programme coordinator for a community programme said that changes are required in the educational system to establish measures and methods to pedagogically stimulate the learning abilities of pupils with intellectual disability. According to her, there are pupils at the special schools who do not develop to their full capacity. In order for that to change they need to have better teachers who organise the education based on the pupils' individual abilities and differentiated to their potentials so that they are stimulated as much as they possible.

In likeness to the institution director, the programme coordinator claims that 'everybody can'. Yet, her view of everybody is later described to be the pupils who are enrolled in the special schools (mild and moderate MR). In the activities that the programme coordinator instructs she has included a couple of children who are enrolled in the local special school. The parents and instructors have established an agreement with the school that the children go to the classes she holds on a weekly basis. The reason for this is that the parents believe that their children lean more in the classes provided in the project then they do at school.

On the topic of pedagogical stimulation and the above-mentioned educational outcome to learn how to read and write, it is interesting to tell the story of Alicia, a 21 year-old woman with Down's syndrome. Her mother told me about the reading and writing class that the participants have on a daily basis in the project. According to her mother, Alicia had learned more about how to read and write by taking these classes then she had done during her years

in school. According to her, it is the motivation that the group gets from the project activities that catalyses their ability to learn, also when it comes to these more theoretical segments. The fact that it was at the project that she succeeded at learning how to read and write and not in school where the expertise is concentrated, contrasts to that discussed above in relation to Alvaro's exclusion from the school system. Alvaro might have had better prospects in developing his cognitive abilities at the habilitative services then he would have had in formal education schools.

In conclusion, regarding prosperous conditions for educability, the respondents from the three sections (policy/service/household) seemed to agree on the importance of recognising the children's capacities in order for them to develop. However, the other side of the coin is that the category 'ineducable' does not provide fruitful circumstances for a person's development capacity, because he or she is perceived as incapable of learning. The range of abilities that persons with intellectual disability have in relation to their participation in society is a reoccurring theme in the following chapters.

6.2 Occupation After the School Years

It was apparent from my contact with individuals in Cuba that work is an important part of being a Cuban citizen and ideally everyone should contribute with his or her share for the greater good of the socialist society. It is presumably this linchpin that stimulates employment in different sectors for persons with intellectual disability. Yet, many with the diagnosis MR are still unemployed and to some extent unoccupied. The concept *la vida familiar* (life in the family) is used both for describing the life-situation of children categorised as ineducable as well as for others with intellectual disability who no longer are enrolled in schools or occupational activities. These individuals are in the care and responsibility of their family members and their everyday life is correspondingly dependent on what the family decides for them. Marco, who occupies a key-position at the ministry of education, said during the interview that his ambition is to reduce the number of persons destined to *la vida familiar* by creating more occupational opportunities for them.

Other actors within the habilitation sphere share Marco's ambition: during the spring term 2015 a project has been initiated with the objective of improving the employability of disabled persons and to widen their range of job opportunities. However, at this stage the project only includes persons with physical or sensory disabilities and persons with mild MR.

In the final school years, individuals with mild MR are more likely then other MR categories to be given the opportunity to participate in work-preparatory activities. These activities take place in the fourth and ultimate level in the educational curriculum for pupils with MR. The likelihood of employment for students who completed the fourth level is high according to Marco and when employed they will receive the same wage as any other worker. When I asked Marco what occupational solutions he suggested for persons with MR who do not reach the fourth level, he answered that a prosperous solution could be creating different workshops (artisanal, production) where these persons can perform manual labour.

6.2.1 The Workshop Format

At the institution there is an artisanal workshop where individuals with both moderate and severe MR work. Some of these workers receive a salary. When I talked to Alvaro and his teacher/defectologist at the psycho-pedagogical centre, they said that he has started to transfer to work at the workshop. Alvaro was especially positive about the fact that he could start to earn money from working there. Dariana is a 40-year-old woman who works at this artisanal workshop; she has also been participating at the institutional activities since she was a small child. The workshop instructor who works closest to her, said that Dariana values her work there tremendously. Dariana has a specific need for the structure and social dimension that her work provides. She is in a safe and loving environment where she is seen for who she is, especially by the director who has seen her grow up at the institution. That same day when the interview with the instructor took place, Dariana was absent from work because the bus that usually transports her and other workers was temporally out of order. She lives far away and this disruption prevented her from going to the institution.

The idea that individuals with intellectual disability can work in a workshop format is also adopted at the community level. Communitarian projects that often are started by family members of persons with intellectual disability, especially Down's syndrome, exist in many forms all across the Cuban provinces. Workshops with an artistic character such as dance, painting, engraving and music are commonly arranged within these projects. I visited three different projects in the three cities Havana, Cienfuegos, and Pinar del Rio: one with a focus on arts, one with a health and sports direction, and one shaped within a Christian catholic platform. In practice they worked with similar activities and workshops during their daily gatherings.

6.2.2 The Ambition for Recognition

It became evident how crucial the participation in the project is for the participants both for the youths and adults with disabilities as well as for their family members and instructors. This empirical observation showed how the difference between being occupied or not has a noticeable impact over the well-being of persons with intellectual disability. One example of this correlation can be found in the narrative that Veronica and Evelyn two women with Down's syndrome's mothers gave about how their daughters were depressed before they started to participate in the project and that they have overcome the depression symptoms by the stimulation they got at the daily activities. They now have the sense of belonging to a group and have a platform for interaction with people on an equal basis that according to the mothers was not possible to achieve to the same extent before entering the project. In addition the family members, especially in the project in Pinar del Rio, gave the impression of being socially stimulated through their own participation, they express a contentment over being a part of the project.

The case of Claudia and her unfortunate circumstances was something that the programme coordinator in Cienfuegos repeatedly mentioned during our interview. Claudia is a 20-year-old woman with Down's syndrome who participated in the project a couple of years ago. She had great dancing talent and flourished when taking part in the activities. At one moment Claudia's parents decided that she should not continue participating in the project. The programme coordinator said that her inoccupation has a negative impact on her well-being. Nowadays she is overweight due to lack of sufficient physical activity. In addition, Claudia's non-attendance in the project activities limits her possibility to develop her abilities and socially interact with peers. Due to her concern for the well-being of the girl, the programme coordinator has tried to persuade Claudia's mother to allow her daughter to participate in the project. Her effort was nonetheless unsuccessful. This young woman spends her days in the domestic sphere (*la vida familiar*), which according to the coordinator is unconstructive for persons with intellectual disability. The fact that Claudia was a talented dancer seemed to have played a part in the disappointment the coordinator expressed.

Contrarily to la *vida familiar*, being occupied is portrayed as having a positive impact over the well-being of the target group. Recognition is a main occupational factor put forth as having a positive affect on the participants' well-being. Through their daily activities they had a personal space for self-fulfilment. Also, endeavours of a communicative and cognitive

character push the individual to participate in the group, community and society. They have art exhibitions and dance performances, which the public attends. A number of the instructors and family members at the three communitarian projects emphasised the significance of having a location were the persons with intellectual disability can realise their ambitions and build relationships in a creative and accepting environment. Being recognised also moderates Yeo's and Moore's (2003) poverty and disability cycle, where limited social contact and low expectations from the community are factors that results in a person having low self-esteem which adds to their limited access to resources and further exclusion (Yeo and Moore, 2003, p. 572).

In addition, at one of the special schools for pupils with MR a handful of the staff members are former pupils with a MR diagnosis, who were employed at the school after they had graduated. The principal presented her employees to me and her recognition of their capacities was explicit in her presentation. Several of the parents and habilitation personnel claim that it is in the occupational and habilitative activities that the target group can reach the feeling of being 'useful', because that is where they have a space where they can accomplish things together with others.

6.2.3 Occupational Opportunities

A person working at the ministry of education told me about persons with a mental retardation diagnosis who work at the ministry office and are responsible for administrative tasks. Several of my informants talked about persons with intellectual disability that are employed. Anabel, who works towards creating a national interest group for persons with intellectual disability, told me about a young man with Down's syndrome "he works at a company within the primary sector, and has all the rights and privileges that a normal worker has" (own translation). According to her, the probability that a person with Down's syndrome will obtain a work position is reliant on whether their family supports them in developing to their fullest capacity. The psychologist and defectologist at the horseback riding centre reasoned in the same way as Anabel: they stress the significant impact that the support of the family has on a child with special needs in the development of his or her abilities. In their opinion, the societal conditions are favourable for the provision of opportunities for the target group: it is the family who can act as an obstacle for this as well. To concretise this argument the defectologist brings up the example of a woman with Down's syndrome who works at a preschool, and that this demonstrates how, in the Cuban society, "we are adequately open towards inclusion" (own translation).

