



## Integrating Disability into Development in Eastern Indonesia:

A Case Study in Theory versus Reality

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## Abstract

This paper looks at patterns of Community Based Rehabilitation (CBR) in two rural, isolated regions of Flores, Eastern Indonesia. It examines methods adapted by local NGOs to integrate children with disabilities (CWD) into the community as it also examines the major constraints that ensure CBR as an approach is far from being realized. While the paper argues for the necessity of a stronger guideline in defining disability and a more gendered focus in research and approach, it also shows how the various methods embraced by the donor agency as well as the local implementing NGOs raise many questions that need to be better understood for future disability activities in rural, low income communities.

**Keywords:** *children; disability; Community Based Rehabilitation; Eastern Indonesia; community development*

# Integrating Disability into Development in Eastern Indonesia:

A Case Study in Theory versus Reality

Laine Berman<sup>1</sup>

## 1. Introduction

In December 2010 I was contracted by a well known international NGO<sup>2</sup> to externally evaluate two projects they were funding in two different areas of the Eastern Indonesian island of Flores. The goals of the projects, both implemented through local NGOs, were to improve the lives of disabled children through “empowering the community to accept disabled children”. Both claimed to embrace the social model of disability which promotes community-based and family-based solutions rather than institutional care. Both locations focused on inclusion of CWD into society through facilitating changes in society in terms of attitudes, social support, information, and economic support that will enable the potential of disabled people to contribute to society. The social model aims to see the person first, not the impairment as it also outlines the potential of disabled people to contribute to society and add economic value, if given equal rights and suitable facilities and opportunities<sup>3</sup>.

Yet the two NGOs employed very different definitions and approaches under the umbrella of CBR. One emphasized surgical and institutional approaches, because of the availability of these resources. The other emphasized a more 'do-it-yourself' approach because no referral systems to medical institutions were available. In both locations, CBR was taken to be a broad ranging approach that included livelihoods support for families with a disabled child, inclusive education, and creating committees to assist families. The problems and drawbacks all emerged as it became clear that there was insufficient research prior to program implementation and that the donor as well as local NGOs had insufficient understanding of CBR and disability in general. Further, there was next to no government support for these rural communities, themselves suffering under extreme poverty, with a lack of access to the most basic of services. Twinned with this is the lack of understanding regarding their own health needs, let alone that of their disabled children.

This case study argues that donor agencies need to do more homework prior to funding local NGOs. They need to recognize the extreme difficulties and barriers that exist in rural regions and provide better support, training, advocacy, and networks to assist this extremely difficult work.

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<sup>2</sup> I have chosen not to identify any of the international or local NGOs involved. The intension of this paper is not to criticize but to emphasize lessons learned and hopefully add something to the discussion on improving disability and CBR programs.

<sup>3</sup> UNICEF. *Research Report on Children with Disabilities and Their Families in Da Nang*. 2009

## II. What is disability?

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others<sup>4</sup>. Disability is thus recognized as a socioeconomic construct that is influenced by differing cultures, social institutions, and physical environments. Disability is caused by a wide range of interacting aspects such as communicable diseases, genetic factors, injuries, aging and many more<sup>5</sup>. Community-based rehabilitation (CBR) was developed as a solution to the problems of disabled persons living in developing countries. It is defined as a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. “Hence, CBR is a strategy for achieving the rights of people with disabilities within the context of their communities and societies. It is also a strategy relevant to community development and to national strategies for poverty reduction. CBR should be an integral component of these national programs and strategies, emphasizing human rights, socio-economic development, and poverty alleviation”<sup>6</sup>.

CBR was born out of a recognition that unless there was a substantial change in disability service provision in Asia, Africa and Latin America, the vast majority of disabled people would never benefit from any services whatsoever<sup>7</sup>. It is still estimated that only about 2% of the disabled people living in developing countries are currently receiving assistance<sup>8</sup>. Meanwhile, estimates suggest that roughly 15 to 20 percent of poor people in developing countries are disabled. Their numbers are rising due to conflict, malnutrition, accidents, violence, communicable and non-communicable diseases including HIV/AIDS, aging and natural disasters<sup>9</sup>. Many studies have noted the direct link between poverty and disability (ibid). In countries like Indonesia, statistics claim disability is below 5% of the population, and do not accurately support expansion of disability programs (compared to countries like the US and Australia where disability affects 18% of the population)<sup>10</sup>. It is noted in the research that as many as two out of every three people who are disabled are not counted in these statistics as the “missing disabled people” and they are dying for reasons that are primarily related to poverty and negative attitudes about disability.

