

# **Mental Health: Promoting Rights, Fighting Stigma**

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Publications of the Associazione Italiana

Amici di Raoul Follereau (AIFO)

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### **Information note on terminology**

Considered that there is no scientific term universally recognized within the scientific community, in this publication the following terms have been used:

- Persons with mental health conditions;
- Persons with mental, neurological or substances use disorders
- Persons with psychosocial disabilities

These terms identify, in their different aspects, the same group of persons who are, for different reasons, mental health system users and are require specific support to achieve a satisfactory level of inclusion in the community.

## Foreword

On 1 December 2011, AIFO launched a multicountry project on Mental Health, co-funded by the European Union. The project targeted four countries: Brazil, Indonesia, Liberia and Mongolia. In three of them (Indonesia, Liberia, Mongolia), AIFO has been working for many years using Community Based Rehabilitation (CBR) as a strategy for the rehabilitation and social inclusion of persons with disabilities within the general community.

In these countries the project focuses on strengthening the capacity of the existing CBR systems to reach and support people with mental disorders. Since 2011 the project has developed in these three countries in very different ways, working and exploring innovative solutions to support local mental health care services through CBR approaches.

In Brazil (Salvador de Bahia, urban area), the project team has worked with the local mental health services in partnership with the *Secretaria da Saúde do Estado da Bahia* of the Ministry of Health. The project objective has been to monitor and assess human rights standards in the mental health services using a multi-stakeholder participatory process, following the World Health Organization QualityRightsTool Kit.

This publication evaluates the impact of CBR upon the improvement of life quality and the defence of human rights of people with mental health problems in low-income and middle-income countries. This report is addressed, in particular, to development workers, professionals in mental health and disability, human rights defenders, persons with disabilities and mental health service users along with their carers and representative organisations. In the first chapters of this publication we introduce the concepts of Community Mental Health, Community Based Rehabilitation and Human Rights Standards. In the second part we report on the experience and the results of working in the four countries involved in the project.

## Acronyms

<u>AIFO</u>	Associazione Italiana Amici di Raoul Follereau Follereau
<u>CAPS</u>	Centros de Atenção Psicosocial
<u>CAPS III</u>	Centros de Atenção Psicosocial (third type)
<u>CBR</u>	Community Based Rehabilitation
<u>CRPD</u>	Convention on the Rights of Persons with Disabilities
<u>DPO</u>	Disabled People's Organisation
<u>EFA</u>	Education for All
<u>HCT</u>	Custody and Treatment Hospital
<u>HDI</u>	Human Development Index
<u>HFA</u>	Health for All
<u>ILO</u>	International Labour Organization
<u>MDD</u>	Major Depressive Disorder
<u>MDG</u>	Millennium Development Goals
<u>mhGAP</u>	Mental Health Gap Action Programme
<u>NGO</u>	Non-Governmental Organization
<u>OHCHR</u>	Office of the High Commissioner for Human Rights
<u>PAHO</u>	Pan American Health Organization
<u>PHC</u>	Primary Health Care
<u>PTSD</u>	PostTraumatic Stress Disorder
<u>SEAP</u>	Secretaria de Estado de Administração Penitenciária
<u>SESAB</u>	Secretaria de Saúde do Estado da Bahia
<u>SHG</u>	Self Help Group
<u>SUS</u>	Sistema Único de Saúde
<u>SWOT analysis</u>	strengths, weaknesses, opportunities and threats analysis
<u>UK</u>	United Kingdom
<u>UN</u>	United Nations
<u>UNDAF</u>	United Nations Development Action Framework
<u>UNDP</u>	United Nations Development Programme
<u>UNESCO</u>	United Nations Education, Scientific and Cultural Organization
<u>UNICEF</u>	United Nations Children's Fund
<u>WHO</u>	World Health Organization
<u>WONKA</u>	World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (World Organization of Family Doctors)and Cultural Organization
<u>UNICEF</u>	United Nations Children's Fund
<u>WHO</u>	World Health Organization
<u>WONKA</u>	World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (World Organization of Family Doctors)

## Summary

1

### **Community Mental Health Definition and Introduction**

This chapter provides a historical introduction to Community Mental Health along with an overview of selected national initiatives to develop mental health services.

2

### **CBR Process, Resources, Principles**

The second chapter analyses the CBR guidelines and their application on the mental health field.

3

### **Community Mental Health Services and Human Rights: Multicountry project**

Chapter three introduces the AIFO multicountry project, its background and its main results and findings.

4

### **Methodology**

This chapter analyses the research methodology and the sources used to write this publication.

5

### **The Project in Indonesia**

In Indonesia, the project provided specific training for health operators and volunteers, and allowed an increase in the number of persons with mental health disorders involved in CBR programs.

6

### **The Project in Liberia**

In Liberia, the project offered persons with mental health disorders the opportunity to be involved in community activities and supported with the home treatment. Furthermore, a relevant action was carried out to promote education and micro grants.

7

### **The Project in Mongolia**

In Mongolia, the project fostered the constitution of self-help groups in 6 districts of the country and organised training activities and workshops on mental health and human rights.

8

### **The Project in Brazil**

In Brazil, the project focused on the assessment of two different kind of mental health services using a multi-stakeholder participatory process, following the World Health Organization QualityRights Tool Kit.

9

### **Conclusions and Recommendations**

### **Annex**

I - semi-structured interview research form for Indonesia, Liberia and Mongolia





# CONCEPTS



# Community Mental Health Definition and Introduction



## 1.1 Mental Health System, an Introduction

*Mental health* may be defined as a state of well-being in which a person realizes his or her own abilities, can work productively, can collaborate with other people and is able to make a contribution to his or her community (WHO, 2005a). This definition, promoted by the World Health Organization (WHO) is a positive definition of mental health, not merely the absence of disease or infirmity.

Like other health conditions, mental health and mental disorders are linked to multiple factors: biological, sociological and psychological, which are themselves interlinked. There are specific vulnerabilities associated with indicators of poverty, low levels of education and low income. Mental Health can be by affected by policies and practices in domains such as housing, education and childcare. While mental disorders increase the risk of physical diseases, and contribute to unintentional and intentional injury, many health conditions increase the risk of mental disorders and comorbidity complicates help-seeking, diagnosis and treatment and also influences prognosis (Prince et al., 2007). Generally, persons with mental health disorders face many difficulties then accessing mental health care. There are different problematic ways of dealing with severe mental health conditions within health systems and these can be summarized as follows:

- A considerable number of persons with severe mental disorder do not receive any medical or psychosocial help as it lacks in the mental health care system.
- Some of these persons are subject to compulsory treatments involving violence, long-term segregation and/or human rights violation.
- Some of them can only access services which are not adequate or equipped with the necessary knowledge, sufficient experience and/or adequate technologies to meet their care needs.

Persons with psychosocial disabilities are, or can be, particularly vulnerable to abuse and rights violation, they often have difficulty in accessing general health care and there is still widespread stigma attached to their condition. Having a national law and policy on mental health is crucial for raising the necessary resources to deliver equitable and affordable treatments; legislation is required to promote access to mental health care and to protect the rights of people with mental disorders (WHO, 2005b, pp. 1 – 4).

To bring mental health within the public health system, many countries have enacted specific legislation creating a mental health system which includes outpatient facilities, day treatment facilities, psychiatric wards in general hospitals, community mental health teams, supported housing in the community and mental health hospitals.

The WHO Mental Health Atlas (WHO, 2011) is part of the WHO Atlas Project for mapping mental health resources in the world; it presents data from 184 WHO Member States, covering 98% of the world population. According to this document 60% of the countries report having a dedicated mental health policy, 71% possess a mental health plan and 59% report having dedicated mental health legislation. There are differences between high-income and low-income countries - only 7% of low-income countries (WHO, 2011, p. 11) (and 29% of lower-middle income compared to 45% of high-income) provide follow-up care at a majority of facilities, similarly only 14% of low-income countries provide psychosocial care at a majority of facilities.

Mental hospitals are the pillar of mental health care in the majority of the countries and are present in 80% of all countries. There are only a few countries where mental health hospitals do not exist. Some of these are African countries and small islands in the Pacific, which lack mental health care facilities, but some are European countries, with exclusively community-based systems of care, such as Iceland, Italy and Sweden.

## 1.2 Community Mental Health, a brief history of deinstitutionalisation in Italy and the UK

At the end of the eighteenth century, Europe started to develop the custodial asylum<sup>1</sup> – a therapeutic and custodial mental hospital where large numbers of psychiatric patients from the community were confined. After the second half of the nineteenth century many district-level asylums were established across Western Europe. These institutions were often built on the outskirts of major cities, and operated as self-sufficient communities with their own water supplies, farms, laundries and factories. Although the state mental hospital remained the dominant public institution in the asylum era, there were also mental health clinics – openly acknowledged private asylums for mental conditions, hydrotherapy clinics and general medical sanatoria for organic mental disorders. After the Second World War general hospitals began admitting patients with mental health conditions into psychiatry divisions (Knapp et al., 2007).

But asylums were not only places for care, above all they were a place to isolate, segregate and make more inoffensive (by the walls) people with mental health disorders. If mental illness is a loss of individuality and liberty, in the asylum this loss became stable and everlasting.

No plans, no future, the state of being in the power of others without being able to direct oneself, having one's day tuned and organized on an impersonal rhythm, dictated only by organizational demands that, by their own nature, cannot take into account individual and particular circumstances: this is institutionalization.

Basaglia, 1964

In the second half of the twentieth century, many Western European countries independently developed a public health care system based on universal access to medical treatment for all citizens. This included the extension of social insurance schemes and the promotion of primary health care as a route to achieve affordable universal coverage (WHO, 2000). These decades saw the gradual inclusion of mental health within social insurance schemes and the welfare state. During the 1950s and 1960s the number of mental hospitals continued to increase, but internationally there was a growing debate on the deinstitutionalisation concept.

In 1961 Erving Goffman, a Canadian sociologist, published *Asylums* (Goffman, 1961), a participant observational study of St. Elizabeth's Hospital in Washington, D.C., a federal institution which hosted 7000 inmates. The work was one of the first examinations of the social situation of mental patients and the hospital world seen as subjectively experienced by the patient (Weinstein, 1982). Goffmann worked for a year in this institution. He placed mental hospitals in the same category as prisons, concentration camps, monasteries, orphanages and military organisations, regarding all these institutions as places of residence and work where a large number of individuals are cut off from the wider society for a period of time. In these conditions patients came to realize that they had been deserted by society. They were often subjected to a permanent restriction of freedom and civil rights. In the following years a large number of books studied these characteristics of mental hospitals and

<sup>1</sup> Philippe Pinel worked in Paris as chief physician of the Hospice del la Salpetriere, after 1795. The hospital housed 7000 psychiatric cases under restraint. He removed the chains from patients and introduced the "traitement moral", the first kind of therapeutic and not only custodial approach to mental health disorders.

provoked a wide debate on a new community model of psychiatric therapy. Deinstitutionalisation, as distinct from simply de-hospitalization (or the mere release of patients from psychiatric hospitals), is a process for the theoretical and practical criticism of the legal, administrative and scientific apparatuses that sustain the asylum (Del Giudice, 1998). Breaking down the paradigm that established those institutions, namely the clinical paradigm, was the real object of the deinstitutionalisation project (Rotelli, 1988).

The process of deinstitutionalisation started in the UK with the *Hospital Plan for England and Wales*, promulgated by the Ministry of Health in 1962 which called for a big decrease in asylum beds and a corresponding increase in psychiatry beds in general hospitals together with day hospitals and community services. This act predicted the closure of half of all mental health beds by 1975 (Killaspy, 2006).

The transformation of the mental hospitals is not only a matter of buildings, the change of a physical pattern, it would be also the transformation of a whole branch of the profession of medicine, of nursing, of hospital administration<sup>2</sup>.

Powell, 1961

This community-oriented model was repeatedly endorsed by ministers and politicians during the 1970s and the first half of 1980s, leading to the progressive demise of those mental hospitals that were not arranged to provide a service reaching out the community (Schulz and Greenley, 1995). Nevertheless, psychiatric hospitals still exist in England and Wales today.

The process of reforming mental health care involved many countries in Europe during the 1970s. Between 1972 and 1982 the number of hospitals with over a thousand beds fell considerably: from 10 to 4 in Sweden, from 55 to 20 in Italy and from 65 to 23 in England (Goodwin, 1997, pp. 9 – 11). Many patients were moved from larger scale psychiatric institutions (mental hospitals) towards the community, where simultaneously alternative psychiatric services were being established, for treatment, care and support of people in their natural environment (Bauduin, 2001).

In Italy, a massive political and cultural movement, centred in Trieste, under the guidance of Franco Basaglia, led to the abolition of the asylums in 1978. Franco Basaglia was a famous Italian psychiatrist who was active from 1960s in the cultural debate on community mental health. In August 1971, he became the director of the provincial psychiatric hospital of Trieste. With a group of young doctors, as well as psychologists, students and volunteers, he began a very active criticism of the institution of the asylum (Del Giudice, 1998). During the 1970s Basaglia and his team promoted the development of several community mental health centres, located in different areas of the city each with a catchment area of about 40,000 people. In 1977 the implementation of the new community mental health model enabled Basaglia to announce a plan to close the psychiatric hospital.

In 1978 Italian law 833/78 established a national health service, under which all those in need could receive treatment. Seven months later, following the new model developed in Trieste, the Italian Parliament enacted law 180/78, which forbade the admission of new patients to mental hospitals after 1980

<sup>2</sup> During the speech, Powell (Minister of Health) provided a graphic depiction of the vision of the Asylum he had: "There they stand, isolated, majestic, imperious, brooded over by the gigantic water tower and the chimney combined, rising unmistakably and dauntingly out the countryside. The asylums which our forefathers built with such solidity."

and restricted the size of psychiatric units at the general hospitals to 15 beds. Community-based mental health centres were developed for the therapy and the long-term care of people with mental health disorders (Goodwin, 1997, pp.17 – 18).

Preventive care is crucial in a health care system; the future, everywhere in the world, is not the creation of new hospitals but a network of preventive care systems.

Basaglia, 2000

The Italian reform law of 1978 has determined a slow but progressive and continual closure of psychiatric hospitals and the growth of a new system of community-based services. The change was introduced thanks to public demand. Full constitutional rights of patients have been recognised. Professionals, mental health administrators and associations of patients and their families have been involved in this process. In Italy, in contrast to other countries, the process for the reform of public psychiatric assistance resulted in the complete transition from an asylum approach based on exclusion and internment to a community mental health work style based on inclusion and the restoration and support of rights of persons with psychosocial disabilities (Del Giudice, 1998). Today, only in Italy and a few other countries that tried out the deinstitutionalisation process, psychiatric hospitals are all closed. Total abolition and closure of asylums are important goals for the deinstitutionalisation movement. For this movement, in some countries despite many changes, the persistence of the psychiatric hospital demonstrates that the move away from institutionalization and the clinical model has not been accomplished.

The denial of the institutional aspect originates, above all, from the eradication of the asylum – replaced by the mental health centre, open and community-based. There is deception if the asylum continues as a hiding place for disturbed patients.

Basaglia, 1969

It is possible to identify two groups of European countries where deinstitutionalisation took place during the latter part of the twentieth century (Knapp et al., 2007):

1 – Countries where, after the 1970s, the notion of mental health care changed radically and the principles of community care took root very rapidly (Italy, Sweden);

2 – Countries where the shift from public hospital to community care was slower and is far from being accomplished (England, France, Germany, etc.).

At present, despite decades of deinstitutionalisation in many countries of the world, resources for mental health are inefficiently utilised. Globally, 63% of psychiatric beds are still located in mental hospitals and 67% of mental health spending is directed towards these institutions (WHO, 2011, p. 10). Community mental health services are still under-developed in many countries in the world.

### 1.3 Community Mental Health Policies

Patients are primarily citizens. Nevertheless, they are often subjected to rights violations, stigma and prejudice. In many places persons with psychosocial disabilities live in a condition of economic marginalisation and are often deprived of their freedom, they may be exposed to degrading or painful treatments and can have difficulties in accessing health care (WHO, 2005b, pp. 4 – 8).

The objectives of sound legislation, in terms of ease of access to care, are to prevent inappropriate institutionalization and to provide for appropriate facilities,



services, programmes, personnel, protections and opportunities, in order to allow persons with psychosocial disabilities to stay in the community.

Not only are community mental health services more accessible to people living with severe mental disabilities, they are also more effective in taking care of their needs compared to mental hospitals. Neglect and violations of human rights, which are too often encountered in mental hospitals, are less likely within community mental health services.

B. Saraceno, 2007

WHO recommends (WHO, 2005) that mental health care is available at community level for anyone who may need it, and supports the development of a public community mental health system linked with the public health care system.

WHO also recommends (WHO, 2001) that good national policies in mental health should aim to provide integrated mental and physical treatment and care through primary care;

- Integrate mental health issues into broader health policies, programmes and partnerships.
- Integrate mental health into services during and after emergencies.
- Include mental health issues within social services development, including housing.
- Mainstream mental health issues into education.
- Include persons with psychosocial disabilities in income generating programmes.
- Strengthen human rights protections for persons with psychosocial disabilities
- Build the capacity of persons with psychosocial disabilities to participate in public affairs.

#### **1.4 The Network of Community Mental Health Systems**

The community mental health system promotes mental health by clinical and psychosocial interventions tailored to the individual patient and by the general promotion of mental health within the community.

The community approach uses a network of decentralised services which comprises (Funk et al., 2010):

Primary health care This is the entry level to the health system. Usually composed of a primary health care doctor and nurse, who provide the assessment and treatment of general health conditions. In some countries general practitioners are required to attend an in-service training on mental health that provides basic knowledge about identification and treatment of mental health disorders. Furthermore, to make the system work properly, it is important that primary health care doctors or nurses are able to refer patients to the right service in the network.

Mental health outpatient facilities These are services specialized in the management of mental health disorders and related clinical problems with staff specifically trained in mental health. They are the hub of a community mental health care system.

Mental health day treatment facilities They provide care for users during the day. These services operate for one or more days a week; they provide specific programmes and therapeutic activities and are also linked with the psychosocial approach.

Psychiatric ward in a general hospital Reserved for acute cases.

Community residential facility A non-hospital, community-based mental health facility that provides overnight residence for people with mental disorders. Mental health care network activities include the promotion of mental health in the community involving the whole population in the context of everyday life.

