

## **CBR WORKS BEST THE WAY LOCAL PEOPLE SEE IT AND BUILD IT**

M. Miles\*

### **ABSTRACT**

*The growth in availability of practical information by which people may manage disability in home and local community, and some problems of transmission and cultural adaptation, are reviewed. There is a growing menace of simplistic globalised packages, promoted by deeply confused 'flying experts', ignoring or dismissing the indigenous concepts, knowledge and skills that are essential to success in disability service innovation.*

### **INTRODUCTION**

'Though Gandhi saw nothing wrong in learning from Europe, his major worry was that since his countrymen had no clear idea of the central principles and weaknesses of their civilisation, they did not know what to borrow and remained vulnerable to passing fashions and crude or subtle pressures of the aid agencies (The author originally wrote 'colonial rulers'. The modern equivalent, i.e. 'aid agencies', is here substituted). Even the most conservative Indians indiscriminately borrowed institutions and values incompatible with the central principles and ideals of their civilisation' (1).

This paper probes some gaps between global ideologies of disability service provision and grass-roots realities. The prevailing imbalance of resource distribution across the world means that for the great majority of disabled children and adults in economically poor countries, most of the formal and informal services available during their lives are provided, and *will* be provided, by resources that already exist in their locality; that is, if anything is provided at all. Services are more effective when already existing resources are enlisted in plans based largely on local concepts, knowledge, skills and design; with a modest level of imports from other countries, suitably adapted. Plans that are well understood by their implementers will be more easily adaptable by them in local situations that are undergoing substantial changes. Such plans may be called CBR, or XYZ; the name is unimportant. What matters is that concerned people in any locality should work towards what they see as appropriate goals for disabled children, and should learn from their own successes and mistakes.

The term 'CBR' has had many uses, some more ludicrous than others. In a southern African country, I once declined to accompany a Nordic team on a trip (eight hours driving each way) to see the 'CBR project' for which their agency was paying. Very late that night the Nordics returned, almost speechless with dust and annoyance. They had been taken to see

some European nuns caring for a few disabled children in an institution. This was the 'CBR project'. Maybe some semantic confusion had arisen. The disabled children were not being cared for 'at home' by families; they were being cared for 'in the community' by the nuns. So it was 'Community Based Rehabilitation'. Some of this kind of confusion is inevitable. Global communication promotes the rapid spread of buzz words, but the meanings rapidly diverge as people with different languages hear them, make sense of them in their own conceptual worlds, and invest them with meaning. (It was also obvious through the 1990s that funding could not be had for work with disabled children unless it was called 'CBR', or 'Inclusion'; so that is what applicants called it, regardless of meaning).

People in impoverished Asian or African countries who must deal with Europeans in the aid game spend a lot of time smiling, nodding and seeming to agree with western plans, while thinking how to bridge the gap between words and realities. They are usually well aware that the westerners understand nothing of the conceptual worlds they are blundering across with their plans and targets. The people hoping to receive aid may be less aware of how confused many western aid 'experts' are about what is happening in Europe or North America, where service policies have lurched round several historical loops under successive ideological master-plans. Frequent looping brings intellectual paralysis, more 'spin' and less actual service provision. Emotive words like 'community', 'rights', 'empowerment' and 'inclusion' are randomly sprayed on every policy. The frontline workforce spends less time in contact with people needing help, and more time sitting in their cars (parked 'in the community') filling timesheets and case reports so that managers can 'prove' the delivery of 'community entitlements'. Those who end up giving 'expert advice' to countries several thousand miles away, have seldom directly participated in this shambles. More often they have lectured about it in departments of social policy or disability studies; or have given courses 'preparing' managers to surf the whirlpool without being punched in the eye (or at least, not too often) by services users who feel 'empowered' by the rhetoric, but find 'care in the community' insufficiently caring.

