THE ROLE OF NGOS IN THE PROCESS OF EMPOWERMENT AND SOCIAL TRANSFORMATION OF PEOPLE WITH DISABILITIES

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ABSTRACT

To date, two general bi-polar models, or approaches to disability have been popularly advanced within the literature, namely, the medical and social models of disability. Within each model, there is a significant degree of variation with respect to where emphasis has been placed. Both models provide pertinent insights into how disability has been conceptualised, but neither model provides an adequate, comprehensive explanation of the phenomenon, with each partially reflecting the "reality" of disability. Both models are deficient in their explanation of how marginalised and often oppressed groups, such as disabled people, are able to recognise their potential to change their present situation, thereby becoming full and active citizens in the contemporary societies in which they live. Both the medical and social models are themselves based on philosophical assumptions about the understandings of human nature, the process of social change and development, and how individuals within any given society are able to function. Both models perceive disabled people as being passive subjects. This chapter has the following objectives. First, to provide an analysis and critique of the medical and social models of disability, and provide some tentative suggestions for the development of another model, which attempts to combine the positive elements of the two previous models. Secondly, to consider the role that non-governmental organisations have and can potentially play in the participation, empowerment and social transformation of poor and marginalised group, with particular reference to disabled people. This chapter focuses on the theories of empowerment and social transformation as espoused by the Brazilian educationalist, Paulo Friere.

INTRODUCTION

The past three decades have witnessed the emergence of the area of Disability Studies, whose intellectual heritage is based on the generic academic disciplines of medical science, psychology, political theory and sociology. The fundamental raison d'être of Disability Studies has been to provide a theoretical explanation of how disability can be understood, as well as to provide normative principles upon which the operational practices for the provision of disability services should be based. The post-war era has also witnessed the global development of the "disability movement". There has been close collaboration between the academic study of disability and those engaged in disability activism.

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THE MEDICAL MODEL

The medical model of disability is considered to be the predecessor of the social model. In this model, disability is defined primarily as a disease state and perceived as a deviation or abstraction from normality. The model asserts that the most significant "problem" that disabled people face is the loss of physical and/or cognitive impairments as well as occupational ability. Hence, the medical model is a deficit model, which views disability as essentially a "problem", focusing upon the individual physical and/or mental impairments. Such a perspective argues that disability resides within the individual, and that it is reducible to the analysis of impairment. The attainment of "able-bodiedness" is considered as the legitimate criterion by which to measure "normality". The medical model thus projects able-bodied people as "better" or "superior" than those who have a disability. The model also assumes that disabled people are biologically and psychologically inferior to those who are able-bodied, and by implication, do not have the competence to make decisions for themselves (1). Thirdly, disability is perceived as a personal tragedy, which occurs in individuals on a random basis - it is just a matter of misfortune (2). Furthermore, the medical model of disability assumes that there is an objective state of "normality" which gives professionals, a dominant role. Finklestein has argued that "the aim of returning the individual to the state of normality is the critical foundation upon which the whole rehabilitation machine is constructed" (3). Furthermore, there is little scope for disabled people and their families to participate within this decision-making.

Critique of the Medical Model of Disability

The medical model has been criticised, especially by the disability movement, and found to be deficient on a number of counts. The principal criticism is that the medical model fails to give consideration to the socio-cultural contexts in which impairments are placed, and that disability is essentially a social, not a biological construct. The emphasis placed upon impairments and physiological conditions perpetuate the notion that disabled people are weak and dependent, and that physical incapacity essentially defines the quality of life that a disabled person is able to live. In criticising the model, one does not question the necessity and validity in receiving high quality

medical support, but rather one challenges the nature of social conditions and relationship that are encountered when disabled people and the medical profession interrelate with each other.

THE SOCIAL MODEL

In ideological juxtaposition to the individualistic medical model, the social model of disability provides a socio-political conceptualisation of disability. The social model has arisen in response to the critique of the medical model. The social model is the total antithesis to the medical model, where the primary focus of analysis has shifted from the deficits of the functional, physiological and cognitive abilities of the impaired individual, to the detrimental and oppressive structure of society, and the negative social attitudes encountered by disabled people throughout their life. Harlan Hahn, writing within the North American context, states that disability stems from"the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of the disabled individual to adapt to the demands of society" (4).

Disability is therefore situated in the wider, external environment, and is not explicable as a consequence of an individual's physical and/or cognitive deficiencies. Thus, in focusing upon the manner in which disability is socially produced, the social model has shifted the debate regarding disability from a bio-medically dominated agenda to one which gives central importance to politics, empowerment, citizenship and choice. Furthermore, disability is the result of society's failure to provide adequate and appropriate services, and the needs of disabled people are not adequately accounted for within the social organisation of society. It is perceived in attitudinal terms as a socio-cultural rather than a biological construct.

A central tenet of the social model is that, irrespective of the political, economic and religious character of the society in which they live, disabled people are subject to oppression and negative social attitudes, that inevitably undermine their person-hood and status of full citizenship. Central to the notion that disabled people are oppressed is the underlying assumption that all societies are characterised by conflict between two competing groups; the dominant and the subordinate.

Finklestein (5) was one of the pioneers in developing a materialist explanation. He postulated that history can be divided into three "distinct and sequential phases", and that within each phase, the manner in which disabled people were socially included or excluded within contemporary society differed. First, the period before the European industrial revolution was characterised by agrarian feudalism and some cottage industries. During this period, there was scant social mobility, where it is maintained that the mode of production did not exclude disabled people from active participation in their local communities. During the second phase, the industrial revolution and its immediate aftermath, disabled people were effectively excluded from being in paid employment, due to the fact that they were not able to maintain the pace set by the factory system. As a consequence, disabled people were separated and socially excluded from mainstream social and economic activity. Finklestein maintains that during the third phase, which is just commencing, disabled people will witness and experience their liberation from social oppression.

The rise of the factory system and the introduction of individual wage-labour, transformed the "means of production", resulting in the separation of home from the workplace, and in the marginalisation of disabled people. Disabled people have become further isolated through the

establishment of closed and segregated institutions, for example, within many so called "special schools" and sheltered training workshops.

A Critique of the Social Model

It is beyond doubt that the genesis and subsequent development of the disability movement, and the theoretical understandings of disability that have thereby ensued, both within the United Kingdom and throughout the world, have brought about a quantum shift in the manner in which disability has been perceived. By purporting that the origins of oppression are located exclusively in "attitudes", it is difficult to determine their social location, and understand how these in turn result in oppressive action. The model is deficient in failing to analyse the socio-political contexts in which attitudes and values are constructed, and how they are in turn transformed into oppressive actions and practices. Due to strong emphasis being placed upon discriminatory social and political structures, the analysis of what it is to experience impairment within the body, and the sociological and psychological implications in relation to this has largely been ignored. Jenny Morris (6) maintains that the social model has effectively denied the fact that the physical and emotional pain and suffering experienced by disabled people due to their impairments has any impact upon their practical daily living.

A further question arises concerning the appropriateness of the western-based notion of "empowerment", which presupposes that rights are exercised and that decisions are made in accordance with the preferences and wishes of the individual, in developing countries. Such an individualised notion of empowerment, as espoused by the international disability movement, runs contrary to accepted social customs and practices found within many such countries. In societies such as India, it is customary that all major decisions, for example who one should marry, the purchase of property and career decisions, are taken not by the individual, but collectively through consultation within extended family and kinship networks. This is particularly the case in rural areas, and operates irrespective of whether disability is present within the family. Thus, a focus on rights and decision-making practices rooted in the ideology of individualism is in many societies, particularly those within the African and South-Asian context, are often at variance with established cultural, social norms and practices.

COMBINING THE MEDICAL AND SOCIAL MODELS OF DISABILITY

Given the limitations of both the medical and social models of disability, is it indeed possible to construct another model, that combines the positive features of the previous models? If this is indeed possible, then what would be the constituent elements of such a model?

The different sets of assumptions for both the medical and social models constitute a internally logical and coherent framework, and from this, each derives a coherent set of policy prescription for the operation and development of disability services. However, it is contended that there is a third alternative, that combines the assumptions regarding the nature of social change, development, and human nature. Such a synthesis has at least the potential to provide a new and potentially innovative framework by which to take forward the debate regarding models of disability and consequently, to produce an innovative approach to the provision of disability services.

An individual's human nature, his/her position in society, and life chances are neither exclusively determined by innate biological characteristics and abilities, nor are they totally prescribed by social, economic and political structure of society. Both these approaches assume that all human beings are essentially passive, in the sense that they are unable to influence the course that their life will take. Such a position gives no credence for the creativity that is inherent within all human beings, as well as the indeterminacy within the human condition. However, it is maintained here that human nature and the dynamics of social change are the product of the continuous interactive relationship between an individual's naturally endowed characteristics and the social environment in which he lives, which is itself shaped by social, political and economic factors. There is thus an inter-dependent and dynamic relationship between an individual and his society. Such an approach posits the integration of biological and social factors in determining the human condition in which neither of these two factors are given primacy from an ontological perspective, but they relate to each other interactively.

Secondly, what are the implications, both in terms of the philosophy of development and operational practices, for NGOs adopting a Frierian approach to empowerment and social transformation, notwithstanding the difficulties and obstacles in adopting this approach? Although Frierian theories of social transformation and change have been in existence since the early 1970s (7), and have been adopted in a number of development contexts, they have not been applied within the context of disability service provision. An investigation that attempts to answer both these questions necessitates a consideration of the generic development literature, which deal with the subject of empowerment and participation of disabled people within their local communities.

Despite protestations to the contrary, the claim that CBR is an efficient and effective strategy for the provision of community-based disability services has largely remained unproved. In fact, there has been scant critical evaluation of CBR. Despite there being no one universal agreed definition of CBR, the strategy assumes that the local community will play a pivotal role in service provision, and that the local community is characterised by benevolence, and is viewed as a homogeneous entity. These assumptions regarding the role of the community have been seriously questioned by the work of Catherine Lysack (8). In addition, it is claimed that CBR is multi-sectorial in approach, but in fact many CBR programmes remain largely dominated by the medical profession, and hence strongly influenced by the medical model of disability. In such situations, the role that disabled people play is mostly that of compliance, rather than that of participation. Protagonists of CBR also assume that CBR is cost-effective, but again, this remains to be proved.

Furthermore, it is arguable how many CBR programmes have been ineffective in achieving their goal of empowering disabled people. In relation to this particular point, it is argued within this chapter that it would be appropriate for CBR programmes to adopt and apply a Frierian approach of social transformation, if their is aim the empowerment of disabled people. The debate regarding the meaning of empowerment, what the implications are for the operational practices of NGOs, and the resultant role that should be played within the context of disability service provision, will be further elaborated on in this chapter.

The raison d'être of Friere's thesis of social transformation is to ensure that all individuals, particularly those who are subject to oppression are made "more fully human" (7). Friere maintained that all individuals, irrespective of the degree of oppression they have been subjected to, potentially

have the innate ability to transform their political, social and economic situation. However, effective social transformation will only occur when marginalised groups, such as disabled people, meet collectively, critically analyse the constraints placed upon them by their social, economic and political environment within a historical framework, and devise strategies for their subsequent alleviation. The theory is premised upon the assumption that all individuals, notwithstanding their class or social position, are innately self-conscious and creative, and able to change their present (and often very oppressive) environment. Frierian strategies have profound implications for the potential role that can be played and expected by able-bodied professionals. Rather than adopting the role of the technocratic expert who analyses the problems and needs, and devises "solutions" for disabled people (analogous to Friere's "banking" method of education), the professional adopts the role of a facilitator, enabling disabled people and other oppressed persons to reflect on and identify their needs and aspirations.

The following discussion attempts to firstly analyse further the concept of empowerment, as understood from a Frierian perspective, and secondly, to link this to the role played by non-governmental organisations (NGOs), and the enhanced role that they can potentially play in fostering and facilitating the goals of empowerment and social transformation. Such an analysis will enrich the understanding of what it actually means for disabled people to live in an inclusivesociety, a concept that has been espoused, but as yet not full explained by the disability movement.

PARTICIPATION, EMPOWERMENT AND THE ROLE OF NGOS

As with the term empowerment, the notion of participation has been imbued by ambiguity within contemporary development discourse, which has further resulted in confusion in the role that the voluntary sector, particularly (NGOs) should play in the field of development. Indeed, many theorists have used the terms empowerment and participation interchangeably, perceiving both terms to be inexorably linked, and this is the position adopted within this chapter. The approaches and strategies that are adopted toward participation varies, according to one's ideological position and how power is conceptualised.

The concepts of "empowerment" and "participation" reflect understandings about the nature of power. Friere, in his conception of social transformation, maintains that power in society is essentially structured on the basis of class (7). In terms of empowerment and community participation, such a conception of power implies that by necessity, the powerless and the oppressed must appropriate for themselves power which has hitherto been in the possession of the powerful. Hence, by definition people can only empower themselves, and power is a "zero-sum" phenomenon.

NGOs have played a key role in the provision of community-based disability services. In order to address how CBR programmes can indeed become facilitators and promoters of the genuine and authentic empowerment, it may be instructive to consider the role that NGOs have and can play in the future with regard to empowerment and social transformation.

DEFINING NGOS

As with so many concepts within development, what constitutes an NGO is open to debate. By their very nature, NGOs are very heterogeneous entities, and range from largebi-lateral funding agencies operating in many countries (such as Oxfam, Save the Children Fund, and World Vision),

to very small organisations operating at village level, whose function is to provide for the immediate needs of their members. The latter are sometimes referred to as grassroots organisations.

Some even debate whether grassroots organisations are indeed NGOs. For example, Jenny Pearce (9) has argued that grassroots organisations differ from NGOs in three important ways. First, grassroots or people's organisations are comprised of individuals who are bound together by particular interests or common characteristics, such as class, gender, cultural identity and even disability. In contrast, the social composition of intermediary NGOs is generally comprised of middle class individuals, who for a multiplicity of reasons and motivations, have elected to work on behalf of or with the poor. Secondly, grassroots organisations invariably have limited yet quite specific aims and objectives. In contrast, NGOs act as intermediaries whereby they provide a link between bi-lateral and multi-lateral funding institutions and grassroots organisations. Thirdly, ultimately grassroots organisations are accountable to their members, whereas NGOs, despite rhetorical statements to the contrary, are ultimately accountable to their funders. Pearce concludes her analysis of the distinction between grassroots organisations and NGOs by stating "It is not helpful to use the term 'NGO' to encompass popular organisations as well as those intermediary institutions established to provide care, facilitate self-help and grassroots democracy, to supply technical assistance, or campaign on issues of importance to the poor. The failure to make this distinction contributes to a tendency to depoliticise popular organisations and politicise NGOs" (9).

The distinction between NGOs and popular organisations, as proposed by Jenny Pearce reflects contrasting conceptualisations of the nature of power. Notwithstanding their apparent heterogeneity, some writers maintain that there are common characteristics that can be identified among NGOs, which Green and Matthias have summarised as follows "... organisations that are formally constituted, with a primarily non-profit-seeking objective of a group or community wider than the direct membership of the organisation and with a decision-making authority independent of government. They may achieve their aims in a variety of ways ranging from direct service provision through to the support of other NGOs (10).

THE CHANGING FUNCTION THAT NGOS PLAY WITHIN DEVELOPMENT

The past two decades have witnessed an exponential growth in the number of NGOs, especially working in South Asia. Edwards and Hulme (11) have collated some illuminating statistics that demonstrate such growth. Within OECD member countries, the number of registered NGOs increased from 1,600 in 1980 to 2,970 in 1993. Over this same period, total expenditure of NGOs increased from US$2.8 billion to US$5.7 billion (12). Accompanying the growth in the number of NGOs has been a diversification in the roles and functions that they perform.

ASSESSING NGOS PERFORMANCE' AND ACCOUNTABILITY

Despite the exponential growth of NGO activity during the past decade, there are still questions regarding their effectiveness in achieving their stated objectives. Allied to this there is also a related debate regarding to whom NGOs are in fact accountable. Both these debates are of major concern to the development of the argument vis-a-vis empowerment and participation of poor and marginalised groups. It will be argued that failure of NGOs in achieving their objectives can be partially attributed to the inability to comprehend the processes and dynamics of social transformation as viewed from a Frierian perspective.

The evaluation of an NGO's effectiveness is indeed a problematical exercise, not least because there are few, in any, universally agreed criteria upon which such evaluations are and can be premised. In many instances, and certainly the case in some of the evaluation reports of disability projects in India, such evaluations tend to be instruments of propaganda. The aim is to impress donor agencies regarding the usefulness of the NGO's activities, (thereby providing evidence that the project of the NGO is of paramount importance, is indispensable, and warranting further financial support), rather than to critically analyse the strengths and weaknesses of the NGO's activities.

Edwards and Hulme (11) are of the opinion that "... there is increasing evidence that NGOs and GROs do not perform as effectively as had been assumed in terms of poverty-reach, cost-effectiveness, sustainability, popular participation (including gender), flexibility and innovation. In terms of service-provision, there is certainly evidence that NGOs are able to provide some services more cost-effectively than governments"

With regard to NGOs and grassroots organisation's performance in terms of promoting democracy, Edwards and Hulme are equally sceptical, partly because many NGOs have failed to adopt democratic structures and operational practices within their own organisations. Once again, the authors poignantly comment:-"... there is little evidence that NGOs and even GROs are managing to engage in the formal political process successfully, without becoming embroiled in the partisan politics and distortions that accompany the struggle for state power. The failure of many NGOs, and even GROs, to democratise their own structures makes them less effective in this process. ... Nevertheless, NGOs and GROs can be proud of their achievements in helping to cement human and political rights in many societies, and in democratising the informal political process by training grassroots activists, building stronger local institutions, promoting micro-policy reform, and undertaking education for citizenship"

It is also illuminating to look at what writers and practitioners from Southern-based countries consider to have been the impact of NGOs and "development projects" on improving the quality of life of the poor. Sithebiso Nyoni, founder director of the Organisation of Rural Association for Progress, Bulawayo, Zimbabwe, has written a strong indictment of the impact that international NGOs and the development industry have had upon the poor, and it is worth considering the argument that he presents in some detail (13). It is also of interest to note that Nyoni, in founding and developing his own NGO, has adopted a Frierian approach to development. Nyoni is of the opinion that in general, NGOs and the resultant industry that has been generated around them have had a negligible impact upon hunger, poverty, and political instability throughout the developing world, which in most instances have remained largely "undeveloped". He comments that "Development has therefore ceased to have any meaning for the poor. In most countries it has become a political slogan used to mobilise the poor for political ends - promising them increased food production, participation and a good life which is never realised. Development is often used in a way contrary to what it means to the poor, with leaders pretending to accept development, but not giving it any substance.... As a result, the rural poor are increasingly being forced to become more and more dependent on their governments and international donor agencies to break the vicious cycles of poverty, hunger and powerlessness and to lead them to development. Almost 40 years of national and international development efforts have passed without any fundamental changes in the lives of the poor.

In agreement with Edwards and Hulme, Nyomi maintains the opinion that many NGOs have failed in the mandate to allieviate poverty and to act as facilitators for the empowerment and social transformation of the poor, because their own internal structures tend to be hierarchical, not democratic. If NGOs cannot listen to those who work within their organisation, then it is not at all surprising that they fail to listen to the view and interests of the beneficiaries of their services? Nyomi thus states that "Most development agencies are centres of power which try to help others change. But they do not change themselves. They aim at creating awareness among people yet they are not themselves aware of the negative impact on those they claim to serve. They claim to help people change their situation through participation, democracy, and self-help and yet they themselves are non-participatory, non-democratic and dependent upon outside help for their survival (13).

A further intractable problem continually faced by NGOs is accountability. This concept is generally understood to refer to the manner by which individuals and organisations report to indentifiable and recognised authorities for the activities they perform. Both international and indigenous NGOs have multiple accountabilities. They are accountable "downwards" to their collaborating partners, those who are beneficiaries or client groups of the services they provide. In addition, they are accountable "upwards" to donor agencies and the government of the host countries in which they are operating. From a legal perspective, NGOs are solely accountable to their board of trustees. However, from a more ethical standpoint, many NGOs consider themselves to be accountable to their beneficiaries, especially for those that endorse a "people-centred" approach and ideological stance to development. Commenting upon the complexity of relationships that NGOs encounter in relation to multiple accountabilities, Brett states "The NGO acts as an intermediary between the donor and the consumer and market competition is excluded. The agency relationships involved are complex, and include those between NGOs and donors, consumers, home and host country governments and between managers and workers. They can also include those between foreign and local NGOs where the former sub-contract out to the latter. Since each of these has differing and conflicting interests and leverage, difficult problems of monitoring and enforcement arise (14).

KORTEN'S TYPOGRAPHY OF NGOS

David Korten (15) had argued that during the past 40 years there has been a four-fold evolution of the role played by NGOs. Although the analysis is presented in terms of four sequential "generations", it must be noted that NGOs that have the characteristics of the first three generations can and do exist within the current development environment. Furthermore, all true development agencies have a philosophy or ideology vis-a-vis "development", which in turn governs their operational approach and also their understanding of the root causes of poverty and underdevelopment. In the absence of such a coherent theory, Korten maintains that any development initiatives undertaken will be cosmetic and illusionary, and that in the long-term, "... runs the risk of inadvertently strengthening the very forces responsible for the conditions of suffering and injustice that it seeks to alleviate through its aid "An organisation cannot have a meaningful strategy without a development theory. ...This logic must make explicit the organisation's assumptions regarding the forces that sustain the problem it is addressing .

It is therefore instructive to consider Korten's analysis of the development of NGOs, to appreciate some reasons for the shortcomings of operational practice that have occurred in the past, as well as to provide some pointers to how NGOs might improve their performance in the future.

The first generation of NGOs, established in the aftermath of the First World War, were primarily concerned with the provision of humanitarian relief and welfare. Thus, services were provided on the basis of meeting immediate needs in the context of natural disasters or crisis situations, such as famines, floods, civil strife and war. Classic first generation NGOs were established by churches and missionary organisations in Africa throughout the colonial era. Such NGOs assume that short-term assistance will provide a sufficient impetus for long-term development generated from indigenous resources, principally provided by the public sector. Korten maintains that first generation NGOs invariably lack a coherent developmental theory and resultant strategy. While such efforts brought temporary alleviation of immediate and often acute needs, this approach did nothing to address the long-term impact of poverty and sustainability. Notwithstanding that the provision of relief and welfare still remains a legitimate activity for NGOs, first generation NGOs fail in meeting objectives associated with long-term development.

Recognising the limitations of providing solely humanitarian relief and welfare, the second generation of NGOs in the 1970s focussed their attention towards establishing community development projects. Such an approach differed from the former in that attention was given to institutional capacity building, in the belief that development initiatives that are started by NGOs will continue once external funding has been withdrawn. Thus, emphasis is given to self-reliance and the establishment of "self-help groups", invariably based at village level. Often the second generation NGOs run parallel services to those provided by government. Furthermore, it is assumed that development initiatives are the result of a "partnership" being established between NGOs and the local community. It is also implicitly assumed that under-development is the result of local inertia and lack of initiative, though the potential for development and progress does reside within the local community. In this scenario, the function of NGOs is to act as a facilitator or catalyst that mobilises local community resources, rather than to be involved in direct service provision.

Describing the rationale behind second-generation NGOs, Korten states that "Second generation strategies differ in the extent to which they focus on human resource development or empowerment as the central issue. While second generation strategies almost universally involve a substantial focus on education, the human resource development tradition assumes that the problem lies exclusively with the individuals' lack of skills and physical strength. The rallying cry of the human resource development group has been the ancient oriental proverb 'Give a man a fish, and you feed him for a day; teach him to fish, and you feed him for a lifetime'" (15).

NGOs that espouse a more radical or militant development ideology maintain that, though education and human resource development are important factors, by themselves they are insufficient to effectively deal with the issues of poverty and under-development, for education alone will not combat the entrenched and often exploitative positions held by local power elites. For such NGOs, under-development is the result of the lack of development on the part of individuals, (that is, using their naturally endowed abilities and potentials to their fullest extent), as well as exploitative economic, social and political structures inherent within contemporary local communities. The development strategies adopted by second generation NGOs, even those that see the power of local elites to be an issue, are perceived to be simplistic, for they fail to take into account the power wielded by national and international institutions, which make the efforts of village development seem rather paltry in comparison.

10

Over the past decade, NGOs have once again began to question and re-evaluate the raison d'être of their approach to development. What Korten has classified as third generation NGOs have recognised that previous efforts by NGOs to achieve long-term development objectives have been limited. This has been explained by the fact that previous development efforts have benefited small pockets of communities or specifically defined groups, and that self-reliant development initiatives are unlikely to succeed without the continuous injection of outside capital that will assist long-term sustainability, Korten states that "A growing number of NGOs are coming to realise they need to exert greater leadership in addressing dysfunctional aspects of the policy and institutional setting of the villages and sectors within which they work. This means moving to a third generation strategy in which the focus is on facilitating sustainable changes in these setting on a regional or even national basis. The more fully the NGO embraces third generation programme strategies, the more it will find itself working in a catalytic, foundation-like role rather than a operational service delivery role, directing its attention to facilitating development by other organisations, both private and public, of the capacities, linkages and commitments required to address designated needs on a sustained basis" (16).

Korten further states that NGOs operating within third generation strategies will often work with governments, since the latter will command the resources that provide the infrastructure for service provision. Given this situation, the role of the NGO becomes one of influencing, but not of controlling the particular system (such as the health, educational or agricultural system). The underlying assumptions of development theory behind third generation NGOs is that the innate inertia that characterises many local communities is the result of the centralisation of economic resources that rarely, if ever, reaches the poor. Hence, the most appropriate development strategy is of a two-fold nature. First, to enhance the capacity of the poor in identifying their needs and aspirations, and secondly, through building alliances and partnerships with those elites who do hold power, with the objective of convincing them to adopt development strategies that meet the genuine needs of poor and marginalised groups. In describing the role played by third generation NGOs, Korten states that "The more fully the NGO embraces third generation programme strategies, the more it finds itself working in a catalytic, foundation-like role, rather than a service provider. It may find that it intervenes in complex national-scale institutional systems comprised of many organisations from both the public and private sectors. It must learn to strategically, positioning and repositioning its own limited resources where they will have the best prospect of shifting system dynamics in the desired direction" (15).

PEOPLE-CENTRED DEVELOPMENT AND PEOPLE'S MOVEMENTS

Korten has identified a fourth generation of NGOs, which focuses on people-centred development, and the institutional and capacity building of grassroots organisations (GROs), comprising of groups of beneficiaries of the services provided by the NGOs. These are synonymous with the people's organisations that have been distinguished from mainstream NGOs by Jenny Pearce (9). Fourth generation NGOs are closely associated with the "self-help groups" that have been established by the NGOs that were involved in fieldwork for my doctoral thesis on the provision of commuity-based disability services in South India.Furthermore, as will be demonstrated, the philosophy and ideology that underpins a people-centred approach to development has a great deal in common with the Frierian approach to education, social transformation, and the empowerment of poor and marginalised groups.

The three generations of NGOs described thus far rely on third parties to provide resources and other technical expertise from outside the local community to achieve development-oriented goals, irrespective of how development theory and the resultant operational practices and roles are conceptualised. Fourth generation NGOs fundamentally differ in this respect, for it is assumed that the requisite knowledge and skills required to solve developmentally-orientated problems actually reside within the local community. This assumption is the very reason for the people-centred approach to development. Given that such knowledge and expertise does reside within local communities, the function and the role of NGOs is to facilitate and act as a catalyst in enabling people within the local community to identify their developmental needs, and the strategies to fulfil them. Thus, the key institutions are people's movements as well as people's organisations. Theorists subscribing to people-centred development maintain that all development initiatives should be as decentralised as possible.

In contrast to other forms of organisations, (notably the private and public sector), social movements and people's organisations tend to be driven by an ideology and vision, rather than service provision or the profit motive. It is Korten's belief that "The power of people's movements has largely been ignored in the field of development. Attention has been focused on money rather than the social energy as the engine of development. The irony is that the surest way to kill a movement is to smother it with money"(15).

People's organisations, which form the backbone of people-centred development, tend to have three defining characteristics. First, they tend to be mutual benefit organisations, that serve the interests and benefits of their members. Secondly, they tend to have democratic as opposed to hierarchical structures, resulting in their leaders being directly accountable to the membership. Thirdly, people's organisations tend to be self-financing. Furthermore, the central belief is that these organisations are conduits for the redistribution of political and economic power previously held by elites. This notion is further emphasised by the assumption that an organisation has a greater possibility of achieving its aims and objectives if financial resources and operational decisions are placed in the hands of its beneficiaries. Other organisations, such as first, second and third generation NGOs have a tendency to serve their own organisation's interests in preference to those of the groups that they are supposed to serve. Commenting upon the function that people's organisations can potentially play within a given society, David Korten states that "People's organisations serve many functions in people-centred development. They are instruments for distributing power within society by strengthening the economic and political power of the previously marginalised. They are the training grounds for democratic leadership and the institutional building blocks of democratisation. They create demands for greater responsiveness to grassroot concerns, providing the collective bargaining power that can enable landless people, small farmers and urban squatters to negotiate on more equal terms with the representatives of government bureaucracies or wealthy private patrons or corporations" (15).

Warren Nyamugasira (17), in agreement with Korten, has cogently argued that there has indeed been a fundamental shift in the roles that NGOs have played within the development process over the past ten years. However, rather than viewing the changes within a generational framework, Nyamugasira maintains that there has been a division of labour between Northern and Southern-based NGOs, which has not resulted in the enhancement of the social, economic and political well-

being of the poor. In fact, it has been argued that those who are poor and marginalised have been significantly excluded from setting any aspect of the development agenda. In the aftermath of the 1980s, many northern-based NGOs made the strategic decision to move away from direct service provision to advocacy as the primary focus, with service provision being the preserve of southern-based NGOs. Hence the role of NGOs based in so-called "developed" countries has become that of a catalyst for social change, through seeking to influence attitudes, changing policies of the government and of the key decision-makers such as the IMF and the World Bank. In effect, such NGOs have taken on the mantle of "the role of the ambassadors of the world's poor". Furthermore "They see their mission as being to represent the political concerns of the poor, injecting the voice of the traditionally voiceless into international decision-making, facilitating the two-way flow of information, and helping to make the world's political and economic institutions more broadly accountable" (17).

The division of labour between northern and southern-based NGOs, in terms of advocacy and direct service provision respectively, is further based on the premise that southern-based NGOs, due to the fact that they are closer to the beneficiaries, will by definition facilitate greater "local empowerment". It is believed that indigenous NGOs will indeed have the comparative advantage in securing long-term and sustainable development, since they are in a position to hear and thereby represent the authentic voice of the poor. It is assumed that these NGOs will have a greater and more in-depth knowledge of the social, cultural, political context that characterise local communities, than international NGOs. However, this last point is indeed a contentious issue. Clement, states that "There is a danger of assuming that Southern NGOs necessarily speak for the poor and the marginalised people. This is a matter which is sometimes avoided out of politeness or fear of offending (Southern) NGO colleagues. Listening to those on the margins requires a stretch for anyone who has become part of the 'development set'.It is harder when based in the North, but even when working for an NGO in the South, there are many filters, barriers and distractions. How to genuinely listen and represent (as opposed to speaking for) different poor communities is a significant challenge for all NGOs. ... What seems to you to be our silence, our reticence, and our lack of purpose is really in fact our strength, our wisdom, and our knowledge" (Clement, personal communication, quoted in (17).

The above quotation highlights the fact that empowerment is a ongoing, continuous process, and has many characteristics which resonate with the principals and axioms of naturalistic inquiry (18). Similarly, commenting on the role of both government and NGOs within the South Asian context, Menike states that "Numerous programmes are initiated by governments and NGOs in developing countries, to 'empower' the Poor. ... When we look at these programmes, we get a feeling, whether initiated by governments or NGOs, (their programmes) are based on the false assumption that we, the Poor, do not know how to overcome our poverty and improve our condition; that we do not have the knowledge about the cause of our poverty and how to overcome it, and that we are lethargic and tend to accept our poverty as our fate¼ ...For us, all of this is quite hilarious. Those who plan their 'empowerment' interventions clearly do not understand our reality, our priorities, our wishes, our thought processes, our constraints and our needs" (19).

THE WAY FORWARD - PAULO FRIERE REVISITED: ADOPTING FRIERIAN TECHNIQUES OF SOCIAL TRANSFORMATION AND THE IMPLICATIONS FOR THE OPERATIONAL PRACTICES OF NGOS

Given that the effort of NGOs to make a significant contribution to the alleviation of poverty in the developing world, have not been very successful, and given the continuing impasse of "the development project" largely failing in their attempt to transform the lives of the poor and the oppressed, what hope is there that future development initiatives will be more successful? As has been argued throughout this chapter, it is maintained that there is indeed hope, particularly if Freirian strategies of social transformation are pursued, in conjunction with the people-centred development as advocated by David Korten of the People-Centred Development Forum. As will be demonstrated below, there is indeed a great deal of similarity between the approaches and ideologies adopted by Friere and Korten.

