

Jorge Manuel Soares Rodrigues da Silva

## **COMMUNITY-BASED REHABILITATION**

### **A BURDEN OR AN OPPORTUNITY?**

**(THE CASE OF MONGOLIA INCLUSION OF CHILDREN WITH COGNITIVE DISABILITIES)**

Universidade Fernando Pessoa

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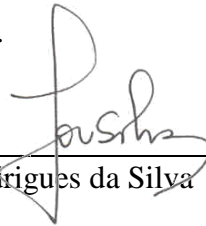
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I hereby declare that the written work I have submitted is an original work which I alone have authored and which is written in my own words.



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Jorge Manuel Soares Rodrigues da Silva

Trabalho apresentado à Universidade Fernando Pessoa como parte dos requisitos para obtenção do grau de Mestre em Acção Humanitária, Cooperação e Desenvolvimento.

## **Sumário:**

A tese de mestrado Community-Based Rehabilitation (CBR) - a burden or an opportunity? The case of Mongolia inclusion of children with cognitive disabilities, estuda a forma como a CBR se constituiu como um instrumento de afirmação da cidadania e coesão social. No plano teórico estabelece o quadro conceptual da CBR e da cidadania, no plano metodológico fundamenta as escolhas do estudo de caso, dando especial atenção ao caso da “grey literature”, validação e generalização dos resultados. Da análise do caso CBR Mongólia, foi possível encontrar evidência importante do impacto nas áreas: da governação, produção de legislação, “accountability”, influência das partes interessadas na implementação de programas de acção; na educação, além de promover a educação inclusiva, foram também identificadas influências na definição dos currículos universitários e na formação profissional dos técnicos de saúde e de educação; já no que respeita à formação da opinião, foram identificadas importantes acções junto dos jovens, nos media e na organização das partes interessadas sob a forma de organizações; foi também possível constatar a importância do CBR na coesão territorial, que se reveste de grande importância para um dos países com menor densidade populacional, em todas estas vertentes foi também possível verificar a importância das ONG’s como veículo de promoção do CBR e da cidadania de diversa forma, definição de políticas, planeamento e implementação de programas, suporte técnico, formação, etc.

**Palavras chave:** cidadania, educação, formação da opinião, governação, Mongólia, reabilitação baseada na comunidade.

**Abstract:**

The master thesis Community-Based Rehabilitation (CBR) - a burden or an opportunity? The case of Mongolia inclusion of children with cognitive disabilities, studies how CBR is constituted as an instrument for the affirmation of citizenship and social cohesion. At the theoretical level defines the conceptual framework of CBR and citizenship, in regards to the methodology it substantiates the choices underlying the case study, giving special attention to the case of "gray literature", validation and generalization of the findings. The analysis of the case CBR Mongolia, enabled to find significant evidence of the impact on the following areas: governance, production of legislation, accountability, the influence of stakeholders in the implementation of action programs; in education in addition to promote inclusive education, were also identified influences within the definition of university curricula and the vocational training of health workers and education; regarding to the formation of opinion, important actions were identified among young people, in the media and organization of stakeholders in the form of organizations; it was also possible to observe the importance of CBR on territorial cohesion, which is of great importance to a country with one of lowest population densities, in all these aspects it was also possible to confirm the importance of NGOs as a vehicle to promote CBR and citizenship on different ways, policy, planning and program implementation, technical support, training, etc.

**Keywords:** citizenship, education, formation of opinion, governance, Mongolia, community-based rehabilitation.

## **Хураангуй:**

Олон нийтийн оролцоонд түшиглэсэн сэргээн засал – дарамт уу эсвэл боломж уу? сэдэвт магистрын ажил нь Монгол улсын оюуны хөгжлийн бэрхшээлтэй хүүхдийн нийгэм дэх оролцоонд олон нийтэд түшиглэсэн сэргээн засалтын иргэний эрх болон нийгмийн харилцан шүтэлцээний уялдааг гаргаж ирэх гол арга хэрэгслийг хэрхэн бүрдүүлдэг талаар судалсан. Судалгааны арга зүйн хувьд авч үзэхэд олон нийтэд түшиглэсэн сэргээн засалт ба иргэний эрхийн үзэл баримтлалын хүрээ нь онолын түвшиндээ кейс судалгааны үр дүнг “албан бус судалгаа”-г ашиглан нотлоход чиглэгдсэн. Монгол улсын олон нийтэд түшиглэсэн сэргээн засалтын талаар судлах явцад дараах чухал үр дүнгүүд гарч ирлээ. Үүнд: засаглал, хууль тогтоомжийн боловсруулалт, хариуцлага, үйл ажиллагааны үндсэн хөтөлбөрүүдийг хэрэгжүүлэхэд хамтрагч байгууллагуудын нөлөөлөл, ялангуяа боловсролын хүрээнд авч үзэхэд боловсролд тэгш хамруулахыг дэмжих, их дээд сургуулийн сургалтын хөтөлбөр, эрүүл мэнд болон нийгмийн ажилтнуудын мэргэжлийн сургалтуудын хөтөлбөрүүдийн тодорхойлолт, түүнчлэн залуучуудын бодол, ойлголт чухал нөлөөтэй болох нь нотлогдсон. Мөн хэвлэл мэдээллийн байгууллага, хүн амын нягтшил багатай газар олон нийтэд түшиглэсэн сэргээн засалт илүү чухал болох нь ажиглагдаж байна. Үүнээс харахад төрийн бус байгууллагууд нь олон нийтэд түшиглэсэн сэргээн засалт болон тэдний эрхийг бодлого, төлөвлөлт, хөтөлбөр хэрэгжүүлэх, техникийн туслалцаа үзүүлэх, сургалт хийх гэх мэт олон замаар дэмжихэд гол хөдөлгөгч хүч болж чадах нь батлагдаж байна.

**Түлхүүр үг:** иргэний эрх, боловсрол, ойлголт, засаглал, Монгол улс, олон нийтэд түшиглэсэн сэргээн засалт.

***“Whatever your hand finds to do, do it with all your might (...)”*** Ecclesiastes 9:10 (NIV)

*And*

***“I will guide you along the best pathway for your life. I will advise you and watch over you.”***  
Psalms 32:9 (NIV)



## **Dedicatory**

To my wife Estela my life mate, for her kind and patient love, by supporting and encouraging whole the journey, wherever God lead us in the mission.

Ana e Margarida, my little daughters by patiently accepted father's absence in various moments.

Noemi, my niece; parents, sister and relatives for understanding our challenges, for the tenderness and affection always expressed despite the distance, the joy and pride for my achievements over the years.

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## ABBREVIATIONS AND ACRONYMS

ADRA.....	Adventist Development and Relief Agency
AIFO.....	Associazione Italiana Amici di Raoul Follereau
APDC .....	Association of Parents of Disabled Children
CBR .....	Community-Based Rehabilitation
CRPD.....	Convention on the Rights of Persons with Disabilities
CwCD.....	Children with Cognitive disabilities
DANIDA .....	Danish International Development Agency
DPO .....	disabled people’s organizations
EACH.....	Every child in Mongolia has access to education and health
GDP .....	Gross domestic product
IDDC .....	International Disability and Development Consortium
NGO .....	Non-governmental organization
PwD .....	Person with Disabilities
UN .....	United Nations
WHO.....	World Health Organization

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## **Chapter I - Introduction**

### **1.1. Subject of the work**

The subject of this work focuses on the possibility of establishing a nexus of causality between the Community Based Rehabilitation and Citizenship.

More specifically, seeks to understand if the process of full-fledged social integration of children with disabilities either constitute a necessary "burden" to society, or despite of common sense, is a factor of social cohesion, citizenship affirmation, and sustainable development opportunity.

The subject unfolds in two components:

a) The theoretical component referring to theoretical developments around the concepts of CBR and citizenship.

b) Use of a practical case focused on CBR children with disability in Mongolia which, starting from the conceptual base established in the previous paragraph, it will be questioned which of the initial perspectives will be worthy of credit (burden vs. cohesion factor).

### **1.2. The motivations**

It cannot be avoided to mentioning that the author has a family member in this condition; therefore comprehend this issue from this point of view can be a way to understand it better in order to assist.



On other hand, academically the author is motivated to better understand and reflect on the surround environment in order to contribute for a mainstreaming inclusive society for all, including those with special needs.

Besides it is intended to apply the learnings from the master in the analysis and action of a practical case, developing the skills in the field as a professional practitioner.

Finally the author aspires contribute to a new approach and that results of this monograph written in English may be a factor of changes for a society for all.

### **1.3. The objectives**

The main research question can be put as follows: Community Based Rehabilitation is it an ineluctable social burden or may it be a mainstay towards accomplishment of citizenship and associately contribute to a more inclusive and sustainable society?

Complementary questions are:

What is Community Based Rehabilitation?

What is citizenship?

As this is an investigation with a practical case, is it possible from the case of CBR in Mongolia argue the initial question? Namely how to identify the affirmation of citizenship in its multiple components from the impact of CBR programs in Mongolia?

These questions can be translated in the following hypothesis:

Main hypothesis: it is possible to prove that the CBR is a factor of social cohesion along with formation and affirmation of citizenship.

Complementary hypotheses if validated the first hypothesis:

a) This connection is expressed in different dimensions (economic, cultural, political, social life, etc).

b) This bond manifests in several ways: participation in community life, inclusiveness, territorial cohesion, education, health care, social welfare, media and public awareness, etc).

c) It is possible to establish a method to prove this connection.

d) It is feasible to confirm previous hypotheses based on the case of the CBR in Mongolia.

#### **1.4. Temporal and/ or spatial boundaries**

The spatial limits of research derived from the object of study of the practical case, which focused on the CBR programs in Mongolia.

Temporal boundaries coincide with the history of CBR in Mongolia, which started in early 1990s in the same year that Mongolia recognized and rectified the Convention on the Rights of the Child (5-7-1990) (UN, 1989) and extending in time up to today. In a more strict sense one can point out 1991 when Associazione Italiana Amici di Raoul Follereau (from now one AIFO) in collaboration with Ministry of Health of Mongolia

started its CBR activities under the name of "TEGSH DUUREN" (Meaning of Capable) (Batdulam, 2008). Indeed, being CBR an operational concepts of research and simultaneously a relatively recent process in time, but which has proved extremely versatile and dynamic, it seems indubitable that all practical and conceptual trajectory from 1991 shape a core part of this work.

### **1.5. Restrictions and limitations**

As far as it can be perceived, to the development of this work were not placed relevant restrictions, beyond the ones that can be expected in a research of this kind and purpose.

Nonetheless, one that can be highlighted is the absence of literature and studies of academic nature published on the subject, in particular relative to citizenship and CBR and CBR in Mongolia (documented in Research on CBR p.24), limitation largely superseded by using Official information and Grey Literature (as mentioned in Methodology p. 30).

Indeed, it must be mentioned that all the work of collecting information and interviews was not subject to obstacle or impediments, the contrary was duly encouraged and praised by organisms entities and responsible. If problems subsisted they were related to excess information.

A constraint felt had to do with the professional status of the author firstly it forced to do the work from Mongolia and the other was not been given the expectable time to conclude it. Although it could be argued that these are not a scientific arguments, the truth is that the limited time for completion left marks on work and not all of them negative some were positive, worthy to be mentioned are the analytical demand and the synthesis effort in argumentation.

In another plan, the work takes more two limitations, which inevitably would enrich it. The first is the absence of a comparison with CBR programs in other countries, due lack of time and limited resources associated with this monograph, that was simply not feasible under the present circumstances, accepting this limitation was a *sine qua non* and as such is assumed.

Another plausible limitation to be considered is the qualitative dimension of the research, is worth mentioning that at the initial phase, methodology was oriented to the use of written questionnaires, which would allow the a more quantitative proclivity, but in the short term this option was discarded because early it was found that in the current state of research in CBR (documented in Research on CBR p.24), more important than proving numbers and statistical evidence would be pave and reveal and argue new perspectives of analysis and viewpoints.

The fact that quantitative perspective was not adopted, does not exclude her as possible, however in certain specific methodological circumstances choices have to be made, that was the case of the quantitative approach it was abandoned under penalty of the effort consistency and internal logic wouldn't be sufficiently robust.

