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Integration of mental health and psychosocial disabilities into community-based rehabilitation and inclusive development in low- and middle-income countries: Case studies from Bolivia, Bangladesh and Nigeria

Members of the Community Mental Health Programme team after an outreach clinic in Akwa Ibom, Nigeria. Photograph by Grace Ryan, 2018.

Grace Ryan, MSc, PhD Candidate, Centre for Global Mental Health, London School of Hygiene and Tropical Medicine

Georgina Miguel-Esponda, MSc, PhD Candidate, Centre for Global Mental Health, London School of Hygiene and Tropical Medicine

Pamela Castro, MSc, Regional Mental Health Advisor, CBM International

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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 overall purpose of this project is to inform the new Community Mental Health Initiative launched by CBM in 2019 [1]. This new initiative is intended to "bring focus and scale to the work CBM does in order to have a greater impact on this area [mental health and psychosocial disabilities]" (CBM 2019, pp.1). CBM has been working in community mental health for over 15 years—including community-based rehabilitation (CBR) for people with psychosocial disabilities. Our aim is to provide more tailored recommendations for the integration of mental health and psychosocial disabilities into CBR in low- and middle-income countries (LMICs), based on existing "real-world" practice. Two key objectives are:

- To develop detailed case studies of CBR programmes taking diverse approaches to mental health integration in different LMIC settings.
- To distil from these case studies key learning about the integration of mental health into CBR in LMICs.

This report addresses the second objective, by comparing three different models of integration observed during field visits to CBM-affiliated programmes in Bangladesh, Bolivia and Nigeria. Reports of these individual field visits are also available.

Information contained in this report will be incorporated into a three-country case study to be submitted as a research article for publication in a peer-reviewed journal. Hence, this report should be considered under embargo until the case study is published. This report may be circulated internally within the offices of CBM International, LSHTM, CDD (Centre for Disability and Development) and other PHRPBD (Promotion of Human Rights of Persons with Disabilities) partners, Caritas Coroico and other Mundo Inclusivo partners, and St. Joseph's Rehabilitation Centre and its Community Mental Health Programme partners.

Any requests for further dissemination should be directed to the lead author for approval (grace.ryan@lshtm.ac.uk).

I. Background

a. Mental Health and Psychosocial Disabilities

The World Health Organisation (WHO) defines mental health as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community"[2]. This state of well-being may be compromised by a mental health condition such as depression, anxiety or psychosis.

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) describes people with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" [3]. The term "psychosocial disability" is used to describe those who fit the above definition of disability as a result of impairments caused by a mental health condition.

b. Community-Based Rehabilitation

CBR is a strategy to improve access to rehabilitation services for people with disabilities in LMICs that aims to make optimal use of local resources [4]. CBR has been promoted by the WHO for nearly forty years. The 2010 WHO CBR guidelines included a special supplement on mental health, which drew mainly from experience, evidence in community mental health, and basic development principles, to make recommendations for the integration of support for people with psychosocial disabilities into CBR programmes [4]. Since then, different organisations have started to integrate mental health into their work, with varying degrees of alignment to these recommendations. In addition, new mental health programmes have been designed to incorporate CBR principles and components.

c. Evidence of Effectiveness

There is now evidence from controlled studies that community-based psychosocial interventions—including CBR—can improve outcomes for people with psychosocial disabilities in LMICs [5, 6]. Much of this evidence comes from stand-alone programmes designed specifically for people with psychosocial disabilities. For example, in 2003 a longitudinal study of a CBR model for schizophrenia in rural India showed it was more effective at reducing disability than outpatient care alone [7]. Even after this model was scaled up to the sub-district level, it continued to improve disability outcomes among people with psychosis [8]. More recently, the COPSI (COmmunity care for People with Schizophrenia in India) trial showed similar results when comparing a collaborative community-based care intervention with facility-based care alone [9]. However, it is generally acknowledged that there is need for more research on CBR for people with psychosocial disabilities in LMICs [6, 10].

II. Rationale

Several previous case studies have been published of CBR programmes designed exclusively for people with psychosocial disabilities, operating either as stand-alone programmes (e.g. Amaudo [11]) or as part of broader mental health systems strengthening programmes. The RISE trial in Ethiopia, for example, added a CBR component to a broader programme of mental health systems strengthening via the PRIME consortium [12, 13]. In other settings, pre-existing CBR programmes have been absorbed into broader efforts to strengthen mental health systems (e.g. the Edawu [14] and Agboke centres in Nigeria). Less is known about the integration of mental health and psychosocial disabilities into existing CBR programmes for people with disabilities more broadly. In

order to produce more comprehensive normative guidance on CBR for psychosocial disabilities, there is a need to systematically document and compare different models of delivery, as well as to identify common challenges and opportunities. This was our aim in carrying out field visits to three different CBM-affiliated CBR programmes integrating mental health and psychosocial disabilities into their work.