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<sup>4</sup> Coleridge, P., C. Simonnot, D. Steverlynck. *Study of Disability in EC Development Cooperation*. European Commission. 2010.

<sup>5</sup> World Bank, Disability and Development Website: [www.worldbank.org/disability](http://www.worldbank.org/disability)

<sup>6</sup> World Health Organization. *International Consultation to Review Community-Based Rehabilitation (CBR)*, Helsinki, 2003.

<sup>7</sup> Lang, R. Empowerment and CBR: Issues raised by the South Indian experience. Chapter 9 in Stone, E. (ed.) *Disability and Development: Learning from action and research on disability in the majority world*, Leeds: The Disability Press pp. 130–148. 1999.

<sup>8</sup> Thomas M, Thomas MJ. (Eds) *Selected Readings in Community Based Rehabilitation, Series 1: CBR in Transition*. Bangalore, National Printing Press, 2000.

<sup>9</sup> World Bank. *Examining Inclusion: Disability and Community Driven Development*. Social Development Notes Number 100/May 2005.

<sup>10</sup> World Health Organization. *ICIDH – 2: International Classification of Functioning and Disability; Beta-2 Draft Version*, July 1999: Assessment, Classification and Epidemiological Group, Geneva, Switzerland, 1999. Krefting, L, Krefting, D. *Community Approaches to Handicap in Development: The next generation of CBR programmes*. 2008.

DFID<sup>11</sup> estimate that more than 50% of the impairments that result in people being labeled disabled “are preventable and directly linked to poverty.”<sup>12</sup>

Disability is, then, first and foremost a human rights issue and cannot be separated from other poverty, health, education, and inclusion issues. The social and economic problems facing the disabled and their families, as well as the communities in which they live, require new areas of activities and new ways of implementing their existing activities. For existing CBR and development programs, this means:

- Changing the focus of program activities from a micro focus on disabled people, or other vulnerable groups and their problems, to a macro focus which includes all aspects of a society.
- Recognizing that developing networks of organizations and close collaboration with government to share resources and responsibilities is the most effective way to implement the broad range of activities necessary to create these broad types of change<sup>13</sup>.

### III. Context of Study

In West Flores the local NGO selected their 6 target villages by choosing 2 villages each from within the 3 districts of Manggarai. The six villages each were identified by having at least 10 CWDs. In Central Flores, the local NGO selected 3 target regions with 11 villages by choosing those that were identified as having the most CWDs. For both regions, access to the sites requires between one to four hours’ drive to reach the main areas. Most of the villages are mountainous and require walking along steep, unpaved tracks to reach many of the beneficiaries. Two out of three villages included in the evaluation process for both regions were clearly extremely poor. As example of the difficulties faced to access these communities and to improve economic conditions, the village of B, in West Flores has good statistics. Of 1,395 residents, there are 339 households with an average of 4.1 people per family living in 169 houses, meaning there average 2 households and 8.25 people living in each house. The 169 houses are grouped into 35 permanent structures, 92 semi-permanent (partial stone, cinderblock or wood and partial woven grass), and 42 ‘emergency’ homes that are usually made entirely of woven grass. All but the 35 permanent structures have dirt floors and two rooms – one for living/sleeping and a separate work/kitchen area. People mainly sleep on the dirt floor on woven mats. Of the 169 houses, 101 are considered unsafe for habitation. Of 339 households, 133 are termed very poor. Sanitation facilities are unknown. What constitutes poverty here is measured by the house alone and the number of residents, not by daily income. If measurements were based on international standards of \$2.00/day, and considering 95% of residents are peasant farmers with no assured income, then it can easily be claimed that most, if not all, residents of B would fall into the very poor group.

In addition, more than half of the villagers live on mountain slopes that are at severe risk for landslide, none have electricity or a stable, close water source. None have road or public transport access and most must traverse narrow, steep, dirt tracks up and down mountains for up to 2 hours in order to reach a public road with transport or

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<sup>11</sup> Department for International Development (DFID), *Disability, Poverty, and Development*, February 2000. See also UNICEF. *Vietnam Child Disability Survey*. Centre for Information and Statistics on Labour and Social Affairs, 2000. [http://www.unicef.org/evaldatabase/index\\_14383.html](http://www.unicef.org/evaldatabase/index_14383.html)

<sup>12</sup> See, footnote 10.

