

BRIDGES and the process of understanding CBR

In August 2015 the project Bridges began its implementation in Brazil and Indonesia. The project aims to explore general CBR initiatives existent in Brazil and Indonesia and to address the specific topic of sustainability. A participatory approach was proposed for the research which implied that people affected by leprosy and disabled people would be active as researchers or co-researchers. During these eight months of implementation, however, the objectives and process of research in each country have been through some adjustments. It could be said that such adjustments must be considered as one of the results of the research process instead of just a methodological change. The process of definition of main concepts such as CBR and participation has presented challenges and yet promisingly overall they open opportunities for local and international understandings of CBR in general. Two main changes were identified.

1. Initially the project aimed at targeting only disability –leprosy CBR initiatives in the two countries. However, the difficulty of finding them determined the inclusion of initiatives that were not necessarily linked to disability but have “somehow” a CBR approach.
2. The study was initially thought as a participatory research implemented together with DPOs and people affected by leprosy. However, differences in processes in each country have also shaped particular processes.

In here, we intend to give an overview of the journey each country has and is still doing in order to understand CBR. This will also facilitate the understanding of some of the changes implemented.

I. Concepts and definitions

“Last January we had a one-week workshop just with the team [Brazil]. We analysed the concept of CBR and its matrix. We compared them with the initial information we collected from some organizations. Then, we realized there is no such a thing as a proper CBR project here, if we look at the WHO definition. So, the question that immediately emerged was, ‘Now what are we going to do? How are we going to continue’? A week after this Huib came and we had another workshop about CBR. After some discussions we concluded that more important than reflecting on the CBR matrix was to keep in mind the four principles of CBR: Multi-sectoriality, Inclusion, Empowerment and Sustainability. As a result, our objectives changed! [Researcher of BRIDGES Brazil]

Having a clear and applicable definition of CBR has been one of the main challenges that the two teams have encountered as is highlighted in the above quote from one of the members of the Brazilian team. In local workshops as well as during the International workshop celebrated in Amsterdam last April, and during the process of data collection it became clear that CBR is a contested concept. A concept that sounds more complicated than what is taking place in reality, but less complex than that reality. The three agencies of the United Nations:

World Health Organization (WHO); International Labour Organization (ILO) and UN Education, Scientific and Cultural Organization (UNESCO) agreed on the following definition:

CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services (WHO 2003)¹

However, while it reads promising on paper, the reality of CBR in Brazil and in Indonesia is more multifaceted and distant from this original conceptualization.

In Brazil, after a Bridges exploratory study that aimed at identifying different CBR initiatives the team concluded that CBR as such is far from being found in the country. In the area researched there is little knowledge, especially among government staff and authorities about what CBR means and the implementation of it. In general, in the country, there is some hesitation about using the term CBR for political and methodological reasons. To explain: the concept of CBR emerged, in parallel with primary health care (PHC) in the 1970s. Like PHC, CBR was promoted initially as a local grassroots initiative to bridge the gap between an increasing “burden” of disability in developing countries and the scarcity of professional and financial resources. Despite the shift regarding areas of implementation (more countries of the “North” are implementing CBR programmes lately) and methodology, CBR has regularly been identified as a strategy solely for “developing countries”. Government authorities find difficult to picture Brazil as a “developing country” thus, using CBR as a generic term is considered problematic for the international image of the country. . On the other hand, at the time that CBR emerged, rehabilitation was recognised as an essential part of the movement toward community participation in health. However, the last two decades have witnessed the appropriation of the Social Model of disability by the social movement of disability around the world including Brazil and Indonesia. This has somehow promoted the problematic understanding that “rehabilitation” as a component of the classic CBR strategy reaffirms a medical model. The main resistance comes from DPOs and persons with disabilities thinking that CBR means lower quality services and cheaper assistive devices. In Brazil, they believe that to accept less would mean accepting that government does not provide uniform services across the country. As a consequence, the term Community Based “Rehabilitation” is not well accepted. New terms such as disability inclusive development or inclusive community development have been already proposed and incorporated in the jargon of the government and International Organizations. The Bridges study in Brazil concluded that although the term inclusive development is more frequent among the government programmes working on issues related to disability, there is still a vague understanding of its definition. Lastly, the term community is also paradoxical. There is the perception that using the term “community based” exonerates the government from its responsibility and participation in implementing community

