Challenges for Universities of the North Interested in Community Based Rehabilitation

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INTRODUCTION

In this paper, we reflect on our experience at the Centre for International Child Health, University of London, with a view to exploring the challenges that face universities of the North as they continue to contribute to disability-related work and service provision in countries of the South. This paper argues that universities of the North have a role as facilitator based upon strong partnerships with colleagues in the majority world. This partnership, as well as enabling creative North-South links, can enable South to South links and, equally importantly, can raise awareness among professionals and professional educators in the North about CBR (Community Based Rehabilitation) and appropriate services in the South. This paper will discuss how Western disability literature impacts upon CBR definitions and planning; it will then present an educational and research agenda for universities of the North. (For information, the term "majority world" in this paper refers to the 80% who have household incomes of less than $7,500 per year, referred to by Robert Chambers, 1997, as "global middle and global under classes".)

SOME HISTORICAL CONTEXT

Disability services in the South in precolonial times often arose from charitable motivations related to indigenous religious or philanthropic concerns. In colonial eras, the development of disability services in the South reflected dominant development and thinking in the North. These developments often ran concurrently with traditional, long-established practices about which very little was written and even less was known by professionals in the North (Mba 1990). It is important to acknowledge that a community system existed long before colonial interventions and that the "community management" of disability ranged on a continuum of solutions from "eradication" at one end, to "idolisation" at the other (Mallory 1993). It is also, of course, important to acknowledge the impact

that colonial influences had on the creation of disability services in the South.

In the post-colonial era, disability services were often built upon the activities of special schools, vocational training centres and other institutions. The special schools that had formerly been run by missions and other charitable foundations were either absorbed into national programmes or affiliated to them, with a view to providing educational opportunities for disabled children and, sometimes, young disabled adults. The schools tended to retain their impairment-specific bases (a carry-over from the past) and for 20 years or more have had leadership from special educators who, as young scholars in the 1960s and 1970s, were trained in more developed countries. The courses which these leaders followed were also impairment-based. Indeed, one of the authors recalls being involved with British Council courses for teachers of "the Blind", "the Deaf" and "the Mentally Handicapped" at Moray House College in Edinburgh during the 1970s. There, students were taught in almost watertight compartments, sealed off from each other as well as from similar courses that were run for Scottish students! A consequence of this exposure for the leadership in the South was the persistence and dominance of impairment-based special education in the South long after such exclusive practices had come to be seen as outdated in Britain. For example, the place of sign language in schools for deaf children and the use of deaf and signing teachers are still issues of current debate in many Southern countries, while they are accepted practice throughout the UK (UNESCO 1988).

It may be that the retention of special schools as a focus for disabled children is appropriate in a country with low school enrolment and where the opportunities for disabled children in an educational ghetto - rather than no education at all - outweigh the disadvantages of exclusion from their local community. This is a local decision. But such decisions must be made in the full understanding that alienation from one's community is a difficult burden to place on any child.

It is frequently the case that if schools remain impairment-based, local disabled people's organisations are also likely to be impairment-specific rather than cross-impairment, and that disabled people's organisations which represent people with physical impairments tend to dominate to the exclusion of others who find it harder to articulate their voice. Rehabilitation International, Disabled Peoples' International and other organisations have done much to address the issues of local advocacy from single impairment towards multidisability organisations.

The nature of disabled people's organisations can be influenced by the ethos and practice of the local special school, especially where former pupils become involved in the organisation. The disabled people's organisation and special school can also influence community perceptions and have an influential impact upon local CBR projects. It is often from such schools, centres or organisations that CBR activities develop as a form of outreach. Present-day CBR programmes remain small and the challenge remains about if and how they can be "scaled up" effectively to meet the needs of larger numbers and become part of national programmes.

