# Field Visit to a Community-Based Rehabilitation Programme Integrating People with Psychosocial Disabilities in Bangladesh

## An Internal Report for CBM International

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*Figure 1. Outside a self-help group in a rural area of Bangladesh*

**Executive Summary:**
A field visit to the PHRPBD (Promotion of Human Rights of Persons with Disabilities in Bangladesh) programme was conducted in 2019 for a case study on the integration of mental health into community-based rehabilitation (CBR) programmes in low- and middle-income countries. While PHRPBD has made impressive strides in mainstreaming people with psychosocial disabilities in its existing programme of rights-based disability inclusive development work, it struggles to meet their needs for high-quality mental health care within Bangladesh's poorly resourced and highly centralised mental health system. This report describes PHRPBD's work on psychosocial disabilities, its strengths and weaknesses, and the opportunities and threats it may encounter in future.

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# X. About this Report

This report was prepared for the project **"Integration of mental health in community-based inclusive development: Current approaches and recommendations for future practice**", carried out by London School of Hygiene and Tropical Medicine (LSHTM) with funding from CBM International.

The aim of this project is to provide more tailored recommendations for the integration of mental health into community-based inclusive development in low- and middle-income countries (LMICs), based on "real-world" practice. Two key objectives are:

- To develop detailed case studies of community-based rehabilitation (CBR) programmes taking diverse approaches to mental health integration in LMICs.
- To distil from these case studies key learning about the integration of mental health into community-based inclusive development in LMICs.

This report represents one of the key deliverables of the project: documentation of the field visit conducted to a CBR programme in Bangladesh in 2019. Information contained in this report will be incorporated into a three-country (Bangladesh, Bolivia, Nigeria) case study of CBR programmes to be submitted as a research article for publication in a peer-reviewed journal as a further deliverable.

# I. Methods

This report presents findings of a field visit to the PHRPBD project, one of the model projects of an initiative by CDD and CBM. PHRPBD is implemented across nine districts by eight partner organisations, and serves people with all kinds of disabilities, including psychosocial disabilities. A field visit was carried out by the author to Dhaka and Chittagong from 1-8 February 2019.

During the field visit, the author audio-recorded and took notes on 26 semi-structured interviews with people with epilepsy, psychosocial or intellectual disabilities, and carers [Table 1]. These were audio-recorded with the potential for future transcription and analysis.

The author also carried out discussions with members of seven self-help groups (one female-only) during meetings. Other stakeholders visited include: three psychiatrist (NIMH, Chittagong Medical College Hospital, private practice); a social service officer and psychiatric social work officer; members of a local government union council; and the staff of two partner organisations (Jugantar Samaj Unnayan Sangstha [JSUS], Songshoptaque), including their directors as well as their community mobilisers and community disability resource persons (CDRPs). Three project staff (two of whom served as translators) and the Director of CDD also answered questions about the project. These discussions were not audio-recorded, but extensive notes were taken.

Field-notes were transcribed electronically and used to develop a narrative description of the programme. Relevant information from project materials (e.g. webpages, pamphlet) and the academic literature have also been added as necessary, to provide a more complete picture of the project and setting.

| *Table 1. Interviews by Gender and Participant Type** | | |
|---|---|---|
| **Type** | **Male** | **Female** |
| **Carers** | **10** | **11** |
| Psychosocial disabilities | 8 | 7 |
| Intellectual disabilities | 1 | 3 |
| Epilepsy | 1 | 0 |
| Unclear | 0 | 1 |
| **Users** | **3** | **9** |
| Psychosocial disabilities | 2 | 8 |
| Intellectual disabilities | 0 | 0 |
| Epilepsy | 0 | 0 |
| Unclear | 1 | 1 |
| **Note: Some interviews involved more than one carer, and some involved both the user and the carer; hence, number of participants does not match number of interviews. Where the user or carer did not contribute to discussions during the interview (even if present), he or she is omitted from this count.* | | |

## A. Strengths and Limitations

The field visit was conducted by the author, an external researcher with experience conducting case studies of community mental health programmes in Nigeria [1]. A systematic approach was used to document the programme, following the Case Study Methodology to Monitor and Evaluate Community Mental Health Programmes in Low- and Middle-Income Countries developed by the Case Studies Project, a collaboration between CBM and LSHTM. The Case Study Methodology has previously been used for the evaluation of community-based mental health programmes in LMICs [1-3].

This is a diffuse programme implemented through local grassroots partners over a wide geographical area. It was not possible to visit the programme's entire catchment area over a short visit. Instead, the decision was made to focus on more intensive visits around Chittagong and Dhaka, where project activities could be observed in a variety of rural and urban settings, in order to better understand how CBR operates in these different environments. The pilot income-generating activity (cattle rearing) was not operating in these areas, and none of the annual mental health camps were being held at the time of the field visit.

Language proved to be a significant barrier. In Nigeria, for example, language barriers proved challenging during some interviews and observations of service delivery; however, the programme's documentation was entirely in English, the national official language. In Bangladesh, Bangla is the only official national language. It therefore was not possible to carry out as thorough of a desk review (particularly valuable for constructing detailed programme timelines) or statistical analysis, as for other programmes visited. This case study relies mainly on primary data collected through interviews and observation and recorded via fieldnotes. Some English-language materials available online and a printed pamphlet provided by the project were included in a limited desk review.

Programme staff served as live translators, introducing the potential for bias and raising questions regarding the fidelity of translation—as well as presenting a burden to busy professionals. Audio-recordings were taken of 26 client interviews conducted in Bangla, though unfortunately this project wasn't resourced for the additional transcription and translation that would be required to ensure accuracy. Therefore, direct quotations are not provided.

It is also worth noting that some of those identified for inclusion in interviews appeared to have intellectual disabilities, epilepsy or other conditions that are sometimes considered to be outside the remit of psychosocial disabilities. Given the very limited access to training and expertise on mental health in this context, it is understandable that not everyone who has been included in the project on the basis of having a psychosocial disability actually has a mental health condition. However, it does mean that some conclusions drawn from this report may not be specific to people with mental health conditions.

