Mental health support groups: From individual suffering to forming a collective of users

Touching Minds, Raising Dignity programme
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Mental health support groups: From individual suffering to forming a collective of users

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“The psychological need that draws people into encounter groups... is a hunger for relationships which are close and real; in which feelings and emotions can be spontaneously expressed without first being carefully censored or bottled up”.

Carl Rogers (1970:11)
Executive summary

Since 2014 Handicap International (HI) has been leading a mental health/psychosocial support programme in four countries in crisis or post-crisis (Togo, Madagascar, Lebanon, South Sudan), namely, the “Touching Minds, Raising Dignity” (TMRD) programme. The overall objective of this programme is to improve the social and civil participation of people living with mental health problems.

The programme comprises a cross-cutting component common to the four countries of implementation. This cross-cutting component includes a research phase followed by a knowledge capitalisation phase aimed at analysing and better understanding the group as a medium of support but also as a key element for improving social participation, representative capacitation, and the advocacy skills of those making use of mental health services.

Linked to and following from the research phase carried out in 2015 into issues related to the emergence and the structuring of support groups (HI, 2016), the current phase of consolidation throughout 2017 enabled the identification of key elements and potential factors that would clarify what constitutes appropriate assistance to support groups throughout their lifespan.

The induction of a support group is a key moment arising from the common will of three groupings: the users, the professionals, and members of the hosting facility. The support group that then emerges constitutes a fourth entity, comparable to a service provider, initially playing a therapeutic role but then quickly taking on a more important mediating function that affects various aspects of the lives of the users of the particular mental health service.

This evolution occurs at various life stages of a group: initially it is focused on the immediate matter of survival; thereafter the group serves a therapeutic role by helping its members heal. The group then transcends its internal dynamics in order better to organize itself. Collectively its members are then in a position to give attention to external issues, such as advocacy, activism of a more political nature or the development of income generating activities (IGAs).

The professionals supporting the group must therefore guarantee a stable framework from the start (clear rules, a facilitator, suitable venue for meetings, etc.), while relying upon local existing sociocultural dynamics that favour sharing (e.g. traditional customs and ways in which people from the community come together).

More broadly, this reflective phase confirms the importance of the groundwork of all concerned: the professionals, members of the host institution and relevant NGO. All those supporting the process need to work together and pay regular attention to the evolving group that they are supporting. They must for instance identify and mentor (an) ethical leader(s), but also anticipate any organisational challenges that may arise specific to persons living with mental health problems, as well as the power dynamic that develops within the collective. Finally, the project once again underlines the need for accurate record-keeping that captures the experiences of those involved in each project, and which will then become a source of learning, appropriate adaptations and the transfer of good practice.
Introduction

Those living with mental health problems on a daily basis or who have a relative with mental health problems can find life very challenging. This challenge is compounded for those living in developing countries and even more so in countries in crisis.

In unstructured contexts where services dedicated to mental health are seldom diversified and generally incomplete, there are very few healthcare professionals, and access to information is almost invariably very limited. Moreover, the situation is aggravated by the often erroneous and strongly negative perceptions people have of mental illnesses, which are deeply rooted in the public imagination. Consequently, people living with mental health problems as well as their parents and their close relatives suffer from an additional psychic pain. This is the result of often chaotic treatment pathways, stigmatization and social isolation phenomena, as well as a deep feeling of guilt arising from their inability to return to a more balanced life. In order to overcome these deficiencies and difficulties, the support group offers a mechanism that is simple and easy to roll out in a large variety of contexts, thus representing an initial solution. The support group constellates users and professionals around common goals and thereby constituting one of the essential steps that enable people living with a mental illness as well as their parents and other close relatives to deal with these challenges together.

But how does a support group structure itself and function? What are the dynamics at play? Are the organisation and ways of functioning of these groups strongly influenced by sociocultural elements? What are the key processes that one can identify at various stages and that can predict the success of a group and would be interesting to support and strengthen?

These are the various aspects explored during the knowledge capitalisation phase. These are inseparably part of the research work that preceded it (2015), and which focused on four types of support groups in Lebanon, Togo, Madagascar and South Sudan.

This knowledge capitalisation document comprises four sections. The first section outlines the methodological framework: what is a support group, which actors come into play in the support groups they represent and what are the expected results. The second and third sections discuss the success factors observed during this programme that throw light on issue surrounding the formation of the groups and their organization. Lastly, the fourth section presents the key success factors that the HI teams must adopt to enable them to define their role and to address the ethical and political challenges flowing from their support of these groups.

This document is not a manual of good practice but a compilation of the knowledge derived from experiences gained through the TMRD programme for those wishing to develop this type of programme in other contexts.
Context, stakes and methodology adopted during the knowledge capitalisation phase

1

Context and challenges of the knowledge capitalisation process

Within the framework of its implementation in the field of mental health, HI has committed itself to promoting the social and civil participation of people living with mental health problems. The goal is to enable them to recover fully their capacity to live in their environment with dignity. To this end, HI has developed an intervention model whereby work is first undertaken with people suffering from psychiatric disorders. These people then receive support on how to "live together", and attain a "good enough" state of mental health, i.e. "the capacity of living with oneself and others (...)". At its core the process aims to enhance social participation, but one can also see strong links with challenges relating to quality of life and empowerment.¹

HI supports the individual and his or her community via two major yet common techniques, namely, personal interviews and support groups. HI can therefore operate at the individual, familial and collective levels. Although these techniques are central to the field of mental health and psychosocial support, they however have to be redefined constantly according to their implementation contexts. In fact, any intervention in the field of mental health or psychosocial support is a translation activity that is informed by cultural, sociological and political dimensions. These interventions must thus be analysed in greater depth and documented so that they can be developed and serve as a source of inspiration for other HI teams, local partners or promoted at a more global level.

Objectives of the knowledge capitalisation process

These objectives are three-fold:

- Better to understand the dynamics of support groups
- Better to understand the place of the support group as a key element of improved mental health
- To access methodological resources that are experience-based in order better to support the groups.

2

The framework of the Touching Minds, Raising Dignity programme

This knowledge capitalization process fits within the framework of the programme “Touching Minds, Raising Dignity (TMRD): putting an end to the social condemnation of people living with mental health disorders in four countries in crisis and post-crisis situations”² developed by HI for the period 2014-2017.

The overall objective of this programme is to enhance the social and civil participation of people living with mental health problems in four countries in crisis or post-crisis (Togo, Madagascar, Lebanon, South Sudan). These four countries all have chronic social, economic and political crises in common, resulting in precarious socio-sanitary conditions that put a strain on the public infrastructure, thus undermining everyone’s capacity for “living together”, an aspect critical to the development of a nation.
HI’s approach with regards to mental health is primarily focused at the community level. At the individual level, however, it aims at preventing the risks of severe psychopathological collapse and, at a community level, to generate a new dynamism that will lead to solidarity and mutual support, both of which are guarantors of social cohesion sufficiently protective of individual mental health (HI, 2012b).

The knowledge capitalisation phase was conceived as a learning process spanning several years:

**Step 1:**
Socio-anthropological research carried out in the four countries, which looked at the inception and the establishment of informal or formal groups supporting people living with mental health problems. This research was the subject of a publication and a summary (HI, 2016).

**Step 2:**
On the basis of the results and recommendations stemming from the study, assistance provided to HI teams on how to mentor the support groups being piloted.

**Step 3:**
Compilation of a knowledge capitalisation document focusing on understanding the inception and establishment of these groups and on how to make them sustainable.

**Step 4:**
Compilation of a practical guide on how to mentor groups providing mental health and psychosocial support.

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The current document is thus the product of the third step and is aimed at ensuring continuity from the first and second steps already implemented. The principal findings stemming from the first two stages of this process are listed hereafter.

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### 3 Presentation of the study areas

The knowledge capitalisation process focused on the experience of four groups in four different countries. There is little similarity in how these groups formed in their respective countries. These include the Family Guidance Centre (FGC) established in Lebanon, the GEBAPRIM group in Madagascar, the GBALENFIT group in Togo and the groups from the Juba Teaching Hospital (JTH) and the Juba Central Prison (JCP) in South Sudan (as well as community-based groups in Juba).
Descriptions of the support groups in the four focus countries

**FGC**
- **Structure**: Initiated in 2015, South Sudan, JTH, JCP, Juba neighbourhoods
- **Type**: Self-help group
- **Aim**: People living with mental health problems and their families
  - Information, sensitization
  - Sharing life situations, mutual support

**GEBAPRIM**
- **Structure**: Initiated in 2008, Madagascar, Mahajanga, Marafato Prison
- **Type**: Support group
- **Aim**: Prison inmates
  - Improving prison practices
  - Rehabilitation

**JTH/JCP and the communities**
- **Structure**: Initiated in 2015, South Sudan, JTH, JCP, Juba neighbourhoods
- **Type**: Self-help group
- **Aim**: People living with mental health problems and their families
  - Information, sensitization
  - Sharing life situations, mutual support

**GBALENFIT**
- **Structure**: Initiated in 2008, Togo, Dapaong, Mental Health Centre
- **Type**: Support group, sensitization, IGAs
- **Aim**: Women living with a mental health problem
  - Improving the living conditions of people living with mental health problems and that of their families
### Characteristics of the support groups in the four focus countries

