

# A Model of Mental Health Care Involving Trained Lay Health Workers for Treatment of Major Mental Disorders Among Youth in a Conflict-Ridden, Low-Middle Income Environment: Part I Adaptation and Implementation

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**Un modèle de soins de santé mentale comportant des travailleurs de la santé non professionnels pour le traitement de troubles mentaux majeurs chez des jeunes gens dans un milieu en conflit à faible revenu : I<sup>re</sup> partie, Adaptation et mise en œuvre**

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## Abstract

**Objectives:** In low- and middle-income countries (LMIC), major mental disorders often remain untreated because of barriers related to access and resources. In rural areas and in conflict-ridden regions, the problem can be exacerbated by increased rates of mental illness and by reduced access to care. This paper describes a project designed to provide mental health services for major mental disorders among youth using a low-cost model in a rural district of the troubled Kashmir valley.

**Methods:** We describe the geographic and political context, the guiding principles and adaptation of the service model (through partnership with a voluntary organization and use of technology), and the implementation of the model using Theory of Change framework. The core of the intervention was to train a pool of lay health workers (LHWs) to provide mental health services to young (aged 14-30 years) people with major mental disorders in their own communities, supported by clinical professionals.

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**Results:** Despite political turmoil and major floods, 40 (male and female) LHWs were trained. The LHWs efficiently engaged in case identification, basic interventions, and data collection on outcomes. Several different stakeholders were engaged in activities relevant to the objectives of the project; however, the use of technologies was moderated by several challenges, including access to internet services and patient preference for personal contact.

**Conclusions:** This service model is applicable in an environment where protracted political and armed conflict, low resources, and geographical isolation make exclusive reliance on scarce professional services impractical.

### Abrégé

**Objectifs :** Dans les pays à revenu moyen et faible (PRMF), les troubles mentaux majeurs demeurent souvent non traités en raison d'obstacles liés à l'accès et aux ressources. Dans les zones rurales et les régions où règnent les conflits, le problème peut être exacerbé par des taux accrus de maladie mentale et par un accès réduit aux soins. Le présent article décrit un projet destiné à fournir des services de santé mentale pour les troubles mentaux majeurs chez les jeunes gens à l'aide d'un modèle peu coûteux dans un district rural de la vallée du Cachemire en proie à un conflit.

**Méthodes :** Nous décrivons le contexte géographique et politique, les principes directeurs et l'adaptation du modèle de services (au moyen d'un partenariat avec un organisme bénévole et de l'usage de la technologie) ainsi que le processus de mise en œuvre du modèle à l'aide de la structure de la théorie du changement. L'idée centrale de l'intervention était de former un groupe de travailleurs de la santé non professionnels (TSNP) afin d'offrir des services de santé mentale à des jeunes gens (de 14 à 30 ans) souffrant de troubles mentaux majeurs dans leurs propres collectivités, avec le soutien de professionnels cliniques.

**Résultats :** Malgré le tumulte politique et de graves inondations, 40 TSNP (hommes et femmes) ont été formés. Les TSNP ont mené à bien efficacement l'identification des cas, les interventions de base, et le collecte de données liées aux résultats. Un certain nombre de différents intervenants s'occupaient d'activités ayant trait aux objectifs du projet; cependant, l'usage de la technologie était modéré par certaines difficultés dont l'accès aux services d'Internet et la préférence des patients pour le contact personnel.

**Conclusions :** Ce modèle de services est applicable dans un environnement où sévissent de longs conflits politiques et armés; les faibles ressources et l'isolement géographique font en sorte qu'il est irréaliste de compter exclusivement sur les rares services professionnels.