During the 1980s and perhaps as far as 1993, i.e. the period when CBR was sexy in the aid game, one could meet people who imagined they 'knew what CBR was' and were keen to correct anyone having a different idea. As CBR has slowly declined as an aid trend, it is now rare to find people who think they are the only enlightened ones. With one meaning or another, CBR will probably be around for decades yet. Many more people will try it the way someone tells them, or (perhaps) the way they think it should be. The more realistically they assess their situation, potential resources and the likely effects of socio-economic trends and changes, the more likely they are to produce results that count as positive within their own context. The more idealistic they are and the more slavishly they follow wondrous schemes devised by far distant planners having no personal, hands-on experience of managing disability service development, the less likely they are to see success. This should be so obvious as not

to be worth writing - but the past 25 years saw floods of misguided importing of hopelessly idealistic schemes, which might perhaps have succeeded in some other, kinder, happier, imaginary world, but hardly in the world of late 20th or early 21st century reality.

### **HINDSIGHT ON INFORMATION**

Histories of medicine, therapeutics, special education and rehabilitation suggest that the discovery and refinement of treatment and management methods has always been far ahead of their distribution to the people at large. In every age some effective knowledge and skill was available to a few people in a few places; elsewhere much less was available and people suffered for lack of knowledge and skill. Some attempts to bridge the gap have been made by locally trained or untrained practitioners, by itinerant quacks, and by various information media. Over a thousand years ago the physician al-Razi (865-925) wrote a manual called 'He Who Has No Doctor to Attend Him' (Arabic: *Man la Yahduruhu Tabib*) to spread useful self-treatment knowledge for common conditions, including hemiplegia, epilepsy and depression. It was disseminated by hand copying, long before the European development of printing. When printed material began to have a larger impact in urban Europe during the 16th century, medical knowledge also became more widely available, though confined by the limits of literacy and weaknesses of communication skills in practitioners. Almost 500 years ago came the first printed vernacular self-help book for expectant mothers, *Rosengarten* by the German paediatrician Rösslin, with advice also on treating children with epilepsy, eye defects or impaired motor abilities. Delegation of responsibility to rural practitioners with briefer training also has a long history. For example, urban British physicians in the Punjab linked up with rural Indian healers in the mid-19th century to provide a wider coverage. A century back, radio communication was born. Fifty years ago television was going public. Ten years back the Internet began its boom. The latest 'Where There Is No Doctor' (by David Werner and colleagues) has over 3 million copies in print in 80 languages. Werner's follow-up manual, 'Disabled Village Children' can be accessed on web pages by 500 million Internet users, and in any small town that boasts a cybercafe. Any page of it can be machine-translated with about 70% accuracy into 30 or more languages at low cost.

Technologies exist that can communicate tested, low-cost, practical knowledge and skill as fully illustrated screen text or video, concerning disability prevention, treatment and management in home and neighbourhood, to populations worldwide during the next 20 years. (If the world decided to forego one small war and do this instead, it could be achieved in two years, while offering polite regrets to the arms dealers for their loss of business). The global population, as far as remote villages, has already been reached by alluring messages and images about Coca Cola, McBurgers and various Hollywood goddesses. Admittedly, the world was not

expected to do much with these commodities apart from buying and consuming them or their pictures. Junk food sales show how far modern messages can penetrate when people have strong economic motivation to communicate across barriers of distance, literacy and culture.

In the disability service game, the drive for effective mass communication is comparatively weak. Several hundred thousand people earn their bread selling small pieces of disability-related knowledge and skill in clinics and schools in cities and small towns worldwide, in several hundred languages. If more and better information were already available and understood in every household, many of those people could be out of a job. More likely, they would upgrade their knowledge and skills to stay ahead and to facilitate the use of the information by each household needing it. But the information is not disseminated, made available in many languages and conceptual forms, facilitated, monitored, recycled, improved. The technical means exist, but the motivation is not there, especially for the difficult part which consists of blending small inputs of exterior knowledge with larger amounts of local concepts and cultural heritage. Much of the energy that should go into disability service and information development is dissipated in management and structures and buildings and politics and mutual throat cutting and conferences. Few of these activities seriously contribute to making the necessary knowledge and skills available in local languages and cultural / conceptual forms so that people could - if so minded -- competently prevent, treat or manage most of their disability by their own resources. What proportion would be so minded, if suitable information were available in appropriate and attractive forms, is not known. Intransigence and non-compliance with disability-related information is a worldwide problem, and the huge rise in availability of advice in info-rich populations leads to many contradictions and uncertainties that are hardly health-generating (2).