<table>
<thead>
<tr>
<th>Name of the support groups</th>
<th>Lebanon</th>
<th>Madagascar</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support group for mothers of autistic children</td>
<td><strong>GEBAPRIM</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Locale</strong></td>
<td>El-Buss (Tyr) Palestinian camps</td>
<td>Mahajanga</td>
</tr>
<tr>
<td><strong>Group affiliation</strong></td>
<td>Beit Atfal Assumoud Association</td>
<td>Marafato Prison</td>
</tr>
<tr>
<td><strong>Objective</strong></td>
<td>To play a part in improving the living conditions of families living with a child affected by an autistic disorder</td>
<td>To take part in the humanization of prison practices and the social rehabilitation of prison inmates</td>
</tr>
<tr>
<td><strong>Observations that led to the creation of the group</strong></td>
<td>Late detection of the disorder and a diagnosis that is misunderstood by the families; significant discrimination by the families themselves and their relatives; suffering and feelings of exclusion felt by parents; failure of the parental function</td>
<td>Prison characterized by extremely difficult living conditions, which lead to various mental health problems; significant stigmatization of ex-prisoners on return to their respective communities</td>
</tr>
<tr>
<td><strong>Profile of participants (size of the group)</strong></td>
<td>Mothers (Lebanese, Syrian, Palestinian) of children affected by autistic disorders (&gt;10)</td>
<td>Prison inmates comprising men, women and minors accused and condemned (between six months and 15 years) (&gt;30)</td>
</tr>
<tr>
<td><strong>Contributors</strong></td>
<td>Professionals (psychiatrist and psychologists, Lebanese and Palestinian)</td>
<td>Professionals (specialized educators and prison guards)</td>
</tr>
<tr>
<td><strong>Criteria for forming part of the group</strong></td>
<td>Mother with a child affected by autistic disorders</td>
<td>“Exemplary” behaviour in prison</td>
</tr>
<tr>
<td><strong>Frequency</strong></td>
<td>Two hours per month</td>
<td>Every day</td>
</tr>
<tr>
<td><strong>Activities</strong></td>
<td>Facilitation of a support group</td>
<td>Organization of activities geared towards education, professional training, leisure and access to rights</td>
</tr>
<tr>
<td><strong>Funding</strong></td>
<td>Beit Atfal Assumoud Association</td>
<td>Penitentiary administration, HI and various civil society organisations (CSOs) intervening in the prison</td>
</tr>
<tr>
<td><strong>Inception</strong></td>
<td>2010</td>
<td>2008</td>
</tr>
<tr>
<td><strong>Nature and duration of the support provided by HI</strong></td>
<td>Collaboration since 2010 (technical and financial support, advice and training)</td>
<td>Collaboration since 2014 (technical and financial support, advice and training)</td>
</tr>
<tr>
<td>Characteristics of the support groups in the four focus countries</td>
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<td></td>
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<tr>
<td><strong>Togo</strong></td>
<td><strong>South Sudan</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Name of the support groups</strong></td>
<td>Various mental health support groups</td>
<td></td>
</tr>
<tr>
<td>GBALENFIT</td>
<td>Juba</td>
<td></td>
</tr>
<tr>
<td>Mental Health Centre (MHC) - Dapaong</td>
<td>Juba Teaching Hospital, Juba Central Prison, the Communities of Juba</td>
<td></td>
</tr>
<tr>
<td>Yendubé Association, congregation of the Sœurs Hospitalières du Sacré Cœur de Jésus [Sisters of Mercy of Jesus's Holy Heart]</td>
<td>To provide information about illnesses and treatments and to share life experiences</td>
<td></td>
</tr>
<tr>
<td><strong>Locale</strong></td>
<td><strong>Group affiliation</strong></td>
<td></td>
</tr>
<tr>
<td>El-Buss (Tyr) Palestinian camps Mahajanga Mental Health Centre (MHC) - Dapaong Juba</td>
<td>Beit Atfal Assumoud Association Marafato Prison Yendubé Association, congregation of the Sœurs Hospitalières du Sacré Cœur de Jésus [Sisters of Mercy of Jesus's Holy Heart] Juba Teaching Hospital, Juba Central Prison, the Communities of Juba</td>
<td></td>
</tr>
<tr>
<td><strong>Objective</strong></td>
<td><strong>Observations that led to the creation of the group</strong></td>
<td></td>
</tr>
<tr>
<td>To play a part in the improvement of the living conditions of families affected by a mental health problem</td>
<td>Late detection of the disorder and a diagnosis that is misunderstood by the families; significant discrimination by the families themselves and their relatives; suffering and feelings of exclusion felt by parents; failure of the parental function</td>
<td></td>
</tr>
<tr>
<td>To take part in the humanization of prison practices and the social rehabilitation of prison inmates</td>
<td>Prison characterized by extremely difficult living conditions, which lead to various mental health problems; significant stigmatization of ex-prisoners on return to their respective communities</td>
<td></td>
</tr>
<tr>
<td>To play a part in the improvement of the living conditions of families affected by a mental health problem</td>
<td>Ostracism of the sick and their families by the community; poverty of families affected by a mental health problem</td>
<td></td>
</tr>
<tr>
<td>To provide information about illnesses and treatments and to share life experiences</td>
<td>Lack of understanding about mental disorders and related treatments, and how these disorders develop</td>
<td></td>
</tr>
<tr>
<td><strong>Profile of participants</strong></td>
<td><strong>Contributors</strong></td>
<td></td>
</tr>
<tr>
<td>Mothers (Lebanese, Syrian, Palestinian) of children affected by autistic disorders (&gt;10)</td>
<td>Professionals (psychiatrist and psychologists, Lebanese and Palestinian)</td>
<td></td>
</tr>
<tr>
<td>Prison inmates comprising men, women and minors accused and condemned (between six months and 15 years) (&gt;30)</td>
<td>Professionals (specialized educators and prison guards)</td>
<td></td>
</tr>
<tr>
<td>Women living with a mental health problem that has stabilized or mothers of a child affected by a mental health problem (&gt;10)</td>
<td>Sister (director of the centre) Psychiatrist, HI facilitators and members of civil society associations</td>
<td></td>
</tr>
<tr>
<td>People living with a mental health problem or members of their family (&gt;15)</td>
<td>Stabilized medical condition, cured or with a child who is sick</td>
<td></td>
</tr>
<tr>
<td><strong>People living with a mental health problem or members of their family (&gt;15)</strong></td>
<td>Hospitalised patient who has been stabilized or with a family member who is sick</td>
<td></td>
</tr>
<tr>
<td><strong>Contributors</strong></td>
<td><strong>Frequency</strong></td>
<td></td>
</tr>
<tr>
<td>Sister (director of the centre) Psychiatrist, HI facilitators and members of civil society associations</td>
<td><strong>Half a day per month</strong></td>
<td></td>
</tr>
<tr>
<td>Stabilized medical condition, cured or with a child who is sick</td>
<td>Half a day per month</td>
<td></td>
</tr>
<tr>
<td><strong>Facilitation of a support group, organization of awareness raising activities in the community, organization of IGAs</strong></td>
<td>Facilitation of a support group</td>
<td></td>
</tr>
<tr>
<td>Hospitalised patient who has been stabilized or with a family member who is sick</td>
<td>Every fortnight</td>
<td></td>
</tr>
<tr>
<td><strong>Facilitation of a support group, organization of awareness raising activities in the community, organization of IGAs</strong></td>
<td><strong>Funding</strong></td>
<td></td>
</tr>
<tr>
<td>Church congregations, private donations, HI</td>
<td>Beit Atfal Assumoud Association Penitentiary administration, HI and various civil society organisations</td>
<td></td>
</tr>
<tr>
<td>Church congregations, private donations, HI</td>
<td>Church congregations, private donations, HI</td>
<td></td>
</tr>
<tr>
<td><strong>Inception</strong></td>
<td><strong>Nature and duration of the support provided by HI</strong></td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>Collaboration since 2010 (technical and financial support, advice and training)</td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td>Collaboration since 2014 (technical and financial support, advice and training)</td>
<td></td>
</tr>
<tr>
<td>2015 (JTH, JCP), 2016 (communities)</td>
<td><strong>Collaboration since 2015 (technical and financial support, advice and training)</strong></td>
<td></td>
</tr>
</tbody>
</table>

**Table**: The table outlines the characteristics of support groups in four focus countries: Lebanon, Madagascar, Togo, and South Sudan. It includes the name of the support groups, their affiliations, objectives, and other relevant details such as group composition, funding sources, and the nature and duration of support provided by HI (Institution for International Cooperation in Development).
Two key concepts that underlie the TMRD programme: Participation and empowerment

Historically, alternatives to psychiatric models (institutional psychotherapy, deinstitutionalization) came from professionals who were often activists critical of institutions that could potentially ill-treat patients through coercion, alienation or the exploitation of the carer-patient relationship. Despite severe criticism by certain professionals in some countries (for example France or Italy), very little recognition was given to what patients had to say in the public space. In contrast, today we are witnessing the emergence of a new dynamic, which signals a more collaborative culture whereby patients and professional seek to share the joint aim of caring and helping patients to re-learn how to live in society. Alongside any attempted hijacking of the process by psychiatrists or, more broadly, those from the mental health sector, are those patients who demand that their unique relationship with the world be acknowledged.

Participation and empowerment are key concepts, strongly underpinning this new dynamic whereby professionals assist people suffering from mental disorders to move towards new ways of relating and of being. These two concepts also underpin HI’s mentoring approach to group support.

Participation

For HI, participation implies the active engagement of those concerned in the design, implementation, monitoring and evaluation of the services or policies that impact upon them.

Participative approaches are characterized by:

- Their involvement at all stages of programming, implementation and the monitoring of a project
- Ceding the highest degree of autonomy given the contexts (from simple consultation to joint decision-making)
- Individual and/or collective participation

Empowerment

Empowerment typically comprises two dimensions: power, derived from the root meaning of the word, and learning put in motion to achieve this power. Empowerment can thus refer to a state (to be empowered) as much as to a process (gaining power). The term, which is difficult to translate into French, is quintessentially polysemous. It can be used at the individual, collective or even political level. At any rate, it refers to a transformative approach (Bacqué & Biewener, 2013) leading to a modification in the balance of power with the aim of
greater autonomy. The concept more readily speaks to the strengthening of individual and community assets, rather than emphasizing any possible deficiencies and weaknesses.

The declaration of the World Health Organisation (WHO, 2010) on the empowerment of the users of mental health services defines the concept of empowerment in the following way: “Empowerment refers to the level of choice, influence and control that users of mental health services can exercise over events in their lives”. The Declaration also states that: “The key to empowerment is the removal of formal or informal barriers and the transformation of power relations between individuals, communities, services and governments” (WHO, 2010:2).

There has been much written about the relationship between the individual and society in the Western world. We can, for example, consider the work of many Western actors in the field of international aid, and that of mental health specialists on how to empower people living with mental health problems, and how to empower their helpers.4

Linkages between these two concepts

As we can see, the concept of empowerment primarily refers to the transformation of power and of autonomy, and the concept of participation in voluntary and sustained involvement. These two concepts are being evoked primarily as a means to contrast two populations that can typically be identified as the “people from below” (those who possess grounded, experiential, intimate knowledge) and the “people from above” (who possess professional and institutional knowledge, and who are normally authoritative and direct the action). In the field of mental health and more generally in the development field, one can categorise the “people from below” as the users and the beneficiaries (individuals, groups) and the “people from above” as representatives of institutions and the NGO.