Activities also encompass measures taken to maximize mental health and well-being among populations and individuals by operating on the potentially modifiable factors underlying mental health. These social and economic factors include income, social status, education, employment, working conditions, access to appropriate health services and the physical environment.

Mental health promotion works at three levels (mentality, 2003) and at each level is relevant to the whole population as well as to vulnerable groups and people with mental health conditions.

Strengthening individuals This kind of action aims at increasing emotional resilience through interventions designed to promote self-esteem, life and coping skills. Examples include mother–infant programmes that enhance the quality of parental relations and can substantially reduce anxiety and depression, promoting a better-organized family life and providing a stimulating environment for children.

Strengthening communities These are actions that increase social support, social inclusion and participation. Some projects provide better neighbourhood environments by promoting childcare and self-help networks or by improvements in the work environment. An effective community development (WHO, 2005a, pp. 220 – 250) also results in improved mental health. This approach focuses on the social, economic, environmental and cultural well-being of communities, with particular attention to poor and marginalized people. It brings people together and uses participatory methods to help them make informed choices, identify solutions to common problems based on local priorities and take collective actions. Furthermore, as a large part of adult life is spent in a work environment, the approach aims to enhance employers' awareness and to create a positive balance between job demands and occupational skills.

Reducing structural barriers to mental health These initiatives are aimed at reducing discrimination and inequalities and at promoting access to education, meaningful employment, housing, services and providing support for those who are vulnerable (mentality, 2003). The work and educational environments should be free from all forms of discrimination and sexual harassment. Employment should be used as a mechanism to reintegrate people with mental illness into the community.

### **1.5 Mental Health in Low- and Middle-Income countries**

Some studies show that mental illnesses and poverty interact in a negative cycle in low-income and middle-income countries (Lund et al., 2011). Mental illness represents one of the highest burdens of all diseases, and is a major factor in perpetuating poverty. Currently, only 36% of people living in low-income countries are covered by mental health legislation. In contrast, the corresponding rate for high-income countries is 92%. Furthermore, outpatient mental health facilities are 58 times more prevalent in high-income than in low-income countries (WHO, 2011, p. 10).

The major barriers to scaling up mental health services in countries with low and middle incomes include difficulties in the decentralization process, inadequate resources and absence of political commitment. Additionally, in low-income countries there are great difficulties in the process of integrating mental health into primary care and a shortage of community mental health trained personnel (Eaton et al., 2011). Over the last five years many countries have reviewed their mental health policies, but despite this progress, plans and resources are often largely inadequate.

Several global programmes that aim at supporting efforts to scale up community mental health services can be identified in recent literature. WHO, with the Mental Health Gap Action Programme (WHO, 2010), promotes specific actions to reinforce the commitment of stakeholders to increase the allocation of financial and human resources for the care of people with mental

health disorders. Globally, a large movement, which includes service users, professionals, non-governmental organisations and other civil society actors, advocates increased coverage of evidence-based interventions, especially in low- and middle-income countries (Eaton et al., 2011).

The social and cultural context of a country has to be taken into account when planning a local intervention and it is also useful to identify local personnel who can assist in the detection of mental illness, facilitate treatment and care, and provide training, supervision and service delivery (Mendenhall et al., 2014). Many of the programmes that aim at improving mental health services in low-income and middle-income countries are focused on promotion of community-oriented services. CBR is a strategy endorsed by WHO for general community development for the rehabilitation, poverty reduction, equalisation of opportunities, and social inclusion of all persons with disabilities (Iemmi et al., 2013). CBR has proved to be effective in dealing with physical and sensorial disabilities, but there are few indications of its validity in mental health care. For this reason, AIFO has started an experimental project to evaluate its effectiveness in mental health care in low- and middle-income countries. In the following chapter we introduce the concept of CBR and its applications in mental health care.

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## CBR Process, Resources, Principles



## 2.1 CBR: an historical introduction

Community Based Rehabilitation (CBR) is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all persons with disabilities (WHO 2004, p 2). There are over one billion people with disabilities in the world, of which between 110 – 190 million experience quite significant difficulties (WHO 2011). Since 1976, the WHO has been strongly advocating for the application of the CBR strategy through a number of publications.

The CBR concept was firstly introduced in 1976 in an unpublished WHO report (Finkenflugel 2004, p 3) as a promising strategy to provide rehabilitation resources for persons with disabilities living in low- and middle-income countries. In that publication, the WHO recommended the provision of essential services and training for persons with disabilities through this community-based innovative methodology.

The outcome of the International Conference on Primary Health Care, held in September 1978, was the Declaration of Alma-Ata<sup>3</sup>. The conclusions of the conference highlighted the large inequality in people's health status, particularly comparing high-income and low- and middle-income countries. It then recommended Primary Health Care implementation as essential health care program, based on practical, scientifically sound and socially acceptable methods. Primary Health Care was conceived to be universally accessible for individuals and families in the community through their full and active participation and at an affordable cost for the countries.

Following the adoption of the Alma-Ata declaration and being committed to the goal of *Health for all*, WHO introduced the CBR.

According to the WHO report, 7 – 10% of the world's population had a disability and this condition lead to serious social, economic, physical and psychological difficulties. Unfortunately, no more than 2% of people in need of some kind of rehabilitation could be addressed adequately and the Institutionally-Based Rehabilitation (IBR) could not meet the demands (Finkenflugel 2004, p 6) due to the high functioning costs.

At first, CBR was mainly a service used to identify potential users in order to ensure a proper use of primary health care and community resources. Also, it aimed at bringing persons with disabilities closer to primary health care and rehabilitation services, especially in low- and middle-income countries. In 1981, the WHO Expert Committee on Disability Prevention and Rehabilitation published a document (WHO 1981, p 9) which included the definition of CBR as a process that involves “measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped person themselves, their families and their community as a whole”. The experts group proposed several recommendations and steps to implement CBR in developing countries:

- Awareness raising efforts to change the widespread perception of rehabilitation as institutional care, implying high costs and low effectiveness.
- Government commitment to ensure sustainability of programmes through the allocation of adequate resources in countries.
- Development of a government programme which should integrate prevention and rehabilitation into the existing community and primary health care services.

<sup>3</sup> International Conference on Primary Health Care, Alma-Ata. USSR, 6 – 12 September 1978

- Training and recruitment of local operators, involving existing professionals and institutions.
  - Use of local skills to develop the necessary technical aids for the rehabilitation (orthopedic appliance).
  - Systematic evaluations of new techniques and methods, conducted by independent experts and also a consumer evaluation completed by persons with disabilities themselves.
  - Promotion of studies and research on the CBR approach, preparing and testing alternative training modules for persons with disabilities, their families, professionals, and local supervisors.
- During the following years, WHO has continued to promote a community-based approach, publishing the manual *Training in the Community for People with Disabilities* (Helander et al. 1989), an important and successful publication in the disability world. It has been a reference point in the debate on disabilities rehabilitation for many years (WHO 2006). Persons with disabilities and workers of all groups, including community workers and experts, provided their views and suggestions for the development of the manual. Various versions were released during the eighties (1980, 1983 and 1989). It has been translated in more than 50 languages and used in over 60 countries.
- The manual consists of modules divided in 4 guides and 30 training packages. Each guide addresses a specific target group: local supervisors, community committee, persons with disabilities and schoolteachers. The training packages were provided to family members of people with various disabilities (Helander et al. 1989, p 11).

The packages addressed various conditions:

- People who have difficulty seeing
- People who have difficulty speaking and hearing or speaking and moving
- People who have difficulty moving
- People who have no feeling in the hands or feet
- People who have fits
- People who have difficulty learning
- People who show strange behavior<sup>4</sup>

The manual described the CBR as a large scale knowledge transfer regarding disabilities and rehabilitation skills to persons with disabilities, their families, and community members. It implied the involvement of the community in planning, decision making and evaluation of the programme.

The publication classified three levels of referral services<sup>5</sup>:

- District Level: basic diagnostic services, medical services and medical treatment equipped with simple orthopaedic appliances, educational services for children and vocational services for adults (training and job placement).
- Provincial Level: diagnostic services for more complex medical conditions, medical services, surgery and treatment of complicated fractures equipped with orthopaedic appliances, complex rehabilitation not provided within district services, special educational and vocational services.
- National Level: highly specialized medical services with complex rehabilitation therapies; institutes of higher education for people living with low frequency disorders.

<sup>4</sup> This was the first reference to mental health care in relationship to the Community Based Rehabilitation. It was written by two psychiatrists of the WHO Division of Mental Health. (Harding & Orley 1989)

<sup>5</sup> As the authors highlighted, the tendency to launch the process at the national level resulted in a significantly high chances of failure as much of the total financial resources were used before reaching the lower provincial and district levels. To bypass this obstacle, the authors suggested to provide higher levels of support in response to community needs, right at the district level. (Helander et al 1989 p 23 – 25)



During the 1990s, along with the growth in number of CBR programmes, other UN agencies, such as the International Labour Organization (ILO), United Nations Educational, Scientific and Cultural Organization (UNESCO), United Nations Development Programme (UNDP), and United Nations Children's Fund (UNICEF) were involved, recognising the need for a multisectoral approach. In 1994, the first CBR Joint Position Paper was published by ILO, UNESCO and WHO (WHO 2010, p 23).

CBR programmes continued to grow in number during the following years; between 1978 and 2002 an ever-increasing quantity of papers on CBR were published (Finkenflugel 2005). Theoretical and descriptive studies were the most common types of papers in the CBR literature however, those who worked with and supported the programmes were not given the opportunity of meeting together, reviewing what they had done and discussing how to continue to use CBR as a strategy for disability rehabilitation.

## 2.2 The Helsinki Recommendations and the revised CBR Joint Position Paper

From 2000 to 2002, the WHO sponsored a series of meetings on CBR. It then invited stakeholders, including other UN agencies, international non-governmental organisations<sup>6</sup>, international organisations of persons with disabilities, and representatives of governments, to contribute to the CBR position paper review. The International Consultation was held in Helsinki May 25 – 28, 2003<sup>7</sup> and the working groups made some important recommendations directed to the various stakeholders:

### Recommendations to Disabled Peoples's Organisations (DPOs)<sup>8</sup>:

- 1 – CBR should be viewed as a strategy;
- 2 – CBR should be inclusive of all persons with disabilities;
- 3 – CBR should be for all, including people without disabilities;
- 4 – CBR should be used to address the essential need to build the capacity of DPOs;
- 5 – CBR must be based on human rights instruments in order to address the needs of people with disabilities;
- 6 – Define the roles of stakeholders;
- 7 – Advocate for the recognition of DPOs' expertise in CBR;
- 8 – Advocate for the development of legislation in support of CBR;
- 9 – Re-define the term "rehabilitation", overcoming the mere medical acceptance of the term

### Recommendations to Governments

- 1 – Develop a national policy on disability;
- 2 – Ensure CBR programmes are coherently and appropriately funded;
- 3 – Promote efforts to achieve the Millennium Development Goals<sup>9</sup> (MDG).
- 4 – Take a leading role in coordinating different stakeholders to promote a multisectoral approach to CBR.
- 5 – Provide capacity building and funding for local DPOs and other CBR users.
- 6 – Support the process to develop a UN Convention on the Rights of Persons with Disabilities<sup>10</sup>.

<sup>6</sup> AIFO – Associazione Italiana Amici di Raoul Follereau collaborated with the WHO in the preparatory phase of the meeting, to develop the background papers, available on the WHO web site

<sup>7</sup> World Health Organization. International Consultation to Review Community-Based Rehabilitation (CBR) Helsinki 25 – 28 May 2003

<sup>8</sup> The DPOs were asked to promote community participation, collaborating with the other sectors involved in CBR promotion and advocating for national policies on disabilities

## Recommendations to International and Local non-governmental organisations, Universities, and Professionals

- 1 – Facilitate coordination among all stakeholders:
  - Have a clear vision of CBR;
  - Have a clear understanding of the roles of all stakeholders;
  - Develop policies and clear strategies for coordination of services;
  - Promote coordinating bodies at different levels.
- 2 – Promote participatory evaluation and research programmes.

## Recommendations to UN Agencies

### Agencies Together Should:

- 1 – Promote CBR as a part of poverty reduction strategies and instruct the case that CBR itself as a poverty reduction strategy.
- 2 – Work to make disability a part of international, regional and national agendas.
- 3 – Promote disability as a Human Rights issue, support Human Rights instruments, including the proposed UN Convention on Disability.
- 4 – Work to create thematic working groups on disability, involving DPOs.
- 5 – Plan follow-up to the Consultation and finalize the Joint Position paper on CBR.

In 2004, following the Helsinki recommendations, the ILO, UNESCO and WHO published the revised CBR Joint Position Paper. According to the amended definition, CBR was to be implemented through the combined efforts of persons with disabilities themselves, their families, organisations<sup>11</sup> and communities, and the relevant governmental and non-governmental health, education, social and other services (WHO 2004, p 2). Persons with disabilities were to have access to all the services which are available in the community, including social welfare and education programmes.

### Objectives of the strategies:

- To support people with disabilities to maximize their physical and psychosocial abilities, to access regular services and opportunities in their communities to become active contributors to the community.
- To promote and protect the human rights of people with disabilities within the community, for example, by removing barriers to their participation.

To address these important elements of CBR, actions were to take place at national, district and local levels.

## **2.3 Disability: evolution of a definition**

The 1980 ICIDH provided a conceptual definition of disability, described “as 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 1980, p 28). This concept was quite different from that of impairment and handicap<sup>12</sup>.

During the following three decades the concept of disability had profoundly changed and it was no longer viewed as merely the result of an impairment. The medical model of disability, which defined the functional limitation as the root of all the disadvantages experienced by people, had been replaced by the

<sup>9</sup> The Millennium Development Goals (MDGs) are 8 development objectives set by the UN for the global community. These regard the reduction of poverty and child mortality, the improvement of maternal health, primary education and gender equality, combat HIV, ensure environmental sustainability, find a global partnership for development (United Nations, 2014)

<sup>10</sup> The Convention on the Rights of Persons with Disabilities has been eventually developed and adopted by UN on January 2007

(UN General Assembly Sixty-first session, resolution 61/106, 24 January 2007)

<sup>11</sup> The first version of Joint Position Paper on CBR prepared in 1994, asked for the involvement of different community organisations in CBR, including DPOs, but did not assign them a specific role. In the revised version, ten years later, DPOs are called to take meaningful roles in the initiation, implementation and evaluation of CBR programmes. (2013)

social model (Crow 2007, p 3) which redefined disability as a social issue and solutions began to focus on removing barriers and on social change, rather than just providing a medical cure.

Persons with disabilities include children born with cerebral palsy, wheelchair users, persons who are blind or deaf or people with intellectual impairments or people with mental disorders as well as people who are subject to non-communicable and infectious diseases, neurological disorders, injuries, and conditions which result from the ageing process (WHO 2014, p 4).

It is estimated that 650 million of people in the entire world population have a disability. Often these people are marginalised, experience extreme poverty conditions, live in institutions, do not receive education and do not have access to employment opportunities. In some countries they are denied the right to own property and are prevented to self-determination. 80% per cent of them live in low- and middle- income countries.

Continuing its evolution path, over the time the concept of disability has been added to the broader context of human rights and it is now defined as the result of the interaction between people with impairments and attitudinal and environmental barriers which hinder their full and effective participation in society on an equal basis with others (United Nations 2010, p 15).

The entire concept of disability has reached a turning point with the entry into force, in May 2008<sup>13</sup>, of the Convention on the rights of persons with disabilities (CRPD). This treaty places disability within the human rights framework, demanding the elimination of whichever legal, economic, political and environmental conditions that may act as barriers to the fulfilment of rights by persons with disabilities.

Following the adoption of the CRPD, the UN established the Committee on the Rights of Persons with Disabilities<sup>14</sup>, comprised by independent experts who monitor the implementation of the Convention (Committee on the Rights of Persons with Disabilities 2014, p 9 – 11).

By August 2014, more than 180 countries had signed the Convention. State parties are expected to send regular reports to the Committee, within two years from ratification and very four year thereafter, on how the rights are being implemented.

There is a constant collaboration between the Committee and DPOs. Moreover, both DPOs and civil society organisations are welcome to submit written submissions and to attend as observers to the Committee's sessions when the draft general comment is read or adopted.

The convention prohibits all forms of discrimination on the basis of disability. Persons with disabilities are entitled to equal law protection and benefits in terms of accessibility, right to life, liberty and security of people.

Furthermore, in article 19, the Convention establishes their right to live in their own communities.

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community

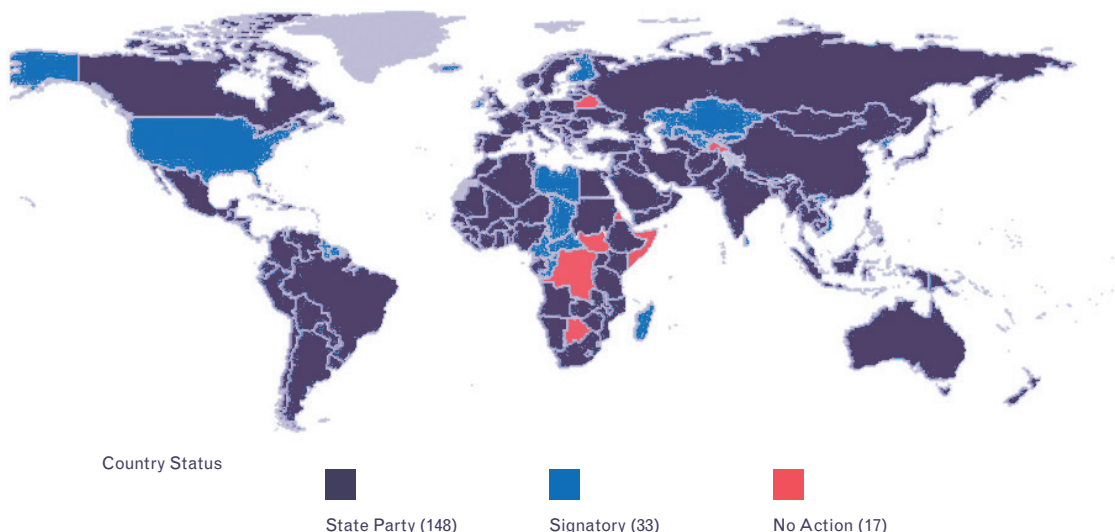
UN CRPD art.19

<sup>12</sup> An impairment was defined as loss or abnormality of psychological, physiological, or anatomical structure or function. A handicap was described as a disadvantage resulting from an impairment or a disability, that limits the fulfilment of a role that is normal for that individual. (WHO 1980, p 27 – 30)

<sup>13</sup> The Convention on the Rights of Persons with Disabilities opened for signature on 30 March 2007 and entered into force on 3 May 2008 (UN 2008)

<sup>14</sup> UN – CRPD art 34, 2007

## Convention on the Rights of Persons with Disabilities



Ratification of the Convention on the Rights of Persons with Disabilities, August 2014 <http://www.ohchr.org> © OHCHR

The relationship between this new “rights-based approach” to disabilities and the CBR theoretical and practical background is clear.