### **'GLOBOTOMISED' MENTALITIES**

The need to be able to defend local choices and differences is becoming urgent as delusions of grandeur and omniscience spread among a growing class of 'globocrats', or (g)lobotomised bureaucrats. The totalising and globalising mentality has existed in the past among some rulers and administrators; yet it was limited by the comparatively weak availability of mass media for disseminating standardised knowledge, and the fact that nobody ever ruled more than a third of the world, nor did they seriously believe that they knew what was going on at the far ends of their empire (or even the other side of town). Now, after 50 years of growing globalisation of knowledge and of economic power, some officials in UN agencies and big INGOs suffer from the delusion that they hold in their hands the health and welfare of billions of little people 'out there', and that the responsibility has been given to them to lead, persuade or coerce the billions into living according to the decrees of Those Who Know Best.

Something of this delusion has entered the disability game. Medical knowledge generated during the 20th century in the Western Europe and North America civilisation achieved urban dominance worldwide through its combination of a strong experimental base, its system of refereed publication of material designed to extend and challenge the system, and the growth of media designed for rapid urban dissemination and feedback, at first nationwide, more recently worldwide. Techniques and therapies for *medical and physical aspects* of disability also got aboard the globalising trend from early in the 20th century. If it worked in London or Paris it was considered workable in rural Lesotho or Peru. With no natural predators, the globalising or McDonaldising medical mentality is able to flourish. (On the ground, however, implementation of grand medical plans does not work on scientific lines but with political expediency, economic chicanery, and a deep mistrust in the population for schemes foisted on them by urban technocrats and foreign dreamers).

Techniques and teaching methods concerned with *learning and socio-cultural aspects* of disability have met greater difficulties of global transmission and replication. The educational field has not seen a body of knowledge that achieved a global spread and urban acceptance equivalent to that of modern 'western' medicine. Learning and teaching processes and outcomes have been much less susceptible to scientific investigation. The nearest approach to global dominance in special education was the spread of 'oral' education of deaf children after 1880; yet that dominance was less than total in practice, however much lip service it received. In pedagogy for children with mental retardation or intellectual disabilities, no single method predominated. Techniques such as the Montessori approach, and behaviour modification, have had a vogue and been partially adopted in the general repertoire; but such fashions often generate exaggerated claims based on anecdotal evidence, which eventually attracts the sceptical gaze of researchers, as has happened with the claims of 'Portage' (3).

Braille's code of dots, for blind people to read, also has an appearance of complete domination as the 'solution' for blind people, and exemplifies an earlier globalising mania and narrow focus. The first schemes for blind reading that achieved international dissemination, i.e. the Lucas method, soon overtaken by William Moon's embossed script, were adapted for use in parts of India in the 1840s and 1850s, China in the 1850s, and Africa in the 1860s, enabling some blind children to be integrated in ordinary schools. The international spread of Braille came later. It was harder to learn but much cheaper to print, and could be produced by blind people independently. By about 1910, it had eclipsed Moon; yet battles raged through the 20th century over attempts to standardise Braille, against local innovations and adaptations. All these efforts now seem problematic because they focused blind education on literacy and were confined to a small proportion of the world's blind population. The majority would probably have benefited more from an earlier focus on orientation and mobility training and activities of daily living and skills for economic gain. (Or perhaps the majority, if ever they could have been consulted, might have had completely different priorities).

The 'triumph' of modern science-based medicine and the increasing complexity of knowledge in every social field might have led to a recognition of the need for a range of complex, flexible, locally-adjustable solutions. Yet such recognition is weak, partly because of the rising politicisation and mechanical 'package-delivery' mentality of service supply. Complexity of demands has tended to stimulate and reinforce a belief or delusion that *there must be a global 'best way'*, an evidence-based global 'best way' across the range of disability services, and this 'best way' can be discovered in a synthesis of the latest western methods and experiments, and then can be launched aggressively across the world, regardless of cultural and conceptual differences.

'We didn't get rid of smallpox by listening to their guddam cultural whoosits and witch-doctors and whatever. We went out there and jabbed good clean western vaccine into them and that's how we stopped smallpox. We gudda do it again with their blind and deaf and epileptic and mentally retarded and whatever other kids they got hidden away in the back room - because We Know How To Do It, and those kids have Gudda Have Their Rights! We-all are one Global Village now so those kids are Our Kids. And all Our Kids gudda have the best we can givvem'. [Slight paraphrase of the apparent sentiments of some globotomised (mis)planners c. 1995-2005].