### Keywords

global mental health, low-to-middle income countries, lay health worker model, conflict in kashmir, india, youth mental health, health technology in low-middle income countries, theory of change, case identification, stakeholder engagement

## Introduction

Mental disorders, especially major depressive, psychotic, bipolar, and addiction disorders, account for a major portion of disability, general morbidity, and premature mortality worldwide,<sup>1-3</sup> and continue to remain largely untreated in low- and middle-income countries (LMICs) because of resource-related barriers, especially in rural areas.<sup>2,4,5</sup> Both incidence and prevalence are relatively high due to the high proportion of younger (under 25 years) people in the population in LMIC, and most mental disorders having their onset before the age of 25.<sup>1</sup> Consequently, three-quarters of the burden of mental, neurological, and substance abuse exists in LMICs.<sup>6</sup>

Large-scale violent conflicts increase the incidence and prevalence of mental illness as well as reduce access to care.<sup>7-10</sup> The aim of this 2-part report was to describe the adaptation, implementation, and results of a low-cost, skills transfer-based, technology-enhanced, service-delivery model designed to address the unmet mental health needs of young people in a rural district, within the conflict-ridden valley of Kashmir, in the state of Jammu and Kashmir, India.

## Background

The state of Jammu and Kashmir, a mostly mountainous region at the northern tip of the Indian subcontinent, has been subject to 3 decades of armed conflict, severely affecting the Kashmir valley. The conflict dates back 70 years following the partition of India, the creation of Pakistan, and a de-facto division of the state into one-third Pakistani and two-thirds Indian control. The 2 countries have not been able to resolve their differences nor have the people of the state had an independent voice in deciding their future. Within the Indian-administered Kashmir valley, this conflict was mostly non-violent for decades until it erupted in a full-fledged armed insurgency in 1989-1990, supported primarily by Pakistan, with an equally severe counterinsurgency response from the Indian armed forces. The people of Indian-administered Kashmir valley have lived in an atmosphere of perpetual siege and have suffered both at the hands of the armed insurgents and the counterinsurgency. This has resulted in more than 70,000 civilian and military deaths, exodus and internal displacement of more than 150,000-300,000 Kashmiri Hindus and 50,000-150,000

Kashmiri Muslims, and the subjugation of a people in their own land.<sup>11-13</sup>

## Impact of Prolonged Armed Conflict on Mental Health of the People

Studies on mental health, conducted during these years of conflict, have demonstrated a high prevalence of mental disorders related to the impact of the armed conflict.<sup>14-20</sup> The worst of the violence has coincided with a documented 30-fold increase in the incidence and prevalence of mental disorders in the region.<sup>7,8</sup> Earlier studies<sup>21</sup> reported that one-third of the population showed evidence of psychological distress and suicidal ideation among adults. More recent studies<sup>17</sup> have reported even higher rates, ranging from 19% for post-traumatic stress disorder (PTSD) to 41% for “probable depression” in adults, and a prevalence of 22% to 27% for childhood disorders (aged 8-14 years).<sup>20</sup> No specific studies on mental disorders in young people (aged 14-30 years)—during the peak years of onset—have been conducted. This substantially increased prevalence of mental disorders among this cohort has also been confirmed by several local surveys.<sup>14-16,18,19</sup> Even as early as 1990-1994, the number of cases seen in the hospital clinics increased ten-fold from 1762 in 1990 to 17,584 in 1994.<sup>18</sup>

## Service Response and Access to Treatment

The well-documented paucity of mental health services in LMICs is related mainly to a lack of trained professionals and adequate structures within an already underfunded and overburdened general health care system.<sup>22</sup> The need to create capacity for the adequate and timely treatment of mental disorders in LMICs has been well articulated in the Lancet Global Mental Health series.<sup>23</sup> The delivery of effective treatments needs to be adapted to the reality of a dearth of trained mental health professionals, including, but not limited to, psychiatrists.<sup>24,26</sup> There has been a strong effort to develop mental health services through the existing, albeit poorly resourced, primary health care in India.<sup>24-26</sup>

In Kashmir, a district mental health program (DMHP) was initiated under a national (Indian) plan in 1996 to provide decentralized community-based mental health services. While several studies<sup>30,31</sup> have shown the feasibility of delivering mental health care through primary health care, including the transfer and sharing of specialists’ tasks, the scale-up of such a model has been hindered by the low level of community participation, a lack of trained staff, and, above all, a lack of political will and funding.<sup>31,32</sup>

## Status of Mental Health Problems and Services in Kashmir

Despite the reported increase in the prevalence of mental disorders in the entire state of Jammu and Kashmir (est. population 12.55 million), there are 41 psychiatrists, who

are situated mostly at the teaching institutions in the 2 main cities of Jammu and Srinagar. For the 10 districts of the Kashmir valley (est. population 6.8 million), at the start of the project, there were 140 beds, with outpatient clinics providing services to patients with a variety of mental disorders through 16 qualified psychiatrists, 12 psychologists, and one social worker; 5-6 psychiatrists were allocated as district-level consultants outside the city of Srinagar. Much of the psychiatric care is provided by a few practitioners on a private fee-for-service basis, thus limiting access to those unable to afford it.

