

# DISABILITY AND CULTURE

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## *ABSTRACT*

*There are two important reasons for including a chapter on culture in a book for community based rehabilitation (CBR) managers. The first is that all development activities take place within a cultural context. Some development planners tend to regard culture, especially in conservative societies, as an impediment to 'development', but any development interventions which do not engage at a significant and not just superficial level with the local cultural context are bound to be short-lived. What is true for development generally is even more true of community level disability programmes because disability is defined by culture, and without an awareness of how disability is perceived in the target culture a disability programme does not stand much chance of being relevant or sustainable. The second reason is that in poor communities, where disabled people are not seen as a priority for development nor included in most mainstream development programmes, an awareness of cultural issues surrounding disability is a key part of the process of integrating disability into general development activities. This chapter examines the question of culture in relation to disability at two levels. The first level has to do with culture and development generally, and underlines the idea that all development interventions must be rooted in a thorough understanding of the local culture; and the second level has to do with culture and disability specifically within the general context of development. This chapter considers both levels in summary form to identify the nature of the territory, and then uses the example of Afghanistan, a country whose distinctive culture appears to be at odds with most generally accepted 'Western' development values, to illustrate the problems and to show how one large-scale CBR programme has tried to deal with them.*

## **INTRODUCTION**

There are two important reasons for including a chapter on culture in a book for CBR managers. The first is that all development activities take place within a cultural context. Some development planners tend to regard culture, especially in conservative societies, as an impediment to 'development', but any development interventions which do not engage at a significant and not just superficial level with the local cultural context are bound to be short-lived. What is true for development generally is even more true of community level disability programmes because disability is defined by culture, and without an awareness of how disability is perceived in the target culture a disability programme does not stand much chance of being relevant or sustainable. The second reason is that in poor communities, where disabled people are not seen as a priority for development nor included in most mainstream development programmes, an awareness of cultural issues surrounding disability is a key part of the process of integrating disability into general development activities.

Disability is defined by culture. The tendency to categorise all people with different impairments as 'disabled' is a fairly recent phenomenon emanating from Western\* societies. Many traditional societies do not have an exact equivalent in their own language for the word 'disabled', and they can seldom match the three-tier concepts in English of 'impairment', 'handicap' and 'disability' espoused by WHO and disability theorists; they usually do however have words for specific impairments such as 'deaf', 'blind', 'lame', and so on. Furthermore what is counted as a 'disability' (ie. that which prevents someone from fulfilling the roles normally expected of them, especially as regards marriage), differs from one culture to another. Among the Tuareg in Mali, for example, freckles and small buttocks are counted as a serious impediment to marriage and could therefore be considered a disability.<sup>1</sup> In other words, the way societies think about disabled people is determined by a variety of cultural variables, including the nature of the impairment. It is therefore essential for planners of community disability programmes to know and understand how different impairments are viewed in the target community in order to plan effective interventions, especially since many disability programmes place changing attitudes among their main objectives.

In most poor communities, where everybody is struggling for survival, disability is not usually seen as a priority in development, except by disabled people and their families. In particular it is rare for mainstream development planners to consider the impact of their plans on disabled people, or to include disabled people specifically in their programmes. But disability must be seen in the wider context of human development and social justice, and for this purpose all development workers need to have an understanding of disability issues. Those working in community disability programmes have a responsibility to research the local cultural factors affecting disabled people and to communicate their findings to the general development debate around them. For example, in Bangladesh poverty alleviation programmes through group guaranteed credit schemes now have millions of beneficiaries, but the number of disabled people (who are usually the poorest people in the village) in these credit groups is very small. Non-disabled villagers are reluctant to include disabled people in their own credit group because they see them as a bad risk and liable to jeopardise the group's chances of further loans. Thus a poverty alleviation programme fails to reach the poorest people. The solution is to encourage groups to include disabled people through advocacy and awareness training of mainstream field workers, and allowing disabled people to demonstrate that they are just as 'creditworthy' as anybody else.

This chapter examines the question of culture in relation to disability at two levels. The first level has to do with culture and development generally, and underlines the essential idea that all development interventions must be rooted in a thorough understanding of the local culture; and the second level has to do with culture and disability specifically within the general context of

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\* The word 'Western' is used throughout this chapter to refer to the cultural values that originated in Europe and North America. Australia, New Zealand and other places not in the West embrace similar cultural values, so 'Western' is not strictly accurate, but other words are no better. 'Northern' is inaccurate because the world is not divided into a rich north and a poor south. 'Industrialised' does not seem satisfactory, nor does 'developed' or 'modern' or even 'capitalist'. So I have opted for 'Western', knowing its shortcomings but also knowing that it is generally understood within the terms of the debate on culture.

<sup>1</sup> Benedict Ingstad and Susan Reynolds Whyte 1995: *Disability and Culture*. University of Californi

development. At both levels it is very difficult to draw global generalisations because every context is different, but signposts in what is an extremely complex and contentious discussion can be identified. This chapter considers both levels in summary form to identify the nature of the territory, and then uses the example of Afghanistan, a country whose distinctive culture appears to be at odds with most generally accepted 'Western' development values, to illustrate the problems and to show how one large-scale CBR programme has tried to deal with them.

## **CULTURE AND DEVELOPMENT**

Amidst the complexity there are some facts. First, cultures are not cast in stone: they have a past, a present, and a future. It is almost impossible to say what is 'indigenous' to a particular society because every country has been subjected to a continual process of cultural evolution and transformation throughout its history, and this process will continue indefinitely. For example, the culture of Pharaonic Egypt was replaced first by a Christian and then an Islamic culture, both outside influences, and today, while there is little overt evidence of Pharaonic culture in the lives of ordinary Egyptians, their cultural history marks them out as different from any of their neighbours. Afghanistan was once Buddhist; it is interesting to speculate about what course the history of this country would have taken had it remained so. Cultures are not 'intact' and sealed for ever by reference to an original, more or less mythical, state: they are being continuously influenced and changed by contacts of all kinds between various peoples.<sup>2</sup>

Second, cultures do not reflect a consensus, but are to a large extent manifestations and often manipulations of power between different agents within a culture. Not everybody in a particular culture is a strong supporter of it, especially when it cuts across their own interests. When a particular culture is defended against outsiders, in the sense of 'we do this in our culture', it is often a power relationship that is being defended. This is particularly true for discussions on gender. For example, women in a Muslim country who have seen other cultures and acquired an education may have a view of the 'sanctity' of their own culture different from that held by Muslim men. However, anyone who dissents from their own cultural values and traditions has a difficult choice to make: the stronger and more conservative the culture the more powerful is the pressure to conform, and to dissent is to court exclusion. In many situations, for men as well as women, conformity is the only way to survive. A dominant culture tends to both breed dissenters and repress them.

