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ABSTRACT

This address begins with a study of self-help by a Mozambican in the 1590s and then imagines a period between the years 2050 to 2150, during which women caring for people with disabilities abolish the need for specialist educational, medical and social services, by multiplying and democratizing the necessary knowledge, skills and design to make them universally available. The paper urges that the cultural and conceptual bases of professional training, originating in Europe, be replaced by local culture and concepts rooted in regional experiences and disability histories. Various models of service provision and evidence of their effectiveness are outlined, including family self-help, traditional healers and teachers, modern centers, and activities described as "Community Based Rehabilitation." It is argued that the worldwide occurrence of causal integration of children with disabilities in ordinary schools has been ignored in policy formulation, suggesting that research evidence does not necessarily affect national policy if it contradicts popular beliefs. The address ends with an appeal for African cultural contributions to research. Appended resource materials include a bibliography of 932 materials from Angola, Botswana, D.R. Congo, Malawi, Mozambique, Namibia, Tanzania, Zambia, and Zimbabwe, concerning social, educational, developmental, and medical responses to disabilities. (CR)

Keynote Address and Resource Material, presented at the Workshop on Research-Informed Disability and Rehabilitation Planning for Southern Africa, held at Harare, Zimbabwe, 29 June - 2 July, 1998.

MODELS OF REHABILITATION AND EVIDENCE OF THEIR EFFECTIVENESS:

Production & Movements of Disability Knowledge, Skill & Design Within the Cultures and Concepts of Southern Africa

M. Miles

Respectfully dedicated to the memory of C.F. VREEDE (d. 13 June 1998). For half a century Frans Vreede worked to increase cross-cultural knowledge and understanding in the field of rehabilitation medicine and education, which he practised and taught in Indonesia before returning to the Netherlands.

ABSTRACT

The address opens with a study of self-help by a disabled Mozambican in the 1590s. It then takes an imaginative leap from the years 2050 to 2150 during which women caring for disabled persons abolish the need for specialist educational, medical and social services, by multiplying and democratising the necessary knowledge, skills and design to make them universally available. The present-time need is emphasised for individual disabled persons' and their families' local knowledge, i.e. how their lives are lived with disabilities, to be aggregated and developed into public knowledge to make national policies more relevant. The cultural and conceptual bases of professional training, originating in Europe, must be replaced by local cultures and concepts rooted in regional experiences and disability histories. Various models of service provision and issues concerning evidence for their effectiveness are outlined, including family self-help, traditional healers and ordinary teachers, modern centres, and activities titled as Community Based Rehabilitation. The fact that the worldwide occurrence of 'casual integration' of disabled children in ordinary schools has been ignored in policy formulation suggests that research evidence does not necessarily affect national policy if it contradicts popular beliefs. The address ends with an appeal for 'culturally African' contributions to research. Appended resource materials include a bibliography with introduction and indexes, of 932 published and unpublished items from Angola, Botswana, D.R. Congo (ex Zaïre), Malaŵi, Mozambique, Namibia, Tanzania, Zambia and Zimbabwe, concerning social, educational, developmental and medical responses to disabilities.

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M. Miles

PREFACE. After spending several years studying disability histories and the long-term effects of misapplied educational importing/exporting between countries with stronger and weaker socio-economic development, I can no longer write without giving some historical background. This paper also takes a leap forward; then it settles into the present, where the majority of disabled people live very largely by self-help and the help of their families and friends. It is their situation that dictates most of my consideration of information, models, evidence, and suggestions for action. The ultimate judges of the effectiveness of rehabilitation models and activities will be no high-powered scientific committee or academic board or conference of journal editors. It will be disabled people, family carers, rural teachers and nurses, village chiefs and grandmothers, mostly living under severe economic constraints, who will know whether or not the researchers and planners are doing anything that helps them to improve their own situation, understood in their own terms. (In this paper, the 'disability' terms are mostly used in an everyday sense, without reference to any particular model).

1.0 ONCE, LONG AGO...

1.1 Writing four hundred years ago from Sofala region, in what is now Mozambique, Friar João Dos Santos pictured an example (see Box below) of the most common *model of rehabilitation*. It is sometimes overlooked by educationists, physicians and therapists when they discuss this field. This model can be called 'auto-habilitation', 'self-help', 'adaptation', 'natural integration' or other terms. We begin here because this model is still today the one most commonly used throughout the lives of most Southern African people in rural areas or poorer townships. (If the model is common, the account is rare: European records seldom reported anything *admirable* concerned with African disability, learning or healing).

Records of South-Eastern Africa collected in various libraries and archive departments in Europe, by GM Theal, historiographer to the Cape Government. 1901. (Reprint, Cape Town: Struik, 1964). Vol. VII. pp. 251-252

(*Extract from a translated account of coastal Mozambique in the 1590s, by Friar João dos Santos*).