This kind of simplistic, neo-imperial baloney seems to have become the default position in some (not all) UN and INGO agencies dealing with health, welfare, mothers and children. The fiasco of the so-called International Classification of Functioning (tested as ICIDH-2) indicates both the delusions of grandeur that may afflict a team working 'globally', and the additional problems of classification and terminology in the disability field, as against the purely medical field (4).

#### **CONFORMIST AND U.N.-CONFUSED**

UN and INGO staff are an odd mixture. Some come up through a privileged urban modernist English-language education, in countries where the modernising urban elite is a small minority battling against the colossal weight of a pre-scientific, traditionalist majority. Modernism and 'scientific progress' have been their guiding light and life-identity. Many are conformist and opportunist, climbing the career ladder by working hard within the current paradigm and never challenging the conventional wisdom. Others have shown some initiative and independent thinking back home, but are dumbed down by being 'called upward' to international working groups and advisory positions, before finally achieving brain-death while cocooned in UN or INGO billets, well paid and well insulated against the realities of life experienced by the majorities still living in rural poverty and urban slum squalor. There are also some who know that 'modern, scientific' solutions have had their day. They feel the chill winds of postmodernism, they know that there is a growing loss of confidence in the ability of the

dominant euro-american civilisation to solve global problems, or even to contain (let alone solve) its own huge social problems. They are also frustrated by their own helplessness amidst the stifling globobureaucracy. Yet they know that there is no comfortable living to be made as prophets of doom -- so they continue churning out the platitudes and hypocritical baloney, at least until their own pension is secured. In retirement some of these worms turn and hiss quietly at the organisations they once served.

Many more international aid people are deeply confused, so are motivated to read the global evidence optimistically. Certainly, much economic and social progress took place across the world during the 20th century. Hundreds of millions of people in Asia and Africa have a higher material standard of living than their grandparents and great-grandparents. Child mortality has been halved or quartered in more than 90% of countries, primary education has doubled or tripled, far more girls can expect a life with some education and paid employment as well as raising comparatively healthy children; more disabled people have access to mainstream services and benefits. **Why not be happy about it all?** The problem is that all 'development' (of the sort sponsored by large-scale euro-american aid) seems to *extend the range* of living standards within target countries, rather than shrinking the range by moving poorer people upward. Extending the range means that the optimists can find plenty of evidence that tens of millions of people have benefited from 'development'. Yet across sub-Saharan Africa and large areas of Asia the population is rising rapidly at the poorer end, so the number of people in desperate poverty hugely overfills the gap left by those who have shifted along the quality of life spectrum.

Earlier gains, e.g. in reducing child mortality, mean that millions of children survive for whom little or no health and educational services are available. In Pakistan for example, school provision tripled since Independence, which was a major achievement by the government; but the population also tripled. The optimist celebrates the greatly increased number of children getting some education. The realist notes that there are now vastly more children growing up illiterate and in absolute poverty than there were 50 years ago; and that with each passing year the 'education' offered in ordinary government schools sinks further below what is needed for economic productivity in the 21st century. If that is so for basic health and education services, the picture for childhood disability services is equally dismal; but it is also more complicated, and UN/INGO data are even further from reality. Many of the 1990s gains in child health and school access are disappearing as AIDS increasingly kills teachers, nurses and community workers across Africa and Asia.

### UNEXPECTEDLY LUNATIC

How should one deal with aid people who seem fairly rational in everyday life, but who transfer ludicrously inappropriate policies from their home country to regions with very different

cultures and economies? Should one tell them they are behaving stupidly? That is unlikely to move things forward. One European agency, full of goodwill, asked me to advise a national disability organisation in southern Africa. The Europeans had paid for a UN disability statement, based on the concerns of wealthy countries with advanced social services, to be translated and printed in local languages. (In this particular country all formal education is in English. Anyone who can read at all can read English; but the European agency did not know this). My report highlighted quotations from reports of two rural branches of the disability organisation. One reported translating the UN document - full of 'rights' rhetoric - into a local language. The other branch reported that they had baked cakes, collected firewood and sold these items at the roadside so that their disabled children could afford to go to school.