Who knows maybe in the future and under other circumstances an investigation on this perspective, may be carried out.

## **1.6. Work Achievements**

The main achievement this study evidence was that CBR beyond a multi-sectoral strategy, the work proved that CBR programs rather than a burden are definitely a model for and citizenship promotion and a sustainable society development opportunity.

Additionally the work supports strong argument in favor of CBR programs as successful inclusive approach with significant impact in the lives of children with disabilities, towards rehabilitation, full right integration and poverty reducing. But mainly the work was also able to produce evidence that there is unquestionably a relation between CBR and citizenship promotion expressed in different dimensions and manifests in several ways, concluding that people with disabilities are not a "social burden", but rather an opportunity to build a more just, inclusive and sustainable society with participation of all.

It is believed that this monograph written in English can be of some value to the actors on the ground, as an additional tool to promote CBR and advocate in behalf of children with disabilities towards break of preconceptions, participation in community life and endeavor that Governments ratify and effectively implement international regulations and legislative reforms on child's rights.

Finally the conclusions show that the role of international agencies remains essential in the consolidating process; empowering and capacity building local communities towards an inclusive society.

## **Chapter II - Community Based Rehabilitation and Citizenship Conceptual framework and Methodology**

This chapter will address scientific and methodological aspects related with the work's object, namely: CBR and citizenship.

It starts by examining the conceptual ballast of CBR, which embraces and substantiates the new approach to rehabilitation that accounts multiple dimensions, from the medical perspective to the societal. In general the conceptual body is essential in a scientific work, in the case of CBR it is even more important, as it is a meta-concept that urges for a clarification in order to fully understand the phenomenon. Then it will be discussed the concept of citizenship, its roots, historical evolution and the way the concept will be argued in case study.

Another concept to be discussed and dissected from the theoretical and operational perspective will be the citizenship, namely in its historical societal and cultural dimensions.

To conclude it will be addressed the research methodology in which concerns the case study adopted model, design and selection and data collection.

## **2.1. Disability vs Impairment - Evolution of the concepts**

CBR is a conceptual framework and a multi-sectoral strategy towards policy planning and intervention in health, education, vocational training, social and other services. Next the health facets will be addressed.

Disability is viewed "*as complex, dynamic, multidimensional, and contested*" (WHO, 2011, p. 3) as well an important development issue. "*Disability is an evolving concept*" (IDDC, 2009, p. 15). Nonetheless there are many different definitions of disability as

it's a "*relative term (restriction or lack of ability to perform a normal human activity)*" (Elwan, 1999).

Based on the International Classification of Impairments, disabilities, handicaps (WHO, 1980) the Disability Prevention and Rehabilitation Report (WHO, 1981) defines it as:

"Disability in the context of health experience is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1981).

Traditionally the concept was linked to religion and people with disabilities were considered punished by the divine for past transgression, or being possessed by evil spirits. The development of science and medicine brought a new understand in which disability has a biological or medical basis. In the decades 60-70 this point of view shifted to a more social perspective (barriers, discrimination, stigma, limited access to basic needs) that disabled people faces. The term gained a social dimension, and in our days is a societal problem rather than individual problem. The focus is promoting social changes and not just medical treatment/cure. Therefore it points to Inclusive Development which is essential to the promotion and protection of the Human Rights of Disabled persons (UN, 2004).

One of the changes that were brought by the shift from a medical standpoint to a more comprehensive approach implied a turn towards the social dimension of the problem, rather than an exclusively medical intervention, so the emphasis nowadays is on integrating disability into development processes (Thomas & Thomas, 2002).

Complementarily it is needed to mention impairment which occurs when a part of the human body is unable to work and perform fully and disability is seen as the consequence of impairment (Eunson, unidentified year).



“(...) the disadvantage and exclusion which arise as an outcome of the interactions between people who have impairments and the social and environmental barriers they face, due to the failure of society to take account of their rights and needs.” (VSO, 2006, p. 6).

Based on this definition, there's a distinction between impairment (limitations as a physical, intellectual, mental or sensory conditions) and disability. Impairment relates to the individuals and can be the result of illness, injury, or inherited. In contrast, disability relates to social. As a matter of fact, the segregation of people with impairments, due to community and environmental prejudice, acts as an obstacle to their complete and equal participation in society. Disability is essentially an issue of rights (VSO, 2006, p. 6).

International Classification of Functioning, Disability and Health (ICF), established by the World Health Organization in 2001, states that disability is an:

“(...) umbrella term for impairments, activity limitations or participation restrictions” (WHO, 2001), “ICF takes into account the social aspect of disability and does not see disability only as a 'medical' or 'biological' dysfunction” (WHO, 2001).

Disability is conceived as the outcome from the linkage between impairments and negative environmental impacts (contextual factors - environmental factors and personal factors). Convention on the Rights of Persons with Disabilities, describes:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Article 1).”

““Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation (Article 2).”

Recognizing that:

“(…) disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN, 2006).

Furthermore there is also a strong relation between poverty and disability, which is compulsory to refer in order to fully understand the phenomenon, as it seems to be indissolubly linked to the vicious circle where millions are trapped. *“Poverty is a cause and consequence of disability”* (UN, 2004). Addressing disability is a decisive step to reduce the risk of poverty and in the same way, addressing poverty reduces disability.

To short cut this dependency, in 2004, UN lunched “A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities”, which emphasizes human rights of person with disabilities and promotes the inclusiveness.

Poverty can't only be seen from the economic perspective, but also from the social perception. The risk of poverty is significantly increased due exclusion from mainstream participation in economic and social activities and from education opportunities (IDDC, 2009, p. 20).

The connection between poverty and disability is aggravated by discrimination, social exclusion and denial of rights simultaneously with lack of access to basic services, not by the impairment itself (IDDC, 2009, p. 20).

Consequently poverty eradication doubtless will be achieved with an inclusive integration of disability issues in deployment policies and by ensuring that people with

disabilities are involved in the all the steps (planning, design, implementation and evaluation) of deployment programs (IDDC, 2005, p. 5).

To corroborate that idea it can be mentioned that estimated disability rates tend to be higher in developed than in developing countries: possible contributory factors may include a greater capacity to diagnose and collection of statistical data. Disabled people have lower education and income levels than the rest of the population.

“Exclusion and marginalization reduce the opportunities for the disabled to contribute productively to the household and the community, and increase the risk of falling into poverty” (Elwan, 1999, p. v).

Additionally behaviors as well as physical barriers such as lack of adequate transportation, physical inaccessibility, can affect access to education and employment opportunities and social participation.

In the political settings there are also opportunities for improvement, as decentralization of political decisions and local governance results in improved citizen participation, better adjusted solutions, capacity building and greater opportunities for poverty reduction (OECD, 2004).

Nevertheless and despite the mention conceptions, it should be worth to mention, that in astonishing number of cases the prevalent paradigm to deal with disability is still addressed it according the two traditional models:

a) “*Medical model is sometimes known as the 'defect model'*” (UNICEF, 2007, p. 14)

Hence, the “social model” of disability, considers:

“(…) disability as the interaction between a person with impairment and the disabling social environment through discriminatory and isolating barriers to access and full participation in society.” (IDDC, 2005, p. 5).

Disability is not an individual's trait, but a multifaceted set of conditions, mainly contextual factors resulting from the social environment.

The medical model sees disability as an individual's problem, caused by illness, trauma, or other physical condition which requires continuous professional health care throughout individual treatments (Disabled World, 2010).

b) The "Charity Model" of disability which as a traditional perception, sees persons with disabilities either as objects of sympathy and charity or sick people in need for a cure and pity, as victims of circumstance.

## **2.2. Rehabilitation**

As consequence of the distinction disability vs impairment, in the eighties of the past century, some new approaches to that problematic were put in practice; one of paramount importance was, undoubtedly, the rehabilitation.

According the Article 26, Habilitation and Rehabilitation, of the United Nations Convention on the Rights of Persons with Disabilities calls for:

"(...) appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life " and stress that "support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas"(UN, 2006).

In fact, Rehabilitation is a key element to empower a person with a disability and his or her family and rehabilitation of people with disabilities is seen as:

## Community-Based Rehabilitation - a burden or an opportunity?

“(…) a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination” (WHO, 2013).

“Rehabilitation means a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life” (UN, 1982).

The term rehabilitation includes all procedures that endeavor to lessen the disabling circumstances’ impact, to achieve social integration, in other words, participation in the mainstream of community life (WHO, 1981).

In all rehabilitation efforts, the emphasis should be placed on strengthening the individual’s abilities, whose rights, integrity and dignity must be respected. Rehabilitation habitually includes (UN, 1982):

“Early detection, diagnosis and intervention;  
Medical care and treatment;  
Social, psychological and other types of counseling and assistance;  
Training in self-care activities, including mobility, communication and daily living skills, with special provisions as needed, e g., for the hearing impaired, the visually impaired and the mentally retarded;  
Provision of technical and mobility aids and other devices;  
Specialized education services;  
Vocational rehabilitation services (including vocational guidance), vocational training, placement in open or sheltered employment;  
Follow-up.”

*“Rehabilitation is cross-sectoral”* (WHO, 2011) and conducted by health professionals in combination with specialists in other fields, such as education, employment, social welfare, etc. In grass-root and poor contexts additionally to family, friends, self-help groups and community moreover it might involve other technicians in community-based rehabilitation (WHO, 2011).

Worldwide situation on rehabilitation seems to be very problematical, as it was shown in the 2005 global survey of the implementation United Nations “Standard Rules on the Equalization of Opportunities for Persons with Disabilities” found that: (UN, 2006)

- in 48 of 114 (42%) countries that responded to the survey, rehabilitation policies weren't adopted;
- in 57 (50%) countries legislation on rehabilitation for people with disabilities wasn't approved;
- in 46 (40%) countries rehabilitation programs weren't established.

Many countries have established good legislation and policies on rehabilitation, but there is an obvious lag on the implementation of these policies.

Other relevant terms in this regards are “prevention” (essential for reducing the incidence of impairment and disability) and “equalization of Opportunities” (full participation and equality), which leads to address the importance of inclusive development as one endeavor towards rehabilitation.

*“Inclusive Development is a consistent and comprehensive approach”* (Okune & Sally, 2007, p. 38), and it's a process that foment ensure equal rights, including participation of the disabled people in society to fight discrimination and exclusion (IDDC, 2009). Disabled people live in communities, and inclusive development starts at home and community. (IDDC, 2005, p. 15) For CBR the term ‘community’ means the smallest administrative area where people live. (WHO, 2003)

Inclusiveness breaks the cycle of Poverty and disability in Development, at individual, family, community and the global level, either boosting the well-being of population and complete the United Nations Millennium Development Goals (IDDC, unidentified year).

### **2.3. Community-based rehabilitation (CBR)**

Community-based rehabilitation (CBR) - is defined as practical cross-sectoral approach to assure community-based inclusive development, towards the implementation of the Convention on the Rights of Persons with Disabilities. It aim to create an inclusive environment for persons with disabilities, ensuring access to health care, education and social welfare, and enabling poverty reduction – all these actions defended by the Convention (WHO, 2010).

CBR means empowering and enabling people with disabilities fully expand their potential with suitable aids and equipment, education, training and support from the community (Elwan, 1999).

The CBR focal point enhances the quality of life for persons with disabilities and their families, assuring provision of basic needs and ensuring participation, rehabilitation, dignity, equity of opportunities and inclusive environment for all disabled people.

It means that CBR programs are implemented through joint task of people with disabilities, their families, communities, and collaboration of relevant government and non-government organizations on health, education, vocational, social and other areas based on community involvement/ownership and multi-sector cooperation (WHO, 2010).

In short CBR aims to promote the access to health, education, social and livelihood and poverty reduction by enabling people with disabilities and their families through promoting empowerment and inclusiveness (society for all). Community involvement is an essential element toward an inclusive development, especially for those who are

discriminated or marginalized from the mainstream of community-based life, particularly persons living in rural or distant areas or even in urban slums (WHO, 2010).

