# LEARNING CULTURALLY ACCEPTED INCLUSIVE DEVELOPMENT MODEL FOR PERSONS WITH DISABILITIES IN INDONESIA

**Abdul Mujib**
**Firmansyah**
**Irwanto**
**Eriando Rizky**
**Widya Prasetyanti**

Forum Komunikasi Difabel Cirebon (FKDC)
Yayasan Tegal-Slawi Mandiri
Fakultas Psikologi, Universitas Katolik Indonesia Atma Jaya
Fakultas Kesehatan Masyarakat, Universitas Indonesia
Netherlands Leprosy Relief, Indonesia

*irwanto@atmajaya.ac.id; irwanto_i@yahoo.com*

## ABSTRAK

Dalam pembangunan nasional yang begitu cepat, Orang dengan Disabilitas (ODD) sering terseok karena kebijakan publik yang ada tidak mampu mengakomodasi keterbatasan dan fmereka sekaligus mengidentifikasi dan mempelajari praktek RBM dan prinsip-prinsipnya di berbagai LSM tersebut. Perjalanan mereka hanya menemukan sedikit contoh dari penerapan prinsip RBM dan pelajaran yang mereka peroleh digunakan untuk rencana pengembangan LSM mereka di masa mendatang.

**Kata kunci**: disabilitas, RBM, LSM, partisipasi, organisasi berbasis HAM

## BACKGROUND

This report is part of a two country comparative study on CBR funded by ILR Bridges project (2015-2016) in Brazil and Indonesia. The writers of this report are members of the FKDC (*Forum Komunikasi Difabel Cirebon*) and DSM (*Difabel Slawi Mandiri*) both are inclusive CBOs based in Cirebon District (West Java) and Tegal District (Central Java) that are Bridges project partners in Indonesia. Both NGOs have been trained and technically assisted to implement the principles of CBR by RBM training center in Solo (Central Java) from 2010-2014 as a part of building inclusion and participation of people affected by leprosy. FKDC has been working on disability issues since 2007 and engaged in partnership to fight against stigma among

people affected by leprosy with the SARI project in 2010[1]. DSM is developed in 2010 to assist and implement NLR Indonesia program for inclusion of people affected by leprosy.

The Bridges project is designed to enable the disability based CBOs to have exit strategies from external fund dependency. Since both the SARI project and NLR has stopped providing the core funding to these CBOs, they need to strategize to developed their organizations based on what they have learned about CBR. To achieve that goal, the Bridges project provided limited fund for leaders of the two CBOs to learn about sustainable community-based development programs and initiatives in their respective district and from disability based organization elsewhere in Java.

Objectives of the Bridges project

1) To explore existing general CBR initiatives in Brazil and Indonesia in order to learn from their success, challenges, obstacles and methodologies.
2) To design and implement a local inclusive CBR strategy by looking at the experiences of general CBR initiatives in Indonesia and Brazil.
3) To strengthen the capacity of selected leprosy CBR programmes in Brazil and Indonesia.
4) To implement participatory/emancipatory methodologies for implementing, monitoring and evaluating the local inclusive CBR strategy
5) To promote the exchange of process-experience within the selected countries and between them.

**History of CBR in Indonesia – a short review**

CBR was introduced by WHO more than thirty years ago in developing countries in the world, including Indonesia, with specific aim to assist persons with disabilities (PwDs) to be able to enjoy their rights, especially to be able to access basic services in health, education, welfare, and employment. This is achieved by promoting and enabling collaboration between community leaders and PwDs, their families, concerned citizens, and private sectors to create and provide equal opportunities for all PwDs in the community (Joint Position Paper, 2004). The concept and strategies continue to evolve since despite of progress, many people with disabilities, especially women, those who experience psychiatric conditions and had multiple stigmatized diseases such as leprosy and HIV are often left behind.

[1] SARI or the Stigma Assessment and Reduction of Impact (SARI) Project in Indonesia 2006-2010 is supporting the development of inclusive FKDC in Cirebon.

Rehabilitation of PWD in Indonesia had started after the Second World War in 1952 by Dr. Soeharso an Orthopedic who established the Rehabilitation Center (Rehabibilitasi Centrum) in Solo. A year later in 1953 Dr. Soeharso initiated to establish the Foundation of Children with Disabilities (Yayasan Penderita Anak Cacat – YPAC) to respond to the outbreak of Poliomyelitis in Central Java. With significant assistance from the local Department of Social Affairs (DSA), YPAC was able to have their own facilities in 1954. Since then, similar initiatives were rolling in major cities in different provinces across the country[2]. The formal CBR coalition was initiated by the Ministry of Social Affairs (MOSA) as a mitigation strategy to respond to disaster situation in Indonesia. After a series of workshop in 2007-2008, in 11 April 2008 the coalition was officially established[3].

