SOCIO-CULTURAL REPRESENTATION OF DISABILITY IN TARGET GROUPS OF REHABILITATION WORK: EXAMPLES FROM *HANDICAP INTERNATIONAL* PROJECTS

Francois DeKeersmaeker

SHORT DESCRIPTION OF HANDICAP INTERNATIONAL

Handicap International (HI) is a Non Governmental Organisation, founded in 1982 in France, 1986 in Belgium, 1996 in Switzerland and 1998 in Germany. Its activities include projects for the rehabilitation of disabled persons (Physiotherapy and Orthopaedics with training of local staff and appropriate technology, support of local organisations of disabled persons, measures for social integration), and the campaign for the ban of landmines (lobby in our countries, mine awareness and demining in affected countries). It runs projects in over 30 countries affected by structural poverty, by war or by natural catastrophes.

INTRODUCTION

Rather than going very deeply into each example, we chose to look for some common points between the different projects of HI, so that from a multiplicity of situations we can go further into the question of defining better ways to consider effectively the specific cultural aspects in the work with disabled people. In order to get these examples, we compiled the internal literature of HI on the subject, but also sent a questionnaire to all the projects in the field, asking them about their experiences, methods, successes and errors. The results of this questionnaire were rich and interesting. However the main remark was: we need to work much more on this issue, and we need more solid inputs to do it correctly. All those responsible for and in projects showed great interest in sharing the results of such a Symposium.

IMPORTANCE OF CONSIDERING SOCIO-CULTURAL REPRESENTATIONS OF DISABILITY IN THE PRACTICE OF THE PROJECTS

- It will guide us in understanding what *Disability* and *Disabled* Person really means in the target group considered (knowing that there are no universal categories of disabilities, but clearly different situations of disability).
- It will help us avoid coming (as a foreign organisation) with a predefined and rigid solution or model, which may not be accepted by the supposed beneficiaries.
- It will force us to be flexible where we could be tempted to adopt standardised responses and methods (especially for an organisation working in many countries, the reaction is often: with so much experience, you must have developed some models).
- It will finally help us to be better integrated in a specific context and therefore to create better chances for the so called beneficiaries (all of them: disabled persons, families, self-help groups, local professionals ...) to actively participate in their own rehabilitation, and even better, be very soon the real actors in the project.

As a first illustration of how deep the consideration can go we will give here an example from our team in Mozambique. One part of the programme is dealing with Cerebral Palsy children and their families in the suburbs of the capital Maputo. After several years of work with this group, the team slowly discovered specific linguistic aspects regarding this form of disability. In fact there are in one local dialect up to 27 different words to describe this phenomenon. Analysing the words showed that they express a very fine gradation in the explanation of the illness. The word used in each case will tell us if the child or its family are considered as a victim or as guilty of causing the disability. According to the origin of the disability (guilt or not), the social position and the acceptance of a treatment will be completely different. Through this example, it becomes very clear that the pathology evolves into a social or community problem, and the treatment will have to take into account this social component. We will have to work with the family on the explanation of the pathology, go through traditional social processes which will allow the disabled child to change from the guilty category to the victim category and hopefully find a socially/culturally acceptable way to get access to a (para)medical therapy. Another rather provocative example: starting a new programme in Albania this year (CBR, support to local networks for disabled people), we heard constantly “we are all disabled in this country”, or “could HI do something for the politically disabled?" This shows how deeply the people there feel they need help at all levels, and that we probably should be careful and modest in our attempt to help one group of disadvantaged people rather than another.

DIFFICULTIES IN IDENTIFYING THE LOCAL BELIEFS AND ATTITUDES OR REPRESENTATIONS OF DISABILITY

Local culture or global context: most of the time, analysing the local situation shows that we are facing a complex patchwork of traditional explanations and socio-economic conditions determining in the last instance the situation of disability in each case. One example in the favelas (slums) of Sao Paolo (Brazil): the part of the city where a CBR project was started is typical for the difficulty of analysing the *local concepts*. Most of the population comes from other parts of the country, so there is no unity in the uses and traditions represented. Brazil is already itself a mixture of several cultures, and this mix is exacerbated in such a favela environment. Nobody trusts anybody, families are split, each one struggles for his daily subsistence: in this context people have no stable references anymore, and explanations as well as treatments for disabilities can be found in many different directions. Religious sects of all types, candomblé, voodoo, new reformist church, all of them are possible recourses for extremely isolated people.

Local disparities and contradictions in the same society: the way the different groups concerned see the disability is not unified. Disabled persons, war veterans, health professionals, local authorities and community will not have the same approach to the interests of disabled people. On the other hand, evolution in the way of dealing with disability may also vary within the same country, and those differences are sometimes ignored by our local partners in project countries. To give an example: during an evaluation visit to Guinea after a request from the local Ministry for Social Affairs, we could feel the big gap between what is being organised in the capital of the country and what is the reality in the more remote provinces. One the one hand, the country is striving for modernity and wants to provide disabled people with modern facilities in a modern system of service delivery. On the other hand, most of the people still live with strong local traditions and representations which are not compatible with the modern systems. In this case, the lack of consideration of local concepts is reinforced by local actors (the politically responsible, educated health personnel, NGO leaders etc.). Finding a middle way becomes a real challenge.

The interaction between actor (especially in the case of a foreign agency) and the beneficiary group inevitably affects the perception of disability in the beneficiary group itself. There is an automatic dominance of our models because of the power that we represent whether we want it or not (money, material, supposed welfare in our countries), be it in a positive or in a negative way. To give an example: a new programme of home visits in some suburbs of Maputo in Mozambique has changed the attitude of mothers with their disabled children. The presence of a disabled child was until then the cause of the isolation of the mother. And suddenly, people came to visit her because of the same disabled child.