#### **2.4. Historic outlook of Community-based rehabilitation (CBR)**

Community-based rehabilitation (CBR) was initiated by the World Health Organization (WHO) following the Declaration of Alma-Ata in 1978 (WHO, 1978). The International Conference on Primary Health Care whom raised attention to the urgent need for worldwide effectiveness actions to deploy and develop primary health care particularly in developing countries intensification cooperation between governments, WHO and UNICEF, and other non-state actors.

According to the number 5, paragraph VII, of the mentioned declaration, primary health care:

“requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate” (WHO, 1978).

Thus reducing exclusion and social disparities in health is one of the key elements to the ultimate goal on primary health care which is better health for all (WHO, unidentified year)

In 1983 the World Program of Action Concerning Disabled Persons of United Nation, estimated that more 500 million people in the world were disabled as a consequence of mental, physical or sensory impairment, and because of this, children and adults in all parts of the world often are segregated and downgraded. At least 10 per cent of children are disabled (UN, 1982).



Almost 3 decades after, the percentage remains the same. In 2009, UN General Assembly estimated also that persons with disabilities are 10 per cent of the world's population, of whom 80 per cent live in developing countries, recognizing the importance of international cooperation and its promotion in support of national efforts, in particular for developing countries (UN, 2010).

With regards to disabled children there is also a sharp relation between disability vs discrimination. Obviously this is a relevant aspect for the study and therefore it's required to address briefly this relation, in order to identify the trend and better understand the relevance of the CBR approach.

Discrimination has historically been heavy burden for disabled people:

*Fear* - Parents and other caregivers are often very fearful for their disabled children. They are afraid that the child will have an accident or be abused by other people.

*Invisibility and ignorance* - Locked in the household or in special institutions, disabled people are often invisible outside their immediate family.

*Stigma, segregation, isolation* – In many societies disabled are segregated because of beliefs, traditional stories, age-old religious convictions and modern myths. They are excluded from any community activities and decision-making or other affairs in society” (VSO, 2006, pp. 14-15).

Taking in consideration this phenomenon from 1980s to present days, the concept of CBR evaluated to become a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services.

At the beginning CBR Early programmes were mainly focused on physiotherapy and primary health care, especially in low-income countries. Years later, in 1989, WHO published an important manual “Training in the community for people with disabilities”

(Helander et al., 1989) which provided guidance and support for CBR programmes, including people with disabilities, family members, school teachers, local supervisors and community rehabilitation committees.

In 2005, the World Health Assembly adopted the resolution 58.23, on disability prevention and rehabilitation, expressly urged Member States “to promote and strengthen community-based rehabilitation programmes” (WHO, 2005).

Recognizing the need of a multi-sectoral approach, as a result of a joint taskforce led by WHO, ILO, UNESCO, International Disability and Development Consortium (from now one IDDC), (as a core group) and the consultation of hundreds of other organizations, in 19<sup>th</sup> May 2010 the World Health Organization (WHO) released the CBR Guidelines (WHO, 2010), a complete document, strongly influenced by “The Convention on the Rights of Persons with Disabilities and its Optional Protocol” adopted on 13<sup>rd</sup> December 2006 (UN, 2006).

Thus CBR enhance a multi-sectoral strategy to support community-based inclusive development for people with disabilities and their families. The mentioned guidelines uphold CBR as a strategy which can contribute to implementation of the cited Convention on the Rights of Persons with Disabilities and disability inclusive national legislation.

The Convention covers also key areas, such as accessibility, personal mobility, education, health, rehabilitation and employment, and draw attention to the actions and measures which states must carry out to ensure the rights of persons with disabilities are accomplished. Nevertheless, it does not create any new rights for persons with disabilities – they have the same human rights as any other person within the community – but instead, makes the existing rights inclusive of, and accessible to, persons with disabilities (WHO, 2010, p. 22).

This 2010 document, brought more guidance after the UN agencies launched in 2004 “A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities - Joint Position Paper 2004” (WHO, 2004).

The Joint Position Paper recognized that people with disabilities should have access to all services which are available to people in the community, such as community health services, and child health, social welfare and education programmes. It also emphasizes human rights and calls for action against poverty, and for government support, and development of national policies. CBR was redefined as “a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities”.

## **2.5. Community-based rehabilitation Matrix – A Framework for deployment**

As it has been argued so far CBR, is a holistic approach to rehabilitation that encompasses a construction of a new paradigm which integrates the medical and social dimensions, and even more important it urges for action, strategically conceived.

In that sense the CBR Matrix (developed in 2004 by WHO) provides the framework and structure of this multi-sectoral strategy. The matrix consists of five key components – health, education, livelihood, social and empowerment. Within each component there are five elements.

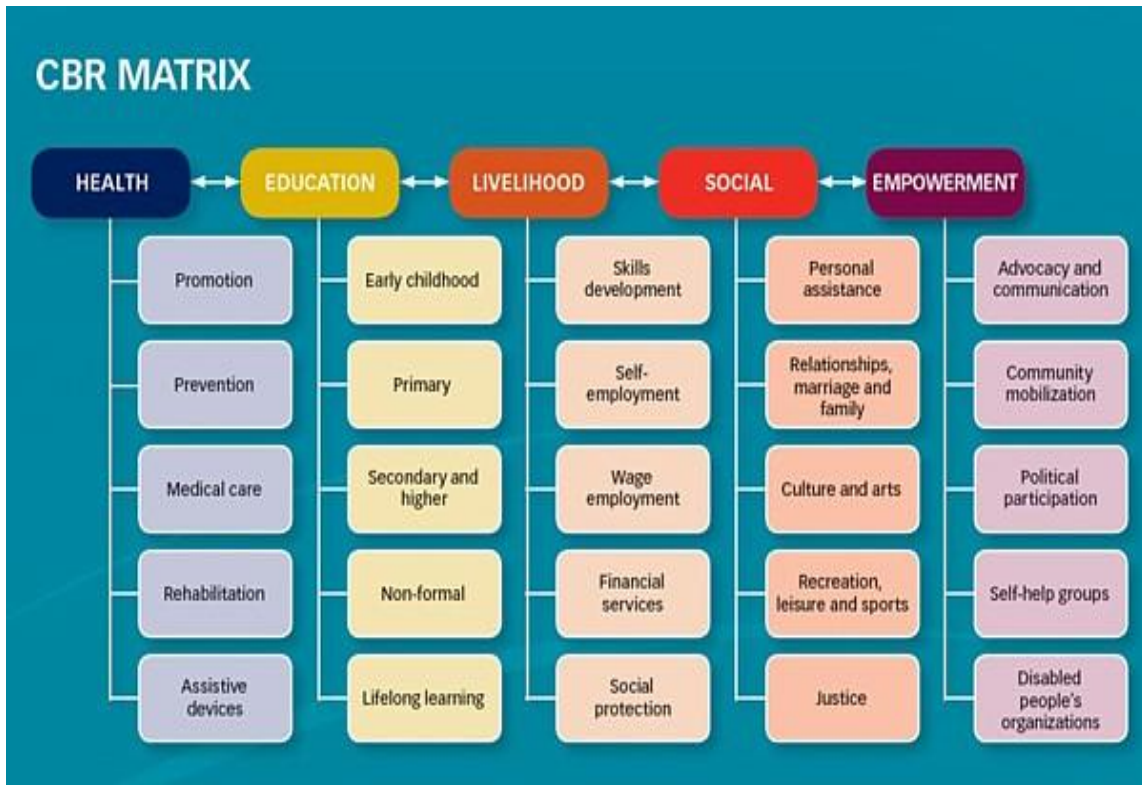


Figure 1 - Community-based rehabilitation (CBR) matrix (Source: WHO)

The first four components relate to key development sectors (multi-sectoral) The final component relates to the empowerment of people with disabilities, their families and communities, to ensure access (mainstreaming/integration) to each development sector, welfare and fulfillment of human rights for people with disabilities.

One important aspect is that CBR programs should not be seen neither as sequential neither it is expected they implement every component and element of the CBR matrix. Instead the matrix has been designed to be “pick and mix”, allowing programs to select options which best meet their local needs, priorities and resources. In other words, programs may decide to address merely some of the components (WHO, 2004).

CBR programs can be implemented local, regional or nationally and the support for people with disabilities and their families should be given within their own communities, including remote and countryside areas. CBR programs are different than

other rehabilitation approaches, and they focused on achieving very specific outcomes in one or more components of the CBR matrix (WHO, 2010).

Some essential keys for sustainability of CBR programmes are: partnerships, community ownership, building capacity, advocacy, mainstreaming. It is important that all key stakeholders are identified and involved from the beginning to ensure their participation and establish a sense of community ownership (WHO, 2010).

The most common stakeholder are: people with disabilities, caregivers and their family members, members of the community (including community leaders, teachers, doctors, etc.), civil society (e.g. nongovernmental organizations, religious organizations and women's groups), disabled peoples Organizations, Government authorities and CBR managers and personnel. Each stakeholder will have specific roles and responsibilities concerning the development and implementation of CBR and participation must be assured (WHO, 2010).

The matrix foresees that a SWOT analysis is one of the tools that can be used to analyze the strengths and weaknesses, the external opportunities and threats.

It also predicts that management cycle includes 4 important steps: Situation analysis, planning and design, implementation and monitoring, evaluation.

The logical framework is a planning tool used to prepare a diagram for the CBR program, which defines the goal, purpose, outcomes and activities, indicators and means of verification. The indicators must be SMART (Specific, Measurable, Attainable, Relevant, Timely) (WHO, 2010).

CBR addresses awareness-raising activities among stakeholders providing information and knowledge about disability which includes society attitudinal, conduct and behavioral changes. Therefore participation in cultural, recreation, political and public

life is essential to generate respect, fighting stereotypes, to promote the dignity, capability and contributions of persons with disabilities (WHO, 2010).

Monitoring is an ongoing process, and evaluation or assessment must identify the relevance, efficiency, effectiveness, impact and sustainability of the CBR programs. Lessons learned assessments may upgrade and refine current projects in such way it can boost better planning through accurate choice of alternatives for future action (WHO, 2010).

## **2.6. Research on Community-based rehabilitation (CBR)**

CBR placed challenges for researchers mostly in regards to efficiency and effectiveness. Evidences accumulated over the years as result of several research studies associated to low-income countries and also diverse experiences and evaluations, identified the effectiveness of CBR programs as effective and some even highly effective (WHO, 2010, p. 33).

Even so, in the last years, a couple number of voices have expressed repeated concerns, about the adequacy of the collected data and substantiation on the topic of the efficacy and efficiency of CBR program (Finkenflugel, Wolffers, & Huijsman, 2005; Kuipers, Wirz, & Hartley, 2008; Mannan & Turnbull, 2007; Mitchell, 1999; Sharma, 2007; Wirz & Thomas, 2002) *cited in* (Robertson et al., 2009).

In 2002, a review published by Wirz & Thomas suggests that evaluations have a tendency to explain practice rather than the effectiveness of the programs. They argued that the use of diverse evaluation methods and the lack of indicators that can be used in order that CBR programmes can be shown to have demonstrable results, in such way that policy makers can justify the use of such programmes (Wirz & Thomas, 2002). The same argument was also mentioned by Kuipers & Hartley (2008) which states that Governments need evidence on based practices, in order to contribute to better planning,

improved policy and decision making. (Wirz & Thomas, 2002) *cit. in.* (Robertson et al., 2009).

In the same direction Finkenflugel, Wolfers & Huijsman (2005), noted that after 25 years of CBR and despite the increase literature produced on CBR, no systematic review is available, and “*therefore its effectiveness cannot be sufficiently established*” *cit. in.* (Robertson et al., 2009).

Another criticism (Mannan & Turnbull, 2007), argues that is expected that future CBR evaluations outlooks available empirical and practical evidence on whether or not it improves welfare and propose a tool for future assessments that measures family quality of life as an outcome. (Mannan & Turnbull, 2007) *cited in* (Robertson et al., 2009).