Rural areas have little or no access to mental health services that can provide appropriate treatment of common as well as major mental disorders; this is despite a dramatic increase in incidence and prevalence. Even though some basic health services are provided through state-funded primary health care settings, these services are unable to incorporate mental health services to rural populations. Incorporating mental health care into the practices of primary health care physicians (PHCP) was undertaken in 2008. Thirty-three PHCPs were trained by the National Institute of Mental Health and Neurological Sciences (NIMHANS) in Bangalore, and this resulted in an allocation of 13 trained PHCPs as district mental health officers. However, within 5 months, only 2 of these physicians still included mental health as part of their practice. Other attempts have included the provision of counselling through non-medical health workers; however, these health workers were attached to institutional settings<sup>27</sup> with questionable impact.<sup>28</sup> In general, the uptake of these initiatives has been poor and the level of training has been perceived as inadequate.<sup>35,36</sup> Further, the “defeat depression campaign” resulted in little impact on the clinical practices of PHCPs.<sup>29</sup>

## Site Description

The district of Ganderbal in the Kashmir valley extends to the north from the outskirts of the city of Srinagar through the Kangan valley to very remote mountainous regions, including the Thajvas glaciers. The district has a population of 297,000, which is predominantly rural (84%), with a low literacy rate (58% compared with the national average of 74%).<sup>30</sup> Within this district, our project aimed to cover an area with a population of 200,000. We selected this region in 2013 because it had little or no access to governmental mental health services. A 2-week Mental Health Gap Action Programme (mhGAP) training initiative delivered by The Royal College of Psychiatrists (UK) in 2013<sup>31</sup> created little improvement in access to mental health services. The mental health needs were served—albeit to a very limited extent—by SAWAB (“Supporting Always Wholeheartedly All Broken-hearted,” an expression in Kashmiri meaning an act of kindness without expecting anything in return), part of Voluntary Medical Society of Kashmir ([www.voluntarymedicare.org](http://www.voluntarymedicare.org)). SAWAB, led by the site

principle investigator (MM), was founded following the major earthquake disaster in 2006, and continues to offer community support.

### **Adapting and Applying an LHW Model to Ganderbal, Kashmir**

Our effort to develop a model of mental health care for this conflict-plagued region is in line with the needs and deficits identified above. A working model of care must be feasible and cost-effective in the context of scarce resources and be adaptable to the specific local culture and socio-demographic and political context. In general, under such circumstances, it is important to prioritize different needs and interventions that aim for cost-effective, mobile, and scalable solutions without needing to rely heavily on a highly educated, professional workforce.

Previous models of mental health care have integrated mental health care into the primary care setting,<sup>32,33</sup> demonstrated their effectiveness in LMICs,<sup>22</sup> and used LHWs as well as telepsychiatry<sup>34</sup> for implementation. Telepsychiatric interventions are feasible and effective,<sup>42,43</sup> linking specialists to remote regions and reducing inpatient utilization and costs.<sup>44,45</sup> The integration of mental health services into primary care and the training of primary care health workers are often suggested as a workable and efficient,<sup>28,29,33,46,47</sup> and, such models are supported by the Government of India. However, in the Ganderbal district, as outlined in the previous section, it was difficult to use primary health care to deliver psychiatric care to young people with major mental disorders who were receiving limited, if any, care from a poorly resourced SAWAB.