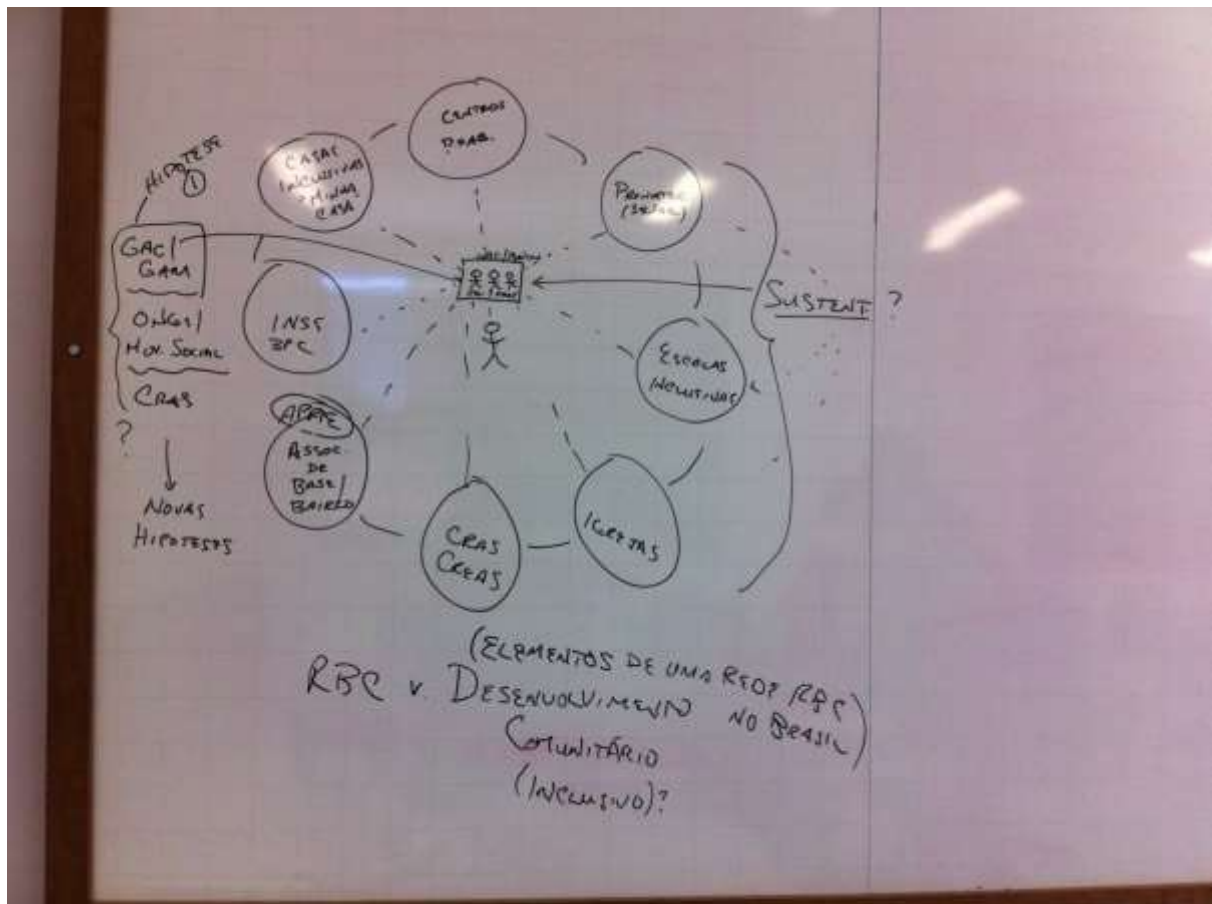
¹ WHO (2003) International Consultation to Review Community-Based Rehabilitation (CBR). Report

initiatives such as CBR. It could be possible that due to this reason the term “disability inclusive development” be more popular when selecting a more appropriate terminology.