One issue considered important for debate among planners today, is whether CBR should be initiated in a community by an external agency, or whether one should wait for the local communities to start CBR on their own? The argument is that CBR is a deployment program and therefore needs to be initiated by the communities. When started externally, is expected that the beneficiaries will hang on passively, expecting charity, without citizenship contribute (Thomas & Thomas, 2002, p. 16).

Community-based interventions often involve different stakeholders including community caregivers who voluntarily offer time and labors, to assist persons with disabilities and their families. Difficulties in finding new community volunteers motivate them and how to measure this ‘cost effective’ comparing with a financial budget seems an utmost research topic (Thomas & Thomas, 2002, p. 20).

Most CBR programs have inadequately personnel, to deal with people with severe disabilities, consequently sometimes severely disabled persons get ignored or uncared for. However many controversies and questions remain. Resources must be allocated to follow a line of investigation in this ground and find answers to these relevant questions (Thomas & Thomas, 2002, p. 21).

Howsoever, many disabled children still remain invisible. Corroborating this, the National Statistical Office of Mongolia, in the 2010 Census Report, relevantly mentioned the necessity of further research about disabled people, which is the intention with the current study:

“(…) it is crucial to evaluate the contributions of disabled persons into the development of the country, study their special needs in relation to social and economic factors and create a reliable and accurate data source which can be used for the purposes of improving the living conditions and livelihoods of disabled persons in Mongolia.”  
(National Statistical Office of Mongolia, 2011, p. 118)

To sum up, critics suggest the need for further deeper studies on the efficiency and effectiveness of CBR in several domains, namely the social and political impact its strategies.

## **2.7. Citizenship**

To conclude the approach to the conceptual background used in the present monograph the concept of citizenship is going to be addressed.

Beforehand, it would be worthily to bound the way the concept will be considered within the study object, as the literature evidences, citizenship is a very complex elusive concept, for it was studied in multiple social, historic and even economic sets. In fact, the debate may include such different instances as: immigration, gender condition, conscience objections in regards to military obligations, globalization, and the power of multinational companies, nationalism, the raze of regional powers, such as the brand new situation of Ukraine, as well as the ethical or social concerns, digital citizenship, just to name a few.



In which regards the concept as it will be used, it remits to political science perspective, that is: the role of each individual or group in regards to the others in order to deploy a more equitable, sustained and inclusive society.

Citizenship was, until recent times, a distinctive phenomenon of occidental societies and their greek-roman matrix. As a matter of the fact, despite its multiple nuances, the essence of citizenship can, in rigor, be distilled and evolve around the greek or the roman paradigms (Heater, 2004).

It all starts in ancient Greece, the cradle of democracy, the citizenship was related to the government of the *polis* (city) and the up bring of democracy. In fact being a citizen encompass to be part in the whole dimensions of the civic life, namely political, administrative, justice and military (Cavalgante, 2007).

It should be mentioned that Greeks put a lot of effort in the education to democracy, both in skills to exercise it (forensic skills, judgment and rhetoric) and in the indoctrination of youth to the obedience to the laws, submission to the government and state defense (Osborne, 2010).

In the greek sense, citizenship is an obligation of each individual to intervene in society related concerns, the direction of these relations is undoubtedly from the individuals towards the society. In that sense they started a long lasting tradition of being a diligent citizen as a way to gather honor and the respect of the fellow as Aristotle expressed: “To take no part in the running of the community's affairs is to be either a beast or a god!” (Osborne, 2010).

Contrarily to Greece a city based state, Roman Empire was vast geographical territory, it should not be a surprise that administration and law, as it is known nowadays has its roots there.

Even though, the citizenship evolves in many different ambiances, during the seven centuries that Roman civilization lasts, probably Cicero's locution "*civis romanus sum*" (I am a Roman citizen) points to its essence, which is a guarantee based view, as it is based in the rights guarantees of the Roman citizen (in fact some of them) in contrast to the non-Romans citizens, it concerns political rights vote and be elected, administrative rights like be a Roman legionary and to ask for justice in court, civil rights such as not to be tortured and marry a Roman citizen, as well as economic rights such as taxes exemptions and the entitlement to trade, among others (Heater, 2004).

To conclude, in the Roman Empire citizenships were bounded in one hand by the imperial circumstances, that can be traced in the civil, judicial and administrative guarantees, and on the other hand by political concerns in the equality before the law, as counterweight against the well known the imperial driftage towards despotism (Heater, 2004).

Another important contribution to citizenship comes from the "Contractualism Theory", which has been one of the most dominant influential theories on moral and politics lead by philosophers like Hobbes, Lock, Rousseau.

Contractualism states that there is a social contract between citizens and the state, by which citizens renounce their natural rights in order to gain protection from the state, it is a cornerstone in this the tradeoff between rights and duties and concomitantly right to rebelling against the state government, whenever the premises of the contract were infringed (Darwall, 2003).

Contractualism give foundations to welfare state, as individuals gave away egoist interests in favor to the government that in turn should pursuit common good, public interest, economic and social well-being of its citizens.

In one hand contractualism ennoble the citizenship, as each one gave a way is self-interests in the benefit of the whole society, on the other hand, as it points out to the representative democracy it alienates ones proactive responsibility towards the society.

In more recent times, the modern citizenship conceptions are due to a British sociologist Thomas Marshall. Whom after the World War II, put the citizenship as a topic in the philosophy and social sciences research agenda, for him citizenship rests in three dimensions; protection by state, participation in democratic life and control of market (Magnette, 2001).

That problem enunciation became prevalent until the end of the century, and within that framework, around eighties and nineties that discussion exacerbates economics and market importance for citizenship around a dichotomy: Liberal-individualist conception versus Civic Republican conception (Magnette, 2001).

In broad terms the liberal conception advocates the supremacy of the individual, in which citizenship is basically limited to tributary and civic obligations of individuals, it assumes individuals as passive politically. On the contrary, in the Civic Republican conception, each one must be politically active with a proactive attitude towards public sphere, reinforcing the idea of a “good citizen” (Magnette, 2001).

These two points of view compared to the previous, besides blistering the emphasis in the economical dimension citizenship, did not contribute with brand new ideas or concepts to the discussion.

Although the documental research done does not reveal effective in finding information susceptible to be scientifically validated, the 21 century seems to be a very promising field of study for citizenship studies.

In fact, citizenship concept in the past decade has been questioned many different ways upon different assumptions, for instance geographical basis of the global citizenship, the decentralization of the question from national boundaries, the digital revolution and challenges to citizenship in such different grounds as; privacy, communication, public opinion, social networks engagement, environmental citizenship, the problem of refugees/immigrants, corporate social responsibility, the role of non-governmental agencies, the social impact of post-cold war conflicts just to name a few of the most visible debates in the area.

To conclude one may evoke Lisa Kauppinen *“A society which is good for disabled people is a better society for all.”* *cit. in* (Commonwealth Secretariat, 2012). In fact this concept is extremely pertinent in this work because the monograph will seek to demonstrate the relation that the CBR is promoting citizenship (society for all). The next topics will introduce the methodology.

## **2.8. Case study methodology**

The choice of appropriated research methodology is crucial towards research success, thus the chosen methodological options should be adequately justified.

In the present case it was opted for a case study, Pamela Baxter and Susan Jack define four criteria (that not have to be met fully), to justify the option for a case study:

“(a) the focus of the study is to answer “how” and “why” questions; (b) you cannot manipulate the behavior of those involved in the study; (c) you want to cover contextual conditions because you believe they are relevant to the phenomenon under study; or (d) the boundaries are not clear between the phenomenon and context.” (Baxter & Jack, 2008, p. 545)

Admittedly all these criteria seem to apply to the study how and why the CBR can contribute to the strengthening of citizenship, using as arguments the context of Mongolia.

The literature documents many styles for the preparation of case studies, the methodological basis used in this work was prescribed by Robert Yin in "Case study research: Design and methods" (Yin, 2009).

There are diverse types of case studies, it is therefore necessary to identify the type. It is a descriptive "*describe an intervention or phenomenon and the real-life context in which it occurred*" (Baxter & Jack, 2008, p. 548), with a holistic single case in the analyzes the focus "examines the global nature of the phenomenon" (Meyer, 2001, p. 334).

The time span of object research it is also an important feature of the case study, as it was early argued (in the Introduction) it will be comprehended between 1991 and the present.

## **2.9. Case study design**

In Yin (2009) case study methodology, the design of research is a central piece in the investigation, both as a practical path for guiding the whole work and as general methodological framework in order to understand the object as a holist entity.

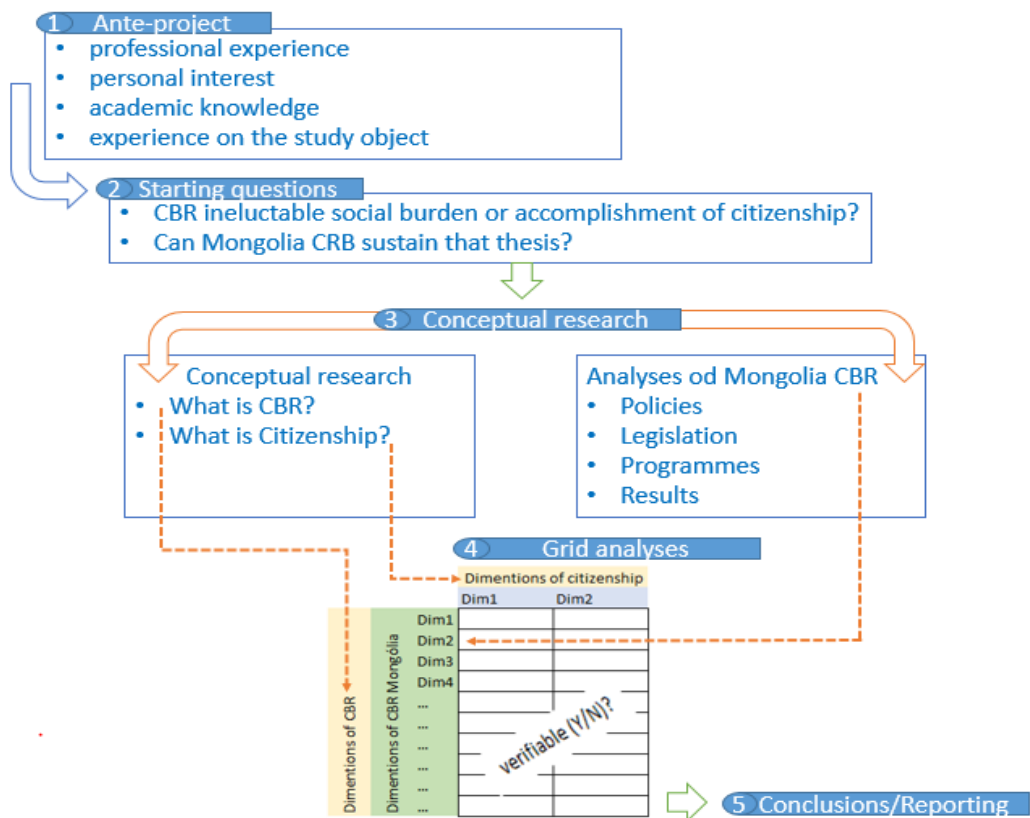


Figure 2 - General methodological framework

**Remarks in case study design:**

1 – Ante project phase, lists the factors that lead to the study object choose and correlative starting questions.

2– Starting questions, are the questions that frame the object of the research, in terms of knowledge, thesis and geographical incidence, hopefully they will be both the lighthouse and the beacons of the research. As lighthouse they shall guide in the appropriate direction whenever research may fall off tracks, as beacons they shall be helpful to set research in boundary whenever research may led into drifting.

3– Conceptual research, once delimited the object on the basis of starting questions, it will be done a research in order to track the scientific and practical knowledge concerning the object of research, in order to stipulate the strict use of concept and the relation among them.

More precisely to understand the foregrounds, dimensions and relations of CBR and Citizenship in one hand and on the other, to establish in which dimensions that dynamic can be analysed in Mongolia CBR (such as education, law, territorial cohesion, etc.).

- 4 – As result of the research, it shall be defined the operational grounds where it is going to be assessed if the conceptual relations foreseen in previous phase are (or not) verifiable.
- 5 – Conclusions and reporting are the last phase of the study case.

