

THE IMPORTANCE OF CULTURAL CONTEXT IN TRAINING FOR CBR AND OTHER COMMUNITY DISABILITY SERVICES

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INTRODUCTION

The arguments of this chapter have relevance not only to CBR, a form of service delivery associated with the majority world, but have equal relevance to community disability services in the West. This is the reason why the chapter title refers to CBR and *other community disability services*. The chapter addresses the issue of how the cultural pluralism of trainers and trainees affects the training process. There are many definitions of CBR and the CBR movement gathers great strength from this diversity of interpretation. This chapter takes the Joint Declaration (1994) 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, and 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 very different ways, from those who interpret rehabilitation as a human rights issues at one end of the continuum to those with a technical rehabilitative focus at the other. By way of introduction I will review the differences of expectation which I believe people bring to the training process. I will then draw upon experience from CICH and from the literature as to the ways in which different constructs can affect the way in which people perceive, plan and train for CBR. An important determinant of these different expectations is peoples' experiences of disability,

of the community and their personal technical skills. This discussion is divided with reference to:

- expectations of training
- expectations of services
- expectations of the rehabilitation process

EXPECTATIONS OF TRAINING

Training for CBR encompasses a wide range of training activities. The training of first level CBR workers (sometimes referred to as *grass roots workers*) must be undertaken at local level, to accommodate to local variation, since the experts who can conduct such training are local. They are unlikely to be sitting at a seminar table in Bonn. Comments in this chapter therefore relate to training of trainers or of professionals who might become involved in CBR. Training for such people is frequently international, with heterogeneous groups from a variety of countries, with very different experiences of disability and of how and why training is provided. If training is to be successful it is vital to consider participants' expectations of the objectives, the process and the outcomes of training, as well as participants' expectations of the content of training.

The expectations of the objectives of training for the trainee 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, the opportunity to stand back and consider strategic moves of a personal or service nature or improving the lives of people with disabilities. 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, whether it is 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 to be frank about his/her motivation for attending the course and almost certainly does not share the expectations of 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.

Similarly 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 a passive activity, decisions as to what is to be taught are made in advance and participants follow the course, rehearsing and regurgitating closed answers to closed questions in 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 large class size is the norm, especially at school, students are expected to follow a prescribed curriculum where the course leader or teacher is seen as the *expert* and the participants as people who *absorb* the expertise.

At CICH course participants following Masters degree and Diploma courses are from both developing countries and from Western countries with work experience (often with NGOs) in developing countries. The first group are often used to passive learning following a curriculum led model with expert input. There follow 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 the participants from the West are often paying for the course themselves and challenge the value they are getting for their money by demanding variation and tailor made adaptations to meet their individual needs. The cultural diversion which leads to this variation of expectations must be addressed if the needs of those participants who are conditioned to accept a passive role are not to be eclipsed by those of their more forceful peers who have such different expectations.

A third area where cultural expectation of training can differ greatly is the expectations of outcomes of the programme. If early experiences of schooling and learning have been dominated by passive learning and didactic (expert centred) teaching, then the participants’ cultural expectation is of *knowledge*. The tutor will design a course which explains the

facts to the participants. Students commit these facts to memory and relate them as proof of learning. Such a cultural expectation of *knowledge* as the outcome of learning is very different from a Western expectation that all experienced participants will bring to a course wide experience of life, of local culture and of disability and that the outcome of the course will be a developing confidence in the validity of these experiences and in the ability to problem solve issues related to CBR.

Similarly, there will be variation among students' constructs of what the course content of a training course 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. 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 all are to achieve their learning 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. It is also worth asking the question where international courses should be held. There is value in enabling people from a range of countries to come together in an environment where they can share and learn from each other. At CICH we believe that for skills based diploma courses this should be in a country where there is academic expertise and good local experience of CBR. In the last few years we have worked with colleagues in Uganda and in India to ensure the sustained development of international courses there. We hope there will be others.

EXPECTATIONS OF SERVICE

CBR has a wide diversity of interpretation, from the initial model of CBR as conceived by WHO in the 1980s and culminating with the publication of the WHO Manual (Helander et al. 1986). There are other interpretations of CBR, e.g.