David Korten trenchantly argues, in agreement with many other development theorists, that the development agenda of the past 40 years has been dominated by the belief that the key to long-term sustainable development is through the pursuance of strategies that promote economic growth. In reality, such policies have in fact failed to benefit the poor. In his critique of conventional development thought, Korten states that "Guided in their development by the growth-centred vision, the institutions of our society are geared to producing growth for the benefit of the few without regard to social or environmental consequences. This is the heart of the failure of these institutions to ensure justice, sustainability and inclusiveness¼. Growth is important, but it must be a new kind, appropriate to our condition. For this reason we must address ourselves to transformation as the development priority of the1990s" (15).

Korten defines the rationale of development thus, "Development is a process by which the members of a society increase their personal and institutional capacities to mobilise and manage resources to produce sustainable and justly distributed improvements in their quality of their life consistent with their own aspirations" (15).

Korten is not alone in holding that a prerequisite for effective development is the adoption of a people-centred approach and that priorities for the development agenda are set by those who will benefit from such services. John Clark states that "At its broadest, 'development' means quite simply 'improving the society'. Since society comprises no more than the people it is made up of, development therefore means 'enabling people to achieve their aspirations'. Development is not a commodity to be measured by GNP statistics. It is a process of change that enables people to take charge of their own destinies and realise their full potential. It requires building up in the people the confidence, skills, assets and freedoms necessary to achieve this goal" (20).

In a similar vein, Robert Chambers has argued that the "development project" has largely failed the poor, primarily because in the past, undue emphasis has been placed upon the role of professionals, who are invariably expatriates. Such emphasis tends to marginalise and exclude the voices of the poor, since privilege and credence are given to the values and modes of thought that are traditionally associated with western-based professional culture. These tend to be characterised by an inherent bias towards conservatism, on a linear conception of progress, and by an undue emphasis placed upon specialisation, precision and quantifiable measurement. Emphasis and privilege

are given to the "core" or the "first", while those in the "periphery" or "last" are to all intents and purposes, marginalised and excluded. In an attempt to present a convincing counter-argument of this historically dominant hegemony, Chambers states that "The normative level is simple: development should be people-centred, people come before things; and the poorest people before the less poor.   It is right to put the last first, to give priority to those who are more deprived - the poor, physically weak, vulnerable, isolated and helpless, and to help them change these conditions. It is also right to enable them to identify and demand what they want   and need. At the conceptual level, development is not a progress in a single direction, but a process of continuous adaptation, problem-solving and opportunity - exploiting under pressure. ... Development is not movement towards a fixed goal but a   continuous adaptation to maximise well-being in changing conditions (21).

That the vast majority of NGOs have not been successful in fulfilling their mandate in poverty reduction and have in fact rarely involved the poor and marginalised people (not least those with disabilities), in setting development priorities, surely begs the question why should this be the case. The gulf in the rhetoric and practice of development, that are founded in the principles of people-centred development and Freirian theories of social transformation and change, remains as wide as ever. It also gives rise to the question of what practical strategies and operational practices should be adopted by NGOs in order to transform such rhetorical statements into reality? Attempts to answer both of these questions exist in the writings of Hope and Timmel (22), who have produced a set of training manuals regarding social transformation specifically written for community workers, as well as the work of Robert Chambers.

Hope and Timmel, in the construction of their training manuals, have drawn heavily upon the principles of social transformation and education, adopted by Paulo Freire. In addition, fundamental to their approach is the belief that the unfettered operation of the market and structural adjustment policies as propagated by institutions as the World Bank have largely failed the poor. What is called for is a radical transformation in the social, economic, political and legal structures upon which societies in the developing world are premised, founded upon the principles of "participatory democracy". Hence, Hope and Timmel state that "We need a system based on participatory democracy at the political level, and   economic democracy built on a deep sense of 'the common good'. We have to recognise that in the so-called 'free world', only the strong are 'free'. ... The 'free market' is extolled as the only system for creating wealth. It is true that capitalism has created wealth in a way that socialism has generally failed to do, but without limits and socially responsible legislation, this wealth has not generally 'trickled down'. [The process of transformation] involves creating new education systems, new patterns of health care, new legal systems as well as a framework for the economy" (22).

Hope and Timmel further maintain that some societies have experienced a high degree of participatory democracy, usually occurring after some historic moment in the life of a particular society. However, it is maintained that when high levels of participatory democracy do occur, structures are constructed that institutionalise such practices. Failure to do so will result in the withering away of such democracy.

Friere has argued that development and education, perceived in terms of increased self-consciousness, are inexorably linked, and that the problem-based method of education is indeed a

pre-requisite for the liberation and oppression of poor and marginalised groups. The ultimate goal of such a process is to enable those who are poor and marginalised to fulfil their creative potentials. Again, parallels can be drawn with the dynamics of social change and human nature that were discussed, particularly with regard to the theoretical framework constructed by Cole (23). Within this context, Hope and Timmel state that "Development and education are first about liberating people from all that holds them back from a full human life. Ultimately, development and education are about transforming society. Development, liberation and transformation are all aspects of the same process" (22).

The preceding arguments will have profound impacts on the manner in which NGOs perceive their role within development process, which will inevitably affect operational practice. It is argued that the role of the development worker is two-fold. First, to encourage and facilitate the local community to claim their rightful share of government resources. This will involve encouraging the community to become aware of what government services are available to them, as well as the fostering and building of alliances with other community members. Secondly, to act as catalysts to enable the local community to innovate and establish mechanisms of meeting their own needs. Of fundamental importance to this objective is to explore, through the application of the Freirian techniques of education, (i.e. the dynamic, and interactive process of reflection, critical analysis, resulting in action), and to identify alternative sources of funding to meet these needs and aspirations.

These two objectives will also have a profound impact upon the manner in which NGO professionals operate in the daily practice with beneficiaries. The implications and ramifications for the role of the professional vis-a-vis their role in the development process is cogently argued by Freire in the following manner. "Some of the dominant class join the oppressed in their struggle for liberation. Theirs is a fundamental role and has been so throughout the history of the struggle. However, as they move to the side of the exploited they almost always bring with them the marks of their origin. Their prejudices include a lack of confidence in the people's ability to think, to want, and to know. So they run the risk of falling into a type of generosity as harmful as their oppressors. Though they desire to transform the unjust order, they believe that they must be the executors of this transformation ... They talk about people but they do not trust them; and trusting the people is the indispensable to revolutionary change. A real humanist can be identified more by his trust in the people, which engages him in their struggle, than by a thousand actions in their favour, but without their trust" (7).

Robert Chambers has made some practical suggestions, both for professionals working in the field and also at an institutional level, on how development can indeed become more people-centred, thereby taking the knowledge and values of the poor and marginalised into account when planning, managing and evaluating development programmes. Chambers attributes the apparent failure of the development industry to inappropriate thought processes and values held by western development practitioners. What is called for is a re-evaluation of these value systems that have maintained hegemony throughout the development enterprise during the past 40 years. Fundamental to this reorientation is for professionals to genuinely believe in the validity and inherent worth of locally-generated knowledge. This knowledge base may or may not resonate with western conceptions of rationality. It is imperative that professionals "hand the stick over" to the potential beneficiaries. In delineating the characteristics of the professional that genuinely espouses a "bottom-up" people-

centred approach to development, Chambers states that "The challenge can be expressed as the paragon of the new professional. She is committed to the poor and weak, and to enabling them to gain more of what they want and need. She is democratic and participatory in management style; she is a good listener; embraces error and believes in falling forwards; finds pleasure in enabling others to take initiatives; monitors and controls only a core minimum of standards and activities; is not threatened by the unforeseeable; does not demand targets for disbursements and achievements; abjures punitive management; devolves authority, expecting her staff to use their own best judgement at all times; gives priority to the front-line; and rewards honesty. For her, watch-words are truth, trust and diversity (24).

At the institutional level, Chambers makes six specific recommendations. First, the NGO or government funding agency should be committed to ensuring the long-term sustainability of the development initiative, and should not be bound by necessarily expecting to see "results" within the initial three-year funding cycle. Thus there should be a commitment to long-term financial continuity. Secondly, NGOs should be encouraged to establish a network of allies with other organisations working in the same field or using the same approaches. The rationale here is to facilitate information sharing. Thirdly, it is recommended the development initiatives should start in a small way and grow incrementally. Fourthly, there should be a large degree of flexibility, so that the project has the ability to evolve according to the principles and axioms espoused by participatory development. Fifthly, it is imperative to encourage and support the development of grass-roots staff. This further enhances the participatory nature of the project, as it is often the case that grass-roots staff have gained the confidence of the poor, and therefore have a more nuanced understanding of their needs and aspirations. Sixthly and lastly, Chambers recommends that expansion and growth of the project should be grounded upon the experience that has been acquired at the grass-roots level (25).

The foregoing discussion of the challenges, pitfalls and failures of NGOs in the pursuance of their overall stated objectives of poverty alleviation and the empowerment/social transformation of poor, oppressed and marginalised groups throughout the developing world, point to the following conclusions. First, long-term "sustainable development" will only be effective when the priorities for the development agenda are set by the community, particularly those who will potentially benefit from services. Secondly, the role of NGOs is that of catalysts and facilitators in assisting those who are poor and subject to oppression, in identifying their needs and aspirations, and consequently devising strategies to realise them. Thirdly, and arising from the above, the priorities for development objectives cannot be devised and orchestrated by exogenous agencies, such as NGOs - they must come from the grassroots.

The necessity for a "bottom-up", people-centred approach to development is now beginning to be recognised by the World Bank. In a "first-cut" draft of the World Bank's "World Development Report 2000/1", which has a focus on attacking poverty, a great deal of emphasis is placed upon the multi-dimensionality of poverty and the imperative need to foster participation. The following excerpts from the draft summary of the report provide a feeling for the genre of the proposed strategy. The report states "In examining the nature of poverty, it is incumbent upon us to start with the voices of the poor themselves. These voices tell us that poverty as perceived by the poor is multi-dimensional, going well beyond monetary income and consumption to include education and health, and beyond these to include risk and vulnerability and a sense of voicelessness and powerlessness" "While there are legitimate differences across societies and across communities on what constitutes poverty,

there are enough commonalities across these, as captured in international declarations and in the voices of the poor themselves, to provide the core objectives for a strategy attacking poverty. These can be classified under the categories of empowerment, security and opportunity." "Voicelessness and powerlessness are intimately linked to material poverty, but they also afflict groups in society such as women and ethnic minorities. An inability to influence decisions which affect their lives, at the local and the national level, is an independent feature of poverty, but also helps to explain outcomes in other dimensions such as health or education" (26).

EMPOWERMENT, "SOCIAL EXCLUSION" AND THE ROLE OF NGOS

NGOs can effectively play a part in the empowerment and social transformation of disabled people. "Social exclusion", was a term originally used by French scholars with reference to poverty alleviation and lack of participation, and both concepts are of prime interest to the disability movement. Arjan de Haan (27) has found the concept of social exclusion to be useful in contemporary discourse within the field of development for two reasons, both of which have direct relevance to the issue of disability. First, social exclusion as a concept perceives deprivation and poverty as being multi-dimensional in character, not being exclusively concerned with the level of income per se, but with other factors as well. Thus, poverty and deprivation are perceived in a multi-dimensional manner, that encompasses additional factors which include the inability to participate within the mainstream of society, the inability and resultant precariousness of securing employment, and the inaccessibility to basic education and health care. Thus, the social exclusion debates have broadened the parameters of the discussion regarding poverty alleviation, which was traditionally solely concerned with material well-being. This debate is now seen in more broader terms, encompassing "participation, autonomy and self-respect" (28). There has been a further composite shift away from debates exclusively concerned with employment towards the more holistic notion of livelihoods. In recognition of these trends, Robert Chambers states that "The raw reality for the majority of the very poor in the world, in the South, and either in rural areas or in the informal urban sector, is not one of jobs in the Northern, industrial sense. It is a reality of diverse livelihoods with multiple activities be different family members at different times, exploiting varied and changing resources and opportunities" (25).

Secondly, rather than being a static entity, the concept of social exclusion focuses upon the dynamic processes that are inherent within the mechanisms and institutions that systematically exclude those who are poor and marginalised from mainstream involvement in society. It is therefore apparent that social exclusion is linked to a number of concepts that have already been developed vis-a-vis disability studies and naturalistic inquiry. Hence, it is argued by the disability movement that disabled people are systematically excluded from contemporary society by the pejorative social attitudes that they encounter, as well as the inhospitable physical environment in which they reside.

The genesis of the concept of social exclusion is derived from France, and has been influential in the development of social policy in that country during the 1980s. Many different definitions and interpretations have been given to the concept, with de Haan beginning his article quoting the one given by the European Foundation as "... a rupture of social bonds - a process through which individuals or groups are wholly or partially excluded from participation in the society in which they live" (29).

Other scholars have defined the concept in a multiplicity of ways, and as in the case with most concepts in development, and in alignment with the precepts of naturalistic inquiry, each is dependent upon how the process of social change is understood. Hilary Silver (30), quoted by de Haan, has devised a tripartite paradigm to explain the different approaches to social exclusion. Notwithstanding the caveat that any schema is inevitably reductionist, such an approach can indeed be instructive. The manner in which concepts such as social exclusion are theoretically understood have profound practical significance, for different theoretical understandings imply and give rise to different policy prescriptions and outcomes. Silver's schema of social exclusion is as follows.

a) The solidarity paradigm perceives social exclusion as a rupture in the social bonds that exist between an individual and the society in which he lives, and is related to both the cultural and moral spheres of life. Those who are poor and marginalised are considered to be outsiders. This conception of social exclusion implies an emphasis upon nationalsolidarity, politicalrightsandduties.

b) The specialisation paradigm, derived from the Hobsian notion of individual liberalism, implies that the individual has the ability to cross boundaries of social stratification through the process of social and economic mobility. Furthermore, the notion of citizenship implies a contractual exchange of rights and obligations between individuals within a given society. According to this paradigm, social exclusion is perceived in terms of discrimination, which is the result of unenforced social and political rights, as well as market failure.

c) The monopoly paradigm views social exclusion as a consequence of the establishment of group monopolies within a society which is characterised by hierarchical power relations. Those who hold social, economic and political power actively restrict the access of others to such powers. In contrast to the specialisation paradigm, the distinction between group identity and inequality overlap. These inequalities are mitigated by "social democratic citizenship", which when implemented, will result in those who have been systematically excluded being able to actively participate in the contemporary society in which they live.

Irrespective of which particular paradigm of social exclusion one adheres to, de Haan maintains that all three have the following common defining characteristics. First, social exclusion is seen as the juxtaposition of social integration. Thus emphasis is placed upon the importance of all members of any society being part of a cohesive entity. Secondly, as has already been mentioned above, social exclusion is considered to be a multi-dimensional construct, which has relevance and the potential for poignant analysis in the political, social and economic spheres of people's lives. Thirdly, social exclusion is perceived as a process, in which the dynamics of mechanisms and institutions exclude the poor and marginalised. Hence, attention is focused upon the manner in which the institutions within society either foster or constrain it.

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DISABILITY AND CULTURE

Peter Coleridge

ABSTRACT

There are two important reasons for including a chapter on culture in a book for community based rehabilitaton (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.[1] 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.

[1] 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. [2]

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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[2]   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.[3] 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.[4] 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.'[5] 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.'[6] 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 ethno-centrism. 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

[3]   Deborah Eade and Susanne Williams 1995: *'The Oxfam Handbook of Development and Relief'*. Oxfam, Oxford.

[4]   UNESCO 1996

[5]   Geertz 1975: '*The Interpretation of Cultures'*

[6]   UNESCO 1995: *'The Cultural Dimension Of Development'*. Geneva

arises from, and is resolved in, a social context which contains mediating factors for god or ill.'[7] 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.'[8] 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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[7]   Bracken and Petty 1998: *'Rethinking the Trauma of War'* Save the Children, London. Chapter by Derek Summerfield: *'The social experiences of war.'*

[8]   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.[9] 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.[10] 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.[11] 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.[12]

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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[9]   UNESCO 1995

[10]   UNESCO 1996

[11]   UNESCO 1996

[12]   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.[13] 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.[14]

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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[13]   Ingstad and Whyte 1995

[14]   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.' [15] 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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[15]   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',[16] 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*'[17] (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.

[16] Tamas, Andy 1996: *'Spirituality and Development. Concepts and Categories. Dialogue on Spirituality in Sustainable Development'.* Canadian International Development Agency. Ottawa

[17] UNDP 1993: *Afghanistan Rehabilitation Strategy. Action Plan for Immediate Rehabilitation. Volume 1: 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 grassroot 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 grassroot 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'.[18]

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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[18]   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.'[19] 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 though 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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[19]   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'.[20] 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.[21] 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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[20]   CDAP, Minutes of staff seminar on cultural values, 2 February 1998.

[21]   Grima, Benedicte (1993): *'The Performance of Emotion among Paxtun Women'*. OUP. Karachi

One senior worker [22] 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.[23] 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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[22]   Wahdat, Hayatullah (1998): Mission Report to Wardak and Ghazni January 1998. CDAP internal report.

[23]   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.[24]

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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[24]   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.[25] 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.[26]

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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[25]   Tamas 1996

[26]   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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COMMUNITY PARTICIPATION: UNCOVERING ITS MEANINGS IN CBR

William Boyce, Catherine Lysack

ABSTRACT

The essential problem for community participation in community based rehabilitation (CBR) is that of defining the exact 'community' to be involved and of determining their level and method of involvement. This issue of community identification is common to most spheres of community work, however in the CBR field there are vastly different interests, for example, persons with disabilities, family members, professionals, bureaucrats, who have in turn widely varying needs, such as independence, support, management, resource development, and who then require unique methods of mobilisation, like advocacy, self-help, training, awareness raising). Perhaps the most unique challenge for CBR is in addressing the breadth of these community interests, needs, and mobilisation methods. This chapter aims to assist in identifying the opportunities and constraints which CBR faces with respect to community participation. The critical lessons from abroad can be summarised as follows: Community diversity reminds us of the disparate interests of communities and that expectations of participation can overburden specific segments of the community, especially women. Examination of the process of eliciting community needs highlights several other problems around the determination of the meaning of disability and what counts as needs. We have learned that the definition of disability is culturally constructed, as are its causes and proposed remediation. We also know that disability may not be a community priority, and what is in the best interests of individual disabled persons may not be in the best interests of the community as a whole. Finally, critical examination of community mobilisation strategies reveals that projects grounded in local participation can still be rejected. Rehabilitation may be believed to be a government responsibility, or CBR may be seen as a second-rate service in comparison to professional and institutional services. The authors show that community diversity, needs identification, and mobilisation strategies have represented considerable challenges to the development of community participation in CBR. Those interested in CBR should take note of these experiences and adapt their plans accordingly. It is asserted that knowing the communities in which we live and work is crucial to this task.

INTRODUCTION

The essential problem for community participation in CBR is that of defining the exact 'community' to be involved and of determining their level and method of involvement. This issue of community identification is common to most spheres of community work, however in the CBR field there are vastly different interests (for example, persons with disabilities, family members, professionals, bureaucrats), who have in turn widely varying needs (independence, support, management, resource development), and who then require unique methods of mobilisation (advocacy, self-help, training, awareness raising). Perhaps the most unique challenge for CBR is in addressing the breadth of these community interests, needs, and mobilisation methods.

It is worth reviewing the development of CBR to understand its particular challenge for community participation. The concept of CBR emerged, in tandem with primary health care (PHC), in the 1970s as rehabilitation was recognised as an essential part of the movement toward community participation in health (1). Like PHC, CBR was promoted initially as a local grassroots initiative to bridge the gap between an increasing "burden" of disability in developing countries and the scarcity of professional and financial resources. After some preliminary success in smaller projects established by non-governmental organisations, CBR was formally endorsed by the World Health Organisation (WHO) in 1978, and larger scale projects were established in Africa, India, and south east Asia. Special publications such as WHO's CBR manual *Training in the Community for People with Disabilities* were commissioned and disseminated broadly (2, 3). The intention of WHO's original CBR model was efficient delivery of "low-tech" rehabilitation services. Unfortunately, the results of this effort were often top-down strategies that rarely incorporated community members in CBR planning, and only marginally involved them in programme implementation (4, 5).

In the late 1980s and early 1990s, there was a dramatic shift internationally which saw the human rights of people with disabilities emerge as a community development issue. This shift, sponsored by international aid agencies and rehabilitation organisations, arose from a realisation that approaches like the original CBR models encouraged passivity among the population, not community participation. The United Nations (UN) further promoted the ideal of participation of disabled people by proclaiming 1983 to 1992 as the International Decade of Disabled Persons. Furthermore, the UN afforded the notion of CBR global recognition in its report entitled the *World Programme of Action Concerning Disabled People* (6). Finally, a *Joint Position Paper on CBR*, issued by a trio of multilateral agencies in 1994, proclaimed that CBR was "... a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities" (7). This document stated that a central goal of CBR in a community development model was to build genuine partnerships between rehabilitation personnel, disabled people, and their families, and to improve community attitudes toward people with disabilities. In addition, through the translation of clinical and technological knowledge into locally relevant information and selfhelp skills, people with disabilities and their communities were to be assisted in taking control of their health and in developing locally sustainable solutions to disability problems. In short, the ultimate goal of CBR became the improvement of the everyday lives of disabled people through basic medical rehabilitation, social inclusion, and political equality.

Thus, it is just recently that issues of rehabilitation have been addressed from a community development perspective. Understandably, the field of CBR is only beginning to learn from the experiences of other community development programmes in poverty, childhood, and women's issues. In our view, however, the international CBR experience does not fully achieve the ideals of a community development approach and requires critical re-thinking by its proponents. Appreciation of basic community development issues such as community diversity, community needs, and community mobilisation strategies are crucial. Common to all three issues is the need to understand the concept of community.

Communities, regions, and nations that consist of diverse multicultural, multiclass groups may not only understand disability differently, but also conceive of disability services in different ways. When this is the case, identification of disability needs and techniques to mobilise community participation in rehabilitation projects are affected as well. Thus, before investigating the specific

components of community participation in CBR, one must be clear about the nature and meaning of community in one's own setting.

THE MEANINGS OF COMMUNITY PARTICIPATION

Community participation is a vast field of study which has been investigated in many sectors such as health, environment, governance, international rural development, and urban renewal. Community participation has become a central value and strategy in these sectors for a variety of reasons including efficiency, equity, and social cohesiveness (8). The phenomenon of community participation has been the subject of lengthy debates on its historical origin, its theoretical basis, and its practical application (9, 10, 11). There is general consensus that primary needs in the development of community participation theory are: to clarify concepts used to discuss participation; to delineate the factors believed to have an impact on participation; and to develop comprehensive methodologies for gathering information about participation which can be applied practically in a variety of settings (12, 13, 14).

This conceptual review begins by describing current definitions of community, before proceeding to more contentious issues of participation.

Definitions of Community

There are two ancient roots to the English word community - the Latin "communitas", meaning common; and the older Greek biocenosis, which is an ecological term meaning "a group of integrated and interdependent plants and animals" (15).

The origins of the modern notion of community are traced to European social philosophers in the late eighteenth century. These scholars noted that the growth of capitalism, industrialisation, and urbanisation altered the relationship between humans and society in a fundamental way, resulting in the loss of inter-dependence (16). Since then, sociological research has attempted to categorise communities empirically, but with only limited success (17). Currently, the term community has two general meanings. The first refers to social ideals of solidarity, sharing, and consensus. This is a relatively recent usage. The second meaning of community refers to actual groupings of people. This is the older and more common usage, but it is also idealist in many ways (15).

Community groupings are defined usually through affinity or through geography. Affinity groups share human characteristics of ethnicity, gender, age, disablement, and sexual orientation. Occasionally, affinity includes socially defined characteristics such as education, social class, and political affiliation, but this usage is less common. It is generally the case that, the greater affinity or shared characteristics present in a group, the more cohesive is its members' sense of community (18).

In contrast, geographically based groups use physical location to define communities and assume that physical proximity provides a set of material and social conditions which result in shared interests. Affinity and geography sometimes coexist to strengthen a community's sense of shared interests. This is not always so, however, since many geographic communities differ markedly on many social affinity characteristics such as wealth and education. Nonetheless, geography can provide a powerful incentive for individuals to assume a shared set of interests since physical proximity increases the likelihood of social interaction (19).

Of interest to CBR, community has also been defined in terms of voluntary organisations, that is, groups which have recognised their affinity or geographic relationships and which value these enough to join together formally (20). In this sense, community implies a 'community of organisations', or formal associations, and the emphasis on individual community members decreases.

Cohen (19) suggests that two central ideas are found in the notion of community. One of these is aggregational and the other is relational. The former idea involves the aggregation, or grouping together, of people who have something in common. The latter idea, however, expresses the opposition of one community in relation to others that are different. This viewpoint contradicts ideal notions of community as being non-conflictual and is supported by numerous studies which demonstrate heterogeneity and conflict in communities (17, 8, 21,22).

Definitions of Participation

Participation has a variety of meanings, focused on sharing in activities by entitlement or right, which derive from basic constructs of democratic theory (23). The notion of participation is used widely, often with an imprecise or no definition, to include almost any situation in which some minimal amount of interaction takes place. Such interaction can imply little more than the presence of a particular individual at a group activity. Pateman (24) suggests that suitable definitions of participation must include four elements - participation by someone, participation with someone, participation in something, and participation for some purpose.

Participation excludes the following situations: where an individual merely takes part in a group activity; where an individual is merely given information on a decision affecting him/her before it is executed; or, where an individual is present at a meeting but has no influence.

A definition of community participation for use in CBR is proposed:

Community participation is the organisation of activities by groups of persons who have disabilities (or their family members/friends), in conjunction with others who do not, to increase their ability to influence social conditions, and in doing so to improve their disability situations.

This definition reinforces the central issue of power in community participation. The outcome of participation is influence over resources and programs by disabled persons. The community is not seen as a cohesive whole with mutual interests, but rather as a constellation of distinct advantaged and disadvantaged groups. This definition is consistent with the principles of community development to which CBR supposedly adheres.

Concepts of Community Participation

Having defined community and participation, there are still two central and linked conceptual questions in community participation:

- Is community participation a means or an end?

- What are the purposes of participation? (See Figure 1).

Figure 1. Concepts of the Community Participation Process

Purpose	Means	Short Term End	Long Term End
Contribution	Instrumental → Participation	Improved Common Benefits	
Organisation Empowerment		Transformational → Participation	Social Equity and Self Management

Participation, like other social phenomena such as education and employment, can be conceptualised as both a means and an end in itself. When understood as a means, *(instrumental participation)* the process of involvement achieves some predetermined common social goal or objective, such as the establishment of a technical aids centre. Participation becomes a way of utilising the existing physical, economic, and social resources of people to attain a valued outcome or benefit, and is also a means to achieving efficiency in project management. This form of community participation tends to be short term and does not necessarily lead to an increased capacity of individual persons to participate.

In contrast, when understood as an end *(transformational participation)* a longer term process develops and strengthens the self-capabilities of people to be involved in social development. An example of this style of participation in CBR may be through the development of a disability policy paper. Participation in this sense promotes goals such as social justice, equity, and democracy (25).

The ends and means distinction is linked to the issue of purpose in community participation. Currently, there are three broad purposes, or functions, of community participation (Figure 1).

1. Community participation as 'contribution' is the voluntary donation of people's resources to a common good or goal (participation as an instrumental means). This purpose values the efficiency obtained in meeting project objectives through people's own efforts. It implies that community interests are cohesive and that internal, community conflicts can be resolved through democratic processes. Participation as 'contribution' is intended to be initiated by the authorities in a top-down fashion and does not necessarily imply that control and direction of activities pass to the local people (26). Any barriers to participation are commonly addressed by educational and motivational strategies.

2. Community participation as 'organisation' is the process of organising or arranging people in common activities (participation as both means and end). In this purpose of participation, the origin and form of the organisation are crucial. Some community organisations are conceived and introduced by external agents such as the government bureaucracy, while others emerge and take form from the process of community members' own involvement (27). In either case, this purpose of participation values the process of organisational development to achieve social integration of disabled individuals, group cohesiveness, and common objectives (24). Any barriers to participation are believed to be derived from operational problems and are usually addressed by technical and resource mobilisation strategies.

3. Community participation as 'empowerment' is a more recent purpose and implies both the development of management skills in local people and the ability to make decisions which affect their lives (participation as a transformational end). Empowerment assumes that people have a right to self-organise and that internal conflicts between social groups are able to be resolved at the local level (28). Rifkin (21) identifies the core concern: "To address the issue of participation, is to address the issue of power" (p.243). This empowerment purpose of participation acknowledges the need for community members to exercise power and values the social equity which is achieved when this happens. Any barriers to participation are believed to derive from social conflict and are often addressed through compromise on conflicting policies or by removal of social barriers through political reform (14,22).

Unfortunately, these different purposes of participation are often not clarified in project planning, thus creating the potential for the rhetoric of 'instrumental participation' to mask the maintenance of inequality in community activities (22). In practice, community participation activities often emphasise more than one purpose, although not often all three. Oakley (13) suggests that a broad distinction can be drawn between projects which emphasise the purpose of participation as 'contribution' and those which focus on the purpose of participation as 'empowerment'.

In many development sectors, the purpose of community participation is claimed to be 'empowerment' of disadvantaged groups, such as disabled persons. This implies that there will be a transformational phenomenon influencing the process of community decision-making. If so, there are a number of implicit assumptions (29,30, 12). First, there should be a basic right of disabled persons to participate and the objective of participation should be to introduce change in social conditions. Second, active participation of disabled persons should improve relationships between them and other community members, and thus reduce their alienation and stigma. Third, through participation, disability groups should gain access to resources and positions of influence. Finally, participation should result in attitudinal changes towards disability in community members, organisations, and society at large.

The theme of participation for disabled persons has recently emerges as a major concept in disability categorisation. In contrast to the initial medically-oriented categories of the International Classification of Impairment, Disability, and Handicaps (ICIDH), the new categories address impairment, activities, and participation (31). This shift suggests not only a more positive set of disablement concepts, but also a clear challenge to clarify the elements of participation. However, we must also be aware that WHO's focus is on assessing and classifying the participation of individuals, and not the participation of communities which are crucial to the success of CBR projects.

COMMUNITY PARTICIPATION IN CBR

Few studies exist of community participation in disability and rehabilitation (32). This critique will also focus on the area of health as a close comparison of community participation mechanisms and dynamics.

Contemporary types of community participation in health and social development activities can be organised into three strata and analysed across a number of features (purpose, benefits or motivation, opportunity, control, and perceived effects) (33, 34, 35, 36, 37, 38, 39) (Table 1).

Table 1. Types of Participation in Disability Programmes

FEATURE	MASS PARTICIPATION	TRADITIONAL VOLUNTARISM	SELF-HELP/ ADVOCACY
Purpose(s) of Participation	Contribution	Contribution Organisation	Empowerment Organisation
Primary benefits or motivation	To benefit oneself and one's wider community	To benefit another group	To benefit oneself and one's group
Opportunity	All can participate in theory. In practice, many do not and some are excluded	Elite members with extra resources	Disadvantaged members, need support
Control	By organisers	By volunteers and organisers	By disadvantaged and organisers
Perceived effects	Efficiency in achieving goals - instrumental -means to an end	Efficiency,Equity of situations and groups	Equity, Involvement - transformation- end in itself
Examples	Immunisation programsDisability campsInternational Disability Day	Local CBR SupervisorsLocal disability committeesCharitable fund raising	Self-help groupsAdvocacy groupsSupport groups for disabled personsParents' groups

Proponents of 'Mass Participation' advocate the participation of everyone in improving the health of the community through immunisation programs and disability camps. In national disability programs, the involvement of virtually all sectors of society is advocated in awareness campaigns such as International Disability Day. This aim, however, is at odds with the widely observed phenomenon of non-participation by the majority of community members, both disabled and non-disabled. 'Traditional Voluntarism' is another type of participation which has extensive roots in most societies. Altruistic in philosophy and often focused on target groups such as disabled persons, voluntarism alone does not allow a transformational process nor an empowerment experience for disadvantaged persons. Finally, there are 'Self-Help and Advocacy' types of participation. Primarily small scale in design, these approaches aim to balance their limited numbers of participants with a wider impact due to transformational processes and to public advocacy.

Numerous contradictions have been noted about community participation in health development projects (40). For example, many projects utilise forms of community 'health education' which emphasise personal behaviour change alone and do not address social determinants of health and disability, such as poverty. Most evaluations of health development programs assign minor importance to community participation, or simply count the number of community members who are involved in program activities (41). In explaining problems in community participation in health promotion projects, analysts have tended to criticise the motivations of individual community members, or the negotiation process between different interests, as being deficient rather than examining the basic organisation and structures which inhibit or support the process.