Third, and in apparent contradiction to the point above, culture provides a key reference point for identity. Especially in threatened communities cultural and religious identity may be one of the few certainties that ordinary people can hold on to. In times of national or communal crisis there is invariably a tendency to retrench into statements of what cultural or religious characteristics define the nation or the community. At such times nationalism and ethnic identity flourish, and the fine cultural distinctions between ethnic groups, even where they are slight, are exaggerated. This can be seen in former Yugoslavia, where, although Serbs, Croats, Bosnians, Albanians and others have always been different to some degree, these differences were less marked when the country was one, and the recent fragmentation of the country has been engineered by playing on these differences.

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<sup>2</sup> UNESCO 1996: *'Our Creative Diversity'*. Report of the World Commission on Culture and Development. Geneva

Fourth, social identity based on religion, nationality, gender, ethnicity, class, and caste - and therefore culture - is learned, not determined by biology.<sup>3</sup> The values and traditions of sub-groups within a society are transmitted down the generations, and tend to be modified with each generation. Age and disability are other aspects of social difference which interact with ethnic, class, and caste identity to produce a mosaic of cultural patterns within any given society. To view culture as uniform in any country will inevitably lead to serious misunderstandings because it ignores the specific and immediate texture of people's lives. It is the culture of the target community that needs to be studied, not simply the generalised culture of the country.

Fifth, and most importantly, to separate culture from development misses the point.<sup>4</sup> Culture is the total manifestation of a people's aspirations, values and behaviour, or as Geertz put it: 'Culture is the web of significance man himself has spun.'<sup>5</sup> It is therefore not simply a factor to be taken into account like the agricultural cycle or climate, but is the entire context within which development happens. The development process, whether it involves outside agents or not, is part of the constantly evolving cultural process.

Nevertheless, despite a general awareness of the points above there is a tendency for present-day development planners to be impatient at what they see as the repressive nature of some traditional values and practices which, in their view, can spell stagnation, oppression, inertia, privilege, and even cruelty. The antithesis of these practices they see as 'modernisation', which carries a heavy connotation of progress towards a Western, 'democratic', rational, secular model of society with a cash-based economy. But whatever the inherently negative effects of some traditional practices and values, it is not the task of outsiders to force change. 'If the nations of the world are to improve their human development options they must first be empowered to define their futures in terms of who they have been, who they are today and what they ultimately want to be. Every community has its roots, its physical and spiritual affiliations, reaching back symbolically to the dawn of time . . . . It is crucial that a people's understanding of its values and other cultural patterns be developed - in the first place by the people directly concerned.'<sup>6</sup> Outsiders do however have an important role in supporting the agents of change within a society.

An important example of the failure of Western 'experts' to listen carefully to and understand local cultures can be found in the subject of psychological trauma resulting from war and violence. During the eighties and early nineties a whole industry grew up around psychological trauma projects and programmes in places like Lebanon, Rwanda, Bosnia and elsewhere, on the assumption that the cycle of violence could only be broken by repairing the damaged psyches of the victims by Western methods of individual psychological therapy. But psychology is also determined by culture: the idea that there is a universal psychology for all mankind is itself an example of Western ethnocentrism. While trauma is undoubtedly real in all societies which experience violence, non-Western societies have their own social mechanisms for coping with it. To quote Summerfield, 'Suffering

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<sup>3</sup> Deborah Eade and Susanne Williams 1995: *The Oxfam Handbook of Development and Relief*. Oxfam, Oxford.

<sup>4</sup> UNESCO 1996

<sup>5</sup> Geertz 1975: *The Interpretation of Cultures*

<sup>6</sup> UNESCO 1995: *The Cultural Dimension Of Development*. Geneva

arises from, and is resolved in, a social context which contains mediating factors for good or ill.<sup>7</sup> War disrupts familiar social patterns and support mechanisms; the first priority for traumatised people is therefore to re-establish these patterns and mechanisms. The idea that traumatised individuals in Rwanda need individual counselling on the Western individual model does not match the perceptions of the people themselves, who generally identify economic problems as their major priority, and want help first and foremost with income generation. Programmes which bring people together for a common purpose, especially income generation, are therefore more likely to be appropriate and effective than expensive projects for individual counselling relying on outside 'experts'.

Development activities which ignore culture as the sum total of people's political, economic, social, and spiritual aspirations, will inevitably lead to alienation, exclusion, and a loss of identity as well as loss of a sense of community. Institutions with a global mandate such as the World Bank and UNDP tend to focus on regularity and similarity rather than diversity, applying wholesale policies according to an externally devised formula. 'Research into cultural suitability often throws up apparently insurmountable obstacles which programme planners prefer to bypass. So they consult their peers rather than the people.'<sup>8</sup> Even when they do consult the people, it is often with the intention of gaining their approval for plans conceived by outside 'experts' rather than engaging with the target community in a real dialogue about priorities and strategies. Programmes and projects conceived and driven from the outside are still the norm, especially when the global development agencies are involved. A vivid illustration of this will be given in the case study on Afghanistan below.

Who sets the developmental agenda is a matter for constant manoeuvring. To say that the problem is rooted in the realm of politics, and that development should be politics free, is simplistic in the extreme. Development is not neutral territory in which politics does not operate. Politics is at its root about who has control over the decisions that affect people's lives, and it operates at all levels of human society, from the relations between individuals within a family right up to global power games. The problem of who sets the agenda for development becomes acute in the matter of human rights. For example, Western ideals of individual freedom of belief are rejected by Islamic societies on the grounds that such freedom leads to social chaos. Freedom of belief is equated in Islam with worshipping more than one god, which is what the entire Islamic project set out to eliminate. So when human rights are talked about in a strictly Islamic country like Afghanistan, who is *entitled* to set the agenda? Female circumcision in many parts of Africa, 'honour killing' in Pakistan of women who are deemed to have transgressed sexually, and the entire caste system in India, are examples of patterns deeply rooted in local culture which are directly at variance with Western ideals of individual freedom. A sense of moral superiority in the face of such injustices can easily lead Westerners into thinking that their knowledge is also superior, and so discount indigenous wisdom.