The current policy in the Department of Social Affairs (DSA) as the government focal point on disability issues, the major approach was institutionalization. Referral and the non-institutional initiatives organized as other services outside of the government program were acknowledged and supported by DSA. In consultation with ILO, they were labeled as CBR. They focused on vocational intervention as rehabilitation (Kuno, 1998). In fact, CBR was established in 1978 in Solo as the CBR Development and Training Center (CBRDTC) under the auspice's of the YPAC lead by Handojo Tjandrakusuma a physician and medical rehabilitation specialist. The center's mission is (Tjandrakusuma, Krefting & Krefting, 2002):

> "Improving the quality of life of people with disabilities in their own families, communities, and countries by developing, implementing and sharing knowledge about community action programs that focus on disability issues" (p.1.)

The center assisted district authorities in Central Java and elsewhere to develop CBR to help improve the quality of life of persons with disabilities. Although in their early work to promote CBR there were not getting many successful stories, the center was able to demonstrate real impacts on organizations of persons with disabilities and on local authorities that concerted organized efforts could help governments and communities to provide better care for their disabled citizens (Ortalli, n.d.). The center remains the only trusted CBR training center and has significant influence in national disability movement until this date.

[2] http://ypac.or.id/v1/profil/sejarah/
[3] Sunusi, M. (n.d). Indonesia CBR Alliance. Slide presentation. http://www.jldd.jp/gtid/AP_CBR/pdf/51.pdf

During the early period of CBR promotion and advocacy in Indonesia, the national economics was thriving at approximately 7.5% annually[4]. At the same time, however, gaps between the rich and the poor was widening rapidly. This was rarely challenged due to the believe of the spill-over effects of economic development and growing utilitarianism ideology by the Indonesian technocrats and proponents of develop mentalism. The department of social affairs who is supposed to take care of the poverty alleviation programs did not get adequate investment. In fact, for as long as MOSA received the mandate as the focal point of the state poverty alleviation program, the budget has never reach 2% of the total national budget[5]. Moreover, bottom-up participation was almost unthinkable under the authoritarian regime of the New Order, nonetheless by persons with disabilities.

Evaluations of CBR programs in Indonesia from 1985 to 2010 (Tjandrakusuma, Krefting & Krefting, 2002; Kuno, 1998; Berman, 2011; Ortalli, n.d.), however, provide valuable lessons as follows:

1) Although CBR may mean differently across regions and organizations[6], philosophical and technical understanding of CBR by local authorities, community leaders, and DPO leaders is crucial to engage PWDs and relevant resources.
2) The involvement of local authorities is important o create enabling environment for safe participation (political and cultural sensitivity of CBR).
3) Capacity building, available technical assistance, and effective monitoring are important components of CBR sustainability.
4) Choices of relevant activities for PWDs to ensure participation and ownership by PWDs
5) To connect with other organizations to develop more inclusive development platform.

Along with the above lessons learned on the development and implementation of CBR principles in Indonesia, we also noted that CBR model which is supposed to be a human rights-based intervention is seriously constrained when applied in communities governed by an authoritarian regime like in Indonesia. In all districts that CBR was implemented and evaluated by Tjandrakusuma et al. (2002) has to be connected with the department of social affairs which provides government support, both financial and political guarantee (in the form of patronage by the wife of an influential state official). Once the support ceased to exist, for example (the CBR lost

[4] Nasution, Anwar, from: https://www.ids.ac.uk/ids/global/Conf/pdfs/nasut.pdf

[5] According to the Ministry of Finance, MOSA (spending) budget in 2016 is 14.18 trillion IDR which is only 1.8% of the national budget (784.1 trillion IDR) - http://www.kemenkeu.go.id/apbn2016 -- in the New order regime, the budget was much lower.

[6] CBRDTC – Solo currently has a guideline for trainees to help them understand CBR in a standardized manner (Tjandrakusuma, Krefting, & Krefting, 2002).

patronage because of rotation of state official duty), community participation will slowly stop as indicated in most of the reviews above. Moreover, as indicated by Berman (2011), due to a lack of understanding of the nature of CBR, it is often implemented as a medical and institutional model which is more difficult to sustain.