Alternate models, such as the use of voluntary specialist teams from larger centres, have provided “psychosocial support and treatment” using mental health camps in collaboration with scant local resources in other jurisdictions facing civil and military conflict.<sup>35</sup> Our choice of a model utilizing trained LHWs was, however, based on several considerations, including strong evidence supporting the training of “lay” (non-professional) individuals to fill the gap due to the absence or scarcity of specialists<sup>36</sup> and the feasibility of using this model in making treatment of common disorders such as, depression and anxiety, available to a larger population, especially those in rural areas, as demonstrated in other parts of India.<sup>37-39</sup> Often these are provided through, or in partnership with, a voluntary organization or a Non-Governmental Organization (NGO). The type of services provided by LHWs can range from prevention to case identification and psychosocial interventions. This model has the potential to build local capacity and has a higher chance of sustainability due to the involvement of local personnel. However, it needs to be tested in a wider range of settings,<sup>39</sup> including high-conflict regions replete with their unique challenges.

### **Using Theory of Change to Guide Local Adaptation and Implementation**

The purpose of this project was to adapt and apply components of an LHW model in the context of protracted civil and military conflict, relative geographic isolation, and limited means of communication, through a partnership with an active voluntary service (SAWAB). Given the complexity of this challenge, we developed a Theory of Change framework<sup>40</sup> that involved backward mapping the pathway to a clearly identified envisioned impact from a well-characterised starting point (see Figure 1). Our theory of change was developed over several weeks through a process of iterative inquiry and dialogue between project stakeholders (principle investigator AM, co-principle investigator MM and his local team, and Co-investigators SI, SL) using teleconference meetings and extensive follow-up through email communications. Consultation with an expert in the use of theory of change within global mental health contexts helped us to reflect on the various factors, assumptions, and considerations involved in influencing the project’s envisioned impact on the untreated prevalence of mental disorders and long-term outcomes (i.e., significant reduction in symptoms and improvement in functioning and well-being) among young people (aged 14-30 years).

The content of the theory was influenced by local knowledge; clinical service experience in youth mental health care, including early case identification; and research in global youth mental health. We began by identifying preconditions that needed to be fulfilled to achieve the desired long-term outcomes of reducing symptoms and improving functioning and wellbeing; e.g., an increase in the number of young people identified with mental disorders in the community: this identified at least 200 cases. This was based on 3 factors: knowledge of the number of cases previously treated by the local SAWAB organization within the preceding 2 years ( $n = 187$ , mean = 94 per year), research of the literature pertaining to unmet need in youth mental health, and an understanding of the feasibility of what can be achieved within the project timeline and scope. Next, we determined the intermediate goals and interventions that would be required to meet the preconditions. An important intermediate goal was to engage key stakeholder groups in the community. We brainstormed a list of different stakeholder groups that would be important to engage in terms of raising their awareness of mental health and how they could access services if they identified a young person in need. We also determined that a key way to facilitate access to care would be through LHWs recruited from the region who would be trained and supervised to deliver basic mental health care. The key assumptions made in asserting that the intermediate goals were attainable and would lead to the longer-term outcomes included: social acceptance by key stakeholders and the need for the involvement of the latter; stability of the social and political context; ability to recruit LHWs (both