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<sup>7</sup> Bracken and Petty 1998: '*Rethinking the Trauma of War*' Save the Children, London. Chapter by Derek Summerfield: '*The social experiences of war.*'

<sup>8</sup> UNESCO 1996

The debate about culture and development is made more complex and urgent by the rapid shrinking of the globe through communication technology and an increasingly transnational economic system, the combined effect of which is to promote cultural homogenisation. Mass changes of culture have occurred throughout history in the expansion of major religions (as for example in Egypt as quoted above), but what is happening today through satellite television, the increasing use of English as a global language, mass migration for either economic or political reasons, and mass tourism, is placing cultural diversity under greater threat today than it has ever been.<sup>9</sup> But while urban dwellers may have access to such mass ‘modernising’ influences, most rural inhabitants do not, with the result that the rate of cultural change between the better off urban population and poor rural people is widening. However, although the global culture tends to be manifested in such superficial matters as food, entertainment, and dress, core values, especially those relating to class, marriage and family life, are slower to change, even in urban areas.<sup>10</sup> It is easy to be misled by superficial signs of change into thinking that the core values have changed. Middle and upper class young men in Bombay or Bangalore dressed in trendy western clothes and designer sunglasses may still marry wives selected by their parents strictly on caste lines.

The effect of a globalised culture has both positive and negative sides to it. It has destroyed or disrupted small self-sufficient economies, alienated people from their own communities, brought stress, loneliness in old age, anxiety, and moral drift, all hallmarks of the West from which it came.<sup>11</sup> On the other hand it has exposed large numbers of people to the marketplace of ideas, new concepts and complex developmental mechanisms, and can encourage an attitude of questioning and self-examination, which are the most important ingredients of any developmental process.

CBR originated in the minds of Western or Western educated specialists and is usually proposed and propelled by development workers who are not from the target culture. It should be an example of positive cross-fertilisation in the marketplace of ideas, rather than an imposed system from outside the local culture. In particular developmental disability programmes should open the way for people to reflect on and question their own values and beliefs in relation to disabled people. We turn now to examine the relationship between disability and developmental values.

## **I. DISABILITY AND DEVELOPMENTAL VALUES**

Disability is particular in development terms because it amplifies and illuminates a range of issues that are at the heart of development discourse and ethics, such as notions of normality, equality, empowerment, rights, survival, the individual versus the collective, discrimination, and social support systems. The following paragraphs outline a view of disability and developmental values that are common in development discourse.<sup>12</sup>

Development is about the process of change. Charity, despite its good intentions, does not promote change; it perpetuates the *status quo* of inequality. (It may however be the prelude to developmental awareness.) Development is a self-generating process which must start with the

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<sup>9</sup> UNESCO 1995

<sup>10</sup> UNESCO 1996

<sup>11</sup> UNESCO 1996

<sup>12</sup> Peter Coleridge 1993: ‘*Disability, Liberation and Development*’. Oxfam and ADD 1993

person or group who are the subject of development. Nobody can develop anybody else, though others can create a favourable or unfavourable climate for our development. We can all either enable or disable each other's development by our attitude towards each other.

Development is closely connected to the idea of empowerment, which means having a belief in our own intrinsic worth and the self-confidence and self-esteem that flow from that. If we think we are not worth much we cannot develop. Low self-esteem is the hallmark of a person who has internalised oppression. Disabled people tend to be most disempowered because they are caught in a vicious circle where negative social attitudes create low self-esteem which produces a type of behaviour that in turn fosters negative social attitudes. The only way out is for disabled people to start the process of change in themselves.

The individual medical model of disability says that the disabled person must try to overcome their disability by some means or other in order to join in with the mainstream. This implies that the disabled person is intrinsically of less value because of their disability. This has devastating implications for the disabled person's ability to grow and develop. It is very insidious, and is present in just about every encounter between a disabled person and other people, especially professionals. In the former communist countries, as an extreme but at least frank example, anybody working with disabled persons is called a 'defectologist'. Disabled people are regarded as defective in the medical model.

The social model poses the opposite view. It says even though the person has an impairment that cannot be changed, she or he is still of equal intrinsic worth. It is society that must come to terms with their disability and accept them as they are.

So we can choose between two basic models of society: a closed, exclusive model where beauty, fitness, and uniformity are most valued and abnormality is rejected, or an open, diverse, and embracing society where difference is valued and people are accepted for what they are regardless of their functional ability or appearance. The dominant culture in relation to disabled people can be changed, and it is both disabled and non-disabled individuals who have to change it - consciously and deliberately.

However, disability is not only a social issue and the social model cannot be used to the complete exclusion of the medical model. Deafness, for example, is itself usually a barrier, regardless of the surrounding attitudes (apart from some remarkable exceptions where everybody in the community uses Sign Language). One cannot say that all problems faced by disabled people stem from negative social attitudes; impairment is definitely a factor. That is why disability is not exactly parallel to race or gender as a social issue. There is a need for a rehabilitation process which does indeed try to lessen the handicap.

In sum there is a need to think of disability as a development and social issue in which the rights and needs of the disabled person can be met by inclusive rather than exclusive social attitudes, coupled with an individually focused rehabilitation process where necessary. This is however not an easy process, as an excursion into the relationship between culture and disability will make clear.

## II. CULTURE, DISABILITY AND CBR

The generalised concept of disability is most relevant in a wealthy industrialised society which has enough resources to pay compensation to those it categorises as ‘disabled’. Disability in Western societies exists within - and is created by - a framework of state, legal, economic, and biomedical institutions.<sup>13</sup> Much medical effort in these countries is devoted to defining degrees of impairment, deciding how far the impairment prevents the individual from functioning, and arranging rehabilitation to reduce the effects of the impairment as far as possible. All this effort happens because the value systems of most Western industrialised societies are based, at least in theory, on fundamental notions of individual human rights, that all people are born equal under the law. However, in poor countries which cannot provide such assessment, compensation or rehabilitation, the concept of disability is less well defined and given less direct attention. In poor societies with a narrow range of skill requirements, the need to define disability in very precise terms is much reduced. For example, while dyslexia may be a considerable handicap in a society which relies on reading skill to be able to get a job and be a fully functional citizen, in a society where reading materials hardly exist it is not a handicap at all.