## 2.10. Selection and data collection

Another matter in which the case study methodology adopted puts strong emphasis is the selection and data collection. In the present work that importance is even greater as the evidence used to prove the thesis is fundamentally documental, the following table summarizes the process used in each stage.

	Dimensions of CBR	Citizenship	CBR Mongolia
Scientific works	*	*	
Official documents	*		*
Legislation	*		*
Grey literature	*		*
Open interviews	*		*

Figure 3 - Selection of data according to the work landmarks

### Remarks in Selection of data - Collection procedures

Official documentation is the case regards mainly information from United Nations sources, as the whole concept of CBR was conceived, supported and deploy by United Nations, it encompasses a variety of documents such as: resolutions, guidelines, conceptual papers, etc.

Grey literature: CBR is not one of most glossed research topics as it was mentioned earlier, in regards to CBR Mongolia the scarcity can be overwhelming, that is the reason why grey literature will assume a great deal of importance within the work.

Semi-structured open interviews, are interviews where the script is defined but the interviewer has freedom to put questions generated spontaneously or to drift into other topics based on the responses of the participant (Mitchell & Jolley, 2012).

Mainly these interviews will be used to gather information, discuss points of view and validate findings, even though there will not be *stricto sensu* script the subject of each interview will be bounded by the research objectives, the openness derived by the fact that during interviews some new topics or point of views may come into light and needed to be enlighten further.

Associated with the issue of data Selection - Collection procedures, there is also the importance of sampling and representativeness in collecting information (Yin, 2009).

It must be mentioned that in this case it should ensure that documental data, are representative of the research subject.

On one hand, since the core of the documentation used is official and legal, the universe is easily identifiable; on the other hand there is the problem of gray literature that in certain academic circles is viewed with suspicion (Cooper et al., 2009). The definition of gray literature has been responsibility of the Grey Literature Network Service (GLNS), an internationally recognized authority, and the definition has gone through many versions, which the latest and complete is the one from 2010:

“Grey literature stands for manifold document types produced on all levels of government, academics, business and industry in print and electronic formats that are protected by intellectual property rights, of sufficient quality to be collected and preserved by library holdings or institutional repositories, but not controlled by commercial publishers i.e., where publishing is not the primary activity of the producing body.” (GLNS, 2010)

The quote was made because the whole gray documentation will be strictly subject to that appraisal, yet this argument by itself does not eliminate the controversy to its use. Despite the documentation used comes from reputable organizations such as the United Nations, the World Health Organization, UNICEF, UNESCO, World Bank, IDDC, VSO, Save the Children UK, among others, is unavoidable the risk of this information



may be biased, in some extent, as it should be conform to these organizations guidelines and editorial policies.

Nevertheless that fact is not decisive for the accuracy of the findings, since documentation is triangulated (Yin, 2009). Furthermore in support to the taken option, some authors argue that in certain types of study and research in areas such as health, the gray literature is critical and essential (Bell, 2009) (Roberts & Priest, 2010) in generic terms *avant la lettre* Pouet in 1920 wrote the following words which are still full of perennity.

“No librarian who takes his job seriously can today deny that careful attention has also to be paid to the 'little literature' and the numerous publications not available in normal bookshops, if one hopes to avoid seriously damaging science by neglecting these.” (Pouet, *apud* Cooper et al., 2009, p. 104).

Another related aspect of collecting data is related to their representativity, there are areas where the problem does not arise, for example legislation in Mongolia, from interviews with subject-matter experts it's possible to collect it exhaustively.

There are however cases where that question is relevant, for example in the case of gray literature, what are then the guarantees that the relevant documents were reviewed? How to ensure that the most important topics were treated? In the first case the open interviews with experts in the field will allow the identification and access to documentary material with a high level of scrutiny.

Regarding the second question will be used the technique of documentary sciences "marginal utility of a document"<sup>1</sup> (Orton, 1995) this means that it will be collected a set of documents that according to the precept used, shall ensure that the most important and relevant topics were identified.

### **2.11. Validity and generalization**

To conclude was left the reference to the validity of the conclusions, which basically depends on the possibility to draw some conclusions based on the evidence.

The work proposes to demonstrate the thesis: CBR while process of full right integration of children with impairments is a factor of social cohesion, affirmation of citizenship and a sustainable development opportunity. Its acceptance depends on the ability to present and craft evidence beyond any reasonable doubt to sustain that argument.

It appears that the evidence to be collected will support the argumentation line, both in quantity and diversity, and the assumption of triangulation (Yin, 2009), seems to be able to materialize, once affirmations shall be supported by different sources of different natures (legislation, official documents, program evaluation, etc.) and any person working with them, it is believed, can reach the same conclusions.

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<sup>1</sup> Consists assessing the quantity and quality of information obtained from reading one more document, the idea behind this technique is as follows, in the first document read about a subject, all ideas are new and quantity data per document is very high, as one progresses in reading more documents the number of new ideas decreases until it reaches a point, where the reading of one more document does not bring new information, statistically it can be said that full information has been reached, and it is unlikely that the continuation of the research brings some added value (Orton, 1995).

The dimension that needs to be clarified is “beyond any reasonable doubt”, for it must be kept in mind that the thesis aims to address gaps in evaluation of CBR, previously identified (Research on CBR), i.e. an assessment that goes beyond the strictly practical and moves headed for new research directions.

The chosen line of research is nonparametric, i.e. is not intended to make assertions in statistical grounds. Being a holistic study, the validity of the results will depend on the inductive construction of arguments and ability to prove that the CBR has real impact in terms of citizenship in different society dimensions and in society as a whole.

Herein lies the essence of the question: which is the dividing line of having or not real impact (effectiveness). It must be acknowledged that involves some subjectivity and to the image of the *"patres familias"* judgment it is axiomatically believed that the conclusions, due the implications in the different dimensions of social life (education, health, law, etc) and also the practices and results evoked, should led a scientifically enlightened reader, to recognize merit to the argument presented.

Generalization is another requirement of the scientific work. The presented work cannot aspire to generalizations for all CBR cases, since each country represents a reality, however, it appears that the method used, with appropriate adjustments, will allow to address additional CBR cases from the perspective of citizenship and, with different arguments, conclude that the CBR is a factor of social cohesion and affirmation of citizenship, i.e. people with disabilities are not a "social burden", but rather an opportunity to build a more just, inclusive and sustainable society with participation of all.

Once taken in due account the methodological grounds of the thesis in the next chapter it will be discussed the CBR Mongolia case against that framework.

**Chapter III - The case of Mongolia inclusion of  
children with cognitive disabilities  
- a burden or an opportunity?**

The previous chapter introduced the CBR as a multi-sectoral strategy towards inclusive development, rehabilitation and poverty reducing, and the methodological basis of the case study.

This chapter intends to demonstrate that Community-Based Rehabilitation beyond promoting rights of Children with Disabilities, at the same time brings a new dimension constituting an opportunity towards sustained integration, cohesion and formation of citizenship.

Therefore, the next pages will briefly characterize Mongolia as country, introduce the case study of Mongolia based on CBR projects, and examining the best practices and lessons learned on local implementations of the program with disabled children.

### **3.1. Mongolia the Country of the Gers**

In order to better understand the social and political environment of the case study, following it will be done a brief characterization of the country.

#### **3.1.1. Environment, geography, culture and religion**

Situated in the North of Asia this landlocked country share borders with Russia (North) and China (Southern), has 1.564.116 km<sup>2</sup> (which is to say that it's the 19th largest country in geographic area). However this recent "democracy" has only about 2.8 million inhabitants. Excluding the capital Ulaanbaatar, Mongolia has a low population density; in fact it is one of the large sparsely inhabited countries in the world. (UNESCO, 2012).



Figure 4: Map of Mongolia (Source: Google maps)

Simultaneously Mongolia has a severe continental climate - long, cold winters for 8 months and short summers. The country is located in high altitude (average altitude of Mongolia is 1580 meters, which makes it one of the highest countries in the world). Less than 10% of this sparsely country is forested and an enormous extension is the Gobi desert. Earthquakes may take place.

As consequence Mongolians have a rather distinctive way of life, which they have been living for hundreds of years. Being nomads, they live in herd camps raising livestock (horses, cattle, goats and sheep) and migrating seasonally in search of fresh pastures. Their dwell are portable tents called “gers”, which are round felt tents with colorful painted wooden doors.

In Ulaanbaatar residents are increasingly suffering from environmental distress due the fact that the capital has one of the world highest levels of air pollution. (UNESCO, 2012).

According the 2010 CENSUS conducted by the National Statistical Office of Mongolia, 49.5 percent of the residents are male and 50.5 percent is female. Moreover population aged 0-14 is 27.3 percent, aged 15-64 is 69.0 percent, and 65 and above is 3.7 percent. Mongolia is a young country, with an average age of 27 years and a hope of life of 69 years. About 33% of population is under the age of 18 years (National Statistical Office of Mongolia, 2011).

Furthermore the 2010 World Bank data reports that 38.7% of the population lived below the national poverty line. (World Bank, 2010) Not only Mongolia's isolation but also poor roads have contributed to a poor economy and mainstreaming. More than one-third of the country lives in extreme poverty.

When looking at religious ranks of the population:

“64.4 percent are with some religious faith, of which 86.2 percent are Buddhist, 4.9 percent are Muslim, 3.5 percent are Christian, 4.7 percent are Shamanist and the remaining 0.6 percent is with other religious faith.” 2010 CENSUS cited in (UN, 2010).

The globalization, western influence and urbanization are affecting the nation in terms of perpetuation of its cultural legacy and identity.

### **3.1.2. Political History**

The Mongols dominated the world in the 13th century and under Chinggis KHAAN (King) established the largest empire in history. After his death the empire was divided in four kingdoms, which become fragmented in the 14th century. At the end of the 17th century and for two hundred years Mongolia came under Chinese rule. In 1921 Mongolians obtained its independence with Soviet support and in 1924, a Communist regime was settled until the 90's (US Mongolian Embassy, 2014).

The Mongolian people's Republic underwent a major transition in the development of its model of governance and political institutions in the decade of 1980. Afterwards 1989 the country Government transitioned from a Communist State based on the Soviet model to a multi-parties democracy following a peaceful and serene revolution in 1990

and transition from state control system to a market economy. The latest Constitution of this Semi-Presidential Republic dated of 1992 (Soni, 2013).

According to the study "Democracy Development in Mongolia: Challenges and Opportunities" (Landman et al., 2005), the political system established meets most of the minimum commonly accepted criteria and democracy standards. Nevertheless this country was able to establish democracy among several post-Communist neighbors who remain, or become undemocratic (Landman et al., 2005).

### **3.1.3. State Organization**

The Britannica Encyclopedia has an accurate definition of the organizational structure of the nation state:

“The country is administratively divided into 21 aimags (provinces) plus the municipality of Ulaanbaatar, with a independent administrative status. Each province has a Governor chosen by the Prime Minister, and the local Assembly (khural) is elected democratically each 4 years. The Governor of the municipality of Ulaanbaatar is also the President of the city. The provinces are subdivided into sums (districts) and bags (subdistricts) in Ulan Bator there are several düüreg (urban districts). The Governors and the President of the Assembly of the provinces and Ulan Bator has enough power and its own management and budget” (Britannica Encyclopedia, 2013).

### **3.1.4. Economy**

Mongolia remains as one of the fastest growing economies in the world, despite government expenditure has continued to add by rhythms which result in budget deficits in 2013-14. Projected real GDP growth of 11.8 and 9.6 percent per year between 2013-



14, results in large measure by investments in the mining sector (mining boom) (IMF, 2013).

On the other hand, 26.4 percent of the population is engaged in primary sector (agriculture, hunting, forestry). This sector constitute two thirds of the rural employees (National Statistical Office of Mongolia, 2011)

The country recently began exploring part of its abundant mineral resources (oil, coal, copper, phosphates, tin, nickel, zinc, gold, silver), having established a Human Development Fund - sovereign wealth fund from mining revenues, for the welfare of citizens (UNDP, 2011).