III. Methods

This report synthesises results of three case studies of CBR programmes in LMICs. A systematic approach was used to document each 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 [15, 16]. The Case Study Methodology has previously been used for the evaluation of community-based mental health programmes in LMICs, as well as for cross-country comparative studies [16, 17]. Please refer to the individual field reports for specific details on the methods used at each field site.

a. Settings

Three CBM-affiliate programmes were visited for this project. These were purposively selected in consultation with the project's Advisory Group: Dr. Laura Asher (University of Nottingham); Dr. Alex Cohen (LSHTM and Harvard T.H. Chan School of Public Health); Dr. Julian Eaton (CBM and LSHTM); Petra Kiel (CBM); Joerg Weber (CBM) and Soumana Zamo (CBM). While the original intention was to observe different models of CBR within the same country or region, advisors noted that models were often similar within regions. Instead, it was decided to maximise the variation in the sample by selecting programmes representing different models or different levels of maturity of similar models, each in a different world region.

- The Community Mental Health Programme of St. Joseph's Rehabilitation Centre, Akwa Ibom, Nigeria
- The PHRPBD project of CDD in Dhaka, Bangladesh
- The Mundo Inclusivo Programme of Caritas Coroico in La Paz, Bolivia

The history of each of these programmes is summarised briefly in the results. Many of the characteristics of these programmes are also described in the discussion of strengths, weaknesses, opportunities and threats included in this report. For full programme descriptions, please refer to the original field visit reports.

b. Data Collection

The first author (GR) carried out field visits to Nigeria (June 2018) and Bangladesh (February 2019). The second author carried out a field visit to Bolivia (July 2019), with remote support from the third author (GME). Please refer to the field reports for the specifics of data collection at each site.

c. Synthesis

The first author (GR) reviewed all three reports and recorded insights via personal memos, which focussed on similarities and differences between these programmes, as well as potential lessons to be learned. These were then organised into a three-part structure, which forms the basis of this synthesis:

1. History of the programmes
2. Models of integration
3. Common strengths, weaknesses, threats and opportunities

The first author returned to the original reports as well as relevant literature to provide a more descriptive narrative on each of these topics.

d. Limitations

It is worth noting here the limitations of this synthesis, which did not involve formal qualitative coding of either the domain tables, individual reports, or the data collected during field visits. This was a highly subjective process and the results should not be considered comprehensive or irrefutable. We intend to share these reports with staff of the participating programmes as well as the advisory group to glean further insights before writing up a final manuscript for publication in a peer-reviewed journal.

There are also a number of limitations to the data collection carried out at each field site, as described in the individual reports. For example, case studies should ideally be carried out over multiple visits, but this was not possible with a limited budget for international travel. Consequently, at no site were we able to observe the full range of activities reported. Language was also a barrier to producing comparative case studies of mental health programmes across three major world regions, and the resource-intensive process of transcription and translation of audio-recordings could not be accommodated in the budget for all three sites at this stage.

e. Ethics

Although formal ethical review by an accredited institutional review board is not always necessary for the conduct of a case study, our field visits involved interviews with service users and carers, and therefore could be construed as human subjects research with vulnerable populations. Ethics approvals were obtained from the London School of Hygiene & Tropical Medicine in the UK (14597), the National Committee of Bioethics in Bolivia (ref: CNB-CEI 01/2019), the Bangladesh Medical Research Council (BMRC/NREC/20I6-2019/931), and the Akwa Ibom State Ministry of Health in Nigeria (MH/PRS/99/Vol.IV/238).

IV. Results

a. History

All three programmes build on local partnerships with pre-existing organisations focussed on disability. Although these organisations were all founded more than twenty years ago, it took many years for people with mental health conditions and psychosocial disabilities to be included in their CBR work. The history of these programmes is described briefly below, and detailed in their respective field visit reports.

i. PHRPBD

PHRPBD is a project of CDD, a not-for-profit organisation focused on disability inclusion in Bangladesh. 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 [18]. CDD has since inception focused on mainstreaming disability within development efforts, and now works in partnership with over 350 organisations both nationally and internationally [18].

PHRPBD started in 2010 with funding from the Australian Department of Foreign Affairs and Trade (DFAT) via CBM. Originally it was implemented through three partner organisations; now there are 12, spread across 11 districts of Bangladesh [19]. Mental health was added in the second phase of the project, after recognising that people with psychosocial disabilities were being left behind. In response to the findings of a baseline study confirming the lack of attention to people with

psychosocial disabilities in Bangladesh, 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 [19]. 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.

ii. Mundo Inclusivo

Mundo Inclusivo is a community-based inclusive development programme administered by Caritas Coroico and financed by CBM Switzerland. Caritas Coroico has been working in rural areas of Los Yungas, La Paz since 1988, when it was first founded. In 1996, it was established as a development organisation and its projects started receiving support from Caritas in Europe and other international funders. In 2003, it established a partnership with Ayuda en Acción (Help in Action in Spanish) which allowed it to expand its work to most communities in the area of Los Yungas.