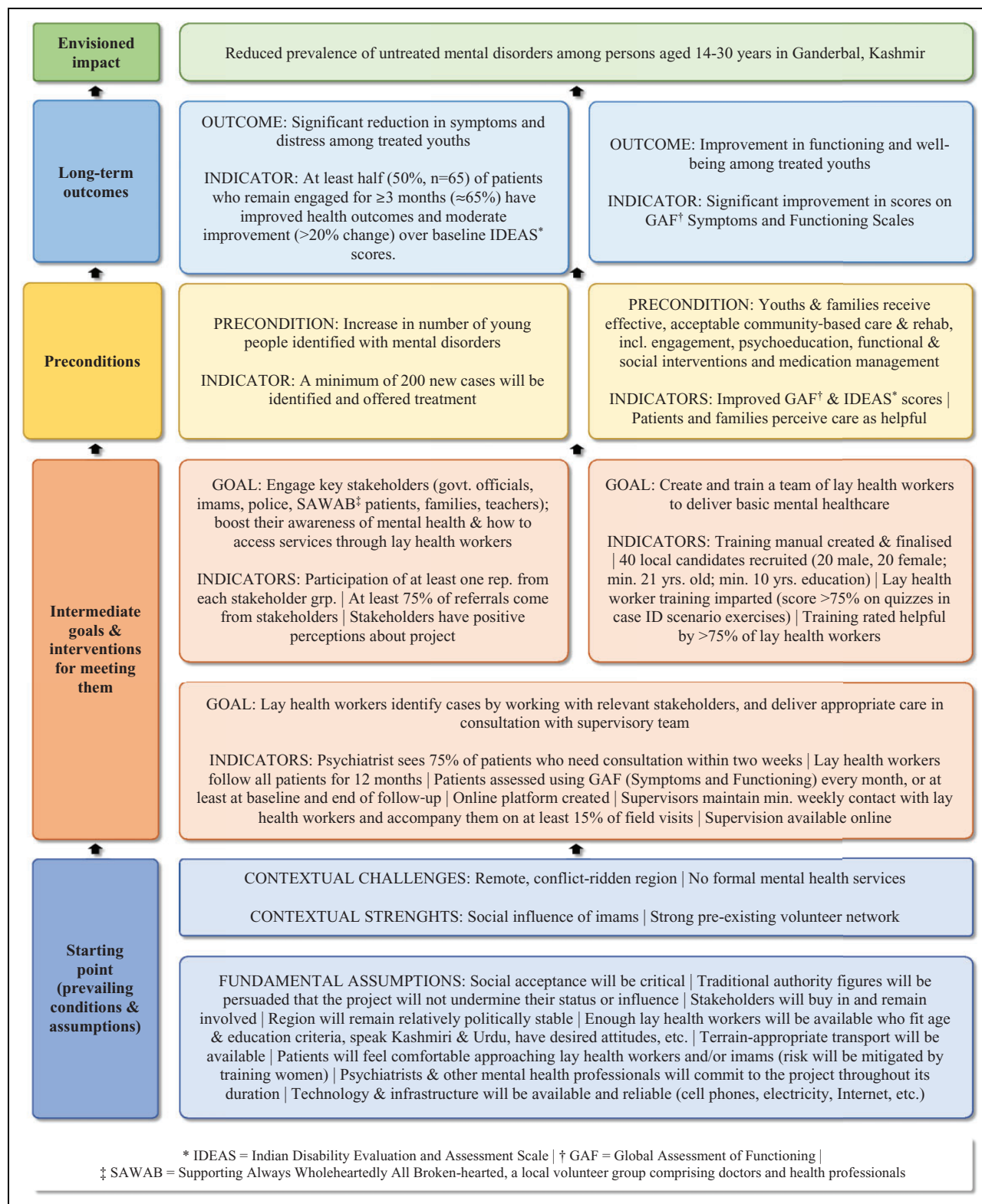


Figure 1. Theory of Change framework for a low-cost model for improving mental health in rural Kashmir, India.

male and female); availability of transport to access relatively remote rural areas; patients' level of comfort with LHWs; availability, willingness and motivation of professionals to provide supervision to LHWs; and access to

technology for LHWs to maintain contact with their patients, for access to training material, and for data collection. The Theory of Change framework served as a blueprint for the implementation of the project and helped communicate its

rationale and approach to key stakeholders and secure their involvement. It can serve as a model for the development and delivery of low-cost mental healthcare services in similar communities (see Figure 1).

### *Adaptation of the LHW Model to Local Context and Objectives*

The implementation of the LHW model required an adaptation to the local needs and political, cultural, and geographic context. We focused on the following WHO-identified major mental disorders: major depressive, psychotic, bipolar and addiction disorders, as well as trauma-related presentations<sup>2,41</sup> in the 14-30 year age range.<sup>1</sup> Apart from being the peak age of onset of mental disorders, this age group forms a relatively high proportion of the population.<sup>42</sup> (The 2011 census shows that 49.91% of the population in India are under 24 years.)