Paradoxically, these blessed mineral resources may become a 'curse'. (Tehmina & Rogier, 2012) Mongolia, needs without delay to promote a diversification through support for non-resource sectors, to heal the consequences of the “Dutch disease”.

### **3.1.5. Mongolia in Worldwide ranks**

There are a couple of international rankings, established by reputed organizations, that eventhough may be questioned scientifically, give a general prospect of political and social development of a country. It was sought important to mention them in order to complete a broad perfil of Mongólia in this regards.

Since its transition to democracy in 1990, Mongolia has made steady and significant progress in the improvement on worldwide ranks.

- Human development Index

According to the 2010 global HDR, Mongolia is in a group of countries where HDI increased by more than 1 percent per annum in 2000-2010 (UNDP, 2011). About ranks, in 2012 the Mongolia occupies the 108<sup>th</sup> position among 169 countries, with 0.675 (UN, 2013).

- Failed States Index

According to the "Foreign Policy" and the "Fund for Peace – 2012 Edition of failed States", Mongolia occupies the position 129 of the world ranking (borderline-Stable) with a score of 58.7. Compared to its Asian neighbors the risk in this country is quite inferior to their counterparts. Even so, five years ago (2008) occupied the position 133 with 57.8 points, which denotes little progress and even some retreat (incipient construction). In fact, global comparative analysis confirm that the Mongolia is on median of failed States with moderate pressure (FPF, 2013).

- Liberty Index

The freedomHouse is an independent organization that stands for monitoring the Freedom in the world. In 2013 Mongolia status was ranked as "Free Country". Political rights of Mongolia and the significant progress in legislative elections (considered free and fair), have enabled the upgrading rank. Additionally Mongolia is ranked 94 of 176 countries surveyed by Transparency International in 2012 in the Index of perception of Corruption (Freedom House, 2013).

- Democracy Index

According to 2012, data analyzed shows that Mongolia remains a failed Democracy (imperfect) with a score of 6.35 (variation between 6.23 and 6.60 in the last 5 years), although clearly above average in the region. In short, no significant progress have been made (there is even some stagnation) (The Economist - Intelligent Unit, 2013).

### **3.1.6. Education**

Mongolia is one of top world ranking leaders in literacy rates, with 98.3% of population aged 15 and above, based on 2010 census (National Statistical Office of Mongolia, 2011). Regarding access to primary education the ratio is even higher, 99% in 2010, which show the universalized system (UNESCO, 2012) and progress in the Education Index 0.675 (UNDP, 2011).

Should be noted that the country Education System grants 12 years of free public education and almost 20% of state budget is spend in the Education sector. Therefore, significant progresses were in the recent years pursuing the Education For All (EFA) goals. Nevertheless, education still faces several challenges in this country, particularly in rural areas, such as deficient education infrastructure and outdated curricula, among others (UNESCO, 2012).

### **3.1.7. Health**

In Mongolia, the existing health system organizational structure is divided mainly in two main administrative units: aimags (subdivided in soums and baghs) and the capital. The main challenge is the provision of health services throughout this wide and low population density. The life expectation at birth is 67.3 years, in 2010 and all over the country, just 45% of the citizens access to safe water and no more than 28% to basic sanitation (WHO, 2013).

In addition, most of Health and Care services are profoundly centralize in Ulaanbaatar (UNDP, 2011), therefore the bagh feldshers (health care providers) play an essential function to get in touch with this nomadic population living in the rural areas. At the community level feldshers are key workers, not merely due providing primary health care, but also because they coordinate other non health related aspects (Batdulam & Como, 2012).

In Mongolia's context, rural bags don't look like villages found in other countries. Actually they match more like large areas inhabited by a scarce and few and scattered population of nomadic herders. Living in tents, distances between neighbors can be remote and isolated. In winter herders travel long distances searching for pastures for their livestock, and the extension range could be between 10-40 kms and in some extreme cases up to 120 kms from the bagh center (Como., 2010).

Accounting the previous social and political Mongolia environment, the research thesis is going to be argue in the next chapter: Community Based rehabilitation- a burden or an opportunity?

### **3.2. Community Based rehabilitation - a burden or an opportunity?**

#### **3.2.1. Governance and International Conventions**

There is a prevailing misconception that citizenship involves a proactive or lay claim to action against legal or any other factual powers. Yet summoned the contractualism theory, it is indisputable that citizenship can be embedded in legislation and government policy, said in other words, in a society with high standards of respect for human rights they do not have to be claimed because they accepted and enforced by their own right.

In this regards is irrefutable that Mongolian legislation accounts very important provisions to the welfare of disable. Yet it can be arguable that there is a gap between the legislation and the real achievements. However is a fact that in Mongolia legal provisions are a standing ground for vindication and proactive action headed for lobbying and a civil mobilization, as it can be sustained later on.

In that sense it should be extolled the rapport between government and the NGOs, because of their influential capacity, technical capacity, operational effectiveness and most of all the scrutiny and accountability they may warrant to stakeholders.

The core legislative framework and instrumental guidance was settled in the Social Security Law for Persons with Disabilities 1995 (last amended in 1998) which includes various provisions towards Government implementation responsibilities such as: (art. 5) rehabilitation and care; education and vocational training (art. 8); employment (art. 9); recreation; and social services for people with disabilities, among others (ILO 2003 *apud* (UNESCAP, 2011)).

As consequence the Basic Education Law includes basic provisions sustaining the instruction of persons with disabilities, for instance: support (financial) (paragraph 36.8.7), provision of opportunities for education (paragraph 38.1.1) right to education under aged 17, among others (paragraph 39.1.3) (ILO 2003 *apud* (UNESCAP, 2011)).

The Higher Education Law 1995 (last amended in 2000), goes in same direction stipulating that students with disabilities are eligible to tuition fee grants, and students coming from families themselves with disabled members, should have access to loans. (ILO 2003 *apud* (UNESCAP, 2011)).

The Labour Code 1999, stipulates an anti-discrimination provision (art. 74 and art. 111). Denying employment to person with disabilities and persons with dwarfism if their physical conditions enable them to be employed in the industrial and service jobs, is prohibits by law. It Employment quota (art. 111) - is required to employers and organizations having more than 50 staff to employ a proportion of 3 percent persons with disabilities (UNESCAP, 2011).

The Norms of Building Planning for People with Disabilities (2004) were established to assist persons with disabilities to participate as active community members, in the areas of employment, education and information. (UNESCAP, 2011).

The State Social Welfare Law includes basic disability benefits (art. 25) from the Social Welfare Fund and the legal requisites for citizens with disabilities to obtain that support. (UNESCAP, 2011).

Particularly as result of AIFO, Save the Children as well other NGOs advocacy was established the Law on the Protection of the Rights of the Child (1996) with:

- a) The National Council for Children (NCC), to develop state policy on child rights and mobilize resources;
- b) Local Councils for Children, under the governorship at the aimag (municipal/province) and soum (district level).
- c) The National Authority for Children (NAC) to implement and monitor state law and policy on child rights, conduct surveys, build the capacity of staff to uphold child rights, and cooperate with non-governmental organizations.

In the mean time, one of the following policy measures as result of CBR programs was the action taken by Government of Mongolia - the National Program on Supporting People with Disabilities (2006-2015) that sets up the following special objectives for disabled people:

“Expand healthcare, treatment and service types for disabled persons meeting their special needs;  
Increase opportunities for disabled persons to live in comfort and develop their skills, create a social environment where their rights are respected and build an infrastructure that provides conditions and opportunity to take part in social life on the equal basis as other citizens” (OHCHR, 2009).

To apply these objectives for disabled children, the following actions have been prioritized: *“Develop an integrated database on disabled children; raise awareness on communities about disabled children’s handicaps and constraints”* (OHCHR, 2009).

Save the Children upon the collaboration with a consortium of NGO’s was involved in the development of a comprehensive child mental health policy; national policy for children with disabilities and ensure their right to education to the maximum extent possible and advocacy on legal and institutional reforms.

Consequently, the Mongolian government has recognized the importance of CBR program and has played a significant role in the strengthening the legal environment for disabled people and in 2007 the Mongolian parliament has approved the amendment of 7 laws out of 15 (Batdulam, 2008).

But a baseline research by ADRA Mongolia, particularly reported gaps in policies, poor implementation of policies and laws concerning Children with disabilities and fee waivers from the Social Welfare Security Law, which are not implemented regularly.

Meanwhile the CBR projects have been working with working groups with the ministries of Social Welfare and Labour, Education and Health. Working groups were established at the policy making level which consists of professional experts and decisions makers. The Working Groups developed Education Assessment Tools for Children with Cognitive Disabilities (CwCD), Early Detection and Diagnosis Health Tools and a Referral System within and between education, health and social welfare sectors in order to provide comprehensive social services for CwCD and their families.

At the same time the action also acknowledged that Girls with disabilities are doubly disadvantaged because of their gender, thus it promoted awareness raising on gender equality, discrimination against disabled children, their families/mothers with disabled

children and required policy makers to take special efforts to provide opportunities for girls and women with disabilities.

As result, in 2009 the Ministries of Education, Health and Social Welfare, among others, with the National Statistical Office undertaken a variety of activities at countrywide levels and released policy recommendations for promoting the rights of disabled children toward participation and association in communities (OHCHR, 2009).

Although progress were made, the 2011 Report of the Human Rights Committee 101st session, noted limited access of persons with disabilities to education, health and social services because of discrimination and prejudice and inadequate structures (arts. 20, 24, 26 of the Convention). As consequence the observatory committee recommends that Mongolia needs to implement measures and strengthen actions to mitigate the situation of persons with disabilities, and facilitate their access to elementary services. (UN, 2011)

Corroborating this inclusive mainstreaming, in June 14<sup>th</sup>, 2013 the General Assembly of United Nations, proclaimed by their Resolution A/68/95, “The way forward: a disability-inclusive development agenda towards 2015 and beyond:

“increasing awareness; promoting good practices; including persons with disabilities in social protection systems; disability-inclusive international cooperation; equity and social inclusion for policymaking inclusive of persons with disabilities; capacity-building and promoting a rights-based approach to disability in the context of the post-2015 framework” (UN, 2013).

Summarily, INGO’s and CBR programs have an important role as actors in supporting and promoting an inclusive society for disabled children. The key effort is ensuring access to rights and social protection, developing sustainable an inclusive community projects. Unfortunately not all assistance and international aid are successful stories in health empowerment in communities. So it’s important for the success of an inclusive program that some crucial aspects must be considered such as: empower the



communities, awareness and advocacy, capacity building, self-supported communities, health and education promotion, monitoring and evaluation.

#### **2.2.4. Education**

Education has always been one of the most important foundations for citizenship, as children are the future of a nation: a nation without educated children does not have a future.

In terms of CBR, education means socialize children to be supportive to other children and to provide children with disabilities the means to become citizens by their own right, as it was stated by United Nations 2002 the resolution “World Fit for Children Declaration and Plan of Action, whose focus is giving every child a better future:

“(…) take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities and children with special needs, to ensure the recognition of their dignity, to promote their self-reliance, and to facilitate their active participation in the community. “ (UN, 2002)

To put it simple, education paves the way to inclusion, as schools facilitate and provide the needed support to ensure that all children engaged in an environment where they can work and learn jointly (UNICEF, 2007, p. 1).

Inclusion and integration, although with similarities are singular concepts. The notion of integration involves bringing children with disabilities into an ‘ordinary’ and standard environment. For instance, in terms of education and schooling, integration mainly means to place disabled children in ‘regular’ and ‘normal’ schools rather than making adjustments in the school environment and teaching approaches. Inclusion on the other hand is an evolved and broader concept, that stresses to ensure that all children can study

and be taught together, and therefore schools are required to adjust and settle the needed modifications in the schooling (UNICEF, 2007, p. 1).

Corroborating the above mentioned, in the Guideline “Active Citizenship and Contexts of Special Education”, education is seen as citizenship, challenging a renovation in the educational system through the implementation of a complementary pattern of children’s social inclusion, towards effectiveness in school. Inclusive education demystifies the perjury that disable children are inactive and it emphasizes community engagement, seeing kids in special needs as interactive citizens. Citizenship is better internalized when developed in an environment that reflects equality, nondiscrimination and other society ideals. Therefore, is particularly relevant to raise awareness for all aspects of inclusive education for citizenship in the classroom, school or community (Alevriadou & Lang, 2011).