<sup>13</sup> See for example Krefting, L & Krefting, T. (Eds) *Selected Readings in Community Based Rehabilitation, Series 1: CBR in Transition*. Bangalore, National Printing Press, 2000.

even to fetch water during the dry season for the day's rations, almost certainly carried by a small child. Children walk an average of 5 kilometers one way over a mountain ridge to reach the only elementary school. Two thirds of their parents did not graduate primary school.

The following tables of disabilities are for purely representational purposes of CWD between the ages of 0 and 18 that were registered by each of the two NGOs evaluated in this study. They reflect one of multiple villages covered by two different local NGOs in West and Central Flores:

**Table 1: List of Disabilities: Village A – West Flores**

	Harelip/ cleft palate	Cerebra l palsy	Mute/ Deaf	Sight problems (not blind)	Unspecifi ed Growth <sup>14</sup>	Unspecifi ed mental slowness <sup>15</sup>	Physical deformit y <sup>16</sup>	Multiple disabiliti es	Epilepsy	Polio	Total
Boys	7	2	1	0	6	0	6	5	0	2	29
Girls	5	0	2	1	7	0	2	1	0	1	19

**Table 2: List of Disabilities: Village 1 – Central Flores**

	Harelip/ cleft palate	Cerebra l palsy	Mute/ Deaf	Sight problems (not blind)	Unspecifie d Growth	Unspecifi ed mental slowness	Physical deformit y	Multiple disabilitie s	Epilepsy	Polio	Total
Boys	1	0	5	7	1	8	3	1	0	0	26
Girls	0	3	2	2	2	3	2	3	1	1	19

Variations among the categories and general findings reveal what the evaluator took to be the lack of responsible leadership by the donor. Since neither local NGO had experience in disability or any medical background, the donor should have provided them with guidance and training such that categories of disabilities and handicaps could be better defined. With no disability network, there was no collaboration encouraged to strengthen local knowledge beyond a project manager being sent to study for two weeks at a hospital for children with cerebral palsy in Malang, East Java. Volunteers with expertise in physical therapy came and trained staff, families, and

<sup>14</sup> Unspecified growths are those that were not linked to any mental or mobility problems. They are cosmetic problems such as a sixth toe or a mole.

<sup>15</sup> No mobility issues. Classified by being slow to learn or antisocial behavior.

<sup>16</sup> Physical deformities are those that are not linked to mental or mobility problems. These include a badly healed break, a dislocated finger that was not treated, club foot, or bowed legs.

traditional healers in massage and other therapy techniques to assist children to use limbs, practice speaking, prevent drooling, and to create crutches, wheelchairs, and parallel bars for mobility training out of found objects.

In West Flores, a church-run hospital exists that has surgical units and physical therapy on a for-profit basis, which may account for the high numbers in operable conditions such as harelip/cleft palate, physical deformities, and unspecified growths which were all treated surgically. In Central Flores there are no surgical hospitals available but there is a school for children with sight and hearing problems. Thus, we find far more sight and mental issues. Sight problems were mainly identified through a child being cross-eyed or needing glasses, a problem in these rural regions that result in slowness in school.

Questions raised by the evaluation focus on how the availability of referral services affected what disabilities were registered and what were not, which children were supported and which were not. Left-handedness, for example, was considered a disability as well as many other 'growths' such as a mole that resulted in no physical handicap at all. How these 'disabilities' were managed by the NGO, providing they had clearer guidelines and more experience, could have gone far toward beginning to change community perceptions.

#### IV. Attitudes toward Children with Disabilities

In striking contrast to the literature on coping with a disabled child<sup>17</sup>, families met during the evaluation process were extremely happy, displaying positive affection and pride for their child. Upon my arrival whole villages joined in the celebration and group discussions about disability<sup>18</sup>. Gatherings included a feast, home-brewed alcoholic beverages, music on home-made drums, and a type of pageant in which the disability was proudly displayed and described in detail for my benefit. In both regional locations, the introduction of the disability support program and the creation of disability forums along with livelihood support initiatives, literally brought disability out of hiding and turned it into something to be valued. In most cases, these were the first 'development' initiatives to be offered these communities, and as such, brought a highly valued status to these families.