Farrant (42) points out that participation is supposed to be a key strategy in health development but there is little resource support for it in practice. Health and rehabilitation development projects are often understaffed and limited in their funding which preclude public involvement in needs identification, skill development, and ongoing participatory activities.

Community members are supposed to be central in participatory strategies, but competition between more powerful professional and bureaucratic interests often marginalises the community in health development (43). Similarly, community experience is claimed to be the primary basis for planning projects, but scientifically based knowledge is often given more credibility by funders (44).

On a state level, Navarro (45) notes that there is a contradiction in the state's advocacy of local autonomy through community development while maintaining centralised, bureaucratic planning of health and rehabilitation programs. At the local level, there is a parallel contradiction in the use of the rhetoric of empowerment without an understanding of power relations in the community (42).

Overall, the geographical and relational dimensions of community, coupled with its positive interpretation, renders the term extremely useful to a multitude of interest groups. Cooptation of the term 'community' happens at national and international levels and implicates academic, service, and advocacy organisations. This practice frequently leads to these bureaucracies defining what constitutes a community, how it should act, and ultimately allocating resources based on these definitions. This tendency to bureaucratise community development is fundamentally opposed to the need for individuals to define themselves voluntarily in terms of shared location or interests. Furthermore, the strong emotional connotations of community may pull local people into alliances they might not otherwise support.

If the meaning of the term can be so manipulated, how are we to recognise genuine community participation? When is the language of community used to mask deep divisions between groups? When is community simply used as a rhetorical device to promote the status quo? These are some of the questions which can be answered through close scrutiny of the successes and failures of international CBR programmes. We now turn to the basic social issues which community participation in CBR must address.

COMMUNITY DIVERSITY

An uncritical embrace of community rhetoric assumes that 'natural communities' exist and consist of harmonious collections of individuals, mutually supportive of one another, and committed

to communal responsibility (46). The international community development experience, however, has clearly demonstrated that communities are very diverse and often tumultuous places (47, 22). There are frequently vast differences within and between communities with respect to ethnicity, age, gender, and socio-economic status which then create problems in the co-ordination of services (48, 49). Vested interests in communities and power structures that permit access to communal goods for some people, while systematically denying such benefits to others, also threaten community development success (50, 51). Additionally, because of a variety of political and developmental trends (changes in land tenure and usage, migrant labour, urbanisation, wars and conflicts leading to large-scale refugee and displaced populations), the cohesive 'traditional' community, may be fast disappearing (52).

Recent analysis of the international disability context suggests that the positive language of community obscures the diversity that is inherent in disability settings (53). Investigating community diversity is imperative for CBR, otherwise neglect of its disparate factions and their contentious needs may derail attempts to mobilise community action around disability. Furthermore, ignoring community diversity risks overburdening particular segments of the population active in CBR, and risks misjudging levels of commitment to a CBR approach.

The first lesson which one can take from the international experience is the need to carefully assess the capacity of community groups to become involved in CBR implementation. When initiatives focus on the poor, the disabled, or other disadvantaged populations, utmost care must be taken so that the burden of organising change is not placed solely on disadvantaged groups. There are important costs involved in participatory activities, including personal time and out-of-pocket expenditures for travel. This has real and profound implications for participation, particularly for women who are the traditional caregivers of disabled people (54). Unless participation is carefully crafted and monitored to take these issues into account, few may be willing to be actively involved in CBR.

The second lesson to be learned about community diversity relates to the matter of disparate interests. The international experience has shown that a powerful vested interest can control the local health agenda and "usurp the resources of development in its own interests, rather than sharing the fruits of development with the deprived and neglected sector of local communities" (55). In such cases, the centralised control of medical professionals and governments is simply replaced by the localised control of powerful community interests (56, 48). If one of the aims of CBR is to address the disability needs of individuals who are not reached by institutional rehabilitation in urban centres, then it is imperative that CBR proponents recognise the diversity of these communities and find ways of including their most marginalised and disenfranchised segments (57). Once the fundamental diversity of communities is recognised, steps to determine the disability-related needs of communities can proceed with assurance that the breadth of community concerns are represented fairly.

COMMUNITY NEEDS

One of the issues to be examined in the area of needs identification is the community's understanding of disability. International experience has shown that determining who is, and who is not, disabled is not at all straightforward. Ingstad and Whyte (58) have described a tremendous

variation between countries and communities as to what constitutes 'disability'. For example, Lysack (59) reports how mental impairments such as mild learning disabilities are simply not recognised as problems by local people, including rehabilitation workers, in many parts of rural Indonesia. The same is true for physical impairments like limb deformities. The label 'disabled' in Javanese society is attached only when people are unable to perform the social tasks common in their communities. Thus, what is considered 'normal' with regard to individual functioning depends, for example, on age and gender but is also highly dependent upon the society in which these norms are generated. The lesson for proponents of CBR is that they must carefully dissect local social and cultural understandings of disability. For CBR to have its intended impact, local meanings of disability causes, the nature of appropriate therapies, and local attitudes toward people with disabilities also need to be examined.

The second major challenge related to identifying community disability needs in developing countries has been the relatively low priority of disability. A recent meeting of international CBR experts confirmed that, in many developing countries, disability issues are ranked well after food security, shelter, education, and income-generation as priority personal and community needs (60). This low priority is reflected at the funding level as well. For example, the recent Canadian International Development Agency 'Strategy for Health' discussion paper (61), fails to mention disability at all.

The low priority of disability matters in communities is a complex phenomenon and is intricately linked to several other issues. The low priority of disability issues is also related to the small numbers of disabled people in any locality. Disabled persons are a minority, and unlike other minorities such as ethnic groups, are often geographically dispersed. This demographic fact results in the lack of a 'critical mass' of disablement necessary for effective programming and lobbying, especially considering disabled persons' mobility limitations. To some extent, low priority is also accounted for by the stigma attached to disability. Negative attitudes, lack of education, and other historical biases within dominant societies prevent people with disabilities from holding substantial personal or political power (62). Finally, the low priority of disability may be due to the notion that disablement is a natural outcome of the ageing process in all persons, and therefore not a problem that requires active intervention. Interestingly, in areas of armed conflict, disability achieves a much higher priority in communities because of both the cause, overt hostilities, and the geographic intensity of the problem (63, 64).

People with disabilities are typically isolated from mainstream political and social life in the community, including the organisational structures of the health system. Hence, they may be unaware of opportunities for participation. Even when relatively powerless groups such as disabled people do find ways to participate, there may be real problems in gaining access to necessary information in understandable forms for policy development, planning, and program implementation. Finally, poor and disadvantaged people, including people with disabilities themselves, may discount the participatory process, preferring instead to rely on professional and governmental management of community health problems (21). Paradoxically, there are anecdotal reports of CBR projects implemented via such top down administrative approaches which would have failed with less authoritarian structures (65). This state of affairs may be particularly common in countries with long colonial histories, like India, where local people had not previously been encouraged to take

51

social development initiatives independently. CBR advocates must remember that people do not automatically know how to participate, and many have never engaged in co-operative community initiatives.

A third lesson that can be extracted from the international CBR experience is that the nature of community need will undoubtedly be contested. For example, CBR experts often believe that disability prevention programmes will improve community conditions. Prevention programmes may be rejected by communities, however, if community members defend the adequacy of indigenous culturally-bound methods for coping with disability (66, 22). A related difficulty is that CBR initiatives emphasising prevention do not possess the immediate impact of quick and visible 'curative' interventions. Providing dramatic proof of the benefits of a community referral system in CBR may be one way to secure community interest. For example, publication of the effects of surgical correction of club foot deformities is one way in which CBR can promote itself (60).

International CBR has shown that disabled people themselves are often interested in fragmented pieces of an entire CBR programme. One popular interest is in receiving adaptive equipment that provides immediate and tangible improvements in daily life (67). However, 'cure' and technical devices are not the principal focus of a community development style of CBR. Thus, sustaining long term commitment to CBR as a community development practice in developing countries has been difficult to achieve (3, 68).

Finally, in the determination of community needs which are critical to CBR development, there are profound difficulties in reconciling individual and community interests. Who speaks for the community and how are personal interests protected? Again, the CBR experience in Indonesia has been instructive. In Central Java, where the wives of prominent local government officials often serve as CBR workers, real conflicts have arisen between the local agenda of disabled people and the policies of government (59).

The lesson for CBR advocates is that community interest must be generated through real consultations with local people and material improvements in their lives. Evaluations of international CBR suggest that the greatest success has been enjoyed when disability is incorporated into broader community development strategies (67, 60, 69). A community development approach integrates a disability perspective into every facet of community activity, from childhood education to nutrition, from agriculture to sanitation, and from family planning to income-generating enterprises. A preliminary step in this direction may be to append CBR activities to already established health and education initiatives. Rather than adding a new layer of paraprofessionals, such as physical therapy assistants and occupational therapy assistants with their accompanying bureaucracies, existing community health workers, public health nurses, and special education teachers could receive additional CBR education and training. In this way, preexisting infrastructures can be utilised efficiently, to maximise the gains for people with disabilities, while searching for better opportunities and more creative solutions over the longer term.

COMMUNITY MOBILISATION

Since the essence of CBR is community participation, it is important to understand how communities have become mobilised in CBR in the international context. First, some communities

view rehabilitation as a government, not a community responsibility, and do not become involved at all (70). Second, some communities, even though they accept that they have a responsibility for rehabilitation, have rejected CBR because they perceive it as a secondrate service in comparison to institutional care (71, 72). These villagers have feared that CBR means replacement of limited professional services with services delivered by unpaid volunteers who have inadequate knowledge and skills. The accelerating pace of modern communication has meant that many communities in developing countries have become aware of what they do not have, and are unwilling to settle for something they perceive to be secondbest.

Third, there is evidence that community mobilisation has many purposes and intentions: from 'efficiency' in gaining community members' contributions of time and money; to 'involvement' of disadvantaged persons in socially supportive activities; to 'equity' in decision making with professionals (32). In its idealised form, CBR is highly reliant on the concept of equity. But, the entire idea of equity may be alien to people who are not used to being asked for opinions that will shape the delivery of rehabilitation services. It is has been very difficult to convince people in developing countries who are suspicious of past community development failures that CBR will be any different (73).

Thus, lack of interest, inexperience, and distrust in community mobilisation efforts characterise a number of international CBR experiences. One can ask why the public should be attracted to CBR services. One potentially powerful motivator, the devolution of central control to local levels, appears to be undertaken primarily for economic reasons. Governments provide the monies for services and leave their configuration and delivery to local groups, thus saving the central planning costs. A growing concern with this approach, which is increasingly voiced in the international context, is that local control may not guarantee financial savings. Especially during periods of economic decline, rural communities are wary of programs which call upon local participation to supply scarce resources. They may also be sceptical of CBR if it does not address issues such as poverty and discrimination that so profoundly affect the experience of disability. Furthermore, local control of disability programs may not eliminate the negative aspects of centralised models. It may just reproduce them on a smaller scale with elite community members at the helm.

Finally, international CBR foreshadows increasing tensions between people with disabilities and able-bodied persons. For example, in many countries of south east Asia where economic competition is fierce, efforts to improve efficiency and enhance market shares mean that commercial enterprises focus their energies on recruitment of fast-working, able-bodied employees. As global modernisation forces national governments to shift resources away from social programs toward economic stabilisation goals, communities may view job accommodation or services for disabled people to be luxuries that they can ill afford. If this occurs, it is possible that disability services, talked about today in the language of independence and empowerment, will revert tomorrow to more traditional models of care.

Charitable organisations, religious groups, and volunteer agencies are still responsible for the care and rehabilitation of great numbers of disabled people in developing countries. Although it is unlikely that this will return as a major trend in the industrialised world, we have already seen in the West significantly increased demands on voluntary agencies and families as government financial

support for community disability programmes are decreased. How will people with disabilities react to losing these hardwon rights and services?

CONCLUSIONS

The overall goal of this paper has been to assist in identifying the opportunities and constraints which CBR faces with respect to community participation. The critical lessons from abroad can be summarised as follows: Community diversity reminds us of the disparate interests of communities and that expectations of participation can overburden specific segments of the community, especially women. Examination of the process of eliciting community needs highlights several other problems around the determination of the meaning of disability and what counts as needs. We have learned that the definition of disability is culturally constructed, as are its causes and proposed remediation. We also know that disability may not be a community priority, and what is in the best interests of individual disabled persons may not be in the best interests of the community as a whole. Finally, critical examination of community mobilisation strategies reveals that projects grounded in local participation can still be rejected. Rehabilitation may be believed to be a government responsibility, or CBR may be seen as a second-rate service in comparison to professional and institutional services.

Suspicion of community based projects in a time of shrinking global economies and diminishing resources for health should not come as a surprise. The off-loading of traditional government responsibilities in areas of health and social services to the private sector is a growing feature of the political landscape. If CBR is to escape this dilemma, it seems imperative that those who are interested in developing a community approach take note of others' experiences. Critical analysis is clearly the starting point for understanding the history and lessons of international CBR. The next step, and undeniably the more difficult, is understanding and applying these lessons at home.

We have shown that community diversity, needs identification, and mobilisation strategies have represented considerable challenges to the development of community participation in CBR. Those interested in CBR should take note of these experiences and adapt their plans accordingly. We assert that knowing the communities in which we live and work is crucial to this task (17).

Community is a term with powerful positive characteristics, but also with the potential to divert attention from significant problems in society. Its idealist basis is easily coopted without regard for its true characteristics and values. We need to be aware of this danger and critically examine claims to community for the legitimate signs of 'communitas' and 'biocenosis' - common concern, integration, and interdependency. The challenge of CBR is in finding ways of integrating persons with disabilities in such communities.

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CBR ACTION RESEARCH - CURRENT STATUS AND FUTURE TRENDS

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ABSTRACT

Research activity in community based rehabilitation (CBR) has been limited and fragmented. This is in part due to the fact that the concept of CBR grew out of a pressing need to alter and improve the social conditions of people with disabilities, primarily in developing countries, rural and remote, isolated communities. These people live in situations where centralised health, social and employment services will never meet their needs. The success of CBR has seen this community based model of service provision grow and extend to countries and communities all over the world, its relevance extending from developing to developed countries, and from rural to urban communities. The concept has proved dynamic and flexible and over a period of several decades a large body of literature has emerged, initially descriptive, but increasingly analytical. In keeping with its social imperative, early resaearch has focused on summative evaluation, frequently required by funding sources, and using a predominantly quantitative research methodology. The importance of this research is obvious, but its limitations have led to questioning of alternative - and additional approaches - in order that a wider range of questions and issues may be addressed. A strong argument is emerging for research to reflect social relevance and to be conducted in a manner which facilitates processes and outcomes which are empowering for the participants. There is a further argument supporting the involvement of participants in setting the research issues and choosing the processes. The need for exploratory and descriptive research requires a qualitative methodology, grounded in the experience and processes of the participants in CBR activities. The result of this approach will be practical action research, which has the capacity to address the sets of practices which provide solutions to practical problems through pragmatic strategic and self-reflective processes. The chapter addresses these complementary approaches, reviews the current research in the CBR literature and current practice, and recommends suggestions for improving the knowledge base, acknowledging that effective research in CBR must be issue driven and oriented towards the achievement of positive social change.

1. INTRODUCTION

Experience in Community Based Rehabilitation (CBR) theory and practice suggests that the place and role of research within CBR appears to be somewhat unclear and, in some cases, quite problematic. This chapter explores some of the reasons why this is the case, and goes on to propose a research framework which may sit more comfortably within CBR. Some key aspects of CBR which might influence and inform the choice of a research framework have been described, and an Action Research framework suggested as the most appropriate research methodology. An introductory description of Action Research, its strengths, limitations and possible applications, is also provided and suggestions made of ways in which the soundness of Action Research can be ensured . Some examples of the application of Action Research in CBR have been provided.

It is by now clearly established that while there is a substantial amount written about Community Based Rehabilitation, mostly comprising opinion, description and subjective analysis, there is actually very little published formal CBR research. Similarly, there is little published about appropriate research methods for CBR. A number of authors have lamented this fact and suggested key topics to which research energies in CBR might be focussed, from policy and organisational issues (Peat, 1998), and the role of women, to the efficacy of CBR interventions and the roles of CBR workers (Wirz, 1996).

2. WHY HAS THE ISSUE OF RESEARCH BEEN A PROBLEM FOR CBR?

CBR has yet to establish a strong research foundation and tradition. There are a number of reasons why a strong research basis has not emerged in CBR, despite the fact that this approach is now well into its third decade. The most significant reason is that during its initial establishment phase CBR was not concerned with research, and it was only when it had become an accepted and robust service delivery model that the issue of research was raised. Many of the reasons for this can be attributed to (a) the particular nature of CBR, and (b) the particular nature of traditional research frameworks. These points are expanded below.

(a) CBR has not been an ideally suitable context for traditional research frameworks

Historically, CBR has primarily focussed on service delivery, not research. The major emphasis within CBR projects has been the provision of services to people with disabilities where none were available. Under such an emphasis, research may have been seen as a threat to precious resources needed for service implementation, or may not have been seen as an issue at all.

CBR may be characterised as being both highly pragmatic and strongly ideological in nature (Kuipers, 1998). From a research perspective, neither of these aspects has been conducive to developing a strong research agenda. At the pragmatic level, CBR is, in essence, a practical response to the needs of people with disabilities. This emphasis on practice rather than theory, enquiry and analysis has not led to the establishment of a strong research base. Similarly, the ideological commitment and enthusiasm that is often associated with CBR has contributed to its extraordinary spread, but has not resulted in the establishment of a strong research base (Miles, 1989). Ideological enthusiasm may not be conducive to fostering the critical analysis and dispassionate approach that characterises many forms of research.

The nature of the questions with which CBR seems to grapple, are not ones that fit easily into traditional research agendas. By and large it would seem that CBR is not overly concerned with narrow clinical rehabilitation questions, but with broader issues pertaining to models of service delivery, community participation, empowerment and the improvement of social conditions for people with disabilities. The level of enquiry of these broader social issues is, of necessity, exploratory rather than experimental. Such exploration and conceptualisation typically does not fit well into traditional reductionistic research frameworks.

Another reason for the poor fit between CBR and traditional research frameworks is that CBR is an evolving entity. Unfortunately, the evolving nature of CBR, while recognised by some authors, has not been clearly conceptualised and described (Kuipers, 1998, Price, 1998). We suggest that since CBR is evolving, the limitations and the strengths of newly emergent forms of CBR have yet

to be clearly explored. Traditional research frameworks do not cope well with nebulous evolving entities. Similarly the evolution in CBR means that a CBR research method has yet to be widely debated and accepted. Boyce's contribution in this area should be acknowledged (Boyce, 1997).

Finally, the emphasis within CBR on service level questions, may have led to a blurring of the distinction between research and evaluation. In instances where the research problems relate to service and structural questions, some assume that service evaluation will suffice as research. Unfortunately this has some negative consequences because, in many instances, evaluation:

- is driven by questions very different from those addressed by research,

- is rarely exploratory in nature,

- may reflect the priorities of funders, government departments or managers,

- tends to be highly quantitative,

- is often only conducted summatively at the end of a programme period

- may overemphasise the measurement of outcome rather than process.

While we believe that research and evaluation can actually integrate well (Quinn & Kuipers, 1999), we also believe that the substituting of evaluation as research has not served CBR well.

In summary then, the nature and history of CBR indicates that a potential research framework should accommodate the practical, service-oriented nature of CBR. Research needs to be grounded in the experience and processes of the participants in CBR activities. CBR is basically a social and community intervention. Consequently, a research method should be employed which responds less to basic psycho-medical needs, and more towards relational, community, and socially oriented needs of people with disabilities. A potential research framework for CBR should accommodate its evolving nature, should recognise that CBR is in itself a learning process, and should support and capitalise upon these aspects. Finally, a potential research framework should accommodate CBR's strong social imperative and recognise the empowerment aspects of CBR practice.

(b) Traditional research frameworks have not been ideally suited to CBR

An overview of research literature in the area of rehabilitation illustrates that the majority of published research is quantitative and experimental in orientation. By this it is meant that the majority of research within the area of rehabilitation depends on setting up of formal experiments, often in structured settings, in which a particular intervention is compared with another or no intervention, and in which success is determined by comparison against predetermined levels through statistical analysis. While it is conceded that this is a very important way of ensuring certainty and developing a body of evidence in the field of rehabilitation, it is suggested that this approach has not been highly appropriate for the current stage of the development of CBR.

Traditional quantitative research tends to focus on minute aspects of rehabilitation interventions, or else upon large group effects. In order to isolate interventions down to a level at which they can be compared or experimented upon, researchers need to remove extraneous factors and focus on

small increments of service. Again, while it is agreed that this may be appropriate in some situations, for the current realities of CBR practice, this 'microscope' approach to research may have been seen as undesirable and an unaffordable luxury.

There is a prevailing view that in order to conduct good rehabilitation research within the traditional framework, the researcher requires considerable technical, research design and statistical proficiency, or at least access to experts who hold these skills. It may be argued that to some extent, this arises from the mystique created by researchers and is not necessarily required. Despite this, we believe that the advanced level of technical expertise necessitated by traditional research designs may have scared CBR workers away from doing research.

In a similar vein, it may be suggested that the prevailing research framework in rehabilitation is highly rationalistic and closely aligned with Western logic and processes of deduction. This experimental, reductionistic approach to knowledge may be quite foreign to many from non-western cultures, and may therefore have been ignored by CBR practitioners in developing countries. Traditional research approaches may also have appeared impractical for workers in the field (Walker, 1993). The apparent distinction between practical service realities and the research mindset may have led CBR practitioners to view the pursuit of research as somewhat remote.

The subject matter of traditional research and the types of methods used may also have been seen as inappropriate for the key issues confronting CBR. Traditional research methods tend to falter in community settings. They may fail to accommodate important social factors such as the importance of 'connectedness' between people, and the place of social and community processes (Price, 1990; Riger, 1993). As such they may not have been seen as a high priority for CBR workers. Similarly, traditional research methods offer limited control to participants (Barlow & Harrison, 1996). In an environment in which empowerment is increasingly seen as central to CBR, the use of such methods may not have been seen as conducive to maximising empowerment.

In summary, a brief look at traditional research methods indicates a number of points of departure for the field of CBR. In order to draw conclusions from this contrast, it might be concluded that a potential research framework for CBR should allow a 'macro' as well as a 'micro' focus. It should be practical, integrated with service delivery and, to the greatest extent possible, seek to demystify the research process. It should also be relevant to community and social issues and, where possible, facilitate desired outcomes and the empowerment of people with disabilities.

As the field of CBR moves from an initial establishment phase to a second consolidation phase it may require a more systematic approach in order to harness what has already been learned, and to translate it into action. Research need no longer be seen as a threat to precious resources and energies, but may be viewed as a necessary part of activity which will help harness and deliver more effective processes and outcomes in continuing implementation. A major challenge which the CBR community now faces is to identify and implement an appropriate research methodology. It is suggested that Action Research might fulfil this role.

3. ACTION RESEARCH: A SUGGESTED ALTERNATIVE

Action research is an approach for fostering collective action in a social setting within a research framework. Action research is not new, nor is it a highly technical approach. It is, however, a

logical way of systematically integrating practice with research. The key principles are change and understanding - action and research. Central to the Action Research approach, is the belief that our action, and changes in our action, will be enhanced by research; and likewise, that research will be enhanced by integrating it into practice. This integration is achieved through a cyclic or spiral process in which action and critical reflection alternate (Dick, 1999).

A core principle of Action Research is that action and research can *both* be enhanced by participation. This means involving people at the action level, by providing information on their action and in planning the changes that are indicated, and at the research level by ensuring that key stakeholders are involved in conducting, analysing and interpreting the research. The Action Research approach is highly conducive to people investigating their own issues, formulating their own accounts of these issues and devising plans to deal with the identified problems (Stringer, 1996).

To expand on the point above, Action Research may be seen as action which is "intentionally researched and modified, leading to the next stage of action which is then intentionally examined" (Wadsworth 1997 p.78) and so on, as part of the research process itself. Action Research can be thought of as following a cycle or spiral of action, reflection, questioning, exploring, drawing conclusions, evaluating options and planning further action. The spiral goes upward towards improvement. In more formal terms this cycle may be described as enquiry, intervention, evaluation (Hart & Bond, 1995) or think, act, look (Stringer, 1996). Fundamentally, Action Research comprises a simple, yet powerful cyclic framework for inquiry (see Figure 1).

FIGURE 1 HERE

CBR practitioners will be familiar with the basic approach, though they may not call it Action Research. Action Research mirrors the typical logic that is used by health and disability workers as they solve problems and respond to people's needs (Hart & Bond, 1995). Concepts of assessing need, developing a rehabilitation response and reviewing progress will be quite familiar to CBR practitioners. A difference is that as this cyclic process is moved from the individual service level to a larger scale, it requires more disciplined co-operation of many stakeholders, clear and consistent documentation and careful planning and follow-up. The issue of documentation is particularly important. Where clear and detailed documentation is not kept, the capacity to replicate is lost, and with it the possibility of learning systematically from previous experience.

As may be evident, Action Research departs somewhat from some of the core notions of conventional research. First, the notion that research should start with a hypothesis and end with a conclusion is seen by Action Researchers as an unrealistic removal of the research process out of the real world. Action Researchers hold that research results will be most useful when they arise from a repeated incremental cycle. Second, the notion that conclusions should be put to a test and judged according to a particular criterion, is seen as somewhat inappropriate. Action Researchers recognise the values context of research and see that judgements regarding the value of an outcome or conclusion are best made by the participants who will be most affected by it.

4. WHY IS ACTION RESEARCH APPROPRIATE?

There are a number of aspects of Action Research which make it particularly appropriate as a research framework for CBR. Some of these attributes of CBR are outlined below.

- *Action Research is participatory.* One of the key indicators of the suitability of Action Research to CBR is its inherent participatory nature. While the degree of participation may vary across Action Research projects, the active involvement of people who are directly affected by the research outcomes and processes is fundamental to Action Research.

Action Research prescribes process, not a particular methodological design or strategy. An important part of the Action Research process is the participation of key stakeholders in all aspects of research. These may include people with disabilities, community members, other service providers, Government and non-government organisations, community groups and many others. In the same way that CBR challenges the myth of the independent, all-knowing professional, so Action Research challenges the myth of the independent researcher. It recognises that research is value driven and based on experience, and suggests that the best locus for these is the values and experience of those who will be most affected by the research. The involvement of people with disabilities in setting the research agenda or significant aspects of it should lead to more relevant and meaningful research. (Ramcharan, 1997).

- *Action Research is a suitable approach for a service-oriented context.* The practical, service delivery focused nature of CBR requires a research approach that is consistent with the practical realities of CBR programmes. The 'Action' component of Action Research ensures that the research is grounded in practice. The cyclic nature of the approach ensures that the benefits and insights flowing from the research return to the practice context.

- *Action research is appropriate where the goals of the research are problem solving and improvement.* In essence, CBR may be seen to be integrally concerned with problem solving and improvement. At the individual level and at the community and societal levels, CBR seeks greater development. Consequently the suitability of Action Research is self evident.

- *The cyclic nature of Action Research accommodates service-generated questions.* In applied settings where research is not the 'core business' of the exercise, research questions are rarely as neatly defined as in pure research settings. Many pure researchers believe that such lack of definition compromises the clarity and benefit of research. The cyclic process of Action Research however, consisting of cycles of action and reflection, allows for a continual refining of research questions and strategies. This gives practitioners the opportunity to refine their skills and methodologies as they clarify their questions, to the point where the research is of optimal benefit.

- *Action Research can accommodate the evolving nature of CBR.* As noted earlier, CBR is not a consistent entity, it varies across contexts, client groups, communities, and geographical regions and across time. Indeed, the success of CBR to date may be partly attributed to its adaptability to various situations and places. An Action Research approach, which follows *principles* for research rather than methodological or technical *strategies* that must be employed, is best suited to such a diverse and changing context. Given its cyclic and iterative nature, Action Research is likely to be the only approach that has application across the diversity of CBR contexts and across the constantly evolving conceptualisation of CBR.

- *Action Research is well suited to 'big picture' research agendas.* Given the nature of the focus of CBR, the questions generated to date tend not to be only about small aspects of treatments, assessments and interventions, but also about broad questions concerning services and service development, and the impact of services as a whole. As a socially oriented approach, which is primarily used in large group and social contexts, Action Research is well suited to such research agendas.

- *Action Research is relevant to community contexts.* Researchers who work in community rather than clinical settings emphasise that these distinctive settings require particular approaches if they are to be accurately researched (Thorburn, 1996; O'Toole, 1995). Typically, research conducted in community settings should be (a) iterative, (b) broadly participatory and (c) practical and socially oriented. Action Research fulfils these criteria.

- *Action Research is consistent with the CBR commitment to demystification.* As noted earlier, there is an inherent commitment within CBR to making rehabilitation information and techniques available and accessible to community members. Action Research is one of the few research frameworks which is consistent with this commitment. Many proponents of Action Research go to considerable lengths to make the language and processes of Action Research understandable to community members. The participatory nature of CBR also ensures that community members hold power over how research is conducted, with whom and how it is disseminated.

- *Action Research accommodates an empowerment framework.* Increasingly, CBR has recognised empowerment as a key objective. CBR authors increasingly stress the importance of promoting empowerment in all aspects of practice (Helander, 1993; Williams, 1995). As indicated above, the commitment to participation in Action Research promotes a situation where the principle of empowerment is central to research.

- *Action Research is compatible with programme evaluation.* As reflected in CBR literature (Jonsson, 1994; Peat, 1997; McConkey, 1995), the purpose of evaluation is to ensure the development and improvement of projects and, by implication, CBR in general. Action Research, with its practical and service based orientation, is quite consistent with this service requirement. An action research agenda will likely involve a step-by-step description of any CBR initiative, the rationale, context, scale, resources, format, content, length and style of training, and will link them in specific terms to the problems encountered and the outcomes. Such detailed analysis of factors affecting a project is an important component of programme evaluation.

- *Action Research is 'community relevant'.* Clearly one of the overriding concerns that should influence the CBR researchers in their choice of methodology is the relevance of this approach to communities. It has been recognised that CBR research should seek to utilise the scarce resources of the community in an optimal manner (Hanumantha-Rao et al, 1993), and build the level of care within the community (Helander, 1993). In our opinion, the participatory and contextually responsive approach used in Action Research would contribute to these ends. Action research agendas tend to be issue driven and oriented towards social change (Ward, 1993). They are ideally conducted in an empowering manner.

5. HOW CAN WE ENSURE THAT ACTION RESEARCH IS SOUND?

Ensuring that research is 'sound', appropriately rigorous, reliable and valid, should be a major concern for all researchers. In Action Research this concern is equally critical. However it is achieved in different ways from traditional quantitative research. Within Action Research and many qualitative research methodologies, the requirement for sound, trustworthy and rigorous research is met procedurally rather than statistically.

In Action Research, the quality and rigour of the research is ensured through three major means (see Dick, 1999):

1. Through careful and considered use and documentation of the Action Research cycles. The more an issue has been researched in multiple and different cycles, over time and circumstances, the greater the level of confidence that the findings are accurate.

2. Through an attitude or posture in which researchers test their assumptions and findings by vigorously seeking out disconfirming evidence in as many ways and from as many sources as practicable. The more an attempt has been made to disconfirm specific findings, and to test them out, the greater the degree of confidence that they are an accurate reflection of reality.

3. Through ensuring high levels of participation of key stakeholders such as community members, people with disabilities, family members. The more it has been ensured that key stakeholders have genuinely participated in the research, the greater the degree of confidence that the findings of the research accurately assess and reflect the issues of greatest importance to those most affected.

As Dick (1999) points out, in Action Research soundness can be achieved through:

*   using multiple cycles of enquiry, so that later cycles can test the results of the earlier ones;

*   combining data collection and interpretation within each cycle, so that interpretations as well as data can be challenged in later cycles;

*   using different methods of data interpretation in successive cycles;

*   involving different participants and information sources at different points;

*   carrying out two or more independent action research studies on similar topics;

*   giving different questions which pursue equivalent information to the same informant or group

*   asking questions which yield overlapping information;

*   using different researchers at different times and including participants as co-researchers;

*   involving a variety of participants, and creating a climate in which they are encouraged to challenge the researcher's ideas;

*   using the available literature as a further source of evidence;

- monitoring the achievement of planned changes; each change is a test of the assumptions and plans that led to it.

Consequently there are no set criteria or formal tests of 'soundness' and Action Researchers tend to avoid terms like reliability and validity. In preference to these terms when evaluating the soundness of Action Research in CBR the following concepts are suggested:

Confirmability   How well was the research conducted and documented so that similar findings could be achieved by different researchers?

Transferability   How thoroughly did the researchers use diverse data sources and approaches in their cycles to ensure that the findings might be relevant to other contexts?