Beforehand it should be enlighten that despite trends towards change, in Mongolia atavistic prejudice against cognitive disability persist, reasons relies in the fact that traditionally having a disability in Mongolia carries a culture of shame and stigma that has obstructed personal development and social acceptance. Children with disabilities are often hidden from outsiders to prevent family embarrassment.

There is greater acceptance of people with physical disabilities. In contrast people and children with cognitive disabilities such as autism, Down’s syndrome and cerebral palsy obtain inadequate diagnosis, limited support services and bear community stigma. Individuals with mental disabilities are often called “abnormal”, or other deprecating labels. Although, official statistics on cognitive disabilities are incomplete, anecdotal evidence suggests that many disabled children remain unregistered for the reason that they are either hidden by their parents because of social stigma attached to disability or not detected because of lack of early diagnosis. In Mongolia According to the National Statistical Office (2007), most health and education caregivers for children with disabilities are centralized in the capital city, where no more than 18.8 percent of them live and the remaining 81.2 percent live in province and rural areas (ADRA Mongolia, 2013).

In Mongolia, insofar the kind of disability and the age of diagnose a disability are both key factors and have a preponderant influence to education access, on other hand, gender appear not to be a pertinent reason. People born with disability or developing a disability in the infancy days as well the Intellectual disabled persons are more prone to be excluded from proper education (Deepak, 2008).

Nevertheless CBR is steadily making is influential way towards a more sustained and inclusive society by awareness raising in legislation making process or streamlining the emergence of civil organizations and obviously in deploying projects.

In fact since late 1990s, projects funded by international cooperation agencies and organizations such as AIFO, DANIDA and Save the Children UK, are centering attention on mainstreaming of children with disabilities in pre-school and day care facilities.

Dates back to 2002 when firstly Save the Children UK started implementing its inclusive education project in Mongolia, establishing the Association of Parents with Disabled Children (APDC) and the raising awareness to this cause with the approval of the National Program of Inclusive Education 2003-2008. In 2008 in order to promote integration of children with disabilities into the pre-school education system, a new Law on Pre-school Education included a provision to include 1-2 children in each kindergarten classroom.

Although the Ministry of Education in Mongolia promotes inclusive education, in practice children with disabilities have limited access to all levels of education, and even with mild hearing and speech impairment, and limb impairment become a reason for exclusion from education (Deepak, 2008).

There is another influential role that CBR is playing in education settings in Mongolia, it is related with scientific research, university syllabus and training. Traditionally, the curriculums of majority educational faculties and universities do not include training on disability or how to work with disabled children. Therefore, new graduated teachers are without knowledge (in the dark) how to educate them. This shows the need to include disability in the teaching curricula and create new standards and methodology, as well as practical schooling intended for work with children with disabilities (Batsuuri M. et al., 2010).

To break this cycle, as example, ADRA Mongolia implemented a CBR project among Children with Cognitive disabilities, called “Ensuring Access to Education and Health for Children with Cognitive Disabilities in Rural Mongolia”. According to the last report published in 2013 the project developed diagnosis and education assessment tools for Children with cognitive disabilities and guidelines to the national curriculum for the Mongolian National Medical University students. The Mongolian State University of Education introduced the programmatic content of newly developed education assessment tools for Cognitive disabled children, in the psychology department, and as a result, all finalist students (future family doctors) started to take classes on cognitive disabilities, early diagnosis and early interventions.

Additionally newly developed or adapted education assessment tools were adapted for the context of Mongolian schools and children and were piloted in both rural and urban target schools and Working Groups completed the development of a training curriculum for teachers, family doctors, social workers and parents of Children with cognitive disabilities.

## Community-Based Rehabilitation - a burden or an opportunity?



Figure 5: Education assessment tools, tests and checklist to assess CwCD



Figure 6: Manual for early interventions/treatments for CwCD



Figure 7: Guide and handbook for the APDC branches and other Disabled Children's NGOs who are working in partnership with the APDC.



Figure 8: Referral System for CwCD between Education, Health and Social Welfare Sectors

Up to a point, CBR is promoting access inclusive education for children with disabilities. Regardless the success stories, challenges remain due to practical obstacles and the absence or diminutive cooperation between families/guardians and school staff (Como., 2010).

Addressing the issue of Children with Disabilities - Cognitive Disabilities, stakeholders, cannot negate the distinctiveness of these persons. CBR projects distinctively are shaping the future in Mongolia by sustainable actions and programs. Advocacy and forum initiatives are expected to lead to better understanding and implementation of existing legislation namely the policy on Inclusive Education and national program on children with disabilities, particularly in rural areas.

Definitely the new generation of educators and the national initiatives taken for promoting awareness of disabled children rights are resulting on inclusive education for citizenship in the classroom.

### 3.2.3. Advocacy

In the footsteps of the ancient Greek tradition, engagement towards societal related issues is the kernel of the citizenship. However in today's society the multiplicity of information and messages may lead to the blurring of social causes that do not have the appealing of breaking news.

According CBR projects in Mongolia took due importance to advocacy, it was done in two actions, one conducted close to the youth another close to the media.

In regards to youth some promising and very interesting results were obtained, not only the CBR gained visibility, but it had objective impact in changing attitudes towards children with CwCD and civic behavior.

The advocacy among journalists was also an initiative worthy and commendable to mention. This action resulted in a nationwide broadcast scheme and created effective space in media channels devoted to the awareness of CBR and CwCD. Furthermore it is tangible that these actions played an important role to reduce stigma, increased the activism and citizenship mobilization.

In regards to youth, as consequence of an interesting research survey conducted nearby 3 dozen young kids, to raise awareness on child protection: "Report of Mongolian children to the United Nations Committee on the Rights of the Child", which sees a grey situation about children living in Mongolia. Some of the recommendations regarding disabled children were:

Create conditions to ensure that all disabled children receive formal education.

Raise public awareness through media (TV and radio stations) on children rights and child protection by broadcasting major information.

Ensure that children are involved and consulted at all levels of decision making related directly to their lives (Child Rights International Network, UK, unidentified year).

Therefore, one of the innovative actions from CBR Projects was the setup of Youth advocates (students) to raise awareness among School communities. The project achieved to mobilize school community to advocate for inclusive education and promote positive understanding of CwCD in school environments and reduce discriminatory attitude of students to CwCD<sup>2</sup>. (ADRA Mongolia, 2013)

Subsequently this strategy resulted in united and cohesive school communities, change of attitude and paradigm. Secondly the activities and training conducted for youth advocates cultivated a culture of understanding and motivating the children with disability. Thirdly there were cases that youth advocate group members help for CwCD in their school to travel between school and homes because the disabled children could not find their way to the school or home and usually require adult escort which enabled opportunity for their parents to work or to have some time to engage in other activities.

Therefore positive outcomes were reported such as reduced incidence of name calling and teasing disabled students, students became more considerate to issues of disabled children in general. The youth advocates also responded that they start to observe changed attitude from teachers to disabled children. These changes had an impact on the society and are leading gradually to a greater social integration.

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<sup>2</sup> School activities had their own slogan such as “Equal life and equal opportunity”, “My dream”, Child’s voice or reflection”, “We are in one family”, ”Lets build together”, “Positive behavior”, “Warm Heart”. Other campaigns “Let’s raise hands for your right” “Every child have to have happiness” “Let’s help for disabled children”, “Current situation of discrimination of children with physical and cognitive disabilities”, “Let’s union for children with disabilities”, “Our participation for education of children with cognitive disabilities”, “I can do all”, “Current education situation of children with disabilities”, “My participation is crucial for solving our problem”. (ADRA Mongolia, 2013)

Consequently, it's evident that important achievements were reached in the society such as respect, opportunity of mainstreaming, social cohesion and formation of citizenship. The Youth advocates mobilized school community for inclusive education and promote positive accepting of CwCD in school environments and reduce discriminatory attitude to CwCD.

Advocacy and public awareness increased public consciousness of disabled children in target areas of the projects implementation and is further expected to lead to gradual movement towards a social model paradigm that will encourage communities not to view disabled and CwCD as having a defect, but as a person who can contribute to the community. The change in attitude and awareness from this action also expected to gradually impact on building an inclusive society for all children in Mongolia, and particularly CwCD can fully enjoy their rights to receive better qualitative health, education and social welfare services, meaningfully participants in decision making, and become productive members of the society.

Other initiative and a pro-civic innovation was conducted by ADRA Mongolia in the EACH Project: the training of Journalists and media people on the issues concerning disable children and CwCD.

This training aimed to increase the knowledge of journalists and media personnel on cognitive disability, to get them acquitted of social model paradigm as well promoting positive images of disabled children and the media's role in advocacy, lobbying and changing public attitudes and preconception towards CwCD.

The training curriculum was developed in close partnership with APDC, Mongolian Newspaper Association, target journalists and other mass media workers. This action demonstrated to be efficient in terms of knowledge dissemination and resulted in activism by media players in actions to reduce stigma. As result the project reported a total of 49 TV spots, 22 newspaper articles, 12 IEC materials through the internet, 16



brochures and 24 banners had been developed and broadcasted for wider audiences (ADRA Mongolia, 2013).

Indeed, media and journalists are one of the main working channels to raise awareness of CBR Program with disable children, public opinion formation and wipe out preconception. This joint advocacy initiative brought the social vision to the daily agenda as topic of humans' rights.

Additionally it increased the activism and citizenship mobilization, created awareness about international norms and conventions with emphasis on human rights of persons with disabilities. In simple words, the intervention of this stakeholder brought a new perspective of the situation, opened the doors and influenced application of international agreements, consolidating the goals of the program.

Hence, the CBR model focuses on changing the system and environment rather than fixing individuals with disabilities. The advocacy activities placed emphasis on the ways that communities can support children/people with disabilities creating mainstreaming and sustainability.

#### **3.2.4. Territorial cohesion**

Mongolia is the most sparsely populated country, as well the second largest landlocked country in the world. Mongolia's isolation and high territorial dispersion and poor basic infrastructures contribute to a poor economy; broad rural to urban migration and living in cold traditional dwellings (gers), which makes life harder and unhealthy especially for children. At the same time, the country continues to experience cycles of socio-economic and political transition. That's why is so important to have strategies and actions that strength the sense of belonging to a nation, inclusiveness and political and public participation in the community.

Thus, inclusion rather than a process for some 'special' children, is a course of action for all children and their respective families and other stakeholders already mentioned. This model promotes an environment where diversity is surely the norm rather than the exception. Whenever the education system fails to provide to non-disabled children the opportunity and experience of grow side by side up in atmosphere of diverseness, that's where most of difficulties happen, and leads to marginalization and exclusion (UNICEF, 2007, p. 1).

Mongolia has a distinctive situation for community based rehabilitation programs. Nation shows political willingness to improve the situation of children with disabilities. Nevertheless insufficient resources were yet allocated and the context of the sparsely nomadic country, harsh climate and deficient infrastructures, makes rehabilitation particularly complex. For that reason implementation and management of CBR programs in Mongolia must be pointed out as a unique example where such a vast territorial extension has been covered. But, on another side, specificities in monitoring the rural areas, assessments and evaluations, made difficult to evaluate the acceptance and real impact on disabled people's lives (Sharma & Deepak, 2002, p. 5).

As one of the important achievement of CBR programs is to promote inclusive development; is empower disabled people and their households, through sharing of ideas and experiences; establishment of self help groups, cooperatives; and promoting disabled people's organizations (DPOs) at community level. Besides, the National Federations of persons with disabilities takes a dynamic participation on CBR program. This strategic approach created across the country a wide activism network, which is raising awareness and are steadily learning to advocate and influence local policy and decision makers (Deepak, 2008).

One example was the establishment of vocational training and Revolving Credit Funds for persons with disabilities and households. In other words, CBR using Micro-credit loans support self help group of the persons with disabilities in their communities to

establish Micro projects that will improve their livelihood and quality of life (Batdulam, 2008).

