



Research and Studies

Emergence and structuring of support groups for people living with mental health problems in Togo, Madagascar, Lebanon and South Sudan

Touching Minds, Raising Dignity programme
February 2016

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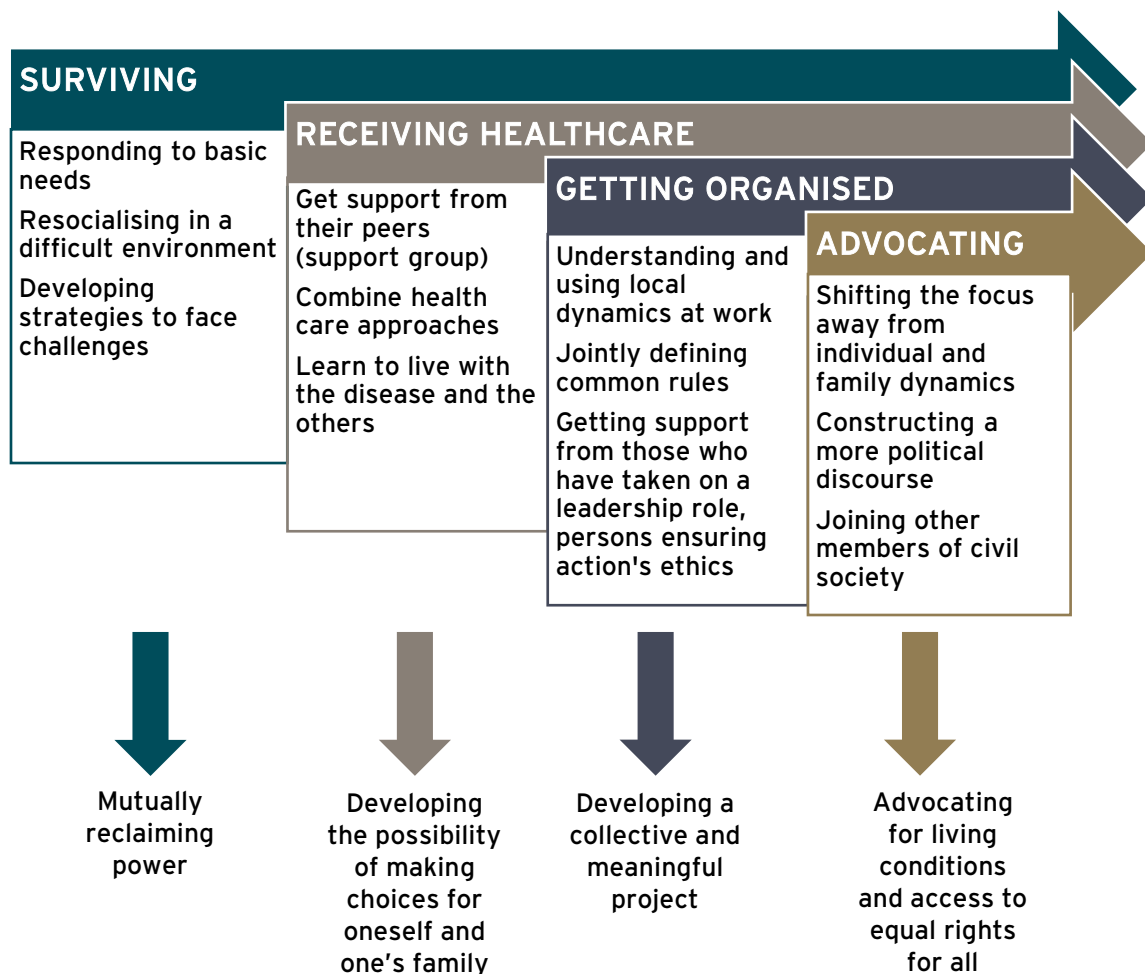
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EXECUTIVE SUMMARY

Based on an ethnographic type baseline study conducted on four support groups for people living with mental health problems, evolving in various contexts (prisons, hospitals, refugee camps and mental health centres) in Madagascar, Lebanon, South Sudan and Togo, this study identifies four dynamics contributing to the emergence and the structuring of these groups: survive, get medical care, get organised, advocate.

Summary diagram of observed group dynamics



Persons living with mental health problems and their family, caught in survival dynamics, and who find themselves in hardships, lack the capacity to stand back, which is necessary to analyse their situation. The aim is, somehow or other, to find the resources to cover basic needs and recover dignity, hope and, eventually, a reason to live. Once freed of this survival dynamic, such persons can contemplate seeking health care. Those

seeking health do so primarily in order to feel safer in terms of basic needs or the basic needs of their relatives, and to overcome the crisis associated with the disease. It is also in order for them to have access to a space of reflexivity that will allow them to express painful emotions and affects. Finally, in the contexts under study, getting health care is being able to get support from peers and the community. Indeed, health care and the idea of healing are still strongly associated within a collective context. Often, institutions and their professionals (psychiatrists, psychologists, sisters) trigger collective awareness, by offering to create support groups, and especially group dialogue. Within these groups, in addition to sharing emotions and affects, individuals will pool potentialities and resources thus enhancing solidarity and self-help mechanisms. When the group is successful, the individuals will recover self-confidence, feel less stigmatised, reconsider the fatality of their condition, of sick persons or parents of sick children, learn or relearn how to make decisions and take part in collective actions. A political awareness can eventually emerge, when exchanges in the support group are organised around a project aiming at changing their living conditions. The group starts looking for alternatives, thus becoming mutually self-helping. Such a group often looks beyond the simple therapeutic project and instead ends up focusing on the members' quality of life and access to rights in general.

The analysis of the results produced by the research highlights the fact that strategies supporting the emergence and structuring of mental health support groups in developing countries should rest on four essential questions: firstly, we should ask which partner(s) should be given priority in the project and which partner institutions should be selected - traditional, religious, or national? Related, what do we mean by leading institutions in a developing country, and how and on whom should we rely locally to carry through a decision to participate (on behalf of individuals, families and communities)? Secondly, we should question relationships between the members of a support group and their institutions, especially in terms of power. Thirdly, is the need to take into account the subjective challenge associated with the mental health problem, especially through institutional reflection pertaining to "the extent to which support groups should be re-empowered, how best to support the empowerment process, both at the level of the group and of the individuals (personalities) constituting the group?" Finally, is the need to provide a strong knowledge management policy, first and foremost focused on the collective ownership of a mental health policy, shared by all actors involved. These various questions enabled us to make five suggestions, all aimed at supporting a steering strategy that should result in the emergence and the structuring of a group that would be supportive, empowering, and participative: set up an ethics and strategic committee; integrate a knowledge management policy that speaks to the implementation of the project's mental health policy; identify, train and supervise ethics proponents; understand how the target population manages its intra and interpersonal relationships (including with institutions); gather all national, religious and traditional actors in the project's intervention area. These questions and suggestions should be ratified at the endline of the *Touching Minds, Raising Dignity* project implementation.

Questions



Suggestions

Summary diagram of questions and suggestions from research findings



INTRODUCTION

GENERAL BACKGROUND

RESEARCH BACKGROUND

In the world, about one person out of 10 suffers from difficulties related to their mental health.¹ The causes of these difficulties are numerous and include conflicts, displacements of populations, incarcerations in run down institutions and chronic illnesses. However, budgets allocated to mental health are insufficient, especially in low income countries, where the needs are however the most dire.²

Handicap International (HI) has been committed to supporting people living with mental health problems since the beginning of the 90's. At the moment, this focus is embodied within three important goals of the association's federal strategy (2011-2015), namely:

- 1- Helping organise care for the wounded, and helping provide for the basic needs of vulnerable groups during humanitarian crises, through psychosocial support and mental health support for suffering individuals.
- 2- Ensuring disabled people and vulnerable groups have access to social, health (including mental health) and educational services, and have access to means of subsistence.
- 3- Ensuring the involvement of disabled people and vulnerable groups in development processes (including groups and civil society organisations (CSOs) who make use of mental health support services, and their relatives).³

In the field of mental health, HI intervenes, *inter alia*, with what is known as "closed" environments. When HI uses this expression, it is in the strict sense of the term (psychiatric hospital and custodial settings), or in reference to the functional meaning of the term (for instance, refugee camps or displaced persons, people whose movements are restricted within their community). Daily life within these environments exhibits certain characteristics of confinement: deprivation of some basic rights, reduced space,

¹ WHO, *Mental Health Atlas*, WHO, 2014.

² Less than US\$2 per inhabitant. Usually, for these countries, a large portion of these funds is dedicated to caring for hospitalised patients, especially in psychiatric wards.

³ Specific articles of the United Nations Convention on the Rights of Persons with Disabilities underline the following:

- the right to an adequate standard of living and social protection (Article 28), quality and accessible health services (Article 25)
- the right to freedom and safety (Articles 12 and 14)
- the right not to be subjected to torture or to painful, cruel, inhuman or degrading treatments (Articles 15 and 16)
- the right to be included in society and to be autonomous (Article 19).

restricted access to services dedicated to respond to basic needs. Various exploratory missions⁴ related to mental health have highlighted the fact that living in these confined or degraded environments leads to a degradation of people's mental health. This interaction between populations already made vulnerable by traumatic events and degraded environments, and without the necessary support to achieve improved well-being, fits in what HI calls a *Situation of Handicap*.

According to the definition provided by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, when interacting with various barriers, may hinder their full and effective participation in society on an equal basis with others.

In this context, HI elected to develop various intervention models aimed at improving the mental health of individuals and their communities. These models, all defined according to specific sociocultural, institutional, partnership and professional contexts at the local level, aim at meeting the needs of people living with mental health problems in order to prevent any risk of social judgement, be it in the form of discrimination, stigmatisation, exclusion or social preclusion.

The present research focuses on this type of environment.

INSTITUTIONAL AND OPERATIONAL BACKGROUND TO THE RESEARCH WITHIN HANDICAP INTERNATIONAL'S ORBIT

This study fits within the framework of the programme *Touching Minds, Raising Dignity: Putting a stop to the social condemnation of people living with mental health disorders in four countries in crisis and post-crisis situations*,⁵ developed by HI for the period 2014-2017.

The overall objective of this programme is to improve the social and individual participation of people living with mental health problems in four countries in crisis or post-crisis (Togo, Madagascar, Lebanon, Sudan of the South). These four countries all have in common the fact that their citizens chronically encounter social, economic and political crises which include precarious socio-medical conditions, the erosion of public infrastructures in a general way, undermining everyone's capacity for "living together", which is key to the development of a nation. To this end, HI proposes to develop innovative pilot intervention models for people suffering psychically, and who are living

⁴ Togo in 2008 and 2013; South Sudan in 2012, 2013, 2014; internal evaluations: Madagascar in 2010, 2011, 2012; Lebanon in 2010 and 2013; and stocktaking missions: Madagascar in 2012.

⁵ The full title of the programme is: "Touching Minds, Raising Dignity, *Putting a stop to the social condemnation of people living with mental health disorders in four countries in crisis and post-crisis situations (Togo, Lebanon, Madagascar, South Sudan)*".

in these closed environments. These models aim to assist individuals to “live together” in a way that is “good enough”, i.e. “the capacity to live with oneself and with others (...)” (Article 2.8, Lyon Declaration, 2011).

HI's approach to mental health is essentially a community approach. At an individual level, it prevents the risks of severe psycho-pathological collapse and, at a community level, it revives solidarity and mutual support, which are guarantors of a social cohesion that is sufficiently protective of individuals' mental health.⁶

The specific objectives of the programme “Touching Minds, Raising Dignity” are as follow:

- **S01** - The promotion of innovative intervention models in the field of mental health and psychosocial support in order to improve the governance of public policies in the health, social and penitentiary sectors.
- **S02** - The reinforcement of technical and organisational capacities of multisectoral services of penal establishments and psychiatric hospitals in order to improve access to health care and meet the basic needs of people living with mental health problems.
- **S03** - The reinforcement of technical and organisational capacity of community services of civil society in order to improve the protection of the rights of people living with mental health problems.
- **S04** - Greater consistency between intervention models, as well as the promotion of innovative ways to capitalise on lessons learned, in order to contribute to the development of international advocacy with respect to social and civic participation of people living with mental health problems, and to reinforce HI and its partners' capacity with regard to mental health/psychosocial support.

This research fits specifically within the framework of SO4, aimed at promoting innovative knowledge models. It aims at understanding how sustainability processes involved in HI partnership approaches are elaborated. It also aims at informing the basis of international advocacy with respect to the social and civic participation of people living with mental health problems.

This research is part of the project's baseline. The same research work will be conducted at the end of the project or endline, especially to control its conclusions and suggestions.

⁶ See “Réunir les solitudes, l'exemple d'un projet de Santé mentale communautaire au Rwanda”, Feedback document, Technical Resources Department, Handicap International, 2012.

CENTRAL QUESTION AND KEY CONCEPTS

CENTRAL QUESTION

The research's central question is as follow:**How do the support groups supporting people living with mental health problems in the four countries of the programme *Touching Minds, Raising Dignity*, be they formal or informal, emerge and structure themselves?**

In the four countries studied, the research focuses on understanding how the various support groups existing in different forms and statuses (support committees, peer groups, community self-help groups or groups of parents of children living with mental problems), are organised and structured. The research also tries to understand how these fit within their sociocultural and political systems and, finally, as the case may be, how they attempt to ensure their sustainability within these systems.

SPECIFIC OBJECTIVES

The specific objectives of the study are as follow:

- Identify the individual and organisational (institutional) determinants fostering the emergence and the formalization of the groups, through the analysis of their history, structuring, and internal policies.
- Describe how these groups operate, the internal relationships governing them, the content of their discussions, and their action mechanisms.
- Analyse the existence and the quality of interactions between the groups and other structures surrounding them (authorities, community actors, service providers).
- Analyse the sustainability of support groups.

This research seen globally is aimed at understanding how knowledge brought by occidental models in terms of individual/society relationships, and local practices, translate when implemented in the field of mental health.

KEY CONCEPTS

This research relies heavily on three key concepts, used more globally by a wide variety of actors involved in the mental health field. These concepts are in line with the dynamic currently adopted by professionals and people in the field of mental health, and who are interested in innovative ways in which to deal with people living with moderate to severe mental problems. In the past, alternative inventions in psychiatric institutions (institutional psychotherapy, deinstitutionalisation) often stemmed from activist

professionals, critical of abusive institutions, characterised by power, alienation or even abusive relationships. Despite the virulence of this professional yet ethnocentric (for example France or Italy) criticism, very little room was left for the direct expression of the patients in the public space. In contrast, we assist today to the emergence of a new sequence, testimony to a more collaborative culture where patients and professionals try to share common healthcare and communal objectives. Some patients also advocate that a specific singularity be acknowledged in their relationship with the world, despite all kinds of “exploitation” by psychiatry or mental health.

Empowerment

A number of research papers currently available, report on the Western models of the individual/society relationship. For example, we could consider the research conducted by numerous actors of foreign aid and Western mental health specialists on the topic of empowerment of people living with mental health problems and their caretakers.⁷

WHO's statement (2010) on user empowerment in mental health, entitled User empowerment in mental health - a statement by the WHO Regional Office for Europe, provides the following definition of empowerment: “Empowerment refers to the level of choice, influence and control that users of mental health services can exercise over events in their lives. The key to empowerment is (...) the transformation of power relations between individuals, communities, services and governments”.

The term empowerment is closely associated with the idea of participation, which, in numerous cases, is one of empowerment's expected results. It refers to possible ways to implement the democratic ideal and the principle of equality of citizens.

»•« Three empowerment models

Claude Deutsh highlights the fact that there are many different ways to position oneself in an empowerment process, these positions relate to both public policies and professionals implementing them. Three ideal models are described as conflicting:

⁷ In 2014, the Collaboration Centre for the WHO in France (CCWHO), focusing on mental health research and training, hosted a seminar on the empowerment issue, leading to the publication of a report entitled *Agir Autrement, Autonomisation/Empowerment*. This report provides a number of guidelines in favour of the defence of the rights, the participation and the information of people living with mental health problems, and their caretakers. Each of these guidelines was subjected to a literature review and made reference, among others, to the CRPD. VASSEUR-BACLE, S., VAGLIO, A, RAFAEL, F & ROELANDT, JL. *Santé mentale en Europe : 21 recommandations en faveur de la Défense des Droits, de la Participation et de l'Information des personnes usagères des services de santé mentale et des aidants*. Congrès Français de Psychiatrie, Nantes, November 2014.

- The radical model. In terms of this model, the empowerment stakes are group recognition, the ending of group stigmatisation, self-determination, the redistribution of resources and political rights. This conception of empowerment is associated with the ideas of justice, redistribution, social change, awareness, and power - the latter being exercised by the people "from the bottom". Empowerment is a process stemming from the development of an individual power and a collective commitment, a political mobilisation in view of in-depth social transformation.
- The socio-liberal model defends individual freedoms with a focus on social cohesion and social life. It takes into account socio-economic and political conditions without questioning the root causes of inequalities. In this model, empowerment is associated with the ideas of equality, opportunities and contestation. Social development and reducing inequalities are major concerns - but without questioning the system. Empowerment plays an essential role in this process, by enhancing capacities and giving individuals the means to choose their lifestyle.
- The neo-liberal model is a political logic focussing on the economy. This logic is embodied in the extension and the dissemination of market values to social policy and all institutions. The idea of empowerment is captured in a poverty and inequalities management logic, in order for individuals to exercise their individual capacities and make "rational" decisions within a market economy context. Within the framework of the removal of the role of the state so that the market and profits rule, the individual is expected to be subsumed by the labour market and the world of consumption so that, consequently, empowerment is equated with leading one's own life, choosing rationally and taking part in civic activities.

Participation

Participation could be broadly defined by the weight "granted" to "people at the bottom" (those who hold lay, experiential, sensitive knowledge) by "people at the top" (those who have professional and institutional knowledge, are regarded as models and who traditionally steer action). The improvement of social participation would require redefining the roles, resulting in "people at the bottom" gradually seizing power from "people at the top" and becoming able to have some say in the decisions affecting them.⁸ There is an entire grading in the weight "allotted" to the "people at the bottom" by the "people at the top". The AFD, based on Pretty's⁹ work, refers to a participatory

⁸ BRESSON M., "La participation : un concept constamment réinventé", Socio-logos, Revue de l'association française de sociologie, No 9, 2014.

⁹ Alternative systems of inquiry for a sustainable agriculture, in Institute of Development Studies Bulletin, vol. 25, (Brighton: Institute of Development Studies, 1994), pp. 37-48 in, AFD, Manuel de la participation à l'usage des acteurs humanitaires, http://www.urd.org/IMG/pdf/MP_CHAPITRE1.pdf (first accessed in April 2015).

typology that can be summarised as follow and where the NGO would represent the “people at the top”, and the population benefitting from the action, the “people at the bottom”:

- The NGO acts alone, without communicating with the population benefitting from the action.
- The NGO informs the population benefitting from the action without organising any consultation on the matter.
- The NGO consults with the population benefitting from the action, without really taking into account any comments made.
- The NGO consults with the population benefitting from the action and takes comments into consideration.
- The NGO partners with the population benefitting from the action to deal with the issue.
- The NGO gives the population benefitting from the action the power to make appropriate decisions by itself.

»•« **Brief history of the forms of empowerment of patients in the decisions affecting them**

The empowerment of people with mental health problems with respect to making decisions affecting themselves can take various forms and is not a specific movement towards mental health. In the past, the first movement observed was the one embodied in Jean-Baptiste Pussin (1745-1811), who arrived sick (suffering from a tuberculosis-type disease) at the Bicêtre Hospital in Paris and who was very quickly diagnosed as “untreatable”. He became the head supervisor for the hospital thanks to his ability to turn his experience as a patient into a skill to assist those living with the same illness. Consequently, he chose his staff among cured patients and convalescents. However, it is only from the classic model emerging in the 50s around alcoholics anonymous, that users’ associations progressively emerged in the field of mental health in developed countries (New-Zealand, Australia and Great-Britain). In the middle of the 80s, these associations largely reproduced the model adopted by Aids and myopathy associations and were structured as self-help associations, usually around a medical diagnosis (depression, bipolarity, schizophrenia). These associations progressively developed a number of activities aimed at improving healthcare and at supporting medical treatment (therapeutic education), as well as living together and developing a strategy to fight against stigmatization.

In the 90s, new initiatives started appearing aimed at facilitating the integration of professional patients; these were called “peer mental health mediators” or “expert patients” in specialized mental health units. These initiatives were progressively institutionalized through public health reviews and laws. The scientific community also actively participated in this movement, sometimes highlighting the economic impact of these types of initiatives, at other times highlighting the impact in terms of recovery of

the persons, or the crucial issue of democracy in terms of regulation of the various forms of domination. For example, the literature review published by J. Repper and T. Carter shows how the integration of these workers in the professional mental health teams leads, on the one hand, to reducing hospitalisation and relapse rates among these peer workers and, on the other hand, to improving users' recovery in these units" (Repper J., Carter T., "A review of the literature on peer support in mental health services", *Journal of Mental Health*, August 2011; 20(4): 392-411). Another example from a recent study conducted in France within the framework of an experimental programme led by the CCWHO from 2011 to 2014, suggests that the mediators' experiential knowledge in terms of "knowing how to deal with domination" should be considered (Demailly L., Garnoussi N. "Le savoir-faire des médiateurs de santé pairs en santé mentale, entre expérience, technique et style", *Revue Sciences et Actions Sociales*, No1, 2015).

Associated with the notion of empowerment, the notion of participation captures the way in which the individual can become an agent of his or her economic, professional, family and social destiny, whilst contributing to society in general. In this Western model of the individual/society relationship, contained in the principles of the Ottawa Charter,¹⁰ these two concepts entail a double requirement, which is difficult to comply with if one has the set idea that it relates to a transfer of power from the people "at the top" to the people "at the bottom". Several organisations comprising people supposedly affected by mental health problems were created against the idea of this vertical movement, to advocate for a number of reasonable arrangements allowing them to participate, at various levels, in the services usually offered by mental health professionals, or to create these themselves for their peers. This is clearly stated by the World Network of Users and Survivors of Psychiatry, whose goals are: "The liberation of our people from institutions (...), provide a wide array of services developed in consultation with user/survivor organisations, which may include peer support, crisis hostels and places of safe respite, and advocacy".¹¹

These various initiatives are testimony to singular relationships with the institutions to which they adhere or contest. A recent article published by Troisœufs and Eyraud provides an interesting typology, suggesting four types of groups, each with different apprehensions of user participation and various expectations or claims in terms of institutionalisation.¹²

¹⁰ "Health promotion works through concrete and effective community participation in the setting of priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities - their ownership and control of their own endeavours and destinies." Ottawa Charter, WHO, 1986.

¹¹ World Network of Users and Survivors of Psychiatry, 2008.

¹² TROISOEUF A., EYRAUD B., "Psychiatisés en lutte, usagers, Gemeurs : une cartographie des différentes formes de participation", *Bulletin National Santé Mentale et Précarité*, Rhizome, No 58, Nov. 2015.

**Mapping various forms of participation in mental health,
based on Troisœufs and Eyraud**

	Self-support groups	Protest groups	Advocacy groups	Groups asserting a difference
Aim	Learn how better to live with the disease	Defend the rights of people in psychiatric care and offer a place of exit from the institution	Promote the inclusion of those in psychiatric care in political decision making bodies and provide more space to users in areas of relevance to them	Promote diversity of experiences and ensure the acknowledgement of singular lifestyles
Means	Share experiences of problems and caring	Organise strong contestation of treatments the members had to endure	Recuperate public participation through negotiation	Redefine people's identity in the light of their experience in a psychiatric institution
Relationship to the institution	The contact person and advisor, mediates between the participants and psychiatric professionals	Take up a position in opposition to the psychiatric institution	Position of negotiator towards the institution, role of national representative before political authorities	Alternative suggestion for the treatment of the disease

As we can see from the above table, these various groups act within a context of tension between, on the one hand, a request for acknowledgement of their experience of the institutions by the users and a request for individual participation in the development of healthcare mechanisms directly affecting them, and on the other hand, a request for the emancipation and recognition of life experiences, which do not necessarily fit within a psychiatric form of treatment.

All these relationships with the institution and all alternative suggestions to medical treatment or to living together make sense in an extended timeframe, often over several

years. This long-term timeframe is often challenged by several issues that individuals and organisations sometimes face, in the NGOs intervention contexts, on a socio-cultural, economic or political level. The issue of the action's sustainability then also becomes a concern for mental health participants working towards the empowerment and involvement of persons living with mental health problems.

Sustainability

The sustainability issue is important for all development actors, and therefore an essential justification for their action. Even in emergency contexts, humanitarian actors try to promote determinants that, in the long term, optimise the organisation of services and their quality and more globally, see out the sustainability of the effects of a project after its conclusion.¹³ In the mental health field, sustainability can be understood in various ways: sustainability of relatively good mental health of beneficiaries as a result of the project's actions, sustainability of the support groups in terms of organisational and financial capacities, sustainability of the partner institutions' support, sustainability of the approaches conveyed through the training programmes offered to local professionals, etc. However, whatever the type of sustainability envisioned, each actor, starting with HI, is aware that a sustainable action is first and foremost a flexible and evolutive action, and that the way it will be sustained is sometimes very different from the way it was originally envisioned.

Finally, it is necessary to point out that sustainability is not an injunction or a compulsory goal for a support group. Here, we are seeking to understand whether the sustainability issue is also an area of concern for the support groups and, if so, how it has emerged - thanks to which outside influence(s) - and how it is envisioned.

Therefore, in this research, we will try to understand how the approach adopted by Western actors (and especially HI), based on a model anchored in human rights, association participation and empowerment, translates into practices emerging in a different socio-cultural milieu and in project locations deeply unstructured by conflicts and/or poverty.

¹³ Concerned about these issues, HI co-authored a study conducted between 2009 and 2012, together with the International Centre for Evidence in Disability (IECD) of the *London School of Hygiene and Tropical Medicine* (LSHTM) aimed at developing a methodological tool to analyse sustainability. This study was based on examples of projects developed by HI in the field of medical rehabilitation¹³ in five countries (Nepal, Cambodia, Liberia, Sierra Leone and Somaliland), and identified various conceptions and dimensions of sustainability. This study enabled HI to develop a methodological guide supporting the implementation of processes geared towards action sustainability.

TARGET POPULATION AND SAMPLING

The target population of this study includes first and foremost the support groups of people living with mental health problems. A support group is studied for each country, supported (or about to be supported), in the context of this study, by HI. These support groups could be informal groupings or, conversely, could be part of civil society organisations working on the issue of persons living with mental health problems. The groups could take various forms: support committees, peer groups, community self-help groups or groups of parents of children living with mental health problems, discussion groups, etc.

With respect to “mental health problems”, we refer to HI’s suggestion, which makes the distinction between:

- People living with severe disorders
- People living with light or moderate disorders.

Still according to HI, when these problems become chronic, people living with these two types of disorders can develop psychic (orientation, memory, relationship to reality, etc.), intellectual (understanding, ideation), or psychosocial (interaction with others) inabilities.¹⁴

The sampling used in this study doesn’t try to be representative of various groups that we could have identified through an exhaustive literature review. It rather aims at highlighting various concrete situations observed in the field. The sampling is therefore responding to a wish to position the study in a programme logic specific to HI, which is why these groups are supported by the NGO. The time constraint for the study (15 days per group) is also the reason for refocusing the sampling on only one group per country, even though HI can support several groups within the same country, even though other groups outside HI’s intended scope of influence could have made very interesting subject material for the study.