Consistency   How carefully did the researchers conduct the study and involve all relevant participants to ensure that the findings are an authentic portrayal of reality in that context?

Essentially, the posture which the researcher must adopt is one in which she or he assumes at all times that the data, the interpretations, the participants and the methods used are all informative, but insufficient. The only way to ensure that the findings arising from these insufficient points are sound is to continually test and retest them.

6. TO WHAT SORT OF RESEARCH QUESTIONS CAN ACTION RESEARCH BE APPLIED?

An Action Research logic and framework can be applied to a wide variety of issues, and has, in fact, been applied in many CBR contexts. As was stated earlier, there is active debate about the development of appropriate research models for CBR, exemplified in the recent work of Boyce (1997), who proposed an integrated model, capable of addressing the needs of descriptive, comparative, predictive and evaluative research purposes. At its simplest, this will involve the documentation of any CBR initiative, a step-by-step description detailing the rationale, context, scale, resources, format, content and length of training, outcomes, and problems encountered. This type of research is exemplified in the recent work of O'Toole and McConkey (1995) in Guyana. Comparative research facilitates the identification of specific factors that may act as catalysts for change, and enables these factors to be assessed for applicability to other settings. Findings from any descriptive studies can be assessed in a similar manner to determine their possible relevance and utility in other contexts and settings. This research would be relevant to the identification of factors which give rise to leadership of people with disabilities in community activities, so that other communities may promote this outcome. Other areas of applicability would include the identification of strategies for promoting community awareness and positive attitude change, length and content of training of CBR workers, strategies to promote work opportunities for people with disabilities in their local community, strategies to promote social integration in specific community activities, strategies for promoting inclusive education in community schools, strategies for promoting training skills in parents of young children with disabilities to facilitate the development of their children. It can be clearly seen that descriptive and comparative Action Research can be applied to any facet of CBR development and activity. Repeated replication will facilitate predictive capability. Many of these aspects are demonstrated in CBR activities that have taken place in Bangladesh,

(CDD, 1998, Khan, 1997, Khan & Bari, 1997), Vietnam (Jones, 1998), Guyana, O'Toole & McConkey, 1995), the Phillippines (Campos, 1995), Jamaica (Bean & Thorburn, 1995), India (Balasundaram, 1995, Vatsa, 1997), Cook Islands (Price, 1996).

Evaluative research can be seen as the measure of maturity of the CBR approach, and enables both positive and negative outcomes to be turned into constructive guidance for future CBR activities. Early purely quantitative and objective evaluation procedures have given way to procedures where objective and subjective information, qualitative and quantitative data, are considered equally necessary and informative. The evaluation tool developed by the United Nations Development Program, 'OMAR in Rehabilitation: A Guide on Operations Monitoring and Analysis of Results' (Jonssen, 1994) emphasises both reliability and validity of measures, but is concerned too with reflecting the focus on individual disabled people, the process of change, and the means by which it is achieved in communities where CBR activities are being introduced or implemented. Perceptions and attitudes are considered as important as the numbers of people receiving services, and assessment of relevance of activity to the needs of people, both with and without disabilities, is of key importance, as is the assessment of the impact of the programme on the whole community.

Even in large scale traditional and quantitative evaluative studies, such as was carried out by the ILO in Ghana after the introduction of a national CBR programme (Rehabilitation International, 1998), case study components of the findings reflected Action Research methodology, and documented the achievement of personal independence and the capacity to contribute to the family in a variety of ways for people who had previously been dependent. The key facilitating factor in achieving this outcome was identified as the disability awareness creation activities and subsequent attitude change, both in the people with disabilities, their families, and in the broader community. Findings such as these are eminently replicable, across a variety of cultural contexts, thus illustrating the value of detailed documentation and building a comparative data base. A call for a methodology for evaluation of CBR programmes in the Indian context details many aspects which mandate an Action Research approach. Some of these include the extent of sensitisation and empowerment of the community, the extent of community involvement, the extent of replicability of the project, the resultant shift from charity to opportunity, from segregation to integration, from dependence to contribution, from indifference to self-confidence. (Punani, 1998).

Perhaps the most complex, ambitious and potentially far-reaching Action Research project conducted so far in the area of disability in community development is the social policy change-agency research undertaken by the Partnerships in Community Living Project initiated in Nicaragua in 1993 and resulting in the Managua Declaration (CILPEDIM et.al. 1996, Roeher Institute, 1997). The purpose of this research was to develop an achievable vision of community development based on a human rights perspective, by means of providing research based information on both the barriers to human rights and the necessary steps to achieve social change. Outcomes from this initiative have been varied and have resulted in changes to medical training which now focus on viewing children with disabilities as part of the normal range of diversity in development as opposed to viewing them as 'abnormal'. Programmes in harmony with this approach include Projimo's Skills Training and Work Programme, where disabled young persons teach unemployed village youth useful skills from coffin making to building children's wheelchairs, (HealthWrights, 1998) and Los Chavalitos, a farm school established for orphaned and homeless street children from Managua, developing environmental conservation and co-operative self-reliance. (HealthWrights, 1999).

Detailed documentation of CBR developments in the communities and countries which participated will provide an important data base of the effectiveness of this type of approach to achieving positive social change.

7. THE ROLE OF THE RESEARCHER IN ACTION RESEARCH IN CBR

Recent attempts to conceptualise the nature and process of CBR have addressed the role of the 'scientist' or researcher (Tjandrakusuma, 1977, UN ESCAP, 1997) in a way that was not evident in earlier definitions (WHO, 1994). Outlining the challenges for CBR in the 21st Century in the Asia Pacific region, Tjandrakusuma separates the roles of the managers, the technical skill specialists and the scientists. The task of the latter is to conduct research which will improve both the strategy and techniques of CBR implementation, a similar role to that envisaged by UN ESCAP for social scientists.

In many instances the role of researcher has been filled by experts connected with donor organisations, ideally with a resultant transfer of skills to local project co-ordinators. In many other instances the role of researcher has not been filled at all, with the resultant loss of important information and opportunities to learn from past activities. The Action Research framework necessitates the inclusion of research activity in all aspects of planning and implementation, to be undertaken by all participants in the CBR process, if research is to feed into improved practice and innovative procedures.

One way of promoting this outcome is by the formation of Networks, which facilitate the sharing of information, skills and research expertise. The Asia Pacific Disability Rehabilitation Journal has played an important role in this respect, and the documentation by Rehabilitation International of extensive CBR resources and activities illustrates the capacity to benefit by sharing. A Network was formed in Solo, Indonesia, in 1996, at a regional Forum on the development of Human Resource Development in CBR. In 1997 an extended international CBR Action Group Network was formed at a Rehabilitation International Conference in Seoul, South Korea. An example of the benefit of exchange of information under these conditions is illustrated by the adoption of a community mapping procedure to locate local resources by a project for street children in Vietnam, based on procedures that had been developed and used in the establishment of CBR developments in the outer Cook Islands (Price, 1996). The exchange took place as participants described their involvement in CBR activities at the Forum in Solo. The scope for such beneficial outcomes will be magnified as opportunities for exchanges are structured within Network Groups, communication facilitated, and Action Research training and guidelines programmed into the Network activities and proceedings, shared and disseminated.

Some initiatives that could be promoted by Networks of people associated with CBR activities include:

- Creation of a research data base

- Organisation of sessions where research facilitators assist in planning, educating and training less experienced participants in Action Research activity.

- Establish mechanisms for practical assistance and relevant feedback, and a mentoring process

- Develop and encourage the awareness, knowledge and skills that lead to documentation of practices, training content, methods of training, implementation, processes and outcomes.

In this way a research culture can be developed, where the careful documentation of procedures and outcomes can be regularly shared with others, tried in different circumstances, modified, documented and shared again. It will facilitate the recognition that CBR is a global movement, and that all who are engaged in CBR activity are contributing to it, beyond the boundaries of their local context.

Experience from past decades has taught that CBR will never be a 'tidy' concept, neatly defined, but is dynamic and constantly growing and changing in response to both evolving philosophical and ethical frameworks, and the diverse social, political, economic, demographic and physical conditions in which it is being developed. A commitment to a practical action-based research agenda will ensure an expanding body of systematic knowledge, that can inform future practice and perhaps prevent repetition of previous mistakes and lessons already learned. It will provide a source of continual encouragement to people working often in physically isolated situations, but sharing a common commitment to a social change agenda embodying universal acknowledgement of the rights of people with disabilities to full participation and equal opportunity within their communities, within societies that are accepting of diversity and supportive of the empowerment of people with disabilities.

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DEVELOPING CBR THROUGH EVALUATION

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ABSTRACT

Evaluation is not an activity which comes easily to most community based rehabilitation (CBR) managers. Evaluation is often viewed as being both a requirement of external agencies and as not contributing significantly to CBR development. Consequently, evaluation methods have not been well incorporated into CBR managers' practices. This omission is in sharp distinction to other CBR management skills such as training and supervision. One can quickly blame this gap on the lack of responsiveness of external evaluators, or perhaps on the desire of local CBR managers to avoid unnecessary criticism. However, there are very important similarities between the issues of disability and evaluation that make them very compatible. The authors suggest that CBR cannot survive without appropriate evaluation mechanisms to explore and understand the information base upon which CBR lies. Furthermore, evaluation, if appropriately conducted, can actually help the development of community programmes. This chapter begins by clarifying the information links between disability, rehabilitation and evaluation and discusses the need to evaluate the key characteristics of CBR. As an example, the authors refer to evaluation of issues in community participation, which is the key characteristic of the CBR approach that distinguishes it from other forms of rehabilitation. It is shown that issues of community diversity, community needs, and community mobilisation all have important implications for evaluation in CBR. The chapter also identifies potential approaches to CBR evaluation which take it beyond the traditional styles of human services evaluation and participatory evaluation in which the field is currently mired, to emerging styles of empowerment evaluation that address the explicit values of community rehabilitation programmes. Investigating these values allows CBR programme managers to not only be responsive to community interests and needs, but also to use the process of evaluation to facilitate the real development of the community.

INTRODUCTION

Evaluation is not an activity which comes easily to most CBR managers. Evaluation is often viewed as being both a requirement of external agencies and as not contributing significantly to CBR development. Consequently, evaluation methods have not been well incorporated into CBR managers' practices. This omission is in sharp distinction to other CBR management skills such as training and supervision.

One can quickly blame this gap on the lack of responsiveness of external evaluators, or perhaps on the desire of local CBR managers to avoid unnecessary criticism. However, there are very important similarities between the issues of disability and evaluation that make them very compatible. We suggest that CBR cannot survive without appropriate evaluation mechanisms to explore and understand the information base upon which CBR lies. Furthermore, we believe that evaluation, if appropriately conducted, can actually help the development of community programmes.

This chapter begins by clarifying the information links between disability, rehabilitation and evaluation and discusses the need to evaluate the key characteristics of CBR. As an example, we refer to evaluation of issues in community participation, which we have suggested in an earlier chapter is the key characteristic of the CBR approach that distinguishes it from other forms of rehabilitation. We show that issues of community diversity, community needs, and community mobilisation all have important implications for evaluation in CBR.

Next, we identify potential approaches to CBR evaluation which take it beyond the traditional styles of human services evaluation and participatory evaluation in which the field is currently mired, to emerging styles of empowerment evaluation that address the explicit values of community rehabilitation programmes. Investigating these values allows CBR programme managers to not only be responsive to community interests and needs, but also to use the process of evaluation to facilitate the real development of the community.

INFORMATION AS THE LINK BETWEEN DISABILITY, REHABILITATION AND EVALUATION

There are key similarities between disability, rehabilitation and programme evaluation in their dependence on, and utilisation of, information. Programme evaluation has been defined as " a systematic and continuous process of information provision for the purpose of <u>determining the value</u> of a programme from a decision making point of view" (1). In other words, evaluation is a process for providing information for ongoing programme re-design. There are many texts on evaluation available, and some CBR managers have backgrounds in well-known evaluation methods such as needs assessment, programme monitoring, management information systems, and impact assessment. These managers appreciate the need for information in programme evaluation. However, programme evaluation at its worst is nothing but masses of information. How can this information be organised and utilised?

There are two basic assumptions in any programme evaluation. First, an actual programme must exist - that is, a set of activities intended to improve a given situation for a group of participants. The programme should be definable and able to be replicated elsewhere. Second, one must be able to compare the programme to reference points to allow decisions to be made which may improve the programme.

Assuming that a programme exists and a comparison can be made, there are two general goals for programme evaluation - accountability and effectiveness. With respect to the accountability goal, there is a generally correct perception that programme organisers and participants have a vested interest in their programmes and are susceptible to bias in their judgements. Relying solely on these judgements may not provide sufficient accountability for publicly funded programmes. With respect to the effectiveness issue, CBR programmes involve complex personal, organisational, social and cultural factors which are not easily 'controlled', in contrast to clinical practice and laboratory settings. Methods of investigation are needed which can accommodate these complex factors to allow determination of specific programme effectiveness and thus contribute to valid decisions on future planning. In the evaluation of traditional human service programmes, these assumptions and goals have led external reviewers to develop certain evaluation methods, performance standards and evaluation criteria for decision making.

Traditionally, evaluation aims at *description* of the context, input, process and output of programmes as well as *analysis* of why the programmes occur in a particular way. In addition, traditional evaluation moves beyond these research objectives to *evaluate*, or make judgements about the value of the programme, and then to make recommendations for change (2). It is this evaluative component which makes programme evaluation important to decision-makers and which requires evaluators to be clear and explicit about their value base. Programme evaluation is sometimes believed to be neutral, or value-free (3). However, many evaluation experts recognise that there must be values present in programmes if there are standards and criteria being applied (4,5).

We believe that evaluation methods are either implicitly or explicitly based on values and a theoretical understanding of the programme. For example, university accreditation standards and methods are based on theories of education and organisation. Hospital management analysis methods are based on systems theory. Social policy analysis is based on a variety of political and economic theories. Thus, evaluation standards and methods are usually linked to a theoretical base. In planning an evaluation, it is critical to state the theory underlying the methods, and the plan for analysis, so that the evaluation sponsor and audience can decide whether these values and assumptions are relevant to their perspective of the programme.

What are the theories which underlie disability and rehabilitation and how are they used to guide CBR programmes? And how will the belief in a particular theory affect evaluation in CBR? The traditional focus in rehabilitation has been on function and independence - with an emphasis on evaluating functional outcomes of treatments for individuals. A second rehabilitation focus developed twenty to thirty years ago and claimed the importance of social integration for persons with disabilities. This focus led to an emphasis on de-institutionalisation and mainstreaming in Western societies and to CBR in the Third World with responsibility being taken by the community - and an emphasis on evaluating the development of services in the community (6). More recently, a third focus claims that community integration, without adequate referral services or knowledge, merely shifts responsibility onto an unprepared community that lacks resources to allow disabled persons to achieve either optimal independence or integration. The central resource which is lacking is information about disability and rehabilitation (7).

In this recent focus, rehabilitation is understood as an information system (8). Information about various personal aspects of disability, such as the individual experience of disability, about consuming rehabilitation services, and about local solutions is created and stored with disabled people and their families. On the other hand, information about providing rehabilitation services, about research in disability, and about technical solutions is created by and stored with various professionals. If these information sources do not exchange data or complement each other there can be an 'information gap' that limits the progress of both groups. Such mismatches can also lead the way to conflict between these groups, whose goals may actually be more complimentary than are their methods.

The idea of disability being a fundamental problem of information, rather than of impairment, continues to develop in the West (Independent Living Movement) and in the Third World (Information Based Rehabilitation) as a complementary strategy to professional and community based approaches to disability.

An information based approach to disability has a number of advantages. It can appreciate the benefits and value in any number of rehabilitation strategies (professional care, community programmes, CBR, community development) since it emphasises the information in these strategies. In theory, information is an unlimited resource and can be shared, unlike financial and human resources. Information can multiply through the process of feedback between individuals, groups and systems. Information transfer can utilise the technology of communication systems. Finally, information transfer in usable forms is less costly than training professionals and establishing individualised services

However, an information based approach can also have disadvantages. Access to information can be restricted, especially to disadvantaged groups such as disabled persons. Information must be at an appropriate level depending on the user's background. Information alone is not sufficient to replace therapeutic skills or technical expertise. And finally, as we have suggested earlier, information is never entirely value-free and may be used to advance non-complementary goals held by different interests.

How is an information based approach to disability different from traditional community education methods? Most importantly, an information based approach focuses on maximising both information content and dissemination to as wide an audience as possible (8). In areas where professional skills and community resources are insufficient to meet the needs of more than a small number of disabled persons, an information approach offers an appropriate, affordable rehabilitation strategy.

CBR evaluation could be based on this concept of information. CBR strategies could be evaluated in terms of information content, and the quality, quantity, dissemination and feedback of the information systems used in the programme. As an example of how information in CBR is useful in evaluation, we turn to the concepts of community participation in CBR - community needs, community diversity, and community mobilisation. Community needs implies that one evaluate the breadth of disability programmes through an appropriate needs assessment and description of CBR activities. Community diversity demands that we evaluate whether stakeholder interests are met by using valid outcome assessments. Finally, community mobilisation requires that we evaluate the methods of involving participants through an in-depth examination of process.

In sum, evaluation in its broadest sense is a fundamental strategy for creating information, managing and organising information, and disseminating information. The needs of CBR and evaluation are complementary since neither evaluation nor CBR can function without information. The real question for CBR managers is not whether to evaluate, but how to gather and disseminate this information.

MATCHING CBR MODELS AND TYPES OF EVALUATION

We have suggested that CBR evaluation be specifically linked to particular characteristics of CBR to improve the relevance of evaluation. We now will explore the methodologies which can be used in CBR evaluation. Michael Patton asserts that: ...the values and methods of any particular evaluation should be matched and be appropriate for the programme being evaluated. When a programme is exploratory and developmental, therefore, the evaluation should be exploratory and

developmental. Where the programme aims to be empowering of participants, the evaluation should likewise be an empowering process" (9, p.26). Evaluation methodologies have usually incorporated values and assumptions implicitly, rather than explicitly, with the result that programmes have been evaluated against standards which may not actually reflect the programme philosophy and objectives (10). This mismatch of methodology to programme objectives may explain the inability of evaluation to demonstrate the impact of many community based programmes.

How CBR is envisioned by the developers and participants of a project will obviously have implications for who is active in running the programme, and how it is run. But the vision of CBR also affects who does the programme evaluation and how the project is evaluated. At the risk of being simplistic, two general CBR visions, with their corresponding approaches to evaluation have been:

1. CBR as a managed service delivery project and a systems approach to evaluation

2. CBR as a communal activity, and a participatory evaluation approach

These two approaches will be described initially, and then a third option for CBR will be advanced:

3. CBR as empowerment, and a values approach to evaluation.

1. CBR AS SERVICE DELIVERY, AND A SYSTEMS APPROACH TO EVALUATION

From its early days, CBR has been promoted by WHO as a method of providing rehabilitation services to disabled people in communities which have few resources. In this view, CBR is placed within the health and social service sector, and parallels primary health care's focus on prevention and treatment roles in a human service program format (6, 11). This model of CBR focuses primarily on individual problems rather than community wide problems. The focus on individuals is partly a fact of demographics and the low geographic prevalence of disability, but also is related to the common perception of disability as an 'unnatural' event, to be either avoided or treated. Disability is not considered to be a natural event, in contrast to childbirth, which is celebrated and dealt with as a community concern in primary health care.

Consistent with this view, the WHO Training Manual focuses on individual outcomes:

The purpose of any rehabilitation programme is to help people with disabilities to do what others do in the home and the community and to become socially integrated. Therefore, the evaluation of a CBR programme should determine whether people with disabilities are doing more as a result of the programme... [including] self-care, communication, moving around, and participation in play, school, social, and work activities. It should also assess whether the goals of full participation and equal opportunities are met (12).

The strategies which evaluation can use to improve knowledge and practice in this service delivery model of CBR are broad and include: applied behavioural analysis, observational evaluation, management analysis, economic evaluations, meta evaluation and social policy analysis. These strategies can be used for planning and monitoring programmes, describing programme utilisation, assessing overall staff performance, improving caseload management, assessing client satisfaction,

and comparing programmes. This traditional language and form of programme evaluation has emerged from a systematic, management-oriented perspective on programmes (including their targets, activities, participants and direction).

Generally, systems oriented evaluation involves an internal or external evaluator who is, or becomes, familiar with a programme, and controls the evaluation process by:

- examining the goals of the programme,

- determining which indicators will be used to measure the extent to which goals are met,

- formulating a research design which incorporates these indicators and is based upon assumed cause-and-effect relationships,

- collecting the data,

- interpreting the data,

- arriving at a judgement and suggestions for the programme to better reach its goals, and

- reporting these to the programme managers (13).

In the human service delivery model of CBR, the WHO manual addresses evaluation by providing a check-list framework for answering questions of individual and programme accomplishment. The Local Supervisor takes the primary role in answering for him/herself, and in helping the family to answer about their disabled family member. Recommendations for action then follow logically from the shortcomings that are identified.

As CBR concepts have expanded in the human service delivery model, an emphasis on rights and opportunities for disabled people has increased, as well as the need for integration of social and governmental sector interventions in education and employment (14). This vision of CBR asserts the need for a broad co-ordinated system involving all levels of society: community, regional and national.

On assumption of the need for a broad-based system, the United Nations Development Programme (UNDP) has designed an extensive systems analysis procedure for the evaluation of CBR programmes called Operations Monitoring and Analysis of Results (OMAR) (15). This method uses a statistical database approach to assess change, based on the WHO model of CBR training.

More recently, the Guidelines For Evaluating CBR Programmes (16) provide a framework to assist CBR programme staff at the local, district and national levels in the why and how of both monitoring activities and comprehensive evaluation. Indicators (numbers or facts, sometimes stories) are sought in order to:

- interpret, discuss, and make plans to improve the programme (monitoring)

- answer questions of progress, effectiveness, efficiency, impact, relevance and sustainability (comprehensive evaluation).

In summary, a systematic, management-oriented approach to evaluation is commonly used for human service programs and prioritises outcomes, or individual change. The central question for this approach, however, is the relevance of the findings to the lives of disabled persons.

There have been many criticisms of the systems approach to evaluation. These criticisms suggest methodological inflexibility and lack of attention to the human elements of community programming. For example, a well known evaluator has stated categorically that:

> Evaluation itself is a methodological activity which is essentially similar whether we are trying to evaluate coffee machines or teaching machines, plans for a house or plans for a curriculum. The activity consists simply in the gathering and combining of performance data with a weighted set of goal scales to yield either comparative or numerical ratings, and in the justification of (a) the data gathering instruments, (b) the weightings, and (c) the selection of goals. (3, p.123-4)

The result of using such a 'methodologically pure' approach is that evaluation findings may not be relevant, nor utilised by programme planners. In response to the problem of the lack of utilisation of evaluation findings, systems evaluation turned to an action research approach. In action research, professional evaluators encourage a greater involvement of practitioners, to make evaluation research more directly relevant to programs. This includes a formal stakeholder approach, in which stakeholders' views are incorporated into the evaluation to meet concerns that evaluations are narrow, unrealistic, irrelevant or unused (17).

Although systems evaluation has made an effort to shift the usual pattern of authority relationships surrounding programme evaluation, and thus to alter evaluation priorities, drawbacks to action research and the stakeholder approach include the facts that:

- inequity of stakeholders is not addressed and assumptions are made regarding their ability to provide input. This is particularly a problem where disadvantaged persons such as disabled persons are asked to state their priorities when they have had little experience in doing so

- few supports are given to the less advantaged to participate equally, such as training in the technical aspects of evaluation

- the degree of real decision-making actually afforded to the different stakeholders is limited within the confines of scientific principles

- justification for this approach is ultimately to increase the use of evaluation findings in decision-making that is, to remedy problems of utilisation, and not to deal with issues of inequity.

Overall, the fundamental focus of service oriented CBR, which aims at the individual level, ultimately may restrain its impact. Evaluation is mostly outcome driven and focuses on the impact of services, assuming that these are the key to changes in the lives of disabled persons.

2. CBR AS COMMUNAL ACTIVITY, AND A PARTICIPATORY APPROACH TO EVALUATION

Another model of CBR stresses community activities, emphasising the participants as active developers rather than passive, albeit grateful, service recipients. In this model, development of the community is stressed, in addition to training people with disabilities. Thus, service provision takes place within the context of community based programmes which aim:

- to create a situation that allows each disabled person to live a fulfilling, self-reliant, and whole life, in close relation with other people

- to help other people — family, neighbours, school children, members of the community — to accept, respect, assist (where necessary), provide equal opportunities for, and appreciate the abilities and potentials of disabled people (18).

When put into practice, the community development model of CBR emphasises a greater focus on community change than on the rehabilitation of individuals. This model also emphasises that systems approaches are not the only ways to conduct credible, rigorous evaluations. Participatory evaluation methods, which are used in many international development programmes, rely on local development of community level processes. Such participatory evaluation often is more relevant to communities with the result that they accept the findings of evaluations and readily support decisions on program changes. While this model also assesses traditional human service issues, evaluation of such programmes attempts to gain the real participation of those involved in the programme. Thus, participants have varying degrees of control of the evaluation process. The central issue for this evaluation approach is how much control do participants have and how does it affect the 'objectivity' of the findings?

Participation of programme participants is advocated at all stages of the participatory evaluation approach: deciding to evaluate, determining the evaluation objectives, selecting evaluation co-ordinators, choosing evaluation methods, writing the plan, preparing and testing the methods (including training the data collectors), collecting the information, analysing the information, preparing and reporting the findings, and deciding how to use the results.

The inclusive philosophy of participation in evaluation lends itself to using different sources of knowledge and forms of information, so that naturalistic observation and qualitative methods are often used (19). However, incorporating participants within the evaluation process does not mean avoiding the use of statistical or quantitative measures of change.

There has been a real evolution in the development of participatory approaches to research and evaluation. Participatory Rural Appraisal (PRA), which has its base in participatory action research (PAR) and rapid rural appraisal (RRA), has been described as "a family of approaches and methods to enable rural people to share, enhance, and analyse their knowledge of life and conditions, to plan and to act." (20, p.67). PRA is used in the fields of natural resources management, agriculture, social programmes, and health. This research approach within rural development was intended to evolve evaluation from eliciting and extracting information by outsiders, to creation of information to be shared and owned by local people. PRA in CBR has offered an expanding menu of methods for acquiring information, from the tried-and-true semi-structured interviews, to more unconventional

group discussions, exercises and activities (21). However, in practice, PRA has often become one more set of tools for the practitioner to use to extract information. For example, field staff often refer to "doing a PRA to provide us (programme staff) with needed information" (22).

As with the Stakeholder and Action Research approaches of system evaluation, a participatory element within evaluation seeks to address relevance and utilisation, and it is an improvement in terms of gaining different sources of knowledge and experience. However, the inclusion of disabled persons in the evaluation process does not guarantee that all useful forms of knowledge will be gathered. Such evaluation can generate a narrow experiential base of information which does not take advantage of outside knowledge or technologies. Furthermore, programme staff and beneficiaries may be merely incorporated into a systematic evaluation structure, and their participation may be used simply for increasing productivity or efficiency of the evaluation (23). At its worst, participatory evaluation can be an exercise in co-opting a compliant group of disabled persons to fulfil a professional agenda.

Finally, what is called participatory research need not address issues of social justice. Justice is not addressed when participants in evaluation activities are exactly those who have been able to afford the time to participate, who reap greater benefits from the program in the first place, and now continue to do so by influencing the evaluation too (24). Thus, a participatory evaluation does not necessarily address the roots of social inequity.

3. CBR AS JUSTICE, AND AN EMPOWERMENT APPROACH TO EVALUATION

It has been stated that the political tendency of evaluation is basically reformist and looks toward modest change, rather than fundamental restructuring (25). The participatory evaluation, although emphasising consensus and involvement among participants, may make assumptions that are no different from a systems approach, that is, being uncritical of the basic dimensions of the 'problem'. (26, 27). Many disabled persons believe that the world is a discriminatory place where they are oppressed and marginalised (28). If CBR is to play a role in the development and transformation of society towards greater justice for disabled people (29,30) then underlying values regarding empowerment must be made explicit in CBR programmes. The perspective and methods for CBR evaluation must also reflect values about a just world for disabled people.

In the empowerment model, evaluation becomes more than a determination of whether programme goals are being met or whether disabled persons are involved. A key distinction between systems or participatory evaluation and evaluation in an empowering style of CBR is the emphasis on evaluation as a development activity in itself, that is, an activity intended to change social injustice in a setting. In re-visiting the earlier definition of an 'empowerment' style of community participation in CBR, we note the crucial importance of people increasing their abilities to influence social conditions and to improve their disability situations.

For example, some key elements of CBR as justice could include:

•   the self-organisation of rehabilitation services by disabled persons

•   explicit, open partnerships with service-providers and non-disabled persons

•   advocacy for changes in legislation, policies, and programme guidelines

- local determination of CBR activities, e.g. freedom to choose economic activities versus therapy or public education

Thus, CBR as justice has goals towards the self-development of disabled people, who can and should be enabled to conduct their own analysis of their own reality. Fernandes and Tandon (31) propose evaluation as a method to achieve these goals when evaluation is a process of liberation and when it affirms the community's ownership of knowledge:

"the approach is an effort to check the present trends of (a) professionalisation and centralisation of knowledge in its generation and utilisation since it can be used to manipulate the actors of a social setting without their having any control over it; (b) the neglect of the actors in the situation not only as sources of knowledge but also as its legitimate owners." [p.21]

House (32) states that it is necessary for evaluators to assume a deliberate theoretical position since evaluation is a political activity and is involved in the distribution of goods in society. House further suggests that evaluation should be founded equally on the principles of truth and justice. Current evaluation methods tend to focus on the determination of 'truth' and assume that 'justice' will be served automatically. However, there is evidence that justice cannot be achieved in an evaluation unless it is specifically addressed. A just evaluation requires a unique set of assumptions and methods of investigation.

As previously noted, one problem for evaluators in community settings has been to devise a methodology for evaluating programmes which have conflicting goals held by different constituents. The stakeholder approach has traditionally treated these conflicting goals as perspectives of equal merit and attempts to provide a balanced view of the programme. However, this does not necessarily resolve conflicts among diverse groups (17). The stakeholder approach also fails to address the degree of influence and power which some participants possess. Those with the greatest resources, or alternately the fewest needs, are more likely to have their perspectives prevail (32). Evaluation methodology can address this problem if it recognises that both the collection and interpretation of evaluation data are systematically biased in favour of those with influence.

An alternate evaluation paradigm has been proposed which explicitly identifies social justice and equality as values which can underlie inquiry (33,34). This critical evaluation perspective assumes that, in addition to focusing on questions of power differences and social justice, the methodology itself must incorporate new methods and analytic tools that are based on an empowerment paradigm (10).

Paulston (35) applies the empowerment paradigm in a comparative evaluation model. Assessment under this comparative model focuses on asking questions from different perspectives. Questions under the 'efficiency' paradigm inquire whether the programme has achieved its goals efficiently. Questions under the 'empowerment' paradigm inquire whether the programme has altered power relations and inequities between dominant and subordinate groups. But when is this information gathered and considered?

Sirotnik (10) has developed a critical inquiry model for evaluation. This model proposes a hierarchy of evaluation methods. Initially, explicit descriptive material is collected about quantifiable

aspects of the programme. These data are then used as catalysts, or sources of information, from which programme participants offer their perspectives. At this stage, the meaning and worth of the data within participants' personal contexts is explored to yield qualitative material. Finally, the quantitative and qualitative data are interpreted together, within a social and historical context, and through reflection on power relationships within the setting. Sirotnik's model represents a significant advance in critical evaluation and is intended as a means for resolving conflicts in programmes. However, it assumes that influential interests will agree to the proposed hierarchy of methods prior to viewing evaluation data. The model also focuses primarily on methods for interpretation of data and ignores the question of bias in initial data collection.

In recent years, the term 'empowerment evaluation' has been discussed. In this model, also known as developmental evaluation, evaluation expertise is incorporated within the actual team designing and implementing a programme. Set evaluation goals are minimised, being over-shadowed by the aim of on-going change and improvement (36). In such cases, Patton notes that:

> ... the evaluation process has had to be highly flexible and responsive. Taking a 20-year, developmental perspective, where the locus of accountability is community-based rather than funder-based, changes all the usual parameters of evaluation (p.315).

In the area of disability advocacy, there are numerous examples of empowerment evaluation (37,38). However, in the field of rehabilitation, empowerment evaluation is very new, perhaps because of the entrenched interests of professional rehabilitation programme evaluators. One example of empowerment evaluation does appear in the CBR literature. Project PROJIMO in Mexico is using in-depth and structured interviews as anthropological techniques for eliciting life stories, which provide the basis for analysis of the disability situation of project participants. Evaluation is described as an informal, co-operative, continuing group activity, without clearly defined roles for the group members. Members of the group participate in collecting and reviewing quantitative and qualitative data, with the aim of monitoring and improving the programme (39). Whether this evaluation has actually contributed to Project PROJIMO's social justice goals is unknown.