In Brazil, there are isolated CBR attempts that work on specific “matrix components” such as education, health, labour insertion. However, four main elements are absent:

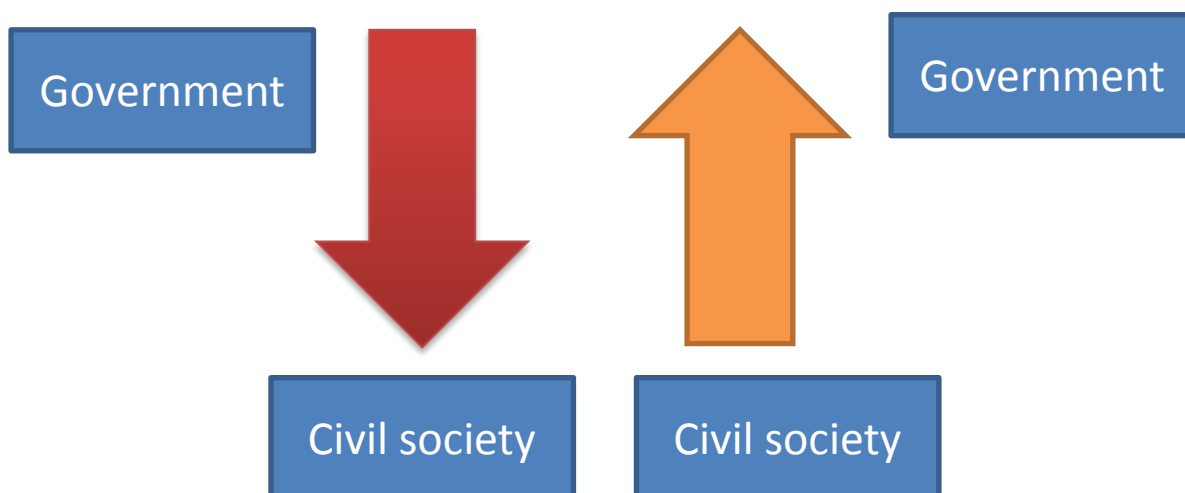
1. Involvement and active role of the government, which in Brazil is central.
2. A ‘cog in the wheel’ or ‘an agent’ to connect various initiatives, government, services, disabled people, families, NGOs and DPOs, etc.
3. Multisectoral collaboration even if the initiatives focus only on specific matrix components.
4. Main role of disabled people and their families in the development of such initiatives.

This is represented in the graphic below developed during one of the workshops in Brazil. In here, the disabled person is in the centre of the initiative linked to different services and spaces. These connections should result from a multi-sectorial effort and should guarantee inclusion, empowerment and sustainability.



Source: Workshop 24-02-2016 Vitoria da Conquista, Brazil.

However, the role of the disabled person and her family is crucial. In view of this, based on the national context, the Brazilian team observes that CBR demands for a twin-track approach, that in this case means, a top down approach (government) working together with a down to the top one (civil society).



The need for multi-sectorial collaboration is very present in the discussion about CBR; however, due to the political and social organization in Brazil, the above diagram would be very much the axe (axis? ideal?) of such model. The government would have a central role especially for sustainability matters while the civil society and especially the disability movement should work parallel and monitor the involvement of the government and other stakeholders.

Another central matter regarding CBR is the search for what could be called the ‘cog in the wheel’ or ‘an agent’ to mobilize all the stakeholders and to bridge the services with the disabled people and their families and to guarantee their rights. The main question that emerges here is who should play this important role and how it should be named: community agent, CBR agent?

The Indonesian team has also struggled with the understanding and the identification of CBR initiatives. In view of this, the team decided to target organizations working in disability but also in other social issues such as drug addiction, women’s rights, poverty alleviation. Many organizations, identified in the selected geographical area, identify themselves as ‘CBR initiatives’. Many of them are governmental. Taking the principles of CBR as reference, it could be said that such initiatives seem to achieve either one or two of them but not all. Also the methodological organization of the initiatives is far from being considered as CBR: there is absence of multisectoral work and although advocacy is a relevant component in different ways, a proper CBR “connector” is missing (the link between disabled people and services). For instance, one of the organizations working on the issue of drug addiction and youth seems to be succeeding in empowering people and creating opportunities for people with addictions to be included in the community. However, minimal support from the government and community (multi-sectoriality) constrains the sustainability and expansion of its success.