Group selection was based on a number of criteria that the groups were required to have in common, namely:

- A number of people sharing similar mental health problems
- A support/management service offered

The following diversity issues of interest were also taken into consideration:

- Diversity of situations (camps, community health centres, prisons)
- Diversity of group profiles receiving benefits

¹⁴ Cf. Handicap International, Document Cadre Santé Mentale, p. 22-23, 2011.

- Activist commitment potential
- Group evolution/maturity level
- Duration of support by a third party organisation

Four support groups are studied in this research:

Name of the group being studied	
Lebanon	Support group of mothers of autistic children of Tyr Family Guidance Center
Madagascar	GEBAPRIM of the Mahajanga Prison
Togo	GBALENFIT Women of the Dapapong Community Mental Health Center
South Sudan	Mental health support group of Juba Hospital

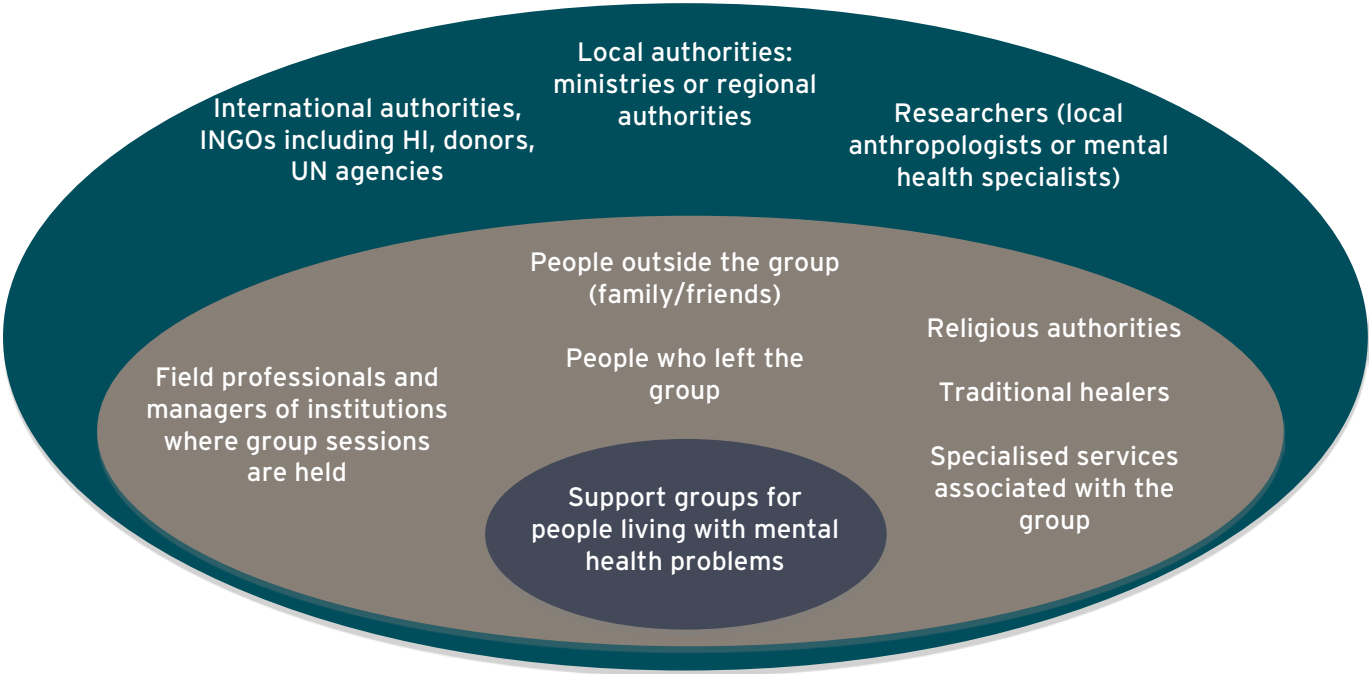
The research also looked at the testimonies of all actors possibly associated with the support groups (see diagram below). Here, we are talking about key informants, namely:

- All actors able to play an immediate supportive roll when it comes to these support groups, such as: previous group members, family and friends, field professionals and managers of institutions facilitating the groups, traditional healers, specialised services associated with the groups, etc.
- To a lesser extent, local and international authorities who played a role in the emergence of these groups and/or were associated with the mental health issue, and researchers working on the same issues

For each country, the breakdown of these actors and the decisions to meet with them are made after consultation with field teams in these countries.

These various populations are represented in the diagram below:

Target study and key informants



METHODS AND MATERIALS

THEORETICAL FRAMEWORK

This research fits within the methodological framework of applied social science studies¹⁵ and more specifically within the field of social anthropology. Suggestion is also made to refer to micro sociology, which, by virtue of its methodology, borrows to a large extent from ethnographic types of work, whilst adding a sociological and psychological sensitivity to the interpretation of interpersonal relationships. Goffman, in his analysis of experimental frameworks,¹⁶ defines micro sociology as the ambition to describe and analyse groups of small size (small gatherings, youth groups, families), in order to learn

¹⁵ UNESCO and OECD (2002) both provide the same definition of applied studies: applied studies are characterized by original projects undertaken in order to acquire new knowledge aimed mainly at a specific and particular goal: to analyse complex problems, provide solutions and suggest a practical use of knowledge. The continuum between new knowledge and its application is essential here.

¹⁶ GOFFMAN E., *Les cadres de l'expérience*, Paris, Les Editions de Minuit, 1991.

how they are structured and the nature of their social relationships. The experimental framework on which micro sociology is applied is understood as a cognitive and practical system providing meaning, which governs the interpretation of a situation and how best to become involved in this situation, be it in relationship to others or to the action itself.¹⁷

The aim is to generate a monograph for each group. In social sciences, a monograph is an “in-depth (survey or study) limited to a given social fact and based on direct observation, and in which facts, by association, contribute to the experiences lived thus falling within the ambit of comprehensive sociology”.¹⁸

PRACTICAL APPLICATION IN THE FIELD

Fieldwork initially consists in monitoring all the support group actors during their meetings and during interventions and reflective times. In addition to this work, participants and key actors are interviewed in order to confirm and strengthen the assumptions being made. During this phase, it is important to identify and account for the successive metamorphoses occurring in the various observed people’s attitudes, practices, interactions and underlying motivations. This is why it is important to articulate this micro sociology within the context of the story, thus giving meaning to action: “the present carries a load, a weight from the past, which has to be updated today in order to understand its current stakes. Analysing a contemporary practice thus entails grasping the underlying historical foundations; it is about striving to understand its current structure, starting from its former transformations.”¹⁹

Because of the specificity of the subject matter of this study, a fine knowledge of the situations encountered in real life and of the needs of the target group is essential. Daily immersion within these groups, through involved or participative observation, is thus critical and is the precursory and founding moment that marks the acquisition of knowledge, and the moment this “micro-society” can be given meaning.

In addition to this immersive work, we need to try to understand and grasp the various concepts and methods that people related to these groups bring into being, whatever or by whomever these may be (including professionals from HI). To this end, individual and group interviews, as well as a review of the main reference documents are a necessary foundation for collection and analysis.

¹⁷ JOSEPH I., Erving Goffman et la microsociologie, Paris, PUF, 1998, p. 123.

¹⁸ Trésor de la langue française, <http://atilf.atilf.fr/>

¹⁹ CASTEL R., La notion de problématisation comme mode de lecture de l’histoire, Problematization way of reading History, Jane Goldstein, ed. Foucault and the history day, Cambridge Plackwell, 1994.

In short, the study is undertaken based on three forms of information collection:

- *In situ* observations (ethnographic type) of the support groups; 23 observation sessions were conducted.²⁰ These observations were meticulous and as comprehensive/holistic as possible, and focused on various aspects of the life of the group (organisation, operation, expressed content, relationship dynamics, action mechanisms, etc.). The idea was to have a set of recurring themes emerge, and to fuel several assumptions that will be cross-checked using the content of interviews and reference document reviews.
- Interviews carried out in France and in the field in the course of the four missions with the various actors, at micro- (direct beneficiaries of the action), meso- (professional, institutional) and macro (political actors) levels of the programme. 128 interviews were conducted.²¹ The main theoretical underpinning of these interviews is that of hermeneutics (biographical interviews, using a “tell me about...” kind of approach). The aim is to encourage follow actors to communicate by orienting them towards the questions raised by the research rather than imposing standardized interview guidelines.
- The reading of “reference documents”: these refer to the records and the minutes of meetings, the support groups’ “projects” and their support mechanisms, all the references used by the professionals, all legal and regulatory documentation, reports documenting public action in each country, and HI’s internal and external assessments.

These three forms of information collection, further described in the annexes, are especially interesting in terms of use since, besides allowing for the collection of a qualitative/“sensitive” set of information, they also make it possible to triangulate this information, which guarantees to some extent the reliability of the research.

STUDY LIMITS

Some limits of this research should be highlighted.

Firstly, socio-anthropological materials were collected in a very short timeframe (15 days per country).²² This constraint led us to give preference to interviews rather than observation time.

Secondly, some key actors, who could have delivered quality content, were unavailable at the time of the visits.

Thirdly, interviews were often facilitated by an interpreter, but this wasn’t systematic. HI professionals were sometimes requested to play this role, leading to biases in the way the research was conducted.

²⁰ Cf. annexes - Summary table of involved observations made.

²¹ Cf. annexes - Summary table of interviews conducted.

²² Cf. annexes on the conduct of the study.

The validity of information gathered and analysis from this research should therefore be balanced against these limitations. Statements and reflections presented in this study should therefore rather be considered as suggestions, a set of avenues for reflection, than as exhaustive research on the subject.

DATA ANALYSIS

Data analysis was first conducted through as exhaustive a survey as possible of the themes stemming from field observations and interviews. As mentioned in the previous paragraph, due to the short timeframe per country visit, interviews played a major role in identifying and structuring these key themes. *In situ* observations were used instead to confirm/ensure the validity of data collected through these interviews. Then, we conducted a more systematic analysis on the way the actors we met used the study's key concepts in their daily practices - *empowerment, participation, sustainability*. At this stage, a first literature review was also conducted, specific to the intervention setting. For this first key stage of the analysis, we therefore took care to keep the statements made within the various socio-cultural settings specific to each country.

However, this initial treatment remains partial. Indeed, the richness of observations and interviews could have led us to conduct a more rigorous and detailed content analysis (for example: by systematic re-transcription and treatment of the text in terms of semantic frequency), but our analysis was primarily geared to enabling us to respond to the questions we raised.

These three forms of data collection are complementary since interviews relate to people's memory, with its selectivity and partiality. Actors interviewed reconstructed their story by telling it based on their values and interests. Conversely, reference documents allow the story to be retraced through version in a timeframe more closely related to the events it reconstructs. Subsequent omissions and rationalisations are fewer and especially capture how actors argue, justify themselves, debate, invent procedures and processes that we placed at the heart of our research work. These remarks are not totally neutral and innocent. A "framework document" or "methodological guidance" for example, fulfils various functions, such as managing activities that we need to keep in mind. Furthermore, these documents often do not, or take little account of informal relationships woven into action and that play a major role - even though we sometimes manage to read between the lines.

A second analysis phase came into play afterwards, during which we tried to compare and identify significant convergences and divergences between observations and analyses made for the four intervention countries. We completed this second level reflection with a literature review focusing on these new major reflection and discussion points presented in this research report.

AIM OF THE STUDY

Our aim is not only to observe and draft reports, which are the first two phases of the field work findings, according to Everett C. Huges. The author draws the researchers' attention to the tension existing between the role of member (who participates) and the role of outsider (who observes and reports). It is impossible simultaneously to observe and participate. This is why we choose to adopt a position known as involved or participative observation, which allows the researcher's involvement and direct participation, whilst at the same time allowing him or her to take the necessary step back to reflect on what is going on. As Laplantine underlines, "we are never objective witnesses observing objects, but subjects observing other subjects within an experiment in which the observer himself is observed".²³ The interest of these involved observations lies in the fact that we position ourselves as indigenous ethnologists, a tactic enabling us to interact with the observed actors.

²³ LAPLANTINE F., *La description ethnographique*, Paris, Nathan, 1996, p. 21.

SUMMARY PRESENTATION OF THE FIELDS STUDIES

	Lebanon	Madagascar	Togo	South Sudan
Name of the support group	Support group for mothers of autistic children	GEBAPRIM	GBALENFIT Femmes	Mental health support group
Location	Palestinian camps at Al Buss - Tyr	Mahajanga	Mental health centre - Dapaong	Juba
Hosting institution	Beit Atfal Assumoul Association	Remand prison of Marafato	Yendubé Association, congregation of the Sœurs Hospitalières du Sacré Cœur de Jésus	Juba Teaching Hospital
Group objective	Act for the improvement of living conditions for families with a child living with autism	Take part in humanising prison practices and the social reintegration of prison inmates	Act for the improvement of the living conditions of the families affected by a mental health problem	Inform the group members of the disease and the treatments, and share in life experiences
Findings leading to the establishment of the group	Late identification of disorders associated with families' poverty levels; diagnoses poorly understood by families; significant discrimination from within families	Extremely difficult living conditions in prison, leading to various mental health problems; significant stigmatisation of ex-inmates when they return to their communities	Isolation of sick people and their families from the community; poverty of families affected by mental health problems	Lack of understanding of the mental disorders and related treatments, and of the evolution of disorders

	themselves and their relatives; suffering and feeling of exclusion experienced by parents; failure of the parenting function			
Types of participants (size of the group)	Mothers (Lebanese, Syrian, Palestinian) of children living with autistic disorders (>10)	Prison inmates, defendants and convicts (from 6 months to 15 years), men, women and under-aged children (>30)	Women living with a stabilised mental health problem or mothers of a child living with a mental health problem (>10)	People living with a mental health problem or members of their family (>15)
Types of actors	Professionals (psychiatrists and psychologists, Lebanese and Palestinians)	Professionals (specialised educators, prison warders)	Sister heading the centre	HI psychiatrists and facilitators
Group entry criteria	Be the mother of a child living with autistic disorders	Know how to read and write, have a basic academic background (high school level), "exemplary" behaviour in prison	Be stabilised in terms of the disease or have a sick child	Be a stabilised patient in the hospital or be the member of the family of a sick person
Meeting frequency	2h a month	Every day	Half a day once a month	Every two weeks
Activities conducted	Facilitation of a support group	Organisation of activities geared towards	Facilitation of a support group; organisation of	Facilitation of a support group

		education, vocational training, leisure and access to rights	community awareness activities; organisation of income generating activities	
Funding sources	Beit Atfal Assumoul Association	Prison administration, HI and various CSOs intervening in prison	Congregation, private donations, HI	HI
Date of creation of the group	2010	2008	2008	2015
Nature and duration of HI's support	Collaboration for 5 year (technical support - advice, training - and financial support)	Collaboration for a year (technical support - advice, training - and financial support)	Collaboration for a year (technical support - advice, training - and financial support)	Collaboration for 6 months at the time of the study (technical support - advice, training - and financial support)

SUPPORT GROUP FOR MOTHERS OF AUTISTIC CHILDREN AT THE FAMILY GUIDANCE CENTER IN TYR, LEBANON

This is a support group located in the Al Bus Palestinian Camp, Tyr, Lebanon, which, since 2010, has worked with mothers of autistic children. This group was created under the momentum of a team of therapists (psychologists, psychiatrists) from the Family Guidance Centre of the Beit Atfal Assumoul association. These therapists are themselves supported by a team of HI technical advisors. The group attracts women from very diverse social and cultural backgrounds (of Palestinian origin, but also Lebanese and Syrian) and has solid foundations. Throughout its evolution, it benefitted from the support of a psychologist, who worked at establishing a clear and reassuring operational framework. In a fraught setting where mental health is a complex topic, and where identity questions (origin, religion, ethnicity, etc.) play a central role, the group managed to build itself up, step by step, just like the centre where it is hosted, i.e. in a protected space, non-discriminatory and favourable to exchange and flourishing because of its members. It seems to be a source of support, of social awakening and empowerment for its members. Indeed, after two years of operation, a number of mothers created a second group, operating alongside the first one, aimed at developing awareness and advocacy initiatives within and outside the camp.

GROUP OF GEBAPRIM IN THE MAHAJANGA PRISON, MADAGASCAR

GEBAPRIM is an informal group established in February 2008 in the prison of Mahajanga, in the North-West of Madagascar. This group was given permission to operate by the prison Director in January 2013, and included about 20²⁴ people, inmates, defendants and convicts, men, women and under-aged children. This support group, focusing on education, vocational training as well as leisure and rights, was established in line with social codes prevailing in the prison, under tight supervision of the prison system. Supported by HI on a regular basis, this group seems to fulfil its essential functions (support to members, improvement of living conditions, providing the possibility of projecting themselves into the future) as well as “generates” empowerment, for its members in the first place, and for a number of other inmates on the fringes of the group. It also contributes - somewhat paradoxically - to the cultivation of corruption and a power system sustaining an extremely strong pyramidal system between inmates, and is therefore, *in fine*, a factor of exclusion and reinforcement of social inequalities. GEBAPRIM is therefore a support group based on peer assistance in a prison environment, which in itself is extremely innovative and unique in Madagascar.

²⁴ The composition of the group regularly changes based on prison releases and arrivals. However, the group includes a majority of adult men sentenced to terms ranging from six months to 15 years.

SELF-HELP GROUP OF GBALENFIT FEMMES IN DAPAONG, TOGO

The Gbalenfit Group, located in Dapaong, in the North of Togo, has since 2008 gathered women from very diverse backgrounds (various ethnic and religious groups), however, all share the common burden of being faced with mental illness. It was created under the initiative of the Sister heading the Mental Health Centre of the Yendubé Association,²⁵ who had noticed how isolated sick people and their families were within the community, in contrast with the spirit of solidarity normally prevailing between the members of rural communities. While it has a real therapeutic and supportive function on a psychosocial level, through discussions and income generating activities, Gbalenfit was, instead, from its inception regarded as a self-help group and not as a support group. The group suffered from somewhat irregular support by a French association, Advocacy France, and throughout the years, by HI. Therefore, after a dynamic start and development, this group is now suffering and struggles to survive.

SELF-HELP GROUP AT JUBA HOSPITAL, SOUTH SUDAN

The self-help group at the Juba Hospital, South Sudan, is very recent (a few months old) and therefore still little structured. It includes between five and 15 people directly or indirectly affected by mental disorders (hospital patients, families and relatives). The initiative to establish the group came from HI that felt the need for such a space for the management of people living with mental health problems, however, the group tries to be one of the regular mechanisms within the psychiatric hospital services. It is supervised by one of the assistant psychiatrists. It is still characterised nowadays by a slightly "rigid" dynamic, but still fulfils some essential functions: on the one hand, it brings necessary information to people often distressed in the face of their situation, namely to people directly affected, and also to caregivers, almost always family members. On the other hand, more generally, it includes people facing similar life challenges for which there is no other meeting and encounter space in Juba. However, it is extremely difficult at this stage to identify true structuring and good operating factors in this group, still very young in its existence and still strongly supported by HI's professionals; it is even more difficult to anticipate a sustainable future for the group.

²⁵ The Yendubé Association is a faith-based association attached to the congregation of the Sœurs Hospitalières du Sacré Cœur de Jésus.

WORK PLAN

This research aims at identifying the various development and structuring dynamics related to these four support groups that we briefly introduced in the previous section.

An analysis led us to identify four major dynamics that we called: “survive”, “get medical care”, “get organised” and “advocate”. Each of these four dynamics is experienced, in varying degrees, observed within groups, and expressed in various ways based on the environment in which these groups evolve.

It should be immediately emphasised that these dynamics do not necessarily follow one another discretely in time. They can carry on operating within the same group. However, all affect at least to some extent the establishment, the structuring and the evolution of a given group.

Summary diagram of observed group dynamics



First, we will present these four dynamics in details in the next four sections, based on situations, examples, stories and testimonies observed and collected, and by taking care systematically to re-include the expression of these dynamics in the various intervention contexts.

We will then conclude the research with the presentation of several, more global reflections on the way actors can improve the manner they support the emergence and the structuring of mental health support groups in developing countries.

PART I - SURVIVING

The members of the four groups under study have or had to deal with the issue of survival in the course of their history. The need for survival is often one of the reasons why people are drawn to one another and create groups, the start of which could eventually become a support group. This is especially true in a closed environment (prison, hospitals and, to a certain extent, refugee camps), where solutions are limited in terms of survival. This issue affects as much those with mental health problem as it does their relatives, as in: How to battle to respond to one's essential needs, or to the needs of one's family, in a hostile environment? How to maintain some sort of hope and confront the adversity associated with the new living conditions (stigma, discrimination, confinement) generated by mental disorders?

To answer these questions, we will observe in more details ways of surviving collectively in various environments: in a prison environment first of all, through the example of the Mahajanga prison, then through the example of the Palestinian refugee camp of Al Buss, Lebanon. Finally, we will touch on the situation of the inhabitants of Juba's urban areas, a city in a process of being restructured.

1. SURVIVING IN AN URBAN AREA, THE EXAMPLE OF JUBA'S DISTRICTS

Just like a number of African capital cities, Juba has encountered exponential growth over the last few decades. From little more than 55,000 inhabitants in 1973, in 2010, Juba's population had increased ten-fold, reaching over 500,000 inhabitants.²⁶ This continuous population increase is partly the consequence of decades of conflicts with the North, and especially since 2013, of the revival of the civil war between supporters of President Salva Kiir and of Vice-President Riek Machar. This conflict, especially harsh, leads to substantial population displacements and gives rise to constant security concerns for the entire country. The capital city's rapid urbanization is mostly happening in a rather uncontrolled manner, and results in the swelling of the city's suburban areas and with a specific dynamic in the area of Juba, where it is associated with forced displacements and returns. Therefore, the majority of Juba's inhabitants includes people who have, once in their lifetime, either been displaced, or been refugees or economic migrants.²⁷ While it is true that the capital city offers numerous economic opportunities, daily life there is however characterized by extreme insecurity and a substantial lack of access to the most basic services. Therefore, part of the population - especially new migrant families - from central and suburban areas, lives from occasional

²⁶ "City limits: urbanisation and vulnerability in Sudan - Juba Case study" report from the Humanitarian Policy Group, published in 2010.

²⁷ Ibid.

work, informal activities, and with no security and very limited access to health care and education. Concerns about what tomorrow will bring are constant and the capacity to project into the future is limited. Far from their communities of origin, traditional solidarity mechanisms disappear and are not a robust solution. According to Lucia Moreno (HI Programme Director), there are no strong cohesive elements on the scale of the city of Juba and, more broadly, on a national scale. She uses the example of the Palestinian people, who embody this determinant through the experience of a common suffering and their opposition to Israel, and explains that the South-Sudanese population, strongly divided nowadays, doesn't have a similar strong sense of cohesion ("the source of pain is not identified as the same by everybody").²⁸ She elaborates on this viewpoint by adding that there is a "form of resistance to investing in things that might be broken later". Dr. Pirus, from Juba University, relates to this idea, describing communities that cannot be defined as such anymore or yet, and people who are only able to see their lives in the short term, in a quest for individual safety. Here, he underlines again the lack of solidarity or consultative structures, immediately visible beyond the family level.

Within an environment characterized by reconstruction, families, and especially families of people living with mental health problems,²⁹ are facing major challenges. Indeed, beyond the daily concern of ensuring the family's livelihood and, besides the difficulty of access to health care and support in the field of health in general, we currently observe a major gap in terms of consideration and management of mental pathologies in their moderate form (between heavy pathology, associated with a de-socializing environment, and minor disorders) in Juba and its periphery. The investment, be it from the point of view of NGOs or the South Sudanese government, seems centred on the management of severe cases (response focused on institutional action and anchored in a development logic), or on a psychosocial intervention for conflict victims (response focused on community action and anchored in a logic of emergency), leaving an "in-between" at the urban level, orphan to any response. The presence of a mental health support group, which is a mechanism aimed at filling this "in-between", then becomes a potentially essential element to finding comfort, responses, and offering persons living with mental health problems practical solutions to improve their situation.

Surviving in such an urban environment means therefore and primarily finding a new structure as a family to stabilize the family's economic situation and integrating within a restructured community, eventually managing to project beyond everyday reality and trying to build a future.

²⁸ The same analysis is given by Michel Raimbaud in his book *Le Soudan dans tous ses états : l'espace soudanais à l'épreuve du temps*, for whom "South Sudan's identity is uncertain, from a religious point of view as from an ethnic point of view. Everything happens as if the "fight" against the northern power was, for the south, the only factor of a sham unity".

²⁹ In this regard, a number of studies highlighted the fact that the South Sudanese conflict, due to its duration and intensity, is especially generating mental disorders. See in this regard M. Ameresekere and DC Henderson's article "Post-Conflict Mental Health in South Sudan: Overview of Common Psychiatric Disorders", *South Sudan Medical Journal*, 2012.

2. SURVIVING IN A PRISON ENVIRONMENT, THE EXAMPLE OF A MALAGASY PRISON

In the prison environment of numerous developing countries, a person sent to prison very quickly faces the need to organize his or her own survival. To rely only on the prison institution to respond to basic needs - feed self,³⁰ sleep,³¹ have access to hygiene³² - is to risk developing physical and mental disorders, irretrievably leading to a drop in one's capacity to maintain, let alone ensure material and financial property. And, while in prison, without any property or finances, individuals are simply left behind, abandoned, neglected or abused.



³⁰ In Madagascar, the budget allocated to food drops every year, while the number of inmates increases. Since July 2015, the central prison only provides one meal a day. This meal mainly includes boiled cassava.

³¹ In Mahajanga prison, the occupancy rate reaches 250%, leading to high promiscuity levels. In some of the rooms, turns are organized so that everyone can lie down. In every room, inmates sleep on their side to gain some space. To avoid pain, a man claps his hands for all the room occupants to turn at the same time.

³² Budgets allowing to ensure health and hygiene services are often close to nil. CSOs, when they can, purchase drugs, detergents, insect and rat traps.



Testimony of a male inmate, member of GEBAPRIM, Mahajanga prison

I was sentenced for rape. I've been in prison since 2012. I've been working at the dispensary for eight months. Before that, I was locked in a ward for two years, I wasn't doing anything, I was sad. The most important thing for me is to be able to move around, this way I have relationships with the managers of the prison administration, and they can see that my behaviour has changed, and facilitate my release. I can ask for parole, but I haven't served five years yet. I have been sentenced to 10 years. I do not have money to make this request or to buy back part of my sentence. A number of co-detainees never received a response from the prison manager, even after sending their request 10 times; even though it is a right once you've served half of your sentence. It is as if their letter never arrived. However, with money, one can buy the remainder of a sentence and meet with the prison manager to be released earlier. Some people don't even serve their jail time. Here, everything is about money. Even for Gebaprim's activities, we need money. We need money for everything. You need to pay some kind of fee ("écolage") to the managers. Prices to pay depend on the inmate. The managers increase the prices if the person has money. They get information on people's financial means. The first time you want to get out of your ward, the two shift superintendents each ask for F50,000. But they do not share with the other managers. If you go out and want to cook the rice your mother gave you, you need to pay other prisoners. If you have no rice, one portion costs MGA350. The coal to cook costs MGA200, and sauce costs MGA1,000. Different sauces are available. The supervisors and prison guards in the corridors regulate this. There are several levels to get benefits. Inmates have the keys and open the doors, they do not earn any money. They do pay to keep the keys and can move wherever they want. A service for a service. Those who resell things are taxed by the supervisors. They import things thanks to their family and resell them. The prison manager offered me the opportunity to buy my sentence back for seven million francs. This is not a lot of money, but my father is dead, my mother works as a seamstress and I don't have this kind of money. Can I buy my jail time back? I do many things in the prison; I thought I was also doing these kinds of things. Surviving here is difficult. The supervisors decide on everything. If you do not agree with them, they beat you with sticks or lock you in the cells. Luckily, I haven't done anything wrong.