Prior to 2004, Caritas supported vulnerable women's groups. Programme staff identified a need to extend their support to children with disabilities whose mothers were participating in these groups. At the same time, there was increased interest from CBM and Caritas in Germany to financially support CBR initiatives. Both of these events led in 2004 to the start of CBR Yanapasiña, which focused on supporting children and adolescents with disabilities and their families.

After several years of expansion and changes among its partners, between 2009 and 2011 the programme transitioned to a new phase in which activities went beyond raising awareness and disseminating information to using an empowerment approach. Enabling the participation of people with disabilities through community mobilisation became a key aspect of the programme. It added a livelihoods component and changed its name to Mundo Inclusivo in 2011. Currently, Mundo Inclusivo is implemented in peri-urban and rural areas in the regions of La Paz, Sorata, Coroico, El Alto, Potosí, Sucre y Riberalta.

It is unclear when psychosocial disabilities were added to Mundo Inclusivo's remit. As of 2016, there were reportedly 120 people with psychosocial disabilities in self-help groups and 56 included in other CBR components [20]. Over the last three years, participation by people with psychosocial disabilities appears to have declined steadily. At the time of the second author's [PC] 2019 field visit, only one person with a psychosocial disability was participating in a self-help group. As the programme had stopped collecting data against mental health indicators, it was not possible to confirm how many were involved in other CBR components, but anecdotal evidence suggests there are currently very few.

iii. Community Mental Health Programme

The Community Mental Health Programme is operated out of St. Joseph's Rehabilitation Centre, originally as part of a broader CBR Programme that is now largely defunct. St. Joseph's Rehabilitation Centre is sited on a property in Ukana Iba belonging to the Catholic Diocese of Ikot Ikpene in Akwa Ibom State, located in Nigeria's oil-rich Delta Region. A rehabilitation centre was initially established here by the first Anglophone African Cardinal of the Catholic Church, with support from the local parish priest, in the wake of the Biafran War. Construction was funded by Swiss Caritas and completed in 1978, the same year that the Medical Missionaries of Mary assumed responsibility for the management of the Centre. At the time, it mainly functioned as a vocational training centre with a physiotherapy unit attached. It became St. Joseph's Rehabilitation Centre after the Daughters of Charity of St. Vincent de Paul in Nigeria started the Ukana Iba Community of St. Joseph's in 1982. It continues to be run by four sisters of the Daughters of Charity.

Building on the services already available at the Centre, CBR was initiated in 1996 with support from CBM's Paul Creswell. Starting in 1994, CBM had begun funding ten church-based CBR projects spread across eight of Nigeria's 36 states, including two in Akwa Ibom: St. Joseph's Rehabilitation Centre and St. Louise's School, which targets children with disabilities. In 2003, the Community Mental Health Programme was established as a service embedded within St. Joseph's broader CBR programme. A community psychiatric nurse was seconded from the government. Additional training on community mental health was provided by CBM, and the field workers and volunteers involved in community outreach for physical disabilities took on responsibilities for psychosocial disabilities. The CBR programme was hard-hit by the withdrawal of CBM funding in 2013, resulting in the near-collapse of its self-help groups, livelihoods and other activities for people with psychosocial disabilities. However, the community psychiatric nurse and four volunteers continue to provide regular on-site and outreach clinics throughout Akwa Ibom with support from the sisters who run St. Joseph's, recognizing that a lapse in services would leave many clients unable to access mental health care.

b. Models of integration

One way of conceptualising the different models of integration observed during field visits is horizontal versus vertical integration.

By our definition, vertical integration refers to a stand-alone programme for people with psychosocial disabilities linked to a broader CBR programme for people with disabilities generally. People with psychosocial disabilities may be referred between the two programmes for relevant services, offering participants a wider range of supports, but the programmes do not necessarily rely on one another to function. This is certainly true in the case of the Community Mental Health Programme operated out of St. Joseph's Rehabilitation Centre in Akwa Ibom, Nigeria. While St. Joseph's CBR programme is now largely defunct, the Community Mental Health Programme continues to operate with a focus mainly on treatment, with some additional community awareness-raising and home-based rehabilitation support. Referrals are made to whatever surviving services remain available at St. Joseph's or via other local organisations.

Horizontal integration, on the other hand, is where an existing CBR programme for disabilities makes an explicit effort to identify and include people with psychosocial disabilities in its activities. Much as a CBR programme may provide assistive devices or facilitate links to general healthcare for people with physical disabilities, it may also help to facilitate access to psychiatric care from existing mental health services and even subsidise the cost of psychotropic medication. However, these programmes do not have their own in-house mental health care providers. In Bangladesh, the PHRPBD project is at early stages of integrating psychosocial disabilities into long-standing work on physical disabilities, using a horizontal approach that broadly echoes its focus on mainstreaming generally. In Bolivia, Mundo Inclusivo once took a similar approach, but appears to have lost interest, resulting in dwindling numbers of people with psychosocial disabilities among its participants.