The Indonesian team has also highlighted that after exploring the different initiatives two more characteristics should be added:

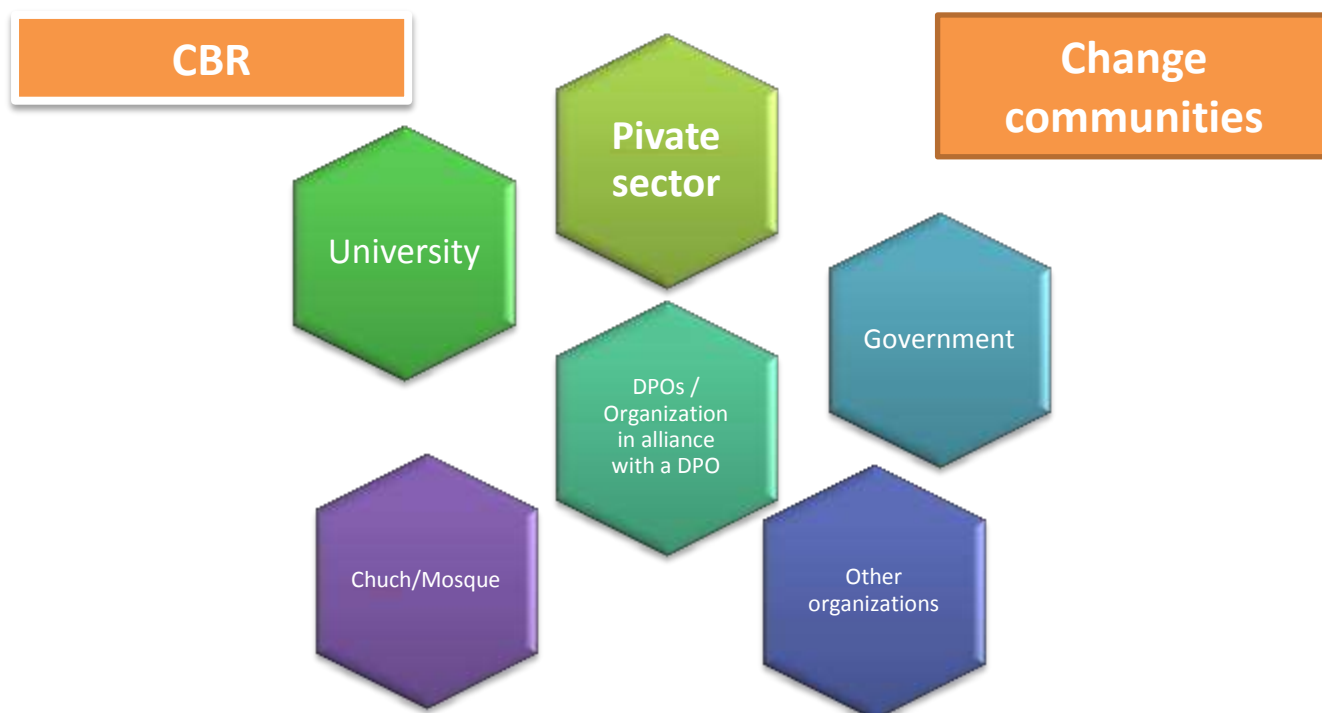
1. Poverty reduction not only for the disabled person but their family and respective community
2. Benefit the community in all the aspects

In line with this reasoning, the team argued that CBR should not be a specific strategy for disability but for community development which includes disability and leprosy. In view of this the team identified the following objectives of CBR:

A CBR initiative should aim at promoting in society/communities:

- Equality
- Community empowerment
- Poverty alleviation
- Independence
- Reduction in discrimination
- Dignity
- Community and group belonging

The team identifies CBR as a strategy that has to be implemented primarily by an organization of disabled people or in close collaboration with an organization of disabled people. In this sense, the members of the organization conclude that such organization and some of its members could have the role of “agents” or “connectors” depending on the same that will be selected.



One of the central findings during the process of conceptualization of CBR was about the relevance of the principles of CBR. The four main CBR principles highlighted by the WHO: multisectoriality, sustainability, inclusion and empowerment are either not visible in initiatives explored or they exist in isolation. This is problematic, as the development and success of one of these principles will depend on the development of the others. They cannot exist in isolation or operate independently. It is important to keep in mind the CBR matrix when developing a CBR project and that multiple components of the matrix can interact;

however, what is most important is to adhere to the principles and to provoke changes that include the whole community besides the disabled people. For instance, educational and rehabilitation services can be offered by many organizations, but without any multi-sectorial work and the participation of other members of the community in those spaces, little is the change that can be made.

