# Field Visit to a Community-Based Inclusive Development Programme for People with Psychosocial Disabilities in La Paz, Bolivia

An Internal Report for CBM International

**September 2019**

*Figure 1. Beneficiary who has received seed capital from Mundo Inclusivo at her expanded business in a local fair*
*Photo Credit: Mundo Inclusivo archive.*

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

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

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

**Executive Summary:**

In 2019, a field visit was carried out in the peripheral areas of La Paz where the program Mundo Inclusivo (Spanish for “Inclusive World”) is implemented. The purpose was to contribute to a series of case studies on the integration of mental health into community-based rehabilitation (CBR) programmes in low- and middle-income countries. The Mundo Inclusivo programme provides support to people with all disabilities (including psychosocial disabilities) and their families, and recently transitioned from a CBR strategy to a Community-based Inclusive Development (CBID) approach. Despite the programme being noteworthy due to its achievements in the inclusion of people with disabilities in advocacy activities, people with psychosocial disabilities remain underrepresented in the programme’s activities and leadership. A new project plan starting to be implemented this year includes only limited work on mental health. This is attributed to challenges identifying and supporting people with mental health needs or psychosocial disabilities, coupled with limited expertise in this area among programme staff. This report describes the Mundo Inclusivo programme, the current strengths and limitations of its psychosocial component, and suggests potential areas of improvement.

# Contents

X. About this Report ..... 4
I. Methods ..... 4
A. Strengths and Limitations ..... 5
B. Ethics ..... 5
II. Findings ..... 6
A. History of the Programme ..... 6
1. Caritas Coroico ..... 6
2. Mundo Inclusivo ..... 6
B. Programme description ..... 8
1. Conceptual Framework ..... 8
2. Promotion and Prevention ..... 10
3. Early detection and intervention ..... 10
4. Mental Health Care ..... 10
5. Psychosocial Support and Rehabilitation ..... 11
6. Self-Help Groups ..... 11
7. Education support ..... 12
8. Livelihood support ..... 12
C. Programme Resources ..... 13
1. Human ..... 13
2. Transportation ..... 14
3. Funding ..... 14
4. Medications ..... 14
D. Information System ..... 14
1. Data Collection, Processing and Reporting ..... 15
E. Service Utilisation Data ..... 15
III. SWOT ANALYSIS ..... 16
A. Strengths ..... 16
B. Weaknesses ..... 17
C. Opportunities ..... 18
D. Threats ..... 18
IV. Conclusion ..... 19
References ..... 20

# 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 Bolivia 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 the findings of visits to two of the three sites where the Mundo Inclusivo programme is being implemented in La Paz, Bolivia. Visits were conducted on 9, 10, 22 and 23 July 2019 to the District Max Paredes and the District Periférica, which are located in peri-urban areas of the city. During the field visit, the lead author of this report interviewed the project coordinator, the three members of staff who support the project coordination (i.e. coordination assistant, inclusive education coordinator and livelihood coordinator), two other staff in charge of carrying out home visits in the intervention areas, three volunteers or community health promoters, and nine beneficiaries, including three service users and six carers (Table 1). All interviews with programme staff were conducted in the main office of Caritas Coroico, the main partner and administrative organisation, and all interviews with beneficiaries took place in the homes of participants. Interviews were audio-recorded by the first author and transcribed verbatim by the second author (a bilingual researcher and native Spanish speaker), who translated relevant quotes to English.

***Table 1. Interviews by participant type***

| Participant Type | Male | Female |
|---|---|---|
| **Programme Staff** | **2** | **4** |
| **Volunteers** | **0** | **3** |
| **Service Users** | **2** | **1** |
| Epilepsy | 2 | 0 |
| Psychosis | 0 | 1 |
| **Carers** | **1** | **5** |
| **Total Interviews** | **5** | **13** |

The lead author of this report also carried out a visit to a Primary Health Care (PHC) clinic located in one of the intervention areas (Max Paredes District), where she observed the delivery of general health services.

The first two authors of this report reviewed documentation provided by CBM, including four biannual reports corresponding to 2014 and 2015, two reports of previous visits to the programme sites conducted by CBM staff in 2014 and 2015, a report of a community health worker meeting

conducted in 2015, and a 2015 evaluation report completed by CBM staff. Authors also reviewed a database of the beneficiaries of livelihood programmes and two documents describing the programme, both of which were provided by the staff of Mundo Inclusivo.

## A. Strengths and Limitations

The current report was developed by three external researchers. Field visits and interviews were conducted by the CBM Mental Health Advisor in Bolivia (first author), who has experience in the monitoring and evaluation of mental health programmes in the country and in the Latin American region, and is also a native Spanish speaker. 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 the London School of Hygiene and Tropical Medicine. The Case Study Methodology has previously been used for the evaluation of community-based mental health programmes in LMICs (Cohen 2011, 2012).

The majority of the programme's beneficiaries have a physical disability. Of those beneficiaries classified by the programme as having psychosocial disability, the majority have been diagnosed with epilepsy. For this reason, most beneficiaries selected by the programme to participate in interviews had been diagnosed with epilepsy. Although it was also possible to interview two participants diagnosed with a severe mental disorder, one was not able to meaningfully contribute to interviews as a result of significant cognitive impairment (i.e. limited understanding and memory problems). Although this beneficiary was not able to provide information, his caregiver was interviewed for this case study.