III METHODOLOGY OF AN EMPOWERMENT APPROACH TO CBR EVALUATION

In the spirit of critical inquiry, we pose some key questions that should be addressed in an empowerment approach to CBR evaluation. We leave the development of answers to these questions ultimately to programme stakeholders.

Who should participate?

How do we address the actual participation of those whose input is hardest to get? This is a realistic dilemma when working in the field of disability. One may need to be pragmatic and start somewhere. It is helpful to begin with programme personnel and organisations of disabled persons. One cannot expect that disabled people will always be able to participate fully, but one use the mobilisation of disabled people to its fullest when it is there.

What goals should be evaluated?

If the overall aim of a programme is empowerment, then progress in this goal must be explored, even though empowerment is an unclear term and highly dependent on the local culture. Focusing

on concrete programme objectives which involve 'stepping stones' to empowerment may include changes in:

- Community and family attitudes
- Integration into public institutions and private enterprises
- Transfer of knowledge and skills through self-help
- Services that directly respond to needs expressed by disabled persons, family members
- Models of partnership and co-operation among staff, disabled persons, community
- Community decision-making and accountability
- Appropriate technology
- Referral network to other services

The need for information to assess these objectives is clear and principles of information based rehabilitation could be valuable here. The key question for empowerment evaluation is how deeply we analyse the findings.

What should be the role of the evaluator?

Can CBR programmes have empowering partnerships with external evaluators? The evaluator would be a resource to those in the programme. The evaluator would be a collaborator, with a role partly as learner and partly as teacher, in the style of developmental evaluation. The evaluator need not have a role in reporting to external groups, nor in accountability. The evaluator instead would assist participants in understanding the context of the programme, how programme activities affect disabled persons' problems, and how to change the programme.

What method should be used?

There are five steps in empowerment evaluation. All are essential and cannot be missed or addressed out of order. However, the steps can be repeated over time. Key questions are addressed at each step.

- *Understanding the problem***:**

  What are we doing now? How did it come to be this way? Why are we really running this programme as we are now?

- *Reflection:*

  Whose interests are being served by the way things are? What is the nature of a just society? How does what we do (or not do) fit into this picture?

- *Identifying needed information:*

  What information and knowledge do we have, or need to get, that bears on the issues? How many disabled people are and are not reached by the programme, and why? Do certain people benefit more than others? Which activities work well? The evaluator may speculate on how this information will actually be useful.

- *Getting and summarising the information:*

  The evaluator can help to develop realistic plans for getting the information in a usable form. Can we assess the information in an open way?

- *Taking action:*

  What are we going to do about all this? What are our options and do they improve the situation?

CONCLUSION - SOME PROBLEMS WITH EMPOWERMENT EVALUATION

Although empowerment evaluation is a new approach for CBR, we should be aware that other approaches, such as participatory evaluation, were also new in their time. There are a few issues which need to be discussed by those interested in CBR as justice and the use of empowerment evaluation to address injustice. First, there is a fundamental issue of whether the external evaluator's primary responsibility lies with the sponsor of the evaluation or with the group being evaluated, especially if it is a disadvantaged group such as disabled persons. There is no easy answer to this question. Perhaps it is worth keeping in mind that the beneficiaries of the programme must be satisfied in the long run or the evaluation will be pointless.

Second, empowerment evaluation is often seen to be either 'unscientific' and not believable, or 'threatening' and not acceptable. These issues are more significant problems of perception than actual problems. We believe that their solution lies in demystifying empowerment evaluation by increasing peoples' familiarity with it.

Third when is the evaluation over? Empowerment evaluation is not a set of applied, time-limited research technologies but rather an ongoing, collaborative, value-driven process of organisational change and improvement. It is a continuous process and becomes part of the CBR manager's tool kit.

Finally, a basic assumption of this evaluation style is that the force of the better argument allows participants to reach a justified consensus. While this is an oversimplified description of the process of critique, the basic requirement for empowerment evaluation is unlimited opportunity for discussion, free of constraints from any source. However, people do not always interact with one another in the way we suggest, except perhaps in the most honest of relationships.   Can CBR actually succeed with this approach?

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A DISCUSSION OF SOME CRITICAL ASPECTS IN PLANNING OF COMMUNITY BASED REHABILITATION

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ABSTRACT

Till recently, the need for systematic planning and management of community based rehabilitation (CBR) programmes had not received much attention. However, due to compulasions such as decreasing funds for welfare work, increasing needs for accountability, cost reduction and improving effectiveness, and the need to improve sustainability and so on, emphasis is now being laid on systematic planning and management of these programmes. This chapter discusses some generic factors that are critical in planning and management of community based rehabilitation progrmmes, based on the work of the authors in different countries in south Asia, south east Asia and Africa. The issues dealt with are the need for planning based on   clear goals and well planned activities in the context of the needs and resources of the community; the need to have a plan to enhance community participation and sustainability; the need to recognise cultural factors in planning; and the need for planning based on research evidence.

INTRODUCTION

Because of poor financial resources, most developing countries had relatively little coverage of services for their disabled citizens till about two decades ago,. To address this problem, the World Health Organisation initiated few model projects in the seventies and eighties, with a service delivery system that was affordable to developing countries and provided wider coverage of services. The key element in this system of community based rehabilitation, was the transfer of minimum and essential rehabilitation intervention skills to families and other volunteers in the community, thereby reducing the costs (1). Over the last two decades, there has been a major growth in the number of community based rehabilitation projects around the world, providing the minimum services required for disabled people in countries that had scanty resources and poorly developed services. Alongside, there have been many changes in the understanding and implementation of community based rehabilitation interventions (2). The focus has now begun to shift from the issue of a minimum level of service delivery, to other management issues that influence effectiveness of services, and to the process of development of community based rehabilitation as a mature method of service delivery for developing countries. Hence the emphasis has shifted towards planning and management, monitoring and evaluation, research, information generation and dissemination, and so on.

 "Management" in relation to development organisations refers to both client management, such as rehabilitation interventions, and programme management, which knits together the different components of the programme to make it function as a whole. Till recently, most development organisations tended to focus primarily on client management. However, due to compulsions such as decreasing funds for welfare work, increasing need for accountability, need to reduce costs and

improve effectiveness, need to improve sustainability and so on, aspects of programme management have grown in importance (3). This chapter discusses some programme management issues that impact on the outcome of community based rehabilitation, based on the work of the authors over the last decade in different countries in South Asia, South East Asia and Africa (3). Though the issues dealt with are not comprehensive, they focus on some common factors that are critical in planning and management of community based rehabilitation programmes.

PROGRAMME PLANNING

Many community based rehabilitation programmes in India and other South Asian countries are carried out by voluntary organisations in the non-governmental (NGO) sector. A close look at some of these programmes shows that they originated as a set of activities without clear goals, and have continued without long term plans. Some programmes were started because of the availability of designated funds for that particular activity at that point in time. With shifts in donor priorities, the activities of some of these organisations changed according to the availability of funds. These programmes often did not have monitoring and evaluation systems, nor did they define their outcomes or attempt to measure them. Instead, they repeated a set of activities year after year, with some illustrations and anecdotes from their clients, to justify why they had to continue their activities. Such activities tended to be donor dependent, cost-intensive, seldom successful, rarely sustained once the donor withdrew support. Therefore, they often became counterproductive to efforts of the local community in developing more appropriate, grass root led rehabilitation services. Consumer satisfaction was also limited, as client needs were rarely taken into account for these activities (4).

Programme planning is thus a crucial component of development activity, but it is by no means synonymous with the preparation of the initial project proposal to fulfil donor requirements. Unlike what is often claimed, it does not also result in curtailment of creativity in a programme. On the contrary, it enhances creativity, and if channelled adequately, it increases effectiveness. It also does not mean that planned programmes cannot be initiated in response to sudden needs for interventions, as in disaster relief. Thus, in any on-going programme, it is necessary to have clear goals and a set of actions for it to be successful.

WORKING OUT DIFFERENT STEPS OF A PROGRAMME PLAN

STAGES	STEPS	WHAT	BY WHOM
PRE-POLICY STAGE			
Pre-policy stage	Problem identification	Determining if disability is a priority in the target area	Catalyst--Donor, Government, NGO etc., or Community or Client groups
Pre-policy stage	Situation analysis	1. Literature review 2. Need analysis / resource analysis	Catalyst or Community or Client groups

POLICIES

Policy	Vision	Long-term end <u>results</u> (Goals)	<u>Stake holders</u> 1.Donors 2.Interventionists 3.Clients
Policy	Mission	Long-term <u>methods</u> to achieve the goals	<u>Stake holders</u> 1.Donors 2.Interventionists 3.Clients
Policy	Objectives	Medium -term <u>directions</u>	<u>Stake holders</u> 1.Donors 2.Interventionists 3.Clients

ACTIVITIES

Activities	Strategies (short term, medium term, long term)	Objective related, quantifiable, measurable, outcome indicators, with targets set for completion in a unit time	Executive Approved by the stakeholders

BUDGET

Budget	Income	<u>Source-wise</u>	<u>Sources</u> Short term, Medium term, Long term
Budget	Expenditure	<u>Activity-wise</u> Short term, Medium term, Long term	<u>For what</u> 1.Recurring Manpower / Material 2.Capital

The different steps taken during a programme plan are summarised in the table. In the pre-policy stage, one needs to determine if disability is perceived as a 'problem' that needs intervention on a priority basis in the target community. This is followed by a current situation analysis, which helps to confirm whether there is a need for intervention, what priority the consumers assign to the proposed problem in relation to other problems, whether the consumers view the proposed intervention as beneficial to them in addressing their problem, and so on. Community based rehabilitation interventions influence the lives of disabled persons, their families and their non-disabled peers in the project area. Hence the needs of the different groups who are affected by the interventions, have to be identified before undertaking strategic planning for the programme. The different groups in the same community can have differing needs that conflict with each other. For example, the needs of disabled persons may not necessarily be related to the priorities identified

by other groups. In most instances, community based rehabilitation programmes have a mix of short term, medium term and long term priorities that are related to integration of disabled persons into society. They may also differ widely from the priorities of other groups in the same community, which usually are short term poverty alleviation and curative health interventions. In situations where the needs of the different constituent groups differ from the priorities of the community based rehabilitation programme, the first strategy should be to reduce this attitudinal gap by changing the attitudes of people favourably towards the rehabilitation interventions. For this purpose the existing beliefs and attitudes of the different constituent groups need to be studied, and strategic plans designed to introduce changes in the attitudes of the groups. The community's attitudes may also be influenced by its experiences of services that existed in the past in the project area. Needs analysis is a method for assessing the opinions of different groups within the local community, such as community institutions, family groups, self help groups of disabled persons and so on, who may be interested in community based rehabilitation services in their area, as well as of interested groups outside the community, such as the government, donor organisations, catalyst NGOs and so on. In the pre-policy stage there is also a need to identify the different material, financial and personnel resources available locally for later use, their accessibility, and the modifications required for utilising them. The resource analysis gives an idea in advance about what new resources will have to be generated for the programme.

Successful completion of the pre-policy stage usually progresses to policy development, which includes defining the vision, mission and objectives of a programme. The 'vision' is the ultimate goal of the programme as long as the programme lasts, while the 'mission' is the sum of all activities to achieve the vision. The vision and mission are timeless and concise statements of what the programme stands for. Objectives are the medium term directions to achieve the vision, that may be changed sometimes if deemed necessary after an evaluation. These components of the policy are best evolved in a participatory and democratic manner involving all stakeholders of a programme, rather than by any particular group. A participatory process of policy development will help to avoid future conflicts and enhance collective action. Once a policy is formulated, it requires to be widely disseminated amongst all stakeholders and other associates of the project. Most organisational members are usually able to articulate the organisation's vision and mission well, but have difficulties in clearly stating their objectives and activities. They often describe numerous objectives that are over-inclusive, without considering whether it is feasible for the organisation to fulfil them at all, in the available time. Sometimes activities are confused with objectives and vice versa, which results in poor strategic plans. Quantitative target setting is rarely followed in most poorly planned programmes.

Selection of activities and formulation of a strategic plan are usually the responsibility of the executives of the programme, and are executed with the approval of the governance (5). Individual activities of a strategic plan are short term components of a programme, usually planned for a calendar year or a financial year. In order to monitor a programme easily, the activities need to be defined precisely, with well defined, quantitative targets for achievement for each activity in a unit time. The expected outcomes, the indicators to measure the outcomes and the resultant impact are also required to be defined clearly. Organisations usually enumerate their activities with quantitative measures of coverage, in the belief that they can represent outcomes and impact. However, without outcome and impact measures, it is impossible to know if a programme has been genuinely successful.

Although some effort is required to develop a detailed strategic plan with well defined activities, targets, expected outcomes and their indicators, such a process can be of significant benefit to the programme in many ways. It helps the organisation to monitor and control the progress of their efforts easily, to clearly define the individual responsibilities to the programme personnel, and to make the programmes transparent and accountable to the stakeholders.

ENHANCING COMMUNITY PARTICIPATION

Community participation was considered as an essential part of community based rehabilitation ever since it was promoted as a suitable approach for rehabilitation in developing countries. In practice, however, most programmes have found it difficult to achieve adequate levels of community participation for several reasons (6). Many developing countries had a period of colonial rule before they became independent, followed by socialist governance in which the state is viewed as solely responsible for all welfare and development work. Concepts of decentralisation and bottom up approaches are relatively new in many of these countries even today. Besides, the majority groups in the community are not altruistic enough to address the needs of the minorities such as disabled persons, until their own needs are met. Another issue is that small, but powerful groups in the community often corner the benefits from development programmes, ignoring the needs of marginalised groups.

Community participation of the highest degree, where the community members take on the responsibility for planning, implementing, sharing the risks of and monitoring a community based rehabilitation programme which benefits disabled people, is desirable, but difficult to achieve. Depending on the cultural context, the ideal level of community participation is viewed in different ways by different people. On the one extreme, a community may be viewed as passively participating by being a recipient of services, while on the other extreme, participation may be viewed as complete ownership of the programme. Developing countries are still unfamiliar with Western notions of consumer ownership of programmes. Hence to begin a programme with the concept of full ownership by the consumers sometimes results in failures. In these countries, it is often necessary to enhance community participation from the inception of the project, in a planned manner, keeping in mind the difficulties that can be encountered as the concept of full community responsibility is introduced. In the context of community based rehabilitation programmes, ways have to be found to motivate the marginalised groups of disabled persons, their families, and communities to achieve a participatory mode of development, in which the community will assume some of the responsibilities to begin with, and move on at a later stage to take on most of the responsibilities of the rehabilitation programme.

Usually, small projects, started in response to community needs result in better community participation, while large projects with apathetic and centralised service delivery systems are viewed with indifference by the community. As in any other strategic plan, enhancing community participation requires clear understanding of the attitudes of people in the community, their current level of participation in the programme and the expected level of participation to be achieved in the future. It is sometimes difficult to define the current level of participation by the community because of inadequate understanding about how to grade the different levels of participation. Answers to certain key questions regarding the current level of participation, and the project's intentions to enhance participation in the future, can give a broad idea about how much more needs to be done in the future.

WHAT IS THE CURRENT LEVEL OF COMMUNITY PARTICIPATION?

Community: ·

- How much does the community know about the programme ?

- How much do they know about the organisation carrying out the programme ?

- How often do they come face to face with the programme personnel ?

- What responsibilities do they carry out on behalf of the programme ?

- What kinds of difficulties do they face in undertaking these responsibilities ?

- How satisfied are they with the involvement in the programme ?

- Do they have any suggestions to improve their participation in the programme ?

- Are all sections of the community equally involved in the programme ?

- Why are some groups involved while others are not ?

Project management :

- What are the future plans to improve community participation ?

Community participation can also be graded in a quantitative format for the purpose of yearly monitoring.

QUANTITATIVE ANALYSIS OF COMMUNITY PARTICIPATION

Involvement of the clients in	Scores			
	Date	Date	Date	Date
Programme interventions				
Programme administration				
Programme planning				
Taking leadership roles in the programme				
Resource mobilisation for the programme				
Monitoring and evaluation of the programme				
Goal setting for the programme				
TOTAL				

Scoring key : No involvement = 0; small involvement = 1; average involvement = 2; good involvement = 3; excellent involvement = 4

Though it is difficult to speedily enhance community participation in programmes from developing countries, having a strategic plan to enhance participation and monitoring its success periodically can result in better sustainability in the long run. It will also influence more realistic goal setting practices during the planning stage.

PLANNING FOR SUSTAINABILITY

Concerns about sustainability of community based rehabilitation programmes surfaced with the threat of diminishing funds for welfare work, and the increasing emphasis on accountability and cost effectiveness. However, the term 'sustainability' tends to be commonly associated even now with 'finding funds' for a community based rehabilitation programme. Such an interpretation of the term ignores the other important aspects that contribute to the meaning of sustainability. Sustainability is a long term concept, that addresses people's central concerns and values, looks to the future, strengthens a community's ability to deal with change, develops processes for finding common ground, strives to benefit all members of the community, emphasises the involvement of people, improves accountability, develops a vision for the future, keeps track of the progress and meets the basic resource needs. Sustainability may be defined as the ability of the system to perpetuate itself using locally appropriate strategies (mission), so that the system continues till its goals (vision) are achieved (7).

Financial sustainability often refers mistakenly, to the ability of the organisation, usually an NGO in a developing country, to access enough funds to maintain its structure and personnel. When funds become scarce, the NGO may sometimes change the goals of the programme, sacrificing the programme in the interest of maintaining itself. This is counterproductive and detrimental to the interests of the programme and its clients. Sustainability of the programme, in more accurate terms, refers to sustaining the vision and mission of the programme, and to keep the programme going till the vision is realised. Usually organisations implementing development programmes go through different phases of growth, which are important to understand while planning for sustainable growth. These are not mutually exclusive, nor does it mean that all organisations go through these different phases and in the same sequence. The initial catalyst phase is generally of one to two years duration, with a high degree of involvement of a few initiators. This is usually followed by a growth phase, where there is creative expansion of the work of the organisation for two to three years. Around the fifth year or so of an organisation's existence, there may be a phase of crisis, sometimes leading to conflicts and resulting in either the collapse of the programme, or a constructive reorganisation. Finally, if the crisis is successfully resolved, there is a phase of sustainable and steady growth which fulfils the vision of the programme.

In planning for sustainability, it is important for planners to first identify the different factors that influence sustainability of a programme in its given social and cultural milieu, and then to develop strategies to improve sustainability in relation to the different factors identified through this exercise.

COMMON FACTORS INFLUENCING SUSTAINABILITY

COMPONENTS OF THE PROGRAMME	FACTORS INFLUENCING SUSTAINABILITY	STRATEGIES TO IMPROVE SUSTAINABILITY
Organisation as a whole	Institution building Developing organisationalvalues Developing self reliance	Establish credible governance Establish appropriate legal frame work Establish institutional ethics Transparency of organisational affairs Influence competitors to become collaborators Generate goodwill from community
Policies	Developing need related policies Developing strategies manageable within available resources Participation of all stake-holders in developing vision, mission and objectives Developing policies congruent with national plans Transparency of policies & strategies Developing valid vision & mission	Institute participatory analysis of needs and resources, carry out literature review and feasibility study before starting the programme Develop strategies through participation of stakeholders Include all direct and indirect stake holders in decision making Refer & consult national plans Clarity of policies and plans Undertake pilot project before starting the programme Develop quantifiable definitions of strategic activities Maintain permanent vision and mission without changes in the interim
Management	Establishing accountability Studying feasibility before initiating strategies Establishing efficient administrative systems Establishing personnel management systems	Improve transparency through frequent communications Effectively use available infrastructure Describe roles & responsibilities of personnel & institute appraisals Establish consensual decision making, regular monitoring, & participatory planning, Respond to consumer feed-back Avoid high staff turnover Institute career planning for personnel Enhance training in appropriate skills

COMPONENTS OF THE PROGRAMME	FACTORS INFLUENCING SUSTAINABILITY	STRATEGIES TO IMPROVE SUSTAINABILITY
Leadership	`Personality' of the leader Transparency in communications Technical skill High motivation Supervisory ability	Promote democratic leadership Phase out unsuccessful strategies Introduce mid course changes when necessary Avoid hidden agenda Enhance motivation of programme personnel Enhance interest of all stakeholders Decentralise operations & involve disabled persons & their families in the programme
Financial	Optimal use of resources Ensuring cost effective and cost beneficial interventions Continuous availability of financial resources Access to national governmental and non-governmental funds Ability to access resources according to national & international economic changes Avoidance of over-funding and expansion beyond the project's capability	Avail multiple sources of funding Access governmental & community funds Designate income & expenditure to activities Institute cost efficiency and cost benefit analysis Avoid over-funding of projects Access a balanced mix of short term medium term and long term funds
Interventions	Training Research Coverage/Quality Monitoring/ Evaluation Awareness	Use proved interventions Use appropriate technology suitable to local culture Train and update intervention skills Undertake research to upgrade interventions Aim for maximum coverage, with available funds at optimum quality Terminate unsuccessful strategies Monitor regularly and make corrections Evaluate periodically and make mid course changes in objectives Institute structured, focused and effective awareness building interventions

COMPONENTS OF THE PROGRAMME	FACTORS INFLUENCING SUSTAINABILITY	STRATEGIES TO IMPROVE SUSTAINABILITY
Phase out	Withdrawal of the catalyst agency Technical & financial self sufficiency Attitude change in the community Permanency of the `vision' & `mission' of the programme Wide dissemination of policies to all stake holders Proven methods of interventions Rapport with the community and the clients Well established administrative system	Define time specified, area specific, sector specific withdrawal plan Improve community participation at all levels of the programme including monitoring and evaluation Empower participation of disabled persons & their families in the project Encourage maximal use of volunteers from the community Avoid mid course changes in `vision' & `mission'.

RECOGNISING THE IMPORTANCE OF CULTURAL FACTORS

Cultural factors play a very important role in determining our behaviour in day to day life. These factors influence our attitudes towards most of the happenings around us, including 'disability'. Community based rehabilitation is context dependent, and the term 'handicap', the most influential parameter for intervention in rehabilitation, is defined in relation to contextual factors that are predominantly cultural. 'Cultural factors' in the broad sense are a set of variables related to tradition, ethnicity and religion, grouped together into a single entity, that influence participation of disabled persons in their milieu. Even across the population of a single country, there are substantial differences in ethnicity, caste, religious practices and so on, which are recognised by different laws applying to different groups within the same nation. What seems to be ethnically correct behaviour in one group of people, may not be recognised as such by a different cultural group. The recognition of these differences in the perception of 'normalcy' and 'disability' is very important in the case of rehabilitation, since what is considered a 'handicap' in one cultural context may be considered normal in another context (8).

The influence of cultural factors is so great, that many community based rehabilitation interventions fail as a result of scanty recognition of these factors. Yet during the planning stages of programmes, most projects recognise culture as only an insignificant determining factor that influences success. For example, Western stereotypes of 'community' are often referred during programme planning of community based rehabilitation programmes in developing countries, where communities have their own individuality that is different from Western norms. These programmes expose themselves to a higher risk of failure because they tend to conflict with the cultural factors of the host country. The concept of individual rights and empowerment, as expressed and understood in the developed world, does not exist in many developing countries. Traditionally in these countries, an individual belongs to a kinship group, with a network of relationships and mutual obligations. Because of this kind of relationships, the concept of empowerment of any individual, whether he is disabled or not, is more complex than in the developed world. In many Asian countries, 'empowerment' of the individual as understood in the western context, is seen as a selfish and

undesirable concept. Being altruistic for the sake of the family and for the larger society has a higher value. Hence an individual tends to remain role-bound, submissive and obedient, and conformity with the traditional systems becomes a virtue in such a situation. In these societies, the term 'empowerment' can at best be interpreted only as a right to access provisions and services on an equal footing as others. Similarly, women in many traditional societies remain segregated from the men, and 'integration' of disabled women into the 'community' is perceived in a different manner from the west. In such societies, disabled women can be integrated into a community of segregated women, but they need to remain separate from the men.

Rehabilitation is a gradual and long process that cannot escape the influences of local cultural factors, particularly because decentralisation of services into the community, and integration of disabled persons into their society, calls for closer attention to cultural factors. There is enough evidence from literature (9,10) to suggest that culturally appropriate community based rehabilitation programmes can be practised in many traditional societies by appropriately adapting strategies to make the programme suit the given cultural context. It is very important for community based rehabilitation planners to give adequate emphasis to these factors during policy development and planning, to avoid the high risk of later failures.

RESEARCH BASED PLANNING

In the early years of community based rehabilitation, there were few publications on this topic. The situation has changed in the nineties with the growth in the number of publications. However, most of the articles in these publications deal with experiential dimensions, descriptions of projects, and a few conceptual issues. Though the number of publications has increased significantly, there are still very few that deal with scientific literature (11). In spite of the recognition of the need for research in this field (12, 13), research has generally been ignored, and community based rehabilitation has grown on experiential accounts rather than with scientific evidence. In an evolving field like community based rehabilitation with new and untested methods, research is essential and may even be considered an ethical necessity. Many of today's practices are untested, such as methods to improve coverage and reduce costs, the shift in interventions to homes, training of families and volunteers, and the change in milieu from the structured and organised environment of institutions to the unstructured and often disorganised milieu in the community, and so on. They need to be empirically verified before being implemented through large programmes. Many questions remain unanswered regarding the methods in community based rehabilitation, which can only be answered through research. Because of the limited resources for rehabilitation in developing countries, the proponents of community based rehabilitation in these countries tend to spend less on research. However, research is necessary for optimal utilisation of resources, instead of random and ad-hoc activities that only lead to poor results and wastage of resources in the long run.

CONCLUSION

Community based rehabilitation planners have not concentrated sufficiently on developing viable programme management systems until now. The field of community based rehabilitation is unlikely to achieve progress and expand, unless good systems are established for efficient management of these programmes. The last two decades have seen many changes and adjustments in community based rehabilitation, but they have not yet conclusively answered what aspects of this

approach need to be modified and how it should be done. One hopes that in the next decade, answers to some of these questions will be forthcoming, that will result in increased attention being paid to research, systematic planning, and more efficient management of community based rehabilitation programmes.

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TRAINING OF CBR PERSONNEL

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ABSTRACT

The issues around appropriate training for community based rehabilitation (CBR) are as varied and numerous as the issues around CBR practice. It is only by exchanging ideas and by evaluating and promoting good practice that the training of CBR personnel can progress in a way which will enhance rather than restrict the development of appropriate CBR in varied communities. This chapter addresses some issues related to trining of CBR personnel, starting with an overview of levels of training, such as grass root level workers, mid-level workers, planners and trainers, and professionals, focusing more on the latter 3 levels. The author goes on to discuss the types of CBR programmes for which personnel are being prepared, namely, CBR as rehabilitation, CBR as equalising of opportunities, CBR as part of development programmes ensuring that all development programmes consider the needs of people with disabilities and so on. The chapter concludes with a brief review of the more readily available training materials in CBR.

INTRODUCTION

This chapter addresses some issues of training, and the first question which must be asked is who are the personnel who are to be trained? Helander (1) and others have described the three levels of community based rehabilitation (CBR) as perceived by WHO and by UNDP. These descriptions clearly refer to three levels of service;

* grass roots (or level one) workers who deliver service in a community

* mid-level workers who organise and support these workers

* professionals to whom referrals can be made from the community or who refer users to the community

Too often CBR projects which follow, in broad terms, the WHO model fail to recognise the need for training and organisation of the second and third levels of service. Other programmes which would not subscribe to the WHO model may have active Disabled People's Organisations (DPO) involvement in planning and training at community level but have little training focus or support for those professionals on whom all community services will have to call at some time.

The basic and most numerous group of personnel involved in CBR are grass roots workers. Such grass roots workers (sometimes called first level workers) may be volunteers or salaried, but the most important fact about their training is that it must be local and geared to the needs of the project they are to serve. Some questions which arise are: how does one include hierarchical complications if volunteers and staff, or staff and parents are trained together? However, most issues related to grass roots training are local and have no real place in a volume such as this and certainly not in a chapter written by someone in London.

MID-LEVEL WORKER TRAINING

Reference to mid-level workers is common in the literature but there seems to be less shared reference as to the role of this cadre of workforce. Are they supervisors of volunteers and grass roots workers with monitoring and record keeping roles, sharing this information with programme managers? Or are they the project managers? This has important implications for training, if management skills are to be part of the battery of skills which mid-level workers require. Is this to be man-management and financial management skills or will the financial management of a project (other than expenditure accounting) be undertaken by more senior staff in the programme?

Do mid-level workers remain operational, seeing families and persons with disabilities (PWD), or are their responsibilities concerned with monitoring and managing volunteers? If they are to be effective managers and to retain credibility with their teams of grass roots workers and the community, it is necessary for them to retain some operational duties. This means that they will need more advanced training in topics such as further rehabilitation techniques, public relations and attitude changing, than those of their grass root worker colleagues. If they are to do their job well as supervisor managers they must be prepared to support and advise their less experienced colleagues.

These demands begin to describe an individual who has a range of skills and knowledge which he can use creatively, either by himself or by supporting others, and begs the question as to the type of training such a person requires. Is training predicated upon the idea of skills transfer where mid-level workers are taught what to do in certain circumstances or upon problem solving? Is the assumption that mid-level workers in different projects will have similar demands from training and should be taught together or should training be project specific?

There are arguments for and against project specific training as opposed to training which is open to people from a variety of projects. If training of mid-level workers is open to people from different projects there is always a danger that good staff will be 'poached' during or after training. Employers may seek project specific training in the guise of being able to meet specific needs, in order to avoid such temptations. Projects of non-governmental organisations (NGOs) s are freer to be more innovative and to change focus in response to need than government services. Is it possible therefore to design a common mid-level training which can meet the needs of both mid-level workers from NGO and government service?

TRAINERS AND PLANNERS OF CBR

An important determiner which people bring to the beginning of a course, is their experiences of disability, of the community and their personal technical skills. This discussion of what people bring to training is divided with reference to:

- expectations of training

- expectations of services

- expectations of the rehabilitation process

Disabled activists in the UK have led the world in the creation and development of theoretical frameworks with which to construe disability issues and thus foster lively debate (2, 3, 4). British

disabled academics have had an important impact on the development of policy and practice in the UK and perhaps in other parts of Europe but as yet none of these theorists have addressed the issue of how their ideas may impact in the South. Nor have any disabled activists of the South explored theoretical bases for their (often very effective) advocacy work. Stone (5) is one of the few who have addressed the dilemma of how to introduce ideas of disabled research activists to Southern partners whose current preference is for the medical model. This is a situation common at the Centre for International Child Health (CICH), London, where we have students who want to move their ideas of planning towards a social model but anticipate little support for this on their return to their home countries.

Lang (6) provides a challenging discussion of the limitations of Northern change for the majority world. One frequently quoted difference between the disability struggles of the North and the needs of CBR is the emphasis on independence (7). Northern society values independence and choice for disabled people as the cornerstones of the disability movement (8). In many countries of the South interdependence rather than independence is the key value and in such a setting, rehabilitation for disabled people which is predicated on the need for independence, is of questionable value (9, 10).

Course participants who are trainers of trainers, or professionals working within CBR settings are much more likely to undertake training in heterogeneous groups. There will be disparity in the countries from which such participants come, in their experiences of disability and of how and why training is provided. The experience of working with such groups, often in London but also on shorter courses overseas, forms the basis of this paper. It is important to consider:

- the course structure including; expectations about the objectives, the process and the outcomes of training (what is sometimes referred to as the "How" of the course)

- expectations of the content (the "What" of the course) of training, (11)

- Ramsden (12) expands this division still further by stressing that course planners must ascertain whether the course structure remains "holistic" with a recognisable composite course ethos, or becomes "atomistic" with such emphasis on the detail of course structure that the overarching objectives become lost.

The expectations of the objectives of training may include; becoming able to do the job better, having enhanced career opportunities and/or higher salary, the chance to be away from home and the day to day activities of the job, opportunity to stand back and consider strategic moves of a personal or service nature, or to improve the lives of people with disabilities. The objectives stated by the trainer are more likely to include both content and personal development focus. The difficulties arise when the huge variation of expectations for undertaking a course are not examined early. In some cultures, the opportunity to take a course of study away from home is seen as an opportunity for personal enhancement and the nature of the training (be it a CBR trainers course, a human resources training or a social policy course) is somewhat irrelevant. For such a candidate, completing the course is the objective rather than the learning opportunities offered by the course. Such a course participant may be unable (because of previous conditioning about frankness of expression) to be frank about his/her motivation for attending the course and will almost certainly not have shared expectations of objectives with other course participants, who have either saved hard personally

or striven to seek funding in order to achieve a place on the training course, nor with the course leader who, at some level, hopes that all participants are there for altruistic reasons.