The pressure to produce results coming from funders, local authorities, the pride of the project's own leaders, put the project under pressure to produce results, as quickly as possible and as visibly as possible. This leads most of the time to an exclusively quantitative analysis of the situation. To give an example in Rwanda (1995). HI wanted to carry out an analysis of the situation of disabled people in the aftermath of the genocide: who is considered as a disabled person in this particular context, how do the rest of the communities deal with them etc. Because of the funding conditions and the wishes of the governmental partners, the study ended up in a rather quantitative survey of predefined classical categories of disabilities, without real analysis of the particular situation of disabled people in Rwanda after the massacres.

WAYS AND METHODS OF IDENTIFYING LOCAL REPRESENTATIONS OF DISABILITY

HI has no recipe to propose. In 15 years and 30 countries we have had lots of trial and error, we suffered sometimes from lots of frustration, we often had to react rather than to act. Those trials, errors and successes built up our experience and our know-how. One thing is important to accept: there is no ideal method and no ideal moment in the project's course to realise the process of identification of the local representations. The process must be on-going and accompany each moment of the project. The actors must be open to further research, and leave space for questioning. There are however a few things that can be pointed out as the general response of HI in its projects:

- Preparing a new programme presupposes an in-depth situation analysis of the region for a possible intervention. After contacts with the local partners, an *exploratory mission* will assess the situation as a whole (political context, economic and social situation, regional differences, governmental and non governmental structures, situation of the disabled person etc.). A Guideline (*Guide for Situation Analysis and Needs Assessment*) is used for such missions.
- European volunteers receive a one month specific training before starting a mission overseas (intercultural concepts, role-plays, visit to another project etc.).
- The purpose of a project is not to act on a specific and predefined category of disability (polio, amputation, club foot etc.) but to act on the different levels that are responsible for a situation of disability (physical deficiency added to a lack of mother and child care systems, poverty in the family, cultural discrimination, absence of political will etc.). Access to school for a child with disability can help him in some cases more than merely physiotherapy treatment; preventing mine accidents by demining and mine awareness projects are just as important as fitting prostheses for the mine victims. This comprehensive approach to disability leads HI to plan projects with comprehensive development goals.
- Using the concept of *Appropriate Technology*. This implies that you should know first what is appropriate (locally available competence and material).

We can also report on some specific responses, where an in depth effort has been made to get the best possible perception of disability. Specific action has been taken most often after a certain period of presence in a project after observing unexplained resistance to the services proposed, or before starting a new component of an existing project. We choose here three examples which reflect three relatively different methods.

- Chad: After 1 year of work with Handicap International, a French physiotherapist and anthropologist decided to carry out a real ethnological study in the south of Chad. For three months, together with two local researchers, he visited the local traditional healers to discover their concepts of disability and their healing practice. The results show first of all that representations of disability are as difficult to isolate as in our culture, because they depend on the whole social organisation and on the exercise of the power. It demonstrates that modernity and tradition continue to live side by side. Traditions are often hidden, but they continue to explain and organise hierarchy and power distribution. Therefore, explanations of illness and disability will induce specific social behaviour that has to be respected before or at least parallel to a *modern* intervention.

- Central African Republic (CAR): a few years after the start of a rehabilitation programme throughout the country, the actors (local PT's) felt resistance from the beneficiaries or noticed unexplained interruption of the treatment. They tried to find an explanation for it and organised a seminar on the question in different regions of the country. They gathered important information about representations of disability and could better understand why people were sometimes reluctant to treat their disabled family members. The two main aspects were the magic origin of the disability (penalty imposed by a sorcerer for bad behaviour or witchcraft from someone as revenge or due to jealousy) and the poor economic contribution to be expected from a disabled family member. In the first case, it means that one should not interfere in magic/witchcraft processes, since the counteraction could be even worse. In the second case, it means that no investment in money and time should be made for a person who doesn't guarantee any income for the family in the future. The programme had to take these elements into account. They decided to focus much more on sensibilisation on the one hand (giving an explanation based on physical phenomena can help demystify and alleviate feelings of guilt; showing the possible autonomy of the disabled person after treatment can give hope that the disabled child will also help in family life) and on integration of traditional curative solutions when possible on the other hand (hot tree leaves on the legs of the child in traditional therapy; hot towels to diminish muscular pain in occidental therapy). From now on in Central Africa, HI is promoting such subjects for students of PT at the end of their studies.
- Mozambique: for her complementary diploma a French PT, back in that country after 8 years, carried out investigations for her complementary diploma and analysed the local representations of disability with open interviews. Here again, the notions of guilt and passive victim were very important to determine the attitude of the family/community towards disability.

WHAT CAN WE LEARN FROM A BETTER KNOWLEDGE OF LOCAL BELIEFS AND CONCEPTS?

A social approach rather than an individual one is the only way to prevent disability and alleviate consequences of an existing disability. It is imperative to avoid a product approach, often driven by emergency situations (our knowhow is our label, as a product that we would only have to deliver). Try to take care rather than provide care. It helps us to better identify of the *target group*: it is not only the patient her or himself, but maybe first the mother, the father, the family etc. Reorientation of the programme's main objectives is sometimes necessary: first sensibilisation, then treatment. It stimulates a greater participation of the beneficiaries (patients, professionals, communities etc.), and most of all, it gives better chances for a real appropriation of the project by them.

CONCLUSION

The method is not the most important. An open mind and permanent questioning are the keys to a better knowledge and understanding of local concepts and beliefs about disability. Adopting an attitude which considers disability as a comprehensive situation (in a specific context, in a specific society and experienced by a specific individual) gives greater chances to the foreign actors to propose the appropriate solutions and for the beneficiaries to understand how they can help themselves rather than accept disability as fate.