NORTH-SOUTH TRANSFERS: THEORIES AND MODELS

Disabled activists and academics in the UK have led the world in the creation and development of theoretical frameworks with which to understand disability (Campbell & Oliver 1996, Davis 1996, Morris 1991, Oliver 1992, Swain et al 1993 for example). The theories and frameworks advocated (most notably, the "social model of disability" and "independent living") have had an important impact on the development of policy and practice in the UK, but as yet none of these academics has seriously addressed the issue of how their ideas relate to disability, services and disabled people in the South. Unfortunately, that gap has not yet been filled by disabled activists and academics of the South who have not yet explored theoretical bases for their (often very effective) advocacy work. The perhaps inevitable result is that Northern theories and models have been transferred to the South - sometimes by Northerners (e.g. educators, researchers, practitioners, activists, development planners, development funders), and sometimes by Southern professionals, practitioners, planners and activists.

A handful of Northern/Northern-trained academics and practitioners have opened the debate on the desirability of such transfers. Lang (1998) provides a challenging discussion of the limitations of Northern disability constructs for disabled people in the South. Mallory et al (1993) discuss the transfer of Northern ideas and ideals of "independence" to Southern contexts, where "independence" may be an empty concept given different socio-cultural constructs of person, family and society (see also Lang 1998, Miles 1996). In many countries of the South, inter-dependence rather than independence is the key value and in such a setting, rehabilitation for disabled people which is predicated on independence, is of questionable value (Miles 1996, Al Sherhery 1996).

It is vital that the transfer of Northern theories, definitions and models to Southern contexts does not go unchallenged, and that a critical approach to Northern theories is fostered amongst Southern students and professionals. To illustrate this further, and to show how this issue is tackled at CICH, the example of Community Based Rehabilitation is used.

Example: Community Based Rehabilitation and Northern Models of Disability

CBR programmes usually include all or some of the following activities: awareness raising, parents' and carers' groups, income generation, rehabilitation, referral networking for education, employment and/or health services. In addition, most people would agree that CBR is essentially about delivering services, based in the community, for and with disabled people. The number of variations on a CBR theme is numerous; so also are the definitions and classifications of CBR, and the criticisms that have been levelled at the concept.

Several of the criticisms of CBR have been informed by developments in disability theory, activism and service provision (see Coleridge 1993 for example); and/or are the outcome of international discussions about disability and development among professionals and organisations (Jaffer & Jaffer 1990, Mendis 1992, Rahaman 1997, Thorburn 1986, UN 1996). For instance, the following questions have been asked when assessing individual CBR programmes and the bigger concept of CBR as a model:

- Does CBR espouse a medical model or a social model of disability?
- Is CBR led by professionals or by a disabled people's organisation?
- Is CBR focused on impairment, disability, or handicap?
- Is CBR a disability programme located in a developing country, or a development programme with in-built disability awareness?

These questions and implicit criticisms reflect developments and thinking in the North, in particular the growth of disabled peoples' organisations, their campaign for rights to self-determination, and their challenges to dominant attitudes, policy and practice. But how useful are these questions when assessing the impact of a programme in the South?

At CICH, we suggest that attempts to classify CBR programmes according to dichotomies like "professional-led or user-led" and "medical model or social

model" are often unhelpful, since they mask the complexity and diversity both of CBR programmes and also of Southern contexts and cultures. For example, we know from our experience that it is possible for organisations seated in a health base to adopt a social model approach to their CBR work, while there are also programmes which are led by organisations of disabled people and which have a strong technical and rehabilitative focus. This in itself suggests that a more flexible approach to defining, planning and evaluating CBR is required. With this in mind, the joint definition proposed by the ILO (International Labour Organization), UNICEF (United Nations Children's Fund) and WHO (World Health Organization) can be particularly useful:

> 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 (lLO, UNICEF, WHO 1994).

The above definition is not overly prescriptive; it leaves space for interpretation by programme planners, trainers and educators. This flexibility is important for several reasons. A flexible, open definition of CBR is an acknowledgement of the wide range of practice that currently exists in and between CBR programmes. Such diversity is a strength, not a weakness. Furthermore, a more open definition allows projects to locate themselves along a continuum of models and activities: some CBR projects have an exclusive technical and rehabilitative focus; others have an exclusive human rights focus; many more incorporate a range of elements, including both rehabilitation and advocacy.