There is equally wide variation in the **expectation of the process of the training.** Depending upon the cultural experiences of group members there will be a wide variation between those who expect the training process to be active or passive, curriculum led or learning centred, or to follow an expert model of learning as opposed to participatory learning. In many cultures in developing countries, learning is seen as an entirely passive activity, decisions as to what is to be taught are made in advance and participants follow the course, rehearsing and regurgitating narrow answers to closed questions on order to demonstrate that they are learning! Such a "cook book" approach to learning is very seldom successful in any domain, but is doomed as an approach for CBR which relies on developing the creative skills of people. Similarly, in cultures which are resource poor and where a large class size is the norm, especially at school, students are expected to follow a prescribed curriculum rather than a learning centred approach to the course, where participants' needs are addressed throughout the course and affect the nature of the course. A further example of curriculum led activity is where the course leader is seen as the "expert' and the participants as people who "absorb" the expertise. Such cultural expectations of the learning process can lead to difficulties in courses with participants from different cultures.

At CICH course participants following Masters degree and Diploma courses come from both developing countries and from Western countries with work experience (often in NGOs) in developing countries. The first group is often used to passive learning following a curriculum led model with expert input. The following are three examples of recent quotes from students who found the interactive style of teaching at CICH difficult when they first arrived in London,

"I find it difficult to challenge the Tutor" (28 year old from India)

"I have never been expected to argue with the teacher" (32 year old from India)

"In my culture I cannot disagree with the teacher' (39 year old from Southern Africa).

Such comments are very typical in early tutorials with new students from the South. In contrast their fellow students with different educational experiences (but often less practical experience) will feel comfortable with an active learning approach. These different experiences influence the style of teaching and learning for an international course. All participants need early in the course to accept responsibility for their learning, to recognise that in an active learning programme it is possible for students to follow the same course while working towards different individual educational objectives. There may well be a single course with common classes, workshops and tutorials but students will chose different emphases for their own study within the confines of the course. In contrast there may be some optional courses which students on an international course can choose in order to develop their specific skills.

Just as there is variation in the style of learning which students from very different backgrounds bring to a course, so too there will be variation among students' constructs of what the **course content** should be. Some participants will expect a course to produce facts and others to develop their ability to know where to find answers. Some will expect a course to develop skills, others to improve their confidence as practitioners. Similarly there will be variation among tutors as to

whether facts or information seeking behaviour is the central theme of a course, and tutors too will be influenced by their personal constructs. The need to explore expectations by course participants and an understanding by the group of how their different cultural experiences have influenced these expectations is essential if any group with diverse cultures is to work well together and if all are to achieve their goals. Time has to be set aside to ensure that this exploration happens, or the dominant group members or an insensitive tutor will impose their constructs upon the group in sharp contrast to the ethos of CBR.

PREPARING HEALTH PROFESSIONALS TO BE INVOLVED WITH CBR

CBR is delivered by at least two, if not three, levels of service; a grass roots (often home based) programme, central CBR resources (perhaps with training facilities, workshops etc.) and the physicians or therapists (the health professionals) to whom referrals are made. This involvement by professionals is an integral part of most CBR programmes but they are seldom given any training to prepare them for this role. Professionals may be involved in CBR because they are motivated by a wish to provide services which address the needs of people with disabilities, or they may be motivated by their own employment/ income generation needs. It is easy for people committed to CBR to sanctimoniously assume the first, but we must recognise that in many countries to carve a practice which meets income generation needs is also a valid motivation.

Professionals rooted in the practice of expert diagnosis of impairments may have different perceptions of who is considered disabled, from CBR workers and families of PWD. In addition there will be cultural variation as to who is considered disabled. Vreede (13) refers to this as ADL, IDL ODL. Wirz and Lichtig (14) note the contrast between two pairs of siblings. One pair has a 10 year old boy with mild/moderate learning difficulties in a rural African society with 30% school enrolment, and his sister of 12 years who is unable to raise her arms above elbow height. Among this pair the boy, able to help with goat herding, is able to perform the tasks of his peers, while she who is unable to lift to carry things on her head or to pound grain, was considered disabled. An identical pair of siblings in London, with 100% school enrolment and supermarket shopping for food, would consider the boy who was unable to keep up with the learning activities of his peers to be disabled, and the sister (with the slight modifications which she and her mother could make to her choice of clothes to avoid over-the-head dressing) as able to undertake all the activities of her peers and hence not disabled. That there is this variation in perception as to who is disabled is very challenging for health professionals who have been trained to be 'experts' who assess and diagnose symptoms rather than observe and discuss with people with disabilities.

Hartley, Lichtig and Wirz (15) discuss the difficulties which arise when Western professionals collaborate with services for people with communication disabilities in the South where the agent of change may be a professional or another person. In Uganda (where there are no speech and language therapists) CBR workers or support teachers (who have had brief training about communication disabilities), work with parents and teachers of children with communication disabilities and are seen as the agents of change. This is in contrast with the biomedical approach by professionally qualified speech and language therapists in other Southern countries. It is tempting to say that the client centred approach is appropriate and that the British collaborator should change the behaviour of colleagues away from the biomedical approach. But such a solution is naive. Wirz and Hartley have Brazilian colleagues who work as a team of around 20 academic therapists in a

medical school. They are in a university system and are preparing students to deliver a service which meets very different targets from those of the UK. The closer they are to a medical model the more credibility they have as a profession, and the more biomedical their research, the greater their standing within the university system. These are realities and well meaning liberal collaborators interested in CBR cannot move in as change agents without taking cognisance of the pile of cards which may come crashing down if changes occur.

Despite changes in attitudes towards people with disabilities, and despite a much greater understanding of the discriminatory practices towards disabled people and greater respect for differences, most parents, on learning that their child has an impairment which will lead to a disability, look for a cure. This search for a cure, with all the financial, emotional and time resources which it involves in the early months and perhaps years of a disabled child's life, is perhaps more marked in the developing world, where the parents know (often at an uninformed/instinctive level) that the facilities for their disabled child are very few, maybe expensive, and may be of poor quality.

Parents of young children in the developing world also know that a disabled child is less likely to be a productive member of the family team and the search for a cure may be as an attempt to redress this economic pressure of the future. Estimates of how much ill afforded family income is spent upon a cure (using traditional and western medicine) are hard to come by in the published literature but observation and practical experience suggest that this is huge. Many parents' first construct of rehabilitation is to seek a medical cure. Sadly, many medical professionals condone this practice, taking considerable fees to see a disabled child and the parents, knowing that there is little or no rehabilitation service and that all they can do is provide a (often inadequate) medical label for the condition which the parents know to be disabling for their child.

The question arises as to whether medical or therapy education prepares professionals for CBR work? This discussion will concentrate upon therapists' education. The majority of therapy services provided in northern countries have developed from the medical model, where people with disabilities are 'referred' for assessment and, if appropriate, they are 'treated' by professional therapists. Therapy delivered by a medical model is characterised by features such as;

- Services being offered FOR or TO people with a disability

- The term PATIENT is used to refer to healthy people who have a disability.

- Services are provided FOR PATIENTS

- The onus for change is with the PATIENT.

The use of such vocabulary reflects a belief that it is the professional who holds the knowledge as to what is best. Knowledge is seen as power ensuring professional control. It is also true that knowledge as power is used in inter-professional rivalry, in the battle for resources and for salary hierarchies.

In the early 1980s, in the UK, pressure from disabled people raised an awareness of a social model of services where the disabled person's needs are central rather than professional practice directed at that person's impairment (3). Swain et al (16) review this issue. However, fifteen years

after the beginning of this debate in the UK, and despite a passing interest in shared responsibility and a nod in the direction of equity for disabled people, it is still primarily the professionals who arrange service delivery for disabled people in the UK.

Services are usually organised from a centre, be it a community clinic, a hospital or a school. With community care initiatives there may well be outreach from that centre to address community needs but the professional is perceived as being centre based.

Student therapists in the South work hard to be awarded a scholarship to follow a degree course in North America, Europe or Australia, or they have been dynamic professional leaders who have established a training course (often against great fiscal and medical opposition) in their home country. In either situation the reality is that students in the South are attending courses where they are exposed to professional training and practice which may have been appropriate when the medical model reigned supreme in the North. Current training questions whether this provides appropriate professional training for social models which accommodate community care needs for any student, from North or South. If training to which overseas students are exposed in the North is inappropriate, it is doubly so in their own home settings.

Course directors in the South, anxious to maintain equality with courses in the North, veer away from innovative training in case it affects the international standing of their course. They too are then shackled to a training which neither prepares therapists for the realities of new working practices of community care in the North, nor to community based working practices of the South. What often happens is that newly trained therapists in the South find difficulty in adapting their new skills to community based service and end up in the relative safety of private practice where they can use their (inappropriate) professional skills.

In order to be effective in a CBR setting therapists have to

- be prepared to "give up" their exclusive rights to knowledge about impairments, to a cadre of workers without professional expertise.

- be able to work as trainers and to support these CBR workers

- develop referral patterns of support to CBR workers

- continue to listen to PWDs and relate to disabilities rather than the impairments as a basis for intervention

- be innovative in service planning

Colleagues in South Africa have taken the lead in the training of co-workers for an alternative form of service delivery through CBR (17). From this base, therapists in South Africa have seen the need to co-operate with CBR, to become involved in training of CBR workers as a way of improving access to therapy services for all the population and not to restrict their services only those who can access central, urban centres (18).

In the Philippines too, innovations have been made in the education of therapists. All undergraduate therapy students at the University of Manila (occupational therapy, physiotherapy or

106

speech and language therapy) undertake a placement in a rural CBR programme, thus ensuring that all therapists have at least an understanding of other ways of working with disabled people (19).

If we support improved access to services for the vast majority of people with disabilities in the South by understanding the aims of CBR and supporting them, we should not continue to provide professional training for students from the South which concentrates upon the needs of the very small minority (20).

TYPES OF CBR PROGRAMMES FOR WHICH PROFESSIONALS ARE BEING PREPARED

A further consideration in training is to concentrate not on the trainees (be it different levels of CBR personnel or professionals with whom CBR personnel must work) but the variation in the type of programmes for which personnel are being prepared. There are many definitions of CBR and the CBR movement gathers great strength from this diversity of interpretation. This paper takes the Joint Declaration (21) as a working definition of CBR. The advantage of this definition is that it is not prescriptive and leaves flexibility of interpretation for programme planners and trainers and educators.

"Community Based Rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, a,-id the appropriate health, education, vocational and social services" ILO,UNICEF,WHO, Joint Position Paper, Geneva 1994.

There is a continuum of interpretations of the Declaration reflected in different practice. At one end of the continuum are those with a technical rehabilitative focus and at the other, those with a human rights focus for their activities. Best practice of course involves a range of different approaches to meet differing needs, and CBR programmes may well be involved with activists, activities and services at different points along this continuum.

Creative use of this definition by UNESCO, ILO, WHO promotes dynamic and multifarious definitions which allow for greater manoeuvre among planners and service providers than more traditional classifications such as:

- Whether it follows a medical model or social model (22, 2)

- Whether it is professional led or DPO led

- Whether the programme focuses upon impairment, disability, or handicap (23,24)

- Whether it is a disability programme or a development programme with disability awareness (25, 26, 27)

Such classifications emerged in the literature of the west over the past 20 years as disabled peoples' organisations asserted their rights to self determination and challenged attitudes, policy and practice.

Traditional CBR programmes have often been classified using some of the four dichotomies listed above (medical vs social model, professional vs DPO led etc.) but simplistic classifications can be misleading. It is possible for organisations seated in a health base to adopt a clear social model to their CBR work, or for organisations which are led by disabled people to have a strong technical focus to their work. Wyller (28) proposes the term "comprehensive model" to encompass concepts of social and medical approaches and to move practice forward.

CBR has then a wide diversity of interpretation, starting from the initial model of CBR as conceived by WHO in the 1980s (culminating with the publication of the WHO Manual (29). There are many other interpretations of CBR e.g.,

- emphasis upon early childhood intervention (30),

- the use of volunteers in a small country with a commonly held expectation of voluntary activity (31),

- the emphasis upon local community committees in the Middle East (32)

- devolving CBR activities from institutions (33).

Because CBR depends upon local activity it is not surprising that there is variation. Culturally appropriate models of CBR have arisen to meet local need. It is interesting that the most widely written about CBR activity that was developed by disabled people themselves, at Project Projimo (34), has never been replicated. On the one hand it seems sad that such an excellent sounding model has not spawned others, on the other one has to accept that Project Projimo, however successful in rural Mexico, was not culturally appropriate to other settings. The lesson, fifteen years after the first moves toward CBR as a way of ensuring culturally appropriate, affordable and accessible services for disabled people, is acceptance of cultural diversity as to how CBR is interpreted in different settings (35, 26).

In much writing about CBR, there is an assumption that there are common community values, and that these must be met by the CBR programme. In reality however, values may differ within a geographical community by caste, by educational or economic status, or by minority groups, and this diversity of values must be described in the planning process. This requires great skill by the planners who bring their own cultural norms to the process. It is enormously helpful to understand something of the cultural norms of a setting which is new to a trainer or planner. Unfortunately CBR is impoverished by a lack of sociological or anthropological literature. Ingstad and Whyte have brought to a wider readership, issues of cultural diversity about disability (36). Cultural variation has not been recorded by people working for and with disabled people in countries of the South and/or in CBR programmes, and the passing of knowledge (which undoubtedly exists) depends upon the unreliable transfer of knowledge through conversation. Orally transmitted knowledge of cultural values can be inaccurate either in the telling or in the understanding, but is also in danger of being out of date. There is, for example, great change in extended family systems with wide urban/rural variation. The idea of the disabled child being sent "back to the grandmother in the village" may have had some reality 15/20 years ago but observations in a CICH project with the Spastics Society of India in Dharavi slums in Mumbai suggest that the modem 40 year old grandmother who was herself an urban migrant is no longer the easy recipient of the role which her mother adopted.

PUBLISHED TRAINING MATERIALS FOR CBR

There are a selection of published training materials suitable for the training of CBR personnel. Some are very well known and widely available and others while equally useful are less well known on the international CBR stage. Thomas and Thomas (37) provided one of the few published reviews of several different training materials. If the training of CBR personnel is to move beyond local boundaries there is a need for more widespread awareness, use and availability of published materials.

Established Training Materials from the 1980s

1. Disabled Village Children (DVC) was a very welcome document when it was published 15 years ago and its great strength is its comprehensiveness. The volume contains information about most disabling conditions and ideas for low cost interventions. The great disadvantage (which is the downside of its comprehensive nature) is that it can be daunting for those who are less comfortable with indexes and cross referencing to find their way around the book.

2. The WHO Manual (29), widely known throughout the world is more user friendly. The material is broken into sections, most pages have a mix of text and illustration and are less frightening for those less comfortable with books. Its disadvantage is that the booklets, if separated from their pack binding, can become lost or misplaced.

   Both DVC and WHO manual are products of their time, the mid 1980s, and are predicated on the idea of skills transfer to field workers (or volunteers/parents) by professionals who will use one of the volumes as a training manual. There was, and remains, a place for such training materials but they reinforce the idea of professional "expertise" and do not reinforce community/non-specialist strengths nor the place of DPOs and other non-professional organisations, in training. In addition, both concentrate on the medical aspects of disability and less on the disabling consequences of lack of income, poor access to school and other inclusion issues which are faced by disabled people and their families in the majority world.

More Recent Training Materials

3. The training materials produced by the CBR Training and Development Centre (CBRDTC) in Solo, Indonesia have gone some way to updating the material available in DVC or the WHO Manual. The CBRDTC material comprises a set of training materials addressing the needs of most disabling conditions. There is a simple booklet for different disabling conditions, and some are related to specific disabilities e.g., "Helping Children who have Eating and Drinking Difficulties" while others are more generic e.g., "Early Detection of Disability for Children under Five" or " Helping to Prevent Disability" The CBRDTC set of training materials also includes information about disabilities which are common but infrequently addressed by CBR training materials e.g., "Helping People with Severe Mental Illness".

4. The Spastics Society of Eastern India has produced an interesting set of training materials that include a series of booklets suitable for trainees, and another set of simpler materials for parents. The booklets for trainee CBR workers have titles such as "Physical Management for the Cerebral Palsied Child" and "Happy Talking: for children with special communication needs". Those

for parents tackle subjects which concern parents e.g., "Toileting for the child with cerebral palsy", "Feeding for the child with cerebral palsy". Both sets are well illustrated and use simple language. In addition to the sets of material concerning different disabling conditions, the series also includes more generic training materials such as "Learning Together: a manual for trainers on CBR'.

5. Handicap International have published a set of training materials (comprising about 40 booklets), which are available in French and English. They concentrate upon physical disability and chronic disease with four sections. Two sections relate to basic anatomical theory and clinical evaluation, while Section 3 relates to physical therapy techniques and devises e.g., booklets entitled "Walking Aids", "Home Adaptations", "Respiratory Treatment" or "Stretching". Section 4 provides specific information on different pathologies such as "Burns", "Osteoarthritis", and "Leprosy". The materials are firmly rooted in the medical model but are useful as training materials for such specific topics.

6. More recently, Hesperian Foundation, who were the original publishers of DVC, is piloting a series of training materials directed more specifically at the parents of children with disabilities. Early, pilot versions of these materials look interesting and should be useful in the future.

7. In addition to the manual "Training in the Community for People with Disabilities" (29), the WHO have produced a small series of training materials which give more specific information about working with people with disabilities. For example, "Promoting the Development of Young Children with Cerebral palsy" and "Guidelines for the Prevention of Deformities in Polio" and "CBR and Health Care Referral Services and "Let's Communicate: a handbook for people working with children with communication difficulties". Most of these are soft-bound books but "Let's Communicate" is produced in the style of the original WHO Manual as a loose leaf folder with a series of booklets. It was produced in collaboration between the Rehabilitation Unit of the Ministry of Health in Zimbabwe and WHO.

8. "Helpful Steps' is a set of training materials produced for the Guyanese CBR programme with accompanying video materials.

An important issue in training is that of acceptability of materials which have been produced and illustrated in other countries. Hartley and Wirz (38) investigated the "acceptability" of different illustrations to planners of CBR workers and were rather surprised at how narrowly tolerant most planners felt their CBR workers would be of different illustrations. For example:

"mothers do not cover their heads in my country"
"women do not wear saris in my country "
"it is not acceptable for a father to be feeding a child in my culture"

We also found that our group of South America informants did not find line drawings of Asian and African people acceptable, African informants felt their CBR workers would want African line drawings, South American informants felt their CBR workers, parents and volunteers would not identify with the messages of training materials if they had Asian people as illustration. This was a very small informal investigation but suggests that work needs to be done as to the acceptability of illustrations of training materials.

CONCLUSION

The issues around appropriate training for CBR are as varied and numerous as the issues around CBR practice. It is only by exchanging ideas and by evaluating and promoting good practice that the training of CBR personnel can progress in a way which will enhance rather than restrict the development of appropriate CBR in varied communities.

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PREPARING OCCUPATIONAL THERAPISTS AND PHYSIOTHERAPISTS FOR COMMUNITY BASED REHABILITATION

Robyn L. Twible, Elizabeth C. Henley

ABSTRACT

The traditional institutional based medical model approach to rehabilitation is expensive, often inappropriate, inefficient and does not meet the needs of most people with disabilities. The escalating cost of health care, the increasing economic constraints, and the shortfalls in service provision have all contributed to the urgent need to develop innovative ways to utilise therapists in the community. Although the move from institutional care to community care is occurring in both the developed and developing world, the infrastructure and funding arrangements varies and therefore the models that are adopted for different countries are necessarily different. Preparing therapists to change practice from traditional institutional services to community services is a professional imperative, especially in developing countries. Such preparation requires special consideration of the complex contextual issues, as well as the reorganisation and reconceptualisation of the philosophies underpinning therapy education and the structural ways in which educationalists teach therapists to provide care. The most vital factor to consider is that the therapists must adopt a major change in attitude to both service delivery models and to their roles as therapists. For the purpose of this chapter, the authors have chosen to focus on the delivery of therapy services using a generic CBR model used in many developing countries. Information has been drawn largely from the authors' experiences of working in developing countries as well as preparing undergraduate and graduate therapists for such work. The chapter discusses the importance of educational and cultural considerations, and of developing reasoning skills in community based rehabilitation (CBR), in the praparation of therapists for community practice. The authors go on to focus on the content areas that specifically need to be addressed to facilitate the process of 'settling in' of therapists and creating an environment for successful outcomes in rehabilitation, such as CBR, community development and disability; therapy, teaching and management skills; generic professional principles, and context specific information.

BACKGROUND

As a consequence of the Ottawa Charter in 1986 and the earlier introduction of community based rehabilitation (CBR) as a strategy to provide 'health for all' (WHO, 1976) health policy has shifted emphasis from institution to community care, with an emphasis on health and wellness and universal access. These major changes have necessitated a shift in emphasis from the institutional medical model to alternative models of health care delivery. This move from institution to the community has generated a significant change in many of the features of health care delivery, mostly to the benefit of the consumer. The impetus for change, coupled with the increasing economic constraints worldwide, provided an urgent need to develop innovative ways of utilising available

health personnel; such personnel are an even more scarce resource in developing countries and require special management.

Traditionally, the major sources of employment and opportunity for therapists (for ease of writing, physiotherapists and occupational therapists will be referred to as therapists) have been medical institutions such as hospitals and rehabilitation centres. Health and rehabilitation services historically have been situated in specialised institutions and while this concentration has significantly advanced the scientific and research base of professional practice it has left observable shortfalls in clinical practice. Institutions provide specialised services for the few disabled people who have access to the institution, while those in rural communities are often denied access to any rehabilitation services. In both developing and developed countries, the majority of people with disabilities do not require the sophisticated technology and highly specialised care provided by therapists in institutions (Peat, 1990). Community based rehabilitation is an approach that has been used primarily in developing countries to facilitate the provision of rehabilitation services to rural and remote areas, where the numbers of people with disabilities are numerous but where the resources are few (Twible & Henley, 1993).

Institutions are usually hospitals or specialist rehabilitation facilities located in major urban areas where it is relatively easy to attract professionally qualified allied health professionals such as physiotherapists and occupational therapists. These university-educated therapists (with a 4-year degree) would come from an entirely different educational background than those 'locally trained' therapists (with training ranging from 3 months to 1 year) who are most commonly found in rural and remote regions of the country. Most of the university-educated therapists' undergraduate programs, even in developing countries, would have been based on curricula that follow the traditional medical model. As a consequence, most graduates of these programs prefer to remain in the large centres and work in the specialist institutions, where they feel more comfortable, have access to technology and resources with which they are familiar and receive more recognition for their work. There are, however a few university programs that are exception to the norm. Several South African schools, such as the University of Cape Town have integrated substantial content relating to community practice into its curriculum (Futter, 1998); the school at the University of the Western Cape has based its entire curriculum on a CBR model (Mpofu, 1998). Similar integrations to greater and lesser degrees can be found in universities in Israel (Maas, 1996) and in some occupational therapy programs in Australia and Canada.

In terms of health care providers, there is also a constancy across English speaking developed countries in the employment patterns of therapists. Studies show that 90% of therapists are employed in institutional care (Partridge, 1987; Burnett, 1991; Health and Welfare Canada and the Canadian Association of Occupational Therapists Task Force, 1987).   From the authors' experiences, in developing countries where therapists are university qualified, the preference for institutional employment is also evident. Another factor of relevance, in therapy service provision is the number of therapists working in proportion to the population. In English speaking developed counties the average physiotherapist : population ratio is 1:1400, which is considered to fall well short of these countries' requirements. In developing countries the situation is more critical with an estimated average therapist : population ratio of 1:550,000. In some countries the situation is dramatically worse; for example, in India the ratio is 1:1,215,000 (Peat, 1990). Because of this lack of

rehabilitation health personnel, it is contingent upon the educators and policy makers to support alternative models of health care delivery and for educators to ensure that therapists are sufficiently prepared with the requisite knowledge and skills to accept the challenge of employment in venues alternative to institutions, such as in community settings.

In summary, the traditional institutional based medical model approach to rehabilitation is expensive, often inappropriate, inefficient and does not meet the needs of most people with disabilities. The escalating cost of health care, the increasing economic constraints, and the shortfalls in service provision have all contributed to the urgent need to develop innovative ways to utilise therapists in the community(Henley & Twible, 1996).

CHANGING PHILOSOPHIES

Although the move from institutional care to community care is occurring in both the developed and developing world, the infrastructure and funding arrangements varies and therefore the models that are adopted for different countries are necessarily different. Preparing therapists to change practice from traditional institutional services to community services is a professional imperative, especially in developing countries. Such preparation requires special consideration of the complex contextual issues, as well as the reorganisation and reconceptualisation of the philosophies underpinning therapy education and the structural ways in which educationalists teach therapists to provide care (culture, politics, environment, social structure, service delivery models - medical vs others, etc.). The most vital factor to consider is that the therapists must adopt a major change in attitude to both service delivery models and to their roles as therapists under these different models. The major differences between institution based therapy and CBR are outlined in Table 1a, 1b,.& 1c.

Preparing Therapists For Community Practice

For the purpose of this chapter, we have chosen to focus on the delivery of therapy services using a generic CBR model used in many developing countries. Information has been drawn largely from our experiences of working in developing countries as well as preparing undergraduate and graduate therapists for such work. The following section deals with cultural and educational considerations when designing educational sessions to orientate and prepare therapists for working in CBR in developing countries. However, the ideal environment in which such information should be provided is in the therapists' undergraduate curricula throughout the world. It is in undergraduate education that attitudes are established and can be most readily influenced, so that graduate therapists are provided with the requisite knowledge, attitudes and skills to work in both institutional and community settings in any country. Finally, consideration must be made of the competencies of the education providers for they are the ones who will undoubtedly exert influence over the learning of their therapists. Faculty who are aware of different service delivery models such as CBR are most likely to incorporate CBR approaches in their teaching activities; however, it is important for all educators to incorporate such information into their teaching, not just those who specialise in CBR.

Cultural Considerations

In most societies the provision of health care involves many different interactions among people whose needs and views on what constitutes health care may be vastly different from each other and from the service provider. This difference can pose problems for both the provider and the recipient

if care is not taken to facilitate the process. When people from different backgrounds come together in a therapy interaction, that interaction is influenced by many factors and the overlap of knowledge and influence between the participants will vary from one situation to another. In some cases, the amount of overlap or sharing will be great; in others, especially if one or more of the participants comes from another culture with a very different medical system, the overlap will be much less. The example in Figure 1 demonstrates a situation where there is a significant amount of overlap (Fitzgerald, Mullavey-O'Byrne, Twible and Kinebanian, 1995). Obviously, the greater the overlap, the easier the interaction and the less the overlap among participants, the more challenging will be the interaction for the therapist to effect a successful outcome.

Educational Considerations

Today, all education programs should prepare therapists to work in multiple environments and a primary objective of educators should be to develop the required competencies in its graduates. Education about alternative service delivery models including CBR needs to be embedded across the curricula and permeate all aspects of the educational process. No one experience will be adequate to ensure that the learner acquires the requisite skills to influence their practice totally. It is the type and method of education that is the crucial factor in improving competence (Carpio & Majumdar, 1992; Robison, 1996).

Workshops and other small group activities have been a useful means of facilitating cultural competency and reasoning skills in CBR, as they challenge the values and biases of the therapists as well as provide opportunities for application of knowledge and skills to expanded local case studies derived from real CBR encounters; these case studies are designed to provide detailed social, geographical, and physical information about clients and the environments in which they live (Henley & Twible, 1999).

The first step in developing competence is recognising and understanding the basic human condition. From this starting point, therapists must develop a compassion for their fellow human beings and a cultural attitude, and as such understand the need for and adopt a client/family-centred approach to practice It is the type and method of education that is the crucial factor in improving competency (Robison, 1996). Therefore, educators must provide learning experiences which establish knowledge-seeking behaviours in therapists who routinely view the client's and family's problems by exploring the 'client's stories' (Clemson, Fitzgerald & Mullavey-O'Byrne, 1999). This information cannot simply be encapsulated into lectures and tutorials, but a variety of methods should be incorporated across the curricula.

Developing Reasoning Skills in CBR

Reasoning in a CBR context is no different from clinical reasoning in other ways. It simply requires consideration of another variable (CBR) which is a vital dimension in effecting a positive outcome in a therapy intervention. Awareness of CBR and using knowledge about CBR are critical elements and opportunities for therapist learning related to these elements need to permeate the curricula.

Enhancing self-monitoring skills is considered to be a favourable way of improving reasoning in any therapy situation (Boud & Walker, 1991; Refshauge & Higgs, 1994; Carnevali, 1995). One

way of facilitating the process is to systematically apply a series of questions or an organisational framework to facilitate this conscious reflection (Bridge & Twible, 1997). In considering reasoning in a CBR and different cultural context, therapists must be 'prompted' to consider culture and other contextual factors routinely throughout their interactions with clients (ie assessment, intervention and evaluation phases of service provision). One strategy is to link these contextual factors to the existing clinical reasoning within the curricula so that culture and community factors are incorporated into all case study analyses that therapists undertake.

In all reasoning situations, novice therapists often make errors because cues are missed and/or underpinning knowledge is missing. Having some means to check current knowledge and understanding is essential, because in practice it is not acceptable to interact with a client without any idea of what the client's potential dysfunction might be (Bridge & Twible, 1997). Awareness of the local context is crucial to the therapist's ability to function in a different environment. For example, the therapist may lack knowledge about the importance of specific role tasks of a female carer within a particular family group and may assume knowledge; the therapist then may suggest inappropriate therapy strategies for the carer. In some client interactions, such lack of awareness may result in the therapist omitting a component of the rehabilitation program that is important to the client in their everyday life. For this reason, therapists need to become sensitised through repeated exposure to real-life case studies which they can critically analyse and propose solutions.

The two most problematic areas that novices face are "problem sensing or noticing" and "problem validation or intervening". (Neistadt, 1992; Rogers & Holm, 1991; Boud & Walker, 1991). Therapists' difficulties lie with firstly recognising the need to acquire the knowledge and secondly applying that knowledge effectively in the therapy process. Therefore, educationally, it is imperative to address both knowledge awareness and the application of newly acquired knowledge.

- **Problem sensing**

Problem sensing requires attending to incoming information and reflecting on its meaning. Development of the ability to notice and attend to cues appropriately in the therapy situation is crucial. The original image of the client is formed automatically as incoming information from the initial encounter with the client and their immediate environment is processed. This processing happens in relation to current values and beliefs and includes predictions extrapolated from theory, past experience and current knowledge of the local context. For example, in inter-cultural interactions cues may be missed because the therapist does not pick up the cultural prompt (ie, that consideration of culture is important) or the therapist does not have culture-specific knowledge related to the specific client.

Another important factor to consider is peoples' beliefs about health and illness, including beliefs about the cause of any illness they experience, what kind of illness it is, the natural course which the illness will take and how it should be treated. Some explanations are common to groups of people and may be seen as having a cultural basis. The sources we draw upon to inform us about our state of health and to explain it to others are popular, professional and traditional (Kleinman, 1980). Authors use the term "explanatory models" to describe the explanations for illness and disability given by health practitioners and their clients and to distinguish between lay explanatory models and the clinical models used by health practitioners.

It is often difficult to match the therapist's perception of a particular illness and/or disability with the client's understanding of their experience of it. The disparity is likely to be even greater when the client and the health professional come from different cultural backgrounds. Thus any therapy interaction can involve a perspective from multiple cultures and several systems within each culture. Narrative reasoning ('client's story') and history taking exercises are an integral part of the therapist/client interaction and therefore consideration of the cultural and other influences should routinely be considered as part of this process. Once awareness has been established, the therapist is able to identify the knowledge that needs to be acquired.

- **Knowledge acquisition**

Therapists usually know to acquire knowledge from the available literature, if they perceive that their current knowledge base is lacking. For CBR and relevant cultural information there are other important sources, such as local CBR workers, cultural informants or brokers, as well as the clients, family members and other community members. The therapist then assimilates all available sources of knowledge and validates the information for the current clinical situation.

- **Using local knowledge appropriately /problem validation**

This local knowledge can then be used to determine the form of the assessment of the client through observation of their performance of functional activities and the physical examination. One of the most useful tools that a therapist in a CBR setting can adopt is a model of functional assessment (See figure 2). This model, adapted from an OT model (Reed & Sanderson, 1980) has been used successfully for the past 5 years by students and therapists in rural CBR projects in southern India. The model sets the client at the centre of the assessment process so that all decisions about management are made from the client's perspective. Using local knowledge, the therapist begins to develop the working hypotheses, validates assessment findings, selects and implements a management program, having considered the implications, assessed the risks and determined the expected outcomes. The focus in problem validation is on the examination of discrepancies between the original clinical image and the real and gradually unfolding scenario (Bridge & Twible, 1997), including the application of local knowledge.