"[Most of the natives] have decayed and broken teeth. They say that this comes from the land in which they live being very humid and marshy, and also from eating hot roasted yams, which is their usual food... Most of [them] suffer from hernia, and some are so maimed by this disease that they are unable to walk. ... We saw a [native] who lived in a village called Inhaguea, who was a cripple, born without a left arm, but nature, that had denied him this most necessary member, endowed him with such dexterity that from a child he was accustomed to work with the right hand and the left foot in such a manner that with these two members, so dissimilar, he could do anything that other persons could do with two hands, as he made wooden bowls and platters and weaved straw mats, by which he earned a livelihood. From this may be seen that providential nature, as Aristotle says, never neglects the necessaries of human life. This will not astonish those who have heard of a cripple of our times who lived in the town of Monte Mor o novo, named Francisco Dias, who, being born without arms, accustomed himself from infancy to using his feet instead of hands which he was without, and ate, drank, played cards, and threaded needles with his feet, and wrote so well that he kept a school in which he taught a number of boys to read and write..."
[ ] = *translation slightly amended or abridged.*

1.2 Note the skilful uses of evidence and argument in the story. Readers in Portugal in the late 16th century were familiar with travellers' stories e.g. about strange people whose heads grow below their shoulders, or 'monsters' with human bodies but the heads of dogs, in distant lands. So we might ask: did Dos Santos intend his account to belong to this sort of travellers' tale? What sorts of evidence, argument and interpretation does he produce to support his story?

a. Brief background remarks on health, disability and nutrition in the area.
b. Personal observation of the present situation in a specific village called Inhaguea, with brief history of origins and development, i.e. the situation reported at birth, then "from a child...". This evidence was given to Dos Santos presumably either by the man himself, or his family or neighbours, or other local informants.
c. Argument from 'Nature' - i.e. having given him only one arm, Nature compensated by giving him greater dexterity in another limb. (?)
d. Ancient authority for the 'compensation' idea: Aristotle said it - it must be true! (?)
e. Similar example from readers' own frame of reference, i.e. a Portuguese man who used his feet instead of his hands, and became a schoolmaster.
f. Specific examples of what the disabled person could do, suggesting that Dos Santos himself saw these activities.
g. Generalisation, i.e. that the man could do with his hand and foot anything that other people could do with two hands. (?)

- *Do you have the impression that the account is accurate? Or mostly accurate?*
- *Which evidence or arguments (if any) raise doubts?*
- *Knowing the Portuguese example, could Dos Santos have invented a similar story, for whatever reason?*
- *Could the whole story have been made up in 1998? What evidence could be brought, for or against such a modern fabrication? Do people falsify historical evidence? Scientific evidence? Evidence about the benefits of this or that rehabilitation model?*
- *If the story is mostly accurate, what is the most important part played by the disabled person's family and local community? Is it correct to call this person 'disabled'?*

1.3 *Further examples.* Another disability text from Dos Santos concerns night blindness, describing symptoms and how they vary from daylight to night. It compares two ethnic groups, the native people and the immigrant Portuguese, and notes the reportedly positive outcome when the latter leave the apparent risk zone. Two further possible remedies are reported, without comment.[1] Further texts report a strongly negative public custom involving rulers and disabilities, and a remarkable case where this custom was repudiated. Dos Santos reported king Sedanda committing suicide because he had acquired a physical deformity. According to custom, another ruler should also have killed himself when he lost a front tooth. Instead he denounced the custom as a foolish one, and refused to follow it. Dos Santos also recorded some notes on albino children, and how they were treated.[2] This is not the time and place to pursue these historical texts - but they give a small signal that some depth of historical record exists in Southern Africa about disabilities and social responses. The notion that disability-related activities in Southern Africa have only recently begun is clearly mistaken.[3] However, evidence of professional or formal community-based rehabilitation models is lacking much before the 19th century.

2.0 GREAT LEAP FORWARD

2.1 Let us imagine for a few moments a situation perhaps one and a half centuries forward, in the mid-22nd century, in which formal professional or community-based rehabilitation models seem to have disappeared altogether. How might this come about?

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[1] *Records of South-Eastern Africa...*, GM Theal. 1901. VII: 134 (Port.) 320 (Engl.).

[2] Theal, Records, VII: 12-13, 33 (Port.), 193-195, 214-15 (Engl.) Earlier Portuguese adventurers in Sofala, c.1505, met a severely disabled community leader, a sheikh who was "infirm, blind, and about seventy years of age". *Ibid.* (4th edn 1927, reprint 1964) *History of Africa South of the Zambesi*, Vol. II (The Portuguese in South Africa from 1505 to 1795), Cape Town: Struik, 187-88. That was in a Muslim community - their tradition of respect for blind men dates back to the Prophet Muhammad.