- emphasis upon early childhood intervention (Thorburn 1991),
- the use of volunteers in a small country with a commonly held expectation of voluntary activity (O'Toole 1991 in Guyana),
- the emphasis upon local community committees in the Middle East,
- devolving CBR activities from institutions (Carpentier 1994).

Culturally appropriate models of CBR have arisen to meet local need. It is interesting that the most widely written about CBR activity developed by disabled people themselves, at Project Projemo (Werner 1985), 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 Projemo, 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 through CBR, is acceptance of cultural diversity as to how CBR is interpreted in different settings (Mallory et al. 1993; Jaffer/Jaffer 1990). In the U.K., an energetic literature written by disabled people has emerged over the past 15 years. Oliver (1992), Morris (1991), Davis (1996) and many others have changed attitudes hugely through their work so that there is now an expectation that disabled people (DP) will be involved in planning, running and managing services for and with disabled people. The disability movement in the U.K. has moved thinking away from a curative medical model of disability towards a social model. Disabled colleagues in the U.K. would stress that we have not moved far enough and that the involvement of DP in planning and managing services is still too limited (Shakespeare 1997). This may be the case but disabled people in the U.K. have changed constructs. These changes of construct may be more limited than disabled people would like, but the arguments, vocally expressed by many disabled people, have persuaded many (perhaps even the majority) in the field that the *pity and charity* construct of disability is inappropriate.

There are other important changes which have influenced constructs in the U.K. and other Western countries. For example, the *Community Care* initiatives and *Direct Payments* and *Disability Discrimination* legislation as well as the movement towards Inclusive Education for children with disabilities over the last eight years in the U.K. may be criticised for being too limited, but they have raised awareness throughout society about disabled people. People with disabilities, including those previously *invisible people* with learning difficulties and multiple disabilities are seen in most settings. The fact that one sees people with multiple disabilities in most supermarkets in the U.K. has probably done more to change public attitudes than any other single fact. In the U.S.A. too the Independent Living movement has helped to change attitudes. I believe that this two pronged influence, on the one hand by articulate disabled people writing about disability issues, and on the other the change in legislation, means that peoples' constructs about disability in the U.K. have changed.

Croft and Beresford (1993) remind us though that the mere involvement of disabled people is not always enough: “not all involvement is necessarily empowering” (1993: 19). This is an important caveat to any complacency for activists in the North. Disabled people have had less success in influencing legislation and attitudes in many countries of the South, with notable exceptions, especially in post conflict settings where disabled veterans (former guerrillas/freedom fighters) have formed active disability lobby groups. This means that people coming to an international training with Western experience often have very different constructs, at the start of a course, from those whose experiences of disability are still influenced by professional dominance in planning.

In addition to different constructs of how different societies consider people with disabilities there is also cultural variation as to who is considered disabled. Vreede (1998) refers to this as ADL, IDL, ODL (1998), Wirz and Lichtig (1998) note the contrast between two pairs of siblings. The one pair with a 10 year old boy with mild/moderate learning difficulties in a rural African society with 30 percent school enrolment and his sister of 12 years unable to raise her arms above elbow height. In this pair the boy was able to help with goat herding and other tasks of his peers, whereas the girl who was unable to lift, to carry on her head or to pound grain, was considered disabled. In the case of an identical pair of siblings in London, with 100 percent school enrolment and supermarket shopping for food, the boy unable to keep up with the learning activities of his peers, would be considered disabled and the sister (with the slight modifications which she and her mother would have to make to her choice of clothes to avoid over the head dressing) would be able to undertake all the activities of her peers and would therefore not be regarded as disabled. The constructs of *disability*, and of *who is disabled* differ, and are created by our societal experiences of disability and hugely influence how services are construed by a society or community. It is vital that this variation is explored at the beginning of an international course if the group experience is to be equally valid for all course participants.