**Emancipatory Research**

For decades or even millennia, the discourse on disability has been focusing on the impairment and deficit of the individual. This occurs as a one-way construction. Basically, everything about a person with disabilities is determined by others – such as parents, medical doctors, social researchers, teachers, politicians, government and so on – but him or herself. Our knowledge about disability has been accumulated through this one tunnel process of so-called objective research where the experiences of being disabled is scrutinized and described by most persons who do not experience disabilities. Such research contributes to the disablement discourse creating misunderstanding and slowing progress in the fulfillment of PwDs' rights of persons with disabilities and the cooptation of the PwDs agenda on the recognition of their rights (Oliver, 1997, 2002; Barnes & Mercer, 1907; Verbrugge & Jette, 1994; Gilson & DePoy, 2004; Masala & Petretto, 2008; UNICEF, 2008). Although some criticisms of this methodology[7] should be taken seriously, especially when PwDs themselves are not ready to participate and to be empowered (Danieli & Woodhams, 2005; Oliver, 2002) this method is worth to be learned and implemented in our work with leprosy and disability. Most of the researchers involved in this project were senior disability activists and some of them have been trained in social research methodology by the SARI team.

Michael Oliver (1997, 2002) indicated that an emancipatory research methodology is a vehicle for social transformation. More specifically, he suggested that:

> "The emancipatory paradigm, as the name implies is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs' (Oliver, 1992:110)[8].

In such a process, PwDs should be able to turn around the social relation of research production. This means that PwDs are not only the subjects (participants) of research, but they also gain ownership of knowledge production and have the power

[7] Danieli & Woodhams (2005) criticized the proponent of emancipatory research by saying that such an approach may in fact undermine the generation of knowledge by shutting down voices of some disabled persons and researchers.
[8] Oliver, 1997, op cit p. 16.

to access and use the knowledge to improve their quality of life. This is consistent with the meaning of empowerment described by Oliver:

> "…empowerment is not in the gift of the powerful; albeit whether they are politicians, policymakers or researchers; empowerment is something that people do for themselves collectively" (Oliver, 1997, p. 19)?

To qualify the implementation of this methodology, Oliver stated that when PwDs have decided to empower themselves, do we contribute to this process?

The following section describes the process in which researchers from two inclusive CBOs are learning about factors that contribute to the development, acceptability, and sustainability of social welfare and rights-based CBOs in their region and at the national level.

**The Development of Inclusive CBOs**

*Forum Komunikasi Difabel Cirebon* (FKDC) was founded in April 2007 by Abdul Mujib. His work started in 2004 when he was asked by the District office of Social Affairs to be an Instructor on Electronics for PwDs. After participating in a number of training workshops, he felt that when the workshop had been completed, there were no follow up actions. Trainees had no umbrella organization and some were still left unemployed. He established a disability organization called "Binangkit Jaya" that was lead by 2 people with disability and 3 people without disability as its board members and 10 people with disability as its members. This organization was able to secure funding from different surces for economic empowerement activities among members and when they grew bigger they transformed the organization into the current FKDC. Since several members of FKDC were recruited as SARI research assiatance, they were motivated to recruit persons affected by leprosy (currently they have 210 members including 50 members affected by leprosy). Some members were trained on CBR development and implementation by Mr. Sunarman from CBRDTC – Solo. To support the inclusion of people affected by leprosy, they also received partial funding by the Sasakawa Foundation for micro-credit activities. FKDC has been able to assist its member to develop varieties of micro businesses. The problem, however, they have not been able to sustain their funding into an evolving capital for the organization.

*Difabel Slawi Mandiri* (DSM) was establised in 30 December 2010 as part of Disability Advocacy and Empowerement program by CBRDTC or PPRBM Solo (Mr. Sunarman) to support NLR initiative to develop inclusive CBR for persons affected by leprosy in Tegal District. It was started with an existing CBO called *Difabel Tegal Mandiri* (DTM) and in 2012 the organization changed its name into

*Difabel Slawi Mandiri* (DSM) to be able to cover Tegal and Slawi District. At present DSM has 142 members, including people affected by leprosy. This CBO is actively engaged in advocacy on the rights of PwDs, micro-credit and business training, and managing small credit cooperative. Until this date, DSM is still dependent on external sources of funding.