However, others argue the opposite, that it is precisely the aspect of providing occupation opportunities that must be further applied for the sake of the well-being of persons with Down's syndrome. According to a programme coordinator, the assurance of job positions is crucial for the well-being of individuals with Down's syndrome, especially adults. This group's current situation in the Cuban society is to stand in the periphery, because they are not included in the occupational market, which according to her they possess the abilities to perform within. She was clear on this point and expanded her argument by saying that exclusion of this group from employment stands in the way of their independence and to create their own family. To exemplify this she referred to Eduardo a 23-year-old man with Down's syndrome who is competent and independent and would, if given the opportunity, be able to perform at a job and have his own family.

In Havana I passed by a carpentry workshop where they run a project to employ young persons with socio-economical difficulties. I asked the head of the project about his understanding of the employment possibilities for persons with intellectual disabilities. He answered that in the manual work sector these individuals might even perform better than workers without a diagnosis, yet in order for them to initially be employed the employers might need inducements for taking them on in the workforce.

In order to achieve occupational participation for persons with intellectual disability different preconditions were highlighted as significant. First, that the family members had an ambition to bring the disabled person to activities and worked with their development of abilities from early childhood years, and second, the existence of occupational locations for them to participate in. The accessibility of these two areas is bound to regional differences in service provision. In Havana occupational and habilitative services/activities such as psycho-pedagogical centres, workshops and horseback riding are dense in matter of quality and quantity. However, in other regions and in the rural areas the provision is scarcer compared with Havana. In Cienfuegos the service is not yet provided despite the national effort on implementation of horseback riding therapy, but the establishment of a riding centre is planned. The mother of Pilar, a 7-year-old girl with Down's syndrome, said that she and her family had moved from Pinar del Rio to Havana because of the existing habilitative services specialised on her pathology that are provided in the capital. Pilar's mother reasoned that through participating in these habilitative services she will have the opportunity to develop

her abilities to their fullest which will be good for her and for her future well-being.

6.3 Security and Overprotection

People's security is of crucial importance for their general well-being, but security can be interpreted in many ways. Something that has emerged as central in this field study is the balance between being safe and being overprotected and how these functionings impact the everyday life of persons with intellectual disability. During the field experience, I encountered people who expressed that persons with intellectual disability have special needs and are often dependent to some extent on other persons in order to tend to these needs . The safety needs of this group were discussed as essential for their well-being at all the three levels: policy, service and household. Nevertheless the conception of how these needs should best be satisfied was shown to differ; whereas the family members brought up the necessity of their protective role, the service personnel brought up overprotection as having a negative impact.

6.3.1 Keep Safe

During the interviews some of the family members brought up inadequate security at the school as a reason for withdrawing their children. In the case of Gerardo, a 15-year-old boy with Down's syndrome living in the outskirts of Havana, his family had decided to take him out of school some years ago because they did not think that the teacher could attend to him enough to assure his physical security. The classroom was on the second floor and they where afraid that Gerardo would jump or fall from the window due to deficient supervision. The boy's mother and sisters said that he had completed the schools years necessary for his educational level and that this also played a part in their decision.

In another case the mother decided to withdraw Francisco from school when he was 14 years old because he on two occasions had left the school unattended and went home and to her workplace. She was too preoccupied to keep Francisco at school so instead she brought him to her workplace until the Cuban social insurance enabled parents to take care of their intellectually disabled children full time and retain their salary. In several of the interviews at the household level, the family members expressed that it was important that the grandchild/child/sibling was under their guardianship, and that they were accompanied by them at all times. In some other cases the project participants were said to be capable of being in public spaces on their own without risking their safety. Eduardo, who was mentioned above, goes unaccompanied to and from the project activities, as does Ricardo, a 31-year-old

man with intellectual disability who lives in the centre of Havana. He takes several buses to reach the centre where the activities take place. The other parents in the project and instructors had trained him to take public transportation on his own, since that was the only way he could continue to participate in the project after his mother passed away.

With regards to security in schools, one of the programme coordinators mentioned the decaying state of the school buildings and how this environment is a safety risk for the pupils. According to her, the options for dealing with this risk are restricted due to the magnitude of building decay and lack of resources to reconstruct them. Based on my own experiences in Cuba, a great proportion of the buildings are in poor condition, especially in Havana,.. However, the school buildings visited in the study were observably in good shape. Another security aspect in relation to spaces was brought up by the director at the institution. According to her, a number of the patients were incorporated to work at a factory where they did a great job, the employer wanted them to continue working there, however due to safety reasons she and her staff decided that it was not a safe enough place for them to be. Thus they did not continue to work there and went back to participate in the daily activities at the institution.

6.3.2 Overprotection Stifles Autonomy

According to the psychologist at the visited institution, a key instrument for the increased well-being by security for the institution participants is a forum where the communication between habilitative staff and parents can take place. He and others working at service level brought up the damage that overprotection causes and how issues related to this destructive behaviour could be highlighted in these communication forums in order to increase the parent's understanding of this issue. Being overprotected hinders the individual from developing a sense of self-confidence as well as abilities. His way of reasoning corresponds with the correlation between low self-esteem, less skills and poverty that Yeo and Moore (2003) include in the disability and poverty figure (Yeo and Moore, 2003).

At the horseback riding centre the negative impact of overprotection was also something they worked at changing together with the family members. The defectologist talked about Gerardo, mentioned above, and that when he came to the centre about three years ago he was very overprotected by his mother and sisters such that they did everything for him. Their conduct had hindered him from learning to do practical things for himself, like getting dressed

and eating. The team at the centre worked with the family members to raise their awareness of how their overprotective behaviour towards him was not favourable for his development.

6.3.3 Communication Forums

In addition, the psychologist shared an experience he had during the 1990s when he started to work at an institution where they did not have these parent forums, which resulted in a negative impact on the patients' well-being. He told a person working at manager level to come and visit the institution so she would grasp the situation and the need for implementing a communication forum. After the visit the manager was choked over the bad state that the patients were in and decided to implement the communication meetings as suggested. This change resulted in an improvement in these persons' life quality according to the psychologist.

One of the community projects published a journal once per quarter, on topics related to intellectual disability as well as updates on activities and performances. One of the program coordinators talked about this journal and said that some of the themes and articles are designed to educate the parents on constructive ways to relate to their child with intellectual disability, as some parents maltreat their children. These journal themes are distributed in an attempt to change parental behaviours for the better.

Persons with intellectual disability are described as a vulnerable group when it comes to neglect, abuse and violence and these conditions were brought up by the respondents working at the institution and special schools. In these locations they have a focus on dealing with these conditions when discovered. Support mechanisms exists at the community level, including the Comités de Defensa de la Revolución (CDR) and Federación de Mujeres Cubanas (FMC) that the institutions and schools contact and cooperate with in order to ensure the person's safety in the household. In cases of maltreatment and violence, the health and school personnel referred to communication with the families as being crucial to protect the well-being of the concerned person. When asking a director working at the policy level about the security of people with intellectual disability he said that Cuba is a secure country and that this group is as safe as any other. From my respondents the common perception was that Cuba is a secure country both in the regards of the socialist security safety-nets as well as low crime rates. Nevertheless, whether the target groups are more vulnerable when it comes to areas of security was not completely agreed upon.

In this section the security and safety of persons with intellectual disability has been highlighted by taking into account how the respondents perceived that this feature impacts the well-being of the target group. Being protected may keep a person away from immediate danger or external threats and at the same time stifle a person's confidence and independence. It is the family members' responsibility to keep each other safe and the boundaries for the reach of their protection are not clear-cut. However, the perception of service personnel is that an open dialogue and perhaps expert guidance about these issues is necessary in order to find the right way for the well-being of the individual. The following subchapter describes the societal function of an association for increasing the well-being of the target group, change sparked at the grassroots to reach the policy level.