CBR strategy works along the lines of the principles enshrined in the UN Convention such as promoting respect of human rights, developing inclusive policies and eliminating disabling barriers, with the common goal of finding a solution to the disadvantages that persons with disabilities experience in their lives.

The involvement of the disabled people’s movement as stakeholder in the policy-making on disability and the role of an inclusive community have been seminal in this shift of perspective (WHO 2011b p 28).

The concept of an inclusive community means that it adapts its structures and procedures to facilitate the inclusion of persons with disabilities, by tackling barriers and working with DPOs and with organisations of parents of children with disabilities.

### 2.4 Effectiveness of CBR strategies

The CBR, in comparison to the IBR, shows some advantages (Finkenflügel 2004):

- Quality: Rehabilitation within community allows for participation in family and community life.
- Coverage: Institutions, if existing at all, can only provide rehabilitation for a limited number of persons with disabilities and only for certain types of conditions. Through CBR, instead, it is possible to potentially reach all persons with disabilities.
- CBR not only enables people with disabilities to develop their abilities but also influences their attitudes and physical environment.
- CBR is far more cost-effective than IBR.

Along with the development of CBR, a range of monitoring and evaluation approaches and methods have gradually been developed. The earliest study on the CBR impact was published by Mendis and Nelson (1982). Several hundreds of articles on CBR development were published between 1978 and 2012, but it was difficult to determinate the real focus of research in CBR (Finkenflügel 2005). Right from the start, the CBR concept was applied very differently. CBR is a complex process, with many people involved in a real community

environment. The outcomes of a project cannot be easily compared due to specific interventions and furthermore, qualitative studies are more frequent than quantitative. Consequently, it is difficult to maintain or improve these outcomes and to compare them within different circumstances or other projects (Finkenflügel 2004, p 17).

Only few articles relate to studies based on concrete interventions and are structured following a “before-after” model. Instead, it is found that most of them have had to retrace the conditions pre-existing to the intervention. Several studies are descriptive case reports and share a common structure: an overall picture of the country with a brief analysis of the perceived needs of persons with disabilities, and the available services given, followed by a description and discussion of the implementation process (Finkenflügel 2005). In a review of 30 articles published between 1987 and 2002, CBR seemed to have had positive results. Following are the conclusion of the study (Mannan & Turnbull 2007):

- CBR is highly effective and valuable for persons with disabilities in the community;
- CBR makes it easier to include persons with disabilities through education programmes;
- CBR makes it possible to train generic community workers in delivery of rehabilitation and prevention services to persons with disabilities and their families.

Notwithstanding the limitation described above, it is safe to state that CBR-type programmes have been evaluated as effective (WHO 2010, p 27). The outcomes for persons with disabilities include increased independence, enhanced mobility, and greater communication and livelihood interventions have resulted in raise of income for them and their families, which leads to higher self-esteem and greater social inclusion.

The need to facilitate and improve the effective evaluation of CBR programmes through a common research framework paved the way for a group of expert to agree on the need of developing best practices guidelines. Putting together such expertises and the available literature, the CBR guidelines were designed (Grandisson et al. 2014). CBR experts recognised the disability complexity and sought to address it.

The debate on these issues has lead to the new WHO, UNESCO, ILO, and International Disability and Development Consortium (IDDC) CBR guidelines and matrix (Hartley 2009).

## 2.5 The 2010 CBR Guidelines and Matrix

In 2010, after the entry into force of the CRPD, the WHO together with other partners published the CBR Guidelines, an instrument addressing operators, persons with disabilities and their families and providing practical indications on how to develop CBR programmes.

The contents of the guidelines were chosen from a range of publication, case studies and unpublished sources of best practices in international and community development (WHO 2010, p 13).

The CRPD is a legal instrument based on the human rights approach which reinforces the CBR programmes. At the same time, CBR principles contribute to achieve the CRPD implementation (AIFO 2009). In fact, CBR can be considered a practical strategy to implement the UN Convention and to support community-based inclusive development.

The CBR matrix provides a visual representation of CBR functions. It consists of five key components, each divided into five key elements. Each of these elements has a dedicated chapter in the guidelines.

The guidelines are made up of an introduction on the basic concepts of the

CBR and seven booklets. The first six booklets examine a specific aspect of the CBR matrix while the seventh introduces four specific issues separately, such as mental health disorders, HIV/AIDS, leprosy and humanitarian crises. They are in fact included in CBR application but, for historical reasons, they are still overlooked when implementing CBR.

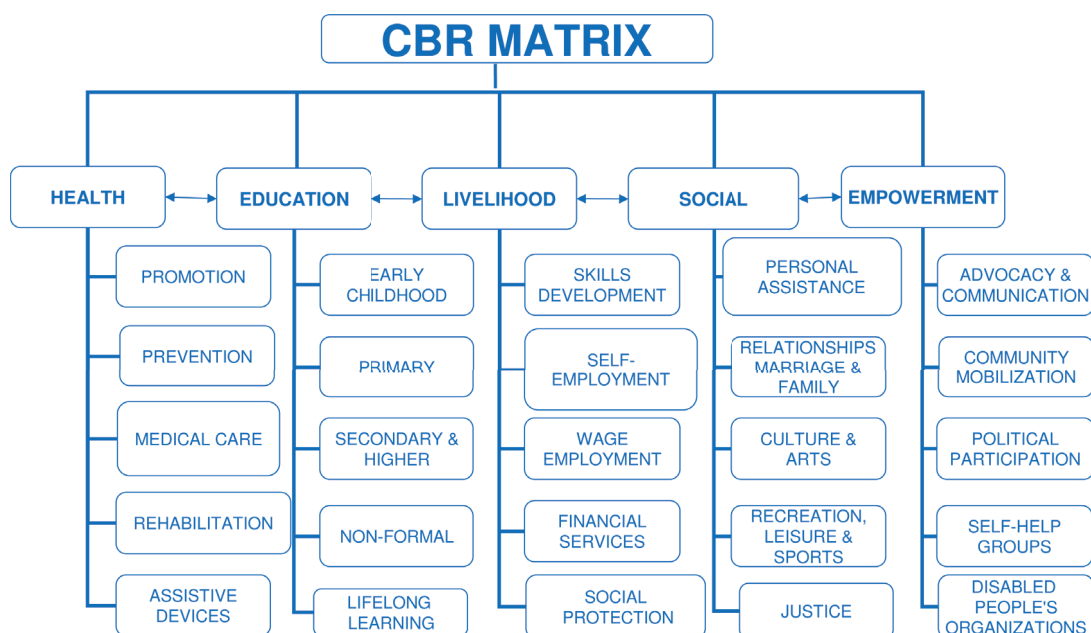
The new Guidelines represent a reference point in the development cooperation programming. They come after widespread application of CBR in many countries, through various mechanisms and in profoundly differing contexts. Furthermore, the CBR Guidelines call for a much greater integration of many different services, like transportation, education, healthcare, welfare and sports that need to be considered when the CBR actions are planned (MacLachlan 2012).

The first issue is health care: in many countries CBR programmes facilitate access to health care for persons with disabilities by working with primary health care in the local community. CBR can be a bridge between them and the health care system, working on prevention and rehabilitation, with activities focussing on health worker training or directly with activities carried out in collaboration with persons with disabilities themselves<sup>15</sup>.

The second issue is education: the role of CBR is to facilitate the creation of an inclusive local school system for children and students with disabilities, to support them and their families in accessing primary education in their local community, and to provide young people and adults with disabilities with continuous learning opportunities, in order to prevent marginalisation<sup>16</sup>.

The third issue is livelihood: persons with disabilities need to access social protection measures and need to be able to achieve personal growth. CBR programmes may be helpful as they encourage specific training in the community as well as working to increase equal access and treatment in workplaces<sup>17</sup>.

The fourth issue is the social component, whose aim is to promote the full participation of persons with disabilities in the social life of their families and communities. The actions seek to encourage them to participate in cultural, social and political activities so as to favour the overcoming of stigma and prejudice<sup>18</sup>.





The fifth issue is empowerment: often people with disabilities have very few opportunities for self empowerment and suffer from low self-esteem; however CBR can activate processes favouring a change of attitude by reinforcing the empowerment process with actions aimed at developing capacity building and peer support. It is important to promote self help groups activities and work together with DPOs.

While all CBR programmes are different, there is a universal sequence of stages that can help as a guide to their development:

- 1 – Situation analysis: in this stage, actions focus on assessing the needs and problems of the community with respect to persons with disabilities and to identify issues to address.
- 2 – Planning and design: in this stage, stakeholders identify the actions that need to be included in the CBR programme in order to promote rehabilitation in the community; they plan how and when to start such actions.
- 3 – Implementation and monitoring: in this stage, the programme is carried out and there are regular monitoring and review done to correct or implement any new issue.
- 4 – Evaluation: the evaluation of the outcomes and the assessment of the overall impact of the programme are set in this phase.

## 2.6 CBR and mental health

In the handbook *Training in the Community for People with Disabilities* (Helander et al. 1989), mental health disorders were included in training packages. The training package was addressed to parents and relatives of an adult who showed strange behaviour, with clear reference to psychosis and correlated disorders.

The 2010 CBR guidelines include a supplementary booklet which contains a specific chapter on the correlation between CBR and Mental Health (WHO 2010b, p 3). The guidelines discuss typical mental health issues, stigma, human rights violations and difficulty in accessing general health care for persons with mental health disorders. This book recommends the implementation of actions to promote mental health, facilitate inclusion in CBR programmes, overcoming stigma and discrimination in the community, help of family members, supporting the recovery process and facilitate access to livelihood opportunities.

As mentioned earlier, WHO includes mental health issues in possible determinants of disabilities, but in practice, CBR projects have often been set up for limited and selected groups of persons with disabilities, especially people with low or reduced mobility, or age groups, like children with mental retardation. Despite the fact that mental health has always been a disability issue, CBR programmes have traditionally excluded people with psychosocial disabilities from their plans (WHO 2010b p 1 – 7).

Despite this, a small number of experiences demonstrate that CBR strategies could be used to meet the complex needs of persons with severe mental health disorders in underserved settings (Chatterjee et al. 2003).

People who experience mental health conditions or intellectual disorders appear to be more disadvantaged in many settings than those who experience physical or sensory impairments (WHO 2011b, p 8).

The new attention of the CBR guidelines focussing on mental health conditions,

can be the start point of a change of perspective in mental health care activities in low- and middle-income countries.

According to a rights oriented approach to mental health, rehabilitation means “to construct (reconstruct) real access to the rights of citizenship and the progressive exercise of these rights, to create the possibility of having them recognised and of activating them, and the ability to practice them” (Rotelli 1999). Therefore community mental health rehabilitation regards the construction of the exercise of rights, the development of exchanges and practices aimed at co-operation (towards social enterprise) (Rotelli 1999).

Following these principles, CBR represent an innovative methodology to promote and protect the rights of persons with psychosocial disabilities and facilitate their inclusion in communities at every level. Furthermore, poverty, hunger and marginalisation can worsen their situation so community and economic development can be used to restore and enhance mental health.

These are the outcomes included in the guidelines (WHO 2010b, p 7 – 20):

- Increase the evaluation of Mental health importance for community development.
- Promote the inclusion of persons with mental psychosocial disabilities in CBR programmes.
- Reduce stigma and discrimination towards persons with psychosocial disabilities in the community.
- Facilitate the access to medical, psychological, social and economic interventions to support the rehabilitation process of persons with psychosocial disabilities.
- Support family members as far as their practical and emotional burden.
- Support the empowering process, with increased inclusion and participation in family and community life.

In the next part of this publication we will present the results of a three-years project focused on CBR approaches in mental health programmes in three low- and lower middle-income countries, Indonesia, Liberia and Mongolia.



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# Community Mental Health Services and Human Rights: Multicountry project

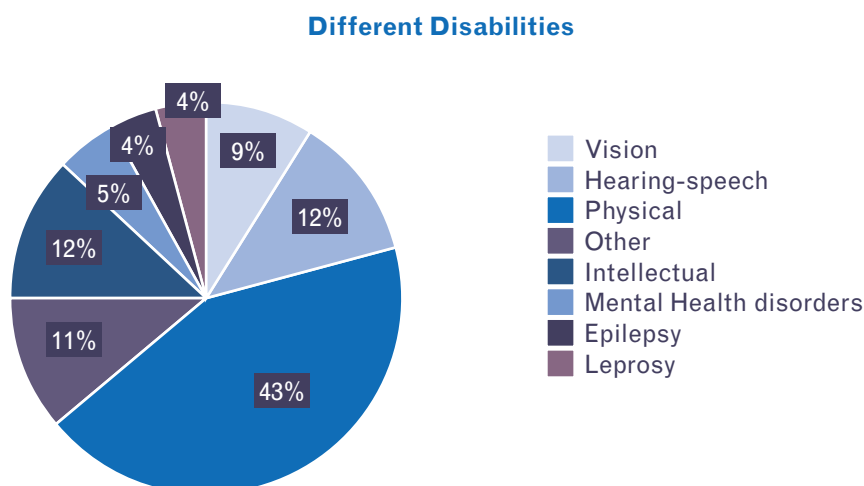


While in the previous chapters we have discussed the international context concerning the development of mental health services at community level and the opportunities that the CBR methodology has opened in the mental health field, here we resume the main features of the international project that AIFO started in 2011 in four low- and middle-income countries. The following chapter will discuss experiences in each of the four country separately.

### 3.1 AIFO

AIFO is an international non-governmental organisation, active since 1961, inspired by the work of French journalist Mr. Raoul Follereau (AIFO 2012). International activities carried out<sup>19</sup> are mainly in two areas: the fight against leprosy and its integration in primary health care services and promoting, supporting and coordinating CBR programmes open to persons with different disabilities, including those caused by leprosy, and persons with mental health disorders. In order to achieve these goals, AIFO relies on the collaboration and networking with other NGOs and governmental institutions and alliances, building alliances and synergies with them.

AIFO supports projects in 20 countries focussing on Community Based Rehabilitation, disability and human rights, leprosy control and rehabilitation, mental health, children at risk and maternal health.



Different groups of persons with disabilities in AIFO supported CBR projects

The work of AIFO includes people with psychosocial disabilities, whom are the most marginalised and excluded groups in a number of societies. Indeed stigma and discrimination, associated to a severe condition of vulnerability, often determines a situation of poverty and human rights violation (Funk M. et al. 2010: IX).

In 2009, During the first Asia-Pacific CBR congress, in 2009, AIFO/Italy (AIFO 2011) organised an international workshop on *CBR and Mental Health* which

<sup>19</sup> AIFO's head-office is in Bologna, in the northern part of Italy. AIFO has about 60 groups of volunteers spread all over Italy. Besides the international activities described in the chapters, AIFO carries out specific activities in Italy which are related mainly to education on development issues (AIFO 2014)

concluded that there was an overall lack of understanding, knowledge and skills about management of persons with mental health disorders. Later, in 2010, AIFO supported the publication of the WHO sponsored work on *Mental health and development: targeting people with mental health conditions as a vulnerable group*, with a foreword in which the Italian NGO affirmed its purpose to use the recommendations of that report in its work for preparing and implementing mental health programmes (Funk M, et al. 2010).

### 3.2 The project protocol

The focus of this research is on the *Multicountry project on small pilot initiatives of promoting and strengthening community mental health*, managed by AIFO/Italy and co-funded by the European Union. This project has been implemented since December 1, 2011, involving 4 countries<sup>20</sup>: the urban area of Salvador in Bahia state of Brazil, the South Sulawesi province in Indonesia, urban area of Monrovia in Liberia and the urban district of Ulaanbaatar in Mongolia (AIFO 2011).

In three of these four countries CBR programmes were already active, so the project could be implemented in collaboration with existing local programmes. In Brazil, where the program was yet to be initiated and implemented, a thorough investigation on the quality of mental health services with respect to human rights was initiated.

Because of these differences in the activities to be implemented in the countries involved, the project acquired two different purposes (AIFO 2011):



Graphical representation of the target countries, re-elaboration from <http://aifomentalhealth.wordpress.com/about/> (AIFO 2014)

<sup>20</sup> In the preliminary phase, the countries involved in the project were five involving also Egypt which later on dropped out of the project due to political instability.

- 1 – Understanding the barriers faced by persons with mental health disorders in accessing CBR programmes and promoting strategies for their inclusion (CBR component of research).
- 2 – Understanding the quality of a mental health services institution in terms of respect of human rights and monitoring pilot strategies to improve the situation (Quality rights component of research, carried out especially in Brazil).

### **3.3 CBR component of the research**

The first goal of these interventions had been to understand which kind of difficulties people with psychosocial disabilities were facing in their participation in different CBR activities.

In each country, all project activities have been coordinated by at least one person identified by the local partner as a focal point for the project, who has worked in close collaboration with AIFO head office CBR programme and mental health services participating in this project.

At the onset, each CBR worker who had at least 2 years of experience with CBR programmes, participated in a 4/5-hours Focus Group Discussions (FGD), so as to better understand the baseline of the CBR operators attitudes, knowledge and skills about mental health conditions and about people with mental health disorders. The FGDs have continuously been convened during the three years of the project as qualitative instrument to gather data, compare opinions, elaborate strategies.

Elaborating from the baseline data results, appropriate training has been organised in each of the target country so as to strengthen the capacity of each CBR programme to be more inclusive of persons with mental health conditions. Trainings and meetings have been the main instrument to promote inclusion and a change of mentality about their role in community activities. The desirable changes related to the inclusion of persons experiencing mental health disorders in CBR programme activities have been evaluated through reports and monitoring activities.

The monitoring activities of inclusion of persons with mental health conditions in different CBR activities have been carried out through a questionnaire and FGDs with them directly and their family members. These FGDs were aimed at involving them in the monitoring activities and at allowing them to share their experiences and participate to CBR activities.

FGDs, activities reports and related comments of the national advisory group were subsequently sent to the project manager in AIFO head office. These documents represent an important information source for this publication, to understand the impact of the project in CBR activities.