EXPECTATION OF SERVICE PLANNING

Course participants arriving from command regimes have few expectations or skills as regards the collaborative planning of disability services. In such regimes, planning of government service is national with little, if

any, local variation and little *consumer input* to the planning process. Disabled people and their families are considered as recipients of service and CBR workers and others working in the rehabilitation process are seen as implementors of a national programme. In national programmes there is often a search for geographical parity rather than good coverage. In direct contrast many NGO services demand a commitment from the community before they will start a service and that service is jointly planned by NGO and Community, e.g. Seva in Action (an NGO in Karnataka State, India) (Rayjendra 1998: 54). Among those in the NGO sector there is often pressure to bring the needs perceived by a local NGO to the planning process when they may be in opposition to those of an international (donor) NGO (Jennings 1997). This introduction has explored how cultural variation affects what participants bring to a training programme in terms of their expectations of the objectives for training, the process of training and the outcomes of the training. Such pluralism is the challenge for international courses and the management of this pluralism to ensure that all participants gain from the experience is as least as challenging as the organisation of course curricula and evaluation. The remainder of the paper will concentrate upon cultural variation of the terms *the community*, the *rehabilitation process* and the *rehabilitation professionals* and the measurement of the success of a programme.

COMMUNITY: THE C IN CBR

Community Based Rehabilitation is predicated on the expectation of community involvement or, at best, community ownership of the programme (O'Toole 1991; Werner 1997). Before this very basic premise is assumed it is necessary to explore the nature of *community*. A question which has to be answered is how does one involve community when the expression of views is politically difficult/impossible? How does one stress the C of CBR in such settings? There is a commonly held maxim within the CBR literature that so called *bottom up* planning is inherently better than *top down* planning. This may be true in a setting where there is genuine freedom of expression and communities are not fearful of expressing what they feel (as opposed to that which they feel they should express!) The government of India proposed a *top down* plan for CBR through their DRCs (District Rehab Centres) with a range of services and staff flowing from that. In a subsequent evaluation after 10 years they were open enough to recognise that there was a gap between the DRC

service and disabled people's awareness of how to access these services and to revise national planning with this knowledge (Rajendra 1998).

Coleridge, writing from Afghanistan, points out that while international NGOs may follow the view that their work should respect local values, at times

local cultural values in Afghanistan conflict with their own values and indeed their own ethics ... discussion about cultural values is often regarded as too sensitive to even embark on ... resulting in activity initiated by foreigners which Afghans receive but which they themselves do not initiate, let alone control. (Coleridge 1998: 1)

It is very important to separate cultural variation from politics. Rehman (1997) shows that it is quite wrong for Western workers to assume that veiled women in the North West Frontier province of Pakistan are either unwilling or unable to take part in group planning activities for CBR because they are *not allowed* to do so by their menfolk. She shows that if care was taken in the planning of meetings women would attend, and be contributory and outspoken about their needs and those of their disabled children (Rehman 1997).

In much writing about CBR there is an assumption of common community values which must be met by the CBR programme. In reality values may differ within a geographical community by caste, by educational/economic status, by minority group (including the diversity which arises in some countries because of the mass migration population movements), and this diversity of values must be described in the planning process. This requires great skill by either a foreign NGO worker or by an indigenous planner who will both bring their own cultural norms to the process. CBR is impoverished by a lack of sociological or anthropological literature. Ingstad and Whyte in their 1995 volume have brought to a wider readership issues of cultural diversity regarding disability (Ingstad/Whyte 1995). Cultural variation has seldom been recorded by people working for and with disabled people in countries of the South and the passing on 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. 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 in Dhavari slums in Mumbai (with the Spastics Society of India) suggest that the modern 40 year old grand-

mother (herself an urban migrant) is no longer the easy recipient of the role which her mother may have adopted.

Early recorded CBR programmes such as those of WHO (1983) and Werner (1985) were, in their different ways, culturally aware, stressing the need to involve the local community, to use local skills and resources and to address the local needs of disabled people and their families. They both aimed to foster independence for the disabled person. Independence is a Western value. Most of the literature by disabled activists in the West stresses the need for independence for disabled people (Swain et al. 1993; Morris 1991; Werner 1996), yet interdependence is the goal of many people of the South (Lang 1998a; Al Shehery 1995). Are CBR trainers and planners too greatly influenced by the articulate writing of Western disabled activists, believing that these are the shared values of disabled people from other cultures, without considering whether independence or interdependence is the goal relevant to that community? CBR trainers and planners of other disability services need to be sure of the relative value placed upon independence or upon interdependence by the society if the planning is to have cultural reality.