Two important challenges to a horizontal integration approach are that: (1) it may be difficult to target and thoroughly address the unique needs of people with psychosocial disabilities without dedicated in-house expertise on mental health; (2) scale-up may be limited by the size of the existing programme for people with physical disabilities.

In both Bolivia and Bangladesh, self-help groups are the cornerstone of the programmes' psychosocial activities, but these groups are capped at around 10 (Bolivia) to 15 (Bangladesh) members. At PHRPBD, self-help groups reserve only one or two spaces for people with psychosocial disabilities, and often these are taken by people with epilepsy or intellectual disabilities. In 2019,

only five of the 299 people with disabilities participating in Mundo Inclusivo had psychosocial disabilities (though 15 more had epilepsy and 198 had intellectual disabilities). The number of people with psychosocial disabilities benefiting from this model of integration is perhaps lower than it might be in a vertical programme. Meanwhile, staff of both programmes—both field staff and mangers—complain that they don't feel they have the proper training and specialist expertise to properly support rehabilitation of people with psychosocial disabilities.

By contrast, the Community Mental Health Programme in Nigeria serves large numbers of people with psychosocial disabilities and epilepsy, but its services are largely biomedical. It's two self-help groups were created explicitly for people with psychosocial disabilities, but one has stopped meeting, and the second now rarely meets. Other CBR activities for people with physical disabilities—to which people with psychosocial disabilities were formerly referred—are now largely defunct. The programme continues to meet their unique needs for mental health care, but fails to address the more general needs they have in common with other people with disabilities—such as livelihoods and human rights advocacy.

In order to better understand these different models and their relative advantages, it would be helpful to have a larger sample, ideally including both successful and unsuccessful examples of horizontal and vertical integration. Currently, only the PHRPBD project really appears to be offering a functioning programme of CBR to a substantial number of people with psychosocial disabilities, and this is at its early stages. However, for the purposes of this report, we have done our best to highlight across this small sample common strengths, weaknesses, threats and opportunities, in the following sections.

c. Strengths

Each programme is unique and has its own strengths and weaknesses, as detailed in the field reports. However, we also noted some common strengths across multiple programmes, often linked to their model of integration, as described further below.

i. "Mixed" self-help groups

For Mundo Inclusivo and PHRPBD, horizontal integration into a CBR programme created mainly for physical disabilities relies largely on the inclusion of people with psychosocial disabilities in existing self-help groups. One of the strengths of the Bangladesh programme, and a former strength of the Bolivia programme, is the use of these "mixed" self-help groups for people with physical disabilities, psychosocial disabilities, intellectual disabilities and epilepsy. Group members in Bangladesh emphasised the importance of involving people with different strengths, limitations and experiences, for mutual learning and for the overall success of the group and its members. Members of a rural self-help group also identified a very pragmatic benefit to this approach. They estimated that there were only half a dozen people with psychosocial disabilities in their ward, which would not achieve the sort of critical mass necessary for an active self-help group. While involving other wards in a psychosocial disability-only self-help group could increase the numbers, it would also increase the distance to self-help group meetings for many members. As it stands, groups are able to meet on a bimonthly basis with an acceptable travel time.

On the other hand, Mundo Inclusivo does in principle have mixed self-help groups (though only one person with psychosocial disabilities is a member), yet distance and transport costs reportedly prevent members from regularly attending meetings, which are usually held once or twice per month. It is unclear why meetings are held far away from where many members live, but this would be worth exploring further in conversation with the programme. In Akwa Ibom, two self-help groups attached to mental health outreach have capitalised on monthly clinic days to arrange meetings, but

one is now defunct, and the other is struggling to continue meeting after the failure of its livelihoods project. In the absence of adequate government benefits, participants require either some form of subsidy for the costs of participation (such as travel, in the case of Mundo Inclusivo), or some other tangible benefit (such as livelihoods activities, in the case of the Community Mental Health Programme) to make participation financially viable. Although we are unaware of any formal research into the effectiveness of mixed versus psychosocial disability-only self-help groups, it does seem logical that drawing on a diversity of skills and experiences could lead to more varied opportunities for livelihoods development. This could be an important area for further study as part of the Community Mental Health Initiative.

ii. Representation

Both Mundo Inclusivo and PHRPBD demonstrate sensitivity to issues of representation for persons with disabilities in their own operations.

Mundo Inclusivo recognises that one of the driving philosophies of a community-based inclusive development approach is that people with disabilities are enabled to lead in programme activities, drive advocacy and fight for their human rights. As the programme matures, Mundo Inclusivo aims to take a step back and provide only an advisory or supportive role to people with disabilities and their families, so that they are leading change. While self-help groups are currently led by programme staff, it is expected that in the future people with disabilities and their families will take over leadership roles.