Regarding sustainability, its definition in connection with CBR initiatives has also been discussed by the teams in the two countries. Organizations that have participated in the study in Brazil agree on the fact that sustainability is primarily connected with financial and economic conditions. In Indonesia the organizations expressed that sustainability is based on the commitment and sense of belonging that members of organizations feel and that financial and economic factors are complementary. Also, in Brazil organizations would identify the role of the government as essential for the sustainability of any CBR initiative. In Indonesia, many of the organizations have reported been sceptical about the involvement of the government. In some other cases they prefer to have the government institutions as one of the clients than having them as partners.

Bridges could conclude that:

CBR is a contextually designed strategy that aims at provoking changes in communities by promoting the inclusion of people with disabilities, facilitating their access to different services and guaranteeing the fulfilment of their rights including their right to rehabilitation and health. There are four main principles that a CBR project has to look at: sustainability, multi-sectoriality, inclusion and empowerment. They are interdependent and in order to make an initiative sustainable, these principles have to be implemented. However, since CBR is a locally constructed strategy these principles can vary and some other principles can appear depending on the needs of people and their context.

Some of the elements identified in regard to sustainability and CBR are:

- At an individual level: commitment; solidarity; acceptance of being disabled; caring for the members of the group.
- At an organizational level: clear mission and vision; clear structure and leadership; support for the development of young leaders; good local and international network.
- At a financial level: long term budget plans; multi-sectorial collaboration and donors.
- At a programme level: monitoring and evaluation practice; participatory planning; implementation; monitoring and evaluation; creative renewal of areas of work.

II. Research process – Defining and practicing participation

A participatory approach was proposed for the implementation of the project. Reference was made to one of the project objectives, namely, training people affected by leprosy and disabled people as researchers, who will implement the study. There is quite some discrepancy, however, between the two countries regarding this objective. In Brazil, the research team is comprised of 3 Master students and 1 PhD student from the Universidade Federal de Ceara, 1 person affected by leprosy and 1 Masters candidate. The team had previously participated in the research INTEGRAHANS that was implemented between 2014

and 2015. This was a geo-social explorative study about the general conditions of people affected by leprosy in some areas of Northeast of Brazil. The team has characterized the methodology as an operational research. It was argued there were difficulties for implementing a participatory research.

The following difficulties were mentioned:

- Limited time and difficulty for training disabled people and people affected by leprosy. One of the coordinators explained that in a previous project there was an attempt to include people who have low level of education as research assistants. Their experience, however, was that it demanded a great amount of time, resources and energy as many of the participants did not even know how to use a computer.
- Concerns about the scientific quality of the data collected and the relevance of the analysis if this was going to be developed by the co-researchers.
- There were no people with disabilities or people affected by leprosy that would have qualified for the job. The team could not identify a DPO besides MORHAN to counterpart the project. There are only two people that have been involved from the MORHAN organization, however, only one is actively involved.
- Concerns about the progress of the project and the deadline for achieving the goals of the project. There is no experience in training disabled people who do not have any knowledge about research.

However, the team has invited a group of professionals affected by leprosy and disabled people to give feedback and technical support to the research, they will fill the role of a sort of steering committee. They expect that the incorporation of disabled people and people affected by leprosy will be a process happening during the coming years.

The experience in Indonesia, on the other hand, has been markedly different. The research has been implemented by 6 members of the two DPOs involved, FKDC in Cirebon and DSN in Tegal. The researchers who belong to FKDC were SARI project researchers and trained the three participants from DSN in Tegal for this research. It is evident that the experience the researchers from FKDC had with SARI and the training DSN had received from PPRBM (a local DPO), about CBR, has been one of the major positive elements for the implementation of the participatory approach in Indonesia.