6.4 Interest Group for People with Intellectual Disabilities

On several interview occasions the informants brought up the importance of having an interest group that deals specifically with issues related to intellectual disabilities. In this section some of these reflections will be highlighted. The creation of an interest group was discussed in order to expand the functionings and capabilities accessible for the target group, to provide channels for instance to improve occupational provision. The possibility for the household and the service level to influence the policy level was dependent on the existence of an interest group.

An interest group for persons with intellectual disabilities does not exist in Cuba, which I noticed before performing this field study. When searching for possible collaborative actors I found interest groups that work with persons with physical disabilities, however, on the internet no trace was found of an equivalent association or organisation directed towards intellectual disabilities. While in Cuba these interest groups regarding physical disabilities seemed to have a significant position in the society. There are local offices throughout the country and even situated in the different districts of Havana where the interest groups work and meet people to give consultation in their specific errands.

I went by one of these offices in the downtown area in Havana and several of the organisations were localised in the same office space: La Asociación Cubana de Limitados Físico - Motores (ACLIFIM), La Asociación Nacional de Ciegos y Débiles Visuales (ANCI), Asociación Nacional de Sordos de Cuba (ANSOC). I spoke to two of the representatives from ACLIFIM and they told me that they also worked with people who have intellectual disabilities. From what they told me about how they work, one of their main functions is to

guide people to find what services and activities are available in the society and to assist individuals in accessing these services. A sort of coordinator function, and as I had observed and the two representatives confirmed there are many habilitative activities provided in Havana. Thus their coordination and guidance is useful in order for persons to find the appropriate services.

Additionally, ACLIFIM work with a range of areas within society and can take part in policy changes since they communicate with the ministries through common platforms. Their policy influence was also confirmed by the ACLIFIM representatives: there are channels for these organisations to give their opinion in issues related to disability and how to achieve increased accessibility. Their voice is channelled and heard in relevant matters. I observed that on the busses there are signs that the buss-fee is 40 cents Cuban Peso (CUP) and that half of that i.e. 20 cents goes to the associations ACLIFIM, ANSOC and ANCI. This sign can give an indication of the status of recognition that these associations have in the Cuban political system.

6.4.1 The Cuban Queue System
With regards to accessibility, people with physical and sensory disabilities have certain rights when it comes to being in the public sphere, they should be able to go past the line if there is a queue at the vegetable market or some other public space. This also includes pregnant women and in some spaces people who have small children. The social codes in regards to these exemptions are strongly followed by common people. At the bus situations people often commented that people with disabilities or children should be given a seat. At one instance I saw a teenage boy with Down's syndrome enter the bus and he was instantly offered a seat.

Although I did not find a document with the formal right to prioritisation in situations when standing in a queue or when using public transportation, these rights were excercised by people living in Cuba. One of the programme coordinators said that only persons with physical-motor and sensory disabilities are entitled to these queue and travel benefits and that they have been derived by ACLIFIM, ANSOC and ANCI. According to her the individuals with intellectual disabilities do not enjoy these benefits formally because they do not have an association that can speak on their behalf.

This matter was drawn to my attention on one of my last days spent in Cuba when I observed a public dispute over the queue system outside a telecommunications office 'Empresa de

Telecomunicaciones de Cuba S.A' (ETCSA). During four days ETCSA had a special offer in the purchase of a telephone line that cost 30 dollars (CUC) the same amount would be given for free to use for calls, 30 dollars (CUC) is approximately a month's wage for a state employee in Cuba, meaning that this offer was a great deal for Cubans. A great number of people were standing in line outside the ETCSA offices these days. Just as I arrived at the office an older woman in a wheelchair insisted on being carried up the stairs by people standing in the queue, and so they did. However, a dispute arose when she forcibly tried to enter the office barrack. Young men physically hindered her from entering. One of the men standing in front of her was explicitly upset and engaged in a loud dialogue about why she should not cut the line based on her physical disability. She did not have the right to pass him because he had been there for three days and on top of it all he had his son who is intellectually disabled with him. Others joined the discussion about whether right for disabled to skip the queue should apply in this situation, the 'no' side dominating the discussion. Finally a man working at an office came out and settled the matter by saying that there is a difference between queuing for food and for a telephone line and that in this case the woman in the wheelchair would not pass the others in line. On the basis of differentiating between the access to goods and services that satisfy basic needs and those who do not, he argued that the right to evade standing in line did not apply in the case of telephone services. Specific rights of accessibility in connection to well-being of persons with disability where discussed in this public dispute.

This example shows how different disabilities are publicly framed in the forming a consensus on when a certain groups' privileges are called for. Whether the existence of an interest group for intellectual disabilities would create different circumstances in a situation like this is uncertain. Yet the frustration expressed by the father whose son was intellectually disabled indicates that the subject of disability is charged, or is it perhaps the way that he mentioned the son's disability that reveals his uncertainty towards what privileges he thought his son's disability should entail. It is that sort of clarification and justification of needs-based rights that the programme coordinator argues an association for people with intellectual disabilities would contribute to. Exclusion from political and legal procedures is one of the main factors that Yeo and Moore (2003) bring up as contributing to the poverty disabled persons experience, thus it hinders their ability to proclaim rights (Yeo and Moore, 2003, p. 572).

6.4.2 Reality-Based Policy
Concurrently, as mentioned above a group of parents have created a group and are jointly

working on the formal establishment of an interest group for persons with intellectual disability. I conducted an interview with Anabel one of the members of this group. She said that they perceive an interest group for intellectually disabled to be a prominent factor for society to be adjusted to and accurately meet the special needs that intellectually disabled have. Anabel says that policy should be based on people's reality and the experiences that people have about their own situation. In the case of persons with intellectual disability they themselves cannot always articulate their experiences, and that is why their parents might better speak on their behalf.

One of the programme coordinators said that when an experienced figure within the disability field visited Cuba ten years ago he reacted strongly to the fact that a parental association for persons with intellectual disability did not exist. The reason for his reaction was said to be the uncommonness of a complete lack of this kind of interest group in a society, especially considering the well-developed education and healthcare system in Cuba.

The significance that an interest group could have was highlighted in this sub-chapter by a description of how some respondents reasoned about the matter of the conditions of well-being for the target group. A description from a participant observation was also included to give an exemplification of Cuban codes in relation to the concept of disability and how these are interconnected with a mechanism of associational membership. These matters will be analysed in the following chapter.