At PHRPBD, each partner organisation has a community disability resource person (CDRP) and a community mobiliser working as frontline staff. Each CDRP-community mobiliser duo must include at least one person with disabilities. 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 CBR activities, by ensuring those “closest to the problem” are in position to address them. Yet similar structures were not in place in the Community Mental Health Programme. More clearly articulating the need for—and feasibility of—representation by underrepresented groups to CBM-affiliated organisations could prove beneficial for this and other programmes.

iii. Social safety nets

In the horizontal approach adopted by PHRPBD and Mundo Inclusivo, both reported successes in supporting participants to access social protection—even advocating, as in the case of PHRPBD, for increases to benefits for people with psychosocial disabilities. For PHRPBD, the support that self-help groups offer in terms of navigating bureaucratic procedures to access benefits also serves as a short-term, tangible benefit that attracts new members. However, it is important to note that in both Bolivia and Bangladesh, disability benefits are not sufficient to meet the basic needs of people with psychosocial disabilities and their families. In Bangladesh, for example, interviewees reported that the monthly cost of their prescriptions is several times the amount of their monthly disability allowance.

In Bolivia, medications for epilepsy should in principle be distributed from primary care centres free of charge to anyone with a disability carnet. Mundo Inclusivo supports families in navigating the long and difficult process of obtaining the disability carnet, first by helping to facilitate diagnosis by a specialist. Community health promoters may accompany participants through doctors’ visits and the long queues at various government institutions, providing practical guidance as well as emotional support.

In contrast, there was very little indication from the Community Mental Health Programme that participants were accessing any sort of government benefits. However, it is possible that this could be due more to Nigeria's underdeveloped social safety net programme than to a weakness of the Community Mental Health Programme itself.

d. Weaknesses

While many of the strengths identified in the previous section focus on more psychosocial aspects of CBR work, provision of more targeted services for people with mental health conditions was generally weak among the horizontal programmes. Livelihoods activities were often unsuccessful, and those that were successful did not include many people with psychosocial disabilities. Finally, basic issues in the monitoring and evaluation of services for people with chronic conditions made programme data—where it was available—unreliable.

i. Awareness-raising

None of the participating programmes provided concrete information on their activities in terms of awareness raising or mental health promotion. Yet they all reported high levels of stigma and discrimination in the communities they served. Explanatory models often centred on the supernatural, and placed blame on people with mental health conditions and their families. More rigorous monitoring of awareness-raising and mental health promotion activities and their outcomes would be of benefit to the Community Mental Health Initiative, in order to understand what is being done and where there are clear gaps that can be addressed, perhaps through a coordinated strategy across CBM-affiliated programmes—though obviously with consideration of the unique local contexts in which these programmes operate. An important starting point might be to address gaps in programme staff's own knowledge of mental health, particularly in horizontal programmes like Mundo Inclusivo and PHRPBD, which do not have their own in-house mental health specialists.

ii. Psychiatric care

While the strength of a CBR approach is that it goes beyond a medical model of disability, it is important to give access to high-quality mental health care high priority, as an essential pre-requisite for many people with psychosocial disabilities to feel enabled to meaningfully participate in other activities of the programme and in society more broadly. However, all three programmes operate within extremely under-resourced mental health systems. At all three study sites, distance to tertiary facilities and long waiting times were described as major barriers to accessing mental health care. In Bangladesh, an interviewee reported waiting up to twelve hours to be seen by a psychiatrist. In Bolivia, a few interviewees reported waiting overnight, with no guarantee of receiving services in the morning.

Both of the horizontal programmes struggle to provide for the mental health care needs of participants with psychosocial disabilities within these systems. Meanwhile, the services of the Community Mental Health Programme's single community psychiatric nurse have proven so valuable to communities in Akwa Ibom that considerable sacrifices have been made in order to continue them, even as other CBR activities have ceased.

PHRPBD has formed agreements with Bangladeshi psychiatrists to offer annual "mental health camps" in the communities it serves. 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. 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. Patients from the camp either phone the psychiatrist or come to their public or private practice for follow-up on an as-needed basis. Unfortunately, follow-up visits often incur fees,

particularly in private practice. Virtually all interviewees asked for more frequent mental health camps, as one of their main recommendations to PHRPBD.

Originally, Mundo Inclusivo had an agreement with the government that enabled a psychiatrist to conduct consultations in the community [21]. This was terminated by government officials after the introduction of Bolivia's Universal Health Insurance (*Seguro Unico de Salud* in Spanish). This insurance increased the demand for health services, including mental health services, and public sector care providers are no longer being allowed by their managers to work off-site. Moreover, people with disabilities previously had priority access to health services; however, since the introduction of the Universal Health Insurance, this is no longer the case.

None of the three study sites currently provides any manualised psychotherapy. A programme report from 2015 indicates that Mundo Inclusivo programme staff and community health providers did provide talk-based therapy for people with psychosocial disabilities in past [21], but this is no longer the case.

iii. Medication

Interviewees in all three countries described the cost of medication as a hardship. A small mark-up on the medications dispensed by the Community Mental Health Programme in Nigeria helps to subsidize its activities. Clients pay approximately 3,000 Naira ($8.23 USD) for one month's supply of medicines. While this is relatively affordable compared to other dispensaries in the state, it still proved difficult for clients to pay, particularly in rural areas. At least two interviewees explained that their families now had to choose between buying medications for the client or for another close family member, such as a brother or mother.