Prior to the intervention, it was clear from discussions that the vast majority of parents with disabled children would not have sought help for a variety of reasons, most of which were linked to their poverty: not having the money for doctors; long, slippery walks over mountain tracks to reach public transport; lack of funds for transport to town; afraid of 'city' life, people, activities; no awareness of the services available; or simply too busy meeting their own day to day needs.

A number of community leaders seemed to understand some of the genetic and health related causes of disability. But most still hold onto the myths and fables related how their own activities caused the defect. Wounding a snake, killing an animal, sinning while away from home when a wife is pregnant are all supposed and believed causes of birth defects. Another woman gave birth to a child with cerebral palsy because she "once had an abortion after running away from her husband". Dreams, moreover, reveal the state of an unborn child, and thus, are

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<sup>17</sup> Gupta, A., Singhal, N. Positive Perceptions in Parents of Children with Disabilities. In *Asia Pacific Disability Rehabilitation Journal*, pp 22-35. Vol.15, No.1, 2004.

<sup>18</sup> As very likely the first 'foreigner' these people have ever seen and one who speaks local languages fluently, I have learned over the years to use my insider/outsider status to full benefit. One point I demand is that food prepared for us may not be bought in any distant market but rather must be prepared entirely from local fields including the rice – that I will verify visually. This allows me to see what is available at any given time and prompts discussions about food. I also request a meat dish, despite my own vegetarianism, because of the fact that rural villagers only eat meat on special occasions.

dangerous and ominous. Cultural beliefs about disability clearly play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation<sup>19</sup>.

Yet as a direct result of the intervention and the livelihood support and status that accompanied it, the evaluation also discovered that unclear guidelines and definitions of disability, handicap or impairment were extremely problematic. Community members placed intense pressure on the NGO staff to include their children and to 'fix' simple cosmetic problems like a sixth toe or a slightly misshapen ear. The parade-like display of 'disabilities' included a lazy eye, a hairy mole, a bent toe, a small growth, none of which should have had any adverse effects on the quality of life of the child. Parental encouragement, however, was bringing undue attention to a 'difference' and very likely making inclusion even harder for those with permanent disabilities.

During the course of the evaluation, I was told of two cases that both led to the conclusion that a guideline for program support, clear definitions of disability, and a code of ethics regarding what should be managed through surgery or even labeled a disability are essential.

Dewi had surgery to remove a sixth toe that did not 'disable' her in any way.

Sira's story is quite different and highly regrettable. Sira's right eye is pale blue and blind. The left is normal. Aside from her blind eye, she has no handicaps, and is a healthy, pretty young woman. Sira was referred to X Hospital for examination. The doctor said her sight could not be restored but the eye should be removed and replaced with a false eye for cosmetic reasons. The doctor removed her eye only to find that the false eye was too large for her socket. The damaged eye was replaced and Sira has been complaining of debilitating headaches and dizziness ever since. She can no longer manage the heavy work required of rural poor farmers. The doctor only comes to the area for short visits once a year so Sira is suffering from what may be malpractice on the part of the doctor and irresponsible selection by the NGO as a result of poorly defined guidelines.

The main point here is that surgery is a very serious issue and should not be taken lightly. The only children to be accepted for surgery by a disability program are those with a debilitating handicap that can radically improve their quality of life. Cosmetic issues should never have been accepted as they create too much risk for families and the NGO and they take time and money away from those children who could radically benefit from it. Most significantly, the NGO lost a good opportunity to change community attitudes toward disability by demonstrating acceptance of difference through their own behavior. Instead, simple cosmetic issues were accepted as 'disability' and thus shifting the scales away from how a community accepts difference.

## V. Gender Issues

Female children generally had lower reported disability prevalence rates than male children – but more cosmetic 'defects'. This finding may be the result of lower risks among female children for some specific disabilities and also possible underreporting of disabilities in female children. It was noted too that no adults with disabilities were seen in any village gatherings (although I was told a few adult men existed, but that they never left their homes), leading us to assume these people were isolated and dying prematurely. Far more understanding of these gender roles is needed, especially in the absence of adults with disabilities. Further, young girls who are mentally handicapped or mute are at extreme risk for sexual abuse, one of the biggest fears mentioned by parents.