7. Analysis

In this chapter the main conclusions from the empirical findings will be analysed using the theoretical framework provided by the capability approach (CA). The well-being conditions of persons with intellectual disability are analysed by referring to the circumstances in the cases described in the previous chapter. In accordance with the CA, the functionings that the target group had reason to value were outlined. It became apparent that the emphasis on a specific functioning has some variance within the four different areas education/occupation/security/interest group. Also, as shown in the chart below, the functionings *being participatory, being autonomous, and being occupied* are perceived to have an overarching importance for the achievement of the target group's well-being.
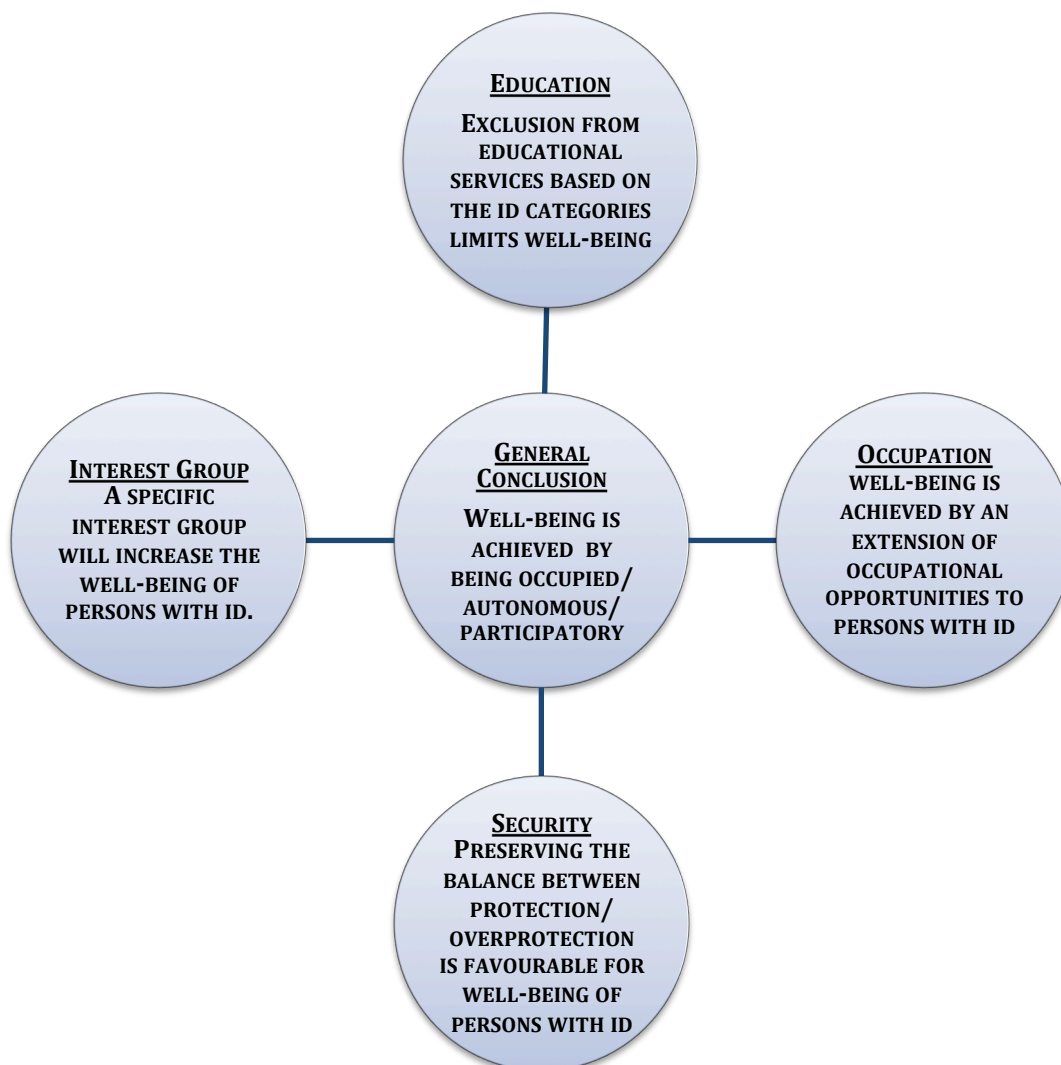
MAIN CONCLUSIONS

Figure 7 Main Conclusions

This finding seems to confirm the argument proposed by Nussbaum (1995), Doyal and Gough (1991), where autonomy is emphasised as a crucial factor for participation and well-being is achieved by assuring certain degrees of participation. Correspondingly, the vast majority of the respondents at the service and policy level talked about increasing the participation of the target group as the main purpose of their work with them. When I asked them how they work with this goal in concrete terms, the standard answer was: by developing their abilities so that they, with consideration for their disability, can act as autonomously possible, and when they function as autonomous actors their possibilities for taking part in society on their own terms are widened. Since the investigation dealt with the provided services and how the respondents from policy/service/household reflect about how these work in the achievement of the well-being of the target group, it is the collected responses that serve as the platform for answering the research question of this study. In order to answer the research question I will discuss the quality of life that Isabel, Gerardo, Alvaro, Claudia, Dariana, Evylin, Francisco and Ricardo have with respect to their range of participation.

In congruence, one of the general conclusions reached in this study is that people's well-being is achieved when they have an occupation. For children this occupational activity is set either in the school services or in the habilitation services, for example the psycho-pedagogical service provided at the institution. For adolescents and adults with intellectual disability the occupations can take place in working places where they have paid employment or in workshops arranged by the local institution or community projects. Multiple reasons were given by the informants for supporting the conclusion of the importance of *being occupied.* These reasons will be explored through some aspects in the abovementioned cases.

7.1 Communication Forums

As already described, some informants highlighted the balance between being protected and being overprotected as crucial for the accomplishment of the well-being of persons with intellectual disability. Family members are usually the main responsible actors for this equilibrium. Therefore an essential well-being factor was claimed to be communication forums as an awareness-raising channel about the constructiveness of this balance and a way for professionals to give the family members guidance of how to reach it. Evidently, a requirement for family members partaking in these communication forums is that the person with intellectual disability is participating in the activities where these are arranged. As a consequence, a person who is unoccupied living a *la vida familiar* has less opportunity to

reach a balance between *being secure and being overprotected* and this is claimed to have a negative impact on their well-being.

Isabel and Gerardo are two adolescents with intellectual disability that spend most of their time unoccupied living *la vida familiar*. However, on a weekly basis both of them are participants in the horseback riding therapy. Based in Isabel's and Gerardo's inoccupation their possibilities (capability set) for having a balance between being protected and overprotected by their family members might be limited. Other activities may actualise this possibility. As highlighted in the case of Gerardo his participation in the habilitative service at the horseback riding centre enabled communication between his family members and the habilitation specialists to raise their awareness on how they could be less overprotective with him. And they had seen results that Gerardo had developed abilities and became more autonomous then he initially was. This was according to them a positive outcome of their work because it has raised Gerardo's quality of life.

In this case well-being was perceived as being achieved through a communication forum that took place at a horseback riding centre in Havana. Yet, in other provinces in Cuba, for example Cienfuegos, this kind of habilitation service is not provided, which might limit the capability set in this matter for the residents in Cienfuegos who have living circumstances similar to Isabel and Gerardo: intellectually disabled and unoccupied. At the same time it is difficult to make a definitive deduction based on what might be the implication of the inaccessibility of this specific habilitation service. As it is shown in a community project other ways of reaching the same end have been created based on local initiative by parents and habilitation specialists. They use journal articles as a means of raising awareness on delicate issues. Hence, creative solutions to increase the quality of life of persons with intellectual disabilities by creating participatory opportunities are found in the many community projects in Cuba.

Nevertheless, when habilitation services vary in both quality and quantity across the provinces, the capability set is more limited for the persons living with more scarce access to these services in order for them to realise the beings they have reason to value. And this occurrence is especially pronounced in the case when individuals like Isabel and Gerardo that live *la vida familiar* which indicate that in exception to the horseback-riding activity they are not a part of the educational and habilitative system in their everyday life. There are

individuals in *la vida familiar* who do not have access to habilitative services because in the region they live services are not provided. Or as in the case of Claudia activities are provided but the family members do not permit her to participate.

As concluded by the informants working in the service sector, the development of abilities is a way that they work with including the target group into society, in that way they can act autonomously and relate to people as competent actors. They portray the participation to be reliant on the range of autonomy they acquire from having a space to develop their capacity. Participation is reached by an extension of autonomy this is precisely the connection that Doyal and Gough (1991) point out as central for satisfying our human basic needs (Saith, 2007, pp. 63–64). In relation to the matter of security the range of autonomy for a person with intellectual disability is claimed to be widened when there is a balance between being protected and overprotected. This balance is a main area that the service personnel work with attaining together with the family.

7.2 Domestic or Public as Occupational Facilitator

Based on the collected material there were two directions about what facilitates the occupational opportunities: family or societal contexts. Respondents at service level emphasise the families influence over the possibilities that a person has to realise the functionings *being socially, physically, cognitively stimulated, being useful, being acknowledged, being autonomous, being participatory*.

According to the programme coordinator, Claudia's well-being could be achieved through her participation in the workshops arranged within the project. There she would have the possibility to realise the functionings *being physically, socially and cognitively stimulated*, and to have space to develop her dance talent and thereby have her own platform for acknowledgement based on her capacity as a dancer. In that way the decision that Claudia's parents made to not let her continue with the project activities has limited her capability set because as unoccupied she is not developing her abilities, and is not socially stimulated to the extent that she could be in the activities. Claudia's options for realising the functionings that the programme coordinator has determined to be valuable for her are restricted in her current stage of inoccupation. Even if Claudia could realise the functioning *being participatory* based on the commodity *occupational service*, her capability set regarding this functioning is narrowed by the social conversion factor *family conditions*.