[3] See many references in J Iliffe (1987) *The African Poor. A history.* Cambridge UP; also M Miles (1998) Disability in civil society and NGOs: historical responses and current developments in Anglophone Eastern and Southern Africa. In: F Hossain & S Myllylä (eds) *NGOs Under Challenge. Dynamics and drawbacks in development.* Helsinki: Ministry for Foreign Affairs of Finland.

2.2 By the mid-21st century, 800 million women around the world were spending much of their time caring at home for their disabled children or grandchildren, husbands and old folk, many of them living in poverty, and most of them paying, directly or indirectly, to be told what to do by physicians, teachers, therapists, nurses etc, and to buy various gadgets and technology. Then several million of these women found that they could communicate with one another on the FreeNet. This soon produced an unprecedented revolution. The women learnt that 70% of their children's impairments could have been prevented at low cost using knowledge already available for the past hundred years; and that 80% of the problems experienced by their disabled relatives could have been much reduced or eliminated by low-cost redesigning of their home and local environments, using knowledge, materials and designs that had been known for at least seventy years. They learnt that 50% of their own effort in caring for disabled relatives was unnecessary, and actually prevented those people from doing daily living activities for themselves.[4] They also heard that their unpaid care work saved governments huge sums of money each year, which had gone to subsidise military expenditure and the comfortable lifestyle of their countries' elites.

2.3 Unlike earlier revolutionaries, these women carers had no interest in overthrowing the government and no grand ideology to impose on their societies. They had a more practical goal. Large groups of very angry women stormed the universities, training colleges and other knowledge and skill institutions, demanding to know where the knowledge was locked up, why it was not freely available for everyone needing it, why huge sums were being spent on advanced technology that might possibly be used to help a tiny number of people, while elementary redesigning was neglected that would certainly assist millions to live their daily lives with more dignity and ability. Around the globe, there was a confused period of several months during which a few professors and leaders of professional unions were unfortunately torn to pieces using traction apparatus, and hundreds of lecturers were forced to teach and demonstrate for 18 hours per day to huge audiences, at the start of the Knowledge To The Women movement. Then things calmed down a little, and serious plans began to be made. The main target was that the necessary knowledge and skills for prevention, redesign, self-help, learning and rehabilitation should be freely available in people's heads and hands and apparatus on every street, in every village, with a big range of knowledge back-up and updating media. One of the women's aims was to abolish the need for specially trained professionals and programs, by making the necessary knowledge, skills and design as common and as free as knowing how to fetch a bucket of water.[5]

2.4 This result they did finally achieve, but it took another century to do it. During the first phase of planning, hundreds of professors around the world were brought before Truth Tribunals for questioning, to find out why the necessary design, knowledge and skills were not freely

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[4] Data (70%, 80%, 50%, 100 years, 70 years etc) are not based on formal research. Any informed guess may be substituted.

[5] Apart from a few isolated outbreaks, the women did not waste resources by shooting everyone who had a university degree, or making professionals spend ten years cleaning public latrines to 'improve their attitude'. This had been tried in 20th century Asia, but did not result in skills being spread to the masses.

available to the women who were in the greatest need of them and who were ready to use them. During the process, some important discoveries were made.

A. There had been some half-baked efforts during the 20th century to make relevant knowledge and skills widely available to the people, under the title of 'CBR'. None of the professors could tell why these efforts had been so small and ineffective. Of course, there had been some opposition by rehabilitation professionals, who earned their living by getting knowledge and skills and using them with people who needed them; but there had always been a minority who tried to work themselves out of a job by teaching the public what they knew and practised. One theory was that the angry voices of Disabled People, amongst the many People's Movements, had raised so many conflicting slogans and ideological critiques that those professionals who were interested in the empowerment of the masses had lost confidence and retreated. Their everyday work was hard enough, without constantly being denounced as Part Of The Problem whenever they tried to give away their skills in the community. The noise, confusion and mutual denunciations of the CBR field also made it unattractive to people whose training was in the orderly application of knowledge and skills to individual 'cases'.