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<sup>19</sup> See Gupta and Singhal, Op.,cit 2004



The evaluation also found that all but one of the field staff from both NGOs were male and no gender training or gender lens was applied to the field work. In no cases did these men spend time in discussions with village women. The (female) evaluator spent a great deal of time in home visits and in meeting with women and was able to ask questions about health, birthing practices, beliefs and attitudes, as well as infant feeding and family nutrition in general. Flores is noted for having one of the highest maternal mortality rates in Indonesia, which in turn has the highest rate in Southeast Asia, and none of the villages visited had a health post or a trained midwife. They did have elderly women called *dukunbaya* or so-called traditional healers/birthing attendants. Women reported to me that they all knew other women who died in childbirth. It was local practice, then, to cut back on caloric intake during a pregnancy so that the baby would be small and thus increase the mother's chance of surviving the birth. The link between disability, maternal mortality, and nutrition was vaguely understood by these women, but not the NGO staff, as a necessary risk.

Further, women – either sisters or mothers, were the main caregivers in each family in addition to taking on the extra burden of a disabled child. Yet it was mainly men invited to attend NGO facilitated discussions and planning sessions. Women were far too busy taking care of family needs to attend.

While collaboration with the government Health Service and community health cadres was said to be very strong, further inquiry revealed how weak indeed it really was. The villages visited did not have easy access to trained health workers; Posyandu (Village health posts) did not provide the support services expected; and those areas that did have health officers were of dubious quality. The health cadre in Village 1 in Central Flores herself does not know much about nutrition despite the fact that she and the village secretary admit nutritional problems are likely the most serious facing the community. The health cadre also explained that there is a trend to use milk powder with young babies as a means of a mother saving her figure and not 'ruining' her breasts. Women reported that they did not exclusively breast feed. One young mother told me that her child's disabilities (cerebral palsy, cleft palate, bowed legs) could be 'cured' by buying him expensive baby formula. Families tend to rely on packaged porridge to feed their babies, which are very high in sugar and chemical preservatives and low in vitamins as well as the variation of foods, tastes, and nutrition babies need. They also must be diluted with water, which is scarce in the community and of unknown purity. Questions arise regarding the safety of this water and how often it causes diarrhea in young children. Do such instant porridges result in child addiction to sugar and sickly sweet snacks? Do these 'modern' feeding styles result in nutritional problems that adversely affect a child's development? Packaged instant foods and sweets have taken over as the main staple, despite the fact that the mothers we discussed this with at the preschool all complained that children demand them, refuse to eat the meals prepared for adults, and that the packaged snacks were too expensive. This trend toward instant 'modernism' clashes head on with 'traditional' beliefs, such as a 'prohibition' toward pregnant women eating eggs or mung beans. I was also told by a parent with a malnourished child that feeding her eggs would cause asthma. The child, who I suspect had worms, had no access to de-worming tablets. The wonderful variety of foods I was served led to lively discussions about what families eat on a daily basis (cassava) as opposed to what they grow to feed their pigs (pumpkin, beans, tomatoes, eggplant, etc.). Livestock (chickens, dogs, pigs) were too valuable to eat regularly and were raised to be butchered on special occasions for *adat* (cultural) ceremonies.

This kind of misinformation and lack of access to very simple cures for common ailments can result in serious developmental problems in children and should be clarified through community-wide campaigns to educate families about nutrition and to advocate for basic health services provided at least through schools. A back to basics move that relies on the broad range of fruits and vegetables grown or found locally would save a lot of money as well as create a new trend toward respecting elders and their knowledge about the types of edible plants and other environmental, historical, customary, and social factors before it disappears with them.

## VI. Programmatic approaches to disability

CBR is built on four main developmental principles: ‘minimum approach to assistance’, ‘participation’, ‘sustainability’, and ‘empowerment’<sup>20</sup>. Taken at each step, the ‘minimum assistance approach’ aims at enhancing self-reliance of the local community and utilization of local resources. This approach involves a partnership with the local community as equal stakeholders and encourages independence and creativity in handling community affairs. Unfortunately, in both locations, NGOs created far more dependency than independence as described in more detail below.