Due to logistical difficulties, self-help and rotating savings groups could not be observed. These groups are not scheduled regularly (once a month on average), and none had been scheduled at the time of the field visit. However, staff involved in coordinating these activities were interviewed. Furthermore, while the programme is implemented in peri-urban and rural areas, only beneficiaries in peri-urban sites were interviewed.

Finally, CBM requests information every quarter. However, for the period between 2019-2022 indicators related to mental health are no longer included in programme's information system.

## 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. Ethics approvals were obtained from the London School of Hygiene & Tropical Medicine in the UK and the National Committee of Bioethics in Bolivia (ref: CNB-CEI 01/2019).

# II. Findings

## A. History of the Programme

Mundo Inclusivo is a CBID programme administered by Caritas Coroico and financed by CBM Switzerland. The history of Caritas Coroico and Mundo Inclusivo is described below and key dates are presented in table 2.

### 1. Caritas Coroico

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. Currently, the organisation has offices and staff working in Sorata, Coroico and Guanay in projects targeting health, agriculture, CBR and social assistance. The organisation aims to support economic development, social inclusion, environment, risk and emergency management, and strengthen democratic exercise (Pastoral Social Caritas Boliviana, 2014). In terms of social inclusion, Caritas Coroico aims to raise awareness within governments and society regarding the rights of people in vulnerable situations, promote inclusion in social and work spaces, provide support to people to advocate for their rights, and enable access to basic services and housing (Pastoral Social Caritas Boliviana, 2014).

### 2. Mundo Inclusivo

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. Although none were active in CBR Yanapasiña at the time, current staff of Mundo Inclusivo report that in its early years the programme mainly raised awareness through the dissemination of information and did not use an empowerment approach (i.e. used passive rather than participatory strategies).

When the CBR Yanapasiña programme started in 2004, Caritas Boliviana was the main partner and lead organisation in charge of its implementation. Initially, it was implemented in two peri-urban districts of La Paz and areas of El Alto and Coroico. In 2008 the programme expanded to the districts of Tarija and Trinidad. In 2010, Caritas Boliviana stopped receiving funding from Caritas in Germany and therefore decided to step down as the main partner. At this point, Caritas Coroico became the lead partner, but their leadership only lasted one year given that the programme's expansion meant the partnership had to be transferred to Caritas La Paz. Caritas organisations in Bolivia have catchment areas, and because Mundo Inclusivo had plans to start working in two more areas of La Paz, it was not possible for Coroico to carry on being the lead partner. At this point, Caritas Coroico remained as a collaborator and was in charge of implementation in Sorata, Coroico.

Meanwhile, between 2009 and 2011 the programme transitioned to a new phase in which activities went beyond raising awareness and disseminating information to start 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. It also began including young people and adults with disabilities. However, at this point most beneficiaries were still children and adolescents, and only a few adults were supported.

The programme was further expanded in 2015 to the districts of Potosi, Sucre, Oruro and Riberalta. A year later, implementation in Tarija was adopted by the local municipality, with Mundo Inclusivo having only an advisory role. In 2016, the programme also began rebranding itself as taking a CBID approach.

Finally in 2019, the administration was transferred back to Caritas Coroico. This last transfer was requested by Mundo Inclusivo staff who felt that the bureaucracy of Caritas La Paz was creating barriers to their work, and led to the programme missing out on funding opportunities. For example, when engaging with government stakeholders, programme staff sometimes needed to schedule meetings at short notice. Caritas La Paz required staff to obtain authorisation to attend meetings or events out of office. Given that this process was lengthy and complicated, staff were not actually able attend meetings. Moreover, on two occasions Mundo Inclusivo was offered foreign funding which they were not able to receive due to long and complicated authorisation procedures at Caritas La Paz. The flexibility of administrative processes in Caritas Coroico coupled with the interest of their leaders has facilitated the progress of the programme.

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. Over the years, the programme has gained experience in the successful implementation of CBR, which has led to the consolidation of implementation strategies. These strategies include promoting empowerment, using a gender approach and working through networks. These experience have been shared through guidelines, which have been published in a Mundo Inclusivo report [Appendix 1]. The success of these strategies has garnered national-level recognition of the programme. For example, in 2017 Mundo Inclusivo organised a National Forum of People with Disabilities which brought together presidential candidates and Organisations of People with Disabilities (OPDs). In this Forum, presidential candidates made a signed commitment to support the needs of people with disabilities.

***Table 2. History of changes of the Mundo Inclusivo programme***

| Timeline | |
|---|---|
| 2004 | • CBR Yanapasiña funded by CBM and Caritas Germany and administered by Caritas Bolivia.<br>• Children and adolescents with disabilities were the sole target population.<br>• Programme activities focus on awareness raising and information dissemination. |
| 2007 | • Caritas Bolivia had another project called Integral Disabilities Program, which covered the regions of Tarija and Trinidad. In 2007, this programme finished and CBR Yanapasiña started covering this geographic area instead. |
| 2009 | • Programme activities start being driven by an empowerment approach, in which participation and community mobilisation are promoted.<br>• Livelihood component is introduced to Mundo Inclusivo programme. |
| 2010 | • Caritas Germany ceases supporting the programme. Administration transferred to Caritas Coroico with CBM Germany funding only. |
| 2011 | • CBR programme is named Mundo Inclusivo.<br>• Mental health component is introduced to Mundo Inclusivo programme.<br>• Young people and adults start being supported by the programme.<br>• Administration is led by Caritas La Paz in partnership with Caritas Coroico (to implement in Sorata), Caritas Trinidad (to implement in Trinidad-Beni) and Kushkan Jaku (to implement in Oruro). |
| 2015 | • Programme expansion to cover the regions of Ribaralta, Tarija, Oruro, Potosi and Sucre through partnerships with other organisations such as Ayninakuna. |

| | |
|---|---|
| 2016 | • CBR programme rebranded as Community-based Inclusive Development (CBID).<br>• Programme starts partnership with the local government of the Tarija municipality. |
| 2019 | • Administration is transferred to Caritas Coroico.<br>• New project phase started with more emphasis in supporting OPDs |