The importance of having an occupation was also confirmed at household-level interviews, Evylin's mother said that Evylin had been depressed before she started in the project. It was the stimuli she got from the workshop activities to develop her abilities and to be a part of a group that contributed to her quality of life and gave it a new meaning. The circumstances in Evylin's case were similar to Claudia being that they both are diagnosed with Down's syndrome their individual conversion factors *intellectual disability* taken together with the commodity *occupational service,* they could assumably have the same participatory conditions. However the social conversion factor *family circumstances* is what differentiates their degree of participation by having an occupation, and since Evylin's parents act on their realisation of how important this occupation in the workshops is for their daughter she has a occupation on a daily bases which Claudia does not have.

As discussed here it was the *family circumstances* that influenced Claudia's and Evylin's occupational degree. Similarly, in Gerardo's case the same factor can be argued to have impacted his relative inoccupation since it is his family that have decided that he should live *la vida familiar*. Yet, for Gerardo other environmental factors such as insufficient safety-routines at school might also be a part of the equation of his current set of life choices. Although, from the service level perspective individuals with intellectual disabilities occupational possibilities are claimed to be the mainly dependent on the factor *family circumstances,* if the family provided the person with opportunities to develop abilities and participate in social settings, his or her capability set to realise the valued beings would in that case be wide-ranging in Cuba.

Another respondent at service level took a different stance by saying that the range of participation that persons with intellectual disability could be radically changed if they had access to an employment position. She took a societal perspective saying that the arrangement of the provision of the commodity *employment* by state initiatives is crucial for achieving the well-being of the target group (she was mostly referring to persons with Down's syndrome). According to her, persons like Eduardo have the capacity to perform within the job-sector but cannot do this because the structure of the system limits their occupational opportunities.

Eduardo's capability set for realising *being useful, being acknowledged, being autonomous and being participatory* is limited according to the coordinator. Even if his individual conversion factors *age, social, cognitive, physical ability* are beneficial for realising these

functionings it is the commodity *employment provision* that narrows his capability set. Nevertheless, Eduardo is occupied in the project workshop and has the possibility to realise these valued functionings through his activity there. Successively, his capability set is widened through his daily occupation.

The coordinator had higher aspirations for Eduardo's life that according to her would give higher quality if he only could obtain paid employment and thereby become even more autonomous. He would perhaps be able to have a household and a family of his own. In Cuba persons with intellectual disability do in some cases have the possibility to gain paid employment. I was presented to such cases at the special school and at the institution, although these where located in Havana and the situation in Pinar del Rio or Cienfuegos is possibly different such that the employment opportunities are not as densely offered where Eduardo lives.

7.3 Educational System

In both the educational and habilitative sectors the informants at the policy and service level talked about the functioning *being educated* when referring to intellectually disabled in more specific terms as *being social stimulated, cognitive stimulated, linguistic stimulated and physical-motor stimulated*. These terms make *being educated* more comprehensible. Which leads me to the following question: is Isabel incapable of developing social, cognitive, linguistic and physical-motor abilities? The answer that the habilitative personnel as well as disability scholars would give is: no. How the educational system can be structured based on this assumption is thus difficult to understand especially when the consequence is that children are unoccupied hence their development restricted. Referring back to the main conclusion: well-being of children with intellectual disability is achieved through their development of abilities. This suggests that the inclusion in the educational system would serve as a good ground for higher quality of life.

One conclusion drawn in this matter is that the educational system limits the capability set for persons with intellectual disability to realise the functioning *being educated*. This conclusion is based on the responses given by the informants that show a discrepancy between the aspiration of participation through development of abilities and the exclusion features of how the categories determine who is incorporated into the educational system. It seems as if the system is statically applied based on the intellectual disability categories instead of based on a persons' capacity level. This is shown in the case of Ricardo who will not have the possibility to study at secondary school level although he might have the capacity to perform at that

educational level. His capability set for realising the functioning *being educated* is in this matter limited by the social conversion factor *norms and inflexible praxis* in the educational system. However, in that he utilises the commodity *educational services* he does have access to the capability set of being educated at least up to a certain level.

That is not the case for Isabel, who is labelled as ineducable, and this affects her capability set for *being educated.* Due to the structure of the Cuban welfare system she is not enabled to be part of the educational system. As a consequence she does not have access to the commodity *educational service* necessary to successively realise the functioning *participation*. In this way, Isabel's well-being is conditioned to her intellectual disability category.

As mentioned above Isabel's capability set for achieving these functionings is widened by her participation in the horseback riding therapy, yet with regards to her development these sessions are provided to a lesser extent than educational services. This indicates that her exclusion from the educational system affects her possibilities to develop her social and cognitive abilities because without the commodity *educational services* these are not sufficiently stimulated. This in turn impacts her capability set regarding the range of both functionings *being autonomous* and *being participatory*.

Schools have the commitment to educate children and in Cuba there are special schools with specialised professionals who have expertise on the suitable pedagogical methods for children with intellectual disability. When I visited the two special schools for pupils with intellectual disability in Havana I was impressed by their pedagogical work and constructive atmosphere. Yet, a respondent said that the pedagogical quality needs to be improved in order to assure the well-being of the target group. In another city two of the workshop participants who are still enrolled in the special school attend the project classes because the probability for them learning how to read and write is higher there than it is in school.

Presumably, the director at the institution is accurate in her account that a patient such as Alvaro is in the environment most favourable for his cognitive development. Perhaps other factors connected to the environment at the institution stimulate his learning abilities to a higher extent at the psycho-pedagogical centre than at a special school. However, if services provided in organisations other than the educational sector are more successful in educating people, the access that people have to education becomes uneven. Hence the access to

education is not only unevenly distributed on the basis of the categories ineducable and severe and profound MR. It becomes a regional matter if actors other than the schools have the educational responsibility for persons with special needs, because unlike the educational system these locations does not branch out to every part of the country. Parents and habilitation specialists initiate these community projects locally, thus the existences of these educational activities are bound to the local engagement at the given time.

7.4 Influencing Policy

An interest group was discussed to be an actor that has impact over policy in order to assure opportunities for well-being among persons with intellectual disability. This was emphasised by informants at the household and service level, their shared perception was that the target group would benefit from having a group that advocates their specific interests. This conclusion is not far-fetched in the Cuban context, similar disability interest groups have an established position in the society and are constantly shaping policymaking.

It is this aspect of participation that Doyal, Gough (1991) and Nussbaum (1995) address in their theorisation of our human basic needs. People must be made part of the decision-making processes in order to satisfy their particular needs. Doyal and Gough ascribe this political participation as being reliant on the range of critical autonomy people have to reflect on their life situation and act for change when the situation calls for it. These are also the objectives for establishing an interest group to jointly identify shortcomings as experienced by the target group and find ways to change these. The advocate actors in the case of the interest group in Cuba were parents of persons with intellectual disability and not individuals with intellectual disability per se. This is an indirect form of political participation, although the purpose is the same with a different set of actors at the front line. Nussbaum emphasised a similar solution in 2009 by saying that guardianship can satisfy the basic human need of practical reason when a person is limited in exercising their right due to their intellectual disability. According to several informants, participation for the target group would be enhanced through the advocacy of an interest group.

In the case of Dariana, she needs to realise the functioning *being transported* in order for her to be present for work at the institution. This is something that the institution has arranged for her and other individuals living a significant distance from the institution. However when that means of transport is not available she has no other transport commodity to access in order to achieve the functioning *being transported*. Perhaps if the public transport was made more

available to Dariana in the same way that it was discussed to be for persons with sensory and physical-motor disabilities, she would have more options for *being transported* to her occupation. Based on the importance that the occupation was described as having for Dariana, her well-being would be increased if she were to have alternative ways to get to the institution. As claimed by an informant at the service level, these needs-based rights can be realised by an interest group for the intellectually disabled.

An interest group for the intellectually disabled could work for an increased accessibility in the public sphere based on the experiences that the target group has. An increased public accessibility could then result in persons with intellectual disability moving more freely in-between locations. Just as Ricardo now goes to and from the project office on his own, others with similar disabilities could succeed with the same if the public transportation were made more accessible for them based on their specific needs. Subsequently, a person's participation depends on their presence at the specific location where the occupational activity takes place.

7.5 Concluding Remarks

I did observe that the persons with intellectual disability in Havana, Cienfuegos, and Pinar del Rio can have a high quality of life, the people with intellectual disability that I met were engaged in a constructive and loving environment. In the locations I visited the level of expertise on disability matters was impressively high and service personnel seemed devoted to contribute to the well-being of their pupils/patients/participants. Yet, some individuals are excluded in different ways from participating in the services provided by the educational and habilitative system, and this was argued as a constraining factor for their welfare.