The active ‘participation’ of the local community including users of services and their families in the rehabilitation process, creates a feeling of ownership and promotes a sense of control over community development initiatives. Active ‘participation’ of the disabled individuals in the family and community, removes the handicap, in that the disability still exists but is no longer isolating. In this respect, families take central roles in the rehabilitation process with as much of the local community as possible. This shifting of responsibility should create a feeling of ownership and promote a sense of control over rehabilitation initiatives including the economic and social development activities attached to it. While participation was strongly present in both locations through decision-making and in managing micro-credit, actual disability support was far less so.

In West Flores, most of the rehabilitation processes and all activities related to medical help were entirely dependent on external financial support and heavily focused on surgery, which means that there can be no sense of control or ownership – only dependence.

In Central Flores, where no surgical support was accessible, far more creative means were developed, including inclusive training for teachers, the creation of inclusive preschools, and intensive physical therapy training for family and local healers. Since the majority of children supported required rehabilitation rather than surgery (which in itself raises questions of discrepancies between the two locations regarding classification and selection of disabilities), rehabilitation processes were taken to the family itself and parents, siblings, local health cadres, and *dukun* (traditional healers) were trained to take on these tasks. Responsibility, then, falls on the family rather than the NGO which is a far better outcome than the dependency that invariably results from support to visit doctors and hospitals.

One major concern was the fact that the program focused on children with disabilities. In most cases, they were too young, and as a child, too marginalized to have any say in their own rehabilitation or participation.

‘Sustainability’ is often the main concern of any development project, including CBR. For West Flores, sustainability was an ethical issue focusing on enabling a CWD to eventually become self sufficient. With next to no alternative support available, the transformation of a disability into a case that is no longer a disability, such as repairing a clubbed foot, harelip, or straightening bowed legs, is clearly a sustained change. Not all cases or interpretations are so straight-forward, however. The emphasis here on a surgical ‘cure’ means that the CBR goals of inclusion of those with permanent disabilities into the social, economic, educational life of the community have most likely deteriorated.

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<sup>20</sup> Turmusani, Majid. *Disability and Development in Kosovo: the case for community based rehabilitation*. nd. [www.aifo.it/english/resources/online/apdrj/apdrj102/kosovo.pdf](http://www.aifo.it/english/resources/online/apdrj/apdrj102/kosovo.pdf) UNICEF. Research Report on Children with Disabilities and Their Families in Da Nang.2009

In Central Flores, the emotional, social, financial, and physical burden of caring for a CWD seemed to increase rather than decrease during the three year life of the intervention. Whereas those trained in physical therapy were actively involved in applying that therapy early on, most families admitted that they eventually stopped the therapy as too time-consuming, and not providing the desired *cure*. In effect, this is a sign that parents were unrealistically informed, either through local knowledge and beliefs or by the NGO, about their children's disability and the expected results of therapy. They had lost hope.

Sustainability in a CBR project will only be reached once attitudes toward disability have changed and government services provide the basic community needs. The evaluation found that such attitudes had not changed at all and that losing hope could actually make matters worse for CWD.

The concept of 'empowerment' of disabled persons involved in the rehabilitation process is the main goal of this project – at least through its title. CBR should in fact facilitate the emancipation of disabled people by letting them be part of the process and serve as a political tool which may contribute towards empowerment. In reality, however, disabled people – and especially when they are children – are last on the list to be consulted regarding the way services are delivered to them and their views are neglected by professionals at all levels. Instead of empowerment, power relations between children and parents, professionals and disabled people only seem to perpetuate their passivity and contribute to their dependency. This is an area that requires much deeper thought, especially where poverty and economic efforts become a family's main concern over and above that of a disabled child. Further, there is a general lack of forward thinking and wanting an easy fix mentality in the community that is CBR's greatest challenge. This is evident both in economic initiatives and in rehabilitation for a child where the long term needs of both are deemed too much of a burden.