B. On more detailed interrogation, the captive professors also admitted that at the end of the 20th century there had been, and several decades later there still were, huge gaps in the available rehabilitation knowledge, skills and design, when it came to *applying them* to the everyday lives of individuals with disabilities. The broad principles of prevention, redesign, self-help and rehabilitation were fairly well established; but remarkably little was known about the nitty-gritty details of how children, adults and aged people with various sorts of disabilities, or their carers or companions, lived their lives. It was not known what they were doing at 6 a.m., 7 a.m., 8 a.m. and so on through the day and evening, where they were doing it, what they were wearing, eating or thinking about, who was present with them in the room, house, school, clinic, market, office, mosque, beer-house etc, who was helping, watching, talking or interfering with them, what things they could do easily, or with difficulty or not at all, which things they could afford easily, with difficulty or not at all, what were their priority wishes, and their distant hopes, and so on. Of course, the individuals with disabilities, and people closely involved with them, had their own private knowledge of answers to these questions, so far as concerned their own life; but there was very little formally accumulated, tested, accredited, public knowledge. In a small number of high-information countries, a few studies had been done. In most of the world even that weak level of knowledge was absent. Without such knowledge, the practice of 'rehabilitation' was rather like the sound of one hand clapping.

C. Further probes revealed that a large proportion of professional rehabilitation knowledge, skill and design had developed into its modern shape in a small number of northern countries where a single major language-family was in use. Its two main focuses were the lives of young and middle-aged wheelchair users in a highly gadgetised urban environment, and the education of blind or deaf children in text-dominated societies. This stock of knowledge, skill and design had formed the basis of training in most other parts of the world, without taking into account the conceptual shifts needed to frame knowledge in the other major language families; without any significant recognition of indigenous traditions and patterns of treatment or therapy; without sufficient awareness that the needs of babies, girls, boys, women, and elderly people might differ substantially from those of young and middle-aged men; and with serious imbalances in the resources available to disabilities outside the two major focuses.

3.0 BACK TO NOW

3.1 I don't know whether women carers will rise up in the 2050s; nor that they will succeed if they do so. I would not bet on any big success. What can be predicted more confidently is that people looking back from the 2050s to the 1990s will regard our efforts now as blunderings in the dark, for some of the reasons outlined above. To gather a substantial amount of information about the lives of sample groups of people with disabilities and their carers is not *very* easy, but nor is it *very* difficult. It does not require a foreign grant-in-aid, nor a high-powered research team;[6] but it does require quite a strong motivation and determination to learn as much as possible, and for what is learnt to be reinvested in action that will generate further demands for knowledge.[7] In other fields of activity, people are constantly finding out detailed, intimate information about groups of other people. Business people find out what things people want to buy, how much they are willing to pay, what colours they prefer, and whether any sexy activity can be associated with the product. They are keenly motivated to find this information, because if they don't find it they may lose their investment or be out of a job - whereas very few people in the rehabilitation field lose their jobs even if what they are offering may be based on largely mistaken views of their clients' lives, or may be conceptually alien. Families who are arranging a marriage, or doing a deal over some cows, may make detailed enquiries about the other parties, or the location and clientele, because the results could have a deep impact on their lives. Unfortunately, one gets the impression in the disability field that practitioners are often keener to seek peer approval than client and community approval; and peer approval seldom depends on having a lot of knowledge of the lives of disabled people and their carers and companions.

3.2 *Information Approaches*. The approach used above to look at what happened in the past, and what might happen in the future, is based on *information* understood in a broad, modern sense:

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[6] A foreign grant, or too much methodological correctness, can sometimes be fatal. These thoughts reflect several years of disability action research in Northern Pakistan, starting with no trained researchers and no research grants, but with urgent practical needs to learn more about childhood disabilities and community resources to meet family and individual needs. The possibilities are discussed in M Miles (1991) Effective use of action-oriented studies in Pakistan. *International. J. Rehab. Research* 14: 25-35.

[7] A model of the research->action->research cycle, in the context of low-cost community-oriented disability services, is the work of MJ Thorburn and colleagues. Thorburn's early job as a pathologist in Jamaica caused her to ask why so many babies died of easily preventable diseases. She looked for answers. The answers she found suggested new questions about practical measures to prevent disease and disability. These measures led to further questions about how to transfer knowledge and skills to more families; which methods of transfer worked best, for which parts of the population; in what circumstances this was so, and why; and what evidence there was for the effectiveness of any of the measures; and so on, testing hypotheses and reporting the results critically, until finally one sees the rare combination of 35 years of published work that is 'science based in social action'. For references, see Medline, ERIC, etc, also *ActionAid Disability News* (1993) 4 (2) 33. and Thorburn & Marfo (eds) 1990 *Practical Approaches*.