On a general basis I encountered that the informants' perception versus Doyal, Gough's (1991) and Nussbaum's (1995) theoretical standpoints shared an understanding of well-being to be achieved through increasing the target group's autonomy and participation. Drawing on Baylies (2002) and Burchardt's (2004) criticism towards the inadequate perspective on disability in Nussbaum's CA analysis, to focus on individuals' capacity as conditional for their quality of life can be seen as an expense wasted on groups that are not considered to possess such capacities (i.e. persons diagnosed with severe and profound MR), as in the case of educational and habilitative services in Cuba.

As discussed in the theoretical framework chapter, the assumption that the degree of participation is dependent on the autonomous abilities of a person is problematic, since it

builds on the pre-assumption that a person with limited cognitive abilities should conform to normal standards, leaving the stigmatising normative systems unchallenged. In this study these pre-assumptions are not satisfactorily confronted either. The target group was often described as able and competent and, compared to non-disabled people, described as having the same abilities as others. In order to participate in society a disabled person needs to develop his or her abilities to a certain standard so that they can be acknowledged by people as having an equal human value. The danger that Baylies (2002) and Burchardt (2004) detect lay in this way of ascribing human value based on abilities, because it builds on the same discriminatory view that disabled persons have less value because of their difference from the norm, leaving the persons with more profound disabilities outside the prosperous participatory attempt.

Baylies (2002) suggests that a more rightful approach would be to acknowledge that all people can develop their capabilities and their well-being should be taken into consideration based on their need to develop. On the one hand, in the case of educational and habilitative services in Havana, Cienfuegos and Pinar del Rio, respondents did emphasise this perspective on capacity based development. On the other hand, the way that the Cuban welfare system is structured upon the MR categories is claimed in this study to create a discrepancy in equal access to educational and habilitative services. As two of the programme coordinators argue the MR category ineducable limits the provision of services for individuals who are not considered to be capable of developing. Thus this group's well-being could be achieved to a greater extent if they have access to services that allow them room to develop.

In the case of the education and habilitation services in Cuba, lack of monetary resources was not viewed to be the main factor for the fulfilment of basic needs, welfare and poverty was rather connected to the functionings being occupied, being autonomous, and being participatory. Yeo's and Moore's (2003) figure of the relation between disability and poverty did correlate to the perception of the importance of having access to education, healthcare and political decision-making even if the poverty aspects that lead to exclusion were shown by applying the CA to be dependent on the fulfilment of other needs that were described to be achieved through ways other than an increase of economical assets (Yeo and Moore, 2003, p. 572). Occupation, participation and autonomy were perceived to be important per se for the welfare of persons with intellectual disability.

8. Final Comments

I came to understand that occupational possibilities for persons with intellectual disability are something that Cuban scholars are concurrently investigating. Considering this direction, it would be interesting to contribute with an ethnographic study within the work places where persons with intellectual disability work. In order to see how the workers and employers reason about the situation and what changes could be undertaken to expand the employment possibilities for individuals with intellectual disability, investigate what is successful in the current arrangement and how the participation on the job market could be expanded in Cuba.

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Interviews

Number 1: MINED staff - Policy level/Service level (N)	7 February	3 hours
Number 2: Defectologist - Service level (N)	12 February	30 minutes
Number 3: Programme Coordinators - Service level (N)	13 February	2 hours
Number 4: MINED staff - Policy level (N)	18 February	1 ½ hour
Number 5: Programme Coordinator - Service level (R)	23 February	1 ½ hour
Number 6: Organisation Head - Service level (N)	24 February	40 minutes
Number 7: Parent/Association member - Household level (R)	26 February	1 hour 20 minutes
Number 8: Rehabilitator+ Physical Educator - Service level (R)	27 February	1 hour
Number 9: Two Programme coordinators - Service level/ H level(R)	2 March	1 hour
Number 10: Two Parents - Household level (R)	2 March	1 hour
Number 11: Two Parents - Household level (R)	2 March	45 minutes
Number 12: Two Parents - Household level (R)	2 March	1 hour
Number 13: Two Parents - Household level (R)	3 March	40 minutes
Number 14: Family Member - Household level (R)	3 March	20 minutes
Number 15: Defectologist + Psychologist - Service level (R)	4 March	1 hour 20 minutes
Number 16: Programme Coordinator - Service level (N)	6 mar	1 hour
Number 17: Family - Household level (N)	8 mar	2 hours
Number 18: Principal - Service level (N)	9 mar	1 hour
Number 19: Assistant Principal - Service level (N)	9 mar	30 minutes
Number 20: Six Teachers - Service level (N)	9 mar	40 minutes
Number 21: Principal - Service level (N)	10 mar	3 hours
Number 22: Parents - Household level (N)	10 mar	40 minutes
Number 23: Programme Coordinator - Service /Household level (N)	11 mar	30 minutes
Number 24: Workshop Instructor - Service level (N)	12 mar	1 hour
Number 25: Workshop Instructor - Service level (N)	12 mar	40 minutes
Number 26: Vice Director - Service level (N)	12 mar	50 minutes
Number 27: Defectologist + Youth - Service level (N)	12 mar	50 minutes
Number 28: Carpenter workshop manager – Service level (N)	15 mar	25 minutes
Number 29: Instructor/Coordinator - Service level (R)	20 mar	1 hour 30 minutes

Number 30: Instructor/Coordinator - Service level (N)	22 mar	2 hours
Number 31: Defectologist + Leader of the centre - Service level(N)	25 mar	50 minutes
Number 32: Director - Policy level/Service level (R)	26 mar	45 minutes
Number 33: Psychologist - Service level (N)	26 mar	1 hour

N = Notes

R = Tape recorded

Observations

Institution Havana:

11 February 9.00 – 12.00

12 February 9.00 – 12.00

12 March 9.00 – 15.00

24 March 9.00 – 9.45

25 March 8.30 – 12.30

26 March 8.45 –13.30

Horseback riding centre:

24 February 9.00 –10.00

27 February 9.00 – 11.30

4 March 9.00 – 11.30

Project Pinar del Rio:

3 March 9.00 – 16.00

4 March 9.00 – 14.00

Special needs school 1 for intellectually disabled:

9 March 8.30 – 14.30

Special needs school 2 for intellectually disabled:

10 March 9.00 – 12.30

Family to adolescent with Down's syndrome:

8 March 11.30 – 13.30

Project Havana:

11 March 9.00 – 15.30

World Down's Syndrome Day in Cienfuegos:

21 March 9.00 – 12.30

Outside ETECA Office Havana:

26 March 15 min at 12 o'clock

Background Interviews

Sweden:

Staff member at FUB, 1 hour in December 2014

Habilitation director Uppsala, 50 minutes in December 2014

Habilitation director Örebro, 45 minutes in December 2014

Habilitation section director Uppsala, 1 hour in December 2014

Habilitation psychologist Uppsala, 1 hour in December 2014

School principal Stockholm, 1 hour in April 2015

Cuba:

Staff at Instituto Cubano de Amistad con los Pueblos, 2 hours in January 2015

Scholar in physical education, 1 hour in February 2015

Scholar in sociology, 1 hour in February 2015

Interview questions
Service level

How is the project evolving?
What is your role in the project? What are you working with at the moment?

Can you tell me about the main aims of the project?

According to you what are the attitudes regarding intellectual disability common people have here in Cuba?

Inclusion is a broad concept commonly used in relation to disability, what does inclusion mean to you? What do you think it means for young persons with intellectual disability? What is your perspective of the common discussion about inclusion of persons with intellectual disability?

According to you how can persons with intellectual disability participation in society be increased?

In what ways are this group included/participatory? And in what ways are they not? How will the project specifically work towards increasing the inclusion/participation of the focus group in society?

What are the criteria for participating in the project? How has the discussion about the criteria been regarding what should be the focus group?

Compared to others, are persons with intellectual disabilities opportunities to do things they would like to do limited?

If yes, in what ways?
What would be necessary to attain for easing those limitations?

Compared to others, are persons with intellectual disabilities opportunities to be safe limited?