A further cultural difference which has an impact upon planning is whether conformity or diversity are valued within a society. If conformity is greatly valued there may be greater difficulties for disabled people and their families than in communities where diversity is valued. An important question for the sensitive planner to ask is, who is the guardian of this conformity? Is it the Islamic menfolk (Rehman 1996), Indian mothers in law or the state? Tembe (personal communication in London 1995) reports that physically disabled people in Mozambique are not eligible for a driving licence even if their impairment is relatively mild. Dlamini (personal communication in London 1997), in Swaziland, reports that unmarried people remain *children* in the eyes of both the state and of many people in the community and as many disabled women do not marry they are viewed as children throughout their lives.

It is important to differentiate between the state and the community. The state impacts upon the lives of disabled people in many ways and at times this impact may contradict the views of communities within that state. For example there are a number of international documents which can affect the lives of disabled people, e.g. the Standard Rules (1994), Declaration of Human Rights and Declaration of Children's Rights, all of which have clauses which protect the rights of disabled people. Many countries have signed such documents but without an independent (free) judiciary to which disabled people can take their concerns about violations of these stated rights such documents have limited value in improv-

ing the position of disabled people. Alternatively, individual state practice may conflict with community views regarding disability. Lang (1998b) cites the example of the Rehabilitation Council of India (RCI), which was established as a statutory body to register all training courses for people working with disabled people. Lang suggests that “this measure is in direct variance with the underlying philosophy of CBR, of enhancing and utilising indigenous resources in the community” (Lang 1998b: 23).

It is important to beware of imposing the interpretation of Western values upon societies which are very different from those of the West. This balance (or perhaps more accurately lack of balance) between the cultural values of a community with regard to disability and those of the state are described by Coleridge and Wahdat as the *CBR conflict zone*. They define the conflict zone as the interface of “local concepts of disability, culture, local social values, poverty and the nature of national CBR” and suggest that the CBR planner needs to be creative in order to manage potential conflicts and deliver a culturally appropriate CBR rather than standard “packaged service” (Coleridge 1998: 9).

REHABILITATION AND THE REHABILITATION PROFESSIONALS

Despite changes in attitudes towards people with disabilities, 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 that involves in the early months and perhaps years of a disabled child’s life, is perhaps more marked in the South. Estimates of how much ill affordable 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 it is huge. In both the West and the South many parents’ first construct of rehabilitation is to consider a medical cure. Sadly, many medical professionals condone this practice, taking considerable fees to see a disabled child with the parents knowing that there is little/no rehabilitation service and that all they can do is provide an (often inadequate) medical label for the condition which the parents know to be disabling for their child.

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 therapists and others to whom referrals are made. It is important to recognise that this secondary referral system is an integrated part of most CBR programmes. The question arises as to whether therapy education prepares therapists for CBR work. The majority of therapy services provided in the West have developed from the medical model, 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 of what is best. Knowledge is seen as power ensuring professional control and as power in interprofessional rivalry, in the battle for resources and in salary hierarchies. In the early 1980s, in the U.K., 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. Morris (1991) and Swain et al. (1993) review this issue. However, fifteen years after the beginning of this debate in the U.K. it is still primarily the professionals who arrange service delivery for disabled people in the U.K.

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 in the face of 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 CBR workers,
- develop referral patterns of support for these CBR workers,
- continue to listen to DP and relate to disabilities rather than the impairments as a basis for intervention,
- be innovative in service planning.

These are tasks for which young therapists are often ill prepared and as a consequence they are often accused of lack of cooperation with CBR programmes. Working with colleagues in Brazil who train therapists has been an interesting exercise. There is a spoken (and genuine) wish by this group to move therapy services out of clinics and into the community. However they find it very difficult to give up their status and position as *the expert* and continue with training which they know to be inappropriate. For example, a follow up of deaf children 12 months after full audiological assessment, showed that only 4 out of 160 had received hearing aids, yet the group continue to train their students to undertake full audiological assessment rather than more creative assessment and training of the mothers in a society where hearing aids are clearly seldom available.

Colleagues in South Africa have taken the lead in the training of coworkers for an alternative form of service delivery through CBR (Bortz 1992). From this base therapists in South Africa have seen the need to cooperate 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 to those who can access central, urban centres (Lorenzo 1995). In the Philippines too, innovations have been made in the education of therapists. All undergraduate therapy students at the University of Manila (OT, Physio and SLT) undertake a long placement in a rural CBR programme, thus ensuring that all therapists have at least an understanding of other ways of working with disabled people (Magallona/Wirz 1994). 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.

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