We implemented the LHW Model following 2 key adaptations:

1. We made extensive use of mobile technology (cell-phones, notebooks, television, and electronic media) for improving community mental health literacy, training, service delivery, and evaluation.
2. We attempted to integrate available infrastructures and resources in the region (i.e., volunteer medical organizations and their networks with primary care services, religious, and cultural leaders, and the Department of Psychiatry of the Kashmir University). To overcome potential social barriers, we built upon the work and networks of SAWAB; relied on the expertise of the project principle investigator (AM) and the site principle investigator (MM), who, being Kashmiri natives, knew the local sociocultural and geopolitical context.

### *Project Objectives*

Our primary objectives were to: 1) Adapt and implement an LHW model to the present context of a prolonged conflict that was affecting civilians as well as poor access to mental health services; 2) Enhance mental health awareness among stakeholders and the local population; 3) Promote the identification of major mental disorders among those not receiving any professional care; and 4) Reduce symptoms and distress and improve functioning and wellbeing among those treated. Our secondary objectives were to: 1) Create a pool of trained LHWs; 2) Strengthen the capacity of the local voluntary organization and its network to meet the mental health needs of an underserved population; and 3) Foster dialogue and joint action on mental health issues among multiple stakeholders.

### *Training of LHWs*

We recruited and trained 40 LHWs (18 males and 22 females) from villages within the Ganderbal district, each worker covering an average of 5000 residents. The LHWs were fluent in Kashmiri and Urdu, at least 20 years old, and had sound knowledge of the local communities. Although not required, most (80%) had a college education and all were retained until the end of the project.

The training of LHWs began in September 2014 and comprised one week of didactic lectures supplemented by 3 months of field training. The didactic lectures were provided by the site principle investigator (MM), the project principle investigator (AM) and collaborators (a psychiatrist, community medicine specialist and a general physician), whereas the field training consisted of direct clinical exposure by shadowing clinicians and direct instructions from clinicians in the outpatient clinics run through the Voluntary Medical Society (VMS). The training was based on a manual developed jointly by the investigators in both countries. The manual incorporated materials taken from numerous expert sources in the field that were available at the time (e.g., the COPSI manual for working with people with schizophrenia and their families,<sup>43</sup> the manual for health counselors from the Manas Program,<sup>44</sup> the WHO's mhGAP Intervention Guide<sup>45</sup>). It included 9 modules covering the etiology of mental illness, principles of providing care (including ethics, compassion, confidentiality etc.), suicide prevention, adherence management, psychoeducation of patients and families, health promotion, psychosocial rehabilitation, and relapse prevention. Further, the training program included extensive discussions on note taking, a protocol for risk management, and fieldwork. Following training, LHWs reported significant positive change in their knowledge of and perceptions about the nature of mental illness, symptoms, treatment possibilities, and the role of counseling, as indicated by a high level (83%) of correct responses on a post-training evaluation (see Supplemental information).

### *Integration of Existing Infrastructures and Stakeholder Engagement*

A key step in the planning and implementation of the project was the engagement of key stakeholders initiated by SAWAB, led by the site principle investigator (MM), in which the trained LHWs participated. A total of 150 potential stakeholders attended at least one meeting. Of these, 50 remained engaged throughout the project. These stakeholders included religious leaders or imams, faith healers (locally called "Pirs"), school teachers, local self-government leaders (in the *Panchayat*), community health care personnel, previous SAWAB patients, and media personnel. Led by MM, the local team informally met with stakeholders throughout the length of the project and formally organized 6 mental health workshops to raise awareness about and de-stigmatize mental illness and improve the

identification and management of mental disorders. Involvement of local imams and *Pirs* was particularly significant based on their high social esteem. They had been the first points of contact for over 80% of SAWAB patients<sup>46</sup> but not major sources of referrals for service in the past. Previous mental health care recipients, who were known to source over 70% of the referrals to SAWAB,<sup>46</sup> were also targeted for engagement. In addition to helping refine the service model and promote the identification and referral of potential patients, stakeholders helped promote mental health literacy, general acceptance, and engagement. For instance, imams were encouraged to speak of mental health issues and the project in their Friday sermons, which are highly attended by the almost exclusively Muslim population. During group discussions with the project staff, stakeholders like imams and village heads expressed trust in the project and enthusiasm for working with the LHWs and project staff to improve mental health services and reduce stigma. In addition, an article in a popular English newspaper, describing the importance of imams actively participating in efforts to increase mental health awareness, was an example of raising local awareness about mental illness.<sup>47</sup>