The long term value of any rehabilitation or development effort must be evaluated in terms of how much it empowers marginalized groups and moves us towards fairer, more fully democratic social structures. Since both regional NGOs have created solidarity groups for families with CWD, their CWD are no longer hidden but given a status in the community, where the burdens of disability are finally openly discussed. This is a spectacular achievement. But is the community rallying together to help support these families and the exceptional burden of handicap – or are they trying to gain inclusion into livelihoods support also offered through the CBR intervention? How can you bring equal rights for disabled people to communities that don't have water, electricity, transport, financial security, safety from natural disasters, opportunities, education, and access to alternatives to the only lives they have ever known? Government agencies (such as Education, Health, Social Welfare) all promised to collaborate more with NGOs and actually take up some of their responsibilities toward these community problems. Can a government made up of fragmented offices that almost never collaborate efficiently actually provide the wide array of services so badly needed in Flores in general, never mind in terms of support for CWD?

## VII. Disability Networks

Sharing responsibilities for different aspects of a program as complex as disability requires co-ordination, co-operation, and collaboration if the program is to succeed. Advocacy and developing networks are essential for the broad support required in reducing the negative impacts of disability and poverty as the main cause of disability. Very few organizations have the necessary technical and financial resources to implement cross cutting development activities.

The fact that these projects started in areas relatively untouched by development projects is in itself overwhelming. CBR is, in the literature at least, assumed to be based on expansion of existing programs and projects already started in the primary sector (people and their families) by direct service organizations (NGOs, government, etc). Normally these activities would include community education, inclusion of disabled persons in existing development activities and provision of basic rehabilitation services in the community. Both NGOs managed to vastly improve on educational options through providing inclusive pre-school education and basic rehabilitation and physiotherapy skills to interested families and community members.

While primary sector activities are starting, implementing organizations need to develop networks to connect them with other organizations working in disability and/or development activities. As networks develop and more people and organizations get involved, the combined strengths help to change policies and legislation that will support inclusion. Getting policy changed and legislation passed will require further expansion of networks and a responsive government. The next step, if any serious development project is to succeed here, is to advocate for government support and ensure that the appropriate bodies are prepared to collaborate. Government must learn to work with NGOs because they do not have the capacity to provide prolonged support and the follow-up required for a program's success.

What a 'disability network' is understood to be and how one is formed in the CBR approach taken here was not clear. A disability network, according to CBR literature, should be composed of disabled people actively creating a self-help community and advocacy group, a Disabled Persons Organization (DPO). A 'disability network' as seen here seemed to be one consisting of NGOs, government agencies, and various stakeholders that all objectify disabled people by providing support of whatever type is decided outside of the disabled persons themselves. Again, if attitudes are to change, positive role models are required.

### VIII. Economic Empowerment

Disability is a development issue because of the fact that it is closely linked to poverty. Poverty is a major cause of disability; it is the main reason why so few services are available; and disability creates more poverty. Economic empowerment is vital to a CBR program. Yet how realistic was this goal within the timeframe allotted? The log frame shows clear objectives and a 'standard' progression (from micro-credit to small business/food processing training), but it does not take into account the cultural, political, health, social and economic barriers facing disability specifically and the rural poor in general. Economic development requires the fulfillment of basic human needs such as water, education, good health, a decent home, job opportunities, and security. Any basic development project also requires electricity and good access to markets, services, and transport. All but one of the villages visited for the evaluation had none of these basic needs at the onset of the project. Out of over 85 people interviewed for the evaluation, only two men had an idea how to create a job opportunity. Women in particular requested Christmas and New Year's presents, money, and other hand-outs with no ideas at all about investments and financial growth – evidence of stereotyped expectations about the immense wealth of NGOs.

In all locations, families stated that economic hardship was their biggest obstacle – above and beyond the needs of a disabled child. Since no other major international donor, the Indonesian government, or magic remedies exist that have been able to eliminate even some of the effects of poverty in isolated, rural communities, it should come as no surprise that the small, under funded efforts seen here have not had much of an impact either. Relieving some of the burden of a CWD by covering medical costs is already a huge benefit, although one that is obviously

not sustainable where the disability is permanent or requires continuous support.

Nevertheless, the micro-credit groups formed in each of the communities visited are examples of best-practices for such groups. They are all group-owned and managed by members in a highly transparent manner. They function perfectly in that members pay monthly membership dues and can then borrow as needed. All borrowers to date have been able to repay their loans although not necessarily within the time allotted.

It is unfortunate, however, that members have not borrowed the money for income-generating purposes but rather for personal needs such as school fees, home repairs, or *adat* (cultural) ceremonies. The lack of creativity to develop new ideas for business purposes is due to the lack of opportunity and the general fear of new ideas that is all too common among rural poor. If nothing else, the micro-credit opportunities protect members from borrowing elsewhere at much higher rates of interest.