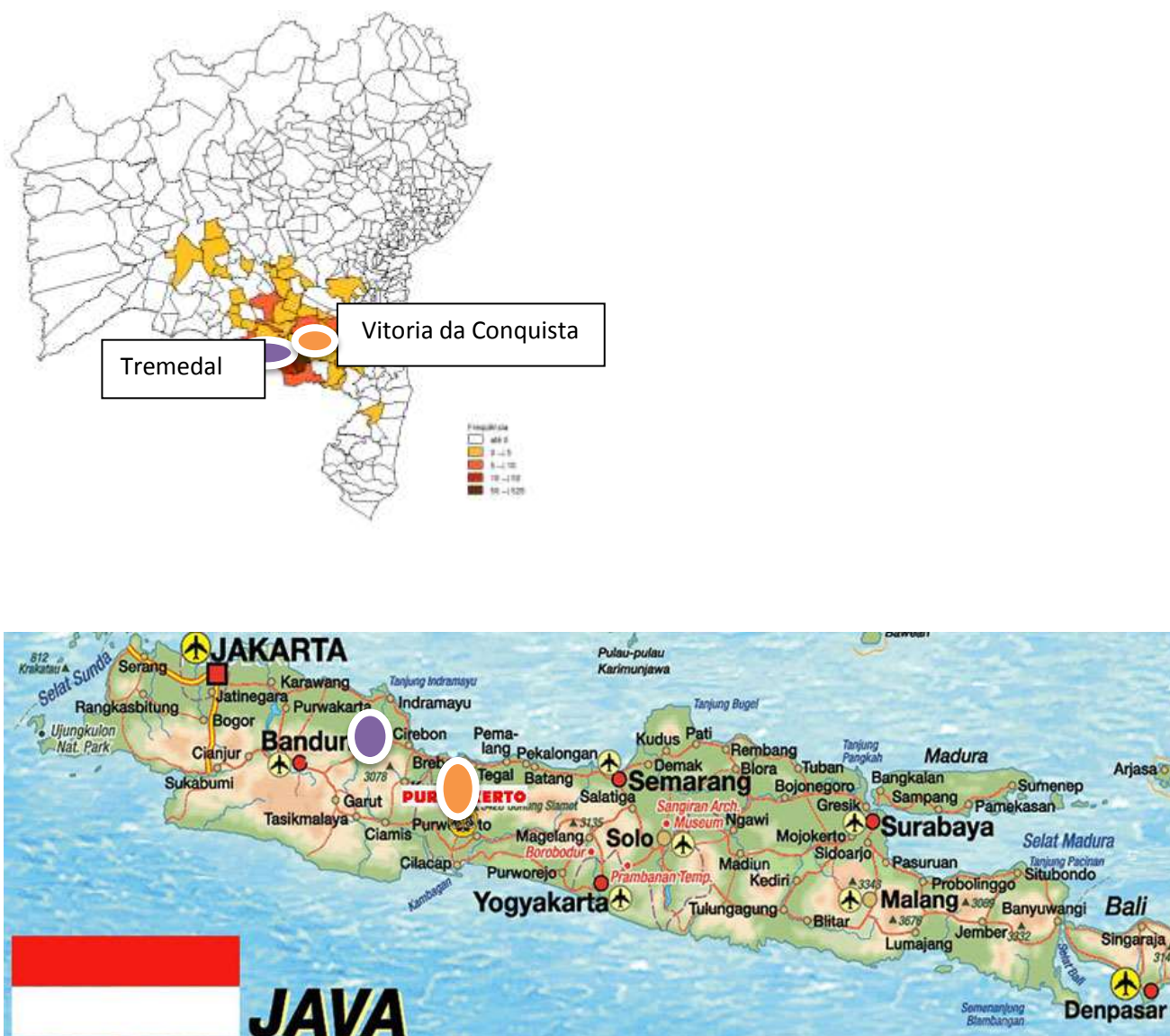
However, there were also some challenges to face. For instance:

- There has been little space for meeting between the two teams (Cirebon and Tegal). More meetings are expected for analysis of the data and the finalization of the project.
- More academic support has been demanded especially for the analysis of data.

The approach that has been taken in each country impacted the design of the instruments, the reflection on the concepts the collection of data and analysis. In Brazil a more systematic and academic analysis has taken place, whereas in, in Indonesia it was less analytical and discussions focused the processes that have emerged from practice and the contact the DPOs have established with the organizations selected for the study.

Due to limitations regarding resources, time and size of the two countries, it was decided to select two specific geographical areas in each country. Brazil decided to work in the municipalities of Vitoria da Conquista and Tremedal, and in Indonesia, Cirebon and Tegal were selected as research sites.