## B. Programme description

### 1. Conceptual Framework

The Mundo Inclusivo CBID programme promotes the full and effective exercise of the rights of people with disabilities. To achieve this, the programme works with people with disabilities, their family members and key stakeholders in the community. The CBID approach aims to empower people with disabilities and their families, promote full and effective participation as well as inclusion in community services and spaces, and holistic development. For Mundo Inclusivo, a key aspect of the CBID approach is that people with disabilities are enabled to lead in the programme activities, drive advocacy and fight for their human rights. Under this approach, the organisation 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.

Self-help and rotating savings groups are fundamental pillars of the work of the programme, as people with disabilities are being empowered to advocate for their rights through these groups. These groups have also allowed for the bringing together and mobilisation of communities. In one instance, a group led to the creation of an organisation of people with disabilities (OPD). Although these are notable achievements, only a few people with psychosocial disabilities are currently involved (in particular in the empowerment and social components of the programme). Most participants have physical or intellectual disabilities.

Another key aim of the programme is to ensure its sustainability, for which two strategies are used: (1) the active involvement of different stakeholders for the creation of local support networks where people with disabilities, churches, schools, health centres, and neighbourhood committees are involved, and (2) capacity building at the community level.

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 for people with psychosocial disabilities
- **Yellow** indicates support that was previously available but is no longer or is extremely limited in scope or supply for people with psychosocial disabilities
- **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 community mental health talks during small events in the community. |
| **Medical care** | • Referrals to specialist services. Previously, a psychiatrist conducted consultations in the community, but the agreement that enabled these visits was terminated by government officials. |
| **Rehabilitation** | • Mostly advice on rehabilitation provided by community health promoters and staff to users during home visits. |
| **Assistive devices** | • Available for clients with physical disabilities. |

| | |
|---|---|
| **Education** | |
| **Early childhood** | • Early detection in childhood through health promoters or networks in the communities (e.g. schools or health facilities). |
| **Primary** | • Inclusion in the public education system is facilitated for children with disabilities (see "Education Support"). |
| **Secondary and higher** | • Inclusion in the public education system is facilitated for adolescents with disabilities (see "Education Support"). |
| **Non-formal** | • Some opportunities for technical training (gastronomy and others) are provided to family members of people with disabilities. |
| **Lifelong learning** | • None other than "non-formal" education and "skills-development". |
| **Livelihood** | |
| **Skills development** | • Referrals to technical training opportunities and support to facilitate access to these opportunities, though support is limited due to resource limitations. |
| **Self-employment** | • Various types of business enterprises are supported through "seed capital". |
| **Financial services** | • None. |
| **Social protection** | • Staff and health promoters provide information and guidance on how to obtain a disability card from the government, with which people can access certain medications for free. |
| **Social** | |
| **Personal assistance** | • None. |
| **Relationships, marriage and family** | • None other than basic counselling and psychoeducation provided by community health promoters and staff to users during home visits. |
| **Culture and arts** | • None. |
| **Recreation, leisure and sports** | • Recreational activities such as group walks are organised with minimal frequency. |
| **Justice** | • None. |
| **Empowerment** | |
| **Advocacy and communication** | • Staff and health promoters provide information regarding the existing laws and norms that protect people with disabilities and mandate that they have access to education and health services. |
| **Community mobilisation** | • Done through self-help groups (see below) and by recruiting and training members of the community as community health promoters. (However, no people with psychosocial disabilities are involved in the leadership of self-help groups and only a couple of family members of people with psychosocial disabilities have been trained as community health promoters.) |
| **Political participation** | • A Forum for OPDs to have a dialogue with presidential candidates was recently organised, however it is unclear to what extent people with psychosocial disabilities were represented. |
| **Self-help groups** | • Nine self-help groups for people with disabilities and family members, although only one user with a psychosocial disability involved. |
| **Disabled people's organizations** | • One was established and still running strong, but mainly for physical and intellectual disabilities. |

### 2. Promotion and Prevention

In interviews, volunteers and programme staff reported that the organisation provides mental health-themed talks during community-based events, such as health fairs. These talks are delivered by the programme staff. However, there was no information available regarding their frequency or impact.

### 3. Early detection and intervention

At the community level, the programme engages with schools, health services and community leaders to identify infants who may have a disability at the earliest possible stage. Early identification is mainly aimed at intellectual or physical disabilities.

The programme seeks that key people at the community refer family members to Mundo Inclusivo. Early identification is done using methods and tools that assess children according to age specific developmental stages. Children identified are supported by community health promoters.

### 4. Mental Health Care

Community health promoters are trained to identify people with psychosocial disabilities, deliver psychoeducation interventions during home visits and refer onward for treatment. According to a programme report from 2015, talk-based therapy was also provided by the programme staff and community health promoters as part of the mental health component to beneficiaries with psychosocial disabilities (Crispin, 2015). However, according to the interviews and field visits conducted, this therapy is no longer provided by the programme. The majority of beneficiaries also reported that community health promoters' support is limited to medication adherence. However, family members reported that after being referred, they receiving psychoeducation, accompaniment and emotional support, which were considered helpful.