No culture is inherently fairer than any other when it comes to defining the place of disabled people. The Christian ethic which inspired the Western notion of individual human rights also equates disability with sin, divine punishment and impurity. The notion of fairness and equality, and individual human rights, may be very different in traditional societies because their belief system gives prominence to such forces as fate, *karma*, and divine punishment which are beyond the reach of human intervention. Thus the fact that some people are disabled may be regarded as the natural order of things, and attempts to redress the balance in terms of ‘equality’ may be seen as misguided. Both ‘Western’ and ‘traditional’ notions of equality have positive and negative features attached to them. While Western industrialised societies may place fairness and equality at the top of their social agenda, a strong argument can be made for saying that what they actually espouse is uniformity and conformity. Either fit in or be excluded, hence the pressure on disabled people to overcome their impairment and be like everyone else. In traditional societies the recognition and acceptance of intrinsic difference may actually lead to a more humane social life, while the passion for equality (or sameness) in the West brings repression and rejection.<sup>14</sup>

This brings us to the most important dilemma facing anyone planning interventions on behalf of disabled people in a culture not their own. How far is one entitled to import Western notions of disability as outlined above, and to make an issue of disability, when in fact it may not be an issue at all for people in that society? If we believe that the only sustainable development interventions are those identified, wanted, conceived, planned and executed by the target population themselves, are we entitled to arrive, as outsiders, with an insistence that disabled people be attended to when this has never been expressed as a local need? For example, in the mountainous areas of northern Pakistan community disability programmes do not exist, but it is common to see mentally impaired individuals wandering about free and perfectly accepted. Who is to say whether this state of affairs is not better than ‘being in a programme’, which might be an expensive way of making them less free?

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<sup>13</sup> Ingstad and Whyte 1995

<sup>14</sup> Ingstad and Whyte 1995

There are a range of other questions which are relevant in this discussion. Consider the matter of integration. At what age are children usually separated from their mothers? What is the role of other siblings, especially girls, in bringing up very young children? At what age are girls secluded in societies which seclude women? What does integration mean in a society which secludes women? How important are festivals and participation in them? What defines public space and private space? What kind of activities take place in people's homes (normally regarded as private space) and what kind of activities take place outside the home? Who is allowed into either? Does no or limited access to public space imply exclusion? Where are public messages delivered or transmitted - in the market place, church, mosque or temple? Who can be or tends to be present in these places? Who actually takes decisions within the family and within the community? How far does education play the role of transmitting the culture? Who controls the educational process and what scope is there for influencing it? Without an understanding of how the target community answers such questions it is not possible to talk glibly of integration as an objective of a CBR programme.

In '*Disability and Society: Emerging Issues and Insights*' Len Barton writes: 'Being disabled involves experiencing discrimination, vulnerability and abusive assaults upon your self-identity and self-esteem.'<sup>15</sup> Is this always the case? Does the definition of disability hinge on the fact that it provokes negative reactions from others? Is it possible to have disability without social discrimination, or does it then cease to be disability? Can we honestly say that a soldier who has lost a leg in war, who is regarded as a hero and who suffers no social discrimination, is not disabled, while a Tuareg man prevented from marrying by the fact that he has freckles or small buttocks is disabled? It is precisely this problem of definition that creates the apparently insuperable difficulty of assessing the number of disabled people in the world.

How far does one go in rejecting cultural patterns and how far does one go in accepting them? Culture (including religion) is what gives meaning to people's lives, so to challenge it is to challenge their meaning system. On the other hand, where it is repressive it has to be challenged. Changing attitudes towards disability, because it is generally non-threatening, can be the starting point for leading people to adopt an inquisitive, questioning attitude towards their culture generally. Nevertheless we have to recognise that an inquisitive and questioning attitude is often seen as deeply subversive in cultures which are most defensive of themselves, and most conservative. The ultimate dilemma in development is how to stimulate change without undermining people's own sense of identity. The task can only be attempted by people from within the culture who have had the courage to start the process of self-questioning, knowing the risks and being sensitive to them, and deciding to stay in their culture rather than opting out of it.

The case of Afghanistan, a deeply conservative culture which has a history of violent resistance to change imposed from outside, provides an appropriate case study to examine these dilemmas in more detail.

## **THE EXAMPLE OF AFGHANISTAN**

Afghanistan provides a dramatic illustration of why culture matters. To many development professionals working for the UN and foreign NGOs in Afghanistan cultural factors appear to present

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<sup>15</sup> Len Barton (ed.) 1996: '*Disability and Society: Emerging Issues and Insights*'. Longman.

obstacles to development. These factors are a mixture of values that derive from culture, ethnicity, and religion, and tend to be lumped together as 'cultural values'. While foreign agencies agree in theory that 'the core concern of sustainability is that the initiative be soundly rooted in the context and the consciousness of the environment in which it operates',<sup>16</sup> and therefore that 'local culture' should be respected, they often find local cultural values in Afghanistan conflict with their own values, and indeed their own ethics. Dialogue to establish a common understanding is usually abbreviated, heavily manipulated by non-Afghan development workers, or entirely absent. The discussion about cultural values is often regarded as too difficult to even embark on. The result is that 'development' remains largely an activity initiated by foreigners, which Afghans receive but which they themselves do not initiate, let alone control.

To illustrate this point, a UNDP strategy document for Afghanistan written as recently as 1993 contains the remarkable statement that 'Given the relatively short (2 year) period for implementation, the programme will have to be developed from best available knowledge, experience, and perceptions. *Prior community level consultations . . . are not realistic for this purpose*'<sup>17</sup> (my italics). Even when more recent attempts have been made to consult local Afghan communities, the agenda has been set by UNDP. For example the current (1998-9) UNDP programme in southern Afghanistan has declared women's empowerment, basic education, and opium poppy eradication as its priorities. The third of these, unsurprisingly in a shattered economy, has met with some opposition from local communities, and whether the first two actually head their own list of priorities is difficult to determine when they were told that grants would not be available for anything else.