In Bangladesh, PHRPBD pays a portion of the cost of medication for clients in vulnerable situations, but the cost is still prohibitive—and made worse by practices of polypharmacy resulting in some clients taking up to five different medications at a time. Most interviewees said they spend a few thousand taka (1,500-4,000; $17-47 USD) per month on medications, several times their monthly disability allowance (650-700). A few interviewees reported having discontinued their medication as a result of the high cost.

In Bolivia, Mundo Inclusivo has helped patients with epilepsy access a disability carnet, entitling them to free medication from primary care facilities (though in practice, stock-outs are common). However, psychotropic medications are not covered by the disability carnet and can be costly. Mundo Inclusivo has provided financial support in certain cases when, as demonstrated by a socioeconomic assessment, there is evidence that a family does not have the ability to pay. In these cases, families receive funds and are also included in livelihood activities in hopes that they will be able to cover their treatment in the longer term. While this appears to be a promising approach, we acknowledge that it is probably much more feasible for Mundo Inclusivo than for the other programmes, as it has such a small number of people with psychosocial disabilities to support.

iv. Rehabilitation support

All three programmes offer home visits by trained, community-based field staff (though operating on a volunteer basis in Nigeria and Bolivia). However, it is unclear to what extent the rehabilitation services provided actually target psychosocial disabilities, specifically. For example, field staff and self-help group members of PHRPBD mainly reported checking on medication adherence and side effects during home visits to people with psychosocial disabilities. While we presume these field visits also cover other topics such as self-care, participating in household chores, and engaging in family and community life, we were unable to confirm whether this was the case. Certainly in

Nigeria, where home visits were drastically reduced as volunteers left the programme and budget for transport was removed, it appears that these visits are now more perfunctory and focus mainly on psychoeducation and treatment adherence. In Bolivia, it seems that rehabilitation support may be more multifaceted. However, field staff reported that the needs of people with psychosocial disabilities are significantly more challenging to address, and they are not trained to deliver psychoeducation to people with severe mental health conditions. During interviews, the family members of people with psychosocial disabilities highlighted that the support from Mundo Inclusivo has enabled their family members to become more independent, although this is to varying degrees. Families attributed most of the positive impact to the effects of pharmacological treatment rather than of psychosocial interventions.

v. Livelihoods

Because the cost of medication is so formidable to participants in all three programmes, livelihoods activities are especially important. Helping people with psychosocial disabilities and their families reach a position of financial security, from which they can afford to pay for their own treatment, reduces the burden on programmes to subsidise or cover the cost of medication, while also fulfilling other key goals of CBR. Failure to adequately invest in and support livelihoods while programmes have external funding could further threaten their sustainability once funding has ended.

Unfortunately, in both Nigeria and Bangladesh, programme-sponsored livelihoods activities have been tried and failed. In Nigeria, the CBR programme received a 50,000 naira grant for economic integration in 2006, but a 2010 CBM report confirmed that this was “still under developed [sic]” several years later [22]. At the time of the first author’s (GR’s) field visit, only one self-help group was semi-active. It had invested in a cooperative-style party rental business, but the tents and chairs purchased could not accommodate large gatherings, and also suffered from wear and tear. As a result, it was no longer financially viable.

A staff member described a PHRPBD pilot income-generating activity on cow-fattening that also failed, due to flooding. A livelihoods officer post has now been created to provide more guidance on this front, and PHRPBD is investigating goat-rearing as a potential alternative to their cow-fattening pilot. In the meantime, several self-help group members have been able to access livelihoods opportunities via links with other organisations or even with other self-help group members. For example, a young woman diagnosed with schizophrenia learned from other group members how to craft faux flowers to decorate autorickshaws, and now earns a monthly income of 1200-1500 BDT (about £10-15 GBP) [19].

While Mundo Inclusivo does employ staff focused explicitly on livelihoods and appears to have a number of different opportunities for people with disabilities available, there are very few people with psychosocial disabilities or family members of people with psychosocial disabilities involved. Unfortunately, due to changes to the programme’s indicators, it is not possible to report the exact number (as described further below).

vi. Monitoring and evaluation

In Nigeria, CBM’s format for reporting aggregated statistics on service utilisation produced unreliable data, failing to accurately distinguish between numbers of individual clients and numbers of contacts with clients via the Community Mental Health Programme. This may also be the case for PHRPBD in Bangladesh. Statistics reported in a PHRPBD project pamphlet do not appear to distinguish between individuals and contacts, either. Meanwhile in Bolivia, no data has been collected on mental health indicators since the new stage of the programme started in 2019. It is important for CBM that affiliated projects are able to report accurate and relevant data on mental health, particularly now

that it has launched its new Community Mental Health Initiative. Lessons could perhaps be learned from other sites, such as Benue State's Comprehensive Community Mental Health Programme (CCMHP) in Nigeria, where a new mental health information and monitoring and evaluation system has enabled reporting on individual contacts and clients for more than 7,000 people since 2014 [23-25].