Community health promoters and other programme staff refer people to psychiatric institutions which provide biomedical treatment. Mundo Inclusivo staff provide constant accompaniment and guidance during the referral process. It is worth noting these institutions are located far from communities (1-1.5 hours away from visited areas), which limits access to services. Additionally, a few beneficiaries reported that, to access these services, it is necessary to wait outside of hospitals overnight. Even then, it is not guaranteed that they will receive services.

Mental health care is also supposed to be delivered at primary health care centres and the distribution of antiepileptic medication is mandated by government regulations. According to the Pan-American Health Organisation, mhGAP trainings have been delivered in Bolivia [Pan American Health Organisation, 2012]. However, the author who conducted the field visits was unable to verify whether health workers at primary care centres are trained in the delivery of mhGAP or other relevant guidelines to provide mental health care. Beneficiaries reported that only certain primary care clinics provide antiepileptic medication, and that this medication is sometimes not available.

All beneficiaries with psychosocial disabilities who were interviewed highlighted that Mundo Inclusivo had provided a great deal of support in enabling access to pharmacological treatments. In some cases, this was achieved by supporting the process of obtaining a disability carnet (described in more detail in "Medications" under "Programme Resources"). In others, support was provided in either navigating the public health system to obtain an appointment or demand medication, or by actually paying the medication.

It is worth noting that the majority of people with psychosocial disabilities supported by the programme have severe conditions and significant levels of cognitive and functional impairment. The needs of this group seem to be significantly more challenging to address than those of

beneficiaries with other disabilities. During interviews, community health promoters reported they are not trained to deliver psychoeducation interventions to people with severe mental conditions.

### 5. Psychosocial Support and Rehabilitation

Psychosocial support and rehabilitation are provided during home visits. People with disabilities are allocated tasks at each visit according to an intervention plan. In many cases, these aim to teach people with disabilities how to do self-care activities (e.g. teeth or hair brushing, dressing independently), but people are also allocated housework, depending on their progress, and starting with easier tasks. People with disabilities are encouraged to remain active and contribute to daily activities. They are also motivated to engage in recreational activities, such as drawing or other crafts. To this end, community health promoters provide guidance and help to identify objects or materials that can be reused from beneficiaries' homes. Community health promoters encourage families to enable the independence of their family members with disabilities by supporting them through the completion of these tasks and promoting their continuous participation.

However, programme staff reported social participation is mainly promoted through the empowerment of people with disabilities and increased awareness about their human rights. Promoting the right to have a family, culture, recreation and justice among people with disabilities is considered a key strategy for people to exercise those rights. Mundo Inclusivo also aims to provide the information, strategies and space to enable the exercise of these rights.

During interviews, the family members of beneficiaries with psychosocial disabilities highlighted that the support from the programme had enabled their family members to become more independent, although this was to varying degrees. It is noteworthy that most times positive impact was attributed to the effects of pharmacological treatment rather than of psychosocial interventions.

### 6. Self-Help Groups

There are nine active self-help groups with an average of 10 participants each, and they take place on a monthly or bimonthly basis at the community level. Currently, these groups are led by programme staff, but it is expected that in the future people with disabilities and their families will take over leadership roles.

Self-help groups aim to provide a space of support for people with disabilities and their families by bringing them together, making them feel accompanied and understood by others going through similar difficulties and facilitating the exchange of relevant information. In these groups, people can learn about their illness and specific care required for different conditions and get advice that addresses common challenges that affect their lives. To this end, participants are encouraged to listen actively, share similar feelings and experiences, exchange ideas or information, support each other and learn to problem solve. For family members, groups provide a space where they can take a break from their care duties, change environments and focus on their self-care and health. However, a current shortcoming is that participants do not receive any support to attend self-help groups, and often distance and transport costs prevent people from attending regularly.

Self-help groups are seen by programme staff and beneficiaries as a key source of emotional support. A beneficiary shared how attending group meetings has helped her: "It is useful to me. It has helped me a lot. Before I was not like this. As a result of my participation in the organisation I have gotten better emotionally with my children. Before I could not accept the illness of my child" (female beneficiary, P7).

In 2016 self-help group participants formed an organisation called Kantati. This organisation has between 30-40 members, of whom three have psychosocial disabilities. Kantati is part of a

government federation which aims to represent people with disabilities in Bolivia, and one of its main objectives is to ensure the political participation of people with disabilities. However, people with psychosocial disabilities reportedly attend only organisational meetings and are not currently represented on Kantati's board.

Finally, the programme developed a manual of a 10-session intervention called "Empowering ourselves", which guides people through the "path to empowerment" and details environmental changes that are necessary to achieve this.

### 7. Education support

The education component of the programme supports children who have not been able to attend schools for a long period of time in their processes of reintegration and inclusion. The programme provides the following:

1. Information to the families about processes of enrolment to the education system;
2. Accompaniment in the school to sensitise and raise awareness among school directors and teachers, so that they can aid the process of inclusion during class;
3. Training for teachers to provide information and guidance on how to adapt class content to the skills and capacities of children with disabilities;
4. Training to family members to provide information and guidance on how to support the learning process.