#### **'DOING DEVELOPMENT' IN AFGHANISTAN**

Among the many challenges facing development agencies attempting to undertake sustainable development in Afghanistan one could list the following:

- Afghanistan presents the classic profile of a war-torn country. The most essential requirements for sustainable development, such as stable communities, shared long-term aspirations, basic health and education services, and legitimate external trade, hardly exist. These factors are not to do with culture, but with the war. But the war has its roots in a conflict in which 'values' (whether cultural, ethnic, or religious) have played an important part.
- Donor governments are reluctant to fund long-term development programmes on the grounds that it is an emergency situation and there is no government in control of the whole country. Funding therefore has short time horizons, usually two years or less, which forces project planning into similarly short time spans, which (as already stated) can be used as an excuse for not starting on a process of dialogue with local communities.

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\* Notably the Habitat programme in Mazar, which has fostered the creation of women's community fora. These fora can be described as grassroot in the sense that they are true community groups in which the members set the agenda for development.

<sup>16</sup> Tamas, Andy 1996: '*Spirituality and Development. Concepts and Categories. Dialogue on Spirituality in Sustainable Development*'. Canadian International Development Agency. Ottawa

<sup>17</sup> UNDP 1993: *Afghanistan Rehabilitation Strategy. Action Plan for Immediate Rehabilitation. Volume I: Executive Summary*. UNDP Kabul October 1993.

- It is increasingly recognised by development agencies that development efforts can play a role in either helping to create a basis for peace or fuelling the conflict. At the same time there is a failure to understand, among both donors and programme planners, that changing perceptions in a way that could lead to peace building is a slow process, especially in a country with such traditional cultural values and ethnic divisions as Afghanistan. Programs which change their focus every two years are unlikely to have the desired impact.
- Although Afghan NGOs exist, they cannot be called grassroots in the sense usually understood. NGOs have emerged in response to the availability of foreign funds, not as an indigenous movement for development and social justice. The open expression of opinion is not possible in many parts of Afghanistan, and creating a grassroots constituency for social justice is not part of the Afghan experience. Hence Afghan NGOs (as well as foreign agencies) tend to 'do projects' rather than engage in a development process based on local constituencies.
- Most importantly, many 'programmes do not know how to define the knowledge people have acquired through generations of survival in often inhospitable conditions and (how to) incorporate this information in the conceptualization and design of development initiatives'.<sup>18</sup>

While there are fortunately some exceptions,\* the general picture is of a series of top-down programmes that recognise (on paper) the importance of consulting local people but in practice generally fail to do this in a way that goes much beyond discussing shopping lists of needs.

All of these challenges boil down to one overriding quest, which is how to engage in a dialogue directed at reaching a common understanding between development workers and beneficiaries. This requires an approach to programme design, implementation, and evaluation which gives importance to process as well as product. This in turn requires much longer time horizons than are currently used by development agencies in Afghanistan. It is a difficult process, which defies neat solutions. For example, how does a development agency get close to local people without playing into the hands of local power politics? With whom does it engage in dialogue about social development (which is of equal concern to men and women) when communities are typically represented only by the most powerful men?

The process requires a commitment to training field workers in each programme who see themselves as social animators, not just technicians, as people who raise questions and encourage thoughtful answers rather than just deliver a service. One programme which has the potential to function like this is a CBR programme because it has cadres of field workers who are engaging on a daily basis with communities at the family and village level.

## **A LARGE CBR PROGRAMME IN AFGHANISTAN**

The Comprehensive Disabled Afghans' Programme (CDAP) was set up by UNDP and UNOPS in 1995 to address the needs of disabled people inside Afghanistan (ie. it did not target the two million plus refugees in neighbouring countries). It has developed into a national CBR programme operating in thirteen provinces of the country employing some four hundred paid staff, more than

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<sup>18</sup> Tamas, Andy 1996

a thousand volunteers, and serving about 25,000 disabled people annually. All the staff are Afghan with the exception of one expatriate programme manager.

The key agents in the field are Mid-Level Rehabilitation Workers (MLRWs), who are both male and female. They each cover a population of between 15-30,000. Their role is to activate local CBR committees (CBRCs) and DPOs (Disabled Peoples' Organisations), recruit volunteers, identify disabled people in their area through a local survey, and then arrange the appropriate service for each disabled person. For example, disabled children need to be integrated into schools, including *madrasas* (Quranic schools), disabled adults need job skill training and loans to set up small businesses, families need to be enabled to help their disabled child to develop, some will need referral to a physiotherapy centre, and others will need a prosthesis or orthosis from an orthopaedic workshop. The MLRW arranges what is needed by referrals to appropriate services and by mobilising local resources such as carpenters, bicycle repairers, tailors and others.

The MLRWs are given a general training of five months spread over a year in topics such as community development, psychology, child development, teaching and learning, and CBR principles, as well as how to work with specific impairments. The MLRWs are supported in their work by a smaller group of specialists: physiotherapists, orthopaedic technicians, employment support specialists, special education resource persons, CBR supervisors, trainers, and a resource centre. The total number of paid staff in one project area may reach 90, half of whom are MLRWs. Each MLRW is expected to recruit up to five volunteers each.

An important aspect of the programme is the Information, Education and Communication (IEC) component, which aims to raise disability issues both within Afghanistan and in the aid community outside it in Pakistan and beyond through newsletters, radio broadcasts, posters, videos, leaflets, and discussions. A key part of this process is a series of regular national workshops on disability in Afghanistan for which it brings together about thirty agencies. The aim of these workshops is arrive at an agreed national strategy for disability in Afghanistan among all the interested parties. They have, for example, agreed a common curriculum for training physiotherapists, agreed a common technology for the thirteen orthopaedic workshops in the country, and started the process of developing a national sign language.

How far can this programme connect with local communities in a way which respects their values but also acts as a catalyst for change? In order to answer this question it is necessary to identify some of the cultural values in Afghanistan which have a direct bearing on development work in general and disability in particular.

## **CULTURAL VALUES IN AFGHANISTAN**

The ethnic nature of the conflict in Afghanistan has to do with where people perceive their identity to lie, and this is inevitably bound up with values, whether cultural, ethnic or religious. This fact alone indicates that there is no single 'Afghan culture'. There is, for example, a difference between the culture of rural and urban communities, even within the same ethnic group; and there is a marked contrast between the cultures of different cities such as Mazar, Kandahar, Kabul, and Herat. It is also difficult to disentangle 'culture' from 'politics'. The Taliban, for example, who insist on such bizarre rulings as shaving under the armpits and having a beard at least six inches

long, indulge in a political manipulation of local customs in the name of religion. Although the Taliban are mostly Pushtun (also called Pathans), their particular brand of politicized culture and religion is not supported by many Pushtuns, especially the more educated. In what follows there are specific references to Pushtun culture because it looms large in many outsiders' perception of Afghanistan, but it must be remembered that about half of Afghanistan is not Pushtun.