### **3.4 Quality rights component of research**

In Brazil, the aim of the project was to monitor human rights respect in mental health care facilities (AIFO 2011). Indeed, sometimes, the health care settings are places where persons with mental health disorders are subject to discrimination and human rights violation, and have no form of protection (WHO 2012).

This part of the project used the "WHO QualityRights Tool kit to assess and improve quality and human rights in mental health and social care facilities" as an instrument to monitor the human rights situation in health facilities. The tool kit has been developed by the WHO, Department of Mental Health and Substance Abuse (Associate to the multicountry project). This is a powerful instrument based on an extensive international review carried out by persons with psychosocial disabilities and their organisations. It has been tested in low-, middle- and high-income countries and is designed to be applied in all of these resource settings (WHO 2012).

Five themes, drawn from the CRPD (United Nations 2007), are covered by the tool kit:

- The right to an adequate standard of living and social protection (Article 28 of the CRPD).
- The right to enjoy the highest attainable standard of physical and mental health (Article 25 of the CRPD).
- The right to exercise legal capacity and the right to personal liberty and the safety of person (Articles 12 and 14 of the CRPD).
- Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the CRPD).
- The right to live independently and be included in the community (Article 19 of the CRPD).

The first step to implement WHO QualityRights tool kit has been to establish a project management team which could provide guidance and coordinate the activities of the operators who carried out the assessment. The research found that is important for this kind of team to have an influential local partnership, to be able to assess the project effectively (WHO 2012), the local partnership was with the Secretary of Health of the State of Bahia, Mental Health Technical Area. The assessment has been conducted by an Evaluation Committee, which was formed by users of the facility, family members, mental health professionals, civil society representatives who had received specific training on human rights standards. The project provided a specific training to introduce the different tools the WHO Tool kit was made of: observation, documentation review, interviewing and reporting the results). This training showed how to use the WHO QualityRights tool kit, describing the WHO tool kit, and providing a guidance on the assessment process, with specific practical exercises.

The project in Brazil involved several facilities identified by the implementing partner, SESAB Secretaria de Saúde do Estado da Bahia (Ministry of Health). The Hospital of Custody and Treatment (HCT) of Bahia was the initial location identified as the project headquarter, however, due to an accident occurred to the infrastructure, the location was moved to Hospital Juliano Moreira (HJM), a vast psychiatric hospital in Salvador where SESAB and the CAPS III Alagoinhas, a mental health centre in the municipality of Alagoinhas, could identify opportunities for de-institutionalisation.

The following chapter will explain how results achieved in the last three years of the project were gathered, then specific actions promoted in each country are described.



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# Methodology



## 4.1 Methodology in the three case studies using CBR settings

The purpose of these case studies is to summarise the status of the mental health and community based rehabilitation programmes in three projects that AIFO has started in 2011 in Indonesia, Liberia and Mongolia. This part of the research aims at promoting an understanding of the different issues related to the inclusion of persons psychosocial disabilities in CBR programmes.

This part of the publication provides an overall synopsis of the available services in the concerned countries, with a brief analysis of the perceived needs of persons with disabilities and the evolution of their plight in the recent past. This will be followed by a description and discussion of the project implementation process.

This research reinstates an overview of the implementation process through a descriptive lens. Given that theoretical papers and descriptive studies prevail over evidence-based reports, this analysis represents a valid method to describe the CBR implementation processes (Finkenflügel 2005).

The descriptive general situation has been identified by using baseline reports provided by the local teams and publications available in scientific literature. In particular, the organisation of mental health care and the presence of local CBR services have been examined.

The Mental Health Atlas (WHO 2011), published by the WHO in 2011, provided general information about mental health care systems in the three target countries. Furthermore, an historical review of published literature has been conducted on each country's policies affecting mental health systems, including plans for progressive deinstitutionalisation.

The case report is based on various data, primarily collected by collaborative local teams, which include:

- Specific local publications and research protocols.
- Monthly reports, written by the local team, regarding organisational aspects of the activities.
- Annual planning of the activities.
- Annual reports of the activities.
- Reports of the meetings with the stakeholders.
- Local focus groups activities and recommendations.
- Other local issues.
- Information collected by a semi-structured questionnaire, sent to the local teams in July 2014
- SWOT analysis

### Local Publications and supplementary protocols

AIFO and The Carter Center worked together to write a 20 page paper by the title *Report on Comparative Study of Community Mental Health in Low and Middle Income Countries: Liberia Case Study* (Cooper & Libanora 2013). The paper focuses on the implementation of the project activities during the first and the second year, and describes Economic and Social Context for Persons with Disabilities, especially psychosocial disabilities, project activities and focus groups recommendations. This paper has been an important reference for the chapter which describes AIFO activities in Liberia.

### Monthly Reports

Many monthly reports have been examined and contributed to the clarification of activity timeline and the frequency of advocacy activities, focus groups and stakeholders meetings.

### Annual plans and reports

The local partners and the teams operating in each country have produced an annual report which describes achieved targets and strategies for the following year. These documents represent the evolution of the project activities and their environmental framework.

### Reports of the meetings with the stakeholders

CBR activities need to be carried out in partnership with persons with disabilities, CBR providers, partners and researchers, to ensure that all stakeholders' needs are understood and met (Lukersmith 2013). These meetings represent a practical instrument, together with the focus groups, to collect required data about persons with mental health disorders' needs and local strategies already operating within the communities.

### Focus Groups

A great advantage of having focus group discussions is that they represent an inexpensive and relatively quick means for data collection. Moreover, focus groups are an effective means to reduce distance between the target population and facilitators (van Wijngaarden 2012). The participant selection process is crucial, since they must represent the study population, namely mental health personnel, CBR workers, people with disabilities, mental health service users as well as other key stakeholders.

### Semi structural questionnaire

A 24 items questionnaire was sent to the local team and it can be found in Annex I. The questionnaire is structured in 14 domains, covering various aspects of the project. Particular attention has been given to environmental framework, implemented activities, along with assessed areas of strengths, weaknesses, opportunities and threats (SWOT analysis).

### SWOT analysis

As anticipated in the previous section, the last domain concerned an overall assessment of the project. We therefore asked the local focal points of the project to list strengths, weaknesses, opportunities and threats in relation to their experience in the programme (van Wijngaarden 2012). The purpose of performing a SWOT analysis was to reveal positive aspects that worked together and potential barriers which needed to be addressed or at least recognised.

All data, collected from these different sources, have been elaborated and they are being presented and discussed in the following chapters.

## **4.2 Methodology in the Brazil case study on mental health and human rights**

The United Nations CRPD represents the human rights-based paradigm that must be respected, protected and fulfilled within the facilities. The second part of the research, settled in Brazil, provides assessment and improvement of the human rights quality in mental health and social care facilities. These activities were carried out using the "Interview Tool" and the "Field Visit Tool" prepared following the WHO QualityRights Tool Kit (WHO 2012). In addition to the annual and monthly reports, the data collection in this project includes a specific questionnaire, based on the WHO tool kit and its evaluation. The questionnaire encompasses 14 domains, but it contains different and specific items in comparison with the questionnaire used in the first part

of the research. The SWOT analysis has been discussed in the final domain of the questionnaire.

In the chapter dealing with the Brazil case study, the programme implementation process and its different phases are described, however data collected during the facilities assessment operations were not included because the elaboration exercise was incomplete at the time the study results were written.

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# EXPERIENCES



## The Project in Indonesia



## 5.1 Introduction and Background

Indonesia is the world's sixteenth largest country in terms of land area and the fourth largest country in terms of population with its 239 millions of inhabitants. It is the largest archipelago in the world, located between Asia and Australia. There are five major islands: Sumatra, Java, Kalimantan, Sulawesi and Irian Jaya or Papua bordering with Papua New Guinea. The other islands are small and mostly uninhabited. More than 80% of Indonesia's land is covered with water; the land area is about 1.9 million square kilometres (WHO Country Office for Indonesia 2008 p 3).

Indonesia's strong economic growth has averaged 5.5 percent per year from 2002 to 2011, this feature has contributed to gains in poverty reduction and contributed to a growing middle class. Since the end of the nineties the country has successfully emerged from the Asian economic crisis and has carried out a complex transition from authoritarianism to democracy (World Bank 2012, p 1 – 3). At present the country is a stable democracy and has a self-assured middle-income economy with global and regional influence (World Bank 2012) but Indonesia is still a very heterogeneous country, and the different regions have developed in an unequal manner. The western areas (Sumatra, Java and Bali) have reached many goals in economic and health fields, and there is arranged a great concentration of wealth in these densely populated islands (Susilo D et al. 2012).

Despite the economic growth, Indonesia still has a vast lower income population (30 million) and over 65 million people barely live above the poverty line, furthermore inequality is growing among the population (World Bank 2012). The Human Development Index still ranks medium level (108 out of 187 countries), below other countries of the area, like Thailand and Malaysia (UNDP 2014) and Indonesia lacks several Millennium Development Goals, particularly in the field of Education and communicable diseases which continue to be the major cause of morbidity and mortality in Indonesia (WHO 2010).

South Sulawesi province is located in the centre of Nusantara archipelago, in the Sulawesi island, the economy is centred on agriculture commodity, plantation, livestock, fishery and mining. the main goal of South Sulawesi province's development is to improve economic growth with the transition from an agricultural to an industrial and service centre. South Sulawesi province consists of 23 districts and regents, with a population of 7.805.024 with the size of 62.482,54 km<sup>2</sup> (AIFO 2014).

The major mortality and morbidity causes are the communicable diseases. In particular malaria, tuberculosis and HIV represent great challenges for the health care system. The second cause of mortality is the tobacco related diseases, like cancer and cardiovascular diseases (WHO 2008).

The average provision of health facilities is adequate for the primary health care level, often offered in centres called puskesmas, but the situation varies sensibly, according to the geographical location, and the number of beds in the hospitals is small and concentrated in central cities (WHO 2008).

Regarding the health facilities in South Sulawesi province there are 31 Public Hospitals, 1 Mental Health Hospital, 42 Private Swasta, 423 Puskesmas (local community health centres) and 1.680 branch units of health care centres (posyandu) (Kaye & Novell 1994).

The project of AIFO was set in Gowa district, in South Sulawesi, which is composed of 18 sub-districts spread on a total area of 188.3 km<sup>2</sup> and with a population of 652 941 inhabitants. The health facilities in the district consist of one regional hospital, 25 community health centres, 119 branch community health centres, and 43 rural health centres (AIFO 2014).

## 5.2 Mental health care situation in the country

In Indonesia over 1 million people suffer from severe mental health disorders (Utami 2012), but mental health has long been neglected, and considered less important than other conditions, despite an estimated 12,3% loss of productive days due to mental and neurological disorders (WHO 2008). The lack of a mental health care system, especially emerges from the constant use of restraint measures called “pasung”. In the country, the use of physical restraint is extremely common still today, especially with low-income families (Puteh et al. 2011).

The history of psychiatry is related to the physical restraint. Several forms of restraint, including shackles, rope, stocks, cages, and being locked in confined spaces, are compulsorily applied to persons with mental health disorders in different parts of the world, both in and of mental health hospitals but historically, the prevalence of the restraints are related to the unavailability of affordable treatment (Minas & Diatri 2008). In Indonesia, pasung may last decades<sup>21</sup> and this determines profound change in the probability of rehabilitation of persons who have been restrained.

The government claims its diligent efforts against pasung and several political campaigns have been launched to achieve a sensible reduction of this phenomenon. Indeed pasung represents neither a product of the ignorance of families and communities, nor is it caused by the refusal of any psychiatric treatment, but by government's difficulties to provide basic mental health care services for persons with severe psychosocial disabilities (Minas & Diatri 2008). In Indonesia there is an officially approved mental health policy which was last revised in 2001 (Directorate of community mental health et al. 2001). In the context of the Health Law number 36/2009, articles 144 to 151 refer to mental health, which is also clearly mentioned in the general health policy, but a specific mental health legislation still doesn't exist (WHO 2011).

There are significant resources and personal limitations in mental health care, and the effectiveness of care activities is altered among the provinces. In the country there are 33 provinces and 438 districts but only 49 mental health hospitals. Eight provinces still do not have any mental health hospitals and 3 provinces have no psychiatrist at all (AIFO 2012).

The Ministry of Health has recently shifted its paradigm from a hospital-based mental health approach to one which is more community-based (WHO 2008). This decision has determined the publication of the priority program by the Directorate of Mental Health, whose objectives are (AIFO 2012):

- Fight against Pasung (Indonesia Free Pasung programs)
- Promotion of Community Based Services of Mental Health
- Provision of services in mental health centres & drugs in puskesmas & general hospital
- Improving the quality of mental hospital services
- Guarantee quick response telephone services (hotline service)
- Implementing counselling service for adolescents with mental health problems
- Training of health workers and promoters
- Monitoring & evaluation

Not only is the systematic recourse to restraint measures a significant violation of an individual's right to self determination but may also be associated with

<sup>21</sup> In a study in Aceh (Indonesia) regarding a group of 59 people, the duration of pasung varied from only few days to 20 years, with an average duration of 4.0 years (Puteh et al. 2011)

significant morbidity and mortality (Moosa & Jeenah 2009), and the prolonged physical restriction may cause physical disabilities such as depleted muscles, which makes the person unable to ambulate (Komalasari 2013). These procedures often hide organisation needs, inadequate facilities and inefficiency in mental health care operators training (Dell'Acqua 2009). So the development of basic community mental health services can help to provide an alternative to restraint procedures for families and for the community in Indonesia (Minas & Diatri 2008).

**5.3 Existing CBR activities**

In the early nineties the Government of Indonesia decided to establish an important CBR pilot programme. AIFO, in partnership with other NGOs, collaborated with the Indonesian Government, to implement the CBR Programme within the Government framework (Ortali 2000). During these two decades AIFO has strengthened the presence, in Gowa and Sidrap districts, of a CBR method which represents the framework of activities for persons with psychosocial disabilities.

**CBR IN SOUTH SULAWESI**

Data situation before mental Health project action

2 DISTRICT (SIDRAP & GOWA), 1 SUB DISTRICT (IN MAKASSAR)
POPULATION 383.926 people
11 LOCAL COMMUNITY HEALTH CENTRES
477 persons with mental health disorders come in health facilities

CBR in South Sulawesi (AIFO 2012)

In 2012, in all the districts and the sub-districts involved in the CBR activities, the project implemented FGDs activities for operators and stakeholders, for the purpose of discussing mental health care issues and their collocation in CBR activities.

In 2013, mental health programmes in the province of South Sulawesi have focused especially on Gowa district<sup>22</sup>, in working areas of 5 (five) local community health centres in 4 sub districts, which are (AIFO 2014):

- 1 – Samata Local Community Health Centre
- 2 – Somba Opu Local Community Health Centre

<sup>22</sup> The total population of 4 sub districts is 259,129.

3 – Pattalassang Local Community Health Centre

4 – Bonto Nempo II Local Community Health Centre

5 – Bajeng Local Community Health Centre

Mental health program is managed by the Puskesmas mental health team along with community volunteers.

#### 5.4 Project Objectives

The intended beneficiaries of the projects are persons with mental health disorders, who have many difficulties in being included in CBR projects.

The programme seeks to provide direct clinical intervention towards persons with mental health conditions, in particular the project implements specific diagnostic workup and provides treatments. Furthermore, the CBR operators refer cases which require further treatment to mental health hospitals.

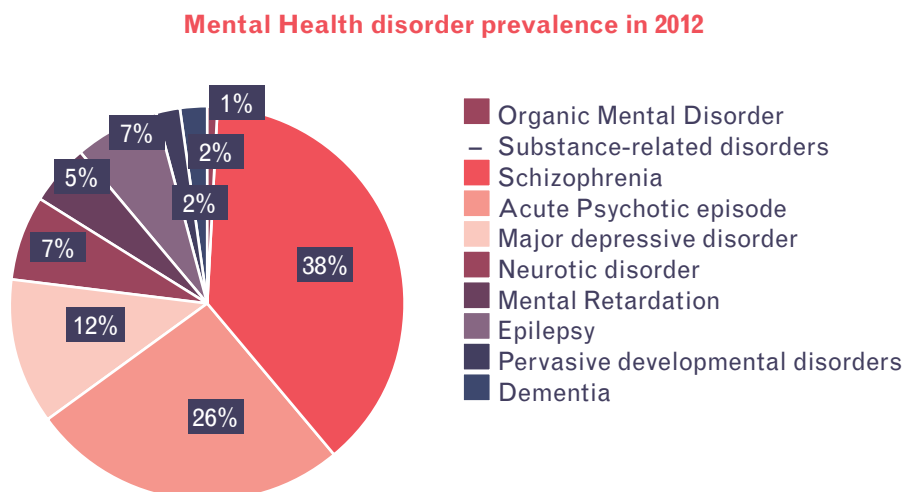
The major objectives of the projects have been:

- Reduce the amount of pasung within the community.
- Invest and develop mental health programs through the CBR methodology.
- Train CBR workers to pay attention to mental health issues during their activities with the whole population.
- Promote the early detection and treatment of mental health conditions in the community.

#### 5.5 Preparatory phase and implementation of the activities

The programme implementation process started in May 2012, in Gowa, Sidrap and in one sub-district of Makassar, when the CBR staff started to gather data about people with mental health problems who had attended the puskesmas, in order to organize a baseline of the situation. The collected data showed the presence of 367 people with mental health problems among the users of the health care centres, in particular 126 of them originated from Gowa district.

The image below demonstrates the prevalence of several mental health disorders among this population:





During 2012 two focus group discussions took place, one in Gowa district, the other in Sidrap district. These are the main findings of the FDGs:

- The two FDGs were attended by a total of 52 people, including CBR Managers, local supervisors, community volunteers and some persons with disabilities.
- People in the community often lacked considerable knowledge about mental health issues, and less than 50% of the participants to the FDG were able to speak knowledgeably about mental health issues.
- The participants greatly valued the awareness raising campaigns about the Indonesian national policy on mental health and the slogan "Indonesia free Pasung 2014", however only a small number of group participants were able to resume the main issues of the national policy in mental health field.