In cases when children have epilepsy, trainings include aspects related to medication adherence, as well as response in the case of a seizure.

In 2018, 402 students attending regular schools were supported by the programme. In 2019, 103 have been supported so far. There is no available data disaggregated by disability type; therefore, we do not have information regarding how many of these beneficiaries had a psychosocial disability.

### 8. Livelihood support

In terms of livelihood support, Mundo Inclusivo provides support in three different ways:

1. Through financial support for microenterprises;
2. Through training for the development of skills that can be used for income generation;
3. Through rotating savings groups.

All types of support are available both to people with disabilities and family members. The number of participants in each component can be found in Table 3. Precise data regarding the number of people with psychosocial disabilities who have participated in this component is not available, however interviews and observations suggest only very few people with psychosocial disabilities or their family members are involved.

***Table 3. Number of participants in each livelihood component of the programme in 2018-2019***

| Livelihood component | 2018 | 2019 |
|---|---|---|
| **Financial support for microenterprises** | **71** | **64** |
| **Skills development for income generation** | **144** | **60** |
| **Rotating savings groups (number of groups)** | **1** | **7** |

Regarding financial support, a couple of mothers of users with psychosocial disabilities currently receive some support from the organisation. This support has helped mothers start small businesses, e.g. selling merchandise at local fairs. There are also people with psychosocial disabilities involved in

trainings, e.g. one person is being trained as a baker and received seed capital to start a business. Currently, only one person with a psychosocial disability is participating in the rotating savings groups.

## C. Programme Resources

### 1. Human

Mundo Inclusivo is coordinated by a team of four people, including: a main project coordinator, a coordination assistant, an inclusive education coordinator and a livelihood coordinator. Coordinators oversee the general programme activities: the education coordinator supports users in their inclusion and integration in schools; and the livelihood coordinator supports users who are part of livelihood activities or who receive other labour support. The project coordinator has worked in the programme since 2011; however, all other staff have worked in the programme for an average of two years. The rotation of personnel is an ongoing challenge of the programme. Ninety per cent of the staff are women who many times are forced to leave work due to family or personal reasons; some examples include pregnancy or having to move to larger cities to access better schooling for their children. Additionally, there are eight members of staff who are responsible for all the different intervention areas, and who oversee and support volunteers and community health promoters. The staff responsible for intervention areas have also worked in the programme of only around two years. Among them, turnover is  an issue for similar reasons.

The programme aims to strengthen local capacity by recruiting and training community members to support people with disabilities and their families. Many community health promoters are mothers of people with disabilities who were benefited by the programme before joining as volunteers:

> "I am a mom of a child with a disability. At the beginning I was shy, I didn't like sharing my things especially about my children. I have seen the self-help groups have made me feel better. […] and in the same way that promoters came to my house and earned my trust and friendship, I have tried to do this with my cases. Earning their trust, understanding them, letting them talk and listening." (female community health promoter, P9)

Between 2016-2018, 136 community health promoters were trained and 31 are still working voluntarily with the organisation. We were not able to establish the reasons behind this turnover among promoters, but the voluntary nature of the role could perhaps result in people not being sufficiently motivated to stay in the organisation long-term.

These community health promoters are a central part of the programme, as they undertake processes of case identification, deliver different interventions to people with various disabilities and support in home visits. Each community health promoter has been assigned cases whom they are in change of supporting on an ongoing basis. At the beginning of their involvement, community health promoters are trained and supervised by the staff allocated to a specific area. This training is delivered in workshops that cover the following topics: the role of the health promoter in the community, disability and types of disabilities, existing laws that protect people with disabilities, CBID, integral approach to disability, early intervention and stimulation. Psychological first aid and mental health are also reportedly covered in trainings. After this, staff conduct home visits with community health promoters and provide feedback to help them improve their skills delivering interventions. Community health promoters stop receiving this support once staff consider them to have developed sufficient experience and expertise.

In the case of the Macrodistrito Max Paredes and the Macrodistrito de Periférica, community health promoters have carried on with the programme activities once they have been trained and this has also allowed to shift resources to new areas.

### 2. Transportation

In urban areas, programme staff and beneficiaries use the public transport system, and whichever routes are not covered by this system are travelled by foot. The average transportation time is 30 minutes.

Given that a central part of the programme is the provision of home visits, there is no budget allocated to service user transportation. However, service users are supported with transport costs when there are meetings or events in which attendance is requested by the programme.

### 3. Funding

Since the start of the Mundo Inclusivo programme, all the funding that has supported the programme implementation has come from CBM. CBM in Switzerland is funding the programme's new implementation stage which started in 2019 and will be supported at least until 2023.

### 4. Medications

In Bolivia, medications for epilepsy should in principle be provided by the public health system free of charge when the required paperwork (i.e. disability carnet) is presented. These medications are distributed in primary care centres. Mundo Inclusivo supports families in the process of obtaining the disability carnet, given that it is a difficult and lengthy process. Firstly, to obtain this carnet people need a medical certificate with their diagnosis from a specialist. Given difficulties in accessing healthcare services, even this first step can be complicated. Mundo Inclusivo has contacts with medical doctors who occasionally help facilitate the process. Beneficiaries also mentioned having to wait in long queues and visit different government institutions. Community health promoters have accompanied beneficiaries in this long and frustrating process, providing both guidance and emotional support.