Therefore, at CICH, we feel that best practice in CBR should: a) involve a range of objectives and methods; b) meet the specific and diverse needs of individuals and communities; c) suit the specific and diverse skills of local development workers, disabled people's groups, and disability professionals; and d) suit the socio-cultural norms of the particular locality and culture. The importance of cultural sensitivity in planning and delivering all disability-related provision is now widely accepted (Groce 1998, Rahaman 1997).

Further, when considering the respective strengths and weaknesses of different CBR programmes, we have found that it is more helpful to adopt a multi-level approach than merely to ask "is the programme led by professionals or led by local disabled people?". Helander (1992) and others within WHO and UNDP

(United Nations Development Programme) identified three levels of CBR:

- grassroots workers who deliver services in the community;
- mid-level workers who organise and support the grassroots workers;
- and professionals to whom referrals can be made from the community, and from whom referrals are made to the community.

Some programmes which subscribe to this WHO model focus exclusively on mid-level workers and professionals, while overlooking the potential and involvement of those at the grassroots level. In contrast, there are other programmes that may be very strong on the active involvement of disabled people's organisations in planning and training at the grassroots, but do little in the way of training or support for the professionals on whom all community services will have to call at some time.

Finally, when considering the various approaches of different CBR programmes, we suggest that it is more helpful to adopt a "comprehensive model of disability" (Wyller 1997), than to argue for either a "medical model" or a "social model". A comprehensive model of disability communicates the importance of integrating both the social and medical approaches. This resonates well with the way in which the MSc in Community Disability Studies course at CICH has developed over the past few years.

Example: Community Based Rehabilitation and Northern Approaches to Research

It is generally accepted that the implementation of CBR programmes must be accompanied by rigorous evaluation and constant revision. Unfortunately, much research which purports to be CBR research is very limited and often merely describes practice. Where CBR research does move away from describing practice towards describing data, it tends to be very impairment-oriented. There is some published work (e.g. O'Toole (1991) and Thorburn et al 1992), which describes different approaches to service planning and demonstrates how practice is informed by evaluation and research. But such examples are few.

In CBR research, the key research questions include:

- What effect will this service have?
- What will it cost?

- Is it what disabled people and family members want?
- What will happen if the service is not provided?

At CICH, we suggest that these questions are best answered through research which embraces both quantitative and qualitative methodologies (see Pope & Mays 1995, and Mays & Pope 1995). Both types of data and method are needed to ensure an holistic exploration of relevant issues which is in line with a "comprehensive model" of disability. Regardless of method, research must be conducted with rigour and transparency, so that results can be verified and used to inform disability service planning. Also, good research practice entails practice similar to that of a good community development worker, who uses problem-solving approaches to enable community members to identify and prioritise problems, and find their own solutions, while the community worker does not impose predetermined values and beliefs upon community members.

Researchers of CBR issues in the South may wish to look to the North for different innovative methodologies. Among the many who can offer both ideological and practical help to researchers is Mike Oliver, who has written extensively about disability research methodologies in the North, especially emancipatory and participatory research (Oliver 1992). Involving disabled people with certain impairments in research can be very difficult. Here, it is helpful to turn to Parr, Byng and Gilpin's (1997) study of aphasia and disability, in which interviewers who themselves had residual dysphasic difficulties interviewed people with long-term dysphasia. This proved to be a very difficult methodological task, but one which revealed unique insights.

Here again, however, it is important to question (and encourage questioning of) the relevance of Northern methodologies to Southern contexts. Stone (1997) has explored the dilemma of how to use research methodologies developed by disabled research activists in the North when doing research outside the North (in China); and how to analyse findings within a social model of disability framework, when research participants appear to adhere to a different, more medical model of disability.