These are presented in the maps below:



Regarding methods and instruments used, both teams started the study by mapping the organizations that could have been considered as CBR. In Brazil selection criteria was based on the CBR matrix. Organizations and government institutions and programmes that were working on issues related to physical and visual impairments (impairments that are related to leprosy too) were included. 9 organizations/institutions have been interviewed from the 25 that were identified. Questionnaires used for the collection of data have been modified over time to ensure its reliability. Questions were based on the four principles of CBR: multi-sectoriality, empowerment, sustainability and inclusion. Some more specific questions regarding sustainability were included. Different questionnaires were designed for NGOs, government institutions and disabled people. Additionally, 250 organizations/institutions will be sent an on-line questionnaire.

In Indonesia the selection was also based on the matrix, however, organizations that are not involved in the field of disability were also included. To date 10 organizations have been interviewed. Special emphasis was placed on the topic of sustainability. They compared the

questionnaires with the Brazilian questionnaires and tried to include some of the questions. The team conducted semi-structured interviews with the selected organizations. 6 more relevant CBR organizations are still in the process of being interviewed by phone due to the geographical distances. Skype interviews with Indonesian experts on CBR are also being conducted. After analysing some of the available data, FGDs will be organized using relevant topics from the analysis for the questions.

The two countries are in the process of writing their reflection based on the data collected. This will be presented in the final report and the research report. The following are brief preliminary results that have been identified.

- None of the selected organizations fit the description of a ‘proper’ CBR initiative. Participants define CBR as “any action that could contribute to the community and reflects one or more of the CBR principles”.
- Understanding of each of the principles is diverse. For instance, what is understood as multi-sectoriality, could be any relationship with government institutions or organizations and does not necessarily mean the establishment of a system to address the needs of disabled people.
- CBR is not an initiative that is necessarily related to disability. For instance, the majority of organizations work with micro-credit. The idea of supporting people to overcome poverty or social rehabilitation are understood as a type of CBR.
- In Indonesia, organizations that have been visited, and were referred as CBR organizations have decided to change their names and call themselves CBI organizations or organizations with an inclusive development approach. Their emphasis is on advocacy and action research. Rehabilitation is not part of their activities.
- These organizations do not receive support from the government, either because they do not want to depend on it, especially if the organizations are fighting against the abuses of the government against disabled people, or because the government does not have any budget for it. In view of that, they have become providers of services for the government (training, programme advisers, researchers).
- These organizations have also made it clear that research is an important component for sustainability and for CBR. They have a research team working constantly in the organization.
- Among the organizations interviewed, emphasis was given to micro-credit programmes.
- Government support in Brazil and group and community support in Indonesia are seen as the most important external factors for sustaining CBR initiatives. This is followed by funding and an economic component.
- Commitment and a sense of belonging, of the members of the organizations, are seen as the most important internal factors for sustaining CBR initiatives.
- Inclusive development is promoted by the governments in the two countries however, in Brazil the knowledge about it is very weak.

III. To be considered for the future

1. The two projects, although they have followed similar steps, have very different approaches. In Indonesia the process has been developed by the two DPOs with

minimal academic discussion. Brazil, on the other hand, has not involved DPOs in this first stage. This is a bit unfortunate as knowledge acquired during these months has not been transferred to disabled people's organizations.

2. The goals of the two countries will be a slightly different regarding implementation over the next three years. It is imperative they reflect on lessons learned and how information collected until now, will be used. Reflecting on the experience of Indonesia, it is evident implementation has to be done by an organization involving disabled people and or people affected by leprosy next year. In Indonesia this is already happening, however, for Brazil this will be a challenge.
3. In Brazil there is urgency to consolidate collaboration with a DPO and/or an organization of disabled people. in Indonesia, there is the need for more academic and technical support. More extensive collaboration with a local university besides UI is needed. Another suggestion could be to involve more Masters and PhD students from UI to support the work of the DPOs.
4. The two countries have a great level of independence and self-determination to achieve their goals. More exchange of ideas and experiences is needed between the two countries.
5. The exchange between countries should include training, field visits and material exchange.
6. The component of exchange has to be seriously considered and supported by a relevant budget. This budget needs to be clearly understood by the teams in each country from the outset of implementation.

BRIDGES teams in Brazil and Indonesia



Part of the Brazilian team: 02/03/2016



Indonesian team: FKDC-DSN workshop, Cirebon, 22/03/2016