One can then see how the two terms interact in a more concrete way. Put simply, participation represents one of the privileged processes that through a gradual and purposeful evolution of the practices existing between the “people from above” and the “people from below”, permits a redefinition of the roles and power relations, by granting the “people from below” the power to make decisions about what affects them thereby contributing to their own ultimate empowerment (Bresson, 2014). The individual can then become the agent of his or her economic, professional, familial and social destiny whilst more or less actively contributing to social life. In this Western model depicting the relationship between the individual and society and captured by the principles informing the Ottawa Charter for Health Promotion5, the articulation of these two concepts comes with a double imperative difficult to fulfil, as it holds out the possibility of co-developing a joint project between the beneficiaries and the institution, against the requirement that power be transferred from those “above” to those “below”.

In fact, a number of organisations representing people who consider themselves affected by a mental health problem have been created. For some, this has been done in order to advocate for provisioning that would allow them to access services generally offered by mental health professionals. But others were established with the aim of providing these themselves for the benefit of their peers. For example, the Global Network of the Users and Survivors of Psychiatry clearly sets itself the goal: “To release all our people from institutions […] and to provide a broad range of services developed in consultation with organizations survivors/users, and who include peer support, the crises hostels, places of safe respite, and advocacy”.

These various initiatives clearly explain the unique relationships they have entered into with the institutions that support their vision or those they oppose. A recent article published by Troisœufs & Eyraud (2015) accurately underlines this tension by exploring four types of groups each of which approaches institutionalization differently, and therefore has differing expectations or grievances.
### Mapping the various forms of participation in the field of mental health

<table>
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<th>Self-help groups</th>
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<td>Sharing experiences of disorders, and of caring</td>
<td>Organizing a strong opposition to therapies that members must undergo</td>
<td>Engaging in public action through the medium of negotiation</td>
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<td><strong>Relation to the institution</strong></td>
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As we can see by reading this table, a degree of tension exists in the manner in which these various groups interact with, on the one hand, a request for recognition coming from the users with respect to their life in the institution and a request that they be permitted to participate in the development of the healthcare systems in so far as it affects them and, on the other hand, a request for freedom and the recognition of their life experiences – demands that don’t traditionally inform psychiatric approaches to treatment.

All these relationships with the institution and suggestions for alternatives to medical treatment or about the way in which each individual can re-learn living in society are long-term, often spanning several years. In the context of interventions carried out by NGOs, lengthy interventions have to contend with multiple organisational and personal problems - sociocultural, economic or political. The issue of the sustainability of any action then also becomes the concern of the mental health practitioners who are working participatively with the view to the empowerment of people living with mental health problems.
An issue to be debated: Sustainability

The issue of sustainability matters to all the actors involved in developmental work. It constitutes both a final objective but also an essential justification for their actions. Even in the context of emergencies, humanitarian actors attempt to lever those determinants that in the long term, will optimize the organization and the quality of services, and more broadly ensure lasting results from a project, even after its termination. When it comes to the field of mental health, sustainability can be construed in different ways: as a relatively sound state of mental health for the beneficiaries as a result of the project’s interventions (outcome), as the organizational protocols and financial capacity of support groups (project systems), in terms of partner institutions (services), as the approaches developed through the training offered to the local professionals (know-how), etc. However, no matter the nature of the sustainability in question, each and every one of the participants, starting with HI, is aware that a sustainable action is by definition organic and flexible, and that the manner in which its effects will last is sometimes very different from what might originally have been intended.7

As a matter of fact, if one considers a mechanism such as a support group, sustainability doesn’t necessarily constitute an injunction or a compulsory aim. It is nonetheless important in the context of the present knowledge capitalisation process to seek to understand whether the issue of sustainability is also on the minds of the members of the support groups, and, if so, what external influence(s) led to their decision to factor sustainability into their planning and how, in each case, they intend ensuring their group’s sustainability.
Part 1: The support group: Definition, participants and positive effects

1 How can one define a support group?

Many groupings of people can be labelled as «support groups»: self-help groups, support groups, focus groups, groups structured around an activity or a project, etc. These groups can be formal or not, formally recognised by the authorities or not, more or less organised and independent of the institutions from which they stemmed.

Over 25 years ago, Romeder et al. (1989) defined support groups as a space where “members, who are victims of a common crisis or upheaval in their lives, share their experience of suffering as equals. Their primary function is mutual personal support, which often takes the form of moral support through the sharing of experiences and information, and through discussion. Often members also develop activities geared towards social change. They volunteer their time, in other words they do it for free” (Romeder et al., 1989: 34).

The WHO’s 2017 definition of support groups is very similar: “Peer support groups are a valuable service and resource that bring together people affected by a similar concern so they can explore solutions to overcome shared challenges and feel supported by others who have had similar experiences and who may better understand each other’s situation” (WHO, 2017: 9).

One can engage with support groups in the field in terms of their organization, their functioning, the way they were structured, etc. depending, for instance, on the relationship they have with their hosting organization or the socio-cultural context in which they evolve. One can however notice a few consistencies common to them all, namely participants:

- Have similar life experiences and wish to share their experience
- Are able to accept themselves as equal human beings worthy of respect
- Are entirely free to decide on whether they want to become a member of a support group or not.

There are other frequent factors (rules of operation, respect for the local pace at which things get done, presence of a facilitator), but not in an invariable way. A few will be mentioned in the course of this knowledge capitalisation document.

Focus on Madagascar

In Mahajanga, HI sought to meet with groups of prison inmates in the hope that these groupings - because they were attempting to do something with their own lives as inmates - would be able to support their peers in jail. For HI, peer support offers a way of supporting prison inmates to deal with harsh prison living conditions and to enable people who won’t be condemned, or those who will be freed, to prepare for their release from jail and their rehabilitation.
2

Which actors play a role in support groups?

The emergence of a support groups generally entails, upstream to its creation, two distinct groups of actors:

- A facility, often an institution (hospital, prison, community health centre, other service venue) that generally accommodates professionals
- Users of mental health services.

In the case of the TMDR programme, a third actor comes into play, i.e. the supporting NGO. If necessary, this role can also be assumed by a civil society association (CSO). Support groups are the result of the systemic interaction of these three actors.

The three types of actors constituting the support group

It is possible to marry this analysis with the “access to services” conceptual framework developed by HI (HI, 2010). Within this framework, one can regard the institution as the regulating entity, the support group as the entity that provides a service, and the users at their usual place of abode. Here, the role of the NGO is to support both the regulating structure (institution) and the service provider (the support group itself).

By distinguishing their roles it will make it possible to understand the patterns of interdependence that exist between actors who make up the support group, as well as clarify the extent to which these patterns influence key processes and the ultimate success of support groups.
3

Why support groups and what outcomes might we expect?

In 2015, an ethnographic study was carried out on the four support groups being mentored within the framework of TMRD (HI, 2016). This study highlighted four dynamics that mobilize people and that contribute to the emergence and the structuring of these groups: surviving, receiving healthcare, getting organised, advocating. Observation of these dynamics also enables one to identify outcomes that gradually and positively affect the various members of the support groups. It is thus valuable to go through each of these steps again in order to spell out these desirable outcomes, which are staggered throughout the evolution of the groups.

All the field visits, observations and interviews carried out within the framework of the knowledge capitalisation process have enabled us to refine and slightly modify our initial hypotheses. Firstly we now see the dynamic “getting organised” as a cross-cutting process that informs each stage of the global structuring of the group. In addition, it was our wish to regard the fourth stage as a collective projection of the group on various outward-focused actions, beyond mere advocacy. This new lens on the process presented below diagrammatically details the essential elements of each phase and the positive effects that flow therefrom.

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Summary diagram of group dynamics observed in relation to some of the group typologies

**Getting structured**
- Understanding and reusing the local dynamics at play
- Defining common rules together
- Relying on ethical leaders

**Surviving**
- Responding to basic needs
- Re-socializing in a difficult environment
- Seeking information about resources
- Developing strategies to face challenges

**Receiving healthcare**
- Getting support from one’s peers
- Combining healthcare approaches
- Living with the disease and with others
- Supporting others

**Getting organized and acting appropriately**
- Shifting the focus away from individual dynamics
- Constructing a structured common discourse, getting involved with civil society
- Initiating collective enterprises

**Discussion group**
- Talk group
- Self-help/community group
- Parental guidance group

**Advocacy actions**

**Development of IGA**

**Service offer**

**Policy activism**

**Group implementing IGA**

**Groups providing a service**
Surviving
Caught in the logic of survival, the person living with mental health problems and his or her family finds it challenging to do what is necessary, namely, analyse their situation. The support group therefore serves a first port of call in that it provides a space of sharing, which is entirely protected, and within which the person feels accepted and understood. The group enables participants to feel less lonely and to find meaning through helping others. The members can share their challenges, alleviate their concerns and then help one another. The group also provides a space of reflection, allowing each and every one to express his or her painful emotions and affects. The members of the group will also learn all over again how to live together by gradually becoming responsible for fostering quality relationships. It is the first opportunity members have to pick themselves up again thereby recovering a sense of dignity, hope and a reason for living. Once freed from a logic of mere survival, the person can think of looking after his or herself.

Alleviating one's sufferings, looking after oneself
Looking after oneself requires an understanding of the kind of suffering that one's illness or the illness affecting a close relative is causing and then finding solutions and developing strategies to deal with the disease and better manage suffering. In this respect, access to information, either via the facilitator or via the sharing of experiences with other members allows for better understanding of the mechanisms and the effects of the psychosis. Participants can then work towards mitigating their feeling of impotence and thus their vulnerability vis-à-vis the disease. Moreover, through the sharing of experiences and advice received, the group allows everyone to find practical solutions to improve their health and their life situation or that of their close relative. The support group also allows participants gradually to invest in common activities with members of the group. These activities are often meaningful and contribute to decreasing the stress of the participants, allowing them gradually to invest themselves as useful members of the group rather than as passive observers. Lastly, in the contexts observed, looking after oneself also entails being able to rely on one's peers and community outside of the group. In point of fact, in the countries in which the research is being conducted, care and the concept of cure are still strongly conceived from a collective perspective.