Regarding psychotropic medication, this is not provided by the public health system and is often costly. However, the programme has provided financial support in certain cases when, as demonstrated by a socioeconomic assessment, there is evidence that a family does not have the resources to buy the necessary medication. In these cases, families have received funds but also been included in the livelihood activities to ensure that in the long term, families can cover their basic needs as well as medication.

## D. Information System

Each user has a file where the following information is recorded: personal information (date of birth, sex, contact details, date of first contact, type of disability, caregiver contact details), disability history (main dysfunction, date when it started, how it started, other problems, if disability has improved or not, if other family members have a similar problem, if care has been sought and where, medication history, other physical health symptoms), participation in work or study, family situation (living arrangements, family members, if the family is supportive, family attitudes towards the person) and participation in different programme components (i.e. livelihood, education, etc). This file also contains the intervention plans that are formulated with the participation of users and family members, where tasks according to their interests are scheduled and progress is recorded. The intervention plans take into account the following information: problems to be addressed, order or priority of problems, goal, how to achieve the goal, who needs to support, how often and an estimated date of resolution for each problem.

Information collected during initial visits is used to assess progress. Mundo Inclusivo staff highlighted that this information was also important to detect medication side effects.

### 1. Data Collection, Processing and Reporting

All data is collected by community health promoters during home visits. Programme staff compile this information in excel sheets and produce reports every three months for CBM and directors of Caritas Coroico. Since the new stage of the programme started in 2019, the programme has not been collecting data on mental health indicators.

## E. Service Utilisation Data

The following information was extracted from the statistical report provided by Mundo Inclusivo to CBM in the second semester of 2019 (table 4). Fifteen percent of programme beneficiaries have a psychosocial disability, including epilepsy. Epilepsy is the most commonly identified psychosocial disability and is often comorbid with other physical and intellectual disabilities. The majority of beneficiaries are children; about a third (n=105) are between 0 and 5 years old and are receiving early interventions.

***Table 4. Service utilisation data for Mundo Inclusivo in 2019***

| | **Children** | | **Adults** | | |
|---|---|---|---|---|---|
| **Type of impairment** | **Male N (%) 152 (51)** | **Female N (%) 82 (27)** | **Male N (%) 34 (10)** | **Female N (%) 31 (10)** | **Subtotal N (%)** |
| Blindness or vision loss | 4 (3) | 1 (>1) | 5 (15) | 5 (16) | **15 (5)** |
| Deafness or hearing loss | 6 (4) | 7 (9) | 3 (8) | 3 (10) | **19 (6)** |
| Speech or communication impairment | 1 (>1) | 0 (0) | 0 (0) | 0 (0) | **1 (>1)** |
| Physical or mobility issues | 8 (5) | 7 (9) | 10 10 | 5 (16) | **30 (10)** |
| Deafblindness | 0 (0) | 0 (0) | 1 (3) | 0 (0) | **1 (>1)** |
| Cerebral palsy | 1 (>1) | 3 (4) | 0 (0) | 0 (0) | **4 (1)** |
| Epilepsy | 9 (6) | 2 (2) | 1 (3) | 3 (10) | **15 (5)** |
| Intellectual or learning deficiencies, developmental delay, autism or other similar | 118 (78) | 59 (72) | 11 (32) | 10 (32) | **198 (66)** |
| Psychosocial disability | 2 (1) | 1 (>1) | 0 (0) | 2 (6) | **5 (2)** |
| Multiple disabilities | 3 (2) | 2 (2) | 3 (9) | 3 (10) | **11 (4)** |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Subtotal** | **152** | **(100)** | **82** | **(100)** | **34** | **(100)** | **31** | **(100)** | **299** | **(100)** |

# III. SWOT ANALYSIS

## A. Strengths

Mundo Inclusivo provides support to people with disabilities and their families through a holistic and person-centred CBID approach. This results in programme beneficiaries receiving health, social and livelihood interventions, which are delivered by community health promoters at the places where beneficiaries live, study and work. Moreover, Mundo Inclusivo targets populations living outside urban areas and in poverty. Due to a lack of information as well as affordable mental health care in the areas where Mundo Inclusivo provides support, the programme beneficiaries would not otherwise be able to access health and social support. Even though the programme did not provide mental health care directly, staff have reportedly provided the accompaniment, guidance and information during the referral process that enabled beneficiaries to access services. Beneficiaries also highlighted that only through the support of the programme, they were able to access essential pharmacological treatments.

During the field visits, beneficiaries reported receiving a significant amount of guidance and emotional support from community health promoters. Even though formal home visits were not observed, the visiting researcher was able to witness interactions between promoters and beneficiaries. These promoters came across as caring, knowledgeable and involved with the families we were visiting. Moreover, beneficiaries gave multiple accounts of the positive relationships with Mundo Inclusivo staff, for example:

> "The person that has visited me the most, with whom I have had more of a relationship and who talked to me and helped me emotionally was [staff of Mundo Inclusivo]. […] I was going through a very difficult situation [when joining the programme] and she has explained to me, has told me my daughter has rights. […] I could talk to her, tell her how I felt. […] She has helped me a lot emotionally." (female beneficiary, P8)

Families of people with epilepsy also highlighted that the information provided by promoters had been very valuable. This included information about side effects, reinforcement of the need to take medication at regular times and the use of strategies (e.g. recording in a calendar) to improve adherence.