Over 2013 several interventions have been implemented, especially in Gowa district:

- 1 – Stakeholder Socialization Meeting On June 26th 2013, a socialisation meeting was carried out involving the local authorities. Fifty-nine people participated to the meeting and among them were delegates of local government, religious leaders, Community Based Organisations and specific health care staff. In this occasion, members of the Clinical Mental Health Hasanuddin University and from Psychological Clinical Mental Health Association of South Sulawesi spoke about mental health issues. This event has been an example of the advocacy activities importance in order to maintain the support of the stakeholders.
- 2 – Training for Mental Health Team of Puskesmas The training of staff of the five puskesmas has been the most important phase in order to achieve an early diagnosis and treatment. The training took place on June 24 – 25, 2013 in SKB Sungguminasa Building. There were 16 participants. The program was focused on the Early Detection of Mental Health issues, their classification were based on ICD 10 and on the guidelines for their treatment. Notions about the handling of particular problems and situations were also given during the training.
- 3 – Volunteers Training Community volunteers, also called cadres in Indonesia, have a primary role within the CBR team, as they take on some of the functions and roles in the care-giving system. They receive a shorter pre-service training and possess lower qualifications; they work in the same community they live in. The typical profile of a cadre is a retired teacher, or a relative or neighbours of a person with disability; in the vast majority of cases, cadres are women. In order to ensure basic mental health care functions in the community, the programme has then organised training on this specific subject for CBR cadres into each puskesmas in district of Gowa, during 2013. Community volunteers can substitute health workers in some health care activities which do not require a specific qualification (Mannan et al. 2012), so that they can help to meet the objectives of the programme through a brief two-days training. It aimed to improve cadre knowledge and understanding of mental health issues in the community and to help reduce the stigma towards psychosocial disabilities. At the time of writing this report, there are 28 community volunteers that are members of mental health staff in the puskesmas of the Gowa district.
- 4 – Establishment of Mental Health Alert Village In two villages of Gowa district two "Alert Mental Health Village" have been implemented. These are simple community meetings, to collect data and to investigate the mental health disorder cases. This action, together with volunteers training, can be important in carrying out the promotion and treatment for the community, including home visits for the persons with mental

health disorders who are not able to visit the Puskesmas. Through these procedures, in the two sub-districts where the "Alert Mental Health Village" have been implemented, the number of persons with mental health disorders attending the puskesmas has increased.

- 5 – Home visit Specific initiatives to provide home visits to meet and get to know persons with mental health disorders and to support their families at home and in the community have been implemented.

### 5.6 Observations and findings

Currently the programme is being implemented in the Gowa district. The mental health professionals which compose the staff in the target areas include 45 persons:

- 1 psychiatrist who is on duty in the mental health hospital and can serve as trainer
- 8 trained general practitioners
- 6 trained nurses
- 2 trained health professionals
- 28 trained CBR volunteers

Since the beginning of the project, in 2012, the number of persons living with mental health conditions attending the CBR project in the Gowa district has increased, going from 158 users to 238 in 2013. The most significant results have been achieved in the community health centres (puskesmas) of Samata and Bontonompo II, which is the same where the Mental Alert Village experimentation has been implemented. Results demonstrate that because of the training activities to improve the diagnosis procedures and of the activity of the mental health alert village groups, the training activities in the community to find new cases, contact them and help their transition into the community are extremely important.

Puskemas Name	Old Cases	New Cases	Total	Growth Ratio
Samata	53	31	84	58%
Somba Opu	19	0	19	0%
Bajeng	19	10	29	52%
Bontonompo II	43	31	74	72%
Pattalassang	22	10	32	45%
Total	158	80	238	51%

### 5.7 SWOT Analysis and conclusions

The experience described in this chapter promotes the involvement of people with mental health conditions in CBR programs existing since the nineties in Indonesia.

The particular training of people, who are often part of the general population, can represent an important instrument in fighting against the still perceived stigma towards persons with psychosocial disabilities. Furthermore the promotion of a diffuse and well established system for early detecting of problems regarding mental health in the community, can help to prevent the most severe forms of marginalisation. The rapid growth in number of persons with mental health disorders attending the services may represent a partial emersion of cases that have had before lived in worst life conditions, without appropriate treatment and recognition of their rights.

Nevertheless some important challenges affect the future experience of community mental health in Indonesia. The struggle against stigma and pasung is far from being accomplished and the public health system investments for the mental health continue to be scarce. Budget limitations determines the lack of training of some health operators and this represents a possible limit to the effectiveness of a mental health service. In the table below the SWOT analysis evaluates the main issues regarding the experiences in Gowa districts:

Strengths	Weaknesses	Opportunities	Threats
Volunteers training.	Broad coverage area of population target.	The endorsement of the Ministry of Health regarding the community mental health care in districts.	Natural disaster, such as: flood, land-slides that usually happen in target areas may cause delay in care service delivery.
Staff knows the target area and the resident because they are part of the area population.	The knowledge of some volunteers is poor: they have only received a two-days training and they are not equipped with a handbook.	Some Puskesmas carry out mental health training on their own.	There still is stigma and discrimination towards persons with psycho-social disabilities therefore their rights are ignored.
There are Staff members with mental health expertise.	Limited budget for continuous staff training and home visit.	There is a national regulation regarding community based mental health efforts.	

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## The Project in Liberia



## 6.1 Introduction and background

Liberia, which means “land of the free”, is an African country located in Western Africa, bordering the North Atlantic Ocean, between Cote d'Ivoire and Sierra Leone. The country has a population of almost 4 million people (2008 census). Indigenous tribes account for over 90% of the population. Christianity, indigenous faiths and Islam are the main religions in the country. The official language is English, but approximately 20 ethnic dialects are spoken (UNICEF 2009).

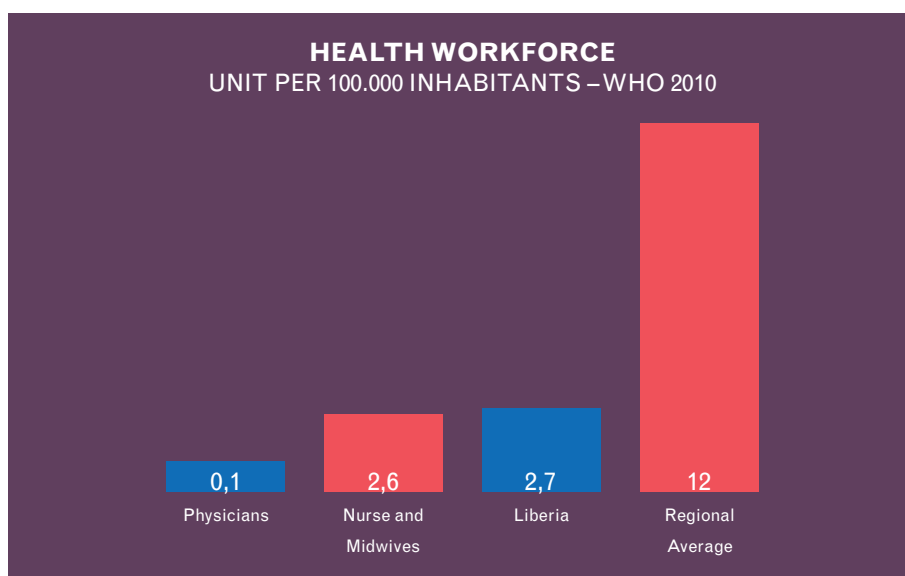
Among Western Africa countries, the history of Liberia is one of the oldest. It was founded by free African-Americans and freed slaves from the United States in 1820. The *American society for colonizing the free people of color of the United States* was established on December 28, 1816 and contributed in founding the colony of Liberia for freed slaves to live in Africa. The first group of Americans settlers of African descent arrived in Africa in 1817 (Truth and Reconciliation Commission 2009).

The conflicts that arose in the few years following its constitution between colons and the United States Government led to a progressive separation of the colony and ultimately, to its independence.

The Constitution of the first Liberian Republic was adopted and the Declaration of Independence was signed in the Providence Baptist Church at Monrovia on July 26th, 1847 (Truth and Reconciliation Commission 2009).

The recent history of the country has been largely influenced by the long and bloody civil conflict that began in late 1989, when the rebels, commanded by Charles Taylor, launched an incursion from neighbouring Cote d'Ivoire. During the following 14 years, the conflict had split the country up and ethnic killings and massive abuses against the civilian population were perpetrated (Johnson et al 2008). In 2005, after the conclusion of a fragile peace process, general and presidential elections took place and created the framework for a long term reconstruction. In 2011, after the end of the civil war, the second democratic elections confirmed the government of President Ellen Johnson Sirleaf (World Bank et al 2013).

Since the end of the conflict, Liberia has started a slow but continuous economic growth. Nevertheless the country has continued to rely on external sources of funding, mainly official development assistance for the country economy and wealth system recovery (UNDAF 2013).



Currently Liberia is classified as a low-income country and the development process is far to be accomplished. The Human development rate is low and below the average for countries in Sub-Saharan Africa, totalizing the 175th place on a total of 187 (UNDP 2014). Inequality among the population is still enormous: 63.8% of Liberia's 3.5 million inhabitants live below the poverty line, 47.9% live in extreme poverty and subsist on less than a US\$1 per day (UNDAF 2013). In particular, gender inequality represents a critical issue: approximately 50 to 70 percent of women and girls were sexually assaulted during the civil war (The Carter Center 2013) and a gender gap is also patent in education, where the illiteracy rate, among women aged 15 to 49, is as high as 60%, which equals twice the male rate.

Decades of civil war wrecked the Liberian health care system, causing its collapse. For several years, only few physicians could be located in the country, with a rate of 0,014 physician per 1000 inhabitants in 2010 (UNDP 2014). Maternal and neonatal mortality still remains very high and the country suffers the massive burden represented by communicable diseases.

Malaria is still the first cause of morbidity and mortality (WHO 2014) and in the summer of 2014, the country found itself in the eye of the storm due to the dramatic widespread epidemic of Ebola virus disease in west Africa, particularly in Liberia, where the number of certified cases exceeded 1500 units by the end of August.

## 6.2 Mental health care situation in the country

The long civil war had many serious and lasting consequences on the health, mental health and psychosocial fields. The critical lack of psychiatrist and the limited access to medicines are problems yet to be solved, while the psychological impact of the conflict continues to cause tremendous sufferings. Up to 2011, the E.S. Grant Mental Health Hospital in Monrovia was the only psychiatric inpatient facility. It had a capacity of 40 beds for a population of nearly 4 millions, and often there were no specific mental health services in the communities.

In Liberia, the number of people with war related psychosocial disabilities, is vast and the situation is worsened by the lack of adequate facilities and personnel. Few years after the end of the war, there was a large number of people who met the criteria for being subject to major depression and post-traumatic stress disorders (respectively 40% and 44%). Moreover, rates of PTSD, MDD, and suicidal ideation symptoms were higher among former combatants than not-combatants and among those who experienced sexual violence than those who did not<sup>23</sup> (Johnson et al 2008).

In 2009, the government commissioned a foreign mental health expert group to develop the country's first National Mental Health Policy. The team of researchers designed a system that addressed both persons with chronic mental health disorders and the many others who suffered from common conditions such as depression and anxiety (The Chester M. Pierce 2009).

Mental Health Plan components include (WHO 2011) a global shift of services and resources from mental hospital to community mental health facilities and the progressive integration of mental health services into primary care.

The components of Liberian mental health system outlined by the national policy document are (Republic of Liberia 2009):

<sup>23</sup> Former combatants experienced higher rates of exposure to sexual violence than not-combatants among females, 42.3% vs 9.2% (Johnson et al 2008)



- Highly trained, multi-disciplinary County Mental Health Teams which provide high quality mental health care.
- Mental health outpatient teams at the local health clinics and health centres which offer a wide range of community-based outpatient mental health services.
- Inpatient care in county hospitals Wellness Units. These units are designed to admit people with severe mental health conditions close to their community, without requiring institutionalisation.
- Restoration of a mental health inpatient facility at the country's general hospital<sup>24</sup> for patients that require long-term care or that are currently in mental institutions.
- Work on prevention of mental health disorders.

The key of the national plan is the integration of mental health in primary health care, so that the responses to conditions related to mental health can be performed with confidence, by general health workers operating in primary health care, who have knowledge and skills in providing mental health care. This aim obviously requires the training of all cadres of health workers in the diagnosis and management of psychosocial disabilities (Republic of Liberia 2009b).

In recent years the national government, in collaboration with an important NGO like Carter Center, has started a local training program for mental health clinicians, in order to build a sustainable mental health system in the country. The main objectives of the program are three (The Carter Center 2013):

- Train a sustainable and credentialed workforce of mental health clinicians, including at least 150 specialised nurses and physician assistants.
- Broaden mental health services coverage beyond the capital area, to reach 70 percent of the population. To achieve this target, the progressive implementation of community mental health services is important.
- Launch an extensive anti-stigma campaign to improve public understanding of psychosocial disabilities.

Up until March 2014, over 120 health clinicians graduated in the *mental health training program* and they currently work in primary care clinics and hospitals among the 15 counties of Liberia (The Carter Center 2014). The progressive improvement of the situation leads to believe that through practical actions, low-income countries can channel their efforts into the development of innovative mental health programmes, oriented to evidence-based services, even within the constraints of limited resources (Abdulmalik et al 2014).

With regard to Stigma, this still remains a large problem that frustrates the spread of positive mental health conceptions. Many people, including some health workers that did not have a mental health training, perceive psychosocial disabilities as a punishment for bad behaviour and epilepsy as a contagious disease and they may consequently be isolated in the community. In addition, the lack of treatments and medications worsens their situation (The Carter Center 2013).

<sup>24</sup> The JFK Mental Health Department is currently the referral source for patients that require hospitalisation. The admission in this facility is possible only when previous treatments at the county hospital have failed (Republic of Liberia 2009b)

### 6.3 Existing CBR activities

Dating back to the late nineties, several NGOs, among which AIFO and Sampson Saywon Boah Institute (SSBI), started CBR programs in Liberia. These projects mainly targeted persons with physical, visual and psychosocial disabilities. In those experiences, the key activities were the training of community volunteers, the improvement of specific medical interventions, and the production of appropriate technologies (Boha L 2009).

AIFO launched a three-year CBR intervention in Liberia between 2010 and 2013. The project aimed to promote a more effective, efficient and equitable access to education, healthcare, livelihood and empowerment for persons with disabilities living in the community (Libanora & Cunsolo 2011). The programme is currently operational in five countries, along with coordination and advocacy activities taking place in Monrovia.

In many cases, people with epilepsy or physical disabilities were more frequently involved in CBR activities than people with mental health disorders; in some counties, this gap was quite significant (Libanora & Cunsolo 2011). This situation shows that for persons with mental health conditions it is difficult to be involved in CBR activities, despite the potential benefits for their autonomy in life, deriving from the opportunities and advantages that the CBR engenders. In Liberia, the activities implemented to promote mental health among the communities are linked to those implemented by AIFO Liberia CBR project and those of The Carter Center Liberia.

During the last two years, specific Community Mental Health Activities have been implemented by the CBR workers in various counties and a complex data collection for a Comparative Study of Community Mental Health in low- and middle-income countries has been developed.

### 6.4 Project Objectives

The intended beneficiaries of the project are persons with mental health disorders, neurological and/or substance abuse conditions, with special regard to those who have been subjected to violence or sexual assaults in the community and are now suffering for the intense stigma that in Liberia is related with a not scientific vision of mental health. This people need help to gain the progressive autonomy.

The main objectives of the project are (Di Dio 2014):

- Train CBR workers and health professionals to strengthen their capacity to recognise and prevent human rights violations.
- Develop a protocol of intervention for synergic activities between the CBR workers in the community and the local mental health services, to ensure diagnosis and treatment of mental health conditions.
- Promote a research about the inclusion of persons with mental health disorders in CBR programmes in Liberia.
- Promote anti-stigma activities involving the population.

### 6.5 The Research initiative “Comparative Study of Community Mental Health in low- and middle-income countries”

The community mental health project started in December 2011, crossing the coverage of the CBR program implemented by AIFO in 6 of the 15 Liberian counties. There are both urban and rural communities in central and south-eastern Liberia: Margibi (population 209,923), Bong (population 333,481), Nimba (population 462,026), Grand Gedeh (population 221,693), River Gee (population 66,789) and Maryland (population 135,038).

In the first phase, while the local teams were implementing the mental health training for volunteers and CBR workers in the counties, AIFO researchers in partnership with Carter Center<sup>25</sup> promoted an ambitious research project to

find out the best solutions to include persons with disabilities in CBR programmes and to promote mental health in the community.

The Research initiative (Cooper & Libanora 2012) promoted by AIFO and the Carter Center had the following objectives:

- 1 – Investigate the level of inclusion of persons with mental health conditions or epilepsy in CBR programmes. In particular the research examined the knowledge and skill levels of CBR workers as well as different aspects of mental health conditions through qualitative methods (focus group discussions) guided by a semi-structured questionnaire.
- 2 – Clarify which opportunities CBR activities can give to these persons and understand who are the persons classified under the CBR programmes as persons with mental health disorders and which obstacles in functioning they faced, through a questionnaire.
- 3 – Administer the WHO QualityRights Tool Kit at the national referral mental health hospital, the Grant Hospital. This part of the research started in 2013 but it stopped in 2014 because of the spread of epidemic Ebola virus disease in West Africa.

The study used two methods of data collection: a survey (150 questionnaires have been administered) and focus group discussions (with a total of 95 participants). Among groups represented in the survey and the focus groups, there were persons with disabilities, mental health clinicians, CBR facilitators, and community health and social workers. The research was carried out in five counties (Bong, Grand Gedeh, Margibi, Montserrado and Nimba).

Following is the sum of some of the findings recorded during the first phase of the research:

- Lack of mental health community services: more than half (62%) of respondents, who were persons with disabilities, reported that they did not get access to mental health services when they needed it. 49% of persons with mental health conditions or epilepsy declared not to have had access to mental health services in time of need. In counties with CBR activities, this percentage raises to 65%. Despite these problems, most people with mental health conditions or epilepsy took medications regularly (76% and 97% respectively) but they had difficulty in accessing medications.
- Inclusion of Persons with mental health conditions or epilepsy in CBR programs: participants of the focus groups of community health and social workers reported that they did not provide mental health services and that there were no services within their communities for persons with psychosocial disabilities. During the focus groups, persons with psycho-social disabilities observed that while persons with epilepsy were targeted by CBR, often they themselves were overlooked by facilitators, who were unaware of them in their communities.
- Exposure to violence and sex assault: participants of the survey were significantly exposed to violence. 37% of them reported that they or someone in their household had experienced violence in the previous 12 months. Among CBR and health operators, rates of exposure to domestic and interpersonal violence was higher than among users.