Opening up and collectively projecting oneself into the future
If the group functions well, the individuals will be able to regain confidence in themselves, feel less stigmatized, thereby extracting themselves from the immediate concerns of survival and care. They will gradually call into question the fatality of their condition as sick people or as parents of sick children, will learn or relearn to make choices and to take part in collective actions. In fact, the exchanges and efforts of the support groups will gradually increasingly take shape around the various projects aimed at improving their living conditions. The group starts to seek alternatives; individuals suggest possible solutions through their experience in the group, or the group transforms into a mutual support group that is then shaped by interactions that members have with those outside the group. This type of group then goes beyond being simply a therapeutic project, but instead focuses on quality of life, sustainable solutions, political action and the members' access to rights in general. Ultimately, the support group promotes citizenship with each and every one becoming more aware of their rights and duties.

A cross-cutting dynamic: Structuring oneself
It is often the institutions and the professionals (psychiatrist, psychologist, sister) from these institutions that drive the creation of support groups and make members walk through this collective awakening. These groups, in addition to offering a safe and welcoming framework, enable the sharing of emotions and affects. Individuals will gradually share potentialities and resources in solidarity with one another and ensure mutual support mechanisms.
These four dynamics and the positive effects they generate are the drivers that make the evolution inherent in a support group possible. And this group primarily acts for the benefit of its own members in order that they might open to the outside world and thereby become involved with individuals beyond the group. These actions could be directed towards the improvement of their overall living conditions, improving the service on offer, collectively generating income, utilising representational and advocacy spaces – additionally, actions could include activism, the impact of which, particular within the political sphere, would be broader. In the end, this constitutes the desirable pathway that we propose to investigate during this knowledge capitalisation phase where we consolidate our experiences, by identifying key contributory factors, but also by spelling out the roles and responsibilities of the various actors involved. More broadly, we shall seek to understand the particular role that support groups play in improving the participation of users of mental health services and their capacity “to seize power”.
Part 2: The emergence of a support group

1

Creating a collective of motivated people

The majority of groups that came into being within the framework of the TMRD programme were the result of professionals aligned with the idea of participative healing and therefore committed to working in group contexts with those suffering from mental health problems yet eager to regain power over their own lives.

The presence of two committed sets of actors, which could comprise several people, is one of the key success factors playing a part in the emergence of support groups. Very often this collective seeks to share skills and resources in order to encourage mutual support and solidarity among group members as for instance arranging home visits so nobody feels lonely. It is the members of this collective who define what should be piloted; employ a vocabulary that makes sense to all involved, and thus create the support that is tailored to its own needs.

Focus on Madagascar

In the prison of Mahajanga, identifying a group within the population of prisoners hasn’t been a simple task. Unlike other project sites of HI, there wasn’t any support committee for prison inmates generally structured as an association, recognized by the local authorities and thus visible to actors outside of the prison. HI however managed to identify GEBAPRIM, an informal collective of prison inmates created in February 2008, comprising about 20 prison inmates, both accused and condemned and including men, women and minors. It was initiated by a group of individuals recognized by their peers, as well as by the penitentiary administration, as being composed of “intellectuals”. The initial objective of the collective was to teach reading and writing to illiterate prison inmates and to uphold spiritual practices in the prison. Historically, GEBAPRIM hadn’t been developing activities on its own initiative but rather implemented activities introduced by the penitentiary administration.

Additionally members of this collective require the attitude of professionals affiliated to the particular institution to be positive. The presence of a stable and holding host facility is an important factor of success, not only as an initial catalyst for the group but also for its development. It is this structure that in the end will mostly accommodate the group and ensure the primary conditions of its existence are met. Lastly, the presence of a third party organization, such as HI, can in some instances facilitate and make the meeting of this collective a reality. The NGO can also support the groups with respect to their host institution. The availability of incidental activities within this host facility, i.e. activities that encourage people to meet and to connect, is a factor facilitating the creation and the evolution of support groups. These activities create fertile ground that could lead to the sowing of other formal or informal groupings that then have the potential to sprout into new mental health support groups.
Focus on Togo

With reference to “groups”, the word “gbalenfit” literally means “let’s make an effort/let’s soldier on, and things will be alright, each one of us will get results”. The concept of a group that serves the interests of individuals also seems to be of significance in the choice of this name.

The development of a project group

The initial drive leading to the creation of a group constitutes a key moment, even if initially the goals are not very clear and the group undergoes a significant change thereafter. However, the first problem against which this collective will run relates to ensuring that conditions support its own existence. To this end, it needs to find allies with whom to collaborate. This group however often hasn’t the means and the necessary perspective required to take stock of its own situation, both because the power relations between the professionals and the lay group members are seldom acknowledged and discussed, but also because members of the group may depend, to some degree, on the institution to which the professional(s) is/are affiliated for their material subsistence and skills to manage the projects and finances. It is thus all about somehow finding the resources to meet the basic needs of the group and then gradually establishing a degree of autonomy distinct from the institution, generally related to the development of the joint project itself. The institution from which the group emerges can then become an invaluable ally from whom the group will then free itself.

The group project can take various forms; it shouldn’t be pre-determined as that’s the task of the members. The project can become an emotional support group and organise, for instance, a party, an awareness-raising event or training workshops, screen a movie on the occasion of World Mental Health Day or set up an IGA. The focus is primarily on identifying the idea/project that triggers the most excitement and passion. The group needs a place to meet regularly. The group can also take a name as a way to shape the group’s identity.

Focus on Sudan

For the support groups established in the JCP and JTH in South Sudan, recreational and physical activities were the entry point to creating a cohesive dynamic. This kind of approach, which doesn’t necessarily have large therapeutic ambitions, illustrates the merit of constellating people around an activity that requires only mild theoretical reflection, because it focuses the attention of participants on the here and now. It encourages informal exchanges between participants within a non-threatening environment thus slowly building trust, which enables the gradual structuring of a real collective project. In addition, by virtue of the way the group is constituted (it is not a place where information is transferred and no one is formally invited to express him or herself), it provides a refuge for members seeking respite from the basic problems that beset them such as financial, hunger and lack of access to treatment, all of which are endemic to such places.
Part 3: Organizing successful meetings

1

The establishment of a collegial framework for meetings

The operating framework of a support group comprises elements generic to all groups, and those that vary from one group to another and which are preferably defined and endorsed in a collegial manner by the group.

Within such a stable framework, one generally encounters the following rules:

- **Respect the point of view of others.** No value judgement permitted about the feelings, emotions and sensitivities expressed. More broadly, it is important that all the participants display a willingness to listen and that the principles of empathy and kindness imbue everything being shared.

- The fact that there is no obligation on anyone to share, time limits for speaking must be respected (no monopolizing the floor).

- The notion of confidentiality. Participants must be able to share personal experiences in full confidence, knowing that the group mores assures confidentiality and that everyone has made a commitment that what is said within the group will remain within the group.

The facilitator, with the agreement of the group, can also decide to set additional conditions and rules. These could for example relate to:

- Duration of meetings, venues, etc.
- “Revolving” roles within the group (facilitation or co-facilitation, upstream preparation, etc.) and consensus on the responsibility of the facilitator.
- Mechanisms for accepting new participants within the group (co-optation, vote), should it be a closed group.
- Whether meetings should be more or less formal: policy for when people arrive late, whether to include a social component (coffee, food), whether physical contact between participants is permissible or not, etc.

Whether the facilitator proposes these rules or whether they are collectively defined, what is important in the end, is that each member is able to comply with them.

The group can have a relatively heterogeneous composition (age, gender, ethnic or religious identity, etc.) and nonetheless function very well insofar as all the participants gather around a common and shared concern/life situation. Apart from these essential rules, the operation of a support group can be relatively flexible from one place to another. It is necessary to allow a sharing dynamic to form that is natural for and specific to the group in question, without seeking to standardize too heavily - just so long as it fits within the initial framework and allows each member to be respected. In particular, one should not be concerned about the emergence of strong individuals within the group, as these can have important federating and stabilizing benefits. Careful attention must nonetheless be given to regulating power relations within a group. This should, if possible, be ensured by an external facilitator in the early days.
Focus on Togo

The two groups Gbalenfit (men and women) were created in 2008 at the initiative of the director sister who took note of how lonely and poor the patients accommodated in the MHC were. The idea of creating a mutual support group emerged from the observation that, in the Moba tradition, farmers are used to helping each other when one of their own encounters difficulties. The farmer who receives the help of others generally invites them to share a meal in return, as reminded by the Moba saying “when you make people sit down, they need something to replenish their energy to get them on their feet again”.

Choosing a facilitator

One or two facilitators must be identified prior to holding the meeting of the support group. This could be the same people from one meeting to another or different people according to the subject tackled, project embarked upon, or according to the agenda. The facilitator is the guardian of the framework and of the operating principles of the group, as adopted by the group as a whole. He or she formally/symbolically opens and closes the meetings. He or she informs the members about the organization and the goals of the meeting. He or she remains attentive to the energy level of members and, if necessary, revives the discussion. If necessary he or she can also define who will be making notes in the event that minutes of the meeting are required.

The other necessary functions to be assumed by the facilitator include:

- Facilitating the meetings, controlling speaking time, taking care to integrate everyone
- Giving useful information
- If a discussion that must lead to a decision is started, facilitating the taking of this decision and its acceptance by all
- Obtaining, on a regular basis, feedback on the positive effects generated by the group
- Managing possible conflicts
- Constituting the link between the host facility, the group and, if necessary, the supporting NGO/association
- Paying particular attention/suggesting personalized support solutions for people going through a difficult phase.

There is no standard profile for a facilitator who can be part of the group or come from any one of the institutions. A facilitator is initially a person who is committed, who motivates others and who gets involved. This person must be identified (he or she is not proposed by an institution), trained and especially supervised. His or her status will take various forms according to the prevailing institutional “anchoring”.

Focus on Lebanon

The (female) facilitator (who is a trained psychologist) of the FGC group initially established a rather strict framework. In addition to the traditional rules (respect, equity, confidentiality, no judgment), this framework for instance excluded physical contact as people were prohibited from touching each other, and the types of subjects tackled during the sessions were restricted and controlled (no evocation of religion, ethnicity, etc. were allowed). In addition, she was the one who regularly initiated the topic for discussion. The purpose of this rather strict framework aimed to contain any possible excesses and any risk of members acting violently.