To summarise, universities of the North have a role as "conduits" to bring the rich disability literature that has developed in the North to the attention of Southern colleagues. Simultaneously, universities and professionals of the North must create spaces where different perceptions about disability and appropriate services can be shared, in the light of ideas and experiences from both North and South. In the 1990s, it is no longer sufficient or appropriate for

Northern universities to prioritise the "transfer of knowledge" through courses designed for students from the South without supporting the development of critical reading and problem-solving skills among their students (Wirz 1998). After all, it is the students who will have to determine for themselves how much information is of value to their home situation, and how far (if at all) they intend to adopt and adapt Northern theories to Southern contexts.

NORTH-SOUTH TRANSFERS: PROFESSIONS AND PRACTICE

North-South transfers extend beyond the transfer of models and methodologies, reaching into the realms of professional practice and knowledge. Over the years, there has been growing recognition of the dilemmas that exist in disability-related work in countries of the South. Many of these dilemmas are linked to North-South transfers of professional training and practice. For example, in both North and South, educational agendas have shifted from segregated, special education towards mainstream, inclusive education. But is this shift always and automatically appropriate? There may be places where school enrolment is low, and where special schools provide the only educational opportunity for disabled children. Does education in an educational ghetto and exclusion from one's own community outweigh the alternative prospect of no education at all? What is the appropriate view to take in the case of a deaf child where special education gives fluency in a language (signed or spoken) which is not used in his or her own community?

This "education dilemma" is discussed by Hartley (1995) together with other dilemmas relating to technical, social and contextual issues. Should hearing aids be provided when there are no facilities to maintain them? Should centralised services be encouraged when they result in children being brought into towns from rural areas and their own communities? Should centralised services be discouraged even though there may be no day-care or school facilities in the child's rural home community, and the child may spend much of the day locked inside whilst all other family members are out working? These are difficult decisions - hardly "choices" - which have to be made in full knowledge of the potential implications on an individual's life and life chances.

Dilemmas such as these are made yet more difficult by the pressures placed on professionals to adhere to "professional fashions". By this, we mean the way in which certain practices and approaches are promoted as the way forward in a given field. The recent emergence and promotion of "inclusive education" can be seen as one example of this. Already, many countries have signed up to the

Salamanca Agreement (UNESCO 1994) in which inclusive education is promoted as the best approach in educational provision in both North and South. But is this appropriate to all countries and contexts, irrespective of other considerations? The experience of many local education authorities in Britain is that the move from special education to inclusive education is neither quick, nor easy, nor cheap. And yet, the model is being promoted worldwide, including contexts where there are few human or financial resources to support it. Isn't there a danger that the current fashion of inclusive education may be pushed and imposed on the South without appropriate, context-specific planning? If so, aren't we setting up professionals and communities to fail?

Another example of Northern fashions being transferred to Southern settings with little regard for context or culture lies with the increased status of Sign Language in the North. There are examples of expatriate rehabilitation volunteers (working on CBR programmes in the South) who have introduced an imported Sign Language to a locality (see Mba 1990 on Nigeria; Winterton 1993 on Nepal). Subsequently, local CBR programme workers have sought advice from Northern professionals on how to record the imported Sign Language so that it can be "taught" to local children, families and workers. At no point was any attempt made by the Northern or Northern/trained professionals to learn about indigenous sign languages from local deaf people, their friends and families!

The power of "professional fashions" is compounded by the often inappropriate nature of professional training provided by Northern universities to students from the South. Here, we consider the nature of professional training for therapists - mainly because therapists often play an integral part in CBR programmes.

Example: Professional training for therapists

The vast majority of professional training for therapists provided in Northern universities is, of course, conducted with Northern professionals in mind, or for those therapists in the South who will work predominantly in tertiary centres in their country. This is where the problems begin. In Britain, for example, most therapy services are rooted in the medical model of disability, which entails the following:

- disabled people are referred for assessment and then, depending on the outcome of assessment, are "treated" by professional therapists;

- services are offered FOR or TO disabled people, who are given the status of "patient" even when they are healthy individuals; and
- the focus for intervention and improvement is the "patient" - and the "patient" has a duty to respond positively to the therapy given.