Doubtless, this strategy is fixing population in their communities through integration of PwD in society.

#### **3.2.4. Other contributes from Non-government Organizations and Community-based rehabilitation Projects**

The article “Why mainstream disability in development?” highlight the extreme relevance that activities supported or implemented by international aid, to integrate and include persons with disabilities in all development activities, as the article 32 of CRPD advocates (IDDC, unidentified year).

For that reason, development policy should offer a platform for society change and for persons with disabilities to be engaged as valued individuals and no longer be stigmatized objects of care and welfare (Albert, 2005).

Hence, NGOs successfully organized policy dissemination forums, advocacy campaigns, school based awareness activities that increase consciousness of government officials, policy makers and among community, about knowledge of actions on cognitive disability issues.

All policy forum initiatives are expected to lead to better implementation of the existing legislation and national programs on children with disabilities; policy on inclusive education, particularly in rural/remote areas; improved funding allocation for those activities in the target areas; and support from the health and education sector to apply the newly developed early diagnosis tools and referral system (ADRA Mongolia, 2013).

Particularly, capacity building APDC parents and Youth Advocates on lobbying and advocacy, led to effectively and meaningfully participate in decision making processes at national and local level, resulted in a increased participation of CwCD, their parents engaging with local government led to the formulation of more appropriate policies and decisions concerning CwCD, and increased support from the national and local government to CwCD, such as budget increase for Community based rehabilitation for disabled children on the province.

Because of that, several amendments to the existing Law on Social Welfare for disabled persons of Mongolia were approved. One important amendment to the existing law 3.1.6 was placed by the provision of an allowance for home care of CwCD. The provision now specifies that “*a person or child who needs permanent care*”, which means people unable to meet their daily needs by their selves, implicitly people and disabled children. Other legislative provisions are in process of being added to the Social Welfare Security Law for Disabled Persons:

Full reimbursement of prosthesis appliances’ costs which for children with disabilities age up to 18 years old once in three years;

Full reimbursement of orthopedic appliances and wheelchairs’ costs for children with disabilities aged up to 18 years old once in five years.

Bear transportation fee for disabled children and their caregivers/guardians to travel:

- To special schools/education institutions;
- To access health services (diagnosis, treatment and rehabilitation) once in a year;
- To rehabilitation centers and children’s camps including 50 percent of the rehabilitation costs

Discount price for meals in kindergartens of disabled children (ADRA Mongolia, 2013).

CBR Projects worked closely with the Ministry of Social Welfare and Labor to carry the parents’ request to adjust the given pension to disabled children, taking in consideration the inflation rates and the living cost in Mongolia. By the new amendment to the law, Children with disabilities, including CwCD, instead of collecting quarterly the social

welfare's pension (30,000 tugrugs, less than 15 euros), will start receiving that amount in monthly bases.

However, CBR approach in terms of Livelihood goes beyond promotion access to social protection (state pensions), to a skills development and encouragement efforts for income generation. In rural communities there are few opportunities for social life, nevertheless, the CBR successfully organizes events for the International Day on Disabilities and PwD are now invited in social events, such as bag meetings and small cultural festivals and sports at Soum level. Talented people with light disabilities are encouraged to study and perform arts in public (music, for example) and to participate in sports competition.

Again, there are many limitations in the implementation of the CBR in Rural areas, and more needs to be done in terms of awareness of local authorities. (Como., 2010)

In other hand, more than 15 NGOs who work for disabled children, and who advocate for child rights and inclusive education, had joined the NGOs networking which APDC has initiated. They are currently leading and boosting their influence among decision makers and society through: Campaigns conducted on Child Rights Day and other special dates; information boards; TV spots and press releases. Implementations of existing laws and legislations of CwCD have been improved to include transportation fee in order to get specialized services in the capital.

To illustrate this, empowering the Association of Parents with Disabled Children (APDC), in Zavkhan, Bayankhongor (provinces) and Ulaanbaatar (capital), resulted in ongoing advocacy, public awareness campaigns, field trainings, policy forums, media actions and school based awareness activities which aimed to increase consciousness of the general public and policy makers on the issues of CwCD and their families (ADRA Mongolia, 2013).

Summarily the CBR projects with CwCD addressed three priority areas contained in the Biwako Millennium Framework (ratified by Mongolia in 2002): early intervention; public awareness on education and health rights of disabled; and strengthening of self help organizations of people with disabilities. The stakeholders and beneficiaries included:

Children with Cognitive Disabilities

Families or parents/caretakers of Children with Cognitive Disabilities

Health practitioners, school doctors and family doctors serving CwCD

Teachers and school administrations

Social workers, social welfare agency officers at district and province levels

APDC staff and board at UB and aimag levels

Youth Advocates (peer educators)

Government representatives of the key Ministries of Health, Education and Social Welfare and local education and health departments at provincial level (policy makers)

Trainers of the project (family doctors, school doctors, social workers, teachers and APDC member parents)

Journalist and media

Today, NGOs are an important part of the social and political structure of the country, as well, very successfully complements government provision of social services to the vulnerable people of Mongolia (Zinamider, 2002).

Doubtless that CBR program in Mongolia raised awareness on the rights of disabled children, namely children with cognitive disabilities, reduced stigma regarding disabilities, influenced policy makers and boosted changes in the general public preconception and attitude toward children with disabilities as burden to society. This results in effective changes for children with cognitive disabilities in Mongolia.

Nevertheless, the role of international agencies cannot end and the extension of CBR programs remains essential in the consolidating process.

The next chapter will summarize the main conclusion and lessons learned about CBR program as affecting positively the Society in citizenship unity and social and territorial cohesion. Finally, recommendations for solutions towards an inclusive society able to improve the wellbeing of CwCD and suggestion on further studies on this subject.

## **Chapter IV – Conclusion and future developments**



This chapter will evaluate the results of research on the question whether CBR is an ineluctable social burden or it may be a mainstay towards accomplishment of citizenship and associately contribute to a more inclusive and sustainable society?

It should be noted that this is seemingly a trivial matter, yet contains in itself an ambition worth to be underlined. On the one hand it modestly intends to open a new perspective on the CBR analysis, in a field of investigation with very poor research. Secondly, because the answer to this question led to the opening of new approaches to the phenomenon, which weren't identified in the examined literature and forced to make a systematization of information on the social impacts of CBR, especially in relation to Mongolia, which did not exist and seemed necessary. In terms of importance in practical terms, it is believed that the produced text can be of some value to the actors on the ground, this statement is made taking in consideration the eagerness and comments received at the stage of gathering information and informal interviews amid the practitioners.

Beginning by assessing the performance of the methodology, which is arguably one of the critical pillars of all research and decisively influences the quality of the final product, the design of the research pointed to a methodology focused on two major areas, one theoretical and another one applied to a practical case.

Regarding theoretical component the characterization of CBR has proved as difficult as productive, in fact it is a multifaceted and complex concept, whose construction includes a set of several other concepts, which systematization gave the necessary stimulus to work. Another key concept defined in the research and that proved fruitful as an analytical tool was the concept of citizenship.

Based on these two concepts, the investigation plan, was to collected information on the CBR Mongolian case, which was relevant in terms of quality, since it is believed it allowed to prove the advocated thesis, both in terms of quantity of sources and

documents, as it permitted the statements made were in most cases triangulated, i.e., corroborated by different kind of sources as assumed in the adopted case study methodology. Indeed, on an overall assessment the adopted model from Yin (2009) proved to be relevant and met the needs of analysis of the chosen case, namely CBR Mongolia.

Even though Mongolia is a democracy, as it was been said, is a minimum model of democratic state according western standards, the country position on worldwide ranks in this regards is self-evident, but the same ranks allows to ascertain that, regardless its weakness and history, it is struggling in the direction of a higher standard democracy, that is enlighten when one compare Mongolia with neighbors countries and states with the some profile. In that sense, as it was proven the effects of CBR in building a more inclusive and participatory society are a non-negligible contribute as far as citizenship is accountable, both at the government of the *polis* and civil rights levels.

Starting with governance, it was found that the CBR has contributed to the international recognition of Mongolia efforts of in terms of human rights by ratifying conventions and collaborate with international organizations like the UN and various NGOs. Are also to emphasize the achievements in terms of comprehensive articulation of the rights of persons with disabilities, as for example the case of labor rights and the elimination of architectural barriers, it should be noted that these achievements were due to the power of collaboration and influence of civil society organizations on the ground.

Collaterally all this way through allowed the government to become more accountable, since the programs and policy coordination are scrutinize by independent organizations, while it should not be forgotten that this whole process has brought the nation gains in skills such as organization and technical skills.

Aligned with the Greek tradition, were dedication to the public cause reflects a commitment that translates the civic vitality of a society. Advocacy in this field in

Mongolia shows two lines of participation which results obtained would be worthy of its own study, namely the intervention with youth and media.

In the case of young people not only allowed to give visibility to CwCD rights, but also had the practical result of changing attitudes, break preconceptions and segregation. In the case of the media, training professionals led to various initiatives in promoting human rights and contributed to the development of civic consciousness and tear down of prejudice across the nation.

This leads us to the consideration of the significant impact of CBR in education, which is one of the mainstays of citizenship. Although it has been established that the education situation of CwCD in Mongolia is not at all perfect and there is still a long way to go, there is no way to hide the advances that have been experienced in law and the organization of the school and educational system. In this context is paradigmatic the joint work of the NGOs Save the Children, UK and others along with the association of Parents with Disabled Children (APDC) for the National program of Inclusive Education.

The impact of the CBR in the educational field is felt in higher education and curriculum innovation, where the curricula of medical schools have begun to integrate disciplines in the CBR area, again with the help and the collaboration of international institutions the NGO ADRA was capable to create and translate a considerable number of early diagnostic tools and promote technical training of health professionals and education at different levels. Definitely the new generation of educators and the initiatives taken to promote awareness of disabled children rights are resulting on inclusive edification for citizenship in the classroom.

The work has presented sufficient evidence from several areas where the CBR was a mean for promoting social cohesion and inclusive society, some of them unaware or unsuspected that one could not even suspect they exist before drafting starts. The emblematic case was territorial cohesion. Again, reminding that Mongolia is the most

sparsely populated country with high proportion of nomadic population, here the CBR programs are seen as a model and example of development of program implementation and resource management in an integrated and systematic way, and research provides multiple other arguments that support the submitted thesis, but that it would be redundant to expose to exhaustion in the conclusions chapter.

Is not for the author to judge, but is convinced that both the methodological options for the chosen case and the reviewed documentation allowed to gather evidence that enables conclusively answer the questions raised.

Permission also, for more two last words regarding motivations. A work of the kind of this one should make sense not only a scientific perspective, but it should also constitute a challenge and a growing opportunity to the author, otherwise then its value will be greatly diminished.

It was not the case, all of the research done has proved a test of overcome perseverance, while applying knowledge acquired during the master constituted itself a possibility of intellectual growth. About personal motivation was mainly due to the fact of having a close family member with health problems that requires rehabilitation, all this effort has led to better understand the disease, on the other hand being a missionary working in INGO, I believe sincerely that it help me to better change lives and somehow gave meaning to the impulse that led me to attend the Masters in such way that would give another scientific consistency to my work/mission.

In conclusion will be mentioned the limitations to the work and development opportunities, upon completion of work, it was found that the main limitations of the study were those predicted, it remains valid the idea that a quantitative nature investigation would be pertinent, that the research subject with other resources could boost the results in another scale and finally there is also the conviction that much of the topics covered would themselves be worthy of investigation themselves (i.e. advocacy, territorial cohesion, media mobilization).

Admittedly, inclusion, citizenship and the recognition of fundamental rights and freedoms are mainstreaming for children with cognitive disabilities. To corroborate this, a final quote: “*CBR interventions only become meaningful when there is real impact in the lives of people with disabilities and real change in society.*” (Heinicke-Motsch, 2010)

Finally, it is believed that this thesis has merit and is itself a strong argument in favor of CBR, perhaps going further in deepening the theoretical approach and the used methodology, it can be a suitable basis for reflection toward other CBR analysis in other contexts.

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