This framework was gradually loosened over time. The psychologist for example allowed more freedom about the types of subjects discussed. She also allowed more tolerance around touching one another. Lastly, more social moments were introduced, such as starting the session with a cup of coffee or tea, or the sharing of a small meal (small cakes or pastry, often prepared by the mothers).
Choosing a suitable framework (venue, time, mode of functioning)

The facilitators are the ones who define the framework of the meeting, how the meeting should take shape, and logistics (the duration of the meeting, the number of people attending, refreshments, etc.). The preparation must also consider group dynamics: is the discussion completely open, does the meeting of the group begin with prayer (if so, from which religions), is the intention to organize a brainstorming. An agenda can help prevent meetings unravelling and someone getting lost along the way.

The meetings of the various support group members must insofar as possible take place in a space that is not too noisy, but not too ascetic either. A place that is accessible to wheel chairs and close to public transport is a bonus. Meetings can also be held in someone’s living room or in a group member’s workspace as long as he or she agrees to announce it publicly.

The first meetings of the support groups generally take place in venues that are shared by professionals and the affected people: private clinics, mental health centres, prison, etc. It is however important to remain vigilant that all group members are as much at ease as possible with the selected time and place. It is advisable to organize these meetings in a neutral space outside the ambit of institutions that might have invested themselves in the development of the group. This seems important in order to consider the distribution of power within the group, and also to avoid the revival of painful memories linked to a period of hospitalization, imprisonment, etc.

Knowing how to identify and exploit existing socio-cultural dynamics that encourage group members to share

The framework (place, time) in which a session unfolds must be supportive. It is possible and even desirable for the group to make full use of sociocultural elements such as traditional meeting times and venues or emphasise spiritual or religious dimensions. This reinforces group security and cohesion, promotes facilitation and the sharing of feelings, thereby enhancing the therapeutic function of the group. For example, if the group comprises women, one will endeavour to respect their traditional daily routine and therefore plan for the group to meet at a convenient time when members have been released from caring for their children or their domestic chores. If it is a group of men, care should be taken to ensure that the group doesn’t encroach on their professional working time. Preferable still would be to identify and plan meetings to correspond with existing meeting times (end of morning coffee break in the Middle-East, afternoon tea, relaxing after the work day, etc.).
Focus on South Sudan

The strong parallel that exists between how prayer groups within Christian churches operate and how community-based support groups initiated by HI operate underlines the strong cultural dimension underpinning group meetings. Generally, within these communities, the religious (possession, etc.) and medical (pathology) interpretations of mental disorder coexist in harmony. Thus most of the time a double diagnosis is made with respect to mental health disorders: one of a psychiatric nature and the other of a spiritual/religious nature. Consequently, the pastor is identified and often called upon as a possible reference point, as he or she is fully recognized as interpreter/carer when it comes to mental health issues, and on an equal footing with hospital teams.

Reliance on the religious community is unavoidable, even though caution is necessary. In actual fact, at least three community-based support groups have been meeting in churches on a regular basis.

Additionally, one should not hesitate to make use of other traditional modes of expression beyond speech. One could for example consider psychodramas, body stress release session, musical role-playing or even other media such as visual arts (drawing, painting, sculpture).

Lastly, suitable meeting and sharing spaces might already exist and could potentially be utilised or adapted. For example, in certain countries of the TMRD programme, prayer groups facilitated by churches already exist, and which, although they do not have a purely therapeutic vocation as regards mental health, offer privacy for sharing, similar to those of support groups.

Ultimately, one should however be careful to ensure that relying on these dynamics doesn’t mean that certain people are excluded.

Focus on Lebanon

Within the FGC, the facilitator knew how to draw on the fact that all the (female) participants came from a common Eastern culture and thus shared the same language as well as a whole set of customs and routines as, for example, special meeting times, relational codes (a specific way of reaching out to people and of communicating, and a need to discuss things), common perceptions with respect to disease, etc. In fact, the support group was established as a free adaptation of the “Sobhié” (literally, “the morning activity”). For the women of the Middle-East, Sobhié corresponds with a meeting time in the morning after the children have left for school and the men for work, and before preparing the midday meal. This meeting generally gathers women from the neighbourhood and takes place in one of their homes. It is the occasion for women to share their news.

5

Communicating about the support group

Communicating about the support group, its objectives and the way it operates is an important success factor because it ensures both visibility and a local anchoring of the group. This makes the group attractive, ensures diversity and forges links with the locals, etc. This communication can take various forms: noticeboard, flyer, radio broadcast, communication on the occasion of a conference, etc.

The communication can also be carried out jointly with other groups that share common objectives (for example in terms of fighting stigmatization). It also allows sharing contact lists, project ideas, tasks for the organization of an event, etc.
Part 4: How can HI position themselves with respect to support groups and the institution?

After having identified or contributed to the emergence of these support groups made up of professionals/people affected by a mental health problem, HI needs to think about the place it will hold in the process, and then operationalize this role in support of the collective. This support can, in point of fact, take various forms, i.e.: the technical transfer of knowhow related to the management of projects/activities, organisational/institutional, and/or financial support. Four important factors in the evolving dynamics of the group have been identified in this phase.

1 The importance of an ethics and strategy committee

An ethics and strategy committee composed of the project carriers and their partners (including the end beneficiaries of the action), must be formed in order to guarantee the continuity and the coherence of the approaches, beliefs and values carried by the support group project.

Many human tragedies are played out under the term “mental health problems”. It is a tragedy for the people directly affected by the disorder but also for their neighbours, their families, their friends and thus also, the other members of the support group.

The indirect behavioural and cognitive effects on the individual and family as the malady takes its toll include a slowdown in cognitive functioning, a diminution in economic prospects and the likelihood of discrimination. On the one hand, some of these behavioural effects cannot be avoided because certain mental disorders require critical protective measures, as much for the person him or herself, as for society. On the other hand, a certain number of behavioural responses observed are partly generated by stigmatization, a lack of knowledge about the causes/consequences of, and the methods of treatment of these disorders, degraded living conditions, etc. As in the case of other diseases [Human Immunodeficiency Virus (HIV), Ebola], we can observe behaviours that are heavily stigmatised, coming as much from the close relatives of the affected people as from the professionals who work with them, including development aid professionals. The latter may tend to focus their attention on the managerial aspects of the policies/projects they’re implementing, rather than directly caring for patients, either because they avoid them (because of their own belief systems and perceptions of the illness) more or less consciously, or because of lack of time and availability. An ethics and strategy committee could guarantee that professionals, technically responsible for implementing the programme, take full responsibility for putting the knowledge they possess to good use through practical support.
2 Grasping the sociocultural modalities pertaining to self and others

Those organizations wishing to support individuals in their therapeutic journey and their empowerment need to carry out, as an upstream activity, a socio-anthropological analysis that will enable them to grasp how the targeted population understands their unique developmental relationship between self and others. To further understanding, it seems important to explore the life journey of the people living with mental health problems, and that of their families. Before attempting to chart their treatment pathway it is necessary to gain exposure, for a time, to their daily lives, to live with their fears, their expectations, their frustrations, to identify the choices and the constraints governing their therapeutic decisions, to understand the perceptions of others, and the power relations they encounter.

Consideration of the cultural dimension of mental health problems makes possible the analysis of perceptions and models of care, group dynamics, etc. But the above shouldn’t constitute a fixed or an anchored point. It is more about taking into account the variability existing between individuals regarding their willingness and ability to take full responsibility for their disease. In this regard, one should also anticipate the organisational issues related to the mental health problems experienced by members of the group.

3 Anticipating the organisational issues related to mental health problems

The capacity to be and to lead a fulfilled life, to think and to consider others can be undermined in certain individuals affected by a mental health problem. Mental health problems come with complex consequences that affect self-esteem (which in turn is affected by possible stigmatization), the recognition and then acceptance of one’s illness, the desire to take care of oneself, the need to tell one’s story in relationship to the disorder in one’s life, etc. To encourage the participation of those living with mental health problems within a support group requires growing their ability to be objective by learning to see their situation from outside themselves, and considering others.

The attitude of those who are suffering towards the professionals seeking to empower them could prove problematic in situations where sufferers might not find any meaning in life or have any desire to be empowered. Individuals vary greatly in their ability or willingness to seize this power, which can sometimes be too heavy to bear. Whether this constitutes a form of denial attributable to the illness that undermines their self-perception, some form of habitual response related to the way they learn or whether it comes from avoidance or withdrawal strategies is unclear.

The issue of high turnover within support groups must be taken into account in the organization of the support group. This high turnover is unquestionably related to the fact that certain members of the group will leave the group for variable periods of time, or even leave it completely, either because they have healed, or because of a relapse and therefore hospitalisation. The issue of break in tenure caused by, for instance, the absence of the facilitator or the president of the support group, must be dealt with by the group as a whole, as it touches on the issue of resilience underpinning any group dynamic. A deputy should be assigned to each position and, if the group facilitates many activities, certain persons can be nominated to manage specific activities.
Focus on Togo

Gbalenfit does not have administrative status recognized by the State. It is an informal group that depends, both for governance and operational purposes, on the association’s MHC. The sister, who is responsible for the MHC, influences the group by monitoring and vetting all their activities. The group proposed the setting up an office, which followed the traditional structure in Togo: a president, a secretary, a treasurer (those elected, with the endorsement of the director sister, were the most literate). Each of these three functions has a deputy and the office also includes four “advisers”, members who are involved with and participate in the life of the group. The office thus comprises 11 people representing almost one third of the group. The office has historically been supported by a sociologist who is supervised by the director of the MHC. When a member of the office is sick, another member replaces him or her until he or she has recovered.

Focus on Madagascar

The support given to prison inmates is based on a model tested in the Malagasy prisons and which was replicated in Mahajanga following two project cycles (six years). The site of Mahajanga has benefited from the HI team’s invaluable experience in the field of personalized psychosocial support, expertise that was rolled out repeatedly over numerous training sessions, supervisions, analyses of practices, and tools that were developed and are now available for use.