The use of vocabulary like "patient" reflects the belief that it is the professional who knows what is best and who is the "expert". Since the early 1980s, disabled people have challenged the notion of "professional expertise" and have sought to redress the power imbalance between therapists and disabled people who use therapy services. The "social model of disability" has played a central role in this (Morris 1991, Swain et al 1993). Regrettably, despite a passing interest in shared responsibility and a nod in the direction of equality for disabled people, it is still largely the professionals who manage and arrange service delivery for disabled people in the UK and have access to the all-important resources.

Students in the South often attend courses where they are exposed to professional training and practice which may have been appropriate when the medical model reigned supreme in the North but now meets neither the needs of Northern nor Southern students. Therapists, whether they are from the North or the South, whether they spend 3/4 years training abroad or follow outdated training programmes in their own countries, are simply not being prepared for the huge changes which are taking place at grassroots level and the challenges of working with and for disabled people who use or require services. CBR in the South and community care and Direct Payments initiatives in the North make very different demands upon professional therapists compared to past notions of "professional practice" (Vasey 1996). For example, to be effective in a CBR setting, professional 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 also to support the grassroots CBR workers;
- develop referral patterns where more specialist input is required;
- continue to listen to disabled people and relate to disabling barriers rather than impairments as a basis for intervention; and
- be innovative in service planning in the face of severe resource constraints.

These are tasks for which young therapists are often ill prepared and as a

consequence are often accused of lack of co-operation with CBR programmes. Newly-trained therapists in the South who experience difficulty in adapting their new (Northern) skills to community-based services are understandably inclined to turn to the relative safety of private practice (based in urban centres) rather than struggle on with community-based practice.

To summarise, if universities of the North support the move towards improving access to services for the vast majority of disabled people in the South (which is central to CBR), it surely follows that those universities should not continue to provide professional training for students from the South which concentrates upon the needs of a very small wealthy group of the population. Universities of the North act duplicitously if they profess to support inclusive services yet provide training which is more suitable for segregated settings. Finally, it is vital that the responsibility to provide information about the latest developments in thinking should be carefully balanced by an awareness of the dangers of imposing Northern "professional fashions" (models, ideologies, practices) without relating these to the economic, social, cultural and political context in question.

BENEFITS OF NORTH-SOUTH PARTNERSHIPS

The dangers and dilemmas noted, there are still a whole range of ways in which North-South partnerships can be beneficial to all concerned, both in training and in research. The following examples are drawn from our experience of partnerships at CICH.

Recently, CICH initiatives to relocate the Diploma for Trainers and Planners of CBR (taught in London for 15 years) to India and Uganda have afforded the opportunity for capacity-building and the development of strong North-South partnerships in training and teaching. The decision to relocate relates to a recognition that the different levels of service delivery and different activities in CBR require different approaches to training. The training of grassroots workers needs a contextual base and is best delivered locally by trainers who are aware of local needs, understand the local community and the wider society, and speak the local language. There is little place for outsiders in this level of training other than as supporters of trainers, or information providers (see Miles 1993 on Information Based Rehabilitation). Accordingly, CICH also supported the development of a Disability Resource Centre in Uganda as part of the relocation of the diploma course. This partnership is mutually beneficial. It enables Ugandan students to access all the information available at CICH in

London; it also provides the opportunity for teachers, students and researchers based at CICH in London to access information generated in the South (e.g. on the impact of Ugandan low-cost aids).

Support has also been given to colleagues in South Africa who have taken the lead in the training of co-workers for an alternative form of service delivery through CBR (Aron 1991, Bortz 1996). From this base, trained therapists in South Africa have been inspired to become involved in training CBR workers as a way of improving access to therapy services for the whole population, rather than restricting their services to those who can access central, urban centres (Lorenzo 1994). Links with South Africa have served to highlight the unique situation which can be found there: the combination of professional and technical development together with sustained commitment provide the ingredients for innovative practices not found elsewhere (Tuomi 1994). Insights from this can inform professional training and also practice outside South Africa.