<sup>25</sup> The Carter Center is a NGO, founded in 1982 by former U.S. President Jimmy Carter and his wife, Rosalynn, in partnership with the Emory University, to advance peace and health worldwide. The Centre has promoted activities in more than 80 countries (Carter Center Overview).

The experience of rape is also widespread: 10% of the respondents reported that within the previous 12 months, someone in their household had been raped. This negative experiences seems to be more common among people with disabilities rather than CBR and health operators.

## 6.6 Implementation of the activities

Over 2013, the project covered the counties of Liberia thanks to a staff composed by 12 mental health clinicians and 10 CBR workers, supervised by one mental health officer and the project manager.

Several interventions have been implemented, following these directions:

- 1 – Community Mental Health Care Interventions: the project has developed a protocol for community based intervention in mental health field. The mental health-trained clinicians conduct community visits twice a week. They assess new cases identified by the CBR workers or follow up the previously assessed cases. The mental health clinician transfers the treatment plan to the CBR workers within 3 working days and he/she registers the treatment plan and performs some supporting actions<sup>26</sup>. Currently, 915 old cases were followed up and over 50% of the people assessed have improved their life quality and became more active in community.
- 2 – Promote inclusive education and Scholarships: the CBR initiative supports the education of children with disabilities, and the CBR personnel is required to talk with the school management and advise the teachers about classroom management techniques for children with behavioural or learning disabilities.
- 3 – Community Awareness and Training of key stakeholders: during a monthly household visit in the community, CBR workers and mental health clinicians organise a meeting for population and stakeholders, to provide correct information and discuss about mental health, epilepsy, disability and other related topics.
- 4 – Self Help Groups: the project promotes the inclusion of persons with mental health conditions in SHGs. According to the AIFO and the Carter Center research, persons with mental health disorders normally have a lower rate of attendance to the SHGs than people with other disabilities.
- 5 – Micro Grant projects activities: the project has implemented, for self help groups and representative organisations of persons with disabilities, a micro grants program to support the SHGs activities start-up.
- 6 – Human Rights Monitoring: CBR workers support persons with psychosocial disabilities to progress in the human rights field at the community level. If a case of abuse is identified, CBR workers cooperate with mental health clinicians to understand the circumstances of abuse or suffered violence. They can also report the case to the police for further intervention.
- 7 – Advocacy and Lobbying for promotion and protection of human rights of persons with disabilities.

<sup>26</sup> CBR workers can be helpful in many follow-up actions: to conduct home visit for monitoring the person's living conditions, to accompany the person to health facilities, to monitor that the person is taking the medications according to the prescription.

## 6.7 Observations and findings

The project has implemented a comprehensive interventions network in Liberia to include persons with psychosocial disabilities in CBR activities, starting with training activities of CBR operators as well as the whole population. A three-weeks introduction training has been organised and an additional three-week course took place during service for 10 CBR workers and 12 mental health clinicians. AIFO has also trained new mental health clinicians in mental health advocacy, human rights and CBR within the Carter Center diploma for mental health clinicians. On the job training and continuous monitoring has been carried out to support all 10 CBR workers and mental health clinicians directly working in the CBR communities.

The government policy encourages the progressive development of a community mental health system, and the application of specific mental health intervention protocols among the community. The intervention protocol developed by the project has promoted the cooperation between public health care, mental health clinicians and CBR workers, so that it would be possible to offer an articulate service for assessment, treatment and follow-up of mental health disorders among the community population. Furthermore the follow-up initiatives include home visit and direct medications monitoring; these are both important instruments of community mental health activities.

The high level of participation to self-help groups and/or to representatives organisations activities are considered as signals of effective empowerment. The project collaborates with DPOs and provides a special micro grant activity aiming at the promotion of self-help groups' activities.

## 6.8 SWOT Analysis and conclusions

The implementation of community mental health services and the training of specialised mental health clinicians represent crucial challenges for the Liberian health care system.

Initiatives like this project, developed on the basis of community mental health, can become valid instruments to promote and protect human rights of persons with psychosocial disabilities, prevent the long-term institutionalisation and improve the quality of the health care system.

The involvement of CBR workers who come from the same community they work in, represents an important advantage to manage the community activities and to locate priorities.

Despite the large efforts made during these years, the country situation still faces some serious challenges:

- during the summer of 2014, the widespread epidemic of Ebola virus created a serious obstacle for NGOs activities and became a vast health emergency that outclasses others issues as mental health care.
- The lack of personnel trained in mental health is still relevant, especially specialised professionals, and the national budget is low. The road to develop a public mental health care network and autonomous from foreign investment is still long.
- It is important that the national health plan provides investments to cover the pharmaceutical cost for drugs addressed to persons with mental health conditions who need it. Currently, many persons reported several difficulties in obtaining the medications and this phenomenon can be a cause for drop out.
- Stigma and a severe lack of information about mental conditions are still present among the general population.

The SWOT analysis in the table below summarised the main findings about these experiences, as identified by the project local staff.

<b>Strengths</b>	<b>Weaknesses</b>	<b>Opportunities</b>	<b>Threats</b>
Dedicated Staffs and trained consultants	Inadequate resources (Financial) for project implementation.	Strong partnership with The Ministry of Health and Social Welfare	Health Emergency for communicable disease in the Country
Expert project managing	Project inability to import psychotropic drugs	Good Mental Health Policy and Plan.	Lack of mental health legislation.
Staffs networking skills.	Low Salaries for Project Staffs.	National Training program for Mental Health Professionals	Lack of essential psychotropic medications
Staffs adaptability skills.	Limited key local project staffs	Signing and ratification of the UNCRPD by the Liberian Government	Overwhelming mental health care needs in post-war Liberia
Staffs Self-motivation and their quest for contributing to community and National development.	No international exposure for local staffs where best practices can be shared.	Strong Partnership with local Authorities and beneficiaries.	Low practical commitment of Ministry of Health and Social Welfare towards a concrete shift towards a community based system of mental health care
		Strong Partnership with The Carter Center	Stigma and Cultural beliefs about the causality of mental illness.
			Low salaries for Health Care Workers.
			Low National budget allocation for mental healthcare

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# The Project in Mongolia



## 7.1 Introduction and background

Mongolia is a country that stretches over a vast area in the heart of Central Asia, between China and the Russian Federation. In 2010, the population reached 2.78 million which lived sparsely over a territory of 1.6 million square kilometres. Because of its very low population density of 1.7 persons per square kilometre, Mongolia is currently considered the least densely populated country in the world (WHO 2010).

Mongolia is built on a rich nomadic culture. 1,2 million people live in the capital, Ulaanbaatar, while the rest of the population is spread across vast steppes where they breed cattle, sheep, goats, horses, yaks and camels. Living conditions in rural areas are quite harsh: during winter the temperatures drop below  $-30^{\circ}\text{C}$  and the infrastructure services are limited and often ineffective (World Bank et al 2013).

Until the end of the twentieth century, the country was deeply imprinted on Soviet models, which have had a strong influence on the development of its institutions until the late 90s, when it began the transition to a multi-party system and a market economy. (Embassy of Mongolia 2013)

Over the last two decades Mongolia underwent a significant and rapid transformation, driven mainly by the growth of the mining industry (UN & Government of Mongolia 2012). In fact, by 2016, the mining sector is expected to contribute to more than half of the GDP and the strong subsequent economic growth may translate into a further reduction of poverty levels (World Bank et al 2013).

After these gradual economic and political transformations, an increasing trend of migration has been observed, from rural to urban areas. People have started to call for better living standards in terms of education, employment and health care. As a result, in 2008, about 50% of the total population were living in Ulaanbaatar, while over 30% of the population lead a traditional nomadic lifestyle (WHO 2010).

Despite the economic growth, poverty affects 30% of population and remains higher among the population living in rural areas (33.3 percent in 2011) than in urban centres (26.6 percent in 2011). Furthermore, access to the health care system and its outcomes is increasingly characterized by large inequalities, both from a geographical and socio-economic standpoint (World Bank et al 2013).

Mongolia has been experiencing a gradual epidemiological transition in morbidity and mortality patterns since 1990. Non communicable diseases, related to genetics, lifestyle and behaviour, have become the leading causes of morbidity and mortality (WHO Western Pacific Region 2011).

During the twentieth century, health care services were publicly funded however, despite the existence of a network of facilities and the consequent improvement of the overall health status, the system proved to be inefficient. Currently the health care system includes public and private facilities and it is articulated on three levels: primary, secondary, and tertiary. Primary health care includes maternal and child health, communicable and non communicable diseases and is free. Secondary and tertiary care include emergency and long-term specialised care and require co-payment by the person concerned (WHO & Mongolia Minister of the Health 2012).

## 7.2 Mental health care situation in the country

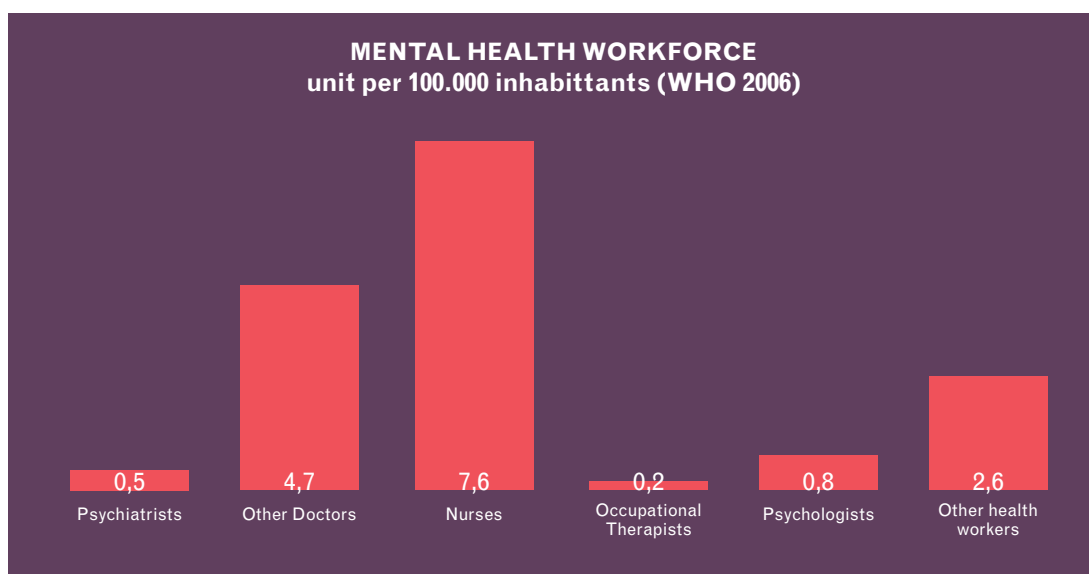
As mentioned, the national health plan articulates the mental health care in community, primary, secondary and tertiary levels<sup>27</sup>.

The plan promotes the strengthening of mental health care at community level,

<sup>27</sup> The National Health Plan of Mongolia introduces the concept of community level of mental health care, considered a pre-specialist step before accessing the primary, secondary and tertiary levels.

it recommends that the managing of the medical therapy, rehabilitation and psychosocial interventions are run within the community, leaving to the hospital (secondary and tertiary level) the management of acute cases (Government of Mongolia 2005). Mongolia adopted a Mental Health Law in 2000, a National Mental Health Program from 2002 – 2007 and a second one from 2010 to 2019. Despite the indications contained in the National Mental Health programs, it still seems that mental health care in Mongolia is based on mental hospitals (WHO 2006).

2% of the total budget for health policies and programmes is dedicated to mental health<sup>28</sup>, most of which is used by mental hospitals (WHO 2011).



Mental Health Workforce (WHO 2006)

Most of persons with mental health disorders receive the treatment in the 7 outpatients facilities. The majority of the beds are located in the only mental hospital, but there are also 21 inpatient units located in provincial general hospitals. Twelve community residential facilities are registered but 7 of these are located within the mental hospital and only two of the remaining five seem to stand outside Ulaanbaatar (WHO 2006) (Saraswati Mini 2008).

Moreover there is an undeniable lack of trained personnel: there are only 17 mental health professionals per 100,000 population. Rates are particularly low with regard to psychiatrist and there are no social workers in the Mongolian mental health workforce (WHO 2006) (Saraswati Mini2008).

Rates of hospitalisation are fairly long: 30% of the patients spent more than 5 years in row in the mental hospitals (WHO 2011).

<sup>28</sup> The global mean percentage of health budget dedicated to mental health is 2.8 percent, but there are many differences among the countries. This percentage is only the 0.5 percent of the health expenditures in low income countries whereas it raises to 5.1 percent in high income countries (Morris et al 2012).

### Beds in Mongolian Mental Health Care System (Saraswati Mini 2008)

National Centre of Mental Health	450 beds
Voluntary facility for alcoholic patients	50 beds
Unvoluntary facility for alcoholic patients	300 beds
Psychiatric inpatient units in provincial general hospitals	5-20 beds each

The number of psychiatric beds per 10,000 population is lower than Japan and other countries of the area, like South Korea, but at the same time, the number of beds provided by the mental hospital has been increased after 2000. Mongolia still maintains a hospital-based care system with an occupancy rate of above 80% (Ito 2012).

However the experimentation of new Community Based Rehabilitation practices has involved the Mongolian mental health system (Chee 2009). During the last five years, new mental health services have used traditional round dwellings made from wooden structures and pelt frames. These “gers” (typical tent of Mongolian nomads) replicate the standard living situations and persons with psychosocial disabilities can access rehabilitation programs within a known environment. The project has also shown that it is possible for persons with psychosocial disabilities to access an effective rehabilitation program in their local community setting (Altanzul et al. 2009).

The transition process to a community mental health model is, however, hindered by the common belief that persons with psychosocial disabilities are better off in appropriate places, in other words in, in mental hospitals.

Currently the shift to a community-based model that provides psychosocial assistance and rehabilitation of persons with chronic mental health conditions is far from being accomplished and it needs to be supported by establishing day care centres and community mental health care facilities. Unfortunately, the majority of primary health care doctors and nurses have not received official in-service training on mental health within the last five years (WHO 2011), making it clear that specific training is necessary to achieve the integration of the mental health in primary health care.

### 7.3 Existing CBR activities

After the great transition of the early nineties, Community Based Rehabilitation was introduced in Mongolia, with the external support from WHO and the Italian NGO AIFO. The programme was firstly introduced in the Western Provinces (Aimags) and in the capital city Ulaanbaatar. Later in 2007, it was possible to extend the programme to other 9 Aimags in the eastern part of the country (Como & Batdulam 2012).

Since 2010, the CBR project, funded by the EU and managed by AIFO and the Ministry of Health of Mongolia, could have covered the whole country however vast distances, lack of roads and means of transportation and harsh climatic conditions have limited the activities of the CBR workers and have determined incomplete coverage of the population (Batdulam 2008)(Como & Batdulam 2012). The National CBR programme includes:

- 1 – Health (Medical rehabilitation service, health education)
- 2 – Education (Inclusive education for children with disabilities, removing the barriers and enrolling them to regular classes)
- 3 – Livelihood (Rotating Credit Fund, Revolving Cattle Fund and Seed money for persons with disabilities and Self-help groups)

4 – Social (Public events and publicity of good practices)

5 – Empowerment (Strengthening the capacity building of the representatives of DPOs)

The CBR programme has achieved important goals in Mongolia and together with the Ministry of Health, it promoted a community based approach to disability and rehabilitation. Over the years, many stakeholders and DPOs have been involved in the planning and implementation process in the community (Depaak 2008).

In December 2011 AIFO started to implement a mental health-specific project in several districts of the capital, Ulaanbaatar. The project covers 6 districts (Suhbaatar, Chingeltei, Han-Uul, Songinohairhan, Bayangol and Bayanzurh) with a target population of about 1.5 million people out of 2.9 million population living in the country.

#### **7.4 Project objectives**

The intended beneficiaries of the projects are persons with psychosocial disabilities and neurological and/or substance use conditions, their families and CBR and mental health operators involved in the training.

During the years the project has pursued the following aims:

- 1 – Create a sustainable positive synergy between the existing Mental Health Services and the CBR Programme. In Mongolia CBR programme is diffused to the whole country and through these resources it would be possible to reach the rural communities. In particular the project implements the use of Self-help groups among persons concerned and their families.
- 2 – Contribute to the integration of mental health to primary health care. The family doctors may represent the intersection of primary health care, CBR and mental health (family doctors are the first contact for people with mental health conditions); therefore they should be the main focus of the training activities.
- 3 – Reduce hospitalisation rates and support the efforts of the Government of Mongolia and the National Mental Health Centre to shift from an hospital-based mental health to a community mental health system (deinstitutionalisation).
- 4 – Support advocacy activities for the rights of persons with psychosocial disabilities by strengthening the representation of persons concerned.

#### **7.5 Preparatory phase and implementation of the activities**

The project started its activities in December 2011.

During the first 4 – 5 months of 2012 the project defined its operational structure, establishing the team headquarters in the National Mental Health Centre, which pledged its collaboration to implement the activities of the programme, as official project partner.

In June, the project organised a first round of focus group discussions (FGDs). FGDs involved two groups of participants from Ulaanbaatar districts: the CBR coordinators and general practitioners as part of the CBR programme. These FGDs were important to promote the discussion among operators and to assess the level of knowledge about and perceptions of mental health at the beginning of the project (baseline).

The project implemented several interventions, following the indications gained in the FGDs and the objectives of the programme:

##### Meeting among CBR stakeholders and National Centre for Mental Health

The three meetings (one per year) discussed the main mental health issues. In particular, recent modifications in mental health law were presented and discussed and in each session the team presented the report of successful activities and guidelines for future implementations. During these meetings

some suggestions emerged regarding the need of strengthening the involvement of users, family members and persons with disabilities in CBR activities, promoting DPOs' activities.

#### Training on CBR and mental health

The training sessions were organised and attended by family doctors (general practitioners), CBR coordinators, other stakeholders as well as mental health workers. Over the three years, six training sessions were organised for mental health specialists including psychiatrists, nurses, psychologists, social workers, rehabilitation specialists, with an overall attendance rate of 86 operators. The trainings provided a general knowledge about mental health conditions, their classification, and the main principle of treatment, especially to general practitioners. Furthermore, the national programme on mental health and the base concepts of community based-inclusive development were discussed during the training of the operators. In 2013, a training focused on Self-help groups strategies discussed the local experiences in establishing SHGs in the districts. Several members of SHGs and families of users attended this training session.