In Madagascar, from the first days a new inmate arrives in the prison, the prison administration will try to understand what is his or her economic potential, what he or she can bring to the institution. To this effect, the administration will hold a meeting with the inmate, during which his or her career, filiation and current personal situation will be examined. From this first meeting, a number of suggestions will be offered the inmate, first by the prison director, then the various professionals of the prison administration, to ease life in prison. People from privileged backgrounds usually do not end up in prison, as they manage to negotiate detention conditions outside the prison against a fee or to pay for their release. Based on the person's financial means and, as the case may be, based on the services the person will be capable of providing to the

professionals of the prison administration, the inmate will be offered the benefit of advantages that will provide him or her greater means to ensuring his or her survival.

Numerous African societies, and this is also the case in Madagascar, a more Afro-Asian culture, are currently living through transition periods associated with the political crisis experienced by the country sometimes going back dozens of years. Some form of "social deconstruction" is seemingly underway, a process of emancipation in the face of the multiple social injunctions populations are experiencing with respect to traditional values. In the past, the self-fulfillment ideal in these countries had nothing to do with the ideal of the sovereign individual (independent, liberal) characterizing Western societies. To fulfill oneself is mostly about living among one's people, ensuring primarily one's own survival and that of one's nuclear family, and then trying to maintain some form of solidarity with one's relatives.

In Madagascar, before arriving in prison, and due to lack of work and the means to ensure survival, a number of people find themselves severed from their families, living alone or in bands on the fringes of the big cities. The figure of family solidarity can then take two forms: the "gang" solidarity, originating from groups organized around small criminal activities. Inside the prison, it mainly appears in the form of corruption, and outside, it appears as theft or begging activities. On the other hand, the bravery solidarity, which is expressed through sports teams (for example soccer) and cultural groups, or in the implementation of socio-educative, psychosocial or cultural activities, prevails.

Traditionally, in Madagascar, the Winnicottian adage of "alone, the individual doesn't exist" means that the individual is socially positioned by virtue of belonging to a family, and having a name, which can historically position his or her filiation up to five generations. This filiation traces a specific destiny that organizes the meaning of one's life, namely, to live among relatives and sustain a good enough life together, for oneself and one's relatives. We can find this form of living together is true also in prison, an ambition which requires looking out for and responding to one's own basic needs so as to survive and, eventually, ensure the survival of the immediate group, the room, the ward. As is the case outside the prison where, to ensure survival, people work especially in the informal sector, which is currently predominant (90% of the population in Madagascar); inside the prison, people look for what allows them to live, they negotiate small deals to find paper, a little bit of rice, a banana, some coal. Inmates end up developing incredible resourcefulness. Just like in the outside world, they live day by day.

Malagasy people especially enjoy festive gatherings with their relatives, the "among ourselves". They really do care about good relationships. People all have networks they connect with, except when they are displaced far away from home. There is therefore a proximity solidarity, which is working well, be it for happy events (weddings, births, baptisms) or for sad events (deaths). Every excuse is good enough for a party, to celebrate or connect with relatives. A party is a time when conviviality is expressed. One accomplishes something by sustaining good living social relationships, to be at peace

with the neighbours, without seeking any gain, for oneself or one's peers. Individuals are not judged by the quality of their work but by their capacity to mobilize conviviality; this is what it means to be trustworthy in a number of African societies. This need to associate with others is often limited by feelings such as the fear of failure, the shame of having failed, the fear of authority, jealousy towards those who have achieved greater success, conformism, the fear of backlash. Fear remains very important within the prison, probably due to the volatile behaviour of prison administration's professionals, who can sometimes be very violent. In prison more than anywhere else, authority is a threat. Inmates are scared of backbiting and jealousy. They are scared of being excluded and banned from the group. Intimacy has disappeared, especially due to spatial proximity. In cases of conflict, groups won't be opposed to one another, it is rather the weakest individual who will be sanctioned, confined, or lynched. Incarceration therefore induces psychological perturbations because of confinement, separation from family, affective or professional break-ups. It induces loss of self-esteem, troubled identity and stigma.

3. SURVIVING IN A REFUGEE CAMP, THE EXAMPLE OF A PALESTINIAN CAMP IN LEBANON

Another survival example that we encountered stems from a very different situation, another field which is more open and permeable from a topographic point of view, but which remains a sort of confined space, sometimes acting as a "mental jail" on populations.

South Lebanon's recent history makes it a crucible for Israeli-Arabic conflicts, especially stemming from recurring conflicts between Israel and Lebanon. The region experienced successive conflicts: the 1948-49 Arab-Israeli war, "Black September", when the region fell under Fatah control, an Israeli occupation from 1982 up to 2000, the rule of Hezbollah, then the Israeli invasion of 2006.³³

South Lebanon is a region that includes mainly a Shiite population, with important Sunnite, Christian as well as Druze communities. Even more than the rest of Lebanon, beyond religious communities, the region is characterized by very distinct strata, which are very independent from one another. The region is characterized by strong social inequalities.

Like other Palestinians established in Lebanon, the Palestinian population of Tyr has been occupying the most modest fringes of the population for decades. On the one hand, it suffers from restricted fundamental rights (restriction of access to Lebanese

³³ The fear of "invasion" should be highlighted. Still very present within South Lebanese communities, it is currently growing due to the intensity of the Syrian conflict affecting the North of Lebanon.

nationality, prohibition of access to certain jobs, etc.). Life, development and therefore fulfilment prospects of individuals, families and communities are extremely restricted.

The "confinement" of the Palestinian refugee, whether adult or child, is not or has very little of a physical nature. It is primarily of a psychological nature. It is a mental and social confinement, a confinement in frozen immediate life prospects and a confinement in a determined future. Therefore, the Palestinian mental prison is not only the consequence of external environmental constraints. It is partly created and reproduced under the instructions of the community.

This "mental prison" generates strong psychiatric disorders, as a number of studies on Palestinian mental health have highlighted.³⁴ Depression, anxiety, psychosis, personality or mood disorders, and where the corresponding prevalence can reach up to 30% of the population. The evolution of Palestinian refugees' mental disorders happens quietly, in a rather pernicious manner. Typical disorders take root over time, but in an entrenched form. The frequency of these symptoms within the population as a whole also makes it more difficult to identify them, in the sense that none of these people perceives him or her as being different or as living on the fringe of society.

Among Palestinian refugees as in Arabic cultures in general, disorders associated with mental health are associated with strong stigmatization. This deviation from the norm is poorly understood, and often assimilated as madness or, for children, as developmental delays. Confinement, if not discrimination of these people, is major. Even more so for children suffering from intellectual disabilities, for whom the community, and even the family, will happily blame the parents, and especially the mother. The "blame" is even more significant in that, as mentioned earlier, the child is the guarantor of cultural integrity and transmission, and the bearer of the Palestinian return ideal.

Accordingly, we can easily imagine the major negative impact that the existence of an autism spectrum disorder - one of the least "understood" and "explainable" disorders - in a child could bring, in terms of discrimination and confinement, not only for the child but, more generally, for the parents and the family.

Within the Al Buss camp, survival is therefore not an issue of a battle to fulfil one's primary needs. When we think about surviving in such an environment, we think more about the need, the impulsion, we could say, to carry on living when everything seems to be falling apart, while the future is static and already written. One needs to see development within the context of a "stolen" childhood, resistance to the injunctions of a life dedicated to fighting against others, and the duty imposed by the vision of a hypothetical return of the original land. One's need is to survive and resist the appearance of mental health disorders, which affect a large part of the population. And finally, parents of children with mental health problems need to find concrete solutions, on a daily basis, to improve the quality of life and the future of the child.

³⁴ See for example Response International's report, "Mental Health Needs Assessment in Palestinian Refugee Camps, Lebanon", 2006.

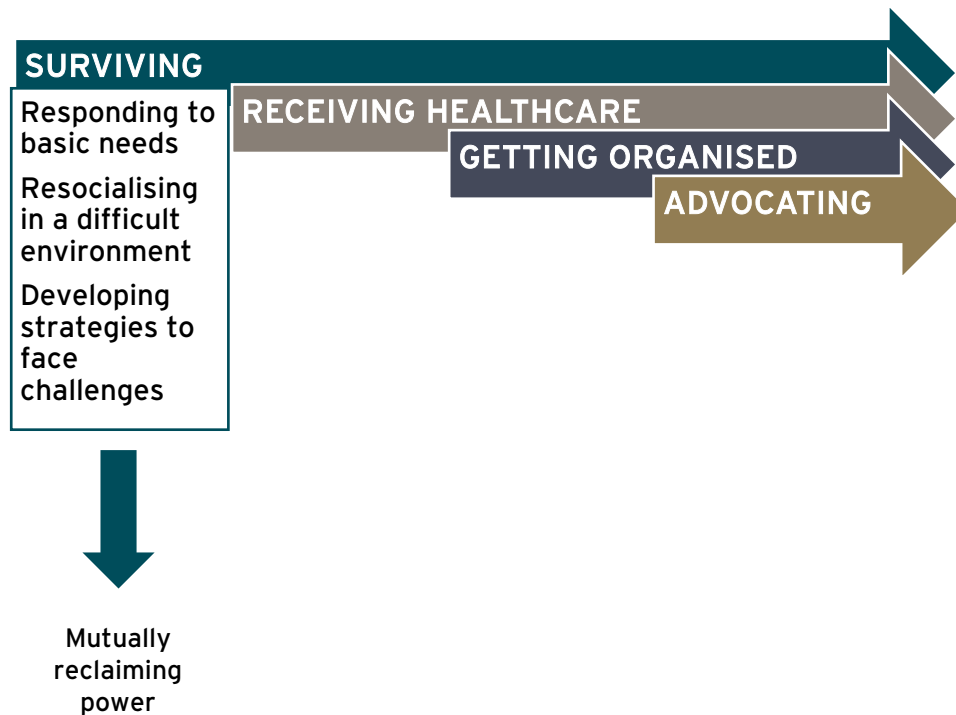
4 SUMMARY - SURVIVAL, MUTUAL RE-EMPOWERMENT

Within a difficult economic and social context, with little community cohesion and undergoing fundamental changes, Juba's hospital support group provides a unique and unexpected space for families and people living with mental health problems. As recent and as insufficiently structured as it is, this group is a first response, still nascent, but providing, first and foremost, comfort and hope. There, the members talk about the problems they share between the families, about simple but concrete solutions to improve the daily life of people suffering, and recreate social connections.

Within an already more structured perspective, groups such as GEBAPRIM, in their prison environments, aim at supporting inmates' survival. More than survival through access to resources to ensure basic needs, the goal is also to maintain some sort of conviviality, humanity and to empower one another. On a psychosocial level, according to GEBAPRIM members, joining this group has allowed them to gain new capacities, to feel less lonely, to find a deeper meaning to life through helping others. The members can share their difficulties with others, lighten their burden and help one another. Activities facilitated allow them to stimulate their memory and reduce their stress levels. They gain recognition from international and local NGOs operating in the prison. They have the feeling that they are bringing justice by providing access to knowledge about the rights of inmates, for those who cannot read and are not informed at all of their rights. They also ensure that the documents placed in the complaint boxes are taken seriously during the committee sessions in charge of opening the boxes. They are motivated to participate in maintaining order within the prison and violence has decreased, both on the side of the prison administration and of other inmates, since they adopted this structure.

And finally, from a slightly different perspective, beyond mental health support, the group of mothers of autistic children of the Al Buss camp offers mothers of children with autistic disorders a specific place where they can be heard and exchange ideas. This unique and peaceful space has managed to avoid societal, ethnic and religious stereotypes. It is a space within which someone is not, or at least for a short while, a refugee or a local, Lebanese, Palestinian or Syrian, Muslim or Christian, rich or poor, where people can forget social pressure for a time, and where each can freely express problems, fears and hopes without fear of being judged.

Surviving is therefore seeking to live, despite the constant concerns of daily life, the weight of confinement, be it physical, social or psychological. It is also, despite constraints and challenges, about making connections with others at all costs, despite differences in culture and origin, finding comfort, recognition and assistance, trying to find solutions together, and dealing with the future.



PART II - RECEIVING HEALTHCARE

"Receiving healthcare" is an expression that appeared systematically in the comments made by the actors we interviewed. However, it has different meanings, each determined by the cultural environment. Be it in the field of health in general or, more specifically, in the field of mental health, the recognition of the dysfunction and the path to healing (or the return to functional life) are both dependent on the person's experience and on what is considered normal or pathological in the particular culture. These determinants therefore vary according to times, individuals, the degree of adherence of these individuals to one medical approach or another, the group to which they belong, the living environment and, eventually, the culture to which they belong. In most societies, several healthcare models coexist, alternate or, more often even, merge. Traditional holistic approaches associating biological dysfunction with social or religious reality alongside Western allopathic medicine, focused on the individual, means that the person living with mental health problems has access to a wide range of therapies, sometimes mutually exclusive, but way more often used on a rotation basis. Therefore, "receiving healthcare" is a plural and diverse action, and which, in any case, is primarily designed in a cultural framework and in connection with others. To understand the various ways of "receiving healthcare", we will look into the observation of healthcare practices encountered in rural, urban and suburban areas in Togo, South Sudan and Madagascar in greater detail, and then describe the healing effects of the Lebanese support group.

1. RECEIVING HEALTHCARE IN RURAL AREAS: COMMUNITY'S Pervasiveness³⁵

In the four countries included in our research, spiritual and religious life is very intense. Whereas in Lebanon, religion is a highly regulated and structuring component of communities' identities,³⁶ in Togo, Madagascar and South Sudan, traditional forms of worship³⁷ are still alive and mix with "imported" religions and the most recent forms of spirituality in some sort of religious syncretism. All religions observed in sub-Saharan Africa, attach a significant role to healing, to prevention of misfortune or compensation for its consequences, in an environment where modern medicine remains out of reach for most of the population, especially for lack of financial means, and where the common belief is that diseases, therapy and healing always have a spiritual dimension. For example, in Togo, urbanization doesn't render ancient practices associating living with the ancestors and the gods of the earth obsolete. Today just like in the past, ceremonies cannot be isolated from divinatory consultations in which followers and clients search for answers to their personal challenges, alleviation of their illnesses, alleviation of daily social issues (cheating between men and women, loss of employment, sudden death, etc.) associated with assumptions of witchery. Recently, Christian saints and devils have become involved in this dogged search for meaning, beyond healing. Ancestral polytheist cults, where trances and possessions are common, far from disappearing, found a new momentum since the end of the 90's.



Fetish market, Lomé

³⁵ This chapter is partly based on the data taken from the 2015-2019 National Mental Health Programme in Togo.

³⁶ For example, in Lebanon, it is currently impossible to get married in a non-religious manner.

³⁷ For example, in Togo, the various religions are Animism (traditional African religions), followed by 50% of the population, Catholicism (26%), Islam (15%) and Protestantism (9%).

In Togo as in rural areas of South Sudan, traditional representations and interpretations are conveyed in various locations and mix with practices usually delivered in these locations: in schools, often religious, these practices mix with socio-educational practices; in hospitals and mental health centres, they mix with healthcare and rehabilitation practices; in churches, temples and prayer camps, they mix with cultural practices. Each activity in the support groups start with a prayer.

»« The rise of communitarianism through the emergence of new churches

New churches are on the rise, especially in Togo, emerging in Madagascar; they are omnipresent in major cities and more scattered in rural areas. Last Hope Church, Assembly of God, Pentecostal Prayer camps, etc. A number of people start their own church within a couple of week with the support of churches based in Nigeria, Korea and the United States. Churches continuously recruit their followers using a door-to-door approach, are visible on campuses and in numerous public locations (for example at crossroads), are in the mortuaries and all places dealing with people suffering, present shows every Sunday in the neighbourhoods and major stadiums. In Togo, these new churches are not part of civil society as they are not considered as falling under the law on associations. However, they currently contribute to creating a new ideal of social success, with national stars preaching the word of God on television and radio. At work as in the streets, or in the taxi driver's car, we noticed that all are connected to religious stations (for ex. Maria radio, Bonne Nouvelle radio, Zion radio). On Sundays, streets are empty, everybody gathers to shout, sing, and praise the word of God. Prophets, deacons and pastors often claim to be masters in parapsychology (a Maslowian pyramid bringing legitimacy to everything), pretending to be able to cure all illnesses, but that the result is in God's hands. Today, some doctors conclude their consultations by entrusting the fate of their patients into God's hands. This phenomenon is associated with a very present fatalism in Togo. Everyone takes every single opportunity to read the Bible, listen to the radio. Some stop working to dedicate themselves to their new church. Others end up divorcing because the couple can't agree on the Saint to worship. For some of the people interviewed, in a few words, the national motto of "Travail, Liberté, Patrie" (work, liberty, homeland) is rather "Fatalism, Liberty, God". Togolese society is therefore currently affected by a strong tendency to psychologization that these preachers convey: for example, a person who doesn't go to work would say "what do you want me to do, you don't want me to go and see my sick child? I didn't come because he was ill, isn't it normal, do you want him to suffer?". New forms of communitarianism are observed. Religious groups are shaped together, and most individuals live only through their communities. Groups can sometimes be rivals and mistrust each other. More and more, we hear things like "he's not from my area, he's not from my church, I cannot entrust anything to him, I cannot confide in him". Each sees only his or her own interests and the interests of his or her religious community.

Negative attitudes persist towards people living with severe mental disorders and intellectual incapacities, delaying the search for modern healthcare. Traditionally, chronicity and relapses are often associated with fatality, spells or possession by evil spirits. The disappearance of symptoms is often associated with the work of a supreme power (typically God) over which no-one has any control. Since religious interpretations of the illness associated with the rhetoric of the traditional healthcare system amplify it, we have seen the establishment of an alliance between the two healthcare systems in terms of interpretation of the illness and therapeutic logics. People suffering from mental disorders are always considered by the community as inferior beings, possessed, "under-aged" or diminished persons, even once stabilized or healed. In South Sudan, these people are referred to as: *demon child, wicked, possessed*. The sick person loses the legitimacy to talk about him or herself - the family or the healers speak on his or her behalf - and, especially, loses the right to decide on a future. The person loses social and family status, thus regressing to a quasi-state of "under-man" or "under-woman". The person is considered useless, almost as if dead, at least for the time in question (*he is now dead for us, he is not part of the family anymore*³⁸). Therefore, the person living with a mental health problem is, in a number of cases, objectified, be it in the relatives and caretakers' rhetoric, as well as in their attitudes and actions. People freely talk about their problems, using "he" or "she" even though these persons are physically present. At no time do family and their relatives consider that the person living with a mental health problem could be an actor in the healing process or improve their quality of life. In this regard, another striking and rather alarming fact is that persons living with a mental health problem often gladly put themselves in this position, in the way that they do not consider they have a right to talk for themselves, of the problems or challenges they encounter, or what they might desire. This is often the case, even though their problems might allow them to live and act in a functional and socially compatible manner with others.



Women tied to a tree,
Prayer Camp, North of Togo

³⁸ "For us, he is dead. He is not part of the family anymore": the words of a father about his son faced with mental health problems. We cannot see in these words a final sentence, but the assertion of a temporary status of the person, who will only "come back to life" and will be reintegrated as a family member once healed.

The care pathway is crossed by healers providing incense, plants and herbal teas, sometimes violently introduced into the body (anal area). Support from witches, exorcists, deacons and prophets is often requested for the most complex cases (psychoses, conversion neuroses). The care pathway can lead some people to be chained by their feet, sometimes naked and for several months, to a tree or in a makeshift shed (especially in prayer camps). It isn't uncommon that when people have epilepsy attacks, the neighbours burn the area where the person fell after the attack, for fear of contagion. While some traditional healers have a good command of their art, others seem to be charlatans.

Only in the second phase, once the illness has become chronic, do the families of people suffering from mental disorders turn to the modern healthcare system. This is why, according to the National Mental Health Programme of Togo, 40% of patients suffering from psychosis present themselves late to the hospitals, in a state of chronicity, sometimes with co-morbidities³⁹ created by parallel treatments.

2. RECEIVING HEALTHCARE IN A SUBURBAN AND URBAN ENVIRONMENT: THE FAMILY LEFT ALONE TO FACE THE MENTAL HEALTH CHALLENGE

The picture can be rather different in urban areas, in a district environment like the one prevailing in Juba, where we observe some strong dilution of traditional collective responsibility, without it being replaced by another form of collective responsibility. In such a context, in most cases, the entire burden of caring for the person living with a mental healthcare problem rests heavily on the family and relatives. Therefore, the family, and especially the head of the family or the caretaker, based on the same logic, needs to assist the person living with a mental health problem go through the steps on the way to healing, but has to go through this alone.

First of all, we need to "give some meaning to the mental health problem", so that healthcare can be based on this understanding, and the treatment flow logically from it. While the entirely traditional explanatory vision cannot be fully relied upon, and the community is therefore incapable of providing an explanation, the vision of the family and relatives usually follows two very distinctive types of logics, the only two acceptable logics in urban communities. On the one hand, it is 1) a religious logic, that can be associated with a traditional vision clustered around the notions of sin, belonging and exorcism; and on the other hand 2) a medical logic, providing a rational explanation (diagnosis) to mental disorder and offering a treatment.

³⁹ Secondary disorders, associated with the initial illness.

Centre de Santé Mentale
 BP : Dapaong/ Togo
 Tél : 91 57 58 63

TARIFICATION DES PRESTATIONS

CONSULTATIONS + soins JOURS OUVRABLES :
 De 7h à 17H, et de Lundi à Vendredi500F

Pour la Première fois : 1^{ère} Consultation : 1200f

Psychologique: Mercredi 9H à 12H.....500F

Mise en observation : Forfait de 4000/ 7j

Permanence :
 Samedi....Dimanche..... Jours férié.....1000f

Nuits (= Gardes) 17H30mn à 22h2000f

Consultations à Domicile + soins+ Déplacement
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NB : Hors de Dapaong, 2500f + la distance (selon le kilométrage).

La Sœur Responsable du centre de santé mentale/ Dapaong

Rates of the services provided by the Mental Health Centre of Dapaong

For example, in Juba, poor diagnoses, sometimes associated with a lack of training by healthcare professionals, the lack of available treatments and support mechanisms for the person, as well as the high cost of health care, result in rather grim prospects in terms of medical healthcare. Additionally, family and relatives really struggle to understand that healing is a long process, which is sometimes never realized. Consultation and what follows, including taking the drugs (and especially injections), should necessarily, in the mind of the people, show an "ill" before and a "healed" after with respect to the person living with the mental problem. A number of people make the mistake of interrupting the treatment that the person living with a mental health problem at the first time of improvement, assuming that the person is healed. Faced with these limited treatment choices and repeated deceptions during health care, temptation is high for the family and friends to give up. Institutionalization in hospital or in prison is a potential alternative (sometimes highly desirable). The other solution is to send the person back to the village, with the family who remained there, since "here, he will never have a place and we do not have the means to support him". These people can therefore revert to traditional and religious systems for an answer.

3. RECEIVING HEALTHCARE THROUGH THE SUPPORT GROUP, REINSTATING THE PERSON AS AN ACTOR

Support groups can gather within the institutions (mental health centres, hospitals), where they co-exist with a more medical and pharmaceutical approach to mental health. However, within the situations we encountered we saw the obstacles with which they have been confronted.

They sometimes struggle to establish themselves due to a context strongly underpinned by modern healthcare, conveyed by the professionals as well as by the members of the family, relatives or caretakers who want to see some treatment, an injection, a drug intake, etc. Indeed, the transmission of a substance into the sick body as much as the care gesture is regarded as something concrete, tangible, which should logically result in something (i.e. healing). From within this perspective, any suggestions flowing from group encounters are deemed far less meaningful, since the positive effect cannot immediately be seen and also imply the participation of people living with a mental health problem and their families. The benefit therefore is seen as having no immediate objective basis, because it requires being felt, lived, and is the result of an investment.

And the support group can imply (but not always) that we give an actor role back to the person living with a mental health problem, so he or she becomes a person in his or her own right. And, usually, it is not considered legitimate that people suffering from a mental disorder talk and express themselves. For example, in South Sudan, a person living with a mental health problem isn't usually entitled to talk ("he/she is not entitled to this", and besides, relatives and caretakers do not see how necessary it is for them to take part in any group mechanism, be it of a therapeutic nature or not. It is assumed that if the sufferer's state requires it, their place is in the family at best, or in an institution (hospital, prison). Therefore, the community, starting with the families and the relatives, are usually not ready to accept that people living with a mental health problem are meant to express themselves or gather in groups.

However, in Lebanon, the right to a voice and being permitted to express suffering is a little more acceptable, due to the history of the country, its "relative westernization" and, therefore, customs and health evolving in tandem. Regarding the Beitfal Assoumoud Centre support group, besides the specific and very containing framework provided by the centre where the group was created, the cultural dimension is respected. All participants share a common background of oriental culture and therefore share the same language, as well as a set of customs and rhythms, like privileged meeting times, relational codes (a way to question and exchange, a discussion habit), as well as common perceptions of illnesses. The discussion group, just like other Family Guidance Centre mechanisms within which it takes place, can be considered as a free

adaptation of the "*Sobhié*"⁴⁰. For women of the Middle East, the *Sobhié* is a meeting time taking place in the morning, once the children have gone to school and men gone to work, and before preparing the meal for lunch. This meeting usually involves women of the district and takes place at the house of one of them. It is an opportunity to share information between women.⁴¹

This group primarily allowed participating women to understand that they were not alone with their questions and challenges, and that other mothers shared the same ones. It also allowed them to regain their position as adults, parents and, eventually, women. This in turn allowed for the reassertion of the importance of the role of mother (and, more globally, of the parents) in the caring of the child. A mother enjoying better mental health is in a stronger position to be expert in her child's situation, to influence the way the therapy unfolds and, therefore, to contribute to the child's well-being. Mothers' testimonies perfectly sum up these points, when they state "the group supported us, made us grow and allowed us to evolve. The group led us to open ourselves to the outside world, instead of letting us focus on our own problems".