Knowing how to formulate a knowledge management policy

1. Taking into account the gestation period of the project: Determinants that influence the sustainability of the project become apparent with careful analysis of all those who are part of the project from gestation throughout the subsequent stages of implementation spanning several years. The professionals and those who benefitted from the project sometimes received the support of many partners (local or international non-governmental organisations (INGOs), institutional actors). The institutional memory of these local actors (partners, team members of other projects) can be shared and utilised provided they are given the opportunity to tell the story of their experiences.

2. Training the teams and the partners in the knowledge and practices underlying the project: The mental health policy heralded by the TMRD programme was formulated in their “Framework document of the programme”. This policy comprises 27 reference documents, the contents of which are disseminated by HI’s technical professionals (technical advisers at head office and the programme coordinator). To ensure familiarity with these resources, those responsible for implementing the programme also received several training sessions conducted by the technical professionals from HI’s headquarters (HQ) and the programme coordinator responsible for implementing the programme (initial training session and seminar held half-way through the project and training sessions conducted by HQ’s technical team and the TMRD programme team during in-country missions). Thereafter, wherever possible, the training was adapted to suit local conditions and repeated by local technical advisers, when such human resources existed.
3. Setting up a continuous training/supervisory mechanism: The new recruits, who sometimes arrived in the programme after the training sessions had already been conducted, seemed to have difficulties applying this knowledge and turning it into know-how. Despite the project leaders being familiar with these documents and approaches, the teams that should be depending on these documents contend that they do not always make use of the documents, as the project leaders fail to understand how the documents talk to the reality on the ground. It’s therefore a challenge for them to link and apply the documents to the project they are implementing. Internalised knowledge is thus a critical success factor. The project teams also sometimes seem to be torn between the expectation of the H1 programme coordination unit and that of the technical advisers who expect them to take ownership of this knowledge, but also to develop their own practice within the context of their local knowledge and conditions. On this last point, where the resource is available, the regular on-site supervision by an external psychologist is highly appreciated as the discussions are then no longer theoretical but have to do with their own practices in real-life situations.

4. Mentoring the ethical leader(s): Key among those who assist in the running of a support group are the professionals who guarantee the group’s ethical principles. These essential individuals, be they psychologists, health agents, project leaders, nuns or technical advisers, through their facilitation, assist in the genuine translation of the mental health projects at the local level. It is therefore essential for the organization to identify them, invest in them, to train them and to offer them, if necessary, adequate supervision. As true interfaces between the organization and the beneficiaries, these people are also the guarantors of ethics and commitment. This is not about ethics shaped according to a Western model (which would be closer to moral principles, if not about control), but a pragmatic form of ethics that adjusts according to the situation, and is respectful of local culture and perceptions without magnifying them. These ethics must be based on a mental health policy co-developed and embraced by all the actors involved.

The practice of each professional must be aligned for the individuals really to come together in groups. From an empowerment and participative perspective, this consistency has to be achieved with the final recipients of the action in mind, which implies that mental health policies are locally anchored and renegotiated. The final beneficiaries of the action will not be drawn in if they suspect that their participation serves interests that are not theirs or that the intent is to seek their approval by breaking down any possible resistance.

5. Assisting support groups form in a flexible way

The mental health support group, in its first stages of evolution, must produce a therapeutic benefit, whether this is to address mental health problems or the psychic suffering induced by these problems more broadly. For many groups, it was noted how important it was to ensure that this therapeutic benefit remained a central aim and stayed in place for as long as the users would need it.

It is normal that other ideas and needs, related or otherwise to the initial therapeutic aim, emerge from the group’s reflection. These objectives will be expressed more easily if they are compatible with the mandate and expectations of the hosting facility. They can however be expressed outside of this hosting facility.
The global context in which the group and their hosting facility find themselves strongly influences the development of its ideas and objectives.

Therefore one can conclude that:

- In cases where the context is unstable and a community is at risk of unraveling, the support group will often be “constrained” to focus its attention on the logic of immediate survival. These survival needs of the group members will intrude on the functioning of the group and stunt its development. It seems that where group members are focused on their own need to survive they have little incentive to preserve a space exclusively dedicated to a therapeutic purpose or the gradual empowerment of its members.

- In contrast when the context is stable and the community well-structured, the group and its members are able gradually to move away from the logic of immediate survival. It also makes it easier to preserve a protective therapeutic space. A group is in fact thus better able to encourage its members gradually to participate in the group and to help them achieve a form of empowerment.

For some of the supported groups, it proved important to draw a distinction between the initial therapeutic objective and subsequent aims, and to give these various objectives adequate space for expression. In Lebanon for example, the group wished after a while to become involved in advocacy. To this end they created a separate space, more open to other members of the family and friends, and which they then called the advocacy group, while retaining the initial configuration of the support group. They thus strived to preserve, as best as they could, the “therapeutic space”, while making provision for certain activities/objectives focused on mobilizing people beyond the confines of the group (families, friends, users/professionals, etc.).

Other groups meanwhile (e.g. Togo, Madagascar) took on new projects (such as IGAs for members of the family) by broadening the initial perimeter of the group. The initial support groups thus expanded to become more inclusive, which by the same token also expanded its ambitions.

One of the roles of the supporting NGO is to reflect on and conscientiously support the group as well as the hosting facility to evolve towards various configurations that would enable them to promote these objectives as best they might, for instance, by working towards the creation of a broad association including distinct IGA associations, advocacy groups or associations, etc. With this intention, HI and/or the hosting facility has to respect the ideas emerging from the group and guide their realization, which requires mentoring the groups so that they can give substance to these ideas and objectives, assisting them develop specific activities, and supporting their implementation.

In addition, once these objectives and the new projects have been settled, HI and the professionals from the hosting facility need to discuss and negotiate clear roles and responsibilities during this mentoring phase. An appropriate way of redefining each person’s role would require regularly reviewing the strong relationships existing between the parties, based on the conceptual framework developed by HI that focused on access to services (HI, 2010).
Conclusion

This first research and learning process that unfolded across four distinct fields has revealed key elements that are potential drivers of success in the mentoring of these support groups at various stages of their life cycle.

This process firstly emphasizes the need for these groups to be adequately inducted into the programme and for them to take collective ownership. It also underlines the need to guarantee a stable framework with regards certain aspects and to be more flexible on others, especially those dependent on local sociocultural dynamics. It also stresses the importance of identifying and mentoring one or several ethical leaders, and of anticipating organisational challenges that come with working with those living with mental health problems, as well as the particular power relations that might develop within any collective. It reaffirms that optimal support requires an understanding of the nuances within an evolving dynamic. Lastly, this process identifies a clear role for each person supporting the group, including appropriate methods of collaboration, and the right distance to keep from the group that would be attentive, respectful and empowering at the same time.

This work certainly lays an initial solid foundation that will allow project managers, as of now, better to prepare, initiate and mentor people via the mechanisms available to them in the various areas of intervention. However, far from being an end in itself, the project needs to be pursued and widened.

On the one hand, it would be necessary to initiate a more in depth, ambitious and systematized exploration of alternative variations of the “support group” mechanism found in other contexts but also following methods that haven’t been tried out here. This should allow for an improved systemic analysis of these groups as well as the manner in which they evolve.

On the other hand, beyond the perceptible positive effects that have for instance been expressed through the feelings shared by the participants, it would be interesting to try and outline in a more rigorous and objective manner the impacts of the “support group” mechanism from a therapeutic perspective and in terms of its capacity to empower people and to engender more gratifying social participation.

Lastly, it would be important to attempt to determine more exactly the place of the “support group” mechanism within broader therapeutic and mentoring strategies targeting people living with mental health problems.

The continuation of the “Touching Minds, Raising Dignity” project, which was enriched through its implementation in an additional country, and which once again includes a research and knowledge capitalisation dimension, should contribute to concretizing these ambitions, over the years to come.
Among the many forms that support groups can take, HI distinguishes five: the focus group, the support group, the parental guidance group, the self-help group and the advocacy group. By way of example, the following practical sheets provide outlines of possible ways in which these five types of groups can be organized.

**Practical sheet 1: The discussion group**

**Why?**

**Main objective:** To ensure the credibility of an intervention using the information received and participants’ contributions to a focus group.

**Specific objective:** To gather qualitative information drawn from real-life experiences through targeted discussion over a relatively short time-frame with a group of people.

**Expected result:** A better understanding of people’s expectations and perceptions in terms of a specific reality.

**Outcome indicator:** Focus group report covering the most significant results.

**Outcomes indicators:**
- The intervention is accepted or validated
- Level of involvement of the participants in constructing a joint project

**For whom?** People from the community: Key stakeholders (community leaders, community decision makers), people with disabilities and vulnerable people.

**How?**

**Before implementation:**
- Define the theme to be discussed
- Identify group members: 6 to 12 carefully chosen participants – limiting the number leads to a better understanding and improved management of the information communicated. The restricted number of participants guarantees group cohesion because each member is able to express themselves freely. For focus groups on the theme of sexual violence, it is recommended that the groups are homogeneous in terms of age and gender
- Decide on a location for the meetings that is accessible to people with disabilities
- Create an interview guide with 5 or 6 questions including the interview objectives and the information to be collected. This guide should be flexible enough to allow any areas of interest broached during the focus group to be explored. To optimise both contact with the group, and information collection, it is recommended that two facilitators conduct the interviews: the first to lead the group and the second to take notes.

**Implementation:**
- Approach the themes in a flexible manner
- Avoid targeting very sensitive subjects that could create difficulties for the participants (these subjects could be kept for the individual interviews)
- Stimulate and moderate the interaction, without giving an opinion
- Observe the participants’ reactions
- Take notes or record the interview (audio or video if permitted)
- Note any institutions cited, terms used, people’s different perceptions, the issues raised by group members, etc.
- Several people should analyse the data to avoid bias
• Provide feedback on the results obtained
• Develop any areas of interest using other survey methods if necessary.

**Attitudes during the activity**
• Be careful to ensure the least forthcoming members of the group take their turn to speak
• Ensure the rules established at the beginning of the session are respected
• Re-focus the discussion if participants stray too far from the subject
• Encourage everybody to participate, give their opinion and react to other people’s opinions.

**Skills required**
• Ability to lead discussions, allowing each person to speak
• Ability to stimulate discussion and re-focus it on the theme at hand
• Listening skills.