- **Frameworks to facilitate reasoning ability**

Fitzgerald, Mullavey-O'Byrne, Twible and Kinebanian, (1995) have identified key principles to consider in acquiring local knowledge and provide frameworks for exploring local issues relevant to individual practitioners and the client population, as well as suggested guidelines for developing policy for the management of clients from diverse backgrounds. Such frameworks would be useful tools with which the therapist should become familiar, to facilitate the transition from one therapy environment to another.

Strategies for Action

Now that we have laid down the conceptual foundation for developing attitude change and specific reasoning approaches, we can attend to the content areas that specifically need to be addressed to facilitate the process of 'settling in' and creating an environment for successful outcomes in rehabilitation.

There are four major areas that need consideration:

- CBR, community development and disability
- Therapy, teaching & management skills
- Generic professional principles
- Context specific information and issues

CBR, COMMUNITY DEVELOPMENT AND DISABILITY

CBR means different things to different people in different parts of the world. Therapists must be well oriented to different models of service delivery and their relative strengths and weaknesses. This also entails a thorough understanding of and an affinity for community development philosophies and strategies, where the focus of attention lies with the community and the individual client. Thus, therapy practice will be community based (in its full context) rather than simply transferring practice from the institution to the community. Additionally, alternative models of management structures for CBR programs should be explored, including the hierarchical structure of the organisation and the varying responsibilities of the different levels of voluntary and paid personnel.

Therapists should have an understanding of disability and its effect on families. It is important for them to understand the impact of disability in the context of the different environments in which therapists may be working, with the constraints that will be imposed on the clients, their families and their communities. In CBR it is crucial that the therapist has a strong belief in client/family-centred practice and that all aspects of therapy, from problem identification to intervention, are directed by meeting the needs of the client and family carers (Clemson, Fitzgerald & Mullavey-O'Byrne, 1999).

THERAPY, TEACHING AND MANAGEMENT SKILLS

- **Therapy**

As outlined previously, there is a significant shift in reasoning needed to successfully move from institution based to community based therapy. The process of therapy in the community should be based on a problem solving approach that is functional in orientation and is driven by the environment, cultural, social and other contextual factors.

Because of the nature of the disabilities encountered in the community, the emphasis in therapy is on management of the disability rather than on 'treatment or cure'. Therapists, in designing management plans, focus on minimising the client's impairments (eg. lengthening short muscles), preventing complications (eg pressure sores) and building on the client's capacities (eg advancing their intellectual capability) to maximise their potential to be able to contribute to their community life. Therapy in the community proceeds at a pace which is a graded step-by-step process, usually attending to one or two problems at a time, and is incorporated into the daily life patterns of the client and their family. It is essential that goals are set with the client that are realistic and achievable, given the demands that are made on the client and the carers in carrying out their normal daily activities.

One of the most important skills therapists need to sharpen is their observations skills. Observation pervades the therapist's life. It requires that the therapist notice and process everything that s/he sees and encounters, including the society, the physical environment of the village, as well as observing the client and family in their own environment, to determine life roles as well as the constraints and benefits of the physical environment in which the client lives. Such finely tuned observations skills will facilitate the therapist's ability to analyse the client's daily activities more effectively when determining problems and looking for appropriate solutions.

Another feature is that the therapist needs to seek out and develop potential sources for the human and material resources that may be needed in future planning of therapy. Local easily available material resources are employed and adapted to suit the needs of the individual client (eg., sandbags for strength training or support for positioning); similarly, local craftsmen such as carpenters and shoemakers are used to make and adapt equipment (eg. walking frames and adapted footwear).

An aspect of therapy that is often neglected in a CBR setting is that of documentation or record keeping. When a new client is seen, it is important that accurate baseline measures are taken and that regular reviews of progress are made by the attending health worker or therapist so that effective therapy programs can be instituted and evaluated. At the field level, such records are invaluable in effective communication between workers who manage the same client and for measurement of normal progress over time. At the project level, the project holder can use the records as a measure of the effectiveness of service provision and can use the information to successfully argue for increased funding.

Clients' assessment findings and management plans must be kept in a simple readable format that is easily accessible by all health workers involved in their care. This requires careful design of an assessment protocol that is functional, easily recorded, meaningful to the worker and the client, and problems for intervention are identified and written in simple functional terms. The problems are prioritised in collaboration with the client and carers and the goals of therapy are written from the client's perspective; that is, the goal describes what the client will be able to achieve, under what conditions and by when. Too often, therapists' aims are written which are not measurable and describe the therapist's plan of action, not what the client will achieve.

- **Teaching**

Therapists are naturally teachers as part of their professional role in that they teach clients and clients' families how to carry out home programs. However, in community practice teaching becomes a primary focus of their professional activities. Also of importance is that therapists use a 'train the trainer' approach with health care workers in teaching therapy skills, rather than the direct simpler approach of teaching a skill on a one-to-one basis with a client. Therapists must expand their knowledge of educational psychology to include such topic areas as learning theories, learning styles and different models of teaching and facilitating learning. Experiential learning has proven to be one of the most valuable modes of knowledge and skill delivery when therapists teach local health workers or village people. Theory can be provided in a formal session, but the formal translation of that theory into practice is an essential step in the process to ensure that technology transfer occurs.

Therapists' newly acquired knowledge and skills in teaching and learning theory are then applied to developing teaching packages as a basis for conducting formal and informal educational sessions in the community with various levels of groups including health care workers, families and the general public. Teaching packages should be developed so that they can stand alone and be used by others. Inherent in the development of teaching packages is recognition of the importance of communication at different levels, designing packages to suit the levels of learners (lay vs professional). The salient features within teaching packages are outlined in Table 2.

- **Management skills**

Management skills of a different nature are required of therapists working in the community compared to the skills required for institution practice. The community therapist requires a broad but extensive knowledge of the organisational structure and lines of authority of the agency for which they are working as well as that of the community in which they will be working. This information includes knowing the existing established systems in operation, such as medical and rehabilitation facilities in the area, referral patterns, access to other sorts of funding and services. In addition, their knowledge base of problem solving strategies that can be used to manage structural or organisational challenges will need to be expanded.

In order for the therapist to operate successfully in a community environment, they need to have high levels of skills in the following areas: communication at different levels - with management, workers, families, peers, etc; teamwork and leadership; negotiation and conflict resolution; networking; organisation and time management. They must exhibit responsibility for themselves and others in management of the workplace and also be able to provide peer support opportunities for learning and constructive feedback.

Generic professional attributes

The most successful therapist will exhibit certain attributes which are generic to their professional performance. Working in a community environment requires creativity on the part of the therapist as s/he will be met continuously with unique challenges, in providing a realistic service, in finding and adapting equipment needs of individual clients and in many other areas. Therapists must take the initiative, often, in creating opportunities to get things done. Many of the issues that need to be tackled in the community are often difficult, the solutions are not always obvious, or the timing is wrong at the given moment. Bringing about realistic change requires the therapist to understand the 'big picture' and the importance of a gradual developmental process (the journey of a thousand miles begins with the first step). Inherent to success in any situation is the acceptance of what can and cannot be changed. The powerful combination of therapist attributes of perseverance, patience, diplomacy and tact will facilitate their day-to-day survival during times of stress and over time will help them to overcome apparently insurmountable obstacles. One must have the belief that change does not occur overnight, but like water dripping on stone, change will happen eventually with perseverance.

There are a number of 'psychosocial' environmental issues which need to be addressed, especially when the therapist comes from a background that is totally different from the community context in which s/he is providing services. The first issue is that of 'project needs vs personal or

individual needs'; the therapist must recognise that the needs of the project should take priority over individual needs, because the therapist is there primarily to provide a community service. There is a danger that those who put their individual needs first will end up contributing little to the workplace; this is another example of a shift in attitude that makes the transition for the therapist from institution to the community an easier one.

Therapists also must be overtly conscious of their image, or how they are perceived by others, whether the project holder, the health worker or the villagers themselves. Working in a community requires psychological preparation for the 'professional expert' role or 'senior management'; this role is very different from the usual status of a therapist among therapists in an institution. Expectations that senior management and others may have of the therapist and the therapist's expectations of what can be delivered may be mismatched; such issues need to be explored and realistic parameters established early, for the benefit of all stakeholders and the service. Therapists therefore must exhibit good reasoning skills to be able to readily assess the situation, recognise their own strengths and limitations and give a realistic estimate of what they will be able to achieve and why. Explanations must be given in a language or in terms that will be familiar to the recipients, so that no confusion remains. Finally, therapists must also be aware of their responsibility to succeed in this environment and the global consequences for mismanagement of same.

Context specific information and issues - knowing where you're going and what you might be doing. This section can be divided into three sub-sections, for ease of clarification: i) common disability information; ii) country details; and iii) personal issues to consider.

- **Common disability information**

It is important to obtain from multiple sources, including the potential host or employer, information relating to the types, incidence and prevalence of different disabilities in the community in which the therapist will be working. The therapist will necessarily be confronted with disabilities and pathologies with which s/he is not familiar, especially if the therapist is moving from one country to another. Ideally, if the potential employer can provide case studies based on real client scenarios, the therapist will be best equipped to determine the similarities and differences between what is expected and what is already known from previous experience. Access to such information is often difficult when the therapist is already working in the rural or remote community; therefore, having such information as a resource beforehand is invaluable. Additional information can be sought from government agencies, non-government agencies, and from colleagues who have worked in such environments. A strategy that is encouraged is to establish a network of colleagues in one's home country to access information and technical resource material if it is required and cannot be obtained 'in country' or from a local source. However, if technical information is brought with the therapist, it should be used as their knowledge resource and not simply transferred to the new environment without the appropriate adaptations to suit the local context.

- **Country details**

Prior to departure the therapist should be thoroughly familiar with the background to the new country, including its history, politics, geography etc. This information is often available in good guide books and through the relevant consulates. Today, of course, much information is also available

through the Internet. On a broad level, information about the health care system and service delivery models in use can be obtained; however, detailed information will need to be acquired on arrival, through consultation with the agencies involved in the provision of health and rehabilitation services.

Local knowledge is also imperative in developing a thorough understanding of the local traditions, customs and culture of the area to be visited. Some differences which often are noticed by foreign therapists and which provide unique challenges are related to concepts of time, attitudes towards independence, as well as child developmental and functional norms for the country. As mentioned in an earlier section, therapists must attune their consciousness to recognise the similarities and differences between this new country and their own. Such sensitivity requires a recognition of and thorough understanding of ones own culture. Without a full appreciation of ones own culture it is difficult to recognise the nuances of another.

- **Personal 'housekeeping' issues**

Therapists should consider all aspects of their intended adventure - why they are going, what do they want to get from the experience and what do they hope to contribute and achieve. Certain challenges are not country specific, but are common to many people venturing into an unfamiliar environment. The less developed the environment, often the more difficult the transition becomes, but this is also not necessarily the case. However, before making the decision to go to another country, therapists must frankly and honestly determine their expectations, explore the realities of life in the new country and whether their expectations match these realities. There are many sources of information as mentioned previously. One of the best sources of information for facing the realities of living in a different country is to speak to those who have been there before and frankly inquire about the difficulties they encountered and the strategies they employed to cope with the problems.

Reflection is invaluable is determining what is important to ones own physical and mental health; how will the therapist cope with differing levels of physical comfort, facilities, hygiene, privacy, lack of family and friends as their network of support, lack of professional support; the list is endless, but each person should think carefully about all aspects of their personal and professional life to confront such difficulties before they arise. Taking care of ones physical and mental health becomes a priority, if the transition into a new environment and new way of life is to be successful. As mentioned before, the therapist's observation skills become particularly well sharpened, in a professional capacity; however, in the personal arena such observation skills will also become a great asset. The general process of ' finding what works' can be facilitated by finding a mentor or support persons who can act as cultural brokers; this local reference group or person can be valuable for reality checks and to validate ideas or approaches.

Finally, at the end of the therapist's time in any country it is important for them to actively seek a debriefing session with their work colleagues and senior management; to evaluate the experience, their contributions to the service and recommendations for change for the future. It is also important to recognise that the therapist must face re-entry issues when returning to their country of origin, which people often find just as difficult or more difficult to manage than the initial move to a new and different environment. For example, the experiences that were most meaningful to them when they lived in another country are not important to their colleagues at home, which often becomes deflating to the therapist on their return.

CONCLUSION

The varied situations in which graduates work emphasise the importance of understanding the unique nature of "people from different environments", recognising that each individual person presents differently and assumptions cannot be applied to all people associated with a particular group. Not only does the therapist need to consider their clinical competencies, communication skills, innovative strategies, a person-oriented attitude and compassion in therapy interactions, but there are other factors relating to management and organisation as well as personal considerations for therapists moving from institutions to the community.

If therapists develop good reasoning skills they can function well in any context by thinking through the issues related to their individual situation, whether at home or abroad. Though the focus of this chapter has been on educating therapists for CBR in developing countries, all therapists working in institutions could benefit significantly by applying the principles of CBR practice to their everyday workplace and would allow the transition from institutional care to community care to occur with relative ease.

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Table 1a. Differences in service provision in institution-based and CBR models - structural issues

Feature	Traditional Institution Based OT & PT	OT & PT in CBR
Historical Factors	• service in hospitals and specialist centres	• rarely provided in the community • if provided, uses an institutional approach
Location of Service	• city based • centralised	• rural and remote communities and disadvantaged urban communities • decentralised
Facility	• purpose built centre that is well equipped	• home or local community centre with minimal resources
Allocation of Resources	• lots of money spent on facilities and equipment	• limited resources - focus of funds is on training and support
Types of Resources	• high technology • high cost • sophisticated • expectation that therapy is dependent on and driven by the technology available • limits resources to those commercially available which require high cost, skilled technical support and high maintenance and are often unsuitable	• low technology • low cost • uses only what is available • adapts local materials and environment to suit client's needs • uses local human resources to make materials that are lo cost, low maintenance and adapted to the local environment (therefore reliable)
Type of Service	• sophisticated, highly specialist care • city based	• generalist care • easily accessible & available to all
Integration	• separate from the community	• integrated into the community
Cost	• limited to those who can afford service • limited to those who can access service	• focus on rural and disadvantaged groups • usually provided at no or low cost
Staff / Population Ratio	• high • university qualified therapists • accredited internationally	• low • "therapists" usually composed of therapy assistants trained in short courses or locally trained health workers • rarely have access to university qualified therapists

Table 1b. Differences in service provision in institution-based and CBR models -therapy issues

Feature	Traditional Institution Based OT & PT	OT & PT in CBR
OT & PT Roles	• direct service provision to the client • 1:1 therapist:client ratio • rarely works in groups • allocates therapy time according to individual needs • ideal care to a few	• mainly indirect • acts as expert resource • teaches/trains local health workers and families to carry out day-to-day therapy • 1therapist:to a given population ratio • often works in groups • allocates time based on needs of the population • good basic care to all
Professional Kudos	• high - preferred employment option for therapists	• low - seen as a poor alternative to institutional employment
Professional Skills	• professional skills are protected and guarded	• transfer of skills to empower multiple levels of workers and families
Locus of Control	• therapist centred	• client/family centred
Status as an Expert	• therapist is seen as the expert • their knowledge and judgements are rarely directly questioned	• therapist is seen as a resource with expert knowledge about disability and pathology • client and family are seen as the expert about day to day functional issues and contextual factors
Knowledge and Information Flow	• is usually one way from therapist to patient - if at all. • not often presented in a form that is consumer friendly	• is a partnership approach based on a two-way flow • mutual respect of both parties and what they have to contribute • usually presented in a form that is consumer friendly and accessible to all involved
Therapy Decisions	• decisions about care rarely involve family	• decisions about management always involve client/family

Feature	Traditional Institution Based OT & PT	OT & PT in CBR
Model of Communication	• use specialist jargon	• use lay terminology that is consumer friendly
Therapeutic Approach	• curative • based on medical science • uses medical model for case reasoning • limits therapy and approaches to the scope of pathologies encountered • best suited for managing short term illnesses and acute problems • focuses on short term care	• manages the disability • based on a problem solving approach with a focus on function • uses a pragmatic functional model for case reasoning • uses many health models and options • best suited for managing chronic diseases and disabilities • focuses on long term solutions
Cultural Competency of Therapist	• Often low - rarely considers cultural factors • therapy often in conflict with cultural values	• High - always considers cultural factors and provides therapy with these factors in mind
Knowledge and Skills Required	• traditional therapy	• management, teaching, networking, organisational, health promotion, as well as therapy skills
Environmental Considerations	• rarely considered • treatment is confined to presenting pathology • patient is discharged from centre rather than prepared for re-entry into the home environment	• always considered • intervention is needs generated and considers social, cultural, physical and other environmental factors • client's program is generated from home based needs

Table 1c. Differences in service provision in institution-based and CBR models -professional issues

Feature	Traditional Institution Based OT & PT	OT & PT in CBR
Generation of Knowledge Treatment Approaches	• High • Clinical reasoning, evidence based practice and research generates knowledge related to treatment issues	• Low • draws upon knowledge derived from institutional practice • uses creativity to adapt knowledge to local context
Generation of Knowledge - Service Delivery Approaches	• Low • tends to provide same therapy regardless of context	• High • uses and evaluates a variety of models to suit context
Research Emphasis	• disease/pathology based - efficacy trials • uses experimental vs control approaches to compare treatments • uses traditional quantitative measures	• functional outcomes • service delivery models • matching approaches to meet needs • efficiency and efficacy • uses quantitative and qualitative measures

Table 2. Features of the ideal teaching package

Features of A Teaching Package
Aims of the teaching package
Objectives of sessionOverview of session and time required
Resources required
Preparation (including before and the day of the workshop)
Venue requirements and layout (accounting for group size)
Teaching, learning and evaluation plan
Group Leader instructions
Workshop script - sufficiently detailed to lead presenter through the process step-by-step
Suggested adaptations/modifications to the session
References and other useful literature as resource material

Evaluation of the session - outline of strategies and instructions
    immediate response to sessions – what they enjoyed
    short term learning that occurred
    long term learning through application in the field

Appendices   Overheads
case studies
other teaching materials
participant handouts
evaluation forms

CURRENT STATUS OF CBR IN AFRICA: A REVIEW

Geert Vanneste

ABSTRACT

Despite the growth in the number of community based rehabilitation (CBR) programmes in Africa, services for people with disabilities in most regions of Africa are still limited to what people can do for themselves, or what can be provided by specialised centres such as residential homes, schools, or sheltered workshops. Most of the 'formal' CBR programmes implemented till now are products of foreign policy and interest, with inputs of foreign manpower and money, and not the result of the inventiveness, creativity and hard work of the local people themselves. This chapter reviews the status of community based rehabilitation in Africa, detailing the types of programmes in the governmental and non-governmental sectors, and discusses the problems related to the implementaion of CBR programmes in the continent. The author goes on to critically analyse issues related to planning of programmes, selection and training of staff, monitoring and evaluation, community involvement, information sharing, role of specialists, use and misuse of funds, sustainability and the role of disabled persons. The advantages and disadvantages of CBR in Africa, in comparison with institutional programmes, are also discussed.

Most "CBR programmes " implemented till now in Africa have not resulted from the inventiveness, creativity and hard work of the local people themselves. They are products of foreign policy and interest, with inputs of foreign manpower and money. Writing an article on CBR in Africa is a risky endeavour for another two reasons. "Africa" is 57 different countries, 350 million population, thousands of tribes and peoples, with cultural, geographical , political and organisational differences. An article on "Community " based rehabilitation in Africa really needs to find some common ground in this particular type of service towards persons with disabilities (PWDs); yet people with field experience may have met quite different situations from those described here.

There is also a wide diversity of meanings currently attached to the term "CBR". The reason is that "CBR" is not just a concept or a working definition, but also an ideology, assuming that community members are willing and able to mobilise local resources and to provide appropriate services to their disabled people. The debate is very much about how far local people can do this by themselves. We therefore have to first agree on a 'working definition" of CBR for this article. Most users of the term "CBR" might agree with the following one: "CBR programmes improve, facilitate, stimulate and/or provide services to people with disabilities and their families and caretakers; within the locations of their families and communities; through local, full time or part time, paid or volunteer, community rehabilitation workers; who are being trained, followed up and managed within a certain organisational set-up".

When we speak about CBR, we think first about programmes, projects or organisations working with PWDs in their communities. Yet it would be wrong to start without mentioning the other type of CBR, which happens day by day in every corner of Africa, naemly, the efforts of several million

parents and family members who live with a moderately or severely disabled person, coping with the situation, doing whatever they can, in living conditions which often make any special attention very difficult. Their efforts, and those of PWDs themselves, should form the basis of any "effective" CBR programmes, projects and organisations. CBR should facilitate, strengthen and improve existing family and community efforts.

TYPICAL PROBLEMS OF POST-COLONIAL SUB-SAHARAN AFRICA

Community based services for disabled people in Africa naturally face all the problems inherent in the particular community they are situated in. Major decisions on health and on education are made mostly by urban elite, seldom representing the interests or wishes of the masses with whom they are hardly in touch. Official government services are extremely weak, because of nepotism, corruption and therefore also a chronic lack of funds. People like to believe that low salaries are the main reason for the dysfunctioning of their official structures. NGO and church organisations, who should offer an alternative or complement the government services, are also mostly in the hands of the same elite, who have achieved their positions by surviving within corrupt systems. Very few find the moral strength to end these habits once they get into better-paid jobs in NGO or church systems.

The main obstacles to bringing about a change in this situation and thus in what is usually called "development" in Africa are the difficulties people encounter in making proper and efficient use of private as well as other (project) money, and a lack of tradition in formal management. Law and order, police, and government revenue collection seem to be just a pretext behind which the "real reality" functions as a parallel world. Nobody seems to be willing or able to do something about these informal organisational structures, because of the practical consequences that may ensue, particularly the corruption at all levels which such a change in mentality and in administration would undoubtedly reveal. This situation ensures that personal and family obligations take precedence over civic spirit and legal duties. High unemployment and large families add even more pressure. These problems will probably persist in future decades, jeopardising the capacity building of strong local CBR projects and organisations, which could have strengthened the existing rehabilitation efforts within the families.

CBR IN AFRICA

It is hard to discover the number of CBR programmes in Africa. Some estimate the number of self proclaimed "CBR programmes" in Sub-Saharan Africa, exclusive of south Africa, to be around 200-220. Some are full fledged programmes, working with full time paid staff, of whom most are local community rehabilitation workers (CRWs) or supervisory staff, working at the homes of people with various disabilities. Most programmes however, work only part-time in the communities, while operating out of a centre, a hospital, or other social services, and they encompass only some CBR components such as outreach work, clinics, parent guidance, referrals etc. They seldom work with all age groups. There are almost as many "types" of CBR programmes as there are programmes. However, most CBR programmes are financed by overseas agencies, hence they plan their programmes to fit the donors' requirements.

TYPES OF CBR PROGRAMMES IN AFRICA

CBR programmes using mainly existing government structures

In several African countries, governments have set up large or small scale CBR programmes, often with financial support from international organisations and local NGOs. With a manager at the ministry level, and existing government employees as supervisors, local community rehabilitation committees are formed to facilitate the work of local volunteers. These volunteers receive a short training of about two to six weeks' duration, and are then asked to provide services to all types of PWDs, basically by making use of the WHO manual "Training in the Communities for People with Disabilities" Some programmes make use of locally available technical staff (physiotherapists etc.)and other resources (hospitals, etc.), whereas others do not.

This WHO model of CBR has been in many respects more of a normative demand, rather than a pragmatic concept. It is of course quite ambitious to try to provide services to a minority group (i.e. disabled people) by the use of existing government structures which everyone agrees are unable to provide even the more vital services to the majority of people, such as primary schooling and basic health care. One reason for relying on existing structures is the hope of decreasing the cost of the programme. In practice, this hope has seldom been justified. Using government services that are full of counter-productive traditions usually absorbs a lot of money that in a new and independent structure could more directly be used for service provision. Such programmes are as a whole often more expensive than the NGO-CBR programmes.

While NGO-CBR programmes usually pay their CBR worker, the WHO model programmes try to work with "volunteers". Yet, despite this they often manage to acquire some expensive four-wheel drive cars, each costing yearly more than the cost of paying proper salaries for 15 or more CBR workers. There are other specific problems with the WHO model. While local "rehabilitation committees " have an important role within the "system", they seldom function at all ("we don't know what to do"; "we have no money"), and good CBR work demands more motivation and qualification than most "volunteer" workers have. It also requires a higher level of rehabilitation skills than most volunteers are willing to acquire and practise without additional incentives and/or full employment. As each volunteer works with only very few PWDs, by the time they get skilled and experienced they already have families and need to earn a living in order to survive.

The NGO type of CBR programmes

These programmes, which are mostly financed by an international NGO, and often carrying its name, emphasise direct service delivery to PWDs, by the use of the NGO's own salaried employees, who are trained and monitored by the programme. Such programmes are usually very expensive, while their quality is often not much better than those using the WHO model described above. However, some NGO-CBR programmes have been quite successful. In the following section, an attempt is made to describe what makes this difference.

Objectives, priorities and planning within a CBR Programme

Programmes often lack clear objectives, and therefore also lack "planning". Their "priorities" are often not geared towards what the community needs most. One of the reasons is that they are

donor driven: "we have to do what we are able to get money for". Another reason is a lack of proper "vision" on disability. Many of the people they serve are indeed "impaired", as individuals, but they are not disabled in the communities where they are living. A clear illustration of this "lack of vision on disability" in disability programmes is seen in the many special schools and sheltered workshops for physically disabled people which have been set up all over Africa. Very often one finds people with disabilities in these schools playing basket ball or some other sport, equipped with different types of orthopaedic aids, while some others may be mildly disabled. Since most of these children come from rural areas, the question is why they could not join the regular schools in their villages, once they had been made mobile. The answer is that the quality of schools for disabled people is much better than the regular schools, and as every thing is provided for them, it also means that their poor families have one mouth less to feed. However, would it not be better to spend the millions of dollars spent by these schools every year, to provide mobility aids to the remote unreached disabled children, or on surgery for almost half of the blind population in Africa? This brings up another question. Do these schools or workshops serve the children or do the children serve the institutions? This illustration shows that a wrong "vision" on disability often leads to choosing the "wrong priorities", unnecessary activity and waste of resources.

In Africa, 95% of disability is poverty related. The social environment for most PWDs is poor, with few chances for education or change. This means also that the objectives of "community based" programmes should be realistic, realising that they will need to be achieved in the midst of poor living conditions, which are at the same time poor conditions for rehabilitation. Therefore, given the vast number of PWDs who are still not reached today, the objectives of rehabilitation should be limited to essential services: to restore abilities or to reduce disabling effects, only to the extent however, that their dysfunctioning is of limiting influence on the integral development of the person (in case of children), and provide opportunities to lead a "meaningful" life in their own community (in case of young people and adults). If not all people can be served, priority should be given to "easy" before "difficult", "young" before "old", "near" before "far". In other words, "cost effective rehabilitation is all about "prognosis", not about "diagnosis".

Objectives of rehabilitation also need to be "objective" and "operationalisable" into clear planning, focusing on clear targets (e.g. ability to walk independently), strategies (e.g. 1. surgery; 2. prosthesis; 3. follow-up at home by…etc.) and methods (referral to hospital x on April 16., parallel bars at home etc).

Selection of CBR Field staff

Most programmes start with the "wrong" staff, through lack of experience in using proper selection criteria. As always, the job of the CRW should first of all be a social promotion of the selected person. In rural areas, this means that anyone having a higher educational level than primary school plus some post-primary schooling, will quickly be frustrated in a job working at the homes of poor people, with lots of displacements, in often poor weather conditions. In urban areas however, the educational level of CRWs can and should, be a little higher. Candidates should also be aware of, accept and be able to perform this physically very demanding job. They should also not expect "promotion", in fact the chances of promotion are almost zero. Many believe that most of the aspects of CBR fieldwork in Africa are better done by women.

Some CBR programmes in Africa experimented by initially selecting 4 candidates for each position of a CRW. These candidates first receive a short training in how to conduct a survey and how to evaluate it; the best two candidates are then chosen and trained in CBR work with one category of PWDs. After this theoretical and practical training, the best of them will get the job, while the other person will receive a compensation for the time spent, and may one day still be of use to the programme.

Training of CBR Staff

A lot of training is often provided to people high up in the organisational structure, who are mostly office - bound, while very few skills are filtered down to the level where the rehabilitation is supposed to take place, which is the home and neighbourhood of the PWDs.

In some curricula of training sessions for CBR staff in Africa, the emphasis is often on "training in CBR concepts, how to motivate the community, how to promote positive attitudes, how to talk to community leaders" etc. Yet this "community" aspect of CBR, however important, does not automatically lead to rehabilitation. It can be an empowering factor, and a necessary condition for "integration" and respect of human rights of PWDs. However people tend to forget that rehabilitation is largely the result of services provided to disabled people. It involves therapy, stimulation and skills training, resulting in changes in how people live and function and also changes in how disabled people interact with their family and community, as a result of the skills training they receive. This goes far beyond the curricula of some of the CBR field workers' training sessions.

Daily management of CBR fieldwork

Lack of formal management is a problem in most CBR programmes. Community based rehabilitation needs community based management! Such formal day-to-day management in the field is unlikely to be done by directors of national programmes, working at the ministry level in the capital of the country, or by NGO directors or supervisors often with advanced degrees, for whom it is hardly attractive to visit the homes of poor people. Even most "supervisors" spend up to 80% of their time at the office. It is not rare to find that a CBR worker, who was supposed to perform a total of 50 visits to a certain family over a period of one year, in reality only entered their house 3 or 4 times. Even a good salary cannot be a substitute for formal management, monitoring and encouragement.

Evaluation

Evaluation in general and case management in particular are very weak in most CBR programmes. Unclear objectives are part of the reason. If we do not know where we are going, how do we know that we have arrived? The most efficient way of evaluation is therefore to install proper "case management", which includes setting clear aims and objectives for each PWD, pointing out a clear strategy, the actions to be undertaken, organising regular case review and evaluation of the services to each individual.

Community Involvement

Some programmes do not involve the community at all, while others are over-taxing the communities. In the prevailing conditions in many African countries, involving the communities,

however nice it might sound, is often an obstacle towards progress of the programme and a burden on the shoulders of those who focus on "direct results". On the other hand, local culture and involving local structures is of course a "condition" towards "real" progress of the community! You do not get your car to the other side of the road by taking a taxi! Some would say….unless you get everyone into the taxi, and pull the car!?

Other programmes, which almost completely rely on existing resources, might indeed be over-taxing the communities. It is precisely the "lack of community", i.e. the breakdown of traditional structures, that contributes to the multitude of problems facing African countries. So it is unlikely that these weakly constructed communities could organise appropriate services for their PWDs.

Knowing that rehabilitation for PWDs is seldom a priority issue in Africa, it is unrealistic to expect countries to invest scarce resources in solving problems of the weakest amongst them, rather than investing in health (vaccinations, basic health services), survival (prevention against AIDS, malaria etc.) and education (primary school education, basic training, etc.) of the "stronger" people who are considered more likely to repay such investment.

Theoretically and ideally, rehabilitation for disabled people is a matter of human rights, for which all people are responsible. Yet practically, in Africa, it is a humanitarian, welfare target. Given the very gloomy socio-economic circumstances, it is sometimes a luxury.

The role of specialists: physiotherapists, occupation therapists, educators etc.

Most local CRWs have few skills to offer on their own. CBR programmes have been placing a lot of trust by just providing CRWs with a training, after which they are being "supervised", but often by people who possess barely more technical know-how than the CRWs themselves. Evaluations have shown that some CRWs may in this case obtain some good results in the field of functional rehabilitation for adult PWDs, but have rather poor results in early intervention in general, developmental stimulation in particular, as well as in treatment of patients with arthritis and stroke. This is particularly significant, given the epidemiological transition in the African region towards more childhood and old age disability.

Programmes therefore should stress the importance of greater direct involvement of specialist personnel (physiotherapists, occupation therapists, special teachers etc.) in the whole process of case management, from the training of CRWs, to advising them on the individual programmes at PWDs homes, to setting clear targets and strategies, till the stage of evaluation. Such a day-to-day involvement by specialist staff in the field is increasingly considered a pre-requisite for a cost-effective CBR programmes(Figure 1).

Figure 1

Use and misuse of funds

The systematic misuse of funds is of course not a problem exclusive to the CBR field! The main cause for the misuse is the unprofessional way in which some donor agencies operate. Some of their representatives come to Africa for a few days, meet with some "very nice" people in whom they put all their trust, and start sending vast sums of money. As a rule, organisations which do not

have their own experienced representatives in Africa will see more than half their funds being misused. Even having local representatives is not always a solution: many of them are inexperienced, often naïve, do not spend time enough in the projects to really see what is happening, or do not have the knowledge or expertise to do so. Organisations using local African representatives will often find that the latter, because of different types of pressure on them, are part of the corruption in projects.