Have you noticed that there is a specific focus on ensuring the safety of persons with intellectual disability? How is it a part of the everyday life of persons with intellectual disability?

What do you see as prosperous in the work with persons with intellectual disability?
Overall theme to approach if relevant: identity.

Cross- Country Comparison

The following tables show the ratings that Cuba, Italy, Bangladesh, Zimbabwe, South Africa, Denmark, and Chile have regarding economic and development indicators. I have selected the countries to compare and made these charts through the source the global economy ("The Global Economy," 2015). The reasoning behind the country selection was to include countries with some variation in the different in these indicators. The selection was based on income level: three high income countries: Chile, Denmark and Italy, two middle income counties: Cuba and South Africa, and two low income countries Bangladesh and Zimbabwe ("The World Bank," 2015). The indicators selected are gross domestic product (GDP), GDP per capita (current), GDP per capita purchasing power parity (PPP), public spending on education, public spending on health, human development index (HDI), literacy rate, and life expectancy.
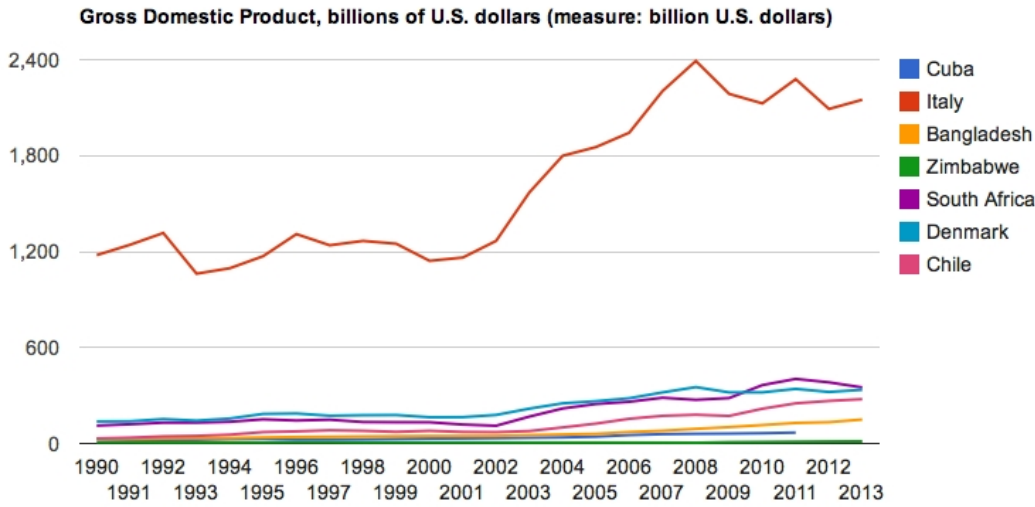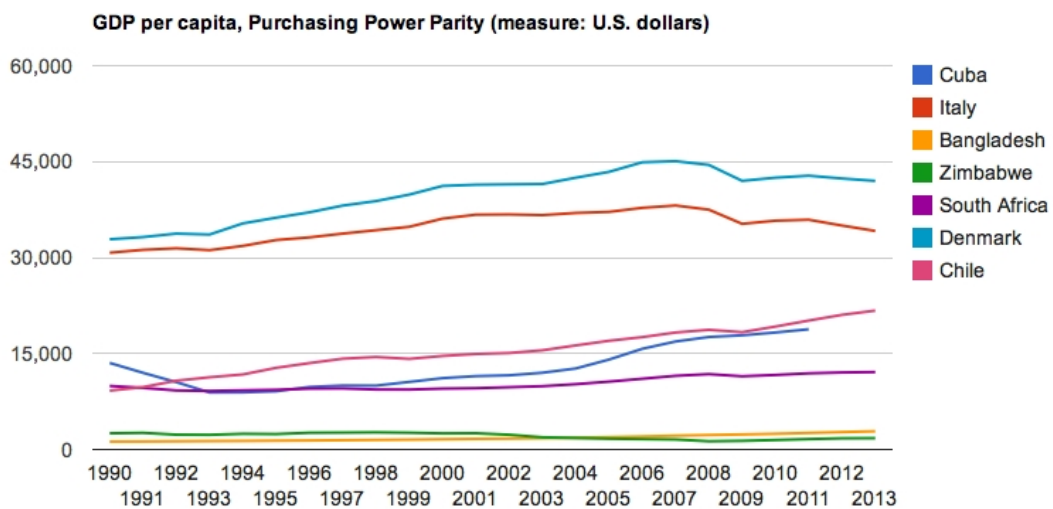

Figure 1. **Appendix 3 Cross- Country Comparison - Gross Domestic Product**

GDP per capita, current U.S. dollars (measure: U.S. dollars)
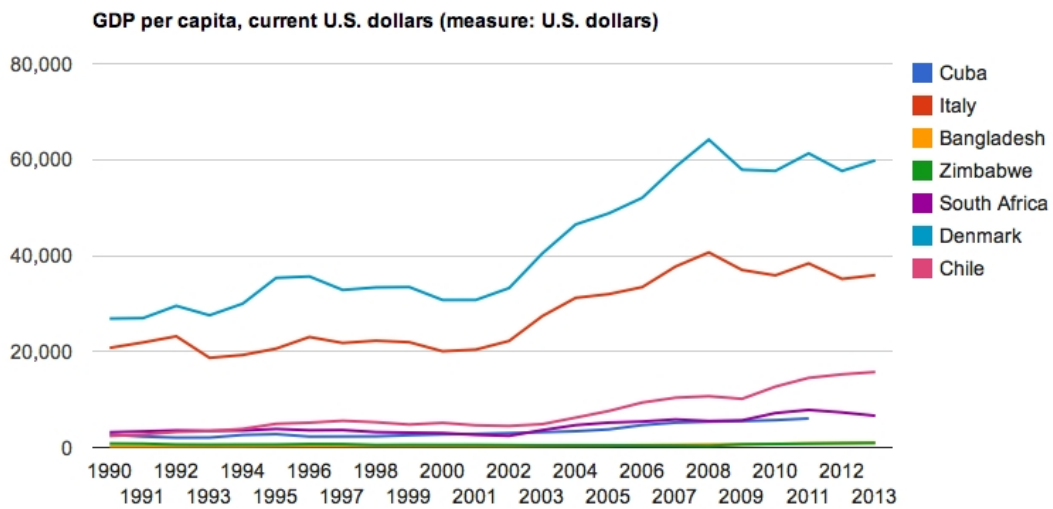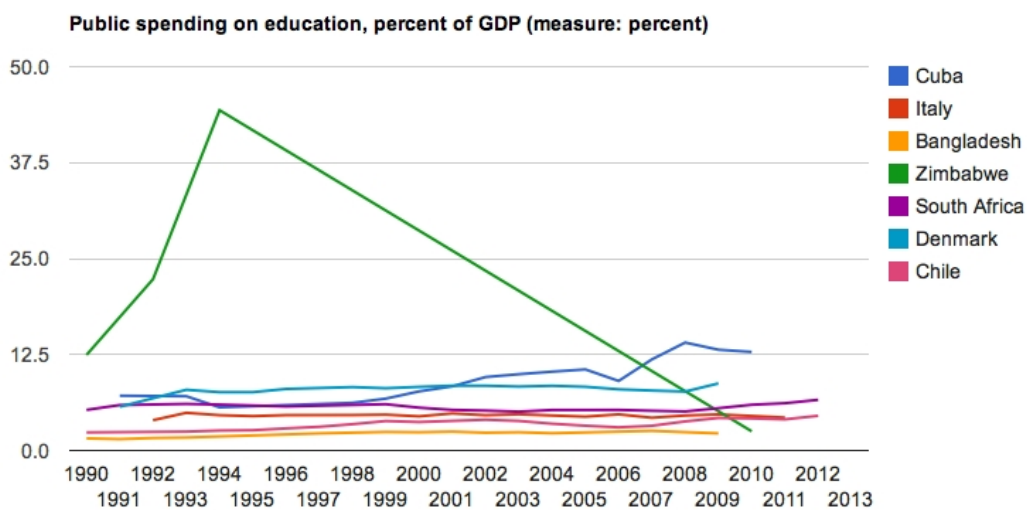
Source: TheGlobalEconomy.com, The World Bank