To help developing these CBOs into a full-fledged CBR, they were assigned to learn from as many other CBOs as they can identify in their respective districts. Semi structured interview schedule was developed together by research team in Indonesia, Brazil, and the Netherlands. Field training was conducted by NLR. Contacts at the local level were made by respective CBOs and at the national level was assisted by NLR. FKDC was able to contact, received responses and observe 15 CBOs at the local and national and DSM was able to contact, received responses, and observe 28 CBOs at the local and national level. Their specific task is to learn from as many CBOs that they could identify as model CBOs on institutional management issues, membership, source of funding, core business model, and sustainability of their organization.

**Lessons Learned from Other CBOs**

Analyses of responses and field notes (observation) were initially conducted by each CBO's team. After familiarize themselves with the results of their analysis, the results were consulted with the NLR team and later consulted with the international Bridges team in the Netherlands (represented by FKDC).

In Cirebon and Tegal-Slawi districts, they did not find any CBOs that were developed and managed according to the CBR concept and principles by WHO. Nonetheless, some of the CBO were established to cater specific needs of their members. Many of them received their financial resources from government, members and community members donation. Some of them are quite solid because they based their activities and funding within certain religious practices and institutions (e.g., Zakat Center). Local CBOs and a number of CBOs outside of Cirebon who receive occasional government funding, project based funding, and member and community members' donation are very fragile. Their activities very much depend on government program and project support for specifically targeted population. When the project stopped, related activities are failing accordingly.

The CBR based institutions, like SABDA (Yogyakarta), SIGAB (Yogyakarta), PPRBM (Solo) have had years of experience of advocating the rights of PwDs through research, training, and self-sustained micro-economic activities. The leadership consists of highly educated PwDs and strongly dedicated their career to helping marginalized population. They also receive funding from government but they are not dependent on government assistance.

They also learned that recruitment of members and beneficiaries is crucial. Some CBOs have hard times to sustain their activities due to recruiting drug abusers who need help with their addiction, but they were not getting enough financial support from their parents and communities. Those recruiting people living in poverty as beneficiaries also had hard times to sustain government funding. If their program activities are based on an ongoing (routine) religious activities (such as alms or Zakat) and their activities are dedicated to children care and education, sustainability is guarantied. Other CBOs were able to sustained their main activities due to dedicated external support – especially parents of children with special needs (Pena Gading, Bogor).

From PKBI and other older CBOs, they also learn the important of nurturing the spirit of volunteerism, how to do effective advocacy, and building capacity to conduct simple research. They also learned that solid management, financial transparency, planned regeneration, and advocacy to local authority and the private sector contribute to sustainability.

FKDC and DSM also learned that building a portfolio on sustained micro-economic activities is quite challenging. Older CBR-based inclusive CBO in Yogyakarta and elsewhere, have had many success stories about helping members with micro businesses. At the same time, they also acknowledged that fierce competition, low tech production mechanism, or higher production costs, no government protection, and weak marketing strategies often becoming issues that eventually beat innovative ideas and businesses.

Aside from all the above lessons learned, FKDC and DSM also realized that the most important lessons learned about RBM is not only the organization of it, but the creation of opportunities for marginalized population to:

1) Improve knowledge about themselves and the world around them. They need to learn to appreciate themselves before expecting others to do so.
2) To have a forum for the marginalized to learn and teach from each other so that as a collective entity they can find better solution to their problems.
3) To be not afraid to participate in the mainstream community activities as very often they are stigmatizing themselves and that they do have the capacity and expertise to contribute to community development.
4) To learn the skills to connect and to work together with different elements or organizations in the community.
5) To appreciate initiatives that come from the marginalized community themselves because of its relevance and commitment to sustain the initiatives.
6) To understand that RBM will enrich existing activities of marginalized population.

### Implication for Future Direction

Both FKDC and DSM recycle their lessons learned within their respective organization as part of their reflective agenda.

FKDC indicated that the Bridges experience will be used to:

1) Improve the management – especially on the role of members in organizational sustainability. This will be implemented during the annual meeting and the election of the new management in 2017.
2) Improve data based on members and their families will be improved so that FKDC will be more sensitive about issues in members families that may affect the organization or need FKDC support. The data will also be useful to create better opportunities for relevant activities and plan for regeneration. This is important for FKDC as children of current members are better educated than their parents at the same time to recognize that they may also have children affected by leprosy or with special needs.
3) To improve knowledge, management skills, and advocacy skills for all FKDC management staff,to deal more effectively with members, government agencies or programs, and with private sectors.
4) To partner with a local university to generate interest on local development issues and inclusive development model.