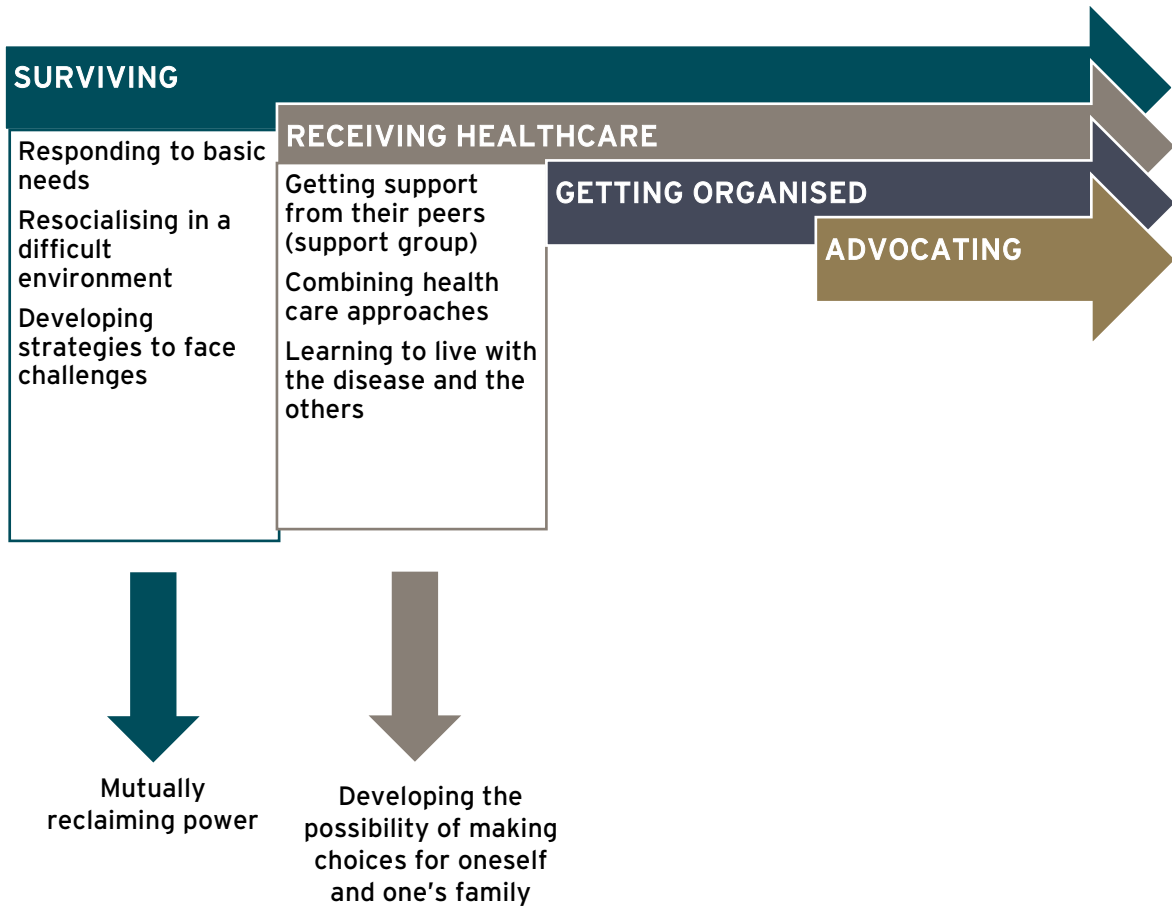
4. SUMMARY - RECEIVING HEALTHCARE, THE EMERGENCE OF THE POSSIBILITY TO CHOOSE

Receiving healthcare is again to put to work various mechanisms of identity development, living together, social framework, etc. We noticed that several paradigms co-exist in the four countries under study. While the medical paradigm seems to be omnipresent, it is mixed with traditional and religious paradigms. People living with a mental health problem and their families often have options, choice, and sometimes do not hesitate to combine their caretaking strategies.

Support groups provide a framework to put this combination to work. These groups are almost always established and facilitated so as to comply with minimum cultural standards (common background), but also rely on new and Western dynamics (human rights, activism for specific publics - marginalized groups, etc.). This combination, this fluctuation, can be found in all the observations made within the groups being studied. Support groups with a therapeutic focus, and especially discussion groups, lead to the emergence of new opportunities to move within the "treatment offered", new possibilities to take decisions, for oneself as well as for one's relatives.

⁴⁰ *Sobhié*: an expression that could loosely be translated as "morning activity".

⁴¹ On the other hand, the FGC from the North offered a similar space dedicated to discussion for the men, while similarly respecting that the traditional meeting time should take place towards the end of the afternoon.



PART III - GETTING ORGANISED

Getting organized means first and foremost to "gather as a group", and for the group members to interact with one another, by serving a common goal, even though cultures, preferences, knowledge and interests can be different".⁴² These last aspects are extremely apparent when considering the diversity of groups that we have studied. On the level of the support groups, to "gathering as a group" also means being prepared to establish relationships, and to recognize and singularize the other as an alter ego. And finally, getting organized also means developing a new common baseline, and aiming at, or risking establishing some form of interdependence. So, what are the common determinants that can be used in these circumstances? How can people gather as a group and work together, on what project?

To understand how individuals choose to come together and get organized, we will observe resocialization and the restoration of traditional solidarity mechanisms in the city of Juba in a more detailed manner, and then, and at a more micro level, we shall focus on the emergence of the mothers of autistic children support group (Lebanon), and finally, on a support group organized in the Mahajanga Prison (Madagascar) in which the members of GEBAPRIM are actively involved.

1. REGATHERING AS A GROUP BY INVESTING IN NEW COHESIVE DYNAMICS: THE EXAMPLE OF THE CITY OF JUBA, SOUTH SUDAN, AND OF THE AL BUSS REFUGEES CAMP

One of the first important aspects, when trying to understand how a group emerges and how it is organized, is the cohesive power of a determinant common to the entire group.

JUBA: INVEST IN THE NEW SOCIAL DYNAMICS OPERATING ON A DISTRICT LEVEL

Juba and its various districts, encountering exponential growth, are a real melting pot of social, cultural and economic backgrounds and exchanges. As mentioned by Pr. Prius, Head of Community and Rural Studies Department at Juba University: "this is not a society anymore in the traditional sense of the term". Districts progressively established themselves without any considerations of tribal or geographic origins, and their social make-up is therefore very diverse. However, a cohesive dynamic is at work,

⁴² March J.-G. and Simon H.-A., Organizations, Wiley, 1993.

thanks to the upholding of common cultural values, still strongly shared by the districts' inhabitants. For example, the following can be identified:

- A true wish to live together, to connect, to live as a community, not to succumb to the temptation of individualism. In this regard, we are still very far from the operating mode of a "Western-type" society, as this can already be the case in other, more modern African capital cities
- The distinct establishment of wealthy people in a position of power, the same applying to the elders⁴³
- Respect for traditional authority, customary judgement (no recourse to the formal justice system, unless it is an absolute necessity and a last resort)
- An omnipresent spirituality (Christianity), which is highly mobilizing, and respect for religious leaders (pastors, priests) alongside the elders.

A value often introduced during interviews should be mentioned, which is however more questionable, since not very noticeable in the field: the feeling of belonging to a new nation and its corollary, the idea of duty, the sense of contributing to the country's reconstruction and emergence. Currently, there is indeed a major tension between the nation's construction ideal and the effective experience of daily life (public services - and therefore health or social services for example - is of poor quality, failures from the state, short term projections for the future, lack of life prospects, etc.).

The end result is that traditional meeting and decision-making times and places (meals, traditional celebrations, village councils, area where the elders meet, etc.) are reconfigured on a different basis, mainly calling upon three dimensions, which can blend: **1) geographic proximity through neighbourly relations and district committees 2) spirituality, through religious congregations and groups that are related 3) the associative dynamics.** These three dimensions are the true basis of decision-making processes and community steering at the district level, but they also feed the common celebration of major events in new communities, such as weddings, funerals, etc.

As in Madagascar, here too, this reinvention of "living together" and the specific challenges in urban areas as well as the tenuous connections with place of origin (and therefore the dilution of traditional social pressures of responsibilities associated with the group of origin) however go hand in hand with the dilution of the social interactive circle, attention being refocused on close family and relatives. The focus becomes the individual and personal achievement. Simultaneously, a number of traditional solidarity mechanisms are disappearing, replaced by solid grass-roots support systems or a solidarity based on reference groups (churches, associations), far more random and less consistent, as this is a recent dynamic that is not to be taken for granted and that rests on a sense of duty.

⁴³The elders are given the authority and the right to speak on behalf of the community; by elders, we mean the people who have been living in the area for long enough, who have done concrete things for the district's community, who know each of the district's families. It is therefore a natural authority, progressively reintegrated in a formal administrative plan.

While the aspects that we have just mentioned are especially true for the urban areas of Juba and the main districts that form part of it (the payams⁴⁴ of Juba, Kator and Munuki), it is less true of the surrounding districts that are far more disadvantaged and poor, insalubrious and more densely populated. Upon arrival in these slums, which are true entrance gates to the main city, people prefer regrouping with their family and relatives who have already settled in. The populations living there therefore gather in a more consistent manner in terms of geographic and ethnic origin. In essence, these are transition areas between urban and rural areas, where a number of perceptions and practices going back to life in the village still persist, recomposed on the scale of small geographic units, relatively homogenous.



Interview with Anthony, President of the Kator district committee, Juba

According to Anthony, the various neighbourhoods of Juba progressively structured themselves based on logic different from that of the village. He describes a very alive social dynamic for the neighbourhood of Kator, which he is heading. He uses as reference the local centre where we were at the time of the interview, to which he had made a significant contribution. Indeed, a number of small group activities were taking place in this centre (discussions, games, meals, etc.) that included some men from very different origins, according to Anthony. For him, tribal/ethnic diversity is not an issue and is even almost never recourse in exchanges or disagreements. The management of the neighbourhood is well structured, and the authority of the "elders", i.e. the authority of the oldest inhabitants, is respected. Inhabitants share their views and jointly take decisions.

A number of committees are dealing with the various aspects of life of the district, each headed by a leader: health, education, women, youth committees, etc. According to him, structuring depends on Juba's neighbourhoods themselves, but he underlines the fact that in any case, the ownership of decisions inevitably lies with the inhabitants.

Group dynamics at play in urban areas are therefore, for the most part, relatively new. They are organised around the following:

- The regulation of community life (traditional courts, community councils, etc.), which can be supported by cultural and identity markers (age/seniority, etc.)
- Enhanced well-being and access to services for a group or a community: access to education for children and the youth of the districts, access to health for underprivileged populations (the support group facilitated by HI and caretakers within the JTH fall under this category)

⁴⁴ The payam is the equivalent of the district.

- Faith, evangelization (to which political groups, for instance, centred on the national sentiment can be attached)
- Major and federating contestations, often organized around an approach based on rights: women's rights, disabled people's rights, etc.

Therefore, it is in this urban, highly dynamic environment, where men and women regather as a group. Besides the mutual support group initiated by HI at the JTH, all structured and operational groups that we met and/or were mentioned seem to draw their legitimacy to exist and act and to carry on existing from one of these dynamics. It further seems that the birth of these groups can be "artificially" induced (e.g. *Young Voice Group*) or inherited from a previous community operational mode (the village councils evolving into district councils, *traditional courts*, etc.).

IN THE AL BUSS CAMP, TRANSCENDING ORIGINS, DIVERSITY AND CULTURAL ASSUMPTIONS WITHIN A PRIVILEGED SPACENS

The Al Buss camp was initially established in 1936 in a then rural area, for Armenian refugees. Subsequently, the camp hosted a first wave of Palestinian, mainly Christian refugees towards the end of the 40's, who lived together in the same areas. Christian Palestinians and Armenians progressively left the camp and mostly integrated into Lebanese society, followed by several waves of Palestinian refugees, who, still today, make up most of the camp's population. The camp suffered from Israeli attacks (by air and sea) in March and April 1978, and suffered major destruction during the 1982 Israeli invasion. Since then, the camp has enjoyed relative stability. Its population is now reaching 11,200 inhabitants, and it is practically integrated into the surrounding urban fabric.

The Al Buss camp is considered "one of the least worse in Lebanon", using a popular expression. On the one hand, it is relatively sparsely populated in comparison with the two main camps of Tyre (Burj el Shemali and Rashidiyyeh each include over 30,000 inhabitants). On the other hand, it is located right next to the sea, and next to a protected archaeological site. It also offers greater social diversity in comparison with the other camps. It includes a Maronite church (still attended in some occasions by Lebanese Christians), as well as a Lebanese hospital (Saad Allah), caring for patients from outside the camp. MK Doraï describes this camp as a place for which the Palestinian community typically feels a strong sense of belonging, in the sense that it "represents three aspects of the socio-spatial Palestinian dynamic: the territorial continuity since it is a place of stability and continuity, a place of "between ourselves", and eventually, a place of connection with the host society".⁴⁵ He also describes the space of the camp as being strongly communitarian, as a "place where the Palestinian community can express its singularity, a place where their specific history can be

⁴⁵ Doraï M.K., "Le camp de réfugié Palestinien d'Al Buss à Tyr" in *Bulletin de l'Association de géographes français, Territoires d'exil : les camps de réfugiés*, 2006, p. 93-104.

expressed and a space where their identity is sustained". This space, controlled by the Lebanese state, is actually the visible face of Palestinian communitarianism in Lebanon. In this regard, the poet Mahmoud Darwish says, referring to his time in Lebanon, that "In reality, we haven't experienced Lebanon. We were living in the ghetto that we had built for ourselves in Beirut. [...] In Beirut, we only saw one's own self".⁴⁶ The camp is therefore a living social space, essentially built with reference to memory, but capable of adapting so as to operate within Lebanese society, however without ever fitting into it.

But it is within this space, this fertile ground of 'among each other', that the BAS association managed to create this centre, permeable to various cultures and origins. We already mentioned that all female participants in the support group of mothers of autistic children come from a common background of average Oriental culture and therefore shared the same language, as well as a set of practices and rhythms. However, social pressure related to compliance with the norm is strong, and modesty and discretion are the rule regarding personal hardships. Even more so, the relations remain tense between the various confessions and social groups in Southern Lebanon, and it isn't common to make friends outside one's community. But the protected environment provided by the centre and the diverse backgrounds of the support group is an opportunity to escape the socio-cultural principle represented by the community of each woman, which is not a favourable environment for free speech, exchange or even personal feelings expression.

2. RELYING ON A CLEAR FRAMEWORK AND OPERATING RULES

The group framework and the existence of operating rules, accepted by all (be it expressed or implied) appear to be a major factor in the future structuring and evolution of a group.

IN LEBANON, THE "CONTAINING" EXPERIENCE OF THE FGC, COMBINED WITH A REGULATION OF EXCHANGES

For mothers of autistic children in Lebanon, it might be, before anything else, the reassuring space of the Family Guidance Centre (FGC), which inspires trust and respect, and ensures confidentiality and that led to the emergence of the group. The FGC isn't beholden to any religion, community, social affiliation or extended family arrangement. Within the camp, it is a space physically protected, almost "hidden" from the rest of the community. Its notoriety is recognized, Shiite women from Lebanon belonging to high social classes do not hesitate to visit this centre rather than a Lebanese centre for their autistic child.

⁴⁶ Darwish M., *La Palestine comme métaphore*, Entretiens, Arles, Sindbad, Actes Sud, 1997, p. 123.

Mothers state that they feel freer since taking part in the group, as it provides them with a breathing space of its own, during the time spent apart from their child, while not being too far away⁴⁷. They still share with their child the same "institutional envelope", in the words of the psychologist facilitating the group, which is important for them.

On the other hand, the initial framework set up by the psychologist was very firm:

- Talking: talking is encouraged, but not necessarily distributed in a strictly fair manner; however, all should be allowed to express themselves
- Mutual respect and that of others' opinions: no judgement may be passed on the content delivered by the participating women
- Physical interaction: it is forbidden to have physical contact with another (a rule aimed at avoiding any act of violence)
- Confidentiality: what is said within the group shall stay in the group (this is to be seen in the light of a certain lack of rigour in this matter in the first years during which the centre ran)
- Restriction on and control of what topics might be discussed during the session (any mention of religion, ethnic origin, etc. is forbidden).

By including the voice of female participants, the framework probably avoided the formation of more classic roles such as leader or scapegoat. Over time the loosening up transformed the group dynamics and its objectives. From a rather psychoanalytic approach (focused on narration, reformulation and the idea of transfer), the group evolved into a more psychotherapeutic approach (discussions and interactions are freer, suggestions, advice).

Characteristics and dynamics informing the group have eventually strongly aligned with the FGC's characteristics and general dynamic. Just like the FGC, the group is a highly "containing" space, a place of trust. Clear rules of association exist. The group is a place for people with multiple, diverse identities. It is a place where participants can set aside their baggage for a short while. One can truly say that this group was built in keeping with the centre's spirit, that it could be considered as one of its avatars. The same could probably be said about other activities conducted by the centre.

3. EMPOWERING AND SUPPORTING AN INDIVIDUAL WHO IS A GUARANTOR OF MEANING, CONNECTION AND TRUST

The importance of one or several central persons playing a mobilizing role also appears as an often decisive and complimentary aspect to the existence of a framework and accepted rules.

⁴⁷ During the time mothers participate in the support group, the children are looked after in a room with dedicated facilitators.

For the group of mothers of autistic children in Lebanon, the primary impetus was provided by the psychologist who first put the idea to her colleagues, and was supported by HI staff. A dynamic relationship was established between the therapist and the female participants. It took a very particular turn, going way beyond simple support by a professional. We felt the psychologist was very attached to this group, which she considers a little like her own child. As she says it, "Mothers bring me a lot, every time we meet. Some days, I struggle to motivate myself to go work at the centre [for one-on-one sessions], but the group sessions, it doesn't matter if I'm feeling good or sick, I never miss one." The therapist therefore admits herself that "the group made her" as much as "she made the group". It is probably also this convergence and this attention that allowed this group, its rules and its operating mode to evolve. A mother from the group has also been extremely active, strongly invested in the therapy at the beginning, then always involved in the development of the various activities as time went by. She is especially respected within the group, on the one hand due to her seniority, and on the other hand for the energy she demonstrated from the inception of the group.

The fine analysis of the support group of mothers of autistic children therefore reveals one main actor, the psychologist who steered the group from its inception, who provided the impetus for the framework to become containing enough, for mothers to be able, in turn, to take position and assume some power. In this, she managed to rely on a mother with leadership qualities, who became her go-between to mobilize and guide the group in its evolution.

In the Mahajanga prison, we observed a similar mechanism fostered by one of HI's professionals, a mechanism which leads us to question the manner the support group action's ethical reach is put to work.

In Madagascar, we observed a support group comprising individuals sentenced to life in which several members of GEBAPRIM took part. In an extremely surprising turn of events, the session observed didn't deal with the discussion of painful situations or on specific themes related to the participant's health/mental health, but on the developmental strategy for a new income generating activity (IGA) within the prison. This particular IGA focused on coal purchasing/selling (see picture). For example, the lieutenant, prison warder and support group facilitator purchased coal for an amount of MAG 30,000⁴⁸. According to him the support group could carry such a project as there was no other way to purchase coal. The group then gives it to the inmates, who sell it for MGA 42,000. This generates a profit of MGA 12,000. Inmates should, in the long term, be able to earn more since they will sell several bags. So far, they have generated 80,000 Ars in profits. The lieutenant keeps the money, following a group vote, while waiting for the group to decide how the money will be used. This support group includes inmates from the same wing, but from different rooms. They see each others during the day, but do not sleep together. The support group does not provide credit, therefore,

⁴⁸ A little less than €10.

people who do not have enough money to purchase coal cannot get any and cannot cook the food their family sent them.

The departure from the therapeutic object of the support group, that we discover at the same time as HI did during an observation within the context of this research, makes the HI specialist in charge of supporting this group very disappointing, and means that he will most likely fear one day being accused by the prison administration of having promoted corruption within support groups supported by HI. He subsequently justified his actions by pointing to the necessity of creating consultative spaces within the prison, spaces dedicated to supervising the sound implementation of activities supported by the prison administration as well as by civil society players intervening in prison. To this end, he supports the development of a monitoring commission within the prison, supervising all the institution's committees.

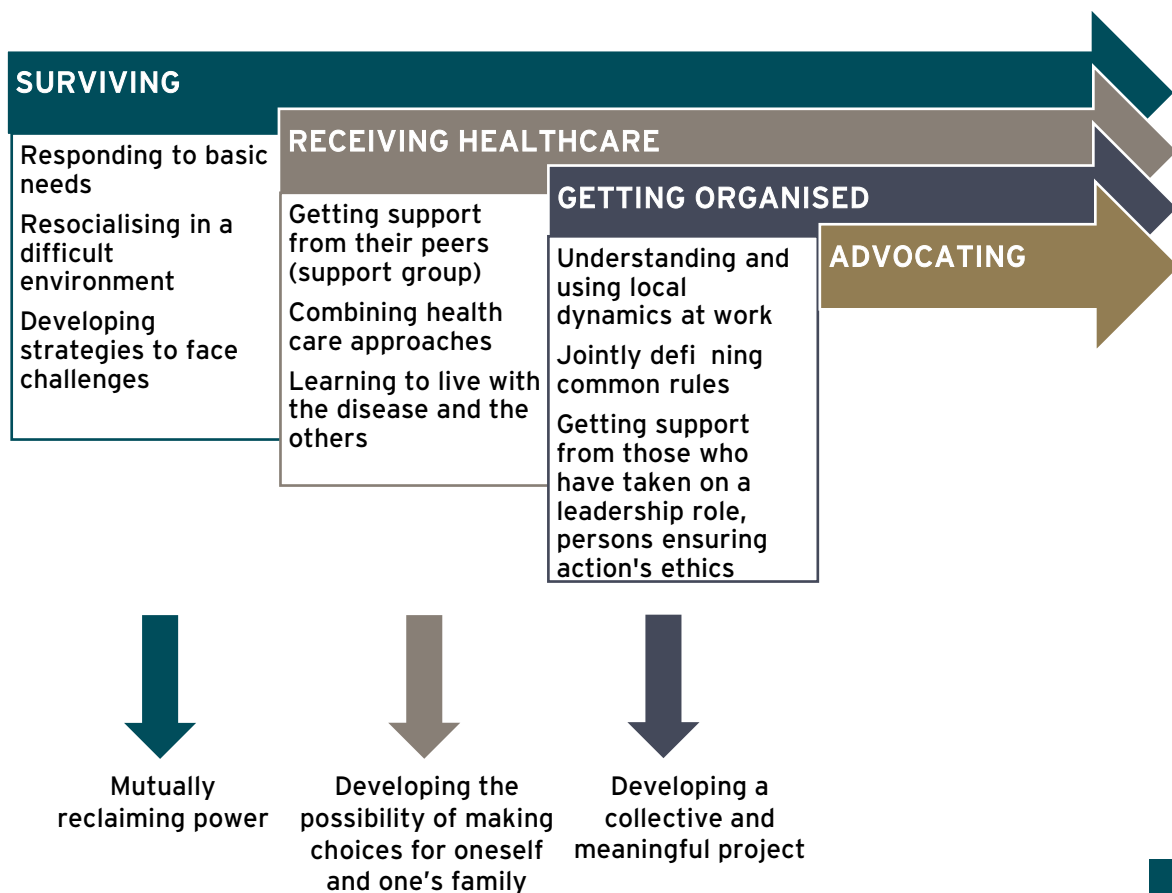


Bag of coal imported in the Mahajanga national prison

The terms of reference of this commission were drafted by HI and then validated by the prison administration. These terms of reference give an insight, in the sections dedicated to the principles and operating modes, into how the NGO tries to ensure a fair distribution of positions between the prison administration, CSOs and inmates, including GEBAPRIM. The aim is to give power back to all actors involved, by allowing everyone to discuss the decisions made, allowing inmates to be more present in the decision-making bodies, while reassuring the prison administration about the safety and humanization challenges related to prison living conditions, which is part of its mandate. On the medium term, HI wishes that this way of ensuring the action's ethical aspects be carried by GEBAPRIM.

4. SUMMARY - GETTING ORGANISED, BUILDING A COLLECTIVE PROJECT THAT IS MEANINGFUL FOR ALL

Getting organized therefore seems to work best with professionals who assume responsibility for the connection between the members of their particular group, as well as the connection between institutions and groups involved. These professionals help the various actors of the project to generate a consistent, coherent and shared system of ideas, which then informs daily actions. They try to maintain a trusting relationship between the partners. They allow the various project actors to carry a consistent, coherent and common system of ideas, providing meaning to daily actions. At the inception of any group, there is no immediate shared meaning capable of building consensus. Therefore, professionals coordinating groups will first resort to a form of ethic, as the basis for defining the group's meaning, to give purpose, to show the path for dialogue and exchange. All these relationships are under constant negotiation and construction. The individuals who take on the role of carrying this ethical mission allow the various actors involved to reflect upon their mutual commitments in action and their collaboration with others. They create an environment of trust between the actors. This means that there should be some form of stability and predictability in terms of behaviour. To ensure their mission, they need to be regularly supported in their practice by receiving training and being monitored, allowing them to obtain a degree of distance and to report on their work.



SECTION IV - ADVOCATING

Advocating is about engaging in a process through which a cause or a theme is supported, because we want this theme or this cause to be defended, because we want to get support and/or, eventually, because we try to influence decision-makers.

For a group, this implies being able to agree on a set of common interests, and therefore on themes that we wish to promote. This also implies identifying the target public that we wish to engage through this advocacy work, and developing actions and messages targeting these groups. And finally, this also often implies merging action with other groups and bodies in the field of civil society. The group members should therefore manage to detach themselves from the strict healthcare dynamic, oriented towards themselves, to open to the outside world and engage in communication aimed at enhancing recognition, actions and, eventually, people's living conditions in a field far wider than the group itself.

We will use the example of the evolution of two support groups in Togo and Lebanon to show various ways in which groups managed to develop this dynamic, as well as the challenges encountered.

1. IN TOGO, THE EMERGENCE OF CIVIL SOCIETY IN THE FIELD OF MENTAL HEALTH

Except for support and discussion groups hosted in some mental health institutions, there are few (Togo, Madagascar), if not any (South Sudan) associative groups or movements comprising users or users' families. Disabled persons' associations are only starting to take up the issue of "mental disability" and gather, under this terminology, all the neurological, psychiatric and psychological disorders a person could experience.

Within the general population, the way people living with a mental health problem are perceived renders them part of the darkness, the hidden, the sacred. Actually talking about these disorders threatens to call them into existence. While medical sciences work towards raising the awareness of the population, human and social sciences, when taught at university, do not currently seem to seize on this question. For example, in Togo, according to Pr. Awesso, there are no anthropology or sociology courses on this theme, except for a few articles written on Down's syndrome. There is also no specific legal provision related to people living with mental health problems. However, Togo commits⁴⁹ to comply with the "Principles for the Protection of Persons with Mental

⁴⁹ Cf.

<http://www.phmovement.org/sites/www.phmovement.org/files/Rapport%20DAS%20TOGOfinal.pdf> (accessed on the 30th September 2015).

Illness and for the Improvement of Mental Health Care"⁵⁰ adopted by the United Nations General Assembly in 1991.