In Afghanistan's eighteen years of conflict traditional value systems have been reinforced in some ways and broken down in others. For example, ethnic identity has become more not less important as the civil war has taken on an increasingly ethnic character; on the other hand the extended family system has tended to collapse when many husbands are killed, leaving thousands of widows. The fact that three million Afghans have experienced different cultures through being refugees in either Pakistan or Iran has also had an important effect on cultural attitudes and expectations. In particular it has demonstrated to many of them that education is the key to development - of the individual and his or her family - and the lack of education in Afghanistan is one of the main reasons why they are reluctant to return. On the other hand, the monastic-style education of large numbers of Afghan boys in the Quranic schools of Pakistan spawned the ultra-conservative Taliban (which means 'students').

The one thing that is common to all Afghans is their commitment to Islam as both a belief system and as a social programme. 'If great numbers believe a prophet is authentic and they are in agreement on the means to apply his teachings in their lives, the result is order and social progress. Unity of belief is linked to collective well-being.'<sup>19</sup> Islam itself brings with it a sense of social responsibility, evident in such things as *zakat* and *ushr*, both forms of donating charity to those who have less. Helping deprived people, which includes disabled people, is a religious (and therefore charitable) duty through which the giver accrues credit for the hereafter. Islam brings a strong sense of morality. People are respected and earn status to the degree that they conform to the moral code. Islam provides a meaning system, a source of hope, and a gathering point. The mosque is the centre of the community - for the men.

The typical Afghan village house consists of a high-walled compound enclosing a complex of mud buildings which accommodate the extended family. From five to thirty people or more may live in this space. Walking through an Afghan village one is conscious that most activities go on behind these compound walls, and are private. Interaction in public spaces is much less than in, for example, an Indian village.

In common with many other poor societies, survival in a subsistence economy like that of Afghanistan depends primarily on cooperation and mutual support within the kin group. The extended family is the prime source of social welfare. Contributing to the family is prized much more highly than making one's own way in the world. Anybody in receipt of a regular income is duty-bound to contribute to the common family fund; dereliction of this duty is despised, and for the vast majority of Afghans unthinkable. If a family member cannot contribute because he or she is disabled, this has an important bearing on their status in the family.

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<sup>19</sup> Tamas, Andy 1996

In traditional rural Pushtun society the survival of the family - or at least the degree to which it flourishes - is related to its *status*, which is related to its *reputation*. Reputation is determined principally by relations between the sexes, which means that men protect the family's '*honour*' by not allowing women to interact in the public domain. Fear of disgracing one's family in some way, however slight, is a very powerful force for social conformity, which is closely tied to religious conformity. The guardians of honour are the senior men in the extended family, who must command the obedience of all other family members. Power resides very definitely in these individuals, and it is used. While these values are strongest in Pushtun society they are also reflected to a lesser degree in the other ethnic groups of Afghanistan. Inability to marry because of disability deprives a man of the possibility of ever reaching such a position, and therefore reduces his status, either potential or actual.

In Pushtun society community decisions are traditionally made by a *jirga*, a permanent council of respected and powerful male elders. Power comes primarily from the number of male relatives a man has, not necessarily from wealth. In all parts of Afghanistan the concept of a *shura* also exists, which is a council formed for a particular purpose. When the central government is strong these two types of council, *jirga* and *shura*, tend to be weak. When the central government is weak they tend to be strong. At the village level people are inclined to give their allegiance first to their own community through the authority of the council and second to the government. Local tribal and ethnic loyalties are therefore reinforced through this mechanism. In the present era when development agencies are active it is common for these agencies to 'consult the community' through a *shura* which either already exists or which is created for the specific purpose of relating to the development agency. The concept of 'good governance' in the modern sense, an objective of some UN agencies, is not easily understood by people who have had traditional community decision-making mechanisms for hundreds of years. The CBR committees (CBRCs) and disabled people's organisations (DPOs) formed within the CDAP programme and their relation to these councils will be discussed below.

It is very difficult for a foreigner to determine what the words '*social integration*' mean in a context where segregation is the norm, where most interaction occurs within the private space of the home, and where women in many Afghan communities only interact socially at rare events such as weddings and funerals. Who is marginalised and what is the measure of marginalisation? The effect is that there are two levels of discourse, one private and one public, one female and one male. Power belongs to the public sphere to which women do not have access. *Jirgas* and *shuras* do not include women as members, although in some parts of the country there are women's councils; there are women only CBRCs in the CDAP programme, and, as already mentioned in a footnote, community fora in Mazar are run by women.

The discussion on gender relations in traditional societies, especially Muslim ones, is complex, and is the point where values clash most obviously with 'Western' values. It is usual in the West to portray Afghan culture as inherently oppressive of women. But most Afghan men and probably many Afghan women perceive it as ensuring respect for women, by protecting them from harassment and from what they regard as the demeaning task of having to engage in wage-earning in the public domain. The idea (frequently quoted in the West) that disabled women suffer the double disadvantage of being disabled and of being female was firmly rejected by well-educated women working for the

disability programme described here. They did not accept that being a woman was in itself a 'disability'.<sup>20</sup> According to anthropologist Benedicte Grima, a Pashtun woman's identity and her emotions themselves are culturally determined. As for the veil as a symbol of oppression, Grima's and other anthropological studies of Pushtun communities reveal that a Pushtun village woman would no more consider going out without her *burqa* (head to foot covering with a mesh over the face) than she would consider going out naked. She regards the veil as an essential part of her public identity as a woman.<sup>21</sup> This does not however apply in other parts of the country. In the northern predominantly Uzbek city of Mazar, for example, before the Taliban takeover of the area women attended a co-ed university dressed in jeans, unveiled.

A 'Western' anthropological analysis might insist that a Pushtun woman's acceptance of the veil as part of her identity means she has internalised the oppression. The same is true of disabled people: accepting an inferior position in the social hierarchy 'as the normal state of things' is to internalise segregation. The process of integration must start with changes in perception by the person segregated. In Afghanistan this is particularly difficult. Attempts to 'modernise' the country by various rulers (especially by changing the role and status of women), most recently the Communists in the 1970s, have been the main cause of conflict.