concepts, knowledge, skills, design and feedback.[8] The 'knowledge and skills' part is fairly easy to understand. When Christine Miles went to work in Pakistan in 1978, we thought she was going to transfer to local teachers her 'knowledge and skills' about teaching children who have special educational needs, with some *cultural* adaptation. But the *conceptual* base on which we 'landed' in Pakistan was substantially different from the base that her knowledge and skills assumed, so a 'transfer' was difficult. When she talked about 'the child', and 'learning', and 'play', we thought these words had universal meaning, even allowing for differences of language and culture. After six or seven years, she realised that, all along, the Pakistanis with whom she had been working had a different idea in their minds of 'the child', 'learning', 'play', and many other basic concepts. In the first year, Christine could not hear the feedback from her colleagues, because it was hard for them to talk about basic concepts which usually are not discussed at all, they are simply assumed. Seven years is a long time - it included her becoming fluent in Pushto, Urdu and local dialects, and working daily in school and family counselling, and engaging in action research and producing information materials... When she did begin to understand a little more of the conceptual world in which her colleagues were living, she realised that some of them had tried to tell her some of this during the first year.[9] But since it was hard to do so, and she did not seem to be hearing, they gave up. (As Administrator of the Centre, it took me even longer to learn anything about the conceptual worlds of Pakistan). By contrast, in 1996 when Christine Miles went to Dar es Salaam to share some knowledge and skills with CBR workers, the first two days were spent getting those women to construct an account of ordinary childrearing in Tanzanian cultures. This became a powerful base from which they could explore differences that might arise through developmental delay and disabilities. The CBR workers discovered, to their surprise, how much relevant knowledge and skill they already possessed as mothers, aunts and sisters.

3.3 Knowledge and skills are underpinned by *concepts*. The knowledge and skills involved in modern biomedical science are taught in institutions around the world, with efforts to achieve uniformity of definition and meaning. The parts of the human arm, how they function and what diseases or defects affect them, are supposed to be 99.9% the same in Hamburg, Harare and Honolulu. (If you are born without arms, medical science still has little or nothing to say about *what to do*. That, you must find out for yourself). The underlying concepts of the body, health, disease, healing, learning, knowledge, evidence etc, are far from being the same in Hamburg, Harare and Honolulu. One reason why indigenous or alternative medicine and traditional healers continue to flourish everywhere is that these systems recognise the concepts that ordinary people have of their bodies and illnesses. Traditional forms of teaching and learning, whether e.g. of

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[8] M Miles (1990) A resource centre developing Information Based Rehabilitation, *in* M Thorburn & K Marfo (eds), *Practical Approaches to Childhood Disability in Developing Countries*, St. John's, Canada: Project SEREDEC, Memorial University, Newfoundland. *Ibid.* (1993) Service development by information, not ideology, *in* H Finkenflügel (ed), *The Handicapped Community*, Amsterdam: VU University Press. *Ibid.* (1996), Community, individual or information development? Dilemmas of concept and culture in South Asian disability planning, *Disability & Society* 11: 485-500.

[9] C Miles (1991), Mobilising skills for special education in Pakistan: a personal, cross-cultural experience, *International J. Special Education* 6: 201-212.

craft skills, tribal customs or religious knowledge, continued for the same reasons. Something similar probably applies to disability and rehabilitation - but we are 30 years behind the biomedical research front when it comes to recognising and trying to bridge between the concepts underlying modern 'scientific' approaches, and the concepts of disability, healing and rehabilitation that ordinary people hold.[10] Some 'feedback' from the latter is expressed in non-compliance with professional advice, and to some extent in the anger of disabled people's groups. Some of the 'educated third generation' among the latter[11] may eventually make an impact in generating knowledge about disability concepts. Some interesting 'bridging' work has also arisen among a group of disabled people in rural Mexico, with some stimulus from Northern friends.[12]

3.4 *Design* is the outcome of knowledge and skills (using feedback from earlier design) applied to realising a concept. It might be the concept of a light, comfortable, effective, low-cost leg brace suitable for forested areas with high humidity; or the concept of an urban transport system in which a blind child with heavy asthma and a wheelchair user with learning difficulties can travel across town to school and to work, without special assistance, with no more expense than anyone else has; or the concept of an easy-reading information package on finance and life options for middle-aged women with one or more disabled children whose husbands have sold everything and gone off with the cash. (The examples are detailed and difficult - that is why design is needed...)

3.5 These five information factors have appeared at some length because they provide neutral possibilities for evaluating and comparing different models of rehabilitation or of disability service delivery (and also for formulating research hypotheses). The fact must be faced that evaluation and comparison of models may threaten professionals' self-image and livelihood. Financial interests and political ideologies enter the picture. Very few people are *both* knowledgeable about what is going on, *and* able to take a neutral stance, uninfluenced by personal considerations. My own view is that any long-standing model is likely to have some merits for some parts of the community - otherwise it would hardly have been sustainable. Study of information factors can reveal strengths and weaknesses, and shows the complementarity of various models and the areas of overlap.

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[10] In May 1998 a workshop in Bonn discussed concepts and beliefs about disability in various parts of the world (*proceedings forthcoming*). The consensus was that no previous international gathering had taken place on this topic. The edited collection by B Ingstad & SR Whyte (1995) *Disability & Culture*, Berkeley, Univ. California Press, seems to have been the first mainstream publication devoted to the anthropology of disability.