Medical rationalisation is one of the means through which the mental health issue can become a social one. However, medical rationalisation does not always have the means of reaching grassroots level. Another option would then be to use alternative routes and meet the interests of religious congregations that have also been working on these issues for a number of years in several countries⁵¹ and which are the only entities having status of association. In Togo, this currently translates into strong collaborations between the Ministry of Health and the three country's mental health centres (MHCs), all faith-based.⁵² From reflections conveyed by these religious congregations, collaboration is currently in the making between the state, these religious congregations and the very people suffering from illnesses.

For example, in November 2011 in Lomé, the sister who initiated the Dapaong MHC and the GBALENFIT group also initiated, from her newly assigned MHC and her support groups, a non-faith-based association called Association Vie Libérée (AVL), gathering people living with mental health problems, professionals, families and friends of sick people (60 members at present). HI is financially supporting the emergence of this association. At the moment, its field of action is limited to Lomé, but it is establishing strategic connections potentially to allow her to establish the association at a national level. To this effect, AVL is benefitting from strong support from the Togolese National Mental Health Programme's focal point. The association joined the Fédération Togolaise des Associations de Personnes Handicapées (FETAPH⁵³) and benefits from Advocacy France's technical support, the latter wanting AVL to make contact with other Togolese MHCs, especially Dapaong MHC and its self-support groups. AVL has been classified as a not-for-profit association since the end of 2012 and wishes to move as far away from healthcare as from the religious dimension (the members of the association's bureau are either "mental health users" or "mental health specialists", in their own words). AVL's goal is to foster access to healthcare and social and economic integration for people living with mental health problems, and to advocate for the recognition of the rights of these persons. At the moment, there is no connection between AVL and the GBALENFIT groups, except for a common story through a sister, a psychiatrist and focal point of the PNSM, Advocacy France and HI, all four especially committed to defending the rights of people living with mental health problems. However, we can see in this approach driven by this sister the first stages of the evolution of a group, from being a support group to being a group rather focused on claiming rights.

⁵⁰ Cf. http://www.un.org/fr/documents/view_doc.asp?symbol=A/RES/46/119 (accessed on the 30 September 2015).

⁵¹ As it is the case for the Congregation of the Soeurs Hospitalières du Sacré Coeur de Jésus.

⁵² In these MHCs, the treatment offered is globally ensured from the funds of these congregations. Support provided by the state is mainly of a technical nature, through medical support provided by one of the country's four psychiatrists.

⁵³FETAPH is organized based on the type of disabilities. Currently, no work has been undertaken on mental health, but the validation of AVL's membership application is a major sign of evolution.

2. IN LEBANON, THE EMERGENCE OF AN ADVOCACY GROUP GROWING IN THE FERTILE SOIL OF THE SUPPORT GROUP

In Lebanon, the group of mothers of autistic children also managed to evolve towards a more political orientation by campaigning for the rights and living conditions of children living with mental health problems and that of their families.

Here, a true logic of empowerment of the group members can be observed, which only came into play rather recently (end of 2014, beginning of 2015). However, it should be noted that at no times, was the empowerment of participants a sought after goal in the support group's practice.⁵⁴ Mothers themselves decided to form a second group, in order to foster the improvement of their children's living conditions. This decision to act then resulted in the establishment of a parents' committee, far larger than the support group, and welcoming parents of children with various disabilities. This committee set the following goals for itself: to find information and opportunities for advocacy to improve the life of disabled children (public spaces and events, blogs, social networks); to connect with other groups, other associations; and eventually, to implement concrete actions that would foster the participation, and result in the fulfilment of disabled children (establishment of a green space, accessible and inclusive, in collaboration with the municipality).

This process, originating from a common mind set, is the result of the improved mental health of mothers. They describe it as follows: the fact of feeling better on a personal level, leads to a shift in focus away from personal issues, to refocus outwardly. In other words, it was only after the group had initially cemented, as one mother mentions, based on "this difference that we share, as mothers of autistic children", and the mothers had managed to go beyond their strong common identity, that the group opened itself to the outside (and therefore to other participants) and that we can truly start talking about *empowerment* through the establishment of a parents group.



Director of the Beit Atfal Assumoud association, Al Buss refugee camp

"The empowerment really comes at the moment the mothers realize that they have power".

It actually seems that the group's mothers managed to shift the paradigm of their perception of the situation of their child and their own situation. It's as if everything stems from the fear of the disability, first lived as an "incapacity" of the child, then

⁵⁴ Mothers clearly state that it is not about the evolution of their own group - that they wish to preserve it as a support group, but about the establishment of another, distinct group. However, it seems clear that this parents' group was an initiative of the members of the support group.

evolving into a wider understanding of the disability in the social sense of the term. From this statement - "we are not abnormal, it is the world we live in that doesn't accept us as it should" - grows the realisation that active steps should be taken to improve this environment and overcome its barriers (physical and social) so that the autistic child is no longer discriminated against, so that this child might live a better life. In this sense, the group followed the same kind of evolution as the one more generally encountered in the centre, in terms of enrichment of its therapeutic approach, moving from paramedical care to action in the community and the environment, in a more inclusive manner.

The natural evolution anticipated at the inception of the group was for it to be capable of progressively freeing itself from the support and the facilitation offered by the psychologist, leading it to open to the outside world and thus to benefit from support by the community workers. It seems that this is now the case since, as one of the mothers testifies: "Yes, the group could operate without [the psychologist]. It would be a pity as she is very dear to us and is very supportive. But we are now capable of moving forward without her if needs be." One expression of this emancipation would clearly be the establishment of this advocacy group.

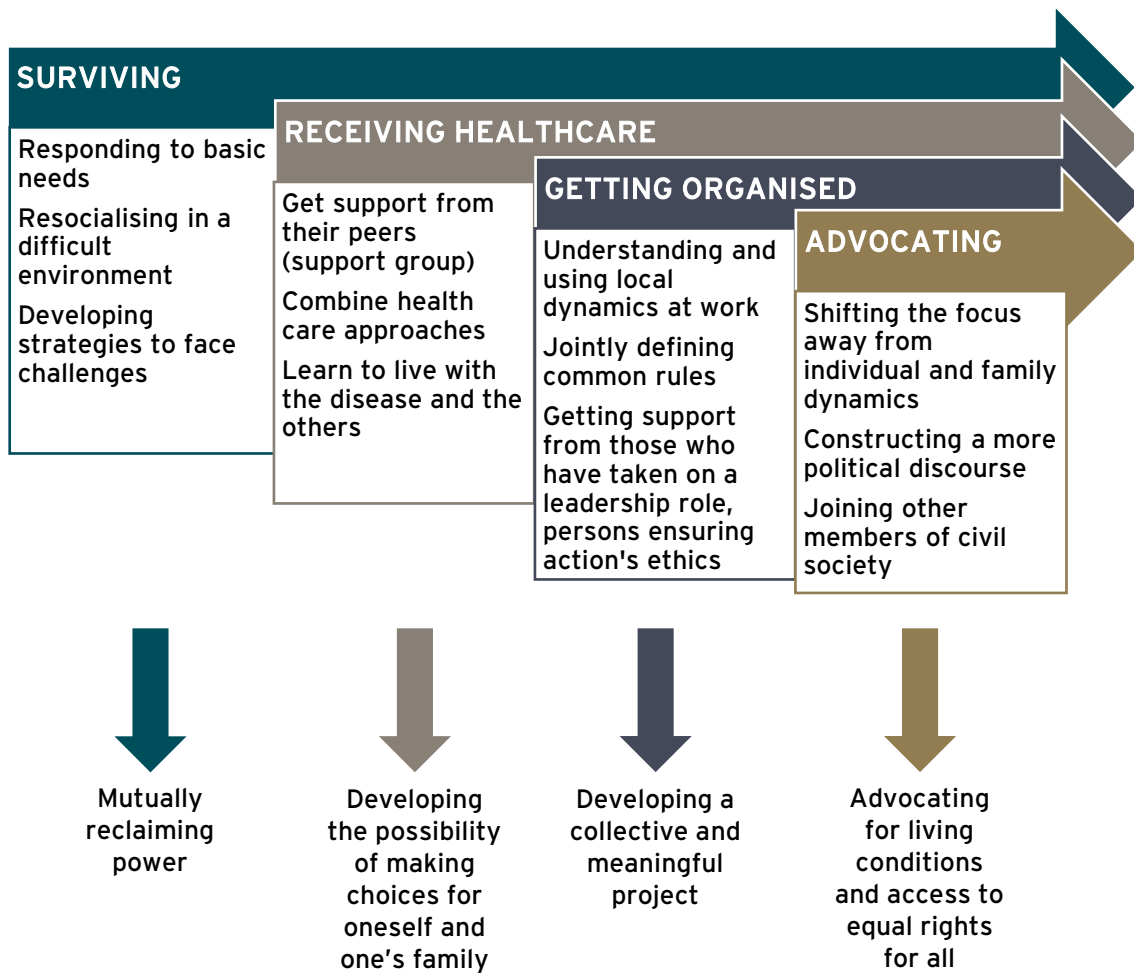
3. SUMMARY - ADVOCATING, CLAIMING EQUAL LIVING CONDITIONS AND ACCESS TO RIGHTS FOR ALL

While the support group evolves to a point where individuals who form the group are able to choose and improve the quality of life for themselves and their family, the advocacy action position extends beyond the individuals themselves and the family circles. The rhetoric becomes more political and actions more militant, focusing on claiming the rights of persons living with mental health problems.

Therefore, we can observe how advocacy actions become elaborated, not within the support group itself, but within a separate entity; *Association Vie Libérée* in one case, Parents group from the BAS centre the other one. The groups therefore are well aware of the specific nature of this action, turned towards the outside world, as well as of the need to preserve the support group in its intention and initial action. Therefore, in both cases, the support group still exists, providing the necessary energy for the action of the advocacy group.

And finally we can see that in both cases, how advocacy and action emerge, within well-structured and functional groups, with some sort of seniority and that have already managed to realign part of their support action in a less exclusive manner, towards the family and the relatives of the people living with mental health problems. This shift seems to be a necessary pre-requirement for empowerment and advocacy actions.

Summary diagram of observed group dynamics



CONCLUSION AND SUGGESTIONS - DEVELOPMENT OF A STEERING STRATEGY FOR EMPOWERMENT AND PARTICIPATION PROCESSES

This study highlighted four dynamics contributing to the emergence and the structuring of support groups in the mental health field.

Caught in survival strategies, individuals find themselves challenged by their capacity to step back, which is necessary for them in order to analyse their situation. Essentially the goal is to live one day at a time and to try, as best as possible, to find resources to provide for their basic needs, their dignity, hope and, eventually, a reason to live.

Once free from this survival logic - and therefore of some elements generating mental disorders - the individual can consider getting healthcare. "Getting health care" has various meanings based on the cultural environments. Beyond difficulties accessing healthcare mechanisms, those living with mental health problems and their family are often faced with a multitude of therapeutic options, the result of the co-existence of traditional approaches with, more recently, allopathic approaches, and often considered in a non-exclusive manner.

On the other hand, getting healthcare, in the environments we studied, often implies getting assistance from peers and the community. Indeed, healthcare and the concept of healing are still considered in a collective perspective. This "natural path" to others goes hand in hand with the evolution of the healthcare approach to group mechanisms. In this regard, we notice that it is often institutions and their specialists (psychiatrist, psychologist, Sister) who initiate collective awareness, offering to host and establish support groups, especially discussion groups. In these groups, besides sharing emotions and affects, these persons will pool potentials and resources to create solidarity and self-help mechanisms. If the group succeeds, the individuals will be able to trust themselves again, will feel less stigmatized, question the assumed fatality of the condition of sick persons or parents of sick children, learn or relearn how to make choices and to take part in collective actions.

Political awareness can then emerge when the support group's discussions start revolving around a project geared to changing their living conditions. The group starts to look for alternatives; people use their experience gained within the group to offer possible solutions, which then turns into a mutual support group. The role of the mutual support group often goes beyond the action that brought it into being by orientating itself towards becoming a therapeutic project focusing on quality of life and access to rights of the members in general. The mutual support group, which can be a distinct mechanism from the discussion group, allows members to undertake actions with others and, as Dumas and Segquier says: "we try to materialize alternatives to one's own

existence; the goal is to change one's daily living conditions, to transform relations to the environment and build a society".⁵⁵

As mentioned in the introduction, three concepts embrace the field of this research: participation, empowerment and sustainability.

The concept of participation "reports on the way the individual can become an actor of his/her own economic, professional, familial and social destiny, while contributing more or less actively to life in a society". This ambition seemed to play an important role in the global action of an organization such as HI, especially in its will to associate, to the greatest possible extent, the users of these services with the decisions affecting them. Based on the classification suggested by AFD, we can say that for most of the groups observed, HI held consultations with the population benefitting from their action, and takes comments provided into consideration, and maybe even had the ambition to partner with the action's beneficiary population to improve their living conditions. In this sense, participation is a determinant, if not a pre-requirement, for empowerment. To a larger extent, it is also one of the key factors of groups' sustainability.

However, this concertation with populations can only go that far, on the one hand in the personal path of the beneficiaries and their families, and on the other hand, in the relationship between the populations and HI, and the institutions providing mental health services.

To conclude this research, we now intend to discuss four key questions related to supporting the emergence and structuring of mental health support groups in developing countries. This research, a contribution to the *baseline* study of the *Touching Minds, Raising Dignity* project, already allows provides some answers to these questions. These answers are "suggestions" which will need to be confirmed during the conduct of the final study of the project.

⁵⁵ DUMAS B., M. SEQUIER M., "Construire des actions collectives. Développer les solidarités", *Chronique Sociale*, 1997.

Questions



Suggestions

Summary diagram of questions and suggestions from research findings



QUESTION 1 - Which partner institutions to choose - traditional, religious, or public?

Various healthcare approaches, and therefore various "therapeutic authorities" co-exist in the various places of intervention. The person living with mental health problems is both connected with institutions, such as a psychiatric hospital or the medical unit of a prison, but also with the person's religious community or to a traditional healer, each therefore representing therapeutic authorities operating for this person. The following question is therefore raised: when we talk about the relation between the person and his or her institution and, potentially, that of participation, to which therapeutic authorities do we relate? And therefore, which choices does HI make in terms of capacity building, for example in view of reinforcing the user's participation? Which institutions to choose - traditional, religious or public?

On the other hand, if these institutions (traditional, religious, and public) really care about providing a mental health service, they only very seldom place the participative issue at the heart of their concerns. The distinction between the "people at the top" (those who have professional and institutional knowledge, and who traditionally steer action are regarded as models), and the "people at the bottom" (those who hold lay, experiential, sensitive knowledge) remains very present. Eventually, HI is the one, within the framework of technical and organizational capacity building, trying to define a participative horizon for institutions. These institutions become involved, often first and foremost because they perceive a financial opportunity in this partnership, while in the second stage, their involvement is sometimes steered by the beliefs held by the people from discussion groups and mutual support groups, and after long hours of work have gone into regulating power relationships between the various institutions, specialists and users. This leads us to our second question.

QUESTION 2 - How do the members of a support group orientate themselves within the institution, with respect to power relationships?

Most of the populations we met are not in a dynamic of wanting to free themselves from the institutions, and do not immediately start working on a new participative project. Once again, support from the NGO leads to the defining of a new horizon, especially, as we've seen previously, through discussion groups, allowing the emergence of critical and conscientisation capacities. Little by little, the populations take hold of these new horizons, primarily since they see in it a way to access healthcare. As we've seen previously, it is only in the second phase that mutual support groups emerge with ambitions which will eventually, one day, come closer to an ideal of emancipation from

the institutions, in a prospect such as the one described by the World Network of Users and Survivors of Psychiatry.⁵⁶

As seen previously, the pathways of people living with mental health problems and of their families are, in many ways, located at the crossroad of these tensions. On the one hand, various health care approaches, and therefore various "therapeutic authorities" co-exist in the various places of intervention. On the other hand, people living with mental health problems and their families are first and foremost looking for solutions to concrete issues encountered in their daily lives, and therefore far from any participatory logic. Are these people and their families truly ready to commit themselves to taking action by participating, with all the responsibilities it entails and, to a certain extent, the endangering it implies? And if the persons really wish to "participate", should they try to reinvest their decision-making power in an institution such as the psychiatric hospital or the prison's therapeutic authority, or lean towards their religious community or the traditional healer, who could represent as valid a therapeutic authority for them? Eventually, under which authority can we assume "a person at the bottom", would place her or himself and therefore, should be drawn into partnership by HI? Who might participate in such a decision-making process?

NGOs should embrace the sometimes contradictory ambition of reinforcing both the power of the people at the top, and the almost contractual obligation in terms of the ideal of participatory democracy in the development field, that of the people from the bottom.

Steering such an *empowerment* process at two levels raises ethical and strategic challenges: for example, how far should we push the envelope with respect to beneficiaries? And to what extent are the beneficiaries ready to welcome this ambition? These challenges should be the focus of special attention, as we shall see later in this conclusion.

QUESTION 3 - How to consider the subjective challenge of the mental health problem?

To suffer from a mental health problem is a singular and personal experience, which can also have sociologic and cultural components. Some individuals suffering from a mental health problem can be affected in their sense of being, and becoming who they are, and of thinking for themselves and thinking in terms of others. Other people suffering from a mental health problem manage to disclose their personal, family and "cultural" stories, often marked by violent break-ups. Living with a mental health problem implies a very

⁵⁶ "Free all our people from institutions [...] and provide a wide range of services, developed in coordination with users/survivors' organisations, including peer support, crisis centres forming part of places of respite and safety, and of places of discussion" Word Network of Users and survivors of Psychiatry, 2008.

complex interaction between self-esteem (the potential stigmatizations the individual could have suffered), the desire to take care of him or herself, the recognition that he or she is ill, the acceptance of the illness, the desire to portray oneself, the need to portray oneself in connection with the disorder itself, etc.

Engagement with those who suffer triggers something in them, and influences the way they grapple with their own questions and affects in connection with personal, family or emotional concerns. Successfully enabling people to live with mental health problems requires that they develop their capacity to see themselves objectively, as well as their capacity to envisage entering in a relationship with others.

The feelings of people who suffer can be very ambivalent towards the specialists who would be trying to give them power which in itself has no meaning for them, or which they have no desire to receive. It could be some form of denial in connection with the illness affecting self-perception, some form of habit associated with the knowledge learning mode, or avoidance or exit strategies, but there are very strong variations between individuals in their capacity or will to take on this power, which can sometimes be a heavy burden to bear.

QUESTION 4 - How to facilitate a strong knowledge management policy providing for the collective ownership of a mental health policy?

The dominant social standard observed in the Western world, where individuals all aspire to rule their own lives, permeates a number of development policies. These policies tend to provide those in developing countries with the information and the means they need - in terms of a Western perspective - to allow them to develop themselves throughout their life. The steering of such support, within the NGOs and the work framework of United Nations agencies, is most often provided by human resources stemming from high-income countries. The projects implemented by these NGOs are short-term, usually six months in an emergency situation, three years in a development context, sometimes six or nine years if the project benefits from additional funding. These short and medium action timelines induce specific support positions, which are often oppositional to a number of local social assumptions. Sometimes, it is necessary to provide for the basic needs of disaster victims, by providing them with water, a roof and access to sanitations. Here, the individual is considered a vessel receiving assistance, a "beneficiary". To make the point it is necessary sometimes also, in terms of a rehabilitation logic, to support aptitudes and capacity development for people considered to have multiple problems (disability, vulnerability, poverty), where the goal is to assist them in *actively* participating in social life. At other times, it might be necessary to support a reflective approach, to work on affectivation and subjectification processes, by listening to the person considered as a "subject". And this in sometimes diverse sociocultural environments, sometimes close, sometimes tangled. Most of the

time, these conceptions of the individual follow one another in the interventions. The social mission of these same NGOs, especially those working in the mental health and social field, see their main goal as re-establishing the social connection, with the assumption that re-establishing the social connection will improve individual's mental health. In this sense, NGOs are crossed by heterogeneous currents and can be considered both as kinds of agents of globalization, in a neoliberal sense, and globalization actors, in the sense that they care about the social connection and individual capacities. The specialists in humanitarian action and development assistance have their own support mechanisms associated with their experiences, trainings, values, history, etc.

Simultaneously, NGOs need to take into account globalization standards and their financial logics. They need to report on their activities, measure their impact, especially in terms of well-being and the quality of life of the target publics (therefore, the impact should be felt within six months to three years), report on the quality of their activities using efficiency, sustainability and effectiveness criteria, etc. NGOs are affected by various management, project and network logics. The daily life of all humanitarian workers at present includes managing 30 to 70 emails a day, if not more, being networking men and women, trainers, managers, often practitioners and managers. They are connected with the beneficiaries, while at the same time with ministries, institutions and specialists from various sectors, including health, social, education, etc. sectors.

And beyond that, all these factors contribute, among other things, to a major turnover of expatriate workers teams. When this happens, some new recruits, key in terms of project steering (technical and/or operational coordinator, programme director), do not always receive the training provided at the start of the projects, as well as information related to the project's history. This knowledge wastage affects technical approaches pertaining to the rollout, especially when it comes to the selection of one activity over another and the forming of partner relationships. This fast team turnover can also impact on partners' turnover rates, which can have a major impact on the support provided to support groups, especially when the one team member leaving was the bearer of the intervention logic and of its ethic.

SUGGESTION 1 - ESTABLISH AN ETHICS AND STRATEGY COMMITTEE

An ethics and strategy committee that includes the project carriers and their partners (including the action's final beneficiaries), could ensure continuity and cohesion with respect to the approaches, positions and values carried by the project.

As previously mentioned, numerous human tragedies hide behind the term "mental health problems". A tragedy for the persons directly affected by the disorder, as well as for their neighbours, families and fellow citizens. One person out of four will be affected one day or another by a mental health problem. Indirect behavioural consequences of the crises associated with the emergence of these disorders - slow down of economic activity of affected individuals and families, and discrimination - complicate these people's lives, who already often suffer from extreme poverty. Some of these behavioural effects cannot be avoided, as some mental disorders do need important protection measures, as much for the individual him or herself as for society. However, a number of behavioural conditions are partly caused by stigmatization, lack of knowledge of the causes or consequences of the treatment modalities of these disorders, of degraded living conditions, etc. Just like for other illnesses (HIV, Ebola), we can see behaviour loaded with stigmatizing representations, both coming from the relatives of the persons affected and from development assistance professionals. By more or less deliberate avoidance, by lack of time and availability, the latter sometimes focuses more on managerial modalities of the policies or projects they are tasked to implement, preventing ownership of the necessary knowledge, expected to be imparted by the professionals who technically carry the programme and are meant to set up the initially targeted support.

SUGGESTION 2 - Integrate a knowledge management policy in the rollout of the project's mental health policy

A knowledge transfer policy at the time of human resources turnover or departures seems necessary here in order to reduce the information and knowledge being lost. A project history does not start on the day the project is launched. By taking into account the project's maturity period, sometimes over several years, one can help access decisive elements to ensure the project's sustainability. This memory can be enhanced by giving local actors (partners, team members of other projects) the opportunity to tell their own story in terms of how they have experienced the project and its development.

The mental health policy carried by the *Touching Minds, Raising Dignity* programme was drafted in a "programme framework document". This policy makes mention of 27

references⁵⁷ carried by HI's technical specialists (head office technical advisor and programme coordinator). Human resources allocated to the programme's rollout received appropriate training and attended awareness raising sessions based on these documents, facilitated by HI's head office technical staff and the programme coordinator. Training was sometimes followed up and adapted by the technical advisors in the intervention country, when such advisors exist.

Upon reading these reference documents, we notice that the mental health treatment HI is suggesting is especially structured with an ecological focus, i.e. the individuals are considered within the framework of their interactions with their environment and their capacity to interact - or not - with this environment. The assistance beneficiaries are not only considered as the recipients of the assistance, they are also considered as participating individuals, actors, connected to the objects existing in their environment. They are connected to their own bodies, their subjectivity, as well as to all the people and objects existing in their environment, and which are likely contributors to the improvement of their wellbeing and mental health: family, culture, work, rights, health, money, etc. Therefore, according to HI, supporting the mental health of people in distress involves the development of actions from all the areas likely to support the connections between the individuals and their objects. We can see the mental health projects of the *Touching Minds, Raising Dignity* programme, the goal of which is to improve the most vulnerable person's well-being, to work in the medical, social, education, legal, justice, economic, etc. sectors. Each of these sectors references their own theories of practice: economics, medicine, psychology, development or humanitarian aid and anthropology. Therefore, for example, support to the GEBAPRIM and GBALENFIT groups implies the implementation of income generating activities with a therapeutic aim, mobilizing knowledge from economics and community psychology and local social development. The AI Buss camp support group was strongly anchored in a psychotherapeutic approach with a psychoanalytic and more intimate focus, and evolved to focus on advocacy actions at a later stage. While the approach adopted by HI seems to be very innovative with respect to how knowledge is adjusted to mental health approaches rolled out in the multiple intervention contexts, it still remains a major challenge. This complexity makes it hard for professionals who do not come with mental health technical education, especially community mental health.

Therefore, some members of HI's staff admit to facing challenges when applying these approaches in their daily practices. New recruits, who sometimes arrived after the training, seem to be experiencing difficulties in trying to get ownership of this knowledge and putting it into practice. While the project managers do know these documents and approaches, the teams who depend on them say they do not always use them, as they cannot link theory with the reality in the field. They can also find it difficult articulating the knowledge with each other, in order to gain a cohesive sense of

⁵⁷Cf. Annex: Summary table of the reference documents of the programme, *Touching Minds, Raising Dignity*.

the project they are implementing. The knowledge ownership issue therefore remains a major challenge according to the project managers we met. Project teams sometimes also seem to be torn between the request for knowledge ownership stemming from the team coordinating the programmes and HI's technical referents, and the need to generate their own practices from their own knowledge and experience of local reality. In this regard, monitoring regularly provided by outside psychologists is highly appreciated on the sites where these professionals are present, since discussions do not stem from theory or practice devised by others, but from their own practice in the field.

Cohesive professional staff practices are necessary for true involvement of individuals and for them to form a group. Within an *empowerment* and participation prospect, this alignment cannot happen without there being any final beneficiaries of the action, which implies that all mental health policies are locally based and re-negotiated. The action's final beneficiaries cannot be mobilized should they suspect that their involvement serves interests other than their own, or when the point is to gain approval and avoid objections.

As WHO underscores, "the need for understanding is closely knit to commitment. Should managers and politicians not fully understand the population's participation concept, what it entails and how it can be facilitated, it is likely that the process will not be fully efficient. This concept implies the will to invest the required time and energy for participation opportunities to be accessible, establish communication and trust, review people's motivation and listen to their point of view. It is also necessary to be aware of and understand the synergy between the population's participation and organizational development. Politicians and specialists should particularly understand how organizational structures, processes and cultures are capable of efficiently responding to the participation of the population, and being open to any change."⁵⁸

Giving cohesion to professional practices within a same organization requires constant adjustment between the organizational (and its management logics), technical (the work of technical staff) and personal conception (values, knowledge, history) areas. To this end, the organizational area will adjust since "the time needed for people's participation is seldom compatible with administration and elected representative's time, the urgency of the results to be produced, the quantitative nature of the assessment criteria, at the expense of more qualitative criteria focusing more on people's evolution and the meaning of the action undertaken."⁵⁹

⁵⁸WHO, "Participation de la population à la santé locale et au développement durable. Approches et techniques." Collection européenne développement durable et santé, n° 4, p. 18, 2000.