#### Workshop on Community based Mental Health and Human Rights

The workshop on the relationship between human rights and Mental Health took place in 2013. Sixty people participated to the event; most of them were CBR operators and mental health clinicians, but there were also several DPOs representatives. The workshop provided the framework to explore the human rights dimension of mental health and strengthening the capacity to prevent and recognise abuses both in the mental health services and at the community level. Furthermore the workshop received the contribution of Dr. Giovanna del Giudice, an Italian Psychiatrist with a specific experience in de-institutionalisation processes. This contributed to promote the discussion on the desirable practice of shifting from hospital based model to community mental health and the role of Community Based Rehabilitation strategy.

#### Self Help Groups promotion

The choice of seeking a SHGs implementation strategy to approach the mental health at the community level represents the peculiarity of the project in Mongolia. In May 2013 the National Centre for Mental Health developed guidelines to establish Self-help groups in the community. The SHGs have been implemented in Han-Uul, Bayangol, Songinohairhan, Chingeltei districts, while in the Suhbaatar district an experience of SHG for persons with psychosocial disabilities was already in place since 2006. The district of Bayanxurh has yet to form SHGs but this is scheduled to be completed. There have been some differences as far as activities and the number of group meetings arranged in the various districts, however it is important to register the in terms of attendance. Notwithstanding, the project needs to be continuously monitored in order to support and motivate the proposals made by members of the SHGs.

### **7.6 Observations and findings**

Currently the staff involved in the project is composed by 2 coordinators, 3 psychiatrists, 2 nurses, 1 psychologist, 1 social worker, 2 rehabilitation specialists, the CBR coordinators (medical doctors) of 6 Ulaanbaatar districts and 2 patient family members. The partnership with the National Mental Health Centre is important for the coordination of the activities and the relations with the health care personnel.

The project focused on training activities for mental health professionals and family doctors, to provide them the knowledge about the mental health issues and the basic training about human rights of persons with psychosocial disa-

bilities. These activities were supported by the National Mental Health Centre and concerned 86 operators during the 6 trainings.

The process of information and organisation of the Self-help groups helped persons with psychosocial disabilities and their families to be more active in the community. These interventions directly involved about 140 persons with mental health conditions.

The CBR activities are spread in all the 21 Aimags of the Country, but the main part of the mental health activities have been achieved only in Ulaanbaatar districts. Fortunately the new mental health policy seems to encourage the implementation of the SHGs experience into the suburban areas as well.

### **7.7 SWOT Analysis and conclusions**

The National CBR programme in Mongolia involves all the provinces of the country and theoretically reaches all persons with disabilities, even those living in rural villages. For a complete transition to a community mental health model, collaboration with a such widespread CBR programme may be crucial.

The training on mental health issues for the general practitioners can help to overcome the lack of professionals in the rural areas of the country and it can allow the home treatment of persons with mental health disorders, favouring deinstitutionalisation and promoting the psychosocial rehabilitation.

Self-help groups promotion is a helpful strategy for the empowerment of persons concerned and their families, and the recent change in national mental health policies seem to call for the implementation of these strategies of rehabilitation also beyond the urban area of Ulaanbaatar.

Despite the efficacy of the project, several challenges need to be overcome during the transition to a community mental health system:

- Trainings for health operators need to be improved also in the rural districts of the country and the professionals, who often work with mental health in the communities and who received only a two-days training about the mental health issues, need to attend a second training session.
- The provision of medication is not enough to provide for people's necessities. Persons with mental health disorders often cannot afford to buy it on their own.



Strengths	Weaknesses	Opportunities	Threats
Mental health professionals received training course on human rights and CBR program and activities.	The training courses for local operators are insufficient to work with the persons with mental health problem.	Mental health law is newly amended, where community based mental health service is promoted.	Negative psycho-social aspect of and the stigmatization may not change automatically with the decrease of hospitalization.
Some drugs are free for the patients registered at the National Center for Mental Health	Drugs are not sufficient to all the patients. Sometimes people need to buy their medicines.	There is National Program on Mental Health in Mongolia.	the National Program has no budget planned and the budget for beds of mental health facility is decreased.
Primary health care system is well developed in Mongolia.	Understanding of the employers and general population is weak.	Social workers may be involved in the mental health projects and they can contribute to help the families.	Some family can't buy themselves the medication, so their family member treatment will be lost.
Community based mental health service can decrease the needs of bed based hospital	General Practitioners are overburdened with their daily duty. So they have less hours to work with people with mental health problem.	The concept of community based mental health service is taught to the students of Health Science University.	National CBR program is managed by the Ministry of Health only. Multi-sectoral collaboration is weak at national level.
CBR program is being implemented in Mongolia for over 23 years. Some experience has been collected.	High turn-over of trained staff in general can influence restarting activities which were already running.		

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# The Project in Brazil



## 8.1 Introduction and background

Brazil is the largest and the most populated country of Latin America. With a Gross Domestic Product (GDP) of US\$ 2.253 trillion in 2012, it became the world's seventh wealthiest economy (World Bank 2012).

Brazil has a highly decentralized Federal system. It is formed by 26 States, the Federal District, and 5,560 Municipalities. Sub-national governments have political, fiscal, and administrative autonomy and provide service to the population in terms of education, health care, infrastructures and public security (World Bank et al 2011).

It is an upper-middle income country which combined economic growth with inequalities reduction. During 2004 – 2010, the annual GDP growth averaged 4.4%, but this economic change went with very rapid social progress, indeed growth in per capita income was several times faster among the poorest than among the richest segments of the population and poverty fell by 40% and extreme poverty by 52% (World Bank et al 2011).

Brazil's Human Development Index (HDI) progressively improved in the last decades, in, which is a summary measure for assessing long-term progress in three basic dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living. HDI value for 2013 is 0.744, positioning the country at 79 out of 187 countries and territories and above the average of 0.740 for countries in Latin America and the Caribbean (UNDP 2014). The above data indicates that Brazil has become a high Human Development country and has achieved the majority of the MDGs. Nonetheless, several important socioeconomic inequalities remain among regions and the poverty concerns over 10 million people, especially in rural areas (PAHO/WHO & Brazilian Government 2007).

The 1988 Brazilian constitution, adopted after a period of dictatorship, recognised health as a citizen's right and a duty of the state. The health system has three subsectors: the public subsector (SUS), the private subsector and the private health insurances subsector, with different forms of health plans, varying insurance premiums, and tax subsidies (Paim et al 2011).

Before 1988 half of Brazil population had no health coverage, but since the end of the eighties, the country has implemented a public and universal system of health care, the so called Sistema Único de Saúde (SUS). States and Municipalities are required to allocate a 12 – 15% of the total budget to health care and the federal government also contributes with money raised from taxes. Currently the SUS reaches almost the total coverage of the population and 75% of the Brazilian people rely exclusively on it for their health needs (WHO 2010). The SUS has vastly improved access to primary and emergency care, it achieved universal vaccination and contributed to cut down the infant and child mortality. Furthermore the SUS has had a key role in production and provision of medications for the pharmaceutical needs of the country (Paim et al 2011).

## 8.2 Mental health care situation in the country

After several years of discussion, the National Policy in mental health underwent a radical change, as a consequence of the approval of Federal Law 10.216/2001. The intention of the government was to shift from a hospital based to a community based mental health care system (Fernandes Pitta 2011).

The mental health programme of deinstitutionalisation has implemented community mental health facilities and projects that can be summarised as follows:

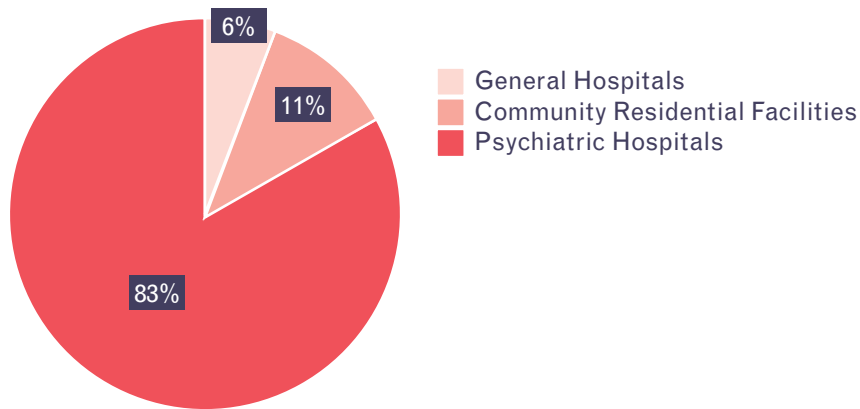
- 1 – Community residential facilities These provide residences for persons discharged from long-stay psychiatric hospitalisations and that have complex needs and no social support. They provide for a total of 4512 beds (WHO 2011).

- 2 – Permanent program of human resources training for the reform of psychiatric care In the SUS, there are 5259 psychiatrists, 12377 psychologists, 11958 social workers, 3119 nurses and 2661 occupational therapists. Because most of the psychiatrists and specialized mental health workers are concentrated in the capitals, rural areas faces the lack of professionals (Mateus et al 2008).
- 3 – Psychosocial Community Centers (CAPS) The CAPS are the cornerstone of the mental health reform and create a network of local or regional healthcare units assigned to a specific population that offer intermediate care between outpatient treatments and hospitalisation (Valdeci et al 2013). They provide mental health care following the community mental health model. The CAPS are divided into three levels of complexity in CAPS I, II and III, the last one enables 24 hours crisis services for a maximum of 7 days in a row or a total of 10 days in 30 days (WHO-PAHO 2007). CAPS I and II provide day hospital and outpatient care. Since 2001, over 1500 CAPS have been activated in the country (WHO 2011). Some CAPS are specialised in the treatment of children and adolescents or in problems related to alcohol and drug use (WHO-PAHO 2007). CAPS include not only medical professionals: also social workers and occupational therapists can help persons in the social rehabilitation process and support the empowerment.
- 4 – Inclusion of mental health care into primary health care There are several experiences of progressive integration of mental health in primary care. Primary care practitioners conduct physical and mental health assessments for all patients. They treat patients who are in the condition to receive direct assistance, or request an assessment from the specialist mental health team, which makes regular visits to family health centres (WHO-WONKA 2008). Even so, these practices are not implemented in all the country and the majority of primary health care doctors and nurses have not received official in-service training on mental health within the last five years (WHO 2011).
- 5 – “Return home” (De Volta para Casa) program it represent a concrete economic benefit that the SUS pays to the person who leaves the psychiatric hospital where he/she had been for a long internment period. These contribution aims to facilitate the process of social inclusion and the active return in the community. More than 2500 people entered in the program up to 2006 (Mateus et al 2008).
- 6 – In-patient units For the management of acute crisis, over 100 community-based psychiatric inpatient units provide over 2000 beds. Moreover there are 592 general hospitals that offer some psychiatric beds in general wards or emergency-care back-ups, without having a formal psychiatric ward (WHO – PAHO 2007).

Despite over ten years since the start of the deinstitutionalisation process, in Brazil there are still about 200 mental health hospitals and over 35000 beds (WHO 2011). The residual psychiatric hospital care model endures because of the difficulties in the deinstitutionalisation process. The north and northeast have fewer CAPS than the south and southeast regions (Mateus et al 2008) and into the same region people who live in urban areas have better access to community mental health services than those living in rural areas (Lovett-Scott & Prather 2014). In addition to beds in mental health facilities, there are also 3677 beds for persons with mental health conditions in forensic inpatient units (WHO – PAHO 2007).

Currently mental health hospital expenditures represent 32.29% of the total mental health budget (WHO 2011).

## Beds in Mental Health Facilities



Beds in mental health facilities - WHO 2011

### 8.3 Project objectives and WHO QualityRights Tool Kit

As mentioned in the third chapter, the project in Brazil focused on improving the quality and human rights conditions in mental health facilities and training people, organisation representatives and operators to advocate for the rights of persons with psychosocial disabilities. In order to achieve these goals, it is crucial to use the WHO QualityRights Tool Kit, a simple instrument to assess and improve quality and the observance of human rights in both outpatient and inpatient facilities. The result of the assessment can be used to ensure a better efficiency and effectiveness for the mental health care and to advocate the modification of mental health policy (WHO 2012).

The tool kit describes a complete process of assessment, step by step:

Establish a project management team and objectives The project establishes a project management team, which comprises representatives from the Ministry of Health, organisations of persons with psychosocial disabilities, family organisations, national human rights commissions, mental health and legal professionals.

Establish an assessment framework Early on in the project, the management team should analyse the organisation of services in the country, determine the scope of the assessment and select the facilities involved in the assessment process.

Establish the assessment committee and their working method The team management establishes the visiting committee in countries. These committee should include persons with mental disorders, their families, mental health professionals and legal and human rights experts.

Train the members of the assessment committee The project provides training for the committee members in how to assess the quality and human rights conditions in mental health and social care facilities using the WHO QualityRights Tool Kit.

Establish the authority of the committee The committee needs the authority to conduct the assessment. It is important that the local authorities give to the committee the mandate to give its effectiveness.

Prepare consent forms and seek ethical approval Consent must be obtained from the staff, service users and family members participating in the assessment before interviews are conducted.

Schedule and conduct the assessment the procedure includes several visits to the facility and meetings with service users and staff.

Observe the facilities Observation is the main part of the assessment process.

Review facility documentation The systematic review of the facility policies, guidelines, standards and records of specific events is important for the assessment. The committee should have access to all service user records and select randomly a number of these for a detailed examination.

Interview service users, family members and staff it is important to select people to interview and to ensure confidentiality of the procedure.

The results of the assessment can be used to improve the conditions in the facilities and, after the publication and discussion, these data can be useful to promote and protect human rights and encourage the development of a full range of high quality community services to support the rehabilitation of persons with mental health conditions.

#### **8.4 Preparatory phase and implementation of the activities**

The project in Brazil worked in partnership with the Secretary of Health of the State of Bahia (SESAB) and the Secretariat of Justice and Human Rights of Bahia and the Secretary for Penitentiary Administration (SEAP).

All the project activities were located in the state of Bahia, between the cities of Salvador and Alagoinhas. According to the local partners, several facilities were selected, to address a multiple facilities assessment.

- At the beginning the Penitentiary Administration Department of Bahia gave the availability of the Custody and Treatment Hospital (HCT) for the assessment, but this activity has not been accomplished, due to the many difficulties that arose after the accident that had involved the facility and that prevented the permanence of the project at HCT.
- The second location for the activities has been an in-patient Psychiatric Hospital, the largest in the State of Bahia (Juliano Moreira Hospital), with 178 beds, historically adopted as a reference point in the state. This hospital is located in the city of Salvador; 45 persons live there, many for the past 20 years.

The third facility where the project took place was an open Centre for Psycho-social Care (CAPS III), with 4 beds, located in Alagoinhas, 120 kilometers from Salvador.

The activities started in February of 2012 and can be summarised as follows:

Team managing Two groups were composed: the Working Group and the Visiting Committee. In both groups there were representatives of persons concerned, families, professionals, managers, social movement, SESAB and Department of Penitentiary (SEAP). The Working Group scheduled weekly meeting sessions.

Assessment Framework The Working Group defined the steps of the project implementation, identified the actors involved in meetings and trainings and discussed themes related to Mental Health, Human Rights, Ethics in conducting interviews.

Training of the visiting committee The first training took place in July 2012. The course started with a general presentation of the WHO Quality Rights Project, with particular attention to the practice exercises and case studies presentation. The second training, in April 2013, provided the Visiting Committee and the Working Group members with theoretical and practical knowledge to use the WHO Quality Rights Tool Kit. The course was conducted by Marta Ferraz, member of the National Human Rights Programme of Portugal, and was attended by 17 participants.

Meeting with the Stakeholders in HCT In August 2013 a specific training was realized at Custody and Treatment Hospital (HCT) to present the partial re-



## Psychosocial Care Centres in Bahia (October 2012)

Districts	CAPS I	CAPS II	CAPS III	CAPS ad	CAPS i	CAPS ad III
LLSIL	17	14	0	4	2	0
NORTH-EAST	11	0	1	0	0	0
NORTH	13	2	0	3	0	0
WEST	9	1	0	0	0	0
SOUTH-WEST	26	3	0	2	0	0
SOUTH	16	4	1	2	1	0
CENTRAL EAST	25	4	1	2	1	0
CENTRAL NORTH	5	2	0	1	0	0
EXTREME SOUTH	9	4	0	3	2	0

sults obtained during the implementation of the project within such premises (from July 2012 to April 2013). Forty people attended the meeting.

Assessment process in CAPS III In December 2013, after a presentation meeting with the stakeholders, persons concerned and professionals, the Visiting Committee started its evaluation at CAPS III in Alagoinhas.

Assessment process in Mental Hospital The project was presented at Juliano Moreira Hospital, where thirty people attended the meeting including persons concerned, families and professionals, and the Committee started its evaluation in early 2014.

Promotion and Advocacy The project was presented in several public meeting as a step in the de-institutionalisation process. An article about the project was submitted at Brazilian Association of Collective Health and the project was also discussed at the first National meeting of Psychosocial Care in December 2013.

### 8.5 Preliminary Observations and findings

The process of assessment with the WHO QualityRights Tool Kit may be a valid methodology to promote the shift to a community mental health model.

Furthermore it can change the relationship between the service users and the mental health staff.

Several staff meetings were held during the assessment both in MHO and in the CAPS III. This offered the opportunity to persons with disabilities to provide valid suggestions, based on the assessment results, to modify the living environment and the care settings accordingly.

During the evaluation process it was possible to benefit from the collaboration of associations of persons with disabilities and their families. The high level of their involvement represent an important target for the promotion of human rights and the battle against stigma.

8.6 SWOT Analysis and conclusions

Some preliminary observations indicate that the CAPS III has a team of various professionals that can articulate the rehabilitation process not only through pharmacotherapy. Instead, in the mental hospital, the staff is composed solely by nurses, occupational therapists and psychiatrists. In that situation, there is a patent lack of activities that foster the right to live independently in the community. When confirmed at the end of the assessment, these findings would support the call for pursuing and supporting the de-institutionalization process.

The assessment process represents only the first phase of the activity promoted by the development of the Quality Right Tool-Kit. Understanding the human rights violations is the first step of an activity of advocacy for a change in policy and practices.

In the future, further training and education sessions should be conducted with staff, persons with disabilities, DPOs and families. These meeting can strengthen the capacity-building in human rights of each stakeholder and promote higher quality standards that must be respected and promoted to improve conditions in the services.