[11] That is, disabled people with academic training who have got beyond slogans and media-directed protest, and who know that 'disabling' social attitudes and structures developing over three thousand years are unlikely to be transformed in less than three hundred years. (Cf changes in the social position of ordinary women - not the educated elite - in Europe and Middle East since 1900; or of Shudras and Tribal people in India since 1800).

[12] Inspired by an escaped biology teacher, the PROJIMO group have taught themselves how to think, to experiment and to weigh up evidence critically - starting with an average of three years formal schooling plus very strong group motivation to push back the boundaries of what people with severe disabilities are supposed to able to do. David Werner (1997) records the process in *Nothing About Us Without Us*, Palo Alto: HealthWrights.

4.0 MODELS & EVIDENCE. (1) Models

4.1 Here, I don't plan to get myself shot or cut up. Fortunately, other speakers with local knowledge will report more specifically on evidence in Southern Africa. My remarks will be more general and conceptual - but intended to have practical implications.

4.2 *Models*. The word is wonderfully flexible in English. Leaving aside the tall, thin girls wearing strange, new clothes, we may list:

a. Own and family self-help efforts.
b. Traditional healers; ordinary teachers.
c. Specialised centres; 'modern' private clinics.
d. Centre-backed Camps or Outreach.
e. Home based package with intermittent support.
f. Community development with integrative changes.

Any of these may play a part in 'CBR', as defined by various people. Different *uses* of the term 'CBR', listed in Appendix 1, focus mainly on issues such as who acts, where they act, who controls, who funds. I shall not denounce any of these uses or models, nor award any prizes. The aim is to get a picture of what is going on and some of the critical issues involved.

4.3 *Own/family efforts unaided; or with Traditional Healer, or ordinary teacher.* These categories cover most of the 'rehabilitation efforts' in Southern Africa; yet, as already noted, very little formal, aggregated, public knowledge exists about how disabled people live their lives; and this lack obviously extends to public knowledge about self-help or family help, or the interactions of disabled people, families, local teachers and traditional healers.[13] 'Modern' rehabilitation professionals will mostly have their own opinion - which may resonate with Gelfand's comment about the physician John Helm in Southern Rhodesia in 1894, who was coping with "dropouts from the n'anga - the blind, the lame, the lepers".[14] We should, however, note the ever-present risk of misleading samples. A report that "almost all the disabled people we see tell us (eventually) that they have tried self-help and have visited many traditional healers, with no lasting benefit" may be true; and the clients' report of the ineffectiveness of previous efforts may be true. But the 'modern' practitioner or rehabilitation centre may be the final port of call, if all else fails. Perhaps there are thousands of disabled people who are satisfied with the results of self-help, family help, the local school or the traditional healers, and who therefore have no reason to go

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[13] Clearly, much more formal study has been made, and published, of African healers faced with common diseases and mental illnesses. So far as concerns educational needs, it is ironic that some useful modern research on disabled children within Southern African families and communities may be more accessible in Britain than in Zambia, e.g. SCM Katwishi (1995) Viability of developing early identification and intervention services for young children with impairments in Zambia. Unpublished PhD thesis, University of Birmingham; SM Kasonde-Ng'andu (1988) Aspects of the upbringing and education of children with special educational needs in a rural Zambian Bemba culture. Unpublished MPhil thesis. University of London. Financial constraints have obviated publication of this work in Zambia, and they would hardly be marketable in Europe. Microform reproduction would be one low-cost alternative, whereby copies of every thesis relevant to disability in Southern Africa could at least be circulated to every university library in the region.

[14] M Gelfand (1988) *Godly Medicine in Zimbabwe*, Gweru: Mambo, p.47.

any further, to set against thousands who visit the special school or modern clinic and report that everything else has failed.

4.4 *Specialised centres. 'Modern' private clinics.* In modern education and rehabilitation centres and clinics, the results of the past 50-80 years of knowledge and skill development are 'institutionalised' in the best sense, i.e. established, practised, monitored, taught, studied and developed.[15] Very few studies now bother to try to show that modern medicine, rehabilitation and special needs education are 'doing a great job' - that is assumed by most people involved in the medical, educational and rehabilitation fields, though there is plenty of dissatisfaction with particular aspects, with the competition for resources, and with the modest pace of change.[16] In fact, viewed against the background of humankind's efforts to develop healing knowledge and special educational techniques since the beginning of historical records, the past 60 years' growth of knowledge is unprecedented. The annual global output represented in *Index Medicus*, *ERIC* and *ASSIA* is colossal; but in terms of knowledge development, the *revolutionary* feature is that hundreds of thousands of people are working night and day to *challenge and change* what is known;[17] and as soon as anything is changed, it becomes the target of ongoing challenge.[18]