⁵⁹" Guide des outils et méthodes de la participation des personnes en difficulté. La participation et le partenariat au service de l'insertion et de la citoyenneté / Union nationale interfédérale des œuvres et organismes privés sanitaires et sociaux." Paris: UNIOPSS, 2003. 37p. <http://i.ville.gouv.fr/divbib/doc/guideparticipation.pdf>

SUGGESTION 3 - Identify, train and monitor ethics proponents

As we've seen in the various groups encountered, here we have to acknowledge the importance of certain persons, who are key to the projects being implemented. These people, be they psychologists, health workers, project managers, sisters or even technical advisors, are key facilitators, the true translators of the mental health projects at a local level. It is necessary for the organization to identify them, invest in them, train them and offer them, as the case may be, appropriate monitoring. As true interfaces between the organization and the beneficiaries, these people are also ethics and commitment proponents. We are not talking about an ethic formatted on a Western model (which would then look like a moral position), but about a pragmatic ethic, adjusted depending on the situations, respectful of the culture and local representations, without magnifying them. This ethic should be capable of relying on a mental health policy that all the actors involved share and co-develop.

SUGGESTION 4 - Grasp how the target population puts its relationship of the self with others (including institutions) to work

Trying to understand people with mental health problems and to empower them to participate in their healing compels, in a way, the supporting specialists to identify problems associated with the people's history and problems related to the private and political commitment of these individuals within society or the arrangements made to assist them.

Organizations willing to support individuals in their therapy and empowerment efforts should conduct, before anything else, a socio-anthropologic analysis to understand how the target population puts its understanding of the singular development of the relationship of the self with others to work. It seems important to explore life trajectories of people living with mental health problems and of their families in order better to understand them. To this extent, the daily life of these people should be shared for some time, to experience their fears, their expectations, frustrations, to try to retrace their care pathways, identify choices and constraints related to therapeutic decisions, understand perception and, eventually, the power relationships encountered in their environments.

For this prospect, the cultural dimension of the mental health problems should be considered, as it especially allows the analysis of representational and health care models, group dynamics, etc. However, this shouldn't be either an attachment or anchoring point. The point is rather to try to take into account variations between individuals in terms of their wishes and the possibility of them becoming actors in their illness.

SUGGESTION 5 - Gather all public, religious and traditional actors in the project's field of intervention

Steering an action aimed at creating a group also requires clarity on the status of the group's participation, as the latter will be affecting the method used and the choice of actions to be implemented. Here, the point is rather to define a framework within which the following can be reflected upon: why does an individual decide, at a given time, to get more involved, if not to become the leader of the group? In which project does this decision fit? How does this project fit in the group dynamic? How does the individual interact with the other group members? These various questions require reworking and reflection, both individually and collectively, with a relevant specialist (head psychologist for example), capable of providing some sort of follow up on the group dynamic.

On a more global level, we notice that within the supportive framework of support groups, decisions made by the NGO induce a major responsibility. International solidarity organizations usually bring the option to initiate major changes on a local, if not national level, thanks to their know-how and the volume of funding they can provide. We should become aware of and monitor power that on the one hand is strengthened, and that which on the other hand is weakened; what is legitimized and what is discredited. In this regard, specialists should question the relevance, ethics, short and long-term goals, potentially negative impacts, etc. The point is actually to view the entire action suggested with quality in mind.

ACRONYMS

General

AFD	French Development Agency
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
HI	Handicap International, Handicap International Federation
ICRC	International Committee of the Red Cross
IEC	Inform, Educate, Communicate
IGA	Income-Generating Activity
MHC	Mental Health Centre
NGO	Non-Governmental Organisation
OECD	Organisation for Economic Cooperation and Development
PME	Planning, Monitoring and Evaluation
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organisation

Country

BAS	Beit Atfal Assumoul
CCWHO	Collaborating Centre for WHO in France
Fatah	Palestinian Freedom Movement
FETAPH	Togolese Federation of Associations of People with Disabilities
FGC	Family Guidance Centre
JCP	Juba Central Prison
JTH	Juba Teaching Hospital
PNSM	National Mental Health Programme, Togo

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I - KEY SAMPLES OF THE MONOGRAPHS OF THE GROUPS THAT WERE STUDIED

MONOGRAPH 1 - A SUPPORT GROUP OF MOTHERS OF AUTISTIC CHILDREN AT THE FAMILY GUIDANCE CENTRE IN TYR, LEBANON

THE BEIT ATFAL ASSUMOUD ASSOCIATION AND THE FAMILY GUIDANCE CENTRE

Beit Atfal Assumoud⁶⁰ (BAS) or National Institution of Social Care and Vocational Training (NISCVT) in English, is an NGO working for Palestinian communities based in Lebanon. The NGO was established in 1976 (initially to take care of orphan children following the massacre in the Tal El-Zaatar refugee camp). Since then, the organization restructured itself to a large extent, by extending its work using a more family-inclusive approach. BAS is officially a Lebanese NGO (some of the Managing Committee members are still Lebanese) but with a Palestinian director, and still has a strong Palestinian identity. BAS provides services in the fields of education, economic and community development, healthcare services and a few emergency aid programmes. The FGC is one of the services developed by BAS within the Al Buss camp in Tyr. BAS offers 10 similar activity centres.⁶¹ The camp, initially established in 1936, includes 11,200 inhabitants at present. In the past, it used to be very distinct from the city, but was progressively absorbed into a denser urban fabric, and then eventually included in it. The urban mix is very strong there.

The FGC is rather recent as it was established in 2007. It resolutely focuses on mental health. The centre is physically organised on several floors, with a large interior patio and vast spaces dedicated to people receiving care and consultations; it is a very quiet and shady place, with relaxing colours. It is located in close proximity to one of the eastern entrances of the camp. One can access it from outside the camp, through a coastal road, or from inside the camp, through small access roads. Due to its position, it combines two slightly incompatible requirements: the need for a local service (people attending the centre with children, etc.), within the camp, with at least a number of

⁶⁰ That we could literally translate as "the house of resilient children".

⁶¹ Al Buss, Baddawi centre, Balbaak centre, Bourj Al Barajneh centre, Bourj El Shemali centre, Ein El Helwi centre, Mar Elias centre, Naher El Bared, Rashidieh centre, Shatila centre.

Palestinian specialists. On the other hand, the need for services to be provided with a degree of confidentiality, away from the other camp residents.⁶²

Increasingly the central idea guiding the thinking of the centre managers is to "follow the child wherever he or she is and with whomever he or she is". The integration of parents in the therapeutic project was rapidly considered obvious, just like the addition of community workers, who play the role of major "socio-cultural interface", and ensure home visits, including follow-up of the various treatments. As a specialist from the centre told us, "If we had only provided typical clinical services, we wouldn't have brought about much change." The team progressively grew and opened to the outside world, and is now cross-disciplinary. The centre deals with children suffering from various disorders.

A general healthcare approach, and especially with respect to mental health, was initiated by a psychiatrist strongly involved in the centre at its inception. At present the staff includes both Lebanese and Palestinian specialists. Similarly, the centre is a place where everyone is welcome, and deals with children and their families irrespective of their national origin. Lebanese, Syrian and Palestinian families therefore mix on a daily basis in this centre.⁶³ FGC therefore cannot be considered as a place geographically restricted to the Al Buss camp. Indeed, thanks to the quality of the services provided, the mix of staff (social, gender, etc.) and that of people attending it, the FGC knits its web of influence far beyond the geographical area of the camp. It serves the entire Tyr community.

HANDICAP INTERNATIONAL'S PROJECT

The HI team supports various initiatives in the mental health field in Lebanon; for example, these initiatives aim at connecting the mental health field actors in order to coordinate and exchange the various approaches and clinical practices implemented; they also aim to transmit know-how and improve professional capacities in terms of disabilities and mental health. It is for these reasons that HI started taking a keen interest in BAS's work and suggested supporting the Al Buss BAS centre in 2010. This support has carried on until today, however on an irregular basis (succession of high points and lower points in the partnership). More specifically, in this respect, HI embraces a support (technical and financial), advisory and training role, through a partnership approach. In terms of the BAS centre, the underlying objective of this support is to improve professional and management capacities of the centre's teams, the better to raise awareness among the community on the mental health issue and, more broadly, to gain autonomy in terms of operation. Through this support, HI hopes to contribute to the improvement of the mental health situation in Palestinian refugee

⁶² On this topic, see Forced Migration Review, "la santé mentale dans les camps de réfugiés palestiniens", F. Forgione <http://www.fmreview.org/fr/jeune/forgione>

⁶³ For example, based on this year's statistics, within the project supported by HI, 16% of children are Lebanese, 24% are Syrian and 60% are Palestinian.

camp. With the BAS centre in Al Buss, HI is dealing with a strong team of professionals in terms of quality, which is a source of expertise. In addition, the adopted approach ("to follow the child and family, wherever they are") is highly congruent with the community mental health approach promoted by HI. One of the technical advisors to this project explained in this regard that she doesn't feel strong tensions during discussions on the therapeutic project suggested by the centre. Here, the partnership relationship seems to be very balanced and fair, and is therefore rewarding for both parties.

The support provided by HI is mindful, but remains discreet and not very invasive. In this regard, HI's intervention doesn't appear to be a decisive factor in the emergence of and the support brought to the support group being researched, but remains a major securing factor, a "safety net" offering a resource that is always available. Indeed, HI never provided any strong guidance on the choices made by the BAS centre's professionals. One of the consequences of this position is that the centre - and therefore the therapeutic project it carries - is already mostly autonomous in terms of decision-making and evolution.

THE SUPPORT GROUP FOR MOTHERS OF AUTISTIC CHILDREN

The initial impetus for the establishment of the groups was provided by the psychologist who started putting her idea to her colleagues for their opinion, and was supported in this by HI's professionals. When it was first established, the group's primary purpose was to "facilitate the acceptance by mothers of the condition of their disabled children". Therefore, the initial impetus focused on two groups of persons for whom accepting the disability was especially difficult: on the one hand, a group of parents of autistic children⁶⁴ which, with a dynamic constantly nurtured through the will and the investment of the parents, developed well; on the other hand, a group of parents of children with mental disabilities, established a while later, with a less significant dynamic. We will try to describe the first group.

This support group includes only married women, all of whom have autistic children. Besides being women, these are truly the only things they have in common. The group is

⁶⁴ The parents of children living with an autism spectrum disorder (that we will refer to hereafter as the camp's caretaker do, by the terms "autistic children") are facing very challenging living conditions in the context of the Al Buss camp. On the one hand, due to the relative poverty of the medico-social services in the Tyr's Palestinian communities (as well as in the communities of South Lebanon), autistic disorder is usually identified very late, and is most of the time mistaken for other pathologies. Additionally, it is often poorly explained to parents, who remain ignorant about the condition of their child and the associated consequences. On the other hand, the family and the community they belong to, which should be the first support network are, the first ones to judge and exclude. This leads to a strong feeling of suffering, misunderstanding and, eventually, exclusion for the parents. And, more than for any other disorder, autism generates a very strong sense of failure with respect to their role as mothers and fathers. Each parent is in a similar situation with his or her autistic child, while feeling and living it differently. It is the informal expression of this suffering and its acknowledgement by therapists that gave rise to the idea of establishing this specific support group.

also diverse in terms of the character of the participants, with some women being more dynamic, others more discreet, more withdrawn. The group gathers about once a month. The meetings always take place in the course of the morning, in a private place (most of the time, in a room dedicated to this time within the FGC, and never at the mothers' houses). A rather strict framework was first established, constructed around the ideas of respect for opinions, confidentiality, and of a regulated distribution of talking time and some sort of control over the topics discussed. The framework, which, at first, could have appeared slightly rigid, was however well accepted and even seemed to provide security for the mothers. It was progressively relaxed with time (types of topics discussed, more friendly conducting of the meeting).

The practice within the group leaves space for discussions, most of the time through storytelling. The psychologist regulates these exchanges and invites the participants to express their personal experiences and feelings about the situations shared. The content expressed by the women of the group is full of emotion, both positive and negative: exclamations, screams, cries, laughs, expressions of joy and anger, distress, etc.

The evolution of this support group is especially interesting, and some of its high points are presented below.

On the one hand, it evolved in terms of content. While most of the discussions were originally focused on the life situation of the child or the mother, daily challenges, suffering, misunderstanding, rejection, the more the group evolved, and the more the mothers dealt with these issues through the lens of their own mother-child relationship. As the discussions evolved, attention given to the mother-child relationship became less important, and the participants started focussing more on their personal situation as mothers, by mentioning other issues such as financial and practical aspects of their situations, couple issues or issues within their own community. The psychologist fostered this evolution for the participants, for example in the sense of progressively reinvesting their quality and their role as women.

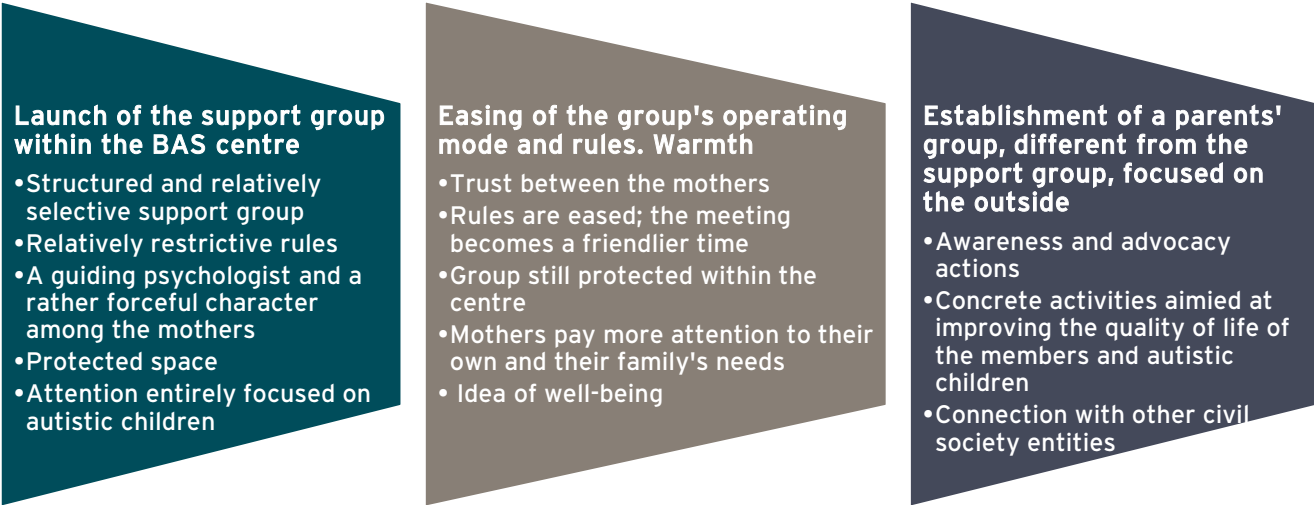
On the other hand, in conjunction with this content evolution, the group progressively opened to the outside. At one stage, the mothers decided to mobilise themselves to act and improve their children's living conditions. This decision to act then manifested in the establishment of a parents' committee, far larger than the support group, and welcomed parents of children with various disabilities. This committee set the following goals for itself: to find information and advocacy spaces to improve the life of disabled children (public spaces and events, blogs, social networks); to connect with other groups, other associations; and eventually, to offer the implementation of concrete actions fostering participation of and fulfilment for disabled children (establishment of a green space, accessible and inclusive, in collaboration with the municipality). Here, the point is not the evolution of the initial support group, but the creation of another group, distinct.

It is difficult to predict the future of the support group as such. The support from the psychologist, still very present, will not last forever; the group will therefore necessarily evolve and transform itself to become another space of interaction. It now includes

people who know one another intimately, and readily define themselves as friends or sisters. We are getting further from the initial therapeutic framework. However, as we previously mentioned, the space of the FGC and the operating framework of the mechanism is very securing. It will probably not be easy to sustain this group outside this framework (in families for example) and without regular monitoring. The sum of the differences/socio-cultural barriers among the participants, eluded for a time, might then reappear with more strength.

Summary - The support group of the Family Guidance Centre of the Beit Atfal Assumoul association, located in the Al Bus Palestinian camp in Tyr, Lebanon, has gathered mothers of autistic children since 2010, and was initiated by a team of therapists (psychologist, psychiatrist). These therapists are themselves supported by technical advisors of HI. This group gathers women from very diverse social and cultural backgrounds (of Palestinian, as well as Lebanese and Syrian origin) and has solid foundations. During its evolution, it was more specifically supported by a psychologist, who set to establish a clear and secure operational framework. Within a difficult context where mental health remains a delicate topic and where identity issues (origin, religion, ethnicity, etc.) play a central role, the group progressively developed itself, just like the centre which hosts it, i.e. into a protected, non-discriminatory space, fostering discussions among and fulfilment of its members. It seems to be a source of support, social awakening and empowerment for its members. Indeed, after two years of operation, a number of women established a second group, operating in conjunction with the first one, aimed at developing awareness and advocacy activities within and outside the camp.

Mapping the major steps in the evolution of the support group studied in Lebanon



MAHAJANGA PRISON

The National Prison (Maison Centrale, MC) is located at the heart of the city of Mahajanga. It includes 8 wards and 27 rooms, including an area dedicated to underage children and another with three rooms, dedicated to women. The theoretical capacity is 350 inmates. In May 2015, the MC counts 893 inmates: 731 defendants (76%) and 162 convicts (24%). An average of 1m⁺ per inmate is available, which implies very problematic living conditions (less than 1m⁺ per person). The prison's team includes 53 staff members, comprising 1 Director, 4 deputies, 25 security agents, 7 clerks, 2 nurses, 5 social rehabilitation agents and 10 professional staff attached to specific services (storeroom and food, penal camp, hospital guard, search, firewood, armoured car driver). The MC is relatively clean, except for latrine management, where a foul smell is always present. The standard of living in the prison is not lower than in the population at large living in the poor areas of the major cities.

HANDICAP INTERNATIONAL'S PROJECT

In Mahajanga, HI is trying to provide support to the inmates; a study published in June 2014 showing that 70% of them suffering from psychological stress directly associated with the prison living conditions.⁶⁵ Using a model of psychosocial interventions in emergency and post-crisis situations, HI is raising awareness among and training the prison staff as well as other prison actors in terms of psychosocial care. The goal is to protect inmates' dignity, prevent psychosocial incapacities and improve the prison's living conditions. To achieve these objectives, the "Quartiers d'avenir" project is based on a method developed during the first stages of the project (2009-2011 and 2012-2014); this method is now formalised in a guide entitled *Interventions psychosociales en milieu carcéral. Programme Madagascar. October 2012.*

To apply this method in the prison, while respecting the principles of HI's partnership approach, "to do with and not for", the NGO tried to meet with inmates associations, based on the assumption that these associations could support their peers in prison because they were trying to develop processes that would speak to their experience as inmates. According to HI specialists, peer assistance enables inmates to help one another deal with deteriorating prison conditions, as well as helps prepare those who are not convicted, or those who are about to be released, to leave the prison and be rehabilitated.⁶⁶ The identification of these inmate support associations wasn't easy.

⁶⁵ Study reference.

⁶⁶ Once released from the prison, ex-inmates are often stigmatized by the village inhabitants and, sometimes, their own family, who rejects them. Furthermore, on occasion they are subjected to a second judgement by the village council, followed by a second sentence to serve. This increases the rate of recidivism.

Unlike in the other sites of the HI project, there was no Inmates Support Committee (ISC), usually structured in association with inmates, recognised by local authorities and therefore visible from outside the prison. The project manager and her assistant therefore conducted research inside Mahajanga prison to try to find some indication of any groups. The purpose was not to establish a group, but to piggyback on an existing one and, ideally, to find a group which, unlike ISCs, included inmates. They found GEBAPRIM.

THE GEBAPRIM ASSOCIATION

GEBAPRIM is an informal association, established in February 2008, allowed to operate by the prison director in January 2013, and includes about 20⁶⁷ inmates, defendants and convicted men, women and underage children. The association was initiated by a group of individuals recognized by their peers, as well as by the prison administration, and who, in the words of the prison's administration managers and the founders of GEBAPRIM, comprise "intellectuals". Initially, in order to be part of GEBAPRIM, the members had to prove they could read and write, have a minimum school level qualification (First Level Certificate), and, in line with the initial goal of the association, undertook to give literacy classes to illiterate inmates⁶⁸ and maintain spiritual practices in the prison through the reading of religious texts. GEBAPRIM then means: "Biblical and literacy students group in the Marafato Prison". Between 2008 and 2010, they mostly worked with Jehovah Witnesses, who came to provide biblical education and administered exams for the inmates. The GEBAPRIM members marked the exams and, in exchange, Jehovah Witnesses provided books to GEBAPRIM, which they could distribute to inmates. They also worked in the field of literacy, especially assisting people writing to their family. In the past, GEBAPRIM did not always participate in these activities, although the prison administration and especially the social rehabilitation manager thought they had been participating. At that time, the association was supported by Médecins du Monde (2010-2012). The association applied for legal recognition as an association in December 2012. According to them, this would provide for better statutes in order to claim compensation. However, receiving payment is not officially accepted in prison. To this day, this application has received no response. The attraction of GEBAPRIM members to religion is not official and appears to be opportunistic, because of the support offered by the Jehovah Witnesses. Progressively, GEBAPRIM opened up and developed activities geared, in the bureau members own words, towards "human solidarity". In 2013, the association changed its name to Génération des Éducateurs et Bienfaiteurs pour l'Avenir Principal des Incarcérés de Marafato.

⁶⁷ The composition of the group regularly changes based on releases and arrivals. However, the group includes a majority of adult men, serving sentences ranging from six months to 15 years.

⁶⁸ About 60% of inmates are illiterate.



The "Mitard" gate of the Mahajanga prison

Since the beginning of the *Touching Minds Raising Dignity* project (2014), HI has provided support to GEBAPRIM through various activities: support from the social rehabilitation agent, support of the organisation's activities from CSOs⁶⁹, coordination of the collaboration between CSOs, the prison administration and the inmates, literacy, support by biblical education organisation, foreign language classes (French, English), rights awareness, sports (basketball, zumba), television broadcast in the wards, radio broadcast in the wards, library management, work with HI to produce soaps, support to letter writing for families, bail request support (assistance to complete the form). GEBAPRIM is currently thinking about changing its name, by rearranging its acronym around the ideas of social rehabilitation and access to rights - which are strong notions promoted by the prison administration and HI.

These activities are steered and facilitated by members of the GEBAPRIM's bureau, the HI officer and the prison administration. At the moment, the goal stated by GEBAPRIM is to facilitate the Civil Society Organisations' work of intervening in the prison, as well as that of the prison administration. The members of this association are all volunteers and do not pay any membership fee to join the group. Conditions for admission are being able to read and write (at first certificate level), so as to be capable of implementing the GEBAPRIM activities, and to have demonstrated "exemplary behaviour", i.e. never

⁶⁹ A very large number of organisations and personalities currently intervene in the prison: some associations visiting from time to time, such as the Rotary Club, some independent persons, evangelists, the Zo Association, the Eden NGO, the HI NGO, the AINGA AIDS NGO, ICRC, ACP, Teen mission, and a number of organisations considered by the prison administration as sects - Jehova Witnesses, Apocalypsie, HVKL, ITK, Libérez mon peuple, FMFKM, the Church of Christ the Saviour - and various religious congregations - FJKM, Toby Malo, the Adventist Church, the Lutheran Church, the Muslims Association.

having tried to escape and never having misbehaved in prison. The association's head office is the office of the prison administration's social rehabilitation manager. Five active members are working in this office, in close collaboration with the staff of the prison administration. They are the ones organising these activities. At present, these persons are not recognized by the Regional Prison Administration Directorate (DIRAP), and are therefore illegal. They are only recognized at the level of the prison director.

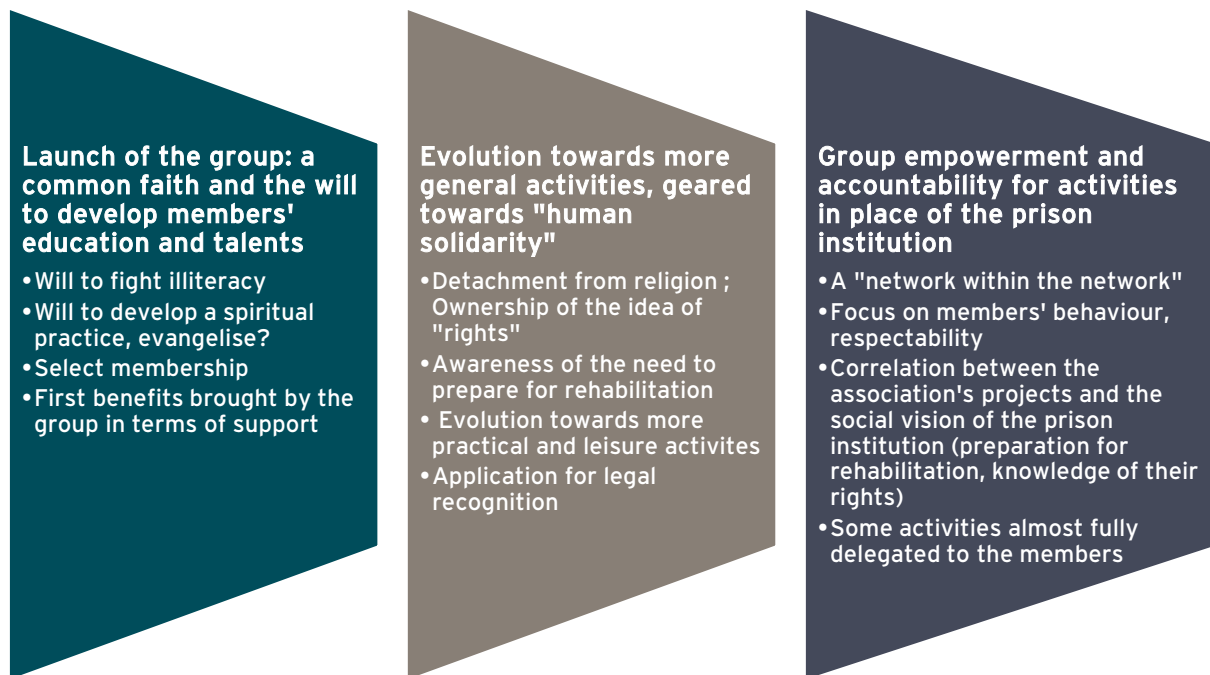
The GEBAPRIM members can play various roles within the prison: literacy teachers, librarian, facilitator, awareness raising officer, peer educator, library supervisor, radio technician. Most of them are considered to be members of the prison's social rehabilitation department. As such, they are part of a number of committees (hygiene, monitoring and complaint box committees), and their point of view is taken into account on an advisory basis. They also have a duty in terms of safety in the prison. If a GEBAPRIM member identifies deviant behaviour or a health problem, he or she can sound the alarm and directly go and see the most appropriate prison staff member. This staff member reacts more quickly for the members of GEBAPRIM than for other inmates. The GEBAPRIM members are present in all the prison wards, outside the wards within the prison, as well as outside the prison, in the forced labour camps or in administrations such as the DIRAP. The social rehabilitation officer of the prison administration decides on the tasks allocated to the various members. They are usually recognised as dynamic and trustworthy by the professionals in the various prison administrations.⁷⁰ The GEBAPRIM members can hold various executive functions in the prison: ward managers, room manager, health manager in a ward.⁷¹ Globally, GEBAPRIM members assist their ward managers in their daily work.