e. Threats

A number of inter-related issues related to human and financial resources threaten the future sustainability of these programmes. These are described further below.

i. Attrition

Substantial attrition among community-based field staff was observed at all three sites. In Bolivia and Nigeria, interviewees attributed high levels of attrition mostly to the withdrawal of financial compensation for their work. In Bolivia, volunteering may be seen as a stopgap to gain experience while awaiting further opportunities for gainful employment. Between 2016-2018, Mundo Inclusivo trained 136 community health promoters, of which only 31 are still volunteering for the organisation. In Nigeria, only four CBR field workers remain, and one is now inactive after family issues forced her from her home. In Bangladesh, partner organisations have resisted trends toward the voluntarisation of community disability resource persons (CDRPs) common among CBM-affiliated projects. However, even PHRPBD salaries and benefits for community-based staff are still not considered competitive, and some have been pulled away to more lucrative work as part of the Rohingya crisis response. Without investing more either in retention (i.e. better compensation) or in the recruitment and training of new volunteers on a regular basis (which requires intensive supervision), programmes will likely see high attrition continue into the future.

Attrition among psychiatric specialists also poses a very real threat to the already limited mental health care available to participants. In Bangladesh, PHRPBD 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. In the Community Mental Health Programme in Nigeria, the single community psychiatric nurse has already passed the age of retirement, and only continues to provide services because no suitable replacement can be identified (and funded).

Finally, attrition among programme staff has been a significant challenge for Mundo Inclusivo specifically, and resulted in loss of crucial institutional knowledge. Other than one project coordinator who has worked with the programme since 2011, all other staff (coordination assistant, inclusive education coordinator, livelihood coordinator, and eight staff responsible for different intervention areas) have worked with the programme for around two years. Interviewees explained that most staff are women, who may have competing family responsibilities, resulting in high turnover. Examples given were staff who had left after becoming pregnant or who moved to larger cities for better educational opportunities for their children.

ii. Leadership

Perhaps related to the problem of attrition is that of leadership. In reports of previous CBM field visits to St. Joseph's Rehabilitation Centre, the decline of the programme was partially attributed to the departure of the CBR Coordinator and the charismatic Paul Creswell, who had a special interest in CBM Nigeria's CBR work. In Bolivia, the loss of a clear focal person to push a mental health agenda has led to the complete omission of mental health from its current work-plan. In Bangladesh, where PHRPBD's activities appear to be relatively successful, the Project Manager and other key staff show a great deal of enthusiasm but express concerns about their own limited expertise in this area.

iii. Training

Both of the horizonal programmes complained of limited expertise and inadequate training on mental health, at all levels—from managerial down to community-based field staff. (For example, PHRPBD staff explained that training for their community disability resource persons is three months long, while the training on mental health is limited to six days, and only covers basics.) Combined with high levels of attrition, inadequate training represents a significant threat. While new staff may be hired, training is insufficient to equip them for work on mental health and psychosocial disabilities, and those in supervisory roles may feel similarly out of their depths; meanwhile, hard-won experiential learning is routinely being lost due to high turnover.

iv. Funding

Funding provided via CBM to both PHRPBD and Mundo Inclusivo is set to end within the next four years. Given the sharp decline in many of Nigeria's essential CBR activities following the withdrawal of CBM funding, these expiry dates raise concerns regarding sustainability. CBM must consider whether it has in place a responsible exit-strategy for these programmes, if there is a chance that funding may not be renewed.

Staff of both St. Joseph's Rehabilitation Centre and CDD described challenges covering the basic operating costs of a service delivery organisation. In Nigeria for example, staff reported having received in-kind donations of vehicles, generators and buildings which—though appreciated— then had to be powered, maintained and secured, without sufficient income to cover overheads. The former State Governor paid for renovations of several buildings and donated an additional one million naira, but the new State Governor has not continued this support. This put St. Joseph's and the Community Mental Health Programme in a perilous position when CBM funding was withdrawn in 2013.

While CDD has been creative in exploring different income sources, 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 [26]. With aspirations of becoming a middle-income country by its 50th birthday [27], 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 [28], which could result in DFAT refusing to fund subsequent phases of the project.

Perhaps because its new four-year phase only just started in 2019, sustainability was not a major topic of discussion with Mundo Inclusivo during the field visit. However, this in itself could be a threat, if the programme does not have a long-term strategy in place to achieve sustainability.

f. Opportunities

In this section, we focus on strengths of individual programmes that could be leveraged by CBM's Community Mental Health Initiative in order to address weaknesses at other sites, as well as general opportunities to strengthen CBR programmes for people with psychosocial disabilities.

i. Community mental health care

While community mental health care is extremely limited in Bangladesh and Bolivia, the quality and accessibility of services provided by the Community Mental Health Programme's community psychiatric nurse in Akwa Ibom appears to be very good. During interviews, many clients reported seeking treatment initially from traditional or spiritual healers or private pharmacists and seeing no change in their symptoms until they came to the community psychiatric nurse. He often spends an

hour or more with new clients, and around twenty minutes with returning clients. He was observed consoling distressed clients and their families, advising them on how to take their medications and handle side effects, and repeatedly advocating for clients to be included in family and community activities and to pursue life goals. These are best practices applied by an experienced hand which are sometimes difficult to come by in overstretched, under-resourced services. A psychiatrist visiting from the Akwa Ibom State University Teaching Hospital also noted that despite the rising cost of medication and the programme's mark-up, the services provided by the community psychiatric nurse remain much more affordable than facility-based care and allow clients to remain in their communities instead of being institutionalised.