This is the gap, or a tiny part of it. It appears wherever one looks, if one's eyes are open when looking. Another long-lived lunacy is, for example, the assertion that services are available to 'only 2%' of disabled people in developing countries - ignoring the reality of disabled children and adults using existing ordinary services (Medline provides ample research evidence). This parallels the belief among many Europeans that everyone in Africa 'lives in a mud hut'. There is often an amateurish reliance on experiences in projects in tiny countries. The aid equivalent of hugging a warm puppy is to visit one of those pocket-sized, pat-on-the-head nations, where the aid advisor can strut about as someone of importance. I once met a UN rehabilitation advisor who flew to Pakistan, an Asian Islamic nation having then 82 million people, direct from Barbados, a Caribbean island of 250,000 people. To address a national meeting the day after he arrived, he used his Barbados master plan, simply multiplying everything by 328 and substituting 'Pakistan' wherever 'Barbados' appeared. (His paper was distributed with the changes fully visible). Such stories are perhaps hard to believe - but there is a well-documented collection and analysis of the ludicrous world of 'flying experts' in agricultural and infrastructural development, where local knowledge, experience and cultural heritage is routinely dismissed in favour of some imported wondrous scheme (5). Some flying experts do retain their personal critical faculties. They continue offering the ridiculous 'package' they are paid to promote, but if challenged will admit that it is merely a gesture toward some distant, ideal future. Provided the rhetoric and ritual are respected, something more realistic can be planned on the ground.

Another blunder is to force CBR into 'Community Development' - as if all these activities require elementary skills that can be learnt from a textbook while cycling between villages. It is often associated with 'Rights' jargon, regardless of the practical constraints on poor people's access to legal rights in the countries concerned, and the questionable relevance of 'rights' ideologies based in western urban (male) individualism as compared with family and group identities in rural areas of developing countries. The effects of aid blunders continue long after the perpetrators have returned to the comforts, certainties and insurance policies

of their home countries. Paper-based 'rights' and 'inclusion' slogans, backed (naturally) by a fraction of the structural and attitudinal changes and resource provisions needed to give them substance, increase the gulf between rhetoric and reality while relieving families and communities of even the 'charitable duty' they may earlier have felt, however half-heartedly, to give disabled children some assistance. For many have-nots, even what little they once had is thus snatched away and replaced by fine-sounding slogans. They would have done better selling firewood and cakes.

### **CONSTRAINTS ON GROWTH OF CBR KNOWLEDGE**

One reason why disability service planning associated with the CBR term (with spray-on 'rights', 'empowerment', 'inclusion' etc) has lost its way is that CBR knowledge is still thin, scattered, mostly unsifted, unreliable, unrecorded or unpublished. There are very few carefully observed descriptions of what actually happens at the front line, e.g. daily lives and activities of children and adults with disabilities in developing countries, whether told by themselves or an observer; daily care, treatment or management activities by relatives and others; ordinary activities of CBR workers with health, education and community development animators; activities of other people in the community, that have some impact, or could have impact, on disabled people (e.g. shopkeepers, builders, police, religious teachers, neighbours). Where such description is lacking, because nobody has bothered to observe and record and circulate it for feedback and collect further descriptions from different viewpoints, 'CBR' remains merely a set of disparate notions in different people's minds with little grounding in lived realities. The lack of observation and description leaves it open for any fool sitting in a distant aid office to dictate what CBR should be, without meeting any contrary evidence. The modest amount published about CBR continues to be mostly on 'What A Great Job We Did', i.e. the heroic struggle to get things going, urgent pleas for funds to expand, anecdotes from grateful clients, etc. No doubt this literature has its place, but the genre seldom contains any serious, critical thinking.

#### **Some constraints on the growth of CBR knowledge are obvious:**

1. Different meanings of 'CBR', as noted above. Through three decades CBR activities have been planned and run by individuals and groups usually knowing very little about what has occurred elsewhere. The tendency to work in ignorance continues because CBR involvement leaves little time for reading and information seeking. CBR knowledge and experience is seldom recorded in a careful, evaluative way. When carefully recorded, it is seldom widely disseminated.
2. Major differences exist in cultural and conceptual underpinnings, e.g. meanings of 'disability', 'health', 'community', and in patterns of interventions, expectations of health and healing.