Rehabilitation services are care not cure

Long term sustainability of programmes is therefore very important. Programmes which are set up for just two to three years may cause a lot of frustration. They may create hope in the lives of disabled people, but once the project disappears, the often poor family may have to cope with the changed attitudes and expectations from the disabled member, which they cannot fulfil without external assistance.

Sharing experiences

As most CBR programmes in Africa are highly dependent on external donors, there is a tendency towards secrecy and guarding of resources, so that little collaboration or mutual learning takes place between programmes. Each proceeds by trial and error, repeating others' mistakes.

Programmes by disabled people for disabled people

There is no doubt that disabled people have a lot to offer to each other, and to any disability programme. In many African countries, disabled people with different disabilities or of one disability group have gathered in meetings, have formed pressure groups, have started their own projects, and some have become full fledged organisations. Some of these initiatives are very meaningful, representing disabled people from different levels of the society. Others however, seem to have an even more patronising effect on disabled people than other programmes. Many of these initiatives failed once they were taken over by disabled people, who had other goals, rather than the fight for better living conditions and for the human rights of their fellow disabled people. Here also, input of foreign money has done a lot of damage.

Is it all that gloomy?

This paper indeed did not say a lot that was positive. Despite the many problems, much has been achieved in some places, often by people who would not even know what "CBR" stands for. They may have been creative simply in organising some practical ways of solving day-to-day problems of PWDs and their families, by bringing together of mothers of disabled children; by organising small neighbourhood day care centres (a community does not stop in front of a wall!); by explaining both the special needs and the "ordinariness" of these kids to schoolteachers; by collecting some money to pay for surgery etc. Such small initiatives however are often jeopardised once foreign money is brought in, which usually leads to a change of leadership style and consequently to a change of objectives.

It would be unfair not to mention here that there are CBR programmes, of the WHO or NGO style, which have been providing good services for some time by using, as far as possible, local

human, material and financial resources. Many of them are still continuing today, though they are dependent on one or two dynamic people who know the art of writing straight on curved lines.

SUMMARY

Advantages of CBR, compared to the institutional approach, as experienced in Africa

a. In time, and in theory, all the disabled people in a community can be reached, and their basic needs met.

b. "Tailor-made" rehabilitation programmes can be established, based on the individual's capacities and needs, and focused directly on integration into the family/community.

c. "Disability" is not a stable situation. Disabled children become disabled adults, with greatly different vulnerabilities and needs. CBR can evolve and adapt to such fluid situations, while the rehabilitation centre will often only be able to "take a photo": i.e. deal with one set of problems at one point in the life of the disabled person.

d. Family members can witness and participate in the progress of a disabled relative, thus enhancing their faith in that person's abilities and potential, and challenging their own prejudices.

e. CBR services, apart from carrying out their core work in rehabilitation, can also contribute towards the prevention of impairments and disabilities, through activities such as primary health care, vaccinations, nutrition and hygiene, etc.

f. CBR programmes can trace many disabled people who would never be found by institutions, and, through referral, can make the work of other existing specialised services more effective.

g. Early detection also allows early intervention which is very important given the increase of childhood disability in Africa.

h. CBR is cost-effective (if well managed!).

Problems of CBR, compared to the centralised approach, as experienced in Africa

a. The poor living conditions of most people with disabilities are also poor conditions for rehabilitation. The objectives of individual CBR programmes therefore have to be very realistic, focusing on essential needs.

b. Community and home-based services by community rehabilitation workers can sometimes be rather routine and boring, for the worker, client and family alike; they may be less challenging than training or education in a centre.

c. Poor families' priorities may be at the level of survival needs, rather than solving problems of a disabled member. Further, the disability of one family member is not always problematic for other family members; so it is sometimes very hard to enlist their active collaboration.

d. The organisation and management of CBR is complex and difficult, in a continent where people either have no tradition of formal management and handling funds, or where traditions were severely weakened during the experience of colonialism.

e.   The usual educational level of the CRWs has been rather low. Better-educated workers do not like to go into the field, and may find it hard to communicate well with disabled people who are often uneducated or undereducated. Front line CBR is a low profile job, which gives no social status to people with higher education.

These factors influence the kind, level and quality of the services which can be provided at the ground level by a CBR programme.

CONCLUSION

Despite the number of CBR programmes, services for PWDs in most regions of Africa are still limited to what people can do for themselves, or what can be provided by specialised centres such as residential homes, schools, sheltered workshops etc., along with a little "casual", unplanned school integration.

By far the most widespread positive resources are those that already exist in the hearts and minds of African mothers, sisters, grandparents, neighbours, and disabled persons themselves. If CBR is to have an impact on hundreds of thousands, rather than on merely hundreds, then programmes must study, value, enlist and enhance these vital existing community resources. No plan should be approved unless some "multiplication factors" are built in, whereby a small input of knowledge and skills can bring into play a much larger amount of latent energy.

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COMMUNITY BASED REHABILITATION IN CHINA: A COMMENTARY

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ABSTRACT

Through fifteen years of extraordinary effort, China has set in motion a nation-wide programme for preventing disability and improving the quality of life of people with disability. A strong and comprehensive framework for rehabilitation efforts is now in place. In an attempt to reach those most in need and least able to access services, China has adopted a community based approach to rehabilitation. However, considering the more than sixty million disabled children and adults and the size of the country, it is truly a challenge to establish viable and sustainable programmes. This chapter describes the current strategies to provide rehabilitation services and consider ways to strengthen the community based rehabilitation (CBR) work in China. Starting with a brief review of disability in China and of CBR internationally, the author goes on to discuss the factors favouring CBR programming in the Chinese context, such as the existing administrative system, the national rehabilitation plan which includes CBR, multi-sectoral endorsement of the plan and of CBR, and the establishment of referral centres for rehabilitation. However, many challenges still remain, related to community participation, sustainability, the role of disabled people, and training of personnel.

A. INTRODUCTION

Through fifteen years of extraordinary effort, China has set in motion a nation-wide programme for preventing disability and improving the quality of life of people with disability. A strong and comprehensive framework for rehabilitation efforts is now in place. In an attempt to reach those most in need and least able to access services, China has adopted a community based approach to rehabilitation. Zhao (1) reports that more than 62 counties are now testing community based rehabilitation services. However, considering the more than sixty million disabled children and adults and the size of the country, it is truly a challenge to establish viable and sustainable programmes.

This chapter will describe the current strategies to provide rehabilitation services and consider ways to strengthen the community based rehabilitation work.

B. DISABILITY IN CHINA

Until recently, disabled children and adults in China were usually confined to their homes. In some cases the extended family or village co-operative systems were able to find suitable productive work (2). However, in the vast majority of cases, even in major cities, no rehabilitation expertise was available to help disabled people improve their abilities. Families with disabled members often used all their resources in seeking cures, quickly becoming marginalised in both the economic and social spheres.

The situation changed remarkably in the early 1980's with the formation of a national welfare organisation for the disabled led by Deng Pufang, himself newly disabled and son of China's then paramount leader, Deng Xiaoping. After his father's return to power, Deng Pufang was invited to visit Canada for medical care and rehabilitation. The visit opened a world of opportunity, which he then made every effort to offer to China's disabled people. He set up a new organisation, which became the China Disabled Persons Federation. It raised funds, instigated a national sample census of disabled people and pushed through a national work plan for the disabled. This movement was legitimised by Deng's leadership, was strongly promoted and was paralleled by an explosion of rehabilitation activity in other government sectors. The conjunction of these developments with the United Nations International Year of the Disabled (1981) and the World Programme of Action for Disabled Persons (1983-1992) was fortuitous.

In 1987 China announced the results of its vast national sample survey of disabled people. The survey reported 4.9% of the population, 51.64 million people, as disabled in 1987 and that 18.1% of households had a member with a disability (3). Guo and Meng (4) report that if people with leprosy, dwarfism and visceral disability had been included in the survey, the disabled population would have totalled about 91 million, or 8.6% of the total population. Although many difficulties arise in comparing prevalence studies because of differences in methodology and in definitions of disability, the Chinese data are very similar to estimates for other developing countries. Helander (5) arrives at a global prevalence estimate for moderate and severely disabled individuals of 5.5% in the year 2000, with 8.5% in the more developed regions and 4.8% in less developed regions.

In addition, China has also to consider the impact of improved standard of living, changing lifestyles and an ageing population. In its 1992 report on China's health status, the World Bank reports that the country is already well into the health transition: ".. in all parts of China, including the poorest areas, infectious diseases have decreased to a point where the chief causes of premature death and disability that remain are the various chronic diseases" (6). The report points out that China has yet to develop appropriate plans to cope with chronic illness and the resulting morbidity and disability. At the same time, the report recommends that China must avoid the costs and problems of the high technology approaches adopted in developed countries.

National rehabilitation planning requires this sort of country wide data, but specific programmes can only be designed with a more detailed understanding of the needs and situation of disabled individuals, their families and communities in which they live. Although every Chinese city and county has reports on disability numbers, there are few studies documenting the expressed and real needs of disabled individuals.

Chen and Simeonsson (7) looked at the needs of families with a disabled child living in rural and urban sites in Hubei Province. In addition to schooling, the expressed needs were similar and not unfamiliar to parents of disabled children elsewhere. Parents primarily needed more information about their child's condition and about available services. They wanted ".. knowledge on how to teach their child and how to handle behaviour. Related areas of need were for financial help for therapy, special services and special equipment, locating a doctor who understood the child and family..".

Kleinman and co-workers (8) studied epilepsy in urban and rural communities in Shanxi and Ningxia Provinces, documenting the effect of this chronic illness on the individual and the family. Families perceived emotional, financial and family and marital burdens as extensive. Suffering was shared by the whole family. The authors emphasise the significance of the family not only as a source of nurture and assistance but as a potential source of over-control, in an effort to maintain the family's status in an unfriendly and ignorant environment.

Phillips and Pearson (9) discuss society's desire for visible social control of people with mental illness. They suggest using the promise of improved control and reduced social unrest as an approach to strengthening community and official support for community programmes. They also identify work programmes as central to community rehabilitation efforts because of the significance of work for social identity and welfare in the Chinese situation. An article describing CBR stations in Shenyang City clearly demonstrates the high value given by local officials, families and the authors to social control and the visible productivity of the disabled people (10).

A paper by Zhao (11) looks at socio-economic status of disabled women in Beijing in 1990 and 1995. While noting recent improvements, the authors describe generally lower education levels and increased unemployment among disabled women, and document the prejudice and discrimination they face from both their families and from the community. They conclude "attention should be paid to the work for disabled women at grass roots levels, especially to those .. below the poverty line."

As elsewhere in the developing world, the majority of people with disabilities in China still lack comprehensive family-oriented services, easily accessible, financially affordable and appropriate to the immediate community and its culture.

C.

D. COMMUNITY BASED REHABILITATION IN THE INTERNATIONAL CONTEXT

In recent decades it has become clear that institutions can neither provide services for all who need them nor provide the appropriate training for community living. These problems of accessibility and appropriateness are exacerbated in rural areas and among the very poor. Most families either do not know of the existence of rehabilitation or expend all their resources in travelling and gaining admission to urban institutions, which are then unable to give them the hoped-for cure and indeed, often give them inappropriate treatment and assistive devices. In fact, most basic needs of disabled people can be met in their own homes and communities, given simple and practical methods and a mentor or coach (5).

Community based rehabilitation (CBR) programming uses existing community structures; uses local manpower; and includes a working referral system for complicated problems. CBR works as follows. A community, often led by a non-governmental group, recognises its responsibility for helping disabled people attain health care, schooling and jobs, and forms a rehabilitation committee. The committee, which includes disabled people, family members, representatives of the concerned sectors and usually influential leaders, selects and supports several local people to become local community workers. They are trained in identifying, assessing and helping disabled people in their own homes and environment. Initially this may include training in mobility and daily activities, followed by helping a disabled child to join a play-group or go to school, or perhaps helping an

adult contribute to the family productivity, attain employment and participate in social activities. The over-riding goal of CBR is social integration and equal opportunities both within the family and the community at large.

Often a higher level co-ordinating body, professional group or rehabilitation resource centre at a district or county level may have spear-headed the awareness of disability and rehabilitation services. That resource centre may provide the technical expertise for training of community workers and a channel for referrals, as well as motivation and monitoring. In CBR, the main focus is on the home and community, but a referral network, a viable management structure and visible, documented outcomes are essential for sustainability.

Describing a successful CBR programme in the Philippines, Estrella (12) discusses the empowering aspects. As a disabled person develops increased independence, self-confidence and motivation in his home and community, he also gains an "increased sensitivity about the difficulties he is experiencing.. he seeks out other disabled persons. He now starts to make demands; he does not wish to be perceived as a client of welfare anymore." She reports that now many self-help organisations have formed and they are not only initiating their own CBR programmes, but are involved in political lobbying for their rights. The ability to be self-sufficient and self-reliant would be invaluable in China's current situation, although political lobbying remains problematic (13)

(1) Factors FavoUring Community Based Programming in the Chinese Context

Faced with a vast population of disabled people, the large proportion in rural areas, and with the goal of extending care to all in a reasonably equitable way, China's central planners concur with international authorities that community based rehabilitation (CBR) is a promising strategy. Indeed, in light of China's highly structured administrative system, the country's achievements in improving health status, the policy of household responsibility and the tradition of extended family support networks, community-based rehabilitation appears made-to-measure for China.

In 1978 China decided to decentralise many administrative functions to provincial, city and county authorities reaching even to the district and township levels in some aspects.

In urban areas each city is divided into districts. These districts are further divided into "streets" and then into neighbourhoods. The district government has full authority to handle day-to-day affairs within its boundaries. Its decisions are implemented through the street offices. Each street usually has a first-referral hospital or clinic, and a selection of social welfare centres. Examples of these are an elderly home or activity centre, a school for children with mental handicap, a work station for people with mentally illness and a welfare factory for those who are blind or deaf (14). The neighbourhood residents' committees are mandated by national ordinance as a means for mass mobilisation and self-government. They co-ordinate and monitor local efforts in social welfare, public hygiene and family planning. They also mediate disputes and ensure local security. This work is all reported back to the street office (15).

In rural areas, the urban structure is paralleled by the counties which are divided into townships and then into villages. Again, each level has an administrative committee. The township level offers a hospital, a junior high school and a variety of economic enterprises, often owned co-operatively by the township. The civil affairs sector of the provincial government has strong ties with the township

government and is concerned with social welfare activities such as providing for those who are indigent (14). At village level, the village committee may be made up of 3-5 officials comprising a party secretary, a labour (agricultural) representative, a social welfare representative and a woman representing the women's federation and involved mainly in family planning. Most villages have a primary school and health clinic. The village teacher and doctor usually have about one year of training in their respective fields, originate from that village and work as farmers in addition to their teaching or medical responsibilities (16). Clearly, both in urban and rural areas, these are infrastructures highly suitable for initiating community based rehabilitation programmes.

In 1988 the top-down endorsement necessary for CBR materialised. The "National Five Year Work Programme for the Disabled" was passed, which mandated the formation of "leading groups" at provincial, city and county levels to oversee its implementation. Three ministries — Civil Affairs, Public Health and Labour — together with the China Disabled Persons Federation drafted this first national plan, which was endorsed by the State Council. In expanded form, it was later incorporated into China's Eighth-Five Year National Development Plan (1991-1995):

> "This work programme was drafted by the State Planning Commission and fifteen other relevant ministries and agencies.. [it] sets the general goals and guiding principles for the work for disabled persons.. The Work Programme stipulates that at least one community based rehabilitation station should be set up in each county or district. Publications on rehabilitation of disabled persons shall be compiled to guide their home based training with professional training" (17).

On May 15, 1991, China promulgated "The Law of the People's Republic of China on Disabled Persons" (18) seeking not only to protect the rights of the disabled but also to promote services for them. CBR was again identified as a national strategy:

> "the work of rehabilitation shall, proceeding from the actual conditions, combine modern rehabilitation techniques with traditional Chinese techniques, with rehabilitation institutions as the core and community based rehabilitation as the basis and relying on the families of disabled persons for support. Emphasis shall be laid on rehabilitation projects which are practical, easy to realise and widely beneficial...." (Article 14)

> "The people's government and departments concerned should at various levels, organise and guide urban and rural community service networks, medical prevention and health care networks, organisations and families of disabled persons and other social forces in carrying out community based rehabilitation work" (Article 15)

China thus has a national rehabilitation plan, which is a multi-sectoral, co-ordinated effort. It includes implementation directions and is officially endorsed as part of the National Development Plan. It has been disseminated to each level and officials are obligated to acknowledge it and report their part in implementing it.

In addition to the comprehensive work of the China Disabled Persons Federation, several ministries have very actively developed expertise in rehabilitation and services for particular groups of disabled people. The Ministry of Civil Affairs, as well as providing welfare services, runs prosthesis/ orthosis-making factories, of which there is at least one in every province and region. They also

manage many welfare factories and vocational training centres and run rehabilitation centres for children linked with several key orphanages. They have actively promoted neighbourhood community service centres, as well as institutional and community networks caring for disabled elderly and people with mental illness. The Ministry of Education has developed courses for training teachers of special education. The 1996 Provisions on Education of Disabled Persons promote inclusive education and there are some rural schools are presently involved in pilot schemes.

The Ministry of Labour has developed the Provisions on Employment of Disabled Persons and the China Disabled Persons Federation (CDPF) is actively monitoring the quota system for employment in some cities, promoting opportunities on the open market whenever possible.

The Ministry of Public Health, for its part, has sparked the development of modern rehabilitation medicine through its hospital accreditation procedures. Many hospitals have long had small departments delivering electrical therapies and traditional rehabilitation therapies such as massage and acupuncture. In 1991, new hospital accreditation standards were issued which required higher level hospitals to add exercise therapy, occupational therapy and other such specialities based on the western practice. Several centres have developed training programmes to upgrade staff to take on these new rehabilitation tasks.

So the framework necessary for country-wide CBR programming exists: an administrative system, a national rehabilitation plan which includes CBR, multi-sectoral endorsement of the plan and of CBR, and referral centres for rehabilitation. In the context of China's family-oriented society, all the structural elements are in place.

E. CHALLENGES FACING COMMUNITY BASED PROGRAMMING

A major dilemma in China is how to achieve sustainable community participation in programmes. Certainly, mass mobilisation for top-down targets is accomplished with ease. However, cultivating community awareness and responsibility takes time, while recruiting committed volunteers and promoting their ownership of programmes may cause undesirable power plays within a community which officials can well do without.

Notwithstanding many changes in recent years, most officials in China still have an intense suspicion of grassroots organisation of the kind required to support CBR (14). This suspicion sustains a fear among the people of organising themselves for any reason apart from private family matters. As a result, developing CBR through community organising techniques is not the natural approach in China that it would be in many other countries.

While it might seem that this should not unduly inhibit the formation of social and non-governmental groups, in reality it means that, even in the social service sector, private initiatives face many unexpected barriers and carry a low status in their interactions with officialdom. So, while there are examples in every province, where private rehabilitation efforts have come from individuals, these remain few, considering China's vast population. Where such initiatives prove successful they usually are co-opted promptly by an official programme. In most cases this leaves both sides happier. Indeed, new regulations for the formation of social organisations and non-profit groups, state that all such groups must be sponsored by a government department, which accepts responsibility for supervision and annual audit. They must comply with specific rules regarding

minimum membership and financial assets. Significantly, there is a limit to any duplication of similar organisations at each administrative level, which allows for little dissension (19).

A second factor delaying the development of CBR is the strong, central direction of the rehabilitation movement, even within the disabled persons movement itself. This may seem to be contradictory. Surely, the capacity to put disability and rehabilitation on the national agenda is enviable as is the national endorsement of the CBR approach?

The China Disabled Persons Federation (CDPF) certainly speaks for disabled people. Many of its officials, at all levels, are disabled themselves or are parents of disabled children. However, the CDPF was initially established as an off-shoot of the Ministry of Civil Affairs with offices and parallel positions at each administrative level. Today, the CDPF is a separate semi-governmental organisation, but it has kept the same lines of authority. The benefits of this power structure are the strength and visibility the CDPF has attained through having its own "person" at each level. On the other hand competition has been created between the sectors and there is duplication of services in many areas.

In fact, many activities of the concerned Ministries and the CDPF seem to draw resources away from the community level. Despite the professed emphasis on CBR, visits by officials and professionals to other countries have left impressions of large institutions, well equipped and well manned, serving disabled people. This has tempted leaders to invest in building centres of expertise which contribute little to the development of CBR. Indeed, raising money to build the China Rehabilitation Research Centre, which opened in Beijing in 1988 proved relatively easy. This first national centre is very impressive, acting both as a direct service centre, as a training centre and as a model. But it has little positive impact on community based rehabilitation. On the contrary, visitors and trainees from other parts of the country and from other sectors, invariably come away determined to establish similar high-tech centres.

In the last few years, much time and effort has been spent raising money to build these rehabilitation institutions. By committing most of its resources to a highly visible rehabilitation centre a local bureau limits itself to serving only the disabled people in its area who are able to access and pay for the services provided. The local bureau argues that it needs to develop a solid base, experience and a strong reputation before it can achieve other goals which may be as important but have less appeal in the competitive bureaucratic world. They further argue that effective community programmes require an institution to provide a resource centre as backup. The controversy lies in the level of sophistication and finances necessary for such a resource centre.

Sadly, too often there is little funding, time, manpower or enthusiasm left over for community programming, which anyway is seen as having little status. Although the local bureau is able to report on community surveys and take visitors to homes of disabled people, in most cases the institution neglects its role as a resource centre serving a community based network, and concentrates instead on building up its visibility.

Another strategy distracting attention away from CBR is the issue of using quantifiable, national targets to jump-start disability prevention and rehabilitation work. As a general rule, such targets tend to focus the efforts of officials and experts on quick in-and-out solutions via massive campaigns.

These, while, without doubt, of benefit to a large number of persons, have not yet addressed the daily problems of disabled people in their communities.

The first Five Year National Workplan for the Disabled launched such a campaign called "three rehabilitation targets". The three targets were: to perform 500,000 cataract surgeries, to perform 300,000 surgeries for poliomyelitis deformities, and to give speech training to 30,000 hearing impaired children. As is typical of such nation-wide mobilisations in China, a truly remarkable job was done and the numbers surpassed the five-year target figures before the end of 1992. Intersectoral committees were formed at each administrative level to organise and co-ordinate the project. Medical teams were identified to go out to county and township hospitals where they would find patients awaiting them for surgery. The costs were divided between the different sectors, levels of government and patients. Training courses were held to improve surgical techniques, audiological testing skills and teaching of deaf children. Central government funded equipment, personnel, the building of classrooms for the deaf and associated research.

There is no doubt that this target strategy, a traditional and well-defined process in China, achieved its goals in treating three highly prevalent disabilities. In addition, there were ancillary benefits in increasing awareness of disability and rehabilitation, and in spreading the realisation that China already has technical knowledge and skills and lacks only a delivery system. But the strategy could never be characterised as anything but a top-down approach, with little input from individual communities. It has left some officials with the impression that helping disabled people is a matter of resources and is amenable to a one-time solution.

While "the three targets plan" was never planned as community based rehabilitation, it would have made an excellent springboard for CBR initiatives. Unfortunately, that did not occur.

Finally, training programmes for rehabilitation personnel have concentrated on professionals and virtually ignored the community level. The Ministry of Public Health set up a partnership with the Hong Kong Society for Rehabilitation and a key medical school, Tongji Medical University in Wuhan, to train doctors in a one year intensive rehabilitation course. The course was endorsed by the Western Pacific Region of the World Health Organisation, the Ministry of Civil Affairs and the China Disabled Persons Federation, with the latter giving start-up funds to the university. It was expected that the graduates would be the seeds for CBR and rehabilitation in general (20).

Once again a top-down metaphor came into play with the assumption that these young doctors would be able to initiate community based rehabilitation projects in their own localities. In fact, about 70% of the graduates have responded to their hospitals' needs to establish rehabilitation medicine departments. Some are involved in community based work peripherally, a few in teaching CBR courses or writing training materials, and a handful have taken part in monitoring work (21). The training course seems to be another example of a well-intentioned programme, with good results, but has yet to evolve into something which can be described as CBR.

A) CBR Development Projects

In fact there are many CBR projects reported as operating in China, but most seem to be isolated activities rather than programmes. The Jin Hua Street Project was established in the southern city of Guangzhou as long ago as 1986. It constitutes a worthwhile demonstration of CBR in the

Chinese context, but it remains a street project that has not been extended to other streets or districts. Another example is a rural project in Pi County, Jiangsu Province, which targets a large number of children and adolescents with polio deformities. The project has developed medical, educational and prevocational aspects for the children, but there are, as yet, no plans to serve children with disabilities other than polio sequelae.

There are many similar small projects started by local social welfare bureaux or the local disabled persons association. In some cases, they don't get much further than a survey and a training course. A World Bank health project in three different regions ostensibly included a CBR component, but in fact accomplished little more than surveys of disabled people and a few training courses. In other cases, disabled children or adults with a particular type of disability are receiving training and assistance, but mainly using an outreach model. These are often initiated by hospitals or welfare institutes. The staff go out to villages or districts to visit selected individuals and conduct training. But there is little time spent developing local community workers and both decisions are taken and funds are controlled by the responsible institution. Those private initiatives which get started have almost all been in urban areas. They have been absorbed into the system, but have not been extended or replicated.

Community organising with disabled people in urban areas appears to be relatively straight-forward. The most obvious entry point for rehabilitation is the civil affairs sector with its organisation of street offices, neighbourhood residents' committees and its reputation for mass mobilisation and mutual help. However, staff of the street offices and neighbourhood committees are overworked and underpaid, yet responsible for implementing a wide variety of directives from above, many of which involved exerting control and making demands on residents(14). Chan (15), in her book, *The Myth of the Neighbourhood Mutual Help*, describes an increasing lack of interest in participating in communal activities among residents of Beijing and Guangzhou, although the rate remains higher than in urban areas in other countries.

Some large cities have welfare systems funded by street and district-owned enterprises. Poorer districts and cities cannot boast the same facilities. Chan (15) feels there are many opportunities for community-based social welfare services using the neighbourhood and street system, but that they require something other than the authoritarian approaches used heretofore. At present many community stations (small centres for disabled persons) are passive, time-occupying services as opposed to short-stay training centres or truly productive work centres. While there is no doubt that some disabled people need caretakers, special schools or sheltered work places, others should be included or integrated when appropriate into regular schools or open employment. In order to better use the potential for community based work in urban areas, an increased understanding of the needs and abilities of the disabled people of the district is essential, together with more training and support for the crucial front-line workers and volunteers. Finally, it is essential that the community plans and takes responsibility for the work.

In rural areas, primary health care appears the obvious entry point for CBR. Unfortunately, the system has disintegrated in many parts of the country since the central government's decision in the late 1970s to reform agricultural production, introduce the household responsibility scheme and abandon the communes. Co-operative medical schemes, which covered 90% of villages in 1976,

covered only 5% in 1985. Village doctors, once paid by communal funds, now rely on fee-for-service and drug mark-ups to earn a living. Preventive health services are neglected because doctors are not usually paid for this work and mobilising community participation is difficult since people don't want to lose time from their work (22). The once-proud, three tier referral system has dissolved as county hospitals or private practitioners become more attractive to families with income. Tormented by a substantial decrease in subsidies from government, township and county health services find themselves in competition for patient fees (23).

For better-off communities able to establish village and township enterprises, and thus re-establish a co-operative fund for social services, co-operative health care schemes are again becoming more common.(22). However, for poor communities with few communal resources it is impossible to subsidise health services. Liu and Hsiao (23) cite a survey in the 1980's of poor households where almost 50% reported that their poverty resulted primarily from the expenses of health care when a family member became ill.

In spite of the disintegration of the primary health care system, several counties have attempted to use it as a vehicle for CBR. In all of these official approval was given, funding was allocated, an intersectoral committee was established either at county or township level, a survey of disabled people in the villages was carried out and village doctors were called in to attend lectures on the training of the disabled.

However, when one of these sites was followed up, the results were disappointing. While the village doctors knew each household with a disabled member, it was obvious that any training given the doctors had been unsuccessful in transferring skills. The village doctors were fascinated by a few useful techniques demonstrated by the visiting students and enjoyed making simple and useful technical aids from local materials. Nevertheless, they reported that most of the villagers couldn't pay them for such services, and anyway didn't want to pay for non-curative interventions. The villagers, for their part, said the doctors charged too much. Village leaders knew little about the project or about rehabilitation. The CBR committee at township level, lacked representation from the villages, let alone from disabled people. In addition, any understanding of rehabilitation was from the medical viewpoint, neglecting the primacy of schooling, productive activity and social involvement (24).

Thus the expectation that a mandate from the centre, together with funding, a committee and a training course, would produce a community-based project was unrealistic. It was assumed that the village doctors were able to cope with problems of which they had little experience and were also enthusiastic to do so. They were expected to do this without regular support, without referral resources and with no show of interest from the centre until the time came to make the annual reports. The villages were given no say in designing the programme, in stating their interests or in managing the funds allocated. With he recent government-approved movement towards village democracy, this situation may change rapidly.

STRENGTHENING CBR IN CHINA

China has established a national rehabilitation structure within which community based rehabilitation can flourish. During the past fifteen years, the Chinese have channeled their resources

and efforts into promoting awareness of disability, developing expertise and specialist centres, particularly at tertiary levels and establishing a voice for the disabled in government and administration. But it is now time to devote more effort and resources to community based programming. Crucial is to find ways to link up officials and national planning with individuals who have reason to care about disability, who are willing to actively work in their own community, ensuring that disabled children and adults are not neglected.

In other countries, non-governmental organisations and disabled people and their carers, have been at the forefront of CBR programming. They have often worked for years in the voluntary sector before gaining government and professional support. In China, government endorsement is already guaranteed and a well-designed plan should be able to secure district and county support. However, there are few groups initiating services at the primary level unless they have been planned and funded from higher levels. The majority of families with disabled members are still searching for help as individuals and, outside of welfare, there is seldom neighbourhood or community networking to support and direct families to services and opportunities.

Certainly, CBR in China needs to use the top-down approach to legitimise and validate programmes in the eyes not only of local officials but also in the eyes of the public. Community rehabilitation services should be easily grafted onto the established networks of health and social welfare and indeed, there are many examples of this. However, officials in developing countries seldom see rehabilitation as a priority measure. Projects initiated from above will collapse when official attention is distracted to new targets and official funding is exhausted. Any top-down project needs to include the involvement of those community-level individuals who care about disability and have a stake in the rehabilitation work. They must be involved as planners and managers themselves. Officials and professionals have to give up some decision-making power and funding decisions to community rehabilitation committees at the lower levels. It will also require that front-line workers are supported and motivated in a variety of simple and effective ways.

More emphasis on sustainability is required in initial planning stages instead of designing projects around targets. If results are measured in qualitative and well as the usual quantitative terms, and if these results are seen to be the result of local actions, community pride and satisfaction will enhance sustainability. It is crucial that community-level indicators of success are defined in terms of increased functional abilities, opportunities and social interactions of disabled people and their families, not only in terms of numbers, buildings and staffing (25).

It would be of great value to developing sustainable CBR programmes if several full-time CBR co-ordinators were recruited for each province. Since they will act as consultants, they should receive training in disability concepts, values and attitudes, rehabilitation measures and CBR planning and management, including participatory methodology for community development and strategies for local awareness and fund-raising issues. They should have a broad job description, which includes substantial travelling, and formal and informal liaison with different players at varying levels. They also should have control of a budget to use for training and consultative activities, as well as small funds for special items and have responsibility for recommending funding requests for CBR seed money and other requirements.

The question, however, immediately arises: under which sector should these co-ordinators be employed? A thorny question indeed, which is often solved in other countries by contracting the job out to NGOs or research institutes.

In addition, it would be beneficial to pilot-test some management elements of CBR, which are neglected in many of the existing projects. These include: a rapid needs assessment, appropriate community-level training, a community level reporting system, and a monitoring system that provides guidance, continuing education and support to front-line workers and community rehabilitation committees as well as report analysis and evaluation. These elements will be vital to the extension and replication of projects. In addition, they will demonstrate the commitment of the project to the achievement of results at the front-line.

China is making every effort to establish equitable rehabilitation services reaching all those in need. It is now necessary to purposefully allocate funds and other resources into promoting, extending and replicating community initiatives, making a concerted effort to encourage and support local inventiveness and leadership.

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FRIDAY MEETING TRANSACTIONS

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FRIDAY MEETINGS

'Friday Meetings' were initiated to improve access to knowledge for development organisations, particularly those involved in non-institutional forms of rehabilitation. These meetings which are held on the last Friday of every odd month, such as January, March, May and so on, are a get together of like minded people to debate themes related to application of different methods and development of skills, in this field. All those who are interested are welcome to attend. The meetings are always conducted at the same venue on the last Friday of odd months, between 2 pm and 5 pm. After an initial presentation on a theme, the emphasis is on discussion between the participants. The opinions generated here can be useful to people who are decision makers, researchers and interventionists.