4.5 To maintain the global validity of the biomedical parts of this knowledge turnover, international committees work ceaselessly and painfully, unifying, defining and developing biomedical terminologies amidst the other rapidly developing scientific terminologies. These efforts with terminology represent a significant difference between the biomedical 'modern centres and clinics' and the educational and social welfare world; and an even greater difference from either self-help and traditional healing or the community-based efforts to be considered next. Self-help or traditional healing very seldom have unified terminologies - some of their activities may be quite effective, but it is very hard to know whether this is so and whether the effects can be

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[15] Ironically, the most ferocious critics of everything 'institutional' are alive and fairly healthy today as one outcome of the knowledge and practice developed and enshrined in those institutions...

[16] There are of course, fierce battles about 'private practice' by professionals whose training has been hugely subsidised by the general public, and who use their government hospital job as a feeder to their private clinic. There are also vigorous arguments about *where* children with special educational needs should be educated - but most of the methods are not in serious dispute.

[17] Manfred Ullmann, reviewing the massive effort of translation and adoption of Greek medical practice in the Islamic world of the 9th century CE, later passed on from Arab sources to Europe, suggests that "The Arabs had received Greek medicine at the last stage of its development and they could do no other than assume that this system was perfect and final." (p.23) He instanced al-Majūsi reporting some contrary voices *only to dismiss them*. It was enough to assimilate the retrieved ancient knowledge - the time was not to come for hundreds of years when the Galenic system would begin to be shaken off by men putting greater faith in knowledge discovered by replicable experiment. M Ullmann (1978) *Islamic Medicine*, transl. J Watt. Edinburgh Univ. Press.

[18] This would be difficult, even impossible, if a single 'profession' were involved in challenge and change - e.g. 'doctors'. A large proportion of the knowledge output comes from associated professionals, who may have little or no specifically 'biomedical' training, and who have not undergone the lengthy and painful hospital-based initiation rites by which young physicians and surgeons are bonded into their profession.

generalised, because private individuals and traditional practitioners do not describe them in a clearly defined, regulated, measurable and testable form and language.[19]

4.6 Comparable problems occur between the 'laboratory' sciences and the educational and social sciences, since international conventions for terminological exactness hardly exist in the latter.[20] Thus a major challenge facing the present workshop will be to consider **how far 'scientific research' leading to 'evidence-based practice' has any application outside the closely defined terminologies and the controllable case studies of the biomedical 'modern centre and clinic'.** To deal with large, floppy concepts like 'community', 'community resources', 'empowerment', 'learning', 'social change', 'access', 'integration', 'inclusion', each with its weight of ideological baggage, clearly requires a different approach. There will also be the task of reviewing research methodologies other than those of biomedical sciences. (We may need then to accept that battles within 'Western' or 'Northern' social science methodologies are far distant from the variegated and multicultured situations of the majority of disabled people in 'southern' or 'eastern' countries.)

4.7 *Camps, Outreach, Home-based packages, 'CBR'.*
"**The first element in the approach to CBR is to learn from the people.**" (Einar Helander)[21] Some efforts have been made to conceptualise the very varied programs claiming to be 'CBR'. Recently McColl, Rubik & Paterson, constructed two 3-dimensional models (cunningly displayed with modern graphics software...) They see programs being defined by the dimensions of *aims*, *beneficiaries*, and *strategies used*; and supported by the dimensions of *human resources*, *structural resources* and *attitudes*; and so manage to fit various program descriptions into their multi-cubes.[22] The cuboid model is worth looking at, but the exercise serves mainly to illustrate the

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[19] This is not intended to denigrate the knowledge contents of all traditional practices, which sometimes are highly elaborated and differentiated, e.g. the many methods and movements in therapeutic massage for a variety of ailments, described by DG Kennedy (1931) Field notes on the culture of Vaitupu, Ellice Islands. *J. Polynesian Society* 40 (No. 158, June) 247-64; or the "sensorimotor stimulation traditionally practised by many grandmothers and mothers" to young children, noted by Mahfoud Boucebci (1981) Special education through neighbourhood centres in Algeria, *Assignment Children* 53/54: 153-63, and photographed admiringly by Frederick Leboyer (1977) *Loving Hands. The traditional Indian art of baby massage*, London: Collins. But while the practices might be, or have been, recognisable to physiotherapists from other cultures, the lack of uniform terminology would have precluded any effective comparisons of results.

[20] International committees do exist for review of educationa and social science terminologies, but they are not in the same league of effectiveness as those working with the lab sciences.