DSM aspire the following:

1) To improve knowledge and skills of management staff to carry out and sustain DSM mission to empower PwDs and people affected by leprosy.
2) To improve network with other similar organizations especially with inclusive developmental organization at the local and national level.
3) To work with the academia to document their experiences for future training and education about inclusive development model.
4) To assist other marginalized community in Tegal to develop CBR based organization and activities.

## BRIEF NOTES ON THIS REPORT

This report is written by Irwanto, Ph.D based on written report from both FKDC and DSM, discussion during visit to Cirebon and Tegal, and final discussion in Jakarta to finalize this report. Although the writer tried his best to stick to existing documents and minutes of discussion, biases may occur which is solely my responsibility.

## (ADDITIONAL) BIBLIOGRAPHY

Barnes, C. & Mercer, G. (1997). Breaking the Mould? Introduction in doing disability research. In Colin Barens & Geof Mercer (ed). *Doing Disability Research*. Leeds, The disability Press, p. 1-14.

Berman, L. (2011). Integrating Disability into Eastern Indonesia: A Case Study in Theory versus Reality. Health, Culture, and Society, Vol. 1, No. 1. , p. 133-145

Lysack, C. L. (1995). Community participation and community based rehabilitation: Indonesian case study. *Occupational Therapy International, 2,* p.149-165.

Gilson, S.F. & DePoy, E. (2004). Disability, Identity, and Cultural Diversity. *Disability Reviews*, 1 (1), pp. 15-24.

Krefting, L, Krefting, D. (2008). Community Approaches to Handicap in Development: The next generation of CBR Programmes.

Kuno, K. (1998). *Community-based Rehabilitation in South East Asia: Case studies from Indonesia and Malaysia.* A dissertation submitted to the School of Development Studies of the University of East Anglia in part-fulfilment of the requirement for the degree of Master of Arts. August 1998.

Kusumastuti, P., et al. (2014). The Problems of People with Disability in Indonesia and What Is Being Learned from the World Report on Disability. *American Journal of Physical Medicine & Rehabilitation*, *93*(1 Suppl 1): 63-67.

Oliver, M. (1997a). *The Politics of Disablement*. NY: Palgrave Macmillan Publisher

Oliver, M. (1997b). Emancipatory Research: Realitic goal or impossible dream? In Colin Barens & Geof Mercer (ed). *Doing Disability Research*. Leeds, The disability Press, p. 15-31.

Ortali, Francessca (n.d.). CBR Pilot Programme South Sulawesi Indonesia Challenges for New Approaches. http://english.aifo.it/disability/documents/journal_articles/Article%20Ortali%20Asia%20Pacific%20journal%203-2000.pdf

Tjandrakusumah, H., Krefting, D. Krefting L. (2002). *Changing CBR concepts in Indonesia: Learning from programme evaluation.* Downloaded: August 17, 2016 from http://digitalcommons.ilr.cornell.edu/gladnetcollect/434/

UNICEF (2008). *Its about ability. An explanation of CRPD*. New York: UNICEF and A World Enabled - Pineda Foundation.

Verbrugge, L.M. & Jette, A.M. (1994). The Disablement process. *Soc Sci Med*, 38 (1): p. 1–14.

## ACKNOWLEDGEMENT

This study would have never materialized without the funding from LRI the Netherlands. We appreciate LRI support and the Indonesian team strong collaboration.

## ABOUT THE AUTHORS

| | |
|---|---|
| Abdul Mujib | Forum Komunikasi Difabel Cirebon (FKDC) |
| | Jalan Sunan Muria No 20, Kecamatan Sumber, Cirebon |
| Firmansyah | Yayasan Tegal-Slawi Mandiri |
| | Gedung Loka Bina Karya (LBK). Jl. Raya Selatan Banjaran |
| | Km. 3 No. 21 Tembok Banjaran Adiwerna Kab.Tegal |
| Prof. Irwanto, Ph.D. | Fakultas Psikologi, Universitas Katolik Indonesia Atma Jaya |
| Eriando Rizky, S.Sos, | Fakultas Kesehatan Masyarakat, Universitas Indonesia |
| Widya Prasetyanti | Netherlands Leprosy Relief, Indonesia |
| | Rumiza Building, Jl. Guntur No. 22, 3rd Floor, Jakarta 12980 |