This model of community-based mental health care could prove valuable in places like Bangladesh and Bolivia, where CBR programmes are struggling to provide adequate psychiatric treatment in heavily centralised and under-resourced mental health systems. Other CBM-affiliated programmes such as CCMHP in Benue State have been able to leverage partnerships with government in order to train community psychiatric nurses to establish clinics in primary care over a large geographic area [25]. Facilitating more cross-site learning could help staff off affiliated programmes to better understand what might be possible for their own sites, in terms of scaling up community mental health care. The Community Mental Health Initiative could also consider undertaking a more rigorous and comprehensive assessment of the various models of provision of psychiatric treatment across its affiliated organisations, in order to identify best practices and develop clearer normative guidance and standards.

ii. Advocacy

Both Bangladesh's recent mental health act and Nigeria's mental health policy and plan emphasise the integration of mental health into primary care. Bolivia also has an ambitious mental health plan, though it has not been codified into legislation. However, there are clear leverage points in each country for mental health advocacy to ensure that political commitments are translated into clear actions that address some of the major challenges these programmes face. Both PHRPBD and Mundo Inclusivo have helped to incubate organisations for people with disabilities that can represent the collective interests of self-help group members—including people with psychosocial disabilities. CBM could consider ways to support this higher-level national advocacy, for example by developing and sharing information for policy-makers in LMIC settings.

Staff of PHRPBD also described the private sector in Bangladesh as an important target of advocacy efforts in order to promote the inclusion of people with psychosocial disabilities in the workplace. 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) to establish quotas for the inclusion of people with psychosocial disabilities in the factories that they do business with.

iii. Synergies

International disability rights advocates have pushed for clear distinctions to be made between intellectual and psychosocial disabilities in the United Nations Convention on the Rights of Persons with Disabilities [29]. Yet these same distinctions are not always made in the field. All three sites involved people with intellectual and psychosocial disabilities as well as epilepsy, and those with less

in-house clinical expertise (i.e. Bangladesh, Bolivia) often conflated these different categories under the heading of “psychosocial disability”.

It is certainly important to ensure that people with impairments related to mental health conditions are explicitly targeted by CBR programmes and not left behind. However, a non-biomedical approach to disability puts emphasis on barriers to inclusion imposed by society, as opposed to symptoms. In all three settings, people with intellectual and psychosocial disabilities as well as epilepsy face extreme stigmatisation—partially as a result of local explanatory models focussed on the supernatural. Those who may benefit from pharmaceutical treatment have poor access and difficulty paying for it. Most sites (except for Nigeria) provide little psychoeducation, and none provide adequate psychotherapy or targeted rehabilitation support. These are common barriers that are perhaps best and most efficiently addressed together, as a single programme of work. Drawing more actively on evidence, resources, organisations and networks for intellectual disabilities, for example, might help to overcome common barriers experience by people with psychosocial disabilities and epilepsy. This could be a point for consideration by CBM, as it shapes its new Community Mental Health Initiative, and WHO, as it develops further guidance on community-based inclusive development for people with psychosocial disabilities.

V. Summary

This report synthesises learning from three different programmes integrating psychosocial disabilities into CBR, Bangladesh, Bolivia and Nigeria. Two main models of integration were identified: (1) vertical, in which a stand-alone programme for people with psychosocial disabilities is linked to a broader CBR programme for people with disabilities generally; and (2) horizontal, in which an existing CBR programme for disabilities makes an explicit effort to identify and include people with psychosocial disabilities in its activities. While it is not possible to draw from this report any indication of the superiority of one model over another, it is worth noting the comparative strength of the community-based mental health care offered by the vertical programme observed in Nigeria, as well as the comparative strength of other CBR-related activities carried out by the horizontal programmes in Bangladesh and Bolivia. However, both Nigeria and Bolivia also offer cautionary tales: the former, regarding the fragility of a CBR programme largely dependent of time-limited project funding; the latter, regarding the need for concerted effort, vigilance and leadership to ensure that the involvement of people with psychosocial disabilities in mainstreaming approaches does not disappear over time. A number of recommendations are made—not directly to these programmes, but rather to CBM as its newly-launched Community Mental Health Initiative begins to take shape. Key to these recommendations is the need for more cross-site learning, in order to identify best practices and formulate more helpful normative guidance on integration with CBR.

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