The GEBAPRIM members do not receive any salary. However, they benefit from numerous in-kind advantages. First of all, they are trained, especially thanks to HI, based on the activities they want to conduct. For example, to conduct the literacy activity, they were trained by HI and the Ministry of Population. Thanks to this training, they can obtain training certificates which they can put to use once released. Other advantages, they are almost all free to move within the prison precinct. Some can go and directly see the doctor and the nurse without making an appointment with the room manager or the room's health manager. All members do not benefit from these advantages; it depends on their level of collaboration with the prison administration. The five members of the bureau benefit from the most advantages. Some of them obtain clothing and food depending on the NGOs with which they conduct their activities. Globally, the GEBAPRIM members do not redistribute the benefits received individually. Each acts on his or her own behalf in terms of the mandate of the association.

⁷⁰ For example, some prison agents do not hesitate to have their young children looked after by a female inmate member of GEBAPRIM.

⁷¹ However, the accumulation of responsibilities includes limits since, as GEBAPRIM members, they take part in activities which happen outside the wards while, as directors or managers, responsibilities are exercised within the wards. Therefore, they rolled out a responsibilities delegation system.

Mapping the major steps in the evolution of the support group studied in Madagascar



MONOGRAPH 3 - THE GBALENFIT FEMMES GROUP, DAPAONG, TOGO

THE MENTAL HEALTH CENTRE OF THE YENDUBÉ ASSOCIATION IN DAPAONG

The MHC is one of the structures of the Yendubé association; a religious association attached to the Soeurs Hospitalières du Sacré Coeur de Jésus.⁷² It is located in the town centre of the city of Dapaong.⁷³ It was created in 2000 in the paediatric hospital, which is the historic structure of the association. Support came from the focal initiative of the mental health national programme at the level of the Ministry of Health. It was the increase in the active file of patients as well as the stigmatization that the hospital was starting to feel through the major presence of people living with mental health problems that caused the association in 2008 to decide to move the MHC to its new premises.

⁷² The Soeurs Hospitalières du Sacré Coeur de Jésus comprises a religious congregation established in 1881 by Italians, Benoît Menni (1841-1914), Maria Josefa Recio (†1883) and Maria Augusta Giménez (†1897), near to Madrid, Spain. It is a congregation of Pontifical right approved by the Holy See on the 25 June 1892. The sisters provide assistance to mental patients, physically and mentally disabled persons.

⁷³ The city of Dapaong plays a strategic role in exchanges in western Africa, as it holds a privileged position for the transport of goods to Burkina Faso, Benin and Niger. Therefore, the local economy is one of the most important in Togo. The city's economic centre is the market, for various commodities, especially fabrics, millet and sheep.

Since its inception, the MHC has been headed by a sister. The centre has the goal of "promoting mental health in the Savanes Region through championing the social rehabilitation of stabilised patients, awareness raising, drug therapy, psychological and occupational approaches, both on a personal and at a community level".⁷⁴ In 2014, the MHC undertook 5,888 consultations for an active file of 1,872 patients. The MHC deals with people living with various problems (based on their internal classification): epilepsy (41,5% of the active file), acute and temporary psychotic disorders (13.1%), chronic hallucinatory psychosis (9.7%), schizophrenia (8.8%), others (27.3%). The average duration for treatment in the MHC is four days, with a hosting capacity of six beds. The MHC conducts awareness raising activities (within the centres, high schools, several villages and through a monthly radio programme), self-help groups (two groups gathering every month), occupation therapy, home-based visits, drug prescriptions (antianxiety medications, hypnotics, neuroleptics, antidepressants⁷⁵). The MHC benefits from partnerships with HI, the National Agency for Employment Promotion (ANPE), the Regional Health Directorate, the Dapaong Hospital, UNHCR and being the focal point of the National Mental Health Programme. The focal point ensures monitoring of the sister heading the group and of the team every six months. The MHC includes 15 professionals: 4 nurses, including the Head Sister, 1 medical assistant with a master's degree in mental health, 1 occupational therapist sister, 1 guard, 1 secretary, 1 cashier, 1 volunteer sociologist, 5 community officers. The MHC is part of the National Mental Health Programme (PNSM) 2015-2019, as the nominated structure for the Savanes Region.

The Yendubé association saw three different directors between 2008 and 2015. In 2010, two congregations merged: the congregation of the Soeurs Augustine Hospitalières, with the congregation of the Soeurs Hospitalières du Sacré Coeur de Jésus. This merger led to the departure of the head sister, Sister Viviane, who had been there since the inception of the MHC, in February 2011. A new sister, Sister Christine, from the congregation of the Soeurs Hospitalières du Sacré Coeur de Jésus, replaced her until June 2014. She then left to undertake training (Masters in Mental Health). Currently Sister Ghyslaine, from the same congregation is replacing her. Sister Viviane had an in-depth knowledge of the local social fabric as she was from the city of Dapaong and was from the Moba ethnic group. Sister Christine is from Cameroon, as Sister Ghyslaine from Burkina Faso. Sister Viviane was trained and supervised by Professor Dassa, a psychiatrist and the PNSM focal point; she considers him as her "master and friend". However, neither Sister Christine, nor Sister Ghyslaine received mental health training. Professor Dassa still supports the head sister of the MHC by coming to Dapaong about every six months to supervise her.

⁷⁴ Cf. Rapport d'activités du Centre de Santé Mentale de l'association Yendubé, 2014.

⁷⁵ The purchase of medicines is funded by the congregation. The head sister gets her supplies directly from the Togo group purchasing organisation and, in case of shortages, from other religious centres of the congregation based in Cameroon and Burkina Faso.

HANDICAP INTERNATIONAL'S PROJECT

In Dapaong, HI's goal is to "improve the social and civic participation of people living with mental health problems".⁷⁶ Since the first exploratory mission conducted in 2008 by the psychology unit coordinator of HI's head office,⁷⁷ various projects have been developed, all in connection with the MHC's support groups.⁷⁸ These projects only received funding from January 2014. Between 2008 and 2011, several support missions to the support groups were conducted by two volunteers from Advocacy France, while HI was especially supportive, due to their past involvement in the transformation of public policies related to people living with a mental disability in France. HI was financially contributing to the work of these missions so as to maintain the connection with the MHC, while themselves awaiting for adequate funding. A strong friendship existed between the people assigned by Advocacy France, Sister Viviane and the MHC's support groups until 2011. In 2012, HI funded the trip of an Advocacy France's member in London, alongside the Mental Health technical referent, as well as the head of West Africa programmes, to present the project to an English donor (Big Lottery Funds). This project submission was unsuccessful.

It was only in March 2014 that the HI Togo programme really managed to initiate its mental health activities, by targeting two types of particular publics, thanks to two funding sources, one from the European Union and the other from the French Development Agency. These publics were: people living in prisons (defendants and convicts) in Lomé, Kara and Dapaong, as well as the beneficiaries from the MHCs in Lomé and Dapaong. At the level of the Dapaong MHC, activities only started in October 2014. The intervention model envisaged at the time the project was formulated was based on an approach developed by Advocacy France, called *Espaces Conviviaux Citoyens*, which aimed at assisting self-help groups to emerge by practising effective user-accountability. This approach is similar to the one developed by HI in Rwanda, called *Community Mental Health*.⁷⁹ Users take ownership of the place and of the organization of activities they wish to conduct (*empowerment* strategy as defined by Advocacy France).⁸⁰

⁷⁶ Cf. general objective of the "Touching Minds, Raising Dignity" programme.

⁷⁷ Cf. exploratory Mission Report, written by Sabrina Célésia in 2008.

⁷⁸ Cf. funding requests for the various projects were submitted to Big Lottery Funds and Grand Challenge Canada.

⁷⁹ Cf. the list of reference documents in the Framework Document of the programme agreement; the reference is called "Réunir les solitudes", Rwanda Programme 2012.

⁸⁰ Cf. <http://www.advocacy.fr/pages/actions/espaces-conviviaux-citoyens-d-advocacy-ecc,29> (accessed on the 30 Sept 2015).

THE GBALENFIT FEMMES SELF-HELP GROUP (WOMEN SELF-HELP GROUP)

Combined with the word "group", the word "gbalenfit", in the Moba language⁸¹ from Dapaong, literally means "let's make an effort/let's fight and it will be fine, each of us will have results." The idea of a group serving the interests of individuals seems to have featured centrally when it came to the choice of this name. Gbalenfit Femmes was established in 2008 upon an initiative by the head sister, who noticed the important roles loneliness and poverty played in the lives of patients coming to the MHC. The idea for the establishment of a self-help group came from the realization that in the Moba tradition, farmers used to help each other when one of them experienced difficulties. The one benefitting usually invites the others in return to share a meal, as is reminded by the Moba proverb *"when you get people to sit, you need something to lift them up"*.

The group doesn't hold any administrative status recognized by the state. It is an informal group depending, in its governance as in its operation, on the MHC of the La Soeur association, which used to coordinate the group, and offered to establish a bureau based on the typical model in Togo: a president, secretary, treasurer (elected by the group as these people were the most literate ones, and approved by the head sister). There is a Gbalenfit Femmes and a Gbalenfit Hommes [i.e. the Gbalenfi Men's self-help group]. The two groups were established simultaneously and operate independently, each with its own bureau, nor holding their meetings at the MHC at the same time. They do however share joint activities, such as the facilitation of World Mental Health Day. Men and women were split into two groups so as, according to the sister in charge who initiated the two groups, to respect mechanisms fostering traditional self-help and solidarity.

This self-help group initially included nine women in 2008, and evolved to reach 48 women in 2011, without age limits (but usually between 30 and 50 years old), from all religions and, in theory, all ethnic groups. However, most of the women currently members are of Moba origin (the group speaks the Moba language and French when the group includes a member from another ethnic group). They discuss the challenges they are facing with their respective diseases and together search for ideas to improve their living conditions. The only condition for being part of the group is to have a stable medical condition or have a sick child. This is what the head sister stipulates to the women at the MHC and who are all in a stable condition, or are parents of children living with a stable mental disorder.

At a financial level, the group operated using a membership fees system. Each member was contributing 100 FCFA⁸² a week, or 500⁸³ FCFA a month. The money collected was

⁸¹ The Mobas are mainly farmers and hunters, from the Dapaong area. They make up 47% of the population of this city, alongside people of Gourma, Mossi and Peuhl origin.

⁸² About 15 cts to the Euro.

⁸³ About 75 cts to the Euro. The members of the group earn between 5,000 and 60,000 FCFA a month (between 8 and 91 Euro/month). The minimum wage in Togo is 35,000 FCFA/month (53 Euro).

quickly placed in a microfinance institution (COPEC), at the initiative of the coordinating sister, thus allowing the group to ask for loans (18% interest rate). These loans were sometimes taken out on an individual basis under group guarantee (joint surety) and were used to reduce healthcare challenges for members, especially drug purchases. On other occasions, they are allowed to conduct individual IGAs (a member started a pharmacy, another one a seed business) or collective IGAs (for example, manufacturing syrups). Income generated by the sale of the produce from these collective IGAs was individual, each selling what he or she produced. The members of the group could refund part of their sales to the group fund, for the amount they wanted. This activity was conducted with the blessing of local authorities, who gave it support.⁸⁴ However, the poverty of the village inhabitants as well as the fear associated with commodities sold by people with mental health problems, considered possessed, didn't really enable them to make much profit. An IGA, which only integrating people who are directly or indirectly affected by mental health problems seems to limit stigmatisation. Furthermore, we noticed that the development of this IGA wasn't based on the recommendations of the community mental health approach suggested in the reference document "Réunir les solitudes", and especially that it doesn't comply with a local development approach.

The group was motivated by the centre's head sister up to 2011 and was supported by two members of Advocacy France, who would come about every one and a half years and visit them (a retired psychiatric nurse and the director of a centre of professional services for people living with mental and intellectual disabilities).⁸⁵ The members of the group were meeting on a monthly basis in a "convivial space" (terminology specific to Advocacy France), regularly utilized by the group members and where women would meet to talk and have lunch together. The meal was funded by the MHC as well as from the IGAs and donations by the head sister's friends, including Advocacy France.⁸⁶ The members sometimes came from very far to take part in the group, and the meal played a motivational and cohesive role in the group.

After the departure of Sister Vivianne, the group gradually broke up. The new head sister, between 2011 and 2014, couldn't financially maintain the convivial space. However, the connection with Advocacy France was maintained through two missions conducted in 2012 and 2013, leading to the funding of an agropastoral training course for the Gbalenfit Hommes group, and the funding of a cereal purchase/selling activity⁸⁷ for the Gbalenfit Femmes group.

At present, there are only about a dozen members in the women's group, meeting for half a day once a month to talk about illness and work on specific projects. The group contributes to the organisation of World Mental Health Day, each 10th of October.

⁸⁴ A bottle of syrup was sold for 2,000 FCFA.

⁸⁵ The last mission took place in May 2013.

⁸⁶ Advocacy France provided funding to the group of up to about 800,000 FCFA (about 1,200 Euro) over two years (2009 and 2010).

⁸⁷ Funds were transferred to the MHC and haven't been used yet.

Supported by HI (which funded training) in January 2015, the group devised an IGA related to soap production.⁸⁸

Due to the drop in its membership base, the group doesn't have enough money at present to operate. The relationship with COPEC was broken in 2011. The group borrows money to the MHC's head sister (10% interest rate). The soap production activity is conducted in partnership with the sisters of the congregation, who host the production workshop and storage in their living quarters. The activity is operational but doesn't generate a lot of income due to the very high cost of raw materials and the still very strong stigmatization of the group members.⁸⁹ Income generated is saved with the head sister, and there is no individual distribution as was the case for the syrup manufacture. Money is mainly used to purchase medicine for the poorest members of the group.⁹⁰

The group is currently thinking about pursuing the IGA project initiated by Advocacy France on the purchase/sale of cereals. The group managed to get another tranche of small funding for the purchase of cereals through a Togolese business owner, but doesn't have enough money to be able to store, and then sell the cereals through a shop. The group thought HI would help them start this new activity instead of supporting the MHC with the funding of a canteen. Currently, there is an unspoken tension between the group and the MHC, and, indirectly, HI, about these projects. The group blames the MHC and HI for developing IGA projects (through the canteen project), without taking their point of view into consideration and without assessing their needs, as occurred in the past during the setting up of the initial project.⁹¹ The head sister would like to reconnect with Advocacy France since its members want this to happen. However, she doesn't know the approach developed by Expertise France. Globally, the requests made by Sister Ghyslaine to HI rather revolve around increasing the centre's funds (funding of human resources, activities and infrastructure) than around a local development vision based on an analysis of resources already in existence within the community, and in connection with local partners (community mental health approach promoted by HI and Espaces Conviviaux Citoyens developed by Advocacy France). At present, there is no connection with local authorities or associations representing people suffering from disability in Dapaong, within the framework of the support given to Gbalenfit groups.

⁸⁸ In 2014, HI provided 750,000 FCFA to support this activity.

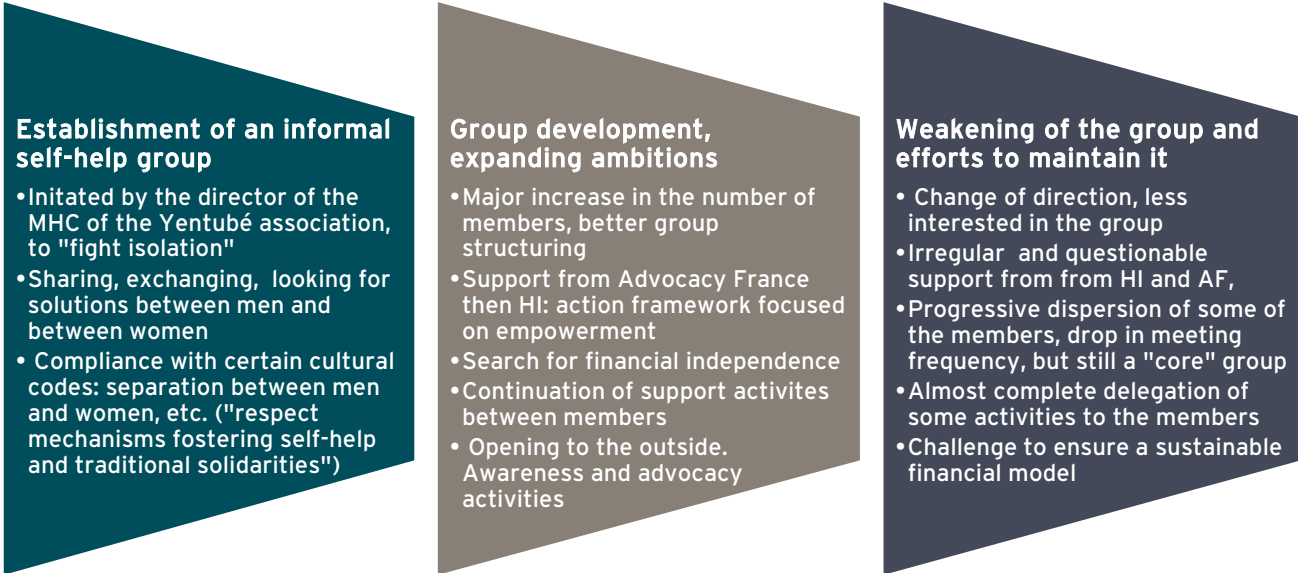
⁸⁹ The cost price of one soap is 250 FCFA, and it is sold for between 275 and 300 FCFA. A member testifies to the fact that in three months, she only managed to sell five soaps. Besides stigmatization associated with the illness, the inhabitants of Dapaong tend to buy their essential items from members of their community (cf. the chapter on the rise of communitarianism in Togo, below). Some members of the group, of Moba origin, live in areas where the majority comprises those from other ethnic groups, which doesn't facilitate the selling of their products.

⁹⁰ In average, a full treatment to overcome a crisis costs 11,000 FCFA for two months. For stabilised patients, treatment costs on average 2,000 FCFA. Consultation fees should be added to this cost, ranging between 500 and 2,000 FCFA depending on the specialists.

⁹¹ Actually, HI is currently thinking of repositioning some of the 2015-2016 convention's budget lines with the MHC around a new IGA, to the level of 1,650,000 AGI, but neither the groups, nor the MHC knows about this. For its part, HI doesn't seem to know that this activity formed part of Advocacy's funding strategy in 2013.

The Gbalenfit Femmes group plays a major psychosocial support role for its members. Most of the current members live in poverty, a situation sometimes exacerbated by the death of a husband or neglect from his behalf once the illness appeared. Rejection from relatives is sometimes still very strong, even for some parents towards their own children. Conversely, some women could find a new balance in their private and professional life thanks to the support provided by the MHC, and especially the Gbalenfit group. A woman testifies to the fact that thanks to the IGAs, she managed to start her own small condiments business and is now making a living from it. Another managed to open a small pharmacy. For others, the group enabled them to learn how to distinguish various types of mental health problems, teaching that was mobilised in the community when meeting people living with mental health problems. For example, a woman testifies that when she now meets someone who falls to the ground, she is not scared like she used to be and, on the contrary, goes to him or her to help, despite the looks other people give her. Even though the members of the group are spread over a rather large territory in and around Dapaong, they sometimes meet in the market or when a specific event affects one of them (death for example). The relatives of some of the members also testify to the containing role played by the group, some members (even stabilised) were less agitated and angry after spending the day with the group.

Mapping the major steps in the evolution of the support group studied in Togo



MONOGRAPH 4 - THE SELF-HELP GROUP AT THE JUBA GENERAL HOSPITAL, SOUTH SUDAN

THE JUBA HOSPITAL AND CENTRAL PRISON

The Juba Teaching Hospital (JTH) is the largest hospital in South Sudan. It aims at providing quality hospital care for people living in the Central Equatorial state, but is also the reference hospital for the entire country. Dr Atong, a psychiatrist, is heading the psychiatric service. She is also the focal point for the entire Mental Health sector for all of South Sudan. She is indeed the only qualified psychiatrist in the country, with Pr. Muhammad Boyd, who is the dean of the Juba medical faculty. She is assisted in her work at the JTH by two *medical doctors*, who should rather be called *medical officers* (as they do not hold the title of doctor), who are in charge of managing the *outpatient department*. They are not really specialised in mental health. Instead they received an "orientation".⁹² Six nurses complete this team. About 10 patients are currently hospitalised in the department. Diagnoses are classified along four main categories: psychosis, schizophrenia, depression and epilepsy. The main approach adopted for the treatment of patients is medication. According to the medical officers, counselling is also provided, but it was difficult to understand precisely what the content of this counselling was. Under HI's initiative, a few months ago, the department started a Mental Health Support Group, which we will discuss in greater details later on in this section.

The Juba Central Prison (JCP) includes two separate buildings for men and women, with a total of three psychiatric wards. The two wards dedicated to men are larger (hosting 97 inmates at the time of the research), while the women's ward is smaller (hosting 18 inmates at the time of the research). Inmates are jailed due to their mental illness, and not because of a crime or an offense. All inmates/patients arrive at the JCP with their diagnosis already established by the psychiatric department's team. Based on this diagnosis and in agreement with the family, a legal agent completes the process with an official recording of their transfer to the JCP. The same legal agent also decides, following an adjustment to the diagnosis, when the patient can be released from the JCP. Health-wise, the support to inmates is provided by the only psychiatric nurse. There are two broad "categories" of inmates: the sick ones, usually considered unable to interact socially, and the ones in recovery, a process associated with resocialization. The classification of the inmates between these two phases and the transition between these phases is based on the diagnosis made by the psychiatric team of the JTH. Treatment is constellated around these two aspects: medical treatment and discussions/support through dialogue with other patients; this support through dialogue (which cannot be qualified as "counselling") is only dedicated to patients entering a

⁹² According to Vivek S., a "Basic Module: orientation on MH", then an "Advanced Module: Therapies, Medications, etc."

recovery, healing phase. It aims at giving these people a new anchorage in the real world. Most of the time, patients don't have much to do. The psychiatric nurse of the JCP told us that this situation wasn't normal, or desirable. According to him, "more activities, leisure, teaching, vocational training, etc. should be organized, at least for the patients capable of attending." But the ward is overcrowded and lacks the necessary operational budget, and there is a severe staff shortage. Also, hygiene is terrible. According to him, it is impossible to offer activities in such conditions. Therefore, there is no common activity, no group within the ward, and therefore no group of mental health users.

In fact, we could consider that these two structures make up a single institutional centre for dealing with people living with mental health problems (PLMHP). The JTH psychiatric department is the "Western" entry gate for the treatment of PLMHP, and the JCP is actually a psychiatric treatment centre in a closed environment, mostly hosting people referred to it by the JTH. For both these structures, medical decisions are centralised around the team of the JTH psychiatric department. The regulation for admissions and discharges is therefore common for both these structures.

The relationship between the members of the team and the head of the psychiatric department is described as complex, thus making all interactions necessary to the project very uneasy. The healthcare project developed by the department is resolutely geared towards medical treatment. While support to such a system is indeed relevant (institutional coordination, use of hospitalisation in some cases), the concrete impact of such action is insufficient. On the one hand, the highly medicalised and "western" approach doesn't seem well adapted to the country's reality and highly disconnected from the community level. On the other hand, this system can only allow support to a limited number of people. And finally, access to healthcare within such a system seems very discriminatory: everyone doesn't have access to the information that such a facility exists; physical access can be challenging for people living on the margins of the city; and finally, funding long term treatment is difficult (medicines are paid for by the families).

HANDICAP INTERNATIONAL'S PROJECT

Within the framework of the "Touching Minds, Raising Dignity" programme, HI is providing financial, organisational, educational and operational support to the professionals of the JTH's psychiatric unit, as well as for the professionals of the JCP. In line with its institutional action, HI also intervenes at a community level to develop healthcare for PLMHP and offer support to their relatives. Through its action, HI aims at improving national mental health policies on a national level, and at improving in a concrete manner healthcare, rehabilitation and, eventually, the quality of life of PLMHP.

The MHPSS project, included in the framework of the "Touching Minds, Raising Dignity" programme, got delayed in South Sudan. Initiated a year and a half ago, it truly only became operational in October 2014, suffering from the recurrence of the civil war in the

south of the country, at the end of 2013, and from challenges in terms of expatriate staff recruitment. Besides the complex and changing situation prevailing in South Sudan as well as the unstable security situation in Juba, there are also inherent challenges to the translation of goals and the rollout of activities in the specific urban environment characterising Juba. There is also a lack of start-up information. The HI team is dealing with major implementation challenges. Therefore, the adopted approach is, understandably, first and foremost pragmatic, in the way that most of the attention is focused on the initiation and the conducting of activities that will result in achievements. The team first focused on securing and developing institutional connections, especially with the JTH's psychiatric department and the men and women in the psychiatric wards of the JCP, a necessary pre-requirement to the implementation of the project. In conjunction, the team did its best to initiate interesting partnerships with some key community actors (Union of Physically Disabled - UPD), but at this stage, however, it doesn't seem to have succeeded in truly emerging with respect to the social dynamic of the project's target areas. The team hasn't fully "domesticated" this project and the corollaries stemming from its implementation.

In addition, a major concern is the obstacle of chronic insecurity in Juba. On a day-to-day basis, this means an almost constant feeling of discomfort and apprehension, which, in the long run, can produce greater stress and fatigue among the teams. In addition, the current situation is characterised by very poor readability. No one is capable of predicting the evolution of the situations in the cities, including national staff themselves.

Currently, there is a major lack, in terms of the consideration and management of mental pathologies in their moderate and medium forms (between the heavy pathology, characterized by a desocializing nature and minor dysfunction) in Juba and its surroundings. The investment, be it from the NGOs or the South Sudan's action point of view, seems focused on managing severe cases (response focused at the institutional level and anchored in a development logic), or on a psychosocial intervention for conflict victims (response focused at the community level and anchored in an emergency logic), leaving an "in-between" at an urban level, orphan to any response.

One could argue that such fragmentation is also apparent in the response suggested by HI with, on the one hand, some support offered by the teams in the institutional field (financial, material and capacity building support, work on national policies) and, on the other hand, some work initiated with community organisations (awareness, advocacy, etc.) that seems isolated from the previous support. However, while HI now offers community monitoring for people released from hospital and from the prison, the momentum remains "vertical", with support focussing on the individual and his or her family. There is very little lateral dynamics between HI teams, and therefore very little exchanges between the families or PLMHD from the same geographic areas. [Assumption: However, in a resocialisation process, these persons and their families are indeed located in this intermediate field of mental health intervention (moderate pathologies) that we mentioned in the previous paragraph. Indeed, these persons, once

back in their community, as well as with their relatives and caretakers, could be fertile ground for a mechanism of group management and support, anchored at a community level.]