[21] E Helander (1993) *Prejudice and Dignity. An introduction to community-based rehabilitation*, New York: UNDP, p.91. During the 1980s, WHO CBR was more like a steamroller than a listening ear. In fact from c. 1975 to 1982 Helander was collecting ideas and listening. From 1983 onward, he and colleagues were busy advocating the scheme in 60 or 70 countries, and defending it against attacks in the UN system. This left little time for 'listening to the people'. By the end of the 1980s, no government had adopted CBR nationally, other UN agencies were edging away, and the Big Push was over. 'CBR' was established on the development agenda - but with many mutually incompatible meanings. Helander acknowledged that "There are no quick and easy solutions" (p.92), and that it would take "as many as 15 or 25 years, if not more" (p.93) of hard work to build nationwide, equitable disability services. (Or, to be realistic, 50 to 100 years...)

[22] MA McColl & J Paterson (1997) A descriptive framework for Community-Based Rehabilitation. *Canadian J. Rehabilitation* 10: 297-306. ('Rubik' gets in there only as an ironic comment on the cubes).

difficulty of constructing any convincing overview.[23] Following one of many ideological crusades of the 1980s, the majority of aid agencies supporting medical, educational and social welfare programs picked up some vague notions of 'CBR'; so by 1990 most programs or proposals involving disability had been driven to repackage themselves as 'CBR', or at least to claim to be a Resource Centre developing a CBR component (unless it concerned education, in which case it had to include the word 'integration' up to 1993, and more recently 'inclusion'). Many schemes with mutually contrary aims and methods were thus lumped under one slogan. The effort by ILO, WHO and UNESCO in 1994 to reach a joint statement about CBR was also a sort of 'committee compromise', satisfying none of the parties and merely patching over their differences.

4.8 My own approach has been to try to record some of the *main current uses* of the term CBR (see Appendix 1), from which one can learn what people on the ground think they are doing.[24] A further contribution is to note *Some typical movements of people and resources in centre-based and community-based rehabilitation* (Appendix 2). Further, one may look at historical antecedents of the current 'CBR' efforts. The WHO's earlier CBR scheme derived partly from the 'Primary Health Care' movement, and the transfer of knowledge to rural people promoted by books like *Where There Is No Doctor*. The latter is the latest (and best illustrated) of a series going back over 1,000 years to Al-Razi (who died in 925 CE) author of the Arabic *Man la Yahduruhu al-Tabib* ('He Who Has No Physician to Attend Him').[25] There is little that is new about such movements, though in earlier centuries they were not packaged with a range of socialist ideologies. Some inclusive educational approaches were also being practised in South Asia long before the development of special educational techniques.

4.9 *Experiences in Africa.* Some descriptions exist of earlier disability services in sub-Saharan Africa, by no means all of which support the current myths about professionals running 'disability palaces', or their 'victims' confined within disability 'warehouses' or excluded from education. Outreach, family support and community based approaches were under trial 35-40 years ago. At a conference in 1963, a mobile artificial limb supply scheme was described travelling around francophone Africa throughout the 1950s. In the same decade (and perhaps earlier) mobile eye teams offered rural ophthalmology in Southern Africa. The East African orthopedic surgeon Huckstep also noted that "Rehabilitation Centres are expensive, and need subsidisation. They are

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[23] My scepticism is perhaps enhanced by the fact that McColl and Paterson clearly have not understood the scope of *information based rehabilitation*, which could be used to describe all the dimensions they portray.

[24] See also the diversity of views expressed in B Kolucki, B Duncan & K Marchael (eds) (1998) *Community Based Rehabilitation: Worldwide Applications. Visions and resources for the 21st Century*, New York: Rehabilitation International.

[25] In South Asia, records exist of children with disabilities being casually integrated in ordinary classrooms for many centuries; some small adjustments, extra attention or new techniques appear from the end of the 18th century onward. Efforts were made to extend basic health care to the rural Punjab from the 1860s onwards, and 'eye camps' bringing surgery to rural Sind and Baluchistan began in 1908. Schemes for social volunteers to visit the homes of sick or disabled children were known in England in the 1880s, and quite possibly earlier elsewhere. Such efforts were made long before the World Health Organisation was born...

obviously not a permanent answer, although they fill a very definite need for a few patients." Sophie Levitt, at the same meeting, agreed that institutions could not be transported from Western countries to Africa, and asked for more efforts to discover "what is uniquely African and what does it mean to work in developing Africa?" In her work, it meant that African parents of cerebral palsied children were "..shown how to handle their children at home as well as our treating the children at the clinic."[26] The balance between hospital and home care for elderly disabled people was also an urgent issue in South Africa in the 1960s.[27] Innovative vocational rehabilitation of blind people in African communities was done by many trainers in the 1970s. In the 1950s a WHO Committee had noted the blind person's rightful place in the African village:

> "To take him away from his village and family in order to teach him skills which he does not need and probably will have no occasion to practise is wasteful, officious and even cruel