3. The field is non-commercial and money can hardly be made from it. With no profits, there is little incentive for investment, no infrastructure, no information systems. CBR lives in borrowed space and temporary budget. Behind the Rights rhetoric, it is charity in practice.
4. Language barriers and lack of web access hinder communities from exchanging their experiences. Barriers between professional disciplines and fears of encroachment make professional exchange harder in most parts of the world.
5. Very few people in CBR have enough independence to look critically at what is going on, without the fear that they may lose their job, or fail to get the next consultancy contract.
6. The longstanding gap between the world of services for disabled *children* and that for disabled *adults* flourishes in the CBR field. This contributes to fragmentation of knowledge. Issues debated between families, children and professionals are separated from debates between disabled adults and another set of professionals.
7. Formal CBR research has been weak or non-existent in most developing countries. There have been probably 20 non-medical doctoral theses directly on CBR plus 20-30 linked with CBR and allied activities, during the past 15 years, and three times that number of theses at a lower academic level. (Estimates are based on a collection of large bibliographies on disability in South Asia, Middle East and sub-Saharan Africa). This is better than nothing, yet the great majority have not been published or made easily accessible. Most have a restricted focus, e.g. measuring effects of one aspect of CBR on specific members of a small population in a given location, sometimes with controls. Taken together with the modest amount of CBR research in refereed journals, they might add up to a body of knowledge; but no serious, critical appraisal has yet been made of even a quarter of this material. (Rather more review has been made of 'CBR' experiences in economically developed countries -- there is money available for doing so, and researchers eager for the money).

Possibilities do exist to set up collaborative recording of experience, stronger critical appraisal and evaluation, with wider dissemination, regular low-cost electronic meetings for exchange, at least in some countries, on the model of a 'Cochrane collaboration for Evidence-Based CBR'. The present *Asia Pacific Disability Rehabilitation Journal*, and the CBR website run by Jönsson, Helander and Herda at: <http://dag.virtualave.net/cbrforum.htm>, carry a slowly growing number of field reports and critical material from various viewpoints.

### **'BAKING CAKES' AGAIN?**

Considering the narrowness and limited quality of 'CBR knowledge', it is easy to focus down to a minimal level of rehabilitation, and miss or dismiss the vast euro-american growth of technical and human knowledge applicable to rehabilitation procedures, which will increasingly be applied, as euro-american disabled people demand it. I noticed this gap recently, reading two doctoral theses. In one, a Dutch specialist in rehabilitation medicine observes and describes some of the paths through assessment and rehabilitation procedures in the Netherlands, from the differing viewpoints of individuals whose daily life and world has been disrupted by serious disease or injury, and of rehabilitation professionals engaging in assessments, therapies and rehabilitation. Van Dijk (2001) gives a detailed, sensitive and far-reaching analysis, bridging across communication gaps that disabled people have long complained about and of which the more perceptive professionals have long been aware (6). The second thesis, from a Belgian physical therapist in francophone Africa, discusses the origins of CBR and describes efforts to develop CBR in Benin and Ghana, with a field survey to assess the inputs and outcomes for over 500 participants aged 0-33 years and to distinguish factors contributing to the success or failure of the CBR work (7). This is a significant contribution to knowledge about the feasibility, planning, costs and outcomes of particular types of CBR in West Africa, in a context where few formal services were available compared with the Netherlands, and where it is probably correct for the main emphasis to be placed on extending at least a basic level of resources to far more of the population.

Would it then be foolish to hope that some attention might also be given to incorporating African service-user perspectives into CBR planning, in terms of both cultural-historical resources and personal knowledge and individual preference and feedback during the rehabilitation processes? Or is this again the contrast between translating some ridiculous UN Declaration, and baking cakes to sell at the roadside so that disabled children can pay school fees? The decision of course lies with people in the countries concerned. Fortunately another form of research has given a remarkable balance between these opposite poles of knowledge: the detailed account by David Werner of 'personalisation' of rehabilitation processes in a remote Mexican village, where disabled children and adults were encouraged to take charge of their environment, mobility aids and gadgets, and to rebuild their lives by their own initiative and mutual help, with intermittent advice from professionals who came to assist rather than to direct (8). This sort of 'CBR knowledge' has been underestimated, whether in Europe or the developing world.