THE JUBA HOSPITAL SELF-HELP GROUP

The Juba Hospital self-help group was established at the beginning of 2015, through an HI initiative, within the framework of the "Touching Minds, Raising Dignity" programme. It is an information and therapeutic group, which doesn't have any ambition to provide individual support or advocacy activities at present. Therefore, there are no other participants' meetings or action besides the time spent as a group. The group meets in the JTH psychiatric department every two weeks or so. At the time of the field visit, about 10 meetings had already been held. Dr Atong didn't initiate this group but approved of its establishment. She delegated the monitoring responsibility of this group to one of her assistants, Dr Kasiro. Unfortunately, Dr Atong didn't have much time for us at the time of the field research and we didn't manage to get her point of view on this self-help group.

The size of the group varies between 5 and 15 persons. It is a rather diverse group on a social level, based on the discussions we had with the members and our observations. Some people clearly come from a well-off background, while others belong to the poorer strata of the population. All were invited to participate based on the fact that they consulted at the centre as patients or as members of the patients' families. Membership also varies depending on the sessions. Therefore, the group includes both patients/users, caretakers and members of HI's team. Group facilitation is mainly ensured by the HI team, which has a strong presence. Dr Kasiro ensures supervision and advice to families.

The sessions are conducted in a rather structured and rigid manner, as we could see from the spatial organisation of the meeting: participants sitting in a row, facing the psychiatrist and HI's team, almost as if situated in a classroom. Discussions are held in a formal manner: participants raise their hands to be allowed to talk, talking time being distributed by HI's team. The therapeutic rationale for this organisation is unclear. The session starts with a brief introduction, followed by the introduction of new participants and a reminder of the reason for these meetings, which is, according to Vivek S., the project manager, to "share experiences and look for answers." During the observed session, Dr Kasiro explained that all people in attendance, he himself included, could be trained in psychiatry, and become "knowledgeable" of their relatives' situation. The floor was then given to the participants.

Through their questions, the participants discussed in an open manner various topics affecting them, such as their distress when faced by some symptoms or behaviours from their relatives, the misunderstanding regarding some medical approaches affecting them (including those initiated by the psychiatric department's team), concerns about the future ("when will my relative be cured?"), or treatment observance challenges. We

cannot truly talk about an exchange as such. It was more a kind of Q&A session, focused on Dr Kasiro, who offered explanations and provided comments and advice, in response to the questions from the members. However, the participants were all respectful, paid attention to the discussions, without any strict rule being formulated at the start of the session. The exchange was held partly in English and partly in Arabic, since some participants only understood one of these two languages, often requiring translation, which slightly reduced the time available and fluidity.

While heeding the necessary precautions on the delivery of findings and analyses based on such short observations, one can argue that this self-help group seems very asymmetric in its mode or operation. Situations and questions are exposed on the participants' side, but the psychiatrist provides answers and suggestions. While some participants shyly start to exchange between each other, at this stage, there is no real balance of functions, for example in the positioning of the caretakers as experts, capable of giving relevant advice to the other members. In the same manner, most of the time the PLMHP are, like the entire management approach, considered in the light of their illness and associated symptoms. Therefore, some PLMHP were in attendance during the observed session, without intervening at any given time or, more specifically, without them feeling they had the legitimacy to intervene.

The position of Dr Kasiro, the "psychiatrist", is rather singular here: he first appeared to be in a position of authority, since he has the knowledge, is a reference and especially a medical reference. From this point of view, he was never challenged in his assertions during the session. The direct consequence of this is that he also is in a position of obligation: indeed, whatever the issue expressed (medical, social, etc.) he has to provide a satisfactory explanation, a solution and advice. In a way, it seems it would almost be impossible for him to say "I don't know" or "I don't understand your request". Finally, he is also in a position of relative weakness, as he often had to justify his decisions and the actions of the psychiatric department that he is representing for the families.

We managed to meet with a number of participants for individual or family interviews. All say these sessions really benefit them. They specify that this benefit first and foremost appears in terms of access to medical information and the provision of advice and strategies, as well as the feeling of not being alone with the illness, seeing that other families are facing a similar challenge and similar life situations.

Summary - The self-help group of Juba, in South Sudan, is very recent and, therefore, very unstable. It includes between 5 and 15 persons directly or indirectly affected by mental disorders. While its dynamic is slightly "stuck", it does fulfil some essential functions: on the one hand, it brings necessary information to people often distressed by their life situation, i.e. to people directly affected, as well as to their caretakers, almost always family members. On the other hand, and more broadly, it gathers people sharing similar life challenges for which there is no other meeting and expression space in Juba. At this stage, it is extremely difficult to identify true structuring and good operating factors in this group; it is even more difficult to anticipate a possible sustainable future

for the group. Indeed, this group is still very young, highly initiated and facilitated by HI's professionals, and takes place in a very institutional environment. This being so, the dynamic seems very interesting and the participants clearly expressed that they appreciated the contribution in terms of information and advice for their daily life. These observations should be contrasted with other, very diverse group dynamics, which we have defined in the course of our field mission.

Mapping the first step in the evolution of the support group studied in South Sudan

Establishment of a formal, self-help group within the framework of the management mechanism implemented by the psychiatric unit

- HI initiative, approved by the JTH director
- Group profile: peers, caregivers and users, strong institutional framework
- Objective of the group: share/exchange, receive information, collect advice and solutions
- Rather rigid operating framework
- Group only recently launched

II - SUMMARY TABLES OF THE MATERIALS STUDIED

CONFIDENTIALITY RULES ESTABLISHED FOR OBSERVATIONS AND INTERVIEWS

- Systematic request for agreement to use the words of the people interviewed or observed, specifying it would be made anonymous.
- Warning, prior to the participation of people observed or interviewed, of the fact that we cannot entirely protect these people, especially if their story reveals characteristics making them easily recognizable.
- Suggestion to help participating people formulate, at all time, requests for confidentiality during interviews and observation times; these requests would systematically be taken into account.

SUMMARY TABLE OF OBSERVATIONS CONDUCTED

In situ observation is about following actors from the support groups being researched every time we could in all their interventions, during the time they were in the field, then also following various actors in connection with the support groups. This provided opportunities for reflection on how people respond in context, i.e. "to meet them where they are, to stay with them by playing a role acceptable to them, allowing us to observe closely some of their behaviour, and to describe them in a useful manner for social sciences, while preventing any harm to the people observed."⁹³

Country	Type of involved observation (meeting location)	Date of meeting (duration)
Lebanon	Observation of the FGC centre (visit and discussion with members of the centre)	27 June (1.5h)
	Observation of the Al Buss refugee camp (visit with a member of the centre)	28 June (1.5h)
	Observation of the informal refugee camp next to the city of Tyr (visit with a social worker)	29 June (2h)

⁹³ HUGHES E.-C., (1996), *Le regard sociologique. Essais choisis*, Textes rassemblés et présentés par Jean-Michel CHAPOULIE, Paris, Editions de l'Ecole des Hautes Etudes en Sciences Sociales.

	Observation of a home visit for a female refugee, member of the support group	29 June (1h)
	Observation of patient care by an occupational therapist	2 July (30 min)
Madagascar	Observation of the Mahajanga prison (visit of all wards)	2 July (1h)
	Observation of a support group of female inmates	2 July (1h)
	Observation of a support group of male inmates sentenced to life	3 July (2h)
	Observation of the Mahajanga prison (ward dedicated to underage children)	7 July (2h)
	Observation of the Mahajanga prison (ward dedicated to underage children, Zumba group)	7 July (1h)
Togo	Observation of the Zegbé psychiatric hospital	22 September (3h)
	Observation of the Dapaong regional hospital	25 September (2h)
	Observation of the GBALENFIT Femmes group	26 September (3h)
	Observation of Bokiccemag Pentecostal prayer camp	27 September (7h)
	Observation of Dapaong MHC	28 September (2h)
	Observation of Mr IBRAHIM's intervention, community relay, at 2 patients' homes	30 September (2h)
	Observation of Mrs KPIEMAME's intervention, community relay, at 3 patients' homes	1 October (3h)
South Sudan	Observation of Juba Teaching Hospital's psychiatric ward	30 September (1.5h)
	Observation of a meeting of the Juba Youth Voice Group's members	3 October (1.5h)

	Observation of the Gabat area and home of a family with PLMHP	5 October (2h)
	Observation of the Juba Central Prison (only environment and external access)	6 October (45 min)
	Observation of life in the Kator community centre	6 October (1.5h)
	Observation of the Kator area and home of a family with PVPSM	7 October (2h)

SUMMARY TABLE OF INTERVIEWS CONDUCTED

Here, the aim was to conduct interviews with the various actors involved in the history and the development of support groups (people in charge, group founders, members of the steering/technical committees, researchers/clinicians or people who played an important role in the groups' history). To conduct these interviews, we worked with three guides: one directed towards support groups, a second one directed towards the specialists involved with these groups and a third one directed towards key informants capable of discussing mental health's socio-cultural dimensions. The point of these interviews, for three different populations, was to implement a comparative approach for each of them (based on the perception they could have about the users/beneficiaries/patients and any problematic(s) issues they might have, the group's history, the current operation of the group, the person's trajectory and the position of the person within the group, the strategies implemented in their professional practice, and other transformations of their practice generated by their connection with other institutions within their environment, such as HI. The comparisons stemming from the analysis of the interviews will allow the building of bridges between traditionally opposing knowledge fields, thus complementing one another.⁹⁴

⁹⁴ Common knowledge/scientific knowledge, local knowledge/instituted knowledge, experimental knowledge/academic knowledge, specialised knowledge/universal knowledge or, to use Michel CALLON's categories, "open-air research"/"confined research".

Country	Type of Interview (II: Individual interview GI: Group interview)	Position and title of interviewees	Date of interview
Lebanon	II	Country coordinator	26 May
	II	Project manager, MHPSS	26 May
	GI	MHPSS Team	27 May
	II	Prior HI PM, FGC	27 May
	II	Technical advisor, MHPSS	27 May
	II	Psychologist, FGC	28 May, 1 & 4 June
	II	Director, FGC	28 May
	GI	Member, People's Committee, AI Buss camp	28 May
	GI	Community workers, FGC	29 May
	II	Female member, Support Group , home interview	29 May
	II	Outreach coordinator, FGC	1 June
	GI	Facilitators, other FGC support groups	1 June
	II	Community worker, FGC	3 June
	GI	Therapeutic team, FGC	4 June
	GI	Female members, Support Group	4 June
	II	Speech therapist, FGC	4 June
II	Professor, Social Training School, Saint Joseph University	5 June	

Mada- gascar	II	Programme director, HI	29 June
	GI	Operational coordinator, HI	29 June
	GI	Project manager's assistant, HI	
	II	Mental Health project manager, RTM	30 June
	II	Priest, researcher, SeFaFi founding member	30 June
	II	Prison expert, HI	2 July
	GI	Regional director, Prison Administration	2 July
	GI	Inspector, Prison Administration, head of the Social Rehabilitation Department	
	II	Manager, Mahajanga Prison	2 July 7 July
	II	Manager, rehabilitation officers, Mahajanga Prison	2 July 4 July
	II	Nurse, Mahajanga Prison	2 July
	II	Coordinator, HI site, Mahajanga	3 July
	GI	20 inmates	3 July
	II	Inmate, GEBAPRIM president	4 July
	II	Inmate, GEBAPRIM literacy teacher	4 July
	II	Inmate, in charge of awareness raising efforts and librarian, GEBAPRIM	4 July
	II	Inmate, GEBAPRIM founder and literacy teacher	4 July
	II	Inmate, in charge of awareness raising efforts, GEBAPRIM	4 July
	II	Inmate, GEBAPRIM founding member	4 July
	II	Inmate, GEBAPRIM educator	4 July

	II	Mother of an inmate, member of GEBAPRIM	5 July
	II	Visiting physician, Mahajanga Prison	6 July
	II	Psychiatrist, Mahajanga Hospital, chief physician	6 July
	II	Officer, Catholic Prisons Chaplaincy	7 July
	II	Ex-inmate, GEBAPRIM ex-founding member	7 July
	II	Lawyer, in charge of legal follow-up/advocacy	9 July
	II	Director of Humanisation of Detention Conditions and Preparation to Social Rehabilitation	9 July
	II	Protection coordinator, ICRC	9 July
	II	Director, Ansanamasina Psychiatric Hospital	10 July
	II	Facilitators supervisor, HI	10 July
	GI	Programme director, HI	10 July
	GI	Operational coordinator, HI	
	GI	Project manager's assistant, HI	
	II	Prison administration regional director	29 July
Togo	II	Programme director, HI	20 Sep- tember
	GI	Programme director, HI	21 Sep- tember
	GI	Togo programme operational and technical coordinator, HI	
	GI	Independent artist	
	II	Supervising psychologist, HI team, Lomé	21 Sep- tember
	GI	Mental health project manager, HI	21 Sep- tember
	GI	Officer for the rehabilitation component, HI	

	GI	Facilitator, HI	
	GI	Technical advisor, Individual Psychosocial Support, HI	
	GI	Technical advisor, Economic Integration, HI	
	II	Professor and psychiatrist, Lomé Campus Teaching Hospital	22 September
	II	MHC manager, Lomé	22 September
	II	President of the Togolese Federation of Traditional Healers, Lomé	23 September
	II	Anthropology professor, Lomé University	23 September
	II	Technical advisor, Individual Psychosocial Support, HI	23 September
	GI	Member, AVL	23 September
	GI	Facilitator, AVL	
	GI	Vice-president, AVL	
	GI	Mental Health project manager, HI	25 September
	GI	Rehabilitation officer, HI	
	GI	Facilitator, HI	
	II	Facilitator, HI	25 September
	II	Clinician psychologist, Regional Hospital, Dapaong	25 September
	II	MHC manager, Dapaong	25 September 28 September

	GI	President, GBALENFIT Femmes	25 September
	GI	Treasurer, GBALENFIT Femmes	
	GI	Secretary, GBALENFIT Femmes	
	GI	MHC sociologist, Lomé	
	GI	President, GBALENFIT Hommes	26 September
	GI	Treasurer, GBALENFIT Hommes	
	GI	Secretary, GBALENFIT Hommes	
	II	Rehabilitation officer, HI	28 September
	II	Member, GBALENFIT Femmes	28 September
	II	Occupational therapy manager	28 September
	II	Secretary, GBALENFIT Femmes	29 September
	II	Treasurer, GBALENFIT Femmes	29 September
	II	President, GBALENFIT Femmes	29 September
	II	Member, GBALENFIT Femmes	29 September
	GI	Community Relay, Dapaong MHC	30 September
	GI	Community Relay, Dapaong MHC	
	GI	Community Relay, Dapaong MHC	
	GI	Community Relay, Dapaong MHC	
	II	Director, ENVOL Association, Dapaong	1 October

	GI	Programme director, HI	3 October
	GI	Togo Programme operational and technical coordinator, HI	
	GI	Independent artist	
	GI	Mental health project manager, HI	
	II	Member, Advocacy France	9 October
	II	Programme coordinator, Touching Minds, Raising Dignity, HI	14 October
	II	Programmes officer, HI	15 October
South Sudan	GI	MHPSS team, HI (1)	29 September
	II	Project manager, MHPSS, HI	29 September
	II	Juba Youth Voice Group	30 September
	II	Nurse, JTH Psychiatric Ward	30 September
	II	Psychiatric chief physician, JTH	30 September
	GI	Women's Health Group	1 October
	II	Head of household with 1 PLMHP	1 October
	II	Traditional healer	1 October
	GI	Equatoria Youth Association for Peace and Dev. Programme	1 October
	II	MHPSS Team (each member)	2 October
	GI	Juba Youth Voice Group	3 October

	II	Project manager, MHPSS, HI (2)	5 October
	II	Programme manager, HI	5 October
	GI	Family with 2 PLMHP	5 October
	II	Psychiatric nurse, Juba Central Prison	6 October
	II	Head of department, Rural and Community Studies, Juba University	6 October
	II	General secretary, Kator area	6 October
	GI	Family with 1 PLMHP	7 October
	GI	Support Group, JTH	7 October
	II	Pentecostal pastor	7 October
	II	Mental health coordinator, IMC	7 October
		Programme manager and coordinator, HI	9 October

SUMMARY TABLE OF REFERENCE DOCUMENTS REVIEWED

This refers to a review of all reference documents on which the various HI proponents agree and to which they commit: everything the specialists consider important (registries of meeting reports, projects, theoretical reference books and articles, laws and regulations, public action and humanitarian aid reports).

Regarding these reference documents, the aim was to proceed systematically to an analysis of the themes covered in these documents: the list of themes drafted by successive iterations, content analysis, for example occurrences of certain principles or ideas.

The aim was also to create files for each country in order to gather the main information surrounding support groups "practices on a meso and macro level".

However, these various treatments remain incomplete, as the richness of these documents could have led us to conduct a content analysis through a text analysis or other methods, but we limited ourselves to conduct this work on those that seemed the most relevant to us, in order to respond to the questions we were raising. We therefore gave priority to ways in which we could use verbal testimonies to crossmatch, complete and clarify reference documents.

These forms of data collection are complementary in that interviews related to the memory of the persons, with its selectiveness and incompleteness. Actors interviewed reconstructed their story, narrating it based on their values and interests. In contrast, reference documents lead to an identification of the standards and values of the institution, the ways the actors argue, justify themselves, debate, and invent procedures and processes that we placed at the heart of our understanding and analysis.

A reference document review and a literature review were very minimal before the field study, in order to avoid influencing observations and the conduct of interviews which, at that stage, was intended to remain rather free of all pre-conceived ideas and assumptions which would affect reflection. The minimal review simply aimed at providing information on a few ideas that are necessary to understand adequately the socio-cultural environment in which research was to be conducted in the various fields.

Framework documents
"Santé mentale en contextes de post-crise et de développement", DRT, April 2011
Guidance note "La recherche à Handicap International", DRT, February 2014
The Disability Production Process
"Appui aux organisations représentatives de personnes handicapées", DRT, 2011
Methodological guides
"Intervention psychosociales et de santé mentale en contextes d'urgence et de post-crise", DRT, June 2013
Methodological guide: "Interventions psychosociales en milieu carcéral", Madagascar programme, 2013
"Les groupes de parole en prison", Madagascar, 2010
"Accompagnement à la vie affective et sexuelle, Guide pratique pour l'animation des groupes de parole", Handicap International France, 2007
"Les droits des détenus: méthodologie et outils de sensibilisation, le guide de l'animateur", Madagascar, 2010
"Accompagnement social personnalisé", Guide for field teams, DRT, 2009
"Le processus d'analyse de la pérennité: l'exemple de la réadaptation fonctionnelle", DRT, 2012

"Renforcement des capacités et relation partenariale : enjeux, modalités et outils", DRT, 2008

Research and studies

"Conditions de vie carcérale et détresse psychologique des personnes détenues", Madagascar, 2012

"Enhanced psychological care services for Palestinian refugee children and adolescents living in Buss camp, Lebanon", 2010

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III - METHODOLOGY TOOLBOX

INTERVIEW GRID 1 - FOR THE SUPPORT GROUPS' MEMBERS

Question No 1: Can you tell me how you came to be in this support group?

Question No2: Can you tell us what this support group does for you?

[Provide details if necessary, but not systematically on the following categories:]

- Living conditions, current situation
- Representation of mental health problems
- Perceived input from the support group
- Feeling of achievement and self-esteem, capacity to deal with the mental health problems
- Future life prospects
- Level of participation in support groups (decision-making bodies, design/planning, establishment/evaluation)
- Engagement in social and civic (community) life
- Interactions (based on the five types of social participation) with local authorities (mayors, village health/development committees), services specialised in mental health (including HI)
- Point of view, prospects

INTERVIEW GRID 2 - FOR THE SPECIALISTS AND FIRST LINE CARETAKERS ASSOCIATED WITH THE SUPPORT GROUPS

Question No 1: Can you tell me what is your connection with this support group?

Question No 2: How did this connection evolve?

[Provide details if necessary, but not systematically on the following categories:]

- History of organisation's emergence, organisational, governance and structuring
- Involvement in the mental health field with other actors (role, relationship with other actors in the disability, social, mental health, protection, etc. fields)
- Goals, resources, realisations and results
- Successes, challenges, constraints, etc.
- Points of view and prospects based on the study's assumptions

INTERVIEW GRID 3 - FOR CULTURAL AND MEDICAL EXPERTS, SOCIAL ANTHROPOLOGISTS, SOCIOLOGISTS AND OTHER SOCIOCULTURAL EXPERTS OR KEY INFORMANTS

Question No 1: What are the main concerns, beliefs and cultural issues to take into account when working in the field of mental health?

Question No 2: Which actions should be avoided?

[Provide details if necessary, but not systematically on the following categories:]

- Local ways of describing emotional challenges
- Existing resources to tackle emotional challenges
- Relationships between genders, relationships in connection with age
- Local power structures (e.g. local ranking system based on kinship, age, gender, knowledge in the field of the supernatural)
- Political situation (e.g. issues of preferential treatment, corruption, instability)
- Interactions with the various social groups (e.g. ethnic and religious groups)
- Socially vulnerable or marginalised groups
- Prior challenges or bad experiences with organisations working in the mental health field
- Acceptation of services provided by individuals who do not belong to the community
- Any other thing that organisations working in the mental health field should know

INTERVIEW GRID 4 - FOR DONORS, UNITED NATIONS AGENCIES, INGOS (INCLUDING HI)

Question No 1: Can you tell me what is your connection with this support group?

[Provide details if necessary, but not systematically on the following categories:]

- Global context (challenges, problematics, priorities...)
- Involvement in the mental health field
- Logic of intervention on this theme
- Existing connections with CSOs and support groups
- Resources, realisations and results
- Successes, challenges, constraints, etc.
- Points of view and prospects based on the study's assumptions

INTERVIEW GRID 5 - FOR STATE AND INSTITUTIONAL ACTORS

Question No 1: Can you tell me what is your connection with this support group?

[Provide details if necessary, but not systematically on the following categories:]

- Global context (challenges, problematics, priorities...)
- Implications, public policies (CRDP, Mental Health Plan), strategy, organisation and governance in terms of mental health (community mental health, Mh Gap programme, connections with possible emergency actions and international organisations rolling out these actions, etc.)
- Points of view and prospects on the study's assumptions

OBSERVATION GRID - ENVIRONMENT IN WHICH SUPPORT GROUPS FIND THEMSELVES

Physical environment of the prison, camp, living place:

- Location of the camp, building, locale within the city, the village, etc.
- Global state of the camp, building, place of life
- Spaces, traffic, private and public spaces "inside" and "outside" perceived spaces
- Places of life accessibility

Social environment of the prison, camp, living place:

- Social environment around the prison, the camp, the living place: city, village, community
- Global social organization within the camp, prison or place of life
- Place of dominance, respect, etc.
- Explicit, implicit ranking systems
- Respect for culture, language, gender
- Relationships between men and women
- Daily rhythm, activities, occupations
- Habits, rituals, meanings and signification, etc.

Basic physical needs:

- Access to water, hygiene and sanitation
- Adequacy of nutritional needs
- Living conditions (spaces, heating, sleeping arrangements, safety)
- Access to health care
- Access to services

Mental health care:

- Access to mental health care (including practices, access to medicines, access to individual and group mechanisms, to rehabilitation care, etc.)
- Composition and qualification of health care staff

Protection questions:

- Gender respect
- Abuse, confinement, exclusion
- Information rights
- Contention, movement restrictions
- Physical, verbal and sexual violence
- Respect for rights, visits, contacts with the outside world
- Judicial systems, confidentiality, transparency of procedures

OBSERVATION GRID - SUPPORT GROUPS**Structuring**

Framework: rhythm, prior information, scope of content, predefined roles, explicit ranking system

Composition: number, age, men/women ratio

Arrangement: hosting venue, spatial division of participants

Relationships content

Expressed relational content (speech content): invite, story, questions, suggestions and proposals, reformulations, formalisations, interpellations, decision-making, etc.

Observed relationships (body language): tone, attitudes, gestures, looks, etc.

Typology of observed relationships

Exchange dynamic: typology (ascending, descending, chain, radiating, free), rhythm/levels (words/silence rate, exchange density, level of participation, inclusion/exclusion)

Positive demonstrations: smiles, laughs, empathy, complicity

Negative demonstrations: sadness, cries, screams, embarrassment, aggression, disdain, disagreement

Other types of demonstration: domination/submission, demonstration of authority, (dis)obedience, (dis)respect, scope, transfers, projections, etc.

The research is organized based on three main phases:

- 1) A phase dedicated to the scope and preparation of the study phase to establish the best congruence possible between HI and the consultants, through better framing of the study, specifications regarding questions, methodology and development of common tools
- 2) An observation phase in the four countries included in the programme (two per consultant), also including sharing of first observations/analyses
- 3) A phase of analysis and exchange concluded by the feedback on work delivery.

These various phases are described in further details below, especially regarding the goals, methods and tools used, as well as deliverables.

PHASE 1/ SCOPE AND PREPARATION OF THE STUDY

- Establish a steering committee for the study
- Clarify the goals, stakes and expectations related to the study project
- Adjust and validate the suggested methodology (including the field visits schedule)
- Collect and analyse key documents (reference documents review)
- Develop observation and analysis tools common to all countries
- Prepare the technical workshop to be held in January in Lebanon.

PHASE 2/ FIELD OBSERVATIONS: LEBANON, TOGO, MADAGASCAR AND SOUTH SUDAN

- On each of the fields of study, obtain a set of consolidated, good quality observations with the view to producing an analysis and conclusions that respond in a satisfactory manner to the research question
- Provide a mid-term review (after two field missions) with the steering committee, and identify adjustments to be made during collection
- At the end of the two observation phases, provide feedback on the prior content and gather the feelings of the teams and steering committee: validate the data collected and the first conclusions of the study, challenges, gaps, etc.

PHASE 3/ ANALYSIS AND DISCUSSION

- Conduct and facilitate the consolidation process for the observations, by highlighting and presenting the steering committee with the first discussions, in order to validate key analyses together
- Draft a preliminary version of the report (draft report) based on discussions between the consultant and the steering committee
- Editing by the relevant HI specialists, final discussions with HI and the research project actors
- Draft the final version of the research report and annexes (based on observations and comments from the steering committee)
- Validation of final report.



Emergence and structuring of support groups for people living with mental health problems in Togo, Madagascar, Lebanon and South Sudan

This study, based on an ethnographic type, focuses on four support groups for people living with mental health problems, evolving in various contexts (prisons, hospitals, refugee camps and mental health centres) in Madagascar, Lebanon, South Sudan and Togo.

The study identifies four dynamics contributing to the emergence and the structuring of these groups: survive, get medical care, get organised, advocate.

The analysis of the results produced by the research highlights the fact that strategies supporting the emergence and structuring of mental health support groups in developing countries should rest on four essential questions. Firstly, we should ask which partner(s) should be given priority in the project and which partner institutions should be selected - traditional, religious, or national? Related, what do we mean by leading institutions in a developing country, and how and on whom should we rely locally to carry through a decision to participate (on behalf of individuals, families and communities)? Secondly, we should question relationships between the members of a support group and their institutions, especially in terms of power. Thirdly, is the need to take into account the subjective challenge associated with the mental health problem, especially through institutional reflection pertaining to "the extent to which support groups should be re-empowered, how best to support the empowerment process, both at the level of the group and of the individuals (personalities) constituting the group?" Finally, is the need to provide a strong knowledge management policy, first and foremost focused on the collective ownership of a mental health policy, shared by all actors involved.

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