In the Philippines, all undergraduate therapy students at the University of Manila (in Occupational Therapy, Physiotherapy and Speech and Language Training) now 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 and Wirz 1994).

Meanwhile, research links with colleagues in Brazil have highlighted the very real difficulties that local professionals face in moving from a medical curative approach to community-based services. In turn, this has made Northern university-based trainers and teachers more aware of the importance of promoting service developments that meet the needs of service users and also the needs of local professionals.

It is the authors' view that universities of the North have much to offer and much to learn from working with students and colleagues in the South. For example, CICH can offer:

- teaching support to extend the range of skills of colleagues from the South, including problem-solving and active learning skills;
- good resources through libraries and increased access to the Internet;
- space to explore ideas which may not have immediate application, but which will build up an individual's body of knowledge (Baltutis 1995, Jennings 1997, Singleton 1996);
- student-centred course design, with flexible course assessment;

- opportunities to do independent research which is not unduly influenced by government or pressure from financial donors;
- peer support through university and student networks, including a forum to share perspectives and exchange information;
- networking opportunities to develop South-South as well as North-South contacts;
- an environment where their contribution is valued, and where the self-confidence that is essential for the success of research and service developments is nurtured.

In turn, Northern partners, like CICH, can gain:

- knowledge which can inform the development of community-based services in the North (e.g. awareness of the positive roles that family knowledge and strategies can play in supporting community-based services;
- understanding about the nature of "interdependence" in families and communities);
- a better understanding of the realities of the developing world, which can ensure that Northern training courses are appropriate to students from the South;
- a better understanding of the key questions for research in countries of the South;
- access to relevant research populations;
- access to local staff and colleagues in the South who can facilitate research; and
- opportunities for information exchange and international networking.

On this last point, it should not be forgotten that the concept of CBR promoted by the World Health Organization in the 1970s and 1980s - as a strategy to combat lack of resources and low coverage of existing services - contributed to changes in Northern countries where more community-based services were gradually introduced.

CONCLUSION

Student therapists from the South work hard to be awarded a scholarship to follow a degree course in North America, Europe or Australia. In addition, there are dynamic professional leaders in the South who work hard to establish and

maintain professional training courses in their home country, often against great fiscal and medical opposition, and often influenced - for better and for worse - by Northern colleagues and courses. How might universities of the North best support these students and colleagues?

It is our contention that universities of the North have a role as facilitator in the context of strong partnerships with colleagues in the South. These partnerships can enable creative North-South links; they can also enable South-South links and, crucially, raise awareness among professional academics and practitioners in the North about service developments and contexts in the South. In turn, Northern universities can act as conduits for ideas, theories, practices and approaches from the North to the South - whilst always recognising that Northern ideas should be critically engaged with, not imposed or adopted without question. The flow of knowledge, learning and training between North and South can and should be two-way. At CICH, we reject the notion that the North has all the answers and all the best models. Indeed, the lessons learned from Southern partners are invaluable and have already influenced both teaching and research at CICH.

The challenge for Southern colleagues is to determine which lessons from the North are appropriate, and how. The challenge for universities of the North is to develop genuine partnerships and actively listen to and learn from colleagues from the South.

Finally, and in relation to CBR, the development of the concept of CBR appears to originate from observation of traditional good practice in the South. These observations were re-packaged by the World Health Organization, originally focusing on rehabilitation needs but - together with impact of contributions from disabled people themselves - the concept of CBR has since developed in diverse and dynamic ways. The process of implementing good CBR programmes must be accompanied by rigorous evaluations and constant revision to ensure appropriate development. It is the authors' view that universities of the North have a valuable role to play in nurturing the skills required to take such evaluation and revision into practice, and equip the promoters of CBR with the skills and confidence to promote best practice in partnership with disabled people. The inevitability of continued imbalance between North and South also reaffirms the need for Northerners who wish to work in countries of the South to have the opportunity to become as informed as possible, hoping to contribute to an improved track record in delivering CBR services.

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