**Monitoring tools**
• Activity report.

**Reference document**
Bouchon M. *Data-collection: Qualitative methods*. Médecins du Monde, 2009

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**Practical sheet 2: The support group**

**Why?**

**Main objective:** To improve the mental health of vulnerable people through their participation in a peer group that encourages a group dynamic, interaction and connections between participants.

**Specific objectives:**
• To build people’s capacities to take action
• To reduce the level of psychological stress
• To contain negative affects and perceptions.

**Expected results:**
• Vulnerable people’s level of distress has been reduced
• Individuals face up to the trying situation they find themselves in.

**Output indicators:**
• Levels of participation and attendance (or justified absence)
• Meeting frequency
• A follow-up form for each participant
• Satisfaction survey: participant feedback.

**Outcome indicators:**
• Confrontation of opinions/perceptions
• The rules established are adhered to
• Changes in individual and collective attitudes.

**For whom?**
Vulnerable people of all ages, all cultures particularly in contexts where social fundamentals have been shattered, for example, isolation, guilt, loss of bearings, etc.

**How?**

**Before implementation:**
• Plan for at least two facilitators
• Have a fixed location for each session that is accessible to people with disabilities and guarantees confidentiality
• Plan the group’s life cycle (number of sessions).

**Implementation:**
• Create a group with the same participants each session (6 to 10 participants)
• At the first session, establish the rules with the members of the group:
  – Frequency and length of meetings
  – Listening to what each person says, what is said in the group stays in the group
  – Respect what each person says, there are no right or wrong answers
  – Do not make categorical moral judgments about what other people say
  – Set up an analytical policy to manage absences, i.e. an absence is analysed in terms of both the issue the person is dealing with and the group dynamic
• Provide participants with feedback or
a summary after each session
• Keep a record of participants’ feedback after each session
• Plan individual time for each participant at the last group session.

Attitudes during the activity
• Be convinced of the value of the process undertaken by the group, in order to be able to motivate participants
• Be able to structure group meetings
• Ensure the rules established with the group at the first session are respected
• Be flexible, capable of adapting according to what the group brings, while remaining a sufficiently stable influence for the group
• Be capable of coping with diverse inter-personal interaction: aggression, passivity, etc.
• Be capable of putting one’s own opinions “on stand-by” in order to let others express theirs
• Facilitate discussion, be a group mediator rather than adopting the stance of an expert
• Be able really to listen and understand other people’s points of view
• Avoid taking notes during the sessions
• Observe participants in their entirety (non-verbal communication, appearance, signs of emotion, etc.)
• Be capable of questioning yourself at any time and to self-analyse, thanks to the debriefings.

Skills required
• To have been trained in the method
• To have good working knowledge of the illustration/mediation used (if there is one)
• To know the specific issues of the group members.

Monitoring tools
• Follow-up form/session form
• Evaluation of the value added to the group dynamic and its development.

Reference documents

Practical sheet 3: The parental guidance group

Why?
Main objective: To enable participants to rediscover a certain balance within the family through their contact with people living in similar situations.
Specific objectives:
• To support parents/teachers in discovering resources
• To help parents to discover different methods for dealing with difficult situations.

Expected results: Parents acquire new methods for handling crisis situations and have rediscovered a certain balance within the family.

Output indicator: Good attendance.

Outcome indicators:
• Group dynamic
• Parents’ perceptions have been challenged and changed
• The perceptions children have of the protective capacity in their surroundings.

For whom?
Parents of children with disabilities, who are often overwhelmed and suffering.

How?
Before implementation:
• Identify the people who will lead the parental guidance sessions according to the skills required for the activity
• If necessary, prepare complementary
training sessions for the session leaders on parental guidance techniques

- Prepare the monitoring and evaluation tools for the activity (attendance register, evaluation sheets, etc.)
- Form a group made up of parents/teachers to develop a common issue
- Try to make the group as diverse as possible
- Determine a neutral location for meeting.

Implementation:

- Present the framework for the activity: The session objective, the frequency of meetings, the duration of each session
- Establish the rules for the group:
  - Respect for what other people have to say (do not judge their opinions)
  - Respect the confidentiality of what is said, anything said or heard should not be passed on to anybody outside of the group
  - Listen to what other people say
- Collect information on future participants’ expectations regarding the scheme (it is possible to hold individual interviews with each future participant)
- Set objectives with the group (experience sharing, information on the disease, etc.)
- Remind participants about each session
- Leave time for feedback at the end of the session
- Plan a project evaluation at the end of the cycle.

NB: Recreational activities could also be set up, for example, a group could be formed for a “cooking together” session.

Attitudes during the activity

- Remind the group of the framework during the first sessions
- Do not make value judgments or moralise
- Listen to each person’s story and experience
- Encourage the participants to share their experience rather than their advice
- Let the group develop in terms of the needs and issues that arise
- Observe participants in their entirety (non-verbal communication, appearance, signs of emotion etc.).

Skills required

- To be trained in leading groups and analysing group situations
- Participation in supervision groups, analysis of professional practices
- Possible candidates: psychologist, social worker, educator, youth leader, etc.

Monitoring tools

- Participant monitoring form
- Session report

Reference document


Practical sheet 4: The community self-help group

Why?

Main objectives:

- To support the recovery of vulnerable people in severe psychological distress
- To improve the mental health of members of the Community Self-help Groups (CSG) by helping them make the most of their collective economic, social and community resources, thus enabling them to meet their own needs/wants.

Specific objectives:

- To learn to live with others by working on a joint project
- To know how to make a plan based on the analysis of strengths and opportunities in the environment (social, community, family)
- To be capable of setting up and managing a project (economic, cultural, social, etc.)
**Expected results:**
- The psychological distress of the CSG is reduced
- The needs/wants of the members of the CSG are met
- The members of the CSG are able to participate in social life of the community, i.e. are able to invest and be creative within their environment.

**Output indicators:**
- Participation rate and punctuality (or justified absences)
- Meeting frequency.

**Outcome indicators:**
- The participants have adopted the mediation actions
- The rules are followed
- Attitudes change as the group develops
- Improvement in the ability to set up and manage projects

**For whom?**
Vulnerable people suffering psychologically who need support. This approach is recommended for people who have difficulties expressing their discomfort verbally.

**How?**

**Before implementation:**
- Create a group (8 to 12 people) in which the participants are always the same, or discuss rules for joining or leaving if the group is to remain permanently open to the community. This group could evolve from a support group
- Decide on a location that is accessible to people with disabilities
- Prepare tools for monitoring and evaluating the activity.

**Implementation:**
- Communicate about the group to attract participants and inform other professionals. Explain the activity objective
- Explain the working framework:
  - Duration of each meeting
  - Location of sessions
  - Frequency (for example, once a week)
- At the first session, create rules with

the members of the group:
- Confidentiality of information
- Respect for what other people say
- Create a clear policy for managing absences so that they can be taken into account in the analysis of the group dynamic and the psychological issues of the absent person
- For the first sessions, define the themes and a method (IGA, theatre, singing, drawing, sport, photo-language, etc.) according to the audience and the objectives defined within the group
- For subsequent sessions, prepare them beforehand
- Provide the materials required (venue, supplies) as well as competent professionals
- At the end of each session, analyse the problems raised by the group and look for possible solutions with the participants
- Have a debriefing meeting with the group leaders after each session.

**Attitudes during the activity**
- Be flexible, able to adapt according to what the group brings, whilst providing a stable influence for the group
- Do not judge other people
- Encourage people to speak, act as the group mediator
- Observe participants in their entirety (non-verbal communication, appearance, signs of emotion, etc.)
- Be able to question yourself at all times and to self-analyse, with the help of the debriefings.

**Skills required**
- To have been trained in this method and in the chosen type of mediation
- An understanding of group dynamics
- Set up evaluation scales for the mediation according to the agreed objectives (development, behaviour, etc.).
Monitoring tool
- Patient follow-up form/session form.

Reference documents
Handicap International, Supporting persons living with trauma by rebuilding social and community links: an example of a community-based mental health approach after the Rwandan genocide of the Tutsis. 2009
Handicap International, A feeling of belonging: an example of a community mental health project in Rwanda. 2012

Practical sheet 5
The advocacy group

Why?
Main objective: To influence decision-makers, governments and stakeholders to ensure that they include people with disabilities in intervention programmes and public action policies.

Specific objectives:
- To provide feedback to government stakeholders and international and local organisations on the main issues affecting vulnerable people, notably people with disabilities
- To recommend making psychosocial and protection projects accessible to people with disabilities, and to support stakeholders to implement this recommendation.

Output indicators:
- Participation rate in clusters and working groups
- Number of meetings with governmental stakeholders
- Number of meetings with international and local stakeholders
- Number of training sessions conducted.

Outcome indicators:
- Number of documents adapted to improve the inclusion of vulnerable people
- Recommendations are integrated into legislation, and humanitarian intervention programmes
- Awareness-raising programmes are carried out by other stakeholders in order to combat discrimination
- Disability is genuinely taken into account in the interventions of partners, or other NGOs, working in the area.

For whom?
Governmental stakeholders, stakeholders from national and international organisations, clusters, mediators.

How?
Before implementation:
- Gather information on policy (public or internal actor policy):
  - Understand the political context
  - Understand the community’s concerns
  - Identify the policy-related causes of poverty and discrimination
  - Understand the perception of disability in the community
  - Identify the stakeholders and the institutions involved in drafting public policy, as well as those capable of mobilising and influencing decision makers
  - Analyse the distribution of political power between the main stakeholders
  - Understand the formal and informal decision-making processes.
- Gather information on the humanitarian stakeholders:
  - Who does what?
  - Identify key stakeholders that are open to suggestions for adapting their activities.
- Evaluate the risk:
  - Plan for themes that hold a risk of violence
  - Plan for the political trends, notably any contextual developments that could influence the advocacy targets.
- Create strategic relationships:
  - Establish links with decision-makers
  - Work with other humanitarian aid organisations.
- Establish credibility:
  - Gather supporting evidence: reviews, studies, etc.
  - Create an evidence-based argument in order to convince politicians
  - Develop expertise to establish
credibility with decision-makers, policy-makers and humanitarian stakeholders
– Develop community links to establish credibility with the public.

• Prepare training beforehand using existing materials where possible adapted to the targeted group:
  – Establish a timeframe
  – Prepare a budget
  – Prepare a logical framework
  – Plan, monitor and evaluate.