Strengths	Weaknesses	Opportunities	Threats
The project team is qualified and committed to work;	Institutions resistance to change;	Inclusion of the project on SESAB's planning of deinstitutionalization;	Cultural tradition and stigma;
Participation of association of users, professionals and family mental health;	Difficulty in choosing and evaluating qualitative data analysis	Support of Human Rights Secretariat of Presidency of Brazil;	Political changes (election of local governments)
Changes introduced by application of Quality Rights before formal step of intervention;	Limited participation of researchers with experience.	Publication of the project at Observatory created by Human Rights Secretariat of Presidency;	

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# Conclusions and Recommendations



The project described in this publication is articulated in different ways in the four case studies according to the characteristics of the context taken into exam. It is not the purpose of this publication to make a comparison among the different experiences reported. In fact, because of the significant historical, economic, and social differences that characterise the various contexts where the project took place, it is pivotal that assessments of the progress made in the health area are made taking into consideration such characteristics. Nevertheless, it is important to underline that the way it was structured, the project has helped in starting a collaboration between local and international partners of high authoritativeness profiles and proven experience in the field in all the countries involved. Thanks to this collaboration, it has been possible to work in synergy with possible rehabilitation projects already existing in the local area or with the ongoing reform actions, if any.

### **9.1 Relationship between the CBR and Community Mental Health**

In those contexts (Indonesia, Liberia e Mongolia) where the main objective of the project was to build an interconnection between the mental health care services and the CBR, the project has favoured the beginning of new and positive relations between the two institutions.

CBR is a methodology which positively uses the resources already existing in the community and creates networks, so that persons with disabilities do not encounter barriers in becoming bearers of rights, carrying out advocacy actions, facilitate the construction of networks between associations, being protagonists in their own community (Turmusani 2002). One of the most important efforts in the deinstitutionalisation process has been to move away from the idea of mental health as a custodial care model. It is important to separate deinstitutionalisation from the mere reduction of the number of beds in mental hospitals due to budget cuts (dehospitalisation). Within the deinstitutionalization framework, the criticism to mental hospitals is closely connected with the way a person is considered: in this case, the inmate as bearer of rights.

The widespread idea of having the individual rights as the key element around which to build the services network allows for positive collaborations between CBR and community mental health. This project should be credited for having showing that it is possible to achieve a change on good practices for persons with mental health disorders.

CBR is based on a network developed within the community, interlaced with primary health care services (World Confederation for Physical Therapy 2003). In the three experiences in Indonesia, Mongolia and Liberia, the project has helped promote a progressive integration of mental health within primary health care. In particular, the general practitioners have been involved in specific trainings and workshops on mental health because thanks to their presence throughout the country, primary health care is well widespread. This represents a valid answer where, especially in some areas, there is a lack of specialised sanitary personnel and territorial services that, instead, is usually present only in large urban centres.

CBR strongly connects primary care and mental health systems and for this reason it can represent an important alternative to psychiatric hospitals, especially when mental health structures lack in the territory. In those places, community based approaches can stop a possible increase of the number of hospital beds of an institutionalisation kind and encourage the development of national policies in favour of solid investments in community services.

Workers and volunteers employed in CBR projects mainly come from the local area and are well integrated in the community where they work (Depaak et al 2011). Training volunteers on the basic principles of community mental health not only improves the ability to single out mental health needs of the commu-

nity, but also represents an instrument to fight against stigma. This is important because it helps diffuse a non-custodial care model and a conception of persons with psychosocial disabilities as bearer of rights accessing rehabilitation services as opposed to a socially dangerous element of the society. The promotion of empowerment activities (Nelson et al 2001) is typical of modern mental health community services tasks. Among the actions implemented by the project, there is the promotion of self-help groups, micro grant activities funding, as well as supporting the creation of users and family members associations and advocacy activities in the mental health field. CBR is based on strategies and skills which are demonstrated to be consistent with the goal of creating empowerment opportunities for persons with psychosocial disabilities.

Important activities to fight stigma addressed to the general population have been diffused alongside workshops where it has been possible to introduce the idea of community mental health. The tasks of fighting stigma and promoting mental health cannot be carried out only by clinicians and experts, rather it is a duty for the whole society to endorse.

Each of the countries involved in the project developed specific features according to the particular characteristics of the area.

Indonesia The work done has allowed to become aware of many situations which hitherto were unknown to services. So it has been possible to develop home treatment in the community and this has proved an important tool in an area where construction is still quite widespread (pasung). In particular, creating meeting groups in the villages has enabled to the monitoring of mental health needs in the community and, as a result, it was possible to establish inclusion and reporting procedures. This is an important and appropriate use of traditional social bounds that exist in local cultures for the promotion of mental health.

Liberia The course of project has encountered a series of difficulties from an economic and social standpoint, further exacerbated by the recent widespread of Ebola. The aim of the project has been to help developing a sustainable network of services which would include mental health within primary care services. The programme has promoted specialised training and has provided financial support for the empowerment of users-developed initiatives (self help groups and associations) in times of great strain for Liberian health system. All these initiatives fall within the wider process of inclusion of persons with psychosocial disabilities in educational, promotion of social inclusion, micro grant, health support initiatives that formed the set of activities of the CBR programme developed in Liberia.

Mongolia The project has involved the National Centre of Mental Health from the very beginning and has been mainly devoted to primary care services training. In a context where the mental hospital is still considered the fulcrum, also from a geographical point of view, to promote synergies with primary care system and community rehabilitation has meant acting to reduce hospitalisation responses in those places where proper territorial services for mental health are still insufficient. Furthermore, the experience in Mongolia has developed specific empowerment activities for users with mental health conditions who belong to various sanitary districts.

## 9.2 Promotion of Rights in Mental Health Care

Brazil is an interesting case. A system based on a large number of mental hospital has been changing for over 10 years moving to a community mental health model. Much improvement has been done so far and there is a good territorial network of services, covering a relevant part of the country. Despite that, mental hospitals are still operating in most part of Brazil.



Thanks to a sound local partnership with SESAB and SEAP, the project activity provided the chance to access three different kinds of structure in mental health network of services: a mental hospital, a CAP III and, up until an accident forced the project to stop, an HCT devoted to care and custody. These activities were already taking place and this has provided the opportunity to build communications between staff and users and family members associations on topics like life quality within the services and the reform of the mental health care system. This is quite important if we think that this took place in a context that is generally difficult to join. Some important results, for example as far as structures liveability, had already been achieved in an intermediate assessment of the project.

In addition, the assessment process provided the opportunity to arrange a public debate on the reform of the mental health care system, and this can be considered an important step forward to highlight good practices and to support the acceleration of the reform progress. As far as this latter issue, to involve associations, users and civil society members has represented a major signal in this perspective.

### 9.3 Study limitations

This study presents the activities carried out by the project in four countries and the few limitations related to the way data have been collected and presented.

Case Study methodology has a descriptive and qualitative approach and often it is not easy to define exact outcome measures, as the processes involved are complex and strongly influenced by their context. Nevertheless, it provides a quick and incisive description of the implemented actions and gives the opportunity to describe in detail the articulated activities which lie underneath the implementation of a service management. However, the aforementioned characteristics affect the possibility of providing useful information, ready to be generalised and with a high predictive index.

Finally it is important to bear in mind that the experiences described in the four countries taken into consideration cannot be easily compared directly because of the relevant differences in the mental health systems and in the implementation procedures.

### 9.4 Final recommendations

Some final recommendations can be formulated regarding a few open challenges the project will face:

- 1 – Improve the training Three out of the four case studies presented run specific training to train CBR operators and sanitary personnel, particularly general practitioners, on mental health issues. The short duration of these courses did not allow the appropriate acquisition of the competences skills needed to guarantee the adequate support. For future actions, it may be appropriate to provide the personnel already trained with a supplementary training before training additional operators.
- 2 – Work with community cadres CBR model makes often use of community workers and volunteers, who have moderate knowledge but are deeply rooted in the community and often have direct experience of working with persons with disabilities. Extending this model to mental health care can be helpful in rehabilitation processes of persons with mental health disorders and in fighting social stigma within the community.
- 3 – Support human rights the effort against cruel and degrading treatments addressed to persons with mental health conditions is crucial both inside and outside mental hospitals. For the future, it will be necessary to broaden the efforts to monitor and improve treatment conditions of persons with mental health conditions in the community and within the hospital.

- 4 – Work in the community One of CBR advantage is the possibility to offer persons with mental health conditions supported reintegration in the community. To value this aspect of the project, through a bigger investment in psychosocial rehabilitative aspects, it is crucial to develop the implemented programmes. Supporting persons with mental health disorders to be reintegrated in the workplace, helping them being active members of the society and holder of social rights are examples of concrete actions to defy stigma and to strengthen bonds within the community.
- 5 – Make treatments available A person who suffers from a severe mental disorder needs a pharmacologic therapy often for a long period of time after the acute stage. Medicine availability and cost affordability are important parameters to guarantee a good recovery in the mid-term. In some cases it seems difficult to find the needed medicines outside the mental hospital. Should this situation not change, increased hospitalisation may occur.
- 6 – Support people and families The care of a person with mental health condition involves the whole family. Implementation of specific activities to involve families, to support home care, to help family members deal with crisis can decrease the hospitalisation and improve life conditions of people with mental health conditions.
- 7 – Support Advocacy and Empowerment To support the creation of users and family members associations and their participation in the decision making is a pivotal process for transition to a community mental health system. Including partnerships and specific activities aimed at better capacity building can improve the rooting process in the community, reduce stigma, and allow more efficient self-advocacy actions in the long term.

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# Annex I

## **Community Mental Health Services And Human Rights semi-structured interview research form**

People with mental health disorders have extremely limited access to support and health services particularly in low-income countries and historically have also been excluded from community-based rehabilitation (CBR) programmes.

The following questions are presented to describe the domains we are going to use for the systematic collection of information about community mental health programs ongoing in the country and about the promotion of the inclusion of people with mental health conditions in CBR activities.

### **Domain 1**

**Environment in which the program is run: physical, sociocultural, socioeconomic and political environments**

Q1

What are the sociocultural attitudes about and behaviors toward people with mental illness?

Q2

Is there any evidence of stigma and discrimination? Describe

### **Domain 2**

**Health system where the program is run: general and mental health services working, as well as alternative sources of care, available in catchment area**

Q3

Which areas of the country are involved in the project? How many people live in the areas?

Q4

Is there a public primary care system working? Do poor people have access to care?

Q4b

Is there a program of community based rehabilitation (CBR) working?  
Do people with mental illnesses have access to care?

Q5

Are there any psychiatric inpatient facilities in or near the program catchment area?

Q5b

How many mental health professionals work in the area? How many of them are employed in the public sector?

Q6

Do families frequently bring members who are ill to spiritual healers before seeking any alternative care?

**Domain 3**  
**History of the program**

Date of the program start (year and month):

Q7

What was necessary to get the program up and running?

Q8

Were people with mental disorders subjected to human rights violation in this country?

Q8b

Did you use any instruments to measure human rights violation presence and size in mental health services?

## Domain 4

### Program conceptual framework: Orientation of services

The AIFO project aims to promote inclusion of people with mental health conditions in the CBR programmes

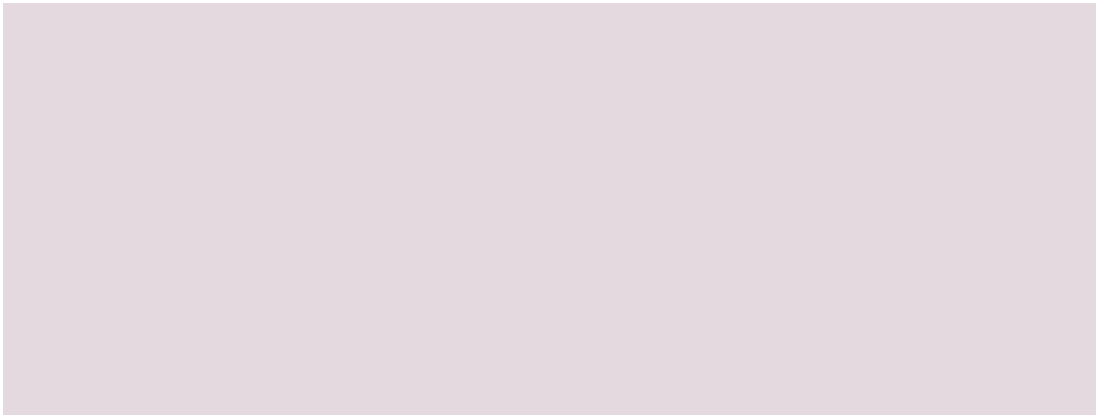
Q9

What services do the program offer?



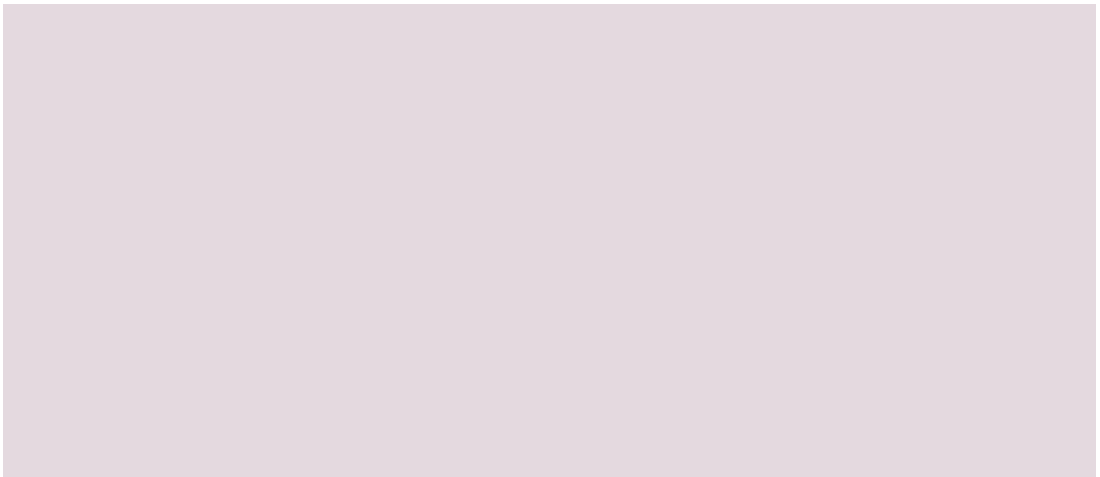
Q9b

Who are the participants involved in meetings, workshops or focus groups?



Q9c

What is the frequency of the activities?



## Domain 5

### Engagement with broader systems. And work in the political sphere.

Q10

What are the relations with public mental health system?

Are there any collaborations with local hospital or other service providers? Describe

Q10c

Are there any collaborations with general practitioners?

Q11

Do the project implement advocacy activities in local authorities? What?



## Domain 6

### Program resources: human, transportation, other

Q12

Please describe the professional and educational qualifications of the staff members working at the program. Are there also volunteers or unsalaried community supporters involved?

Q13

What other resources does the program have? Describe them.

Q14

Who manages the day by day activities?

**Domain 7****Client characteristics: diagnostic categories, sociodemographics, treatment coverage****Q15**

How many people with mental health disorders are involved in the program?

**Q15b**

What is the program average duration for a single client?

**Q15c**

Resume the main results of the program to promote change in mental illness treatment in the country area.

**Domain 8****Pathways to care:, referral networks****Q16**

In what way does the program promote inclusion of new cases in the treatment protocols? Does community know about the existence of the program? Do clients ask themselves to be included in the program or are they identified?

## Domain 9

**Types of intervention: analysis of the local situation, training for operators, clinical or psychosocial interventions, self-help groups & livelihood programs**

Q17

Does the program provide an analysis of situation about mental healthcare system, specifically concerning stigmatization and respect of human right among people with mental disorders? What instruments are used in the research?

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Q18

Does the program provide specified training for mental health local operators?  
How many trainings have been organized since the starting of the project?  
How many operators have attended the trainings or the meetings?

Q19

Does the program provide any direct clinical intervention? Which one?

Q20

Does the program provide any direct psychosocial intervention? Which one?

Q21

Does the program promote the constitution of Self help groups? Describe how.

Q21b

Does the program work in collaboration with disabled people organizations or with association of users and family? Do these associations have a role in antistigma campaigns and promotion of human rights in mental health facilities?

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**Domain 12****Outcomes**

Q22

Examine each type of intervention provided or promoted by the program and describe the current outcome. Do the interventions improve the target population lives in terms of overall quality, access to healthcare and rehabilitation? Do the local operators involved in the training contribute to modify the approach to mental health rehabilitation in their work, after the formation?

**Domain 13****Information system**

Q23

Does the program publicize its activity among general population?  
Describe how (articles in newspaper, public debate, advocacy activities...)

## Domain 14

### Swot analysis

Finally, looking at the overall activity of the project, we need to ask about the strengths, the weaknesses, the opportunities and the threats in relation to your experience in the program. The purpose of performing a SWOT is to reveal positive forces which work together and potential problems which need to be addressed or at least recognized.

Strengths, Weaknesses, Opportunities, and Threats analysis helps to identify the positive and negative aspects in the program and in the external environment. It can be helpful for short or long-term planning.

Firstly fill in the table with your own opinion about the project strengths and weaknesses. These are internal factors, think about human, financial, physical resources of the project and decide which are positive and which dangerous, as far as the project mission and vision. Then examine the external factors and forces which can help or prevent the project from reaching its goals. These are respectively called opportunities and threats. External factors include local political problems or opportunities, legislation, local events, cultural tradition...

These are some questions useful to accomplish the SWOT analysis:

#### Q24

Make a list of the main Strengths of the program:

- What useful resources are there?
- What are the best staff abilities?
- Does the staff develop any specific knowledge or expertise that local operators still don't have?

#### Q24b

Make a list of the main Weakness of the program:

- What weaknesses in the project has become clear during the intervention?
- Are there any knowledge (or expertise), missing at the moment, that need to be improved or would be helpful in the project?

#### Q24

Make a list of the main Opportunities in local environment

- Is the health care system currently under reformation?
- Are there protective factors (family/society)?
- Are there independent budget to improve the project goals?
- Are there good public primary care services?
- Are there specific health promotion programmes?
- Does the government support the vision of the project?

#### Q24d

Make a list of the main Threats in local environment

- Are any other priorities perceived as more important, in the country?
- Are budgets being cut?
- Are there major political changes or national disaster?
- Are essential contributors (like primary care service) not effective?
- Are there any physical dangers for operators or service users?
- Are there systematic violations of the human rights?

[illegible]

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