The programme seems to have had a particular impact in supporting people with psychosocial disabilities to participate in their communities and feel like productive members of their households. The family of a woman with schizophrenia reported that before they started receiving support from the programme, they did not know what illness she had or where to access care. Mundo Inclusivo facilitated access to health services and has carried on supporting this woman. She is now a member of Kantati, the aforementioned OPD. Her sister, who is also a community health promoter in the programme, reported the following about her progress: "I feel very happy about her situation because I have seen enormous results. I can compare to how she was ten years ago and now she is independent. She can easily socialise and people can come to her and communicate with her, which makes me and my father happy." (female community health promoter and carer, P13)

## B. Weaknesses

Mental health is not currently addressed as a cross-cutting issue by the Mundo Inclusivo programme. The programme was recently granted funding by CBM which will cover activities from 2019-2022. Even though programme leaders report mental health is an important component of their work, it was noticed that mental health indicators were recently excluded from the programme reporting and people with psychosocial disabilities are minimally represented in key programme components, such as the empowerment and livelihood components. This suggests there is low prioritisation of mental health which may have resulted from an absence of strong leadership and will probably result in missed opportunities to fulfil the mental health needs of both people with physical disabilities who are already supported by the programme, as well as other members of the communities supported by Mundo Inclusivo who have psychosocial disabilities. A report from a previous field visit conducted to the programme had already suggested that mental health might not be prioritised within the programme (Gomez, 2014). This report highlighted that programme leaders in certain implementation sites had not mentioned conducting any activities related to mental health (Gomez, 2014).

At present, interventions or referrals to mental health services are only available to beneficiaries with psychosocial disabilities, who represent only a small proportion of the programme's beneficiaries (7%). Moreover, mental health interventions mainly consist of facilitating access and improving adherence to biomedical treatment; other talk-based interventions are not available. In the past, the programme had set up a collaboration with a psychiatrist who conducted home visits to people who required it (Crispin, 2015), however this collaboration ended due to the introduction of the Universal Health Insurance (Seguro Unico de Salud in Spanish). This insurance increased the demand for health services, including mental health services, and managers from health government services are no longer allowing health personnel to work off-site. Moreover, people with disabilities previously had priority access to health services; however, since the introduction of the Universal Health Insurance, all the population is treated equally. This has resulted in people with disabilities facing increased barriers to accessing health services.

Community health promoters reported that they face many difficulties identifying people with psychosocial disabilities in the communities and enrolling them in the programme. It seems community health promoters have not received sufficient training to identify people with psychosocial disabilities. Relatedly, many families are resistant to enrol in the programme due to stigma, and appropriate training and strategies to address this are also lacking. Due to this lack of training, community health promoters need constant support from the technician at each visit. Furthermore, community health promoters are only trained to support people with mild or moderate mental illnesses; people with severe mental disorders are immediately referred to staff, which means only eight members of staff are available to support people with these needs.

According to observations during field visits, only one person with a psychosocial disability is currently included in the self-help and rotating savings groups. This is misaligned with the early programme targets recorded in 2014 reports which required all people with psychosocial disabilities in the programme to be included in at least two CBR matrix components (Crispin, 2014). Therefore, it is possible that further support and training are necessary to ensure group facilitators have the skills to enable people with psychosocial disabilities to participate in these groups.

## C. Opportunities

Mundo Inclusivo has been working in all the components of the CBID matrix for a number of years. In this sense, the programme has extensive experience and is ideally placed to start strengthening its mental health component.

According to a report from 2014, the programme conducted different activities to assess the needs of people with psychosocial disabilities and strategies to address these needs given the scarcity of services at the local and state level (Crispin, 2014). At this point, the programme was also reported to have established links with the local primary care services. According to information gathered in the field visits, there is still communication with these services, which could be strengthened and utilised to ensure people with mental health needs have access to quality services. Furthermore, Mundo Inclusivo could also support illness management at the community level and facilitate communication between beneficiaries and health services.

The programme primarily targets children, who could be greatly benefited by the inclusion of mental health promotion and prevention strategies. Given the nature of the programme, these strategies could be designed using a multisectoral approach which includes interventions at the school and community platforms. These strategies have the potential to help communities become more inclusive of people with psychosocial disabilities, and complement efforts that the programme has undertaken to reduce stigma and discrimination of people with physical disabilities.

The programme has also built a strong network of community health promoters who have enabled the implementation of the CBID approach. These promoters are members of the community who understand local norms; therefore, they could help develop strategies for the identification of people with psychosocial disabilities that are culturally appropriate and relevant. Promoters could also aid in the process of adapting existing talk-based interventions and then deliver them in the community. Existing evidence indicates that community health promoters can identify people with mental disorders and provide support during treatment when adequately trained and supported (Bajali, et al. 2012). Community health promoters could support the treatment management of people with severe mental disorders as well as provide talk-based interventions. These promoters could also receive training and support to address issues such as stigma and discrimination in the community.

Finally, self-help groups are at the core of the CBID strategy of Mundo Inclusivo, and efforts could be done to increase the representation of people with psychosocial disabilities in them. Groups have been a particular strength of the programme as they have enabled people with disabilities to get together, share concerns, build support networks and begin collective action for the advocacy of their human rights. Existing self-help groups could be utilised to also empower people with psychosocial disabilities, as well as help them feel included and part of a support network. Members who have been part of these groups for a number of years could be a great source of support and encouragement for people with different needs but who might have similar experiences, such as challenging health needs, and experiences of stigma and discrimination.