Despite being asked repeatedly and in differing language each time, neither parents nor children could imagine a future any different from that which they have now. In all villages in both locations, members of the cooperative complained that there was not enough economic support to meet the enhanced expense of caring for a CWD. They all requested additional support. Yet not one could describe how they would invest funds in an income generating project. Most of the pigs provided during the pilot project phase were slaughtered for ceremonies or died before they could reproduce.

## IX. Conclusions and Implications

The issue of disability in Indonesia has taken on the status of a buzz-word, much like gender had some ten years ago. Talk among the NGO community as well as government agencies are all about mainstreaming disability – at least on public celebrations of the International Day of the Disabled. Yet, in the contextual realities of village life, especially in Eastern Indonesia where 'development' and the basic health and nutritional needs of the non-disabled are ignored, is it feasible to talk about the needs of the disabled? In a region with the highest maternal mortality rates in the country, and where women intentionally starve themselves during pregnancy to ensure a small child and, at least according to local beliefs, improve her chances of surviving the birth, can we really implement a program based on the ideals and assumptions of CBR?

According to the literature, CBR is based on the understanding that disability is essentially a human rights issue. Yet CBR programs, like the two discussed here, have generally advocated a medical or technocratic approach, and have not just overlooked the social and political dimensions of disability. They seem to have undermined these dimensions by providing 'cures', classifying a difference as a disability, providing unrealistic expectations regarding the goals of therapy, and ignoring the gendered roles and responsibilities that are clearly so significant in recognizing root causes and effects of disability on the rural poor. But then, again, is it fair to blame the implementer when the donor did not provide the appropriate capacity building for a regional NGO, because they themselves did not know and were responding to the buzz word and the availability of funding? Taken a step further, is it fair to advocate for the rights of one group, albeit one that is severely marginalized, while the mainstream is also severely in need? Meanwhile, the rights of women to decent health care (despite claims by the government that trained midwives have been based in every village) in general are so violated that they are afraid of childbirth. Can CBR be implemented properly without taking on these root causes of disability, poverty, and ignorance first?

While the programs evaluated deal mainly with children, it is important that disabled persons, either adults or teens, are included in a meaningful way to provide role models, encourage inclusion and respect on their terms rather than those of the community, and to rethink the underlying goal of "rehabilitation". Too often the tacit objective of rehabilitation - especially as it was approached in Flores from the top down- is to normalize disabled

persons into the existing discriminatory society. By contrast, the goal of the alternative, bottom-up approach is to empower disabled persons to join in an organized struggle, to change our present society into one that is fairer, more truly democratic, and more accepting of human differences<sup>21</sup>.

Children with disabilities who attend school or vocational training were far more likely to have long fulfilling lives including friends and social and economic status than those CWDs who did not attend school or vocational training. But it must be noted that these schools and opportunities were not in their home villages, where access, mobility, and any economic opportunities were lacking, but rather in towns far away. Thus, it seems that fuller participation and greater opportunities for CWDs require moves away from their families in order to minimize their social isolation, maximize their integration in the (new) community, and ultimately lead to a more productive life. This fact too is difficult to reconcile in CBR.

The lack of knowledge and experience regarding disability, CBR, and its broad, social, political, and economic aspects, as well as the gendered concerns of responsibility and health in general, found in both the donor organization and the implementing local NGOs has resulted in strengthening, not reducing, barriers to inclusiveness. In West Flores where the focus was on surgery and a 'cure', and the 'lost hope' found in Central Flores that exposes unrealistic understanding of what would be gained by therapy, both reveal major set-backs in the community empowerment goals of CBR. The eagerness to have one's child included among the disabled in order to access livelihood opportunities in both project regions resulted in a skewing of what is a disability and a handicap. The lack of guidelines, the lack of a support network, the lack of experience and full understanding of CBR, gender, health, and simple contextual knowledge, i.e., the lack of detailed research by the donor and the local NGOs prior to implementation all show how the best intentions will go astray where no firm foundations are built first.

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<sup>21</sup> See also Werner, D. *Strengthening the Role of Disabled People in Community Based Rehabilitation Programmes*. HealthWrites. 1994.

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