### Use of Technology

LHWs received training materials on their netbook computers, which they used to access psychoeducation materials (videos, documents, for example). LHWs collected data through a simple electronic tool accessible through Android iBall tablets and synchronized to a cloud-based database. The database was accessible via a web-based portal developed specifically for this project. LHWs also encouraged medication adherence and treatment engagement through personal visits and regular phone and SMS contact with patients. Our use of technology in patient engagement (e.g., being in touch or sending reminders by text, among others) was not as extensive as planned. Most contact was made through home visits (>90% of patients received home visits). The LHWs generally agreed that using technology improved service delivery and quality of care but “could not replace direct contact.” Challenges identified by the LHWs in using technology included inadequate mobile network coverage, low mobile phone ownership rates because of poverty, power outages, network blackouts (purportedly imposed for security reasons), and difficulties in text messaging because of the relatively low literacy rates in the region.

Print and broadcast media were used to promote mental health awareness, reduce stigma, and advertise project services.<sup>48</sup> We commissioned short programs that used drama and song (integral to local cultural and social fabric) on local TV and radio to disseminate information on mental disorders through culturally determined models of attribution that emphasize local legends and metaphors; this allowed us to convey the impact of the conflict on mental health and promote the need for treatment.<sup>49</sup>

### Case Identification and Intervention

Individuals (14-30 years) living in the region with putative mental disorders were identified in their villages by assigned LHWs using several methods. These included direct contact with or knowledge about families, who have members known or thought by the community to have emotional and mental difficulties. Cases were also identified by several stakeholders, especially local imams or *Pirs*;<sup>46</sup> other health workers and individuals who had sought and received mental health services in the past from SAWAB; or through direct approach by families. Following any of the above trajectories, the LHW visited the patient and family and conducted a preliminary informal assessment regarding the nature of the problem and the difficulties faced by the patient and the family. Once identified as possibly showing symptoms of mental illness, the LHW arranged for consultation with a psychiatrist within 2 weeks.

Two rooms were rented in a building in the town of Ganderbal (population 28,233) to be used as the project clinic for consultations and as a dispensary for medication. A psychiatrist visited the new clinic every 2 weeks to provide a psychiatric diagnostic assessment to individuals identified by the LHWs and to recommend treatment (medication or counselling or both). The psychiatrist involved the LHW in the initial assessment, discussed the treatment plan, and provided a framework for close follow-up with the LHW. The LHWs routinely conducted door-to-door home visits in their respective villages and the SAWAB psychiatrist visited some patients at home only if the patient was unwilling or unable to travel to the clinic. All medications and counselling were provided free of charge. A patient in urgent need of hospitalization had access to the free inpatient facilities at the hospital in Srinagar.

Counselling, initiated by a SAWAB psychologist and then supported by the LHW, included the provision of non-judgmental, culturally appropriate support and psychoeducation. LHWs, who also worked with patients' families, teachers, and peers to reduce stigma, addressed comorbid substance use and facilitated social, occupational, and/or academic reintegration. LHWs offered a follow-up of 12 months to all patients, with more frequent contact (minimum once in 2 weeks) in the first 3 months and in crisis situations.

LHWs had continual access to their training materials online and received support and supervision during face-to-face meetings, field visits, and web-based video conferencing with SAWAB professionals. The feedback from the LHWs indicated a high level of satisfaction with their work, strong emotional reactions on occasion related to sharing similar traumatic experiences with their patients, and identified advocacy as an important role.

In Part-II of this report, we describe the methods of assessing and results on the clinical, functional, and quality of life outcomes for individuals treated in this program. We further discuss the implications of the model used and the outcomes achieved.



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## Data Access

The senior author and all other authors had full access to the data. The data are saved as per regular research protocol and can be made available with mutual agreement depending on the purpose for such demand, through approach to the senior and corresponding author (A.M.).

## Declaration of Conflicting Interests

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## Supplemental Material

Supplemental material for this article is available online.

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