## D. Threats

Community health promoters provide the majority of the support offered by Mundo Inclusivo. These promoters work on a voluntary basis. Rotation has always been an important issue, given that the majority of volunteers will work in the programme during the times when they are looking for more steady employment opportunities, and their level of participation could be different depending of personal circumstances. Furthermore, even though promoters receive training, they still require a considerable amount of technical support while conducting home visits and delivering interventions.

The scarce availability of mental health services in the intervention areas. coupled with the high costs of medications, results in families facing many difficulties in accessing medications regularly. Medication costs present a constant threat to the family economy; therefore, families are highly dependent on the programme's support. Primary health care clinics sometimes provide this medication, but currently, coordination between the programme and these primary care services is non-existent for beneficiaries with psychosocial disabilities. These reinforce the need for people with psychosocial disabilities and their family members to be included in livelihood activities.

It seems that one of the reasons mental health has been neglected is the absence of a staff member with interest and experience in mental health service delivery. This lack of expertise has not allowed the programme to address some of the issues identified in the community, and these unresolved issues have not allowed the programme to carry on working in the mental health components. According to interviews and observations, the mental health component of the Mundo Inclusivo programme has significantly declined since 2016 at which point 56 people with psychosocial disabilities were included in other CBR components and 120 were part of the self-help groups (Crispin, 2016). Programme staff report this has been due to numbers only reflecting people identified for the current programme stage which started in 2019, however the number in the previously mentioned 2016 report were also for the second semester of the programme.

Information gathered through this report suggests reduced interest in psychosocial disabilities, lack of mental health-specific leadership, greater identification challenges and high severity of symptoms of people with psychosocial disabilities might lead to reduced prioritisation of people with psychosocial disabilities and an increased unmet need.

## IV. Conclusion

Throughout the years, the programme has been implementing a strong CBR model. However, the mental health component has not been a priority and has been steadily declining to the point where currently it is almost non-existent. The absence of a cross-cutting mental health component is an important omission in any CBR programme. Even though self-help groups are an important source of emotional support for all beneficiaries, this seems to be a secondary gain of groups, and strategic planning regarding the emotional/mental health component is lacking. In this case, previous efforts and investment addressing mental health needs should be leveraged and further developed.

The lack of leadership and expertise related to mental health in the programme has probably had a negative impact on the programme. CBM could facilitate access to ongoing support to help the programme develop strategies to include mental health in all the programme activities. Additionally, people with psychosocial disabilities need to be better represented in all programme activities.

Mundo Inclusivo has had a strong impact empowering people with disabilities to engage in advocacy resulting in the generation of Disability People Organisations (DPOs). It is necessary that the programme uses its experience engaging people with physical disabilities to also enable the inclusion of people with psychosocial disabilities. It is essential that the voices of people with psychosocial disabilities are also heard, so they can have an active role in the fight for their rights.

Strategies to further ensure the sustainability of the programme must be developed. At present, community health promoters and primary care workers have not received adequate training in the management of mental disorders. Moreover, there is little coordination between the programme and the primary care services. This has resulted in people with severe and complex needs being supported almost solely by programme staff, and in beneficiaries receiving mainly biomedical interventions. Further capacity building is necessary to ensure people with severe conditions can be

holistically supported by the community health promoters and primary care services in the intervention areas.

## References


Balaji, M., Chatterjee, S., Koschorke, M., Rangaswamy, T., Chavan, A., Dabholkar, H., Dakshin, L., Kumar, P., John, S., Thornicroft, G. and Patel, V. (2012). The development of a lay health worker delivered collaborative community based intervention for people with schizophrenia in India. *BMC health services research*, *12*(1), p.42.

Cohen, A., Eaton, J., Radtke, B., George, C., Manuel, B. V., De Silva, M. & Patel, V. (2011) Three models of community mental health services In low-income countries. *International Journal of Mental Health Systems,* 5**,** 3-3.

Cohen, A., Eaton, J., Radtke, B., De Menil, V., Chatterjee, S., De Silva, M. & Patel, V. (2012) Case Study Methodology to Monitor and Evaluate Community Mental Health Programmes in Low-Income Countries. CBM International and London School of Hygiene and Tropical Medicine.

Crispin, R. (2014) Narrative Monitoring Report for CBM International [*Reporte Narrativo de Monitoreo para CBM Internacional*], 15 July. CBR-Mundo Inclusivo

Crispin, R. (2014) Narrative Monitoring Report for CBM International [*Reporte Narrativo de Monitoreo para CBM Internacional*], 23 December. CBR-Mundo Inclusivo

Crispin, R. (2015) Narrative Monitoring Report for CBM International [*Reporte Narrativo de Monitoreo para CBM Internacional*], 8 July. CBR-Mundo Inclusivo

Crispin, R. (2016) Narrative Monitoring Report for CBM International [*Reporte Narrativo de Monitoreo para CBM Internacional*], 8 January. CBR-Mundo Inclusivo

Gomez, N. (2014) Mundo Inclusivo Project Visit Report, 13 August. CBM International

Panamerican Health Organisation (2012) mhGAP training for PHC professionals in La Paz, Bolivia. PAHO. Retrieved on 20/12/2019 from: https://www.paho.org/bulletins/index.php?option=com_content&view=article&id=1361:mhgap-training-for-phc-professionals-in-la-paz-bolivia&Itemid=0&lang=en

Pastoral Social Caritas Boliviana (2014). Plan Estratégico Institucional 2014-2018. Retrieved on 23/09/2019 from: http://www.caritasbolivia.org/index.php?option=com_flippingbook&view=category&layout=list&id=2&Itemid=233