### **Disempowering knowledge**

One constraint is that the CBR field is plagued by high-level baloney and spin, lies, distortions and unsifted data, e.g. that grossly inflate numbers of disabled people and dismiss from the reckoning most of the informal local resources. Certainly, even those disabled children in

developing countries who have access to some formal services still don't have a lot going for them. For the majority, life is nasty, brutish and short, even in their own terms. Yet when one studies the social histories of how services develop, attitudes slowly change, things get done, chances open up, in Asian and African societies across centuries, it becomes apparent that the complex and multi-layered truths are indivisible. This means that the simple slogans and half-truths, i.e. the stock-in-trade of advocacy organisations, politicians and UN agencies, in the long run obscure the truth and do not serve those disabled children well. They affect people's behaviour adversely. If people know that on the ground some services are used by 20 to 30 per cent, but the globocrats, politicians, foreign academics and other fools in big cars continue to insist that it is only 2 per cent, this inevitably diminishes people's confidence in their capacity to change their lives and make their communities and societies less brutal. When high-level baloney overrides hard-won experience, it is very disempowering.

### **THE INFORMATION APPROACH AND CBR**

CBR can usefully be viewed as an information system (9). Knowledge, skills and design are obviously needed in CBR, whether we think of a disabled baby, a politician drafting a law about access to public transport, or an elderly deaf person learning new income-generating skills along with others at the local mosque. Underlying the necessary knowledge and skills there are many deep local concepts of how life is lived, how family members relate to one another, the behaviour expected of children, how disabilities affect living, differences in gender roles, etc. These underlying concepts vary from area to area, and between regions, and between one religion or philosophy and another. Therefore it is impossible to define CBR and the aims and objectives of CBR on a global basis, once and for all. To some extent, CBR has to be discovered and practised by people for themselves, in each country, each town, each neighbourhood.

### **Scaffolding**

Discovery for oneself does not mean that the knowledge, skills and design developed in one place cannot be used in another. Of course some imported knowledge and skills can be useful, mainly as scaffolding, to a lesser extent as building material, to enable people to construct CBR to their own design, based on their own conceptual foundations, rooted in their own country, their own histories, their own ways of living and being. Such a construction cannot be imported en bloc from one country to another. It can seldom be imported from city institution to rural village, or urban slum. On the other hand, it is rare to find it successfully constructed by villagers or slum dwellers entirely by their own efforts. Partnership is needed. Mutual listening and learning is needed. Some of those with one sort of knowledge and skill (maybe modern, urban, biomedical) may need to listen and learn from people with another sort (e.g. rural, survival-based, with religious elements) and vice versa. People with a traditional

heritage of concepts may need to delve into their folklore, art and drama, to uncover the positive and the ambivalent views of disability and assistance, and decide which are the authentic and valuable parts on which they will build. They are likely to do this only if they find that the offer of help from the city or foreign CBR advocate includes a genuine respect for different cultures and concepts.

## CONCLUSION

CBR works best the way local people see it and build it.

\* 4 Princethorpe Road  
Birmingham B29 5PX, UK  
m99miles@hotmail.com

## REFERENCES

1. Parekh B. *Colonialism, Tradition and Reform*. New Delhi: Sage, 1989: 79-80.
2. Crysanthou M. *Transparency and selfhood: Utopia and the informed body*. Social Science & Medicine 2002; 54: 469-479.
3. Brue AW, Oakland T. *The Portage Guide to Early Intervention. An evaluation of published evidence*. School Psychology International 2001; 22: 243-252.
4. Miles M. *ICIDH Meets Postmodernism, or "Incredulity toward Meta-Terminology"*. International Rehabilitation Review 2000; 51 (1): 32-36.
5. Chambers R. *Whose Reality Counts? Putting the first last*. London: Intermediate Technology Publications, 1997.
6. Van Dijk AJ. *On Rehabilitation Medicine*. Delft: Eburon, 2001.
7. Jadin O. *La stratégie de Réadaptation à Base Communautaire (RBC) au Bénin et au Ghana*. Louvain-la-Neuve: Catholic University of Louvain, 2001.
8. Werner D. *Nothing About Us Without Us*. Palo Alto: Healthwrights, 1998.
9. Miles M. *Service development by information, not ideology*. In: Finkenflugel H, ed. The Handicapped Community. Amsterdam: VU University Press, 1993: 107-124.