Figure 2. Appendix 3 Cross- Country Comparison - Gross Domestic Product per capita

GDP per capita, Purchasing Power Parity (measure: U.S. dollars)

Source: TheGlobalEconomy.com, The World Bank

Figure 3. Appendix 3 Cross- Country Comparison - Gross Domestic Product per capita Purchasing Power Parity

Public spending on education, percent of GDP (measure: percent)

Source: TheGlobalEconomy.com, UNESCO

Figure 4. Appendix 3 Cross- Country Comparison – Public Spending on Education


Health spending as percent of GDP (measure: percent)
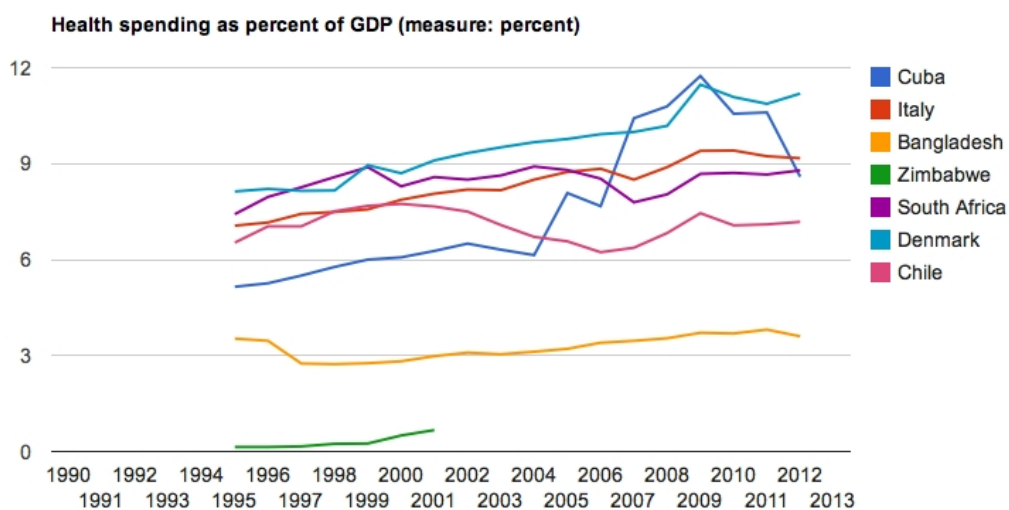
Source: TheGlobalEconomy.com, The World Bank

Figure 5. Appendix 3 Cross- Country Comparison – Public Spending on Health
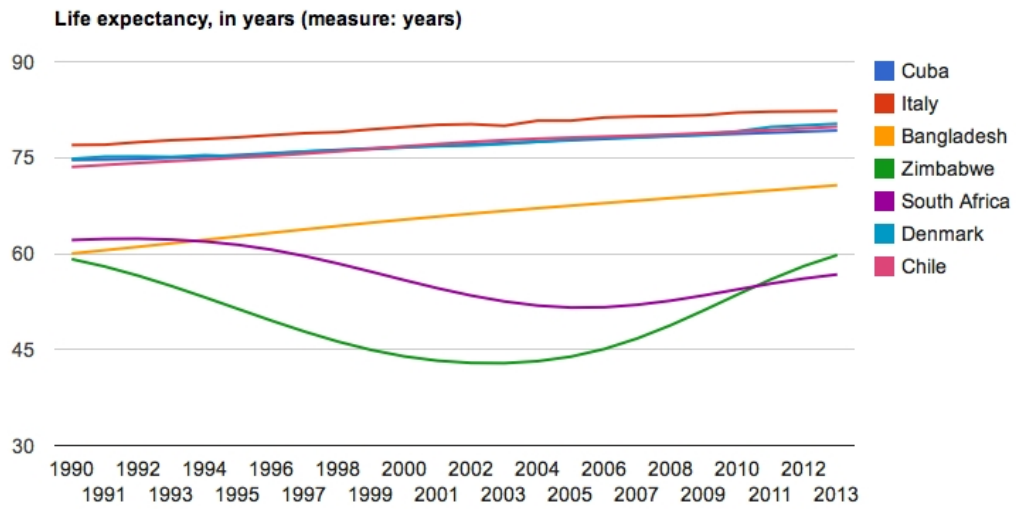
66

Human Development Index (0 - 1) (measure: points)
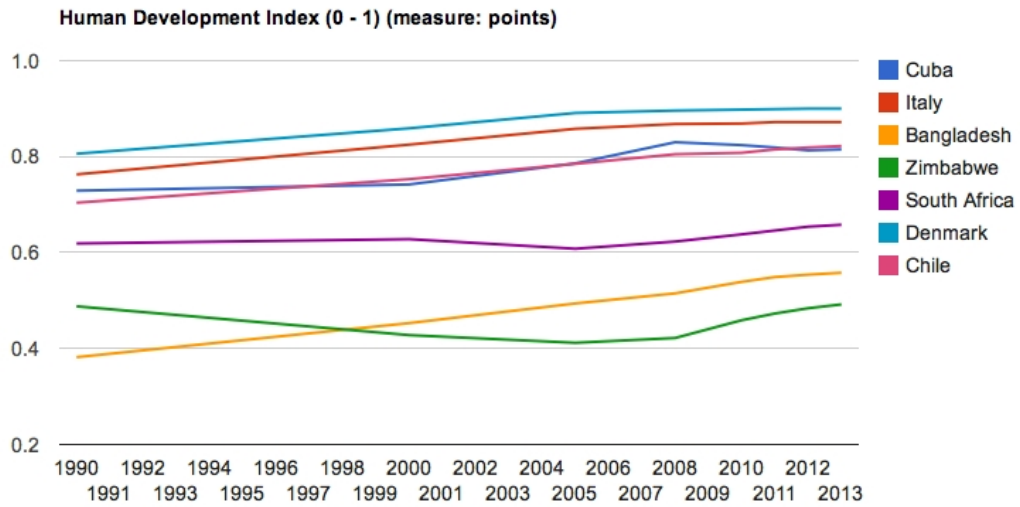
Source: TheGlobalEconomy.com, The United Nations

Figure 6. Appendix 3 Cross- Country Comparison – Human Development Index

Literacy rate (measure: percent)
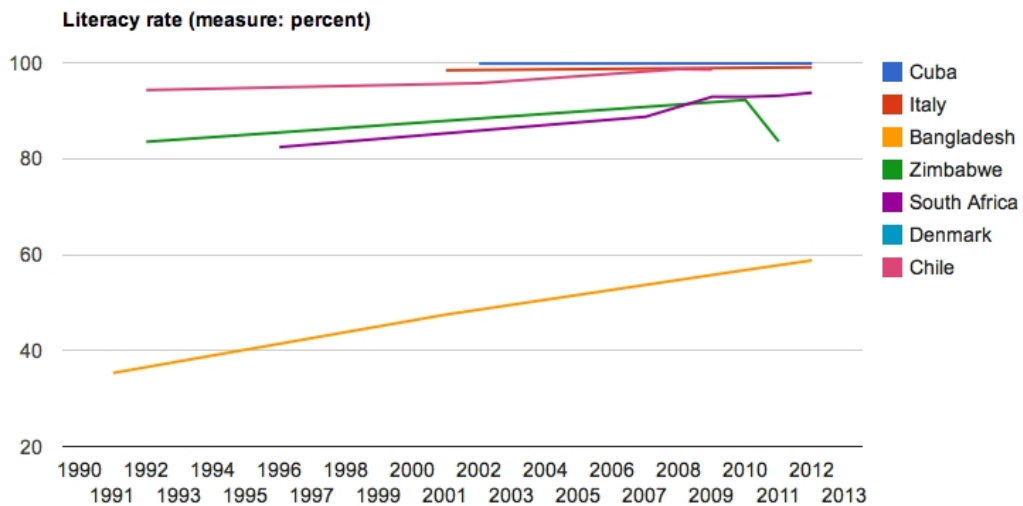
Source: TheGlobalEconomy.com, UNESCO

Figure 7. Appendix 3 Cross- Country Comparison – Literacy Rate

67

Life expectancy, in years (measure: years)

Source: TheGlobalEconomy.com, The World Bank

Figure 8. Appendix 3 Cross- Country Comparison – Life Expectancy