#### **DISABILITY, LOCAL VALUES, AND CBR IN AFGHANISTAN**

In Afghanistan local surveys indicate that probably about 3-4 % of the population of 20 million is disabled. This gives a figure of about 700,000- 800,000 people in the whole country. War injuries (mainly from mines) and polio account for about half this number. The other half is composed of people with mental retardation, cerebral palsy, leprosy in certain areas, deafness, blindness, and multiple impairments.

Services for disabled people have tended to focus on the provision of orthopaedic aids and physiotherapy. This is because the appalling conditions in most hospitals mean that a limb damaged by a mine explosion will be amputated rather than saved, so amputees are the most visible manifestation of disability in the country. One foreign NGO is working with deaf people and two others with blind people. There are almost no institutions for any category of disabled person.

The original design of CDAP, written in 1994, was a classic example of an external, non-consultative project formulation, written by three European development specialists from Sweden and Germany who did not visit Afghanistan during the formulation stage. The present project document, written in early 1997, had the benefit of a major evaluation of the programme conducted in the summer of 1996. However, that evaluation did not seek to probe cultural relevance explicitly. This task belongs to ongoing monitoring of the programme, and must be built in to its management and implementation strategy. This means, as stated earlier, that its staff must be trained as social animators, to raise questions, to be objective and reflective about their own culture, and not simply to deliver a packaged service.

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<sup>20</sup> CDAP, Minutes of staff seminar on cultural values, 2 February 1998.

<sup>21</sup> Grima, Benedicte (1993): *The Performance of Emotion among Paxtun Women*. OUP. Karachi

One senior worker<sup>22</sup> in CDAP has identified what he calls a *CBR conflict zone* in the programme, where local concepts of disability, culture, poverty, the nature of CBR, and local social values meet. The following paragraphs explore this conflict zone and summarise conclusions that can be drawn so far on whether the programme is in tune with local values and whether it can be used for stimulating and animating a development process that is wider than disability.

We have already identified a number of factors leading to the segregation of disabled people, in particular the importance of being able to marry in order to conform to social norms of acceptance and because marriage is an essential economic arrangement. Where marriage is impossible, the individual lives in a kind of liminal limbo. Not only may a disabled person not be able to get married, but the presence of a disabled person (male or female) in a family may affect the marriage chances of other members of the family (because disability is regarded as shameful) and cause resentment towards the disabled person within his or her own family.

Apart from the crucial matter of marriage is it possible to identify other attitudinal factors affecting disabled people in Afghanistan? It is often thought that disabled people get a particularly rough deal in poor countries like Afghanistan, and extremely negative myths are perpetuated, for example that disabled children are killed at birth. Attitudes to disability in Afghanistan have never been systematically researched, but all one can say at this stage is that anecdotal evidence points in the opposite direction from these myths. In rich countries like America it seems that disabled people get their worst treatment from the wealthy. 'Successful' Americans obviously feel more threatened by disability as a 'defect', and therefore a departure from what they aspire to, than people of lower social status do. Discrimination against disabled people seems to occur, according to American researchers, in direct proportion to wealth.<sup>23</sup> In a country as poor as Afghanistan it may be that there is less discrimination towards disabled people than there is in America. Poverty is a great leveller. On the streets of an Afghan town it is common to see a disabled child being pushed along in a crude cart by other children, with no sense of embarrassment. Amputees are such a common sight that they are accepted as part of the normal scene in a bazaar. The caring and concern shown by both mothers and fathers towards their disabled children, especially the mentally retarded, never fails to impress. The main problem is not neglect but over-protection, under-stimulation, and ignorance of how to help the child develop.

However, this does not mean that it is better to be a disabled person in Afghanistan than in America. Most obviously, the survival rate of disabled Afghans is low, as a result of inadequate or non-existent health services, not because their families reject them. There is, for example, almost no treatment for spinal injuries, which means that many paraplegics and most quadriplegics die within a year of injury from pressure sores or urinary complications. Some disabilities are more 'acceptable' than others. Amputees, partly because their ability to communicate and reproduce is not impaired and partly because they may be regarded as having made a sacrifice in war, are easily accepted. Other disabilities, especially congenital ones, are often regarded as a shame, and

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<sup>22</sup> Wahdat, Hayatullah (1998): Mission Report to Wardak and Ghazni January 1998. CDAP internal report.

<sup>23</sup> Murphy, Robert (1987): *'Encounters: The Body Silent in America'*. In Ingstad, B. and Whyte, S.R (ed.) (1995): *'Disability and Culture'*. University of California Press.

are largely absent from public view. It is common for parents to claim that their child became mentally retarded after a rocket attack in order to conceal the congenital nature of the disability.

Disability is still generally seen as a medical problem or one brought about by divine punishment or a person's bad luck, which can be removed only through either medical or religious intervention (or both). The quest for a cure has often been protracted, expensive, and hopeless. Such attitudes (by no means unique to Afghanistan) make it difficult for a CBR programme, which offers no cure, to gain early respect.

The notion of *empowerment*, as described in the section on disability and developmental values above, is very problematic in Afghanistan. The word is inappropriate. In a seminar on cultural values with the CDAP management team already referred to, the word 'empowerment' (especially in its local language equivalent) was rejected by all the participants on the grounds that power in Afghanistan means power over somebody else. It is not regarded as win-win, only as win-lose. One can only be empowered at the expense of another. The group favoured the word 'enablement' instead. But even this is a concept not easily understood in a situation where people may not aspire to individual development at all, imbued with cultural values that are dominated by the need for collective family survival and kin-group solidarity.

The formation of DPOs has brought 'rights' into the consciousness of many disabled people at the village level. By rights they usually mean equal access to what limited services are available, especially health and education. DPOs tend (as elsewhere in the world) to be dominated by men with mobility impairments, which in Afghanistan means amputees. Given that many of these will have been disabled in war and are therefore ex-soldiers they are often forceful, and are not obviously lacking in self-esteem. The main problem is to achieve representation of other disabilities in the DPO.

The attitude towards themselves of people with sensory and other impairments is often depressed. This is particularly true of women.