Attitudes during the activity
• Be objective and trustworthy
• Establish trusting relationships with the different stakeholders (political, humanitarian and community)
• Be diplomatic and persuasive.

Skills required
• Having valid information about the subject at hand
• Being recognised as a reliable source of information
• Being comfortable when speaking.

Monitoring tools
• Activity report
• Action plan
• Logical framework
• Evaluation form.

Reference document

**Annex 2: The knowledge consolidation process**

Resources underpinning the theoretical framework
This knowledge capitalization process draws on several reference frameworks:

• On the one hand, it draws on the framework, methods and tools specific to knowledge management (generating, tracking and sharing knowledge). To ensure the most congruence possible with HI’s reference framework, the team was largely informed by HI’s methodological guide: “Learning lessons from experience” (HI, 2014).

• On the other hand, it draws on the reflective framework, methods and tools used in the field of systemic analysis in relation to project management (reflection on the factors supporting the sustainability of the support groups that were analysed). Following the same logic mentioned above, the team was informed by HI’s practical guide: “The sustainability analysis process: the case of physical rehabilitation” (HI, 2012a).

• Lastly, it draws on the reflective framework, methods and tools particular to socio-anthropology (the main reference framework used to collect field data).

**Practical approach to a knowledge capitalization process**

**How to define knowledge capitalisation concretely**
Knowledge capitalisation can be defined as the initiatives taken, methods followed, and techniques applied that enable an organisation to recognise, identify, analyse, organize, document and share the knowledge of its members (Tisseyre, 1999).

• It enables the organisation to compile its reference documents (e.g. technical reference documents, implementation
guidelines, strategic documents, standard specifications) in order better to clarify its aims, work methods, and to take stock of the results and impact of a given intervention.

- It helps the organization mitigate the risk of losing skills (people transferred to another service or section in the organisation, people leaving the organisation, etc.)
- It feeds the decision-making process and thus shapes action going forward.

The knowledge capitalisation process entails compiling content (know-how, practices) in an integrated and presentable form that emphasises the value of the content. Our experience has shown that the process of valorising content (analysing, communication, provisioning) is almost as important as the intrinsic value of the content itself.

Organizing a consolidation process in practical terms

We drew a distinction between two specific phases: a period of observation and synthesis conducted at the local level which remained contextual, followed by a period of analysis and reflection of a more global and cross-cutting nature.

Phase 1: Observations, findings and first contextual analyses done at a national level

Initially the findings and analyses of the dynamics were conducted by taking into account the contextual elements specific to each mission. Feedback was in the form of a case study, which was interpreted and then compiled into documents specific to each country, and then shared.

The proposed methodology to follow for this first period is outlined below:

Sequence 1.1: “Identify”
- Conduct an incremental review of the literature, including: proposals and project reports, internal and external evaluations, knowledge capitalisation documents that were produced following the field visits conducted by the consultants (step one of the TMRD project).
- Organize round-table discussions and one-on-one interviews with all of the people responsible for current and former projects.
- Jointly identify the groups, experiences and dynamics worth exploring in greater depth.

Sequence 1.2: “Observe and share”

For each selected project, collect in-depth comparative information, including through:
- Individual and group interviews with the actors involved (beneficiaries, group members, helpers, professionals, etc.), and, where possible.
- Observations - but taking into account the limits already set at step one of the TMRD programme.

Sequence 1.3: “Analyse and give feedback”

Compile the first draft of a concise knowledge management assessment by project or country which, after submission, will be studied by the project teams and the steering committee, and who will also provide feedback.

Phase 2: Cross-cutting analyses of and reflections about the TMRD programme

Once all the field missions have been conducted, a second period of analysis, sharing and feedback follows. It is about appraising, on a case-by-case and country-by-country basis, the cross-cutting validity of the reports before attempting to draw more general lessons about the programme from which concrete recommendations will be formulated. On the basis of a proposal by the consultants, it would be advisable to involve the steering committee in order to reflect on and validate a whole set of findings, analyses and recommendations relating to the following aspects of the programme:
- Emergence and the establishment of support groups.
- Mentoring of support groups.
- The sustainability of support groups.

Sequence 2.1: “Synthesize, choose”

In order to garner experiences and know-how, build a generic project-based template that includes questions that will provide information about, for instance: context, themes, type of project and activities,
approach adopted, involvement of local, national and international partners, outcomes, successes and challenges encountered. This template should end with a question that establishes what value each project had from a knowledge capitalisation perspective (i.e. was it a significant experience that was successful or, alternatively, problematic).

Submit this template to the steering committee together with the sense of the group as a whole, of the most significant experiences that could be extrapolated to a more general context.

**Sequence 2.2: “Organize, analyse, and recommend”**

On the basis of experiences gleaned on the ground, submit a draft analysis of the main strengths that emerged with respect to technical expertise, acquired by the project teams by emphasizing the lessons learnt and good practices that appear valid seen from a cross-cutting perspective (potentially in the form of a presentation). Any thinking that touches on the sustainability of the particular project, as also the empowerment of participants will be given careful attention. This document/presentation will need to be validated by the steering committee.

**Sequence 2.3: “Give feedback”**

On the basis of the previous discussions, compile a draft knowledge capitalisation report (preliminary knowledge capitalisation report) that should include the concise country-based sheets and that will clearly present the findings, analyses and recommendations that are deemed valid at a global level with regard to the emergence, establishing and mentoring of support groups in Mental Health Psychosocial Support (MHPSS). This report should also describe in detail the methodology, tools and sequences used so that the process can be repeated in the future if necessary.

Following the editing of this preliminary version and after receiving feedback from the steering committee, write a final report.

Make the outcome of this first knowledge capitalization process available to all the teams in a readable and accessible format. The manner in which the feedback is to be presented to the team - and potentially to external actors - must be thought through at the beginning of the knowledge capitalisation process. If necessary, suggest the issuing of a communiqué on the outcome of this knowledge capitalisation process and the lessons learnt (e.g. an intervention can be organised during the HI seminar regularly held in Paris).
Annex 3: Selected reference list

Guides and books

- Handicap International (HI) (2016). Emergence and structuring of support groups for people living with mental health problems in Togo, Madagascar, Lebanon and South Sudan (brief). Touching Minds, Raising Dignity programme.
- World Health Organization (2017). Creating peer support groups in mental health and related areas. WHO Quality Rights training to act, unite and empower for mental health (pilot version).

Articles and texts


• First International Conference on Health Promotion (1986). Ottawa Charter for Health Promotion.


• URD/ANALP. Participation handbook for humanitarian field workers, 2012.

• Troisoeufs A. & Eyraud B. (2015). Psychiatrisés en lutte, usagers, Gemeurs... : une cartographie des différentes formes de participation [Struggling psychiatric patients, users, facilitators: mapping the various forms of participation], in Bulletin National Santé Mentale et Précarité, Rhizome, n°58, p. 3-4.

Other ressource

• Handicap International (HI) (2012b). A feeling of belonging: An example of a community mental health project in Rwanda. Technical Resources Unit.

Annex 4: List of acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ART</td>
<td>Action for Recovery and Transformation</td>
</tr>
<tr>
<td>CSHG</td>
<td>Community-based self-help group</td>
</tr>
<tr>
<td>CSO</td>
<td>Civil society organisation</td>
</tr>
<tr>
<td>FDA</td>
<td>French Development Agency</td>
</tr>
<tr>
<td>FGC</td>
<td>Family Guidance Centre</td>
</tr>
<tr>
<td>HI</td>
<td>Handicap International (Humanity &amp; Inclusion)</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>ICED</td>
<td>International Centre for Evidence in Disability</td>
</tr>
<tr>
<td>IGA</td>
<td>Income generating activity</td>
</tr>
<tr>
<td>INGO</td>
<td>International non-governmental organisation</td>
</tr>
<tr>
<td>JCP</td>
<td>Juba Central Prison</td>
</tr>
<tr>
<td>LSHTM</td>
<td>London School of Hygiene and Tropical Medicine</td>
</tr>
<tr>
<td>MHC</td>
<td>Mental Health Centre</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organisation</td>
</tr>
<tr>
<td>TMRD</td>
<td>Touching Minds, Raising Dignity</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>WHOCC</td>
<td>World Health Organisation Collaborating Centre</td>
</tr>
</tbody>
</table>
Notes

1. Declaration of Lyon, Article 2.8 (2011).

2. The complete title of the programme is: “Touching Minds, Raising Dignity: putting an end to the social condemnation of people living with mental health disorders in four countries in crisis and post-crisis situations (Togo, Madagascar, Lebanon, South Sudan)”.

3. For instance in French, one uses the words “capacitation”, “encouraging independence”, “potentiation” or even “power to act”.


5. “The promotion of health requires the effective and concrete participation of the community in setting the priorities, making decisions and in formulating and implementing the planning strategies aimed at the improvement of health. At the heart of this same process, power is devolved to the communities, which are considered able to take their destinies into their own hands and to assume responsibility for their actions.” The Ottawa Charter for Health Promotion, WHO, 1986.


7. Aware of this issue, HI, carried out a joint study between 2009 and 2012 with the International Centre for Evidence in Disability (IECD) of the London School of Hygiene and Tropical Medicine (LSHTM) that aimed at designing a methodological tool that would enable them to analyze this aspect of sustainability. The study is grounded in the work of HI in the field of functional rehabilitation in five different countries (Nepal, Cambodia, Liberia, Sierra Leone and Somaliland) and identifies various conceptions and dimensions of sustainability. This study enabled HI to develop a practical guide showing how to implement processes geared towards ensuring the sustainability of an action.

8. Adjusted following the second explorations emanating from the knowledge capitalisation process.

9. In the Moba language as spoken in Dapaong (city in the north of Togo).

Mental health support groups: From individual suffering to forming a collective of users

This knowledge capitalisation document comprises four sections. The first section outlines the methodological framework: what is a support group, which actors come into play in the support groups they represent and what are the expected results. The second and third sections discuss the success factors observed during this programme that throw light on issue surrounding the formation of the groups and their organization. Lastly, the fourth section presents the key success factors that the HI teams must adopt to enable them to define their role and to address the ethical and political challenges flowing from their support of these groups.

This document is not a manual of good practice but a compilation of the knowledge derived from experiences gained through the TMRD programme for those wishing to develop this type of programme in other contexts.