### B. Ethics

Although formal ethical review by an accredited institutional review board is not always necessary for the conduct of a case study, this field visit involved interviews with service users and carers, and therefore could be construed as human subjects research with a vulnerable population. Ethical approvals were secured from LSHTM (United Kingdom) and the Bangladesh Medical Research Council.

## I. Findings

### A. History of the Programme

PHRPBD is a project of CDD, a not-for-profit organisation focused on disability inclusion in Bangladesh. The history of CDD, PHRPBD and the project's inclusion of people with psychosocial disabilities is described further below.

#### 1. CDD

Executive Director A.H.M. Noman Khan founded CDD in 1996 after several years working as a development researcher in Bangladesh's NGO sector—an experience that exposed him to the needs of persons with disabilities [4]. As described on the project website, CDD has since inception focused on mainstreaming disability within development efforts (CDD 2019, n.p.):

> "[Since] 1996 [CDD has] focused on an ambitious and revolutionary strategy to include persons with disabilities within mainstream development efforts, by ensuring their needs are integrated into all phases of the planning of development interventions. CDD's strategy also emphasises the importance of simultaneously removing other barriers to inclusion such as negative misperceptions of disability, lack of physical accessibility, difficulties in communicating and the low level of skill, confidence and leadership capacity of persons with disabilities themselves."[5]

CDD now works in partnership with over 350 organisations both nationally and internationally [4]. It employs around 140 staff (mostly project managers and specialist disability trainers) working across five office and training centres (Dhaka, Savar, Dinajpur, Gaibandha Chittagong, Cox's Bazar) [4].

#### 2. PHRPBD

PHRPBD started in 2010 with funding from the Australian Department of Foreign Affairs and Trade (DFAT) via CBM. The project started work with 12 partner organizations across 11 districts of Bangladesh; currently there are nine partner organizations across eight districts [Box 1] [6]. Mental health was added in the second phase of the project, after recognising that people with psychosocial disabilities were being left behind. The lack of attention to people with psychosocial disabilities in Bangladesh was confirmed through a baseline study, as reported in a recent project pamphlet and summarised in Box 2, below [6]. In response to the findings of the baseline study, PHRPBD adopted two key objectives: (1) To prevent mental health conditions from leading to psychosocial disabilities; (2) To include people with mental health conditions in all aspects of the community. The first

activities explicitly targeting people with psychosocial disabilities (i.e. identification via community surveys, inclusion in self-help groups, mental health camps) were launched in 2016.

***Box 1. Example of PHRPBD Partner Organisation: Jugantar Samaj Unnayan Sangstha***

JSUS is a women-led local Bangladeshi NGO established in Chittagong in 1997. In its early years, the focus of JSUS was on child labour. It ran an education programme and a savings programme for children's families. Through this work, JSUS identified persons with disabilities in need of support, but didn't feel it had the in-house expertise necessary to address those needs. JSUS reached out to CDD in 2006 and received the management and other trainings necessary to become a partner organisation. JSUS is currently run by an Executive Director and Assistant Executive Director with expertise in microfinance and accounts, a programme manager in charge of social interventions, and a monitoring officer. It runs a number of different projects in partnership with CDD as well as other NGOs, such as Save the Children and BRAC (Building Resources Across Communities).

In partnership with CDD, JSUS began implementing PHRPBD in two wards of Chittagong City Corporation in March 2010 [7]. Each ward in its catchment area is served by two community workers: a community mobiliser and CDRP. As part of PHRPBD, JSUS started ten self-help groups for persons with disabilities (mostly adults)—including one women-only group. However, the first phase did not address psychosocial disabilities.

In 2016 JSUS began working on mental health, starting with a community survey. Stakeholder meetings were then organised with carers, government representatives, and other key stakeholders. Mental health care was provided via a screening camp, in which 53 people with mental health conditions (32 females, 21 males; mostly psychosis) were identified in the JSUS catchment area. Through PHRPBD, the organisation was able to provide some medication support as well as regular follow-up to monitor medication adherence and side effects.

***Box 2. Findings of Baseline Situation Analysis on Mental Health Conditions in Project Locations***

- **Prevalence:** No reliable survey data from which to estimate prevalence of mental health conditions in Bangladesh
- **Explanatory models:** Mental health is commonly seen not as a medical issue, but rather as a curse resulting from sin, bad wind, ghosts, spirits, and other supernatural causes; many seek care from traditional healers and "quacks".
- **Stigma and discrimination:** People with mental health conditions are stigmatised, harassed and abused; consequently, they are often hidden by their families and excluded from development initiatives and other activities.
- **Gender:** Women with mental health conditions are particularly vulnerable to abuse from their families and neighbours.
- **Psychiatric care:** Psychiatric facilities are few, overcrowded, understaffed and difficult to access for many. There are no psychiatrists or psychologists working in the public sector at the district or sub-district levels, and no medication available at the sub-district level. There is also no orientation on mental health among primary care service providers in community clinics, upazila health complexes, etc.
- **Social services:** There is very little awareness about mental health among public-sector service providers, who do not have the knowledge or skills to practically address barriers to inclusion in their planning or budgeting. Even one-stop service centres for persons with disabilities have no specific strategy, training or human resources to address mental health.

## B. Description of the Programme

### 1. Conceptual Framework

PHRPBD is working to mainstream mental health and psychosocial disabilities within its existing programme of rights-based disability inclusive development work. The project applies a four-part strategy to meet its objectives, with a number of interventions proposed to enact each strategy, as described in a recent PHRPBD pamphlet (pp. 6) and summarised in the below table [6].

Central to many of these activities is the self-help group, supported by a Community Mobiliser and CDRP. Self-help group members participate in community surveys to identify people with psychosocial disabilities, notify community members about upcoming mental health camps, welcome people with psychosocial disabilities and their carers to join their groups, and from there, offer a supportive network to share learning (for example, on how to access a disability allowance) and advocate for the rights of members (for example, to help children return to school). As a staff member explained, PHRPBD takes the position that empowerment via self-help groups is the starting point to achieving other aspects of inclusion.

**Table 2. Project Strategies and Interventions for Mental Health**

| Strategies | | Interventions |
|---|---|---|
| **1** | **Identification and Treatment** | Survey working area to identify people with mental health conditions and establish baseline. Develop a database. Organise mental health camps to diagnose and prescribe. Provide support paying for medication on an as-needed basis. |
| **2** | **Awareness raising on mental health** | Develop awareness-raising materials to sensitise the community. Sensitise self-help group members through meetings. Arrange further sensitisation and regular meetings with carers. Conduct additional meetings with local government, faith groups and schools. |
| **3** | **Capacity development** | Organise basic training on mental health, counselling, etc. for project staff. Organise exposure visits for more experiential learnings. Arrange training for carers. |
| **4** | **Inclusion** | Include people with psychosocial disabilities in existing groups (e.g. self-help groups, savings groups), activities (e.g. income-generating activities and training, other vocational training), services (e.g. education, disability allowance), and advocacy (e.g. with local government and higher government officials) |

Table 3 outlines the key elements of the World Health Organisation's CBR Matrix and uses a red/yellow/green system to characterize the support currently available:

- **Red** indicates that support has never been available.
- **Yellow** indicates support that was previously available but is no longer or is extremely limited in scope or supply for people with psychosocial disabilities, specifically.
- **Green** indicates support that is currently available for people with psychosocial disabilities.

***Table 3. Alignment of Services with CBR Matrix***

| Health | |
|---|---|
| **Promotion and Prevention** | • Occasional stakeholder meetings and some print materials for community sensitisation |

| | |
|---|---|
| **Medical care** | • Infrequent (annual) mental health camps and some financial support for medication<br>• Self-help groups and family members may help facilitate access to follow-up care in tertiary facilities on an as-needed basis |
| **Rehabilitation** | • No occupational therapy or other rehabilitation targeting people with psychosocial disabilities specifically, though CDRP offers general rehabilitation support |
| **Assistive devices** | • Available for clients with physical disabilities |
| **Education** | |
| **Early childhood** | • School sensitisation and advocacy to include children with disabilities in mainstream schools at all levels<br>• Successful advocacy to at least one union council to ring-fence funds for educational support of people with psychosocial disabilities |
| **Primary** | |
| **Secondary and higher** | |
| **Non-formal** | • None other than "skills-development" |
| **Lifelong learning** | • Some initiatives for lifelong learning (e.g. CDD leadership training) |
| **Livelihood** | |
| **Skills development** | • Mostly informal training between self-help group members |
| **Self-employment** | • Some successful examples resulting primarily from efforts of self-help groups (e.g. selling faux flowers) |
| **Financial services** | • Some access to interest-free loans via linkages to government and from collective savings of self-help groups |
| **Social protection** | • Support to access government social safety net programmes and advocacy to increase budget and scope of social protection |
| **Social** | |
| **Personal assistance** | • None/no evidence |
| **Relationships, marriage and family** | • Some indication of carers' meetings and parents' groups |
| **Culture and arts** | • Some inclusive arts and cultural programming in collaboration with government in which people with psychosocial disabilities have participated |
| **Recreation, leisure and sports** | • Some indication of picnics and other social activities being organised by self-help groups |
| **Justice** | • Some examples provided of support from self-help groups to seek justice following infringement of members' rights<br>• In-house legal advisor and links to Bangladesh Legal Aid and Services Trust (BLAST) |
| **Empowerment** | |
| **Advocacy and communication** | • Inclusion of people with psychosocial disabilities in advocacy meetings |
| **Community mobilisation** | • Some community mobilisation (e.g. disability surveys, community sensitisation meetings), though limited for psychosocial disabilities |
| **Political participation** | • None other than participation in "advocacy" |
| **Self-help groups** | • Self-help groups for disabilities include members with psychosocial disabilities |
| **Disabled people's organizations** | • Apex body comprised of representatives elected from self-help groups |

## 2. Promotion and Prevention

The project does not appear to use any targeted strategy for mental health promotion or primary prevention (though much of its work on mental health could be considered secondary or tertiary prevention). However, PHRPBD does describe awareness-raising as "one of the crucial strategies" for achieving its objectives (PHRPBD n.d., pp.5), and reports that CDD has developed a set of mental health flash-cards, posters and leaflets on mental health for community sensitisation [6]. It also reports that meetings have been held with various stakeholders to raise awareness, for example with carers of people with psychosocial disabilities, schools, local government and faith groups [6]. It appears from discussions with one of the partner organisations that a community theatre activity is also in the works. However, additional follow-up is needed to verify process indicators such as number of materials distributed, number of stakeholders who have participated in meetings, etc., in order to better understand the extent of this work to-date.

## 3. Mental Health Care

In Bangladesh, mental health care is heavily centralised in understaffed tertiary facilities concentrated in largely urban areas. Tertiary care is provided via the NIMH (200 mental health beds), Pabna Mental Hospital (500 mental health beds), and psychiatric departments in the Bangabandhu Sheikh Mujib Medical Univeristy (40 mental health beds) and 64 Medical Colleges (up to 20 mental health beds) [6]. According to figures cited in a recent NIMH study, there are also 3,900 mental health beds in residential facilities [8]. The authors of the NIMH study observe that compared to the rest of the country, areas in and around Dhaka have five times the density of mental health beds; yet 70% of the country's population live in rural areas [8].

According to an interviewee in NIMH's Social Work Department, Bangladesh has 220 psychiatrists (most of whom run private practices alongside public sector work) and 60 clinical psychologists (10 public, 50 private). There are only four government-funded psychiatric social workers posts. 5,000 trained mental health nurses make up the majority of Bangladesh's mental health workforce (though a PHRPBD pamphlet claims that only 1,200 nurses have been trained in mental health [6]). Ten thousand primary healthcare physicians have also received a seven-day training on the management of common psychiatric disorders [6]. However, recent literature states that there is no substantial mental health care available in primary or secondary care facilities [9], and that referrals from general practitioners to tertiary care are negligible [8].

Understaffing takes a significant toll on the quality and accessibility of mental health services in Bangladesh, as observed during visits to a Medical College and to the NIMH. One interviewee reported waiting for outpatient care for as long as 12 hours on some occasions. Inpatient wards at the Medical College were overcrowded, with men and women sometimes mixed together due to overflow in gender-specific wards. Some inpatients were physically restrained.

A study on pathways to care for psychiatric outpatients at the National Institute of Mental Health found that traditional healers were the second most popular care providers, after private psychiatrists [8]. Twenty percent of respondents in the study sample had visited a traditional healer, 5% had visited a religious healer, and 2.5% had visited a homeopath [8]. During the field visit, many interviewees also reported having sought care from traditional or religious healers before being identified by the project. Cost for non-medical treatment varies: one interviewee reported paying 500-1,000 BDT (approximately £5-£10 GBP) for one-time treatment by a traditional healer; another spent an estimated two lakhs (200,000 BDT, or nearly £1,800 GBP) on traditional healing over ten years. Although the author did not hear any reports of abusive practices by traditional or religious healers, some interviewees did complain of the cost and ineffectiveness of the services provided.

As a community-based alternative, PHRPBD organises annual mental health camps. However, treatment is mainly pharmaceutical, and project staff recognise a major gap in terms of the provision of psychotherapy and psychoeducation for people with mental health conditions and their families. Between 2016-2017 a total of 24 mental health camps were held across all 11 of the districts involved in the project. The psychiatrist typically sees around 50 people at each mental health camp, spending 15-20 minutes with new patients to explain their condition and treatment. Less time is spent with current patients, unless they are experiencing problems. 936 people were assessed by a psychiatrist [Tables 4-5], and 311 received support from PBHRPBD to pay for their medications. Patients from the camp either phone the psychiatrist or come to their public or private practice for follow-up on an as-needed basis. Self-help groups may sometimes organise group trips for follow-up. Self-help group members and CDRPs may also carry out home visits to check on patients and how they are managing their medications.

Self-help groups have played an important role in alerting community members about the mental health camps and convincing families to bring their relatives—sometimes physically accompanying them to the camps. However, self-help group members report that it can be logistically difficult to transport people with severe conditions to the camps, and some family members do not want to allow those with mental health conditions outside, due to stigma. In one case, for example, a man whose brother had epilepsy and severe cognitive impairment brought the brother to the mental health camp in chains. The man's daughter also had epilepsy, but without the same level of impairment. She was not allowed to go to the camp, as the man feared that it might affect her marriage prospects.

## 4. Self-Help Groups

PHRPBD describes itself as "one of the model projects for CDD and CBM for promoting rights and community empowerment through Self Help Group (SHG) Initiatives" (CDD n.d., pp.3) [6]. Before forming self-help groups, two persons with disabilities from each project location of the 12 partner organisations completed 28 days on CDD training on Leadership and Rights [10]. Trainees then established groups in their local communities with support from the trained community-based personnel of the local partner organisation [10].

As of September 2019, 108 self-help groups have been formed, engaging 1500 persons with disabilities [6,11]. Each self-help group has around 12-15 members with an executive committee of five members: a president, a secretary, a treasurer/cashier and two other members [10]. Either the president or secretary must be a woman. One eighth of all self-help groups are dedicated exclusively to women, though others include both women and men in mixed groups [10]. Among the mixed groups, 40% of members are women [10].

Most self-help group members have physical impairments (e.g. visual, hearing, motor functioning, etc.) though since 2016 people with psychosocial disabilities have been included. In most of the self-help groups visited, one or two members had psychosocial or intellectual disabilities. In group discussions, many members said that they were initially wary of including people with psychosocial disabilities, whom they worried would be disruptive to meetings. Eventually, however, they came to see the inclusion of people with different kinds of disabilities as a strength and an opportunity to learn from one another.

Self-help groups organise fortnightly meetings, and the last meeting of each month is used to make an activity plan for the following month [10]. A conference paper from 2015 by Taslima Akter, the current manager, provides a succinct description of their general activities [10]:

> "They regularly communicate with the Union Parishad (local body of elected public representatives) members, local government offices and other stakeholders. The group members engage with community awareness raising, local resource mobilizations, inclusion activities, advocacy campaigns, etc. They identify different advocacy issues during their regular group meetings, discuss among themselves on those issues [sic]. By using their training-learning on advocacy campaign design, they make their advocacy plans on various issues. They make lists of school age children with disabilities and involve with counseling and advocacy activities for the admission of those children [sic]. Many of the groups have started group savings scheme [sic]. Among those some of the groups have started providing loans to the group members from the savings for different types of livelihood activities like, poultry, cattle rearing, running grocery stores, etc. They also take advocacy initiatives to be involved in safety net programs of the government." (Akter 2015, n.p.)

Each of the 12 partner organisations has established an apex body, comprised of around 16 members (two from each of approximately eight self-help groups for each partner organisation) [10]. Apex bodies provide a management structure for self-help groups and are able to advocate for the collective benefit of their members across multiple locations; much of their advocacy work focuses on the district- and sub-district levels of government, though they sometimes also work at the divisional and national levels [10]. Apex bodies also compile lists of local resources, so that they can provide referrals to relevant services for self-help group members [10]. Apex bodies meet every two months and operate with a quarterly action plan [10].

## 5. Livelihoods

As observed in Akter's 2015 conference paper, most self-help group members live in poverty and have an expectation of receiving short-term and tangible benefits from the project—particularly in the area of livelihoods support—making it difficult at times to secure buy-in regarding longer-term objectives such as sensitisation and advocacy [10]. However, recent years' successes may be changing perceptions regarding the benefits of self-help groups.

During discussions with self-help groups, it appeared that many members valued assistance they had received through the self-help group in navigating confusing bureaucratic procedures to access the government's social safety net programmes (e.g. disability allowance). In one interview, a mother said she had taken her daughter to government offices previously to apply for disability allowance, but because she didn't understand the process, she was ignored by officials; the self-help group helped her to finally apply successfully. In another case, a member was asked by a government official for a bribe to arrange the disability allowance; the self-help group members were able to make a complaint to the upazila office.

Self-help groups and apex bodies are also advocating for more spending on disability. For example, City Corporations have municipal funds already allocated to disability, but there's no specification on how they should use it. Advocates are working to advise on this, to ensure the money doesn't go unspent. They are also advocating for a quota of government tenders to be given to people with psychosocial disabilities. In another example, advocacy at the union level resulted in 50,000 taka being allocated for assistive devices.

Self-help groups collect dues from members, and savings may be used for loans. One group reported savings of 100,000 (1 lakh) BDT (approximately £900 GBP). During visits, several stories were shared in which self-help group members had taught each other marketable skills and initiated small business activities. For example, a young woman diagnosed with schizophrenia was taught how to craft faux flowers to decorate autorickshaws, and now earns a monthly income of 1200-1500 BDT

(about £10-15 GBP) [6]. Other stories emphasised the role of self-help groups in protecting the financial interests of members in vulnerable positions when family members threaten to assume control over their land or other property.

PHRPBD does not currently undertake much direct livelihoods support, except for in one pilot where grant support was provided to eight self-help groups in one project location. This pilot consisted of two cycles of cow-fattening. In the first cycle there was widespread flooding, resulting in only two groups making profits, two making losses, and four breaking even. The second cycle is now underway and appears to be more profitable. A livelihoods officer post has now been created to provide more guidance on this front, and PHRPBD is investigating goat-rearing as another potential livelihoods activity.

In other locations, some participants have accessed livelihoods opportunities via links with other organisations; one self-help group shared the example of a girl who had been taught how to sew and given a sewing machine by a local foundation. Sometimes participants are also able to access interest-free loans through linkages with the social department.

## 6. Additional Psychosocial Support and Rehabilitation

PHRPBD takes a mainstreaming approach to education, sensitising teachers and parents so that children with disabilities can attend public schools. For example, a young woman with polio reported that when she completed class five, a school refused to admit her, because the classroom was not on the ground floor. She protested, saying that she could make it up the stairs, but the school still refused, until she went with five self-help group members to speak to the teacher about the rights of persons with disabilities to public education.

Unfortunately, in interviews and discussions with self-help groups, it was unclear to what extent people with psychosocial disabilities were benefitting from PHRPBD's efforts in education. However, one union council did indicate that as a result of PHRPBD advocacy, they had ring-fenced some of their budget for education support to benefit people with psychosocial disabilities [Box 3].

Project staff also pointed to major gaps in terms of occupational rehabilitation and psychotherapies for people with psychosocial disabilities, due to the shortage of specialist mental health workers in Bangladesh. At NIMH, a psychiatric social work officer explained that even in tertiary care, the emphasis is on showing families how to support rehabilitation, because there are too few staff to provide ongoing one-to-one support.

Another social service officer suggested that further training and awareness-raising is also needed for those working in social services. He explained that people working in social services do not receive sufficient orientation on mental health and how to communicate with people with severe mental health conditions, and fear violence from people with psychosocial disabilities.

***Box 3. Example of local government advocacy: Halidhor Union Council***

Bangladesh has a devolved structure of government. The country is divided into 64 districts (*zila*), which are further divided into 493 sub-districts (*upazila*). Rural *upazilas* are further divided into union councils (*parishads*). Each *parishad* is comprised of nine wards, with each ward typically representing a single village.

In a meeting with Halidhor Union Council in Malghor, Anowara, the government-appointed secretary reported that Songshoptaque had arranged training and awareness-raising activities for ward members on mental health. As a consequence of these activities as well as the advocacy of self-help groups and their apex bodies, the union is seeking to allocate more of its 50,000 BDT

annual budget for disabilities to psychosocial disabilities. For example, while funding for the social safety net programme remains limited, more allowances have been made for people with psychosocial disabilities this year. Some funds have been set aside specifically for school stipends for people with psychosocial disabilities. The union is also planning its own version of a mental health camp. They have identified a trained doctor at the sub-district level who has seven days of training in the identification and referral of people with mental health conditions but cannot provide direct treatment.

Through PHRPBD, the union council has also taken a more inclusive approach to disability generally. The union has 13 standing committees implementing different kinds of activities. Four persons with disabilities are now committee members. The union has developed its action plan on disabilities across the nine wards in concert with self-help groups, their apex bodies, and Songshoptaque, as well as local government. Another concrete demonstration of the union's support for the project is that it arranged a meeting room for self-help groups.

## C. Programme Resources

### 1. Human

Each partner organisation has its own management structure [e.g. Box 1], and staffing varies between the partners. At some organisations, there appears to be a concerted effort to hire persons with disabilities. CDD employs a cross-site Project Manager for PHRPBD, who manages the project across the 12 partner organisations.

As part of PHRPBD, each local partner organisation employs two community-based staff: a CDRP and Community Mobiliser. Qualifications are a secondary certificate and a willingness to work. In each CDRP-Community Mobiliser duo, at least one should have a disability. Both receive salaries from the project, plus compensation for their phone use and a festival allowance. While there has been a trend toward voluntarisation of similar positions at other CBM-affiliated sites, the partner organisations have insisted on compensation. However, salaries are still not considered competitive, and needs for staffing in response to the Rohingya crisis have contributed to staff turnover.

Field staff receive a very basic six-day training on mental health, and an exposure visit to ADD International's mental health programme. This training focused on what is mental health, symptoms and how to assess them, but staff still feel underprepared to manage complex cases. The general CDRP training is three months long, so staff consider the mental health training to be very short in comparison. While CDRP conduct home visits to help transfer skills to persons with disabilities and their families, the support they provide to those with psychosocial disabilities is not especially targeted, focusing mainly on medication adherence and life skills.

### 2. Funding

Funding for the parent organisation CDD comes from many different sources. The main Training and Learning Centre is often rented out as an accessible events facility close to Dhaka city, to generate additional income for the organisation. According to the Director, CDD also sells some training and assistive devices, collaborates with universities on research, runs a braille press for the government, and receives project-specific funding from national and international organisations.

PHRPBD is one of these projects, funded by the Australian Government's DFAT via CBM Australia. PHRPBD has been awarded 82,247,574 BDT (£741,997 GBP) for its current phase of activity, from July 2018 to June 2021 [4]. However, this funding is time-limited and not specific to psychosocial disabilities.

### 3. Medications

Medications are prescribed by the psychiatrist at outreach camps and follow-up visits. Bangladesh is considered to be largely self-sufficient in the production of generic drugs from the country's essential medicine list, though issues with stock-outs have been observed in public facilities [12,13]. Quality control can also be an issue; during annual testing by the government laboratory in 2004, 300 of 5,000 drug samples were identified as counterfeit or poor quality [13,14].

However, interviewees did not voice concerns about stock-outs or efficacy. Rather, they almost unanimously complained about the price of medication. PHRPBD covers a portion (30-50%) of the cost but expects families to become habituated to paying toward medication on a regular basis, reasoning that this will contribute to sustainability when the project ends. Families are expected to be weaned off medication support during the project's lifetime. Most interviewees said their medication costs a few thousand BDT (1,500-4,000) per month, several times their monthly disability allowance (650-700), and causes significant hardship. A few interviewees reported stopping medication for this reason.

Polypharmacy appears to be contributing to the high cost of medication. Most interviewees reported receiving multiple prescriptions from the psychiatrist. One teenage boy (age 18), for example, was prescribed three medications plus a vitamin supplement. Another young man (age 25) was initially prescribed five medications, and after experiencing severe side effects such as tremors, was reduced to three, but continues to complain of drowsiness. Several other interviewees complained of weight gain and sleeping too much—problematic side effects that can be substantially worsened by polypharmacy.

The infrequency of mental health camps, lack of specialist supervision and barriers to accessing follow-up care from facilities mean that issues with medication may not be swiftly addressed, incurring unnecessary losses to the programme's budget for medication support, as well as financial and physical difficulties for participants.

### 4. Transportation

Although CDD does have some vehicles, PHRPBD does not appear to have its own dedicated transport. Auto-rickshaws are commonly used across short distances. One CDRP reported having been provided a motorbike by the partner organisation. The project pays for fuel.

Self-help group members reported travelling short distances for meetings and camps, and had little trouble paying for transport when necessary. However, in at least one case where a client was acutely ill, restraints were use, and it proved quite difficult to reach the camp. In another rural area, a woman who was pregnant didn't feel she could make the 30-minute drive by auto-rickshaw across poor roads and missed the annual mental health camp.

By contrast, transport to tertiary care facilities was often described as expensive, lengthy and difficult, particularly given high levels of traffic in urban areas of Bangladesh. At the Medical College, a woman waiting for outpatient mental health care explained that she had travelled for a day and a half from her district. Another young man reported that it took him an hour and a half to reach the Medical College by auto-rickshaw, but still cost him 500 BDT each way, in addition to the 700 BDT for the doctor's services, and he was expected to go every 15 days. Together with his 3,000 BDT monthly prescription, this brought his total mental health care cost to 6,400 BDT (£58 GBP) per month—about ten times the monthly disability allowance.

## D. Information System

The WHO'S 2007 Mental Health AIMS (Assessment Instrument for Mental Health Systems) report for Bangladesh states that the government's health department receives data from the main psychiatric hospital and less than half of community-based psychiatric inpatient units (45%) and mental health outpatient facilities (28%) [15]. It also describes the information gathered from these facilities as "insuffient" (WHO 2007, pp. vi). More recently, an assessment by Nazmun Nahar Nuri and colleagues (2018) has found the quality of data collected through the NIMH mental health information system to be poor [16].

Staff reported that data is regularly collected for the project's purposes, though the methods of data collection, storage and analysis were not observed during the field visit. The main source of data on people with psychosocial disabilities comes from the annual mental health camps, where diagnosis is recorded. Tables 4-5 show data from the 2016 and 2017 mental health camps, as reported in a recent project pamphlet [6]. Further analysis is needed to disaggregate by gender, age, diagnosis and year of assessment, and to verify whether these numbers represent individuals or contacts (as some individuals are likely to attend multiple camps and could therefore be double-counted). It is also unclear how and whether this data feeds into the national mental health information system.

**Table 4. Gender and age group of clients presenting to mental health camps, 2016-2017**

| | Males | Females | Sub-totals |
|---|---|---|---|
| **Children** | **169 (18.06%)** | **119 (12.71%)** | **288 (30.77%)** |
| **Adults** | **308 (32.91%)** | **340 (36.32%)** | **648 (69.23%)** |
| 18-35 | 198 | 208 | 406 |
| 36+ | 110 | 132 | 242 |

**Table 5. Diagnoses of clients presenting to mental health camps, 2016-2017**

| | 2016 | 2017 | Sub-totals |
|---|---|---|---|
| **Psychotic disorders** | **139 (14.85%)** | **144 (15.38%)** | **283 (30.24%)** |
| Schizophrenia | 35 | 37 | 72 |
| Other psychosis | 104 | 107 | 211 |
| **Mood disorders** | **157 (16.77%)** | **125 (13.35%)** | **282 (30.13%)** |
| Depression | 104 | 79 | 183 |
| Bipolar disorder | 53 | 46 | 99 |
| **Neurological disorders** | **84 (8.97%)** | **68 (7.26%)** | **152 (16.24%)** |
| Epilepsy | 43 | 23 | 66 |
| Dementia | 41 | 45 | 86 |
| **Neurotic and stress-related disorders** | **33 (3.53%)** | **67 (7.16%)** | **100 (10.68%)** |
| Anxiety | 19 | 35 | 54 |
| Obsessive-compulsive disorder | 14 | 32 | 46 |
| **Developmental and behavioural disorders** | **37 (3.95%)** | **30 (3.21%)** | **67 (7.16%)** |
| Intellectual | 28 | 25 | 53 |
| Attention-deficit hyperactivity | 6 | 3 | 9 |
| Autism | 3 | 2 | 5 |
| **Substance use** | **5 (0.53%)** | **7 (0.75%)** | **12 (1.28%)** |
| **Other** | **21 (2.24%)** | **19 (2.03%)** | **40 (4.27%)** |

# II. SWOT Analysis

## A. Strengths

Over the past three years, PHRPBD has made impressive strides in mainstreaming people with psychosocial disabilities within its existing programme of activities. By taking an empowerment approach, in which people with physical and psychosocial disabilities support one another in enacting a shared agenda, the project has resulted in a number of exciting policy "wins" at the level of local government [e.g. Box 3]. Leveraging the country's rapidly evolving social safety net programme to provide short-term tangible benefits appears to offer a "hook" into self-help groups, which then serve as local hubs for advocacy, resource mapping and networking, skills development and other project activities.

Several dramatic examples of improvements to human rights were shared. For example, one woman in a self-help group explained that they had previously been to a neurologist, who said her daughter's condition was untreatable. She thought the situation was hopeless and chained her daughter at home. Eventually the girl was identified by the self-help group, taken to the camp, and then showed some improvement. The girl is no longer chained at home and now attends self-help group meetings with her mother. These are promising outcomes, which should be explored further, using more rigorous methods of research.

In addition to the many achievements of the project cited throughout this report, PHRPBD has taken careful consideration of the local context in its design, as described further below.

### 1. Representation

PHRPBD's structure reflects its sensitivity to issues of representation for persons with disabilities as well as for women with disabilities, specifically. As described above, each CDRP-community mobiliser duo must include at least one person with disabilities (though all those encountered during this field visit were male). The project allows for women-only self-help groups and also sets quotas for the number of women in mixed groups and in the leadership of these groups. Sensitivity to representation undoubtedly contributes to the success of project activities, by ensuring those "closest to the problem" are in position to address them.

Some outstanding issues related to gender were observable, however—particularly in regard to mental health services. Members of the women's self-help group explained that they were not always comfortable speaking to male service providers about their problems. At least one young woman was prevented from attending a mental health camp, for fear that it might affect her marriage prospects. Another woman with a male carer could not make the long journey to a hospital to receive follow-up care, as a female attendant was needed to accompany her on bathroom breaks. These are concerns which may need to be taken into consideration in future.

### 2. Rural/Urban Spread

The inclusion of both rural and urban areas under the project is also a strength. Several interviewees, including a social welfare officer, commented on the difficulty of identifying persons with disabilities in high-migration urban areas and connecting them to services. On the other hand, rural areas have much poorer access to mental health care and fewer options for paid employment. While many mental health programmes focus either on urban areas—for logistical reasons—or rural areas—to target the most underserved populations—PHRPBD does both. Operating through local partner organisations means being able to draw on their unique skills, networks and contextual understanding, appropriate to each environment.

## B. Weaknesses

Despite PHRPBD's many impressive achievements, there are a few areas which could be addressed to strengthen the psychosocial component of this project.

### 1. Mental Health Expertise

Aside from the psychiatrists engaged in the project, PHRPBD does not have any specialist in-house expertise on mental health. Staff of the project and partner organisations reported that they did not have adequate training in mental health or the competencies to handle complex or severe cases. They also had very limited opportunities to learn from other organisations working on mental health in Bangladesh. While PHRPBD's mainstreaming approach means that people with psychosocial disabilities benefit from their diverse expertise and networks in areas such as social protection, justice and advocacy, it may mean that their more specific and unique needs (e.g. mental health care, as per the below) are not adequately addressed. CBM's new Community Mental Health Initiative could offer opportunities to learn from other CBR programmes for people with psychosocial disabilities in different countries.

### 2. Treatment

Annual mental health camps were generally acknowledged to be insufficient, as was the budget for medication support. In several instances interviewees reported that they had stopped taking medication or were only taking it intermittently, due to cost. In some families where multiple members were prescribed medication, it was particularly difficult to pay, and families had to choose who would receive their medication and who would go without it. Taking a more active approach to addressing the issue of polypharmacy at mental health camps could ultimately improve patients' quality of life while reducing the financial burden to families as well as to the project. Meanwhile, many barriers to accessing mental health care remain.

### 3. Livelihoods

PHRPBD does not currently provide much direct support to livelihoods activities, other than its pilot income-generating activity. Its mainstreaming approach means that participants may identify livelihood opportunities elsewhere within the project's broad network, or even within their own self-help groups. However, it is important to note that people with psychosocial disabilities are often actively excluded from poverty-reduction interventions such as micro-credit in LMICs [17], and it is possible that they may face additional stigma and discrimination that pose a barrier to involvement in external programmes. Participants emphasised the need for more skills training and project-specific livelihoods activities. A new PHRPBD post has been added to address this issue, specifically.

## C. Opportunities

In addition to opportunities to address weaknesses described above, there are also opportunities for PHRPBD to increase the scope and impact of its work; for example, through engagement with healers, private sector advocacy, and reaching more people with psychosocial disabilities.

### 1. Healers

Many interviewees described accessing services from traditional and spiritual healers, such as imams and temple leaders. Further collaboration with healers could be worth exploring further, to help identify people with psychosocial disabilities and ensure that their human rights are protected. A recent NIMH study [8] reports that training courses on mental health for traditional and religious healers are being undertaken in Bangladesh [18], and that there is evidence that healers can play a role in improving referrals to mental health care in Bangladesh [19].

### 2. Private sector

Dhaka is the centre of Bangladesh's multi-billion-dollar garment industry and is also home to many other factories (e.g. auto-rickshaws). With support from the project, a few interviewees have already found salaried employment in factories, and project staff expressed an interest in sensitising factory owners in order to find more jobs for persons with disabilities—including psychosocial disabilities. At an international level, project partners like CBM could consider supporting this advocacy by appealing to big-brand buyers of Bangladesh exports (e.g. H&M, Walmart, J.C. Penney).

### 3. Scale

In some interviews and self-help group discussions, participants pointed out that self-help groups are capped at 15 members (with only one or two spaces for people with psychosocial disabilities), but there are more people in their communities who could benefit. They explained that if more funding were available, the project could easily expand by creating more groups.

## D. Threats

The project relies on relationships with sympathetic psychiatrists to offer mental health camps; however, these psychiatrists are few, and any turnover or policy-related restrictions on their practice could severely threaten access to services. Attrition among community-based staff could also be of concern in future. Meanwhile, Bangladesh's changing relationship with development agencies could put project funding under threat. These issues are explored further below.

### 1. Humanitarian Crises

Bangladesh is prone to cyclones, flooding and other natural disasters. In Dhaka, deadly fires and factory collapses have also made headlines in recent years. Meanwhile, violence in nearby Myanmar has resulted in over 900,000 Rohingya refugees fleeing to Bangladesh. Without proper planning and investment of emergency aid into building more robust mental health systems, humanitarian crises can place substantial strain on already overstretched services. The Rohingya crisis, especially, was cited as a cause of turnover among CDRPs, and as a possible reason for shortages of psychologists to serve the general population in Bangladesh—as they instead are being hired for more lucrative work with NGOs.

On the other hand, the CDD Director expressed ambitions to develop a programme of disaster responders for mental health in Bangladesh. If emergency aid could be leveraged to build the capacity for a new cadre of mental health workers, then these workers could perhaps play some role in building up PHRPBD's in-house capacity for addressing mental health in non-humanitarian settings, as well.

### 2. Recruitment and Retention

A psychiatrist raised several other issues in terms of recruiting and retraining mental health workers. One of these was violence. This concern is not unique to the mental health profession, according to a "call for action" published in the *International Journal of Community Medicine and Public Health* last year [20]. Health workers may switch careers or emigrate to avoid danger to themselves and their families in Bangladesh. Other issues raised include the stigmatisation of mental health care workers and low salaries. Consequently, even some paid positions for psychiatrists in hospitals remain unfilled.

A threat mentioned by partner organisations is the trend toward voluntarisation of CDRP-type staff among CBM-affiliated programmes (as was witnessed at the Bolivia and Nigeria sites). CDRP and Community Mobilisers already complained that their salaries and benefits were not competitive, and (as described above) some had already left to work with the Rohingya population.

### 3. Mental Health Act

In 2018, a new Mental Health Act replaced Bangladesh's 100+ year-old Lunacy Act of 1912 [21]. Unfortunately, the first author was unable to source an English-language copy for closer scrutiny. However, updated legislation must undoubtedly open new opportunities for PHRPBD to engage in advocacy to improve mental health services.

There have also been some concerns raised about unintended consequences of the 2018 Mental Health Act. A 2019 commentary published in *Lancet Psychiatry* highlights that medical practitioners may be punished for providing false certificates of mental illness [21]: "The new provision of punishment might create fear among the existing small workforce to provide a formal diagnosis and subsequent care in ambiguous cases" (Hossain et al. 2019, pp. e1). Overzealous application of the Mental Health Act could make mental health professionals more reluctant to provide the certification necessary for people with psychosocial disabilities to access benefits.

On the other hand, there is also a threat that implementation of the 2018 Mental Health Act may not be zealous enough. Several interviewees, including local government officials as well as a psychiatrist, had not yet heard of the Mental Health Act. The authors of the 2019 commentary point out that the new Mental Health Act is not accompanied by a mental health policy or action plan to guide its implementation—or to pay for it [21]. According to the WHO, only half of countries in the South-East Asia region include estimates of necessary human and/or financial resources in their mental health policy or plan; of those, only half have actually allocated those resources [22]. If PHRPBD depends on implementation of the Mental Health Act alone to improve mental health service provision, then participants with psychosocial disabilities may continue to receive sub-standard care.

### 4. Overseas Development Assistance

While CDD has been creative in exploring different funding strategies, the Director explained that as a non-profit organisation focussed on service provision, it requires continuous funding. Time-limited, project-specific funding can be unreliable and is becoming harder for the organisation to secure as Bangladesh becomes less-aid dependent [23]. With aspirations of becoming a middle-income country by its 50th birthday [24], Bangladesh—like India before it—may not continue to attract international development funders to the same extent in future. It is also important to take into consideration repeated cuts to Australia's foreign aid budget in recent years [25], which could result in DFAT refusing to fund subsequent phases of the project.

### 5. Stigma

Stigma was repeatedly mentioned as a barrier to involvement in the project's activities. Self-help group members reported that families sometimes prevent people with psychosocial disabilities from participating in surveys, camps and self-help groups, due to stigma. There were also reports of people who were taken to a mental health camp, only to be chained up after returning home. There was a general conviction that more community sensitisation is needed on mental health, specifically, in order for the project to fulfil its full potential.

## III. Conclusion

PHRPBD is an exciting project that has made tremendous effort to "walk the talk" in terms of mainstreaming, representation and empowerment for persons with disabilities. The inclusion of people with psychosocial disabilities is a recent development for which project and programme staff generally feel underprepared. However, they have made strides toward improving access to treatment within an extremely under-resourced mental health system. At the same time, they have facilitated access to social protection and included people with psychosocial disabilities in broader

efforts to promote the rights of persons with disabilities, resulting in some encouraging policy "wins" at different levels of local government. The author would recommend a more in-depth study of this programme to be carried out by a bilingual Bangla-English speaker, in order to better understand its nuances and more rigorously and accurately report its achievements to-date. However, the overall impression at this stage is of a project willing to learn-by-doing and generating some important lessons along the way, which may be of relevance to other CBR programmes seeking to integrate mental health into their work.

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