CBR by its nature is long-term, time consuming, usually not very visible, and with few material inputs. What is the general community view of a CBR programme? How do they compare it with other aid and development programmes which bring more material benefits? Does a programme lose credibility and value in the eyes of the local community if it is dealing only with 'ideas and paper'? A common response from CBRCs and DPOs, as well as individual disabled people, when asked for their recommendations to improve the programme, is that it should deliver some kind of 'incentive', by which they mean material handout. The employment support element of the programme, which gives skill training and loans to disabled people, is what many adults see as its main value. CBRCs also regularly ask that such loans and training be extended to very poor non-disabled people such as widows.

What status do CBR workers hold in the community? Are they respected for what they do? If yes, is that because others admire them for working with disabled people? Is religion a major motivating factor for them? How far can they be catalysts for wider change in the community? As already noted, the potential for a CBR programme to make a contribution to development on a scale wider than disability rests on these field workers. Their selection and training is therefore of

crucial importance. It is worth stressing that the physical energy required to be a CBR worker (MLRW in this programme) in rural Afghanistan is considerable. To cover a population of 15-30,000 they have to travel large distances in extremes of climate on roads which in many cases hardly exist, either on foot or on a bicycle, or in one case on a horse. To keep up the level of visiting required day after day, month after month and year after year, in numbing cold and blistering heat, demands a very special kind of commitment. The astonishment perhaps is that a CBR programme works at all under these conditions.

When questioned on their motivation for the job MLRWs frequently report that religion does play an important role, coupled with a desire to serve their community. Getting to know their community brings its own rewards for many, who see their status rise by the fact of having to mobilise people. Employing disabled people as MLRWs presents a problem because of the physically taxing nature of the job, but a few MLRWs are disabled.

The entry points for dialogue with local communities are the individual families, and the CBRCs and DPOs at village and district level. The membership of the CBRCs is drawn from local health workers, teachers, disabled people, parents of disabled children and other interested persons. Sometimes they are congruent with local *shuras* dealing with general development issues in their own community, sometimes they are independent of these *shuras*. Disability is not a sensitive political issue; it is not something which people fight over. These CBRCs represent neutral territory. Dialogue with these groups is likely therefore to yield a closer reading of what people think and feel about development issues generally, and they can be used as an entry point for such discussions. At the same time their members see their membership as giving them more status in the community than they had before, as well as experience of organising, debating, and deciding. They count for something in their own eyes, and in their own communities. Disability does indeed open pathways to a different view of development that is not based either on power or materialism.<sup>24</sup>

Separate female CBRCs exist in both Taliban and non-Taliban held areas. The sense of personal and group empowerment in these all-women committees is probably greater than it is for men because women have so few opportunities outside the home to have any influence on community affairs.

To illustrate the role of these committees, the minutes of a (male) CBRC in Herat in January 1998 reveal that over two meetings they discussed the following issues: finding a place to run a vocational training course in tailoring for disabled women, raising the money to provide lunch for the trainees, identifying a skilled person to act as trainer, the lack of textbooks in schools, home schooling for girls, malnutrition in several families. They arranged the training course successfully, and identified women who could provide home schooling for girls. As can be seen, their discussions were not limited to disability issues. They were obviously and justifiably proud of the two achievements of arranging the tailoring course and home schooling for girls. The field worker, who had instigated the formation of this committee, remained in the background, observing and encouraging, a genuine but discreet change agent. Something was happening in this community that was indeed developmental. The word 'empowerment' came immediately to mind in observing this process, even though it may not translate well into Farsi.

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<sup>24</sup> Coleridge 1993

## CONCLUSIONS

People feel threatened when their values are attacked or start to disappear. When there is fighting everywhere, when the economy is in ruins, when the future holds no hope for one's children, to see one's whole value system also threatened means that the sky has fallen in. The core values described for Afghanistan, in particular Islamic charitable duty, the strength of the extended family, honour, well-defined roles for men and women, and respect for senior males, bring order and predictability to a society living in a harsh and unpredictable environment. It is perhaps inevitable that poverty, war, and destruction stimulate the emergence of leaders who preach the loss of traditional values as the cause and a return to traditional values as the cure. The same phenomenon has occurred in Europe and elsewhere. For foreigners to challenge these values as 'counter developmental' is not likely to be met with a positive response, especially when 'western values' are not necessarily seen as producing a more cohesive society. Development programmes have to take Afghan values as the given starting point and work within them.

If development is about moving forward on a path towards greater understanding and control over our lives, a process which is more than the provision of material benefits is necessary. Material benefits, even though they are absolutely necessary in a country as poor as Afghanistan, do not amount to development. Culverts, bridges and wells, though vital, do not in themselves make people more inclusive, democratic, or peace loving. A shift in perceptions is necessary. A process must be engaged in which focuses on aiming to change perceptions, not to change culture. Changing perceptions is the key to altering behaviour. An enormous difference to the way we live our lives can be created by a shift in perceptions about things we have always taken for granted or never questioned.<sup>25</sup> The difficulty is that our perceptions are conditioned by our cultural background, and changing them is not something that most humans do spontaneously. Some outside trigger is required. Seeing development as the creation of self-sufficient communities who do not need outside influence is not only unrealistic; it is a flawed model. We all need external stimuli to enable us to grow and develop.<sup>26</sup>

The role of a development worker is to give people the confidence that they do have the ability to develop themselves. At the same time he or she needs to challenge perceptions, from within the culture. Well-trained field workers working within their own cultural context are in a much better position to challenge stereotyped perceptions than foreigners. The role of foreigners is to ask the questions of the field workers but not to provide the answers; these must be provided by local people from reflecting on their own context and values. Foreigners can ask the questions in different ways, which include providing the materials and the experiences which challenge field workers to change their own perceptions. Discussions on cultural values need to be a regular and normal part of the process of running a development programme and not ignored or left aside as 'too sensitive'. In this way a thinking, questioning, experimenting cadre of field workers can be created who are true catalysts for change within their own culture.

A CBR programme is at base about changing perceptions. Evidence from the CDAP programme shows that changing perceptions about disability can be an important step on the road

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<sup>25</sup> Tamas 1996

<sup>26</sup> Zeldin, Theodore (1994): *An Intimate History of Humanity*. Minerva. London

to deeper understanding about more general development processes. As one field worker in Herat recently said during a discussion about development, 'If we had started a CBR programme twenty years ago in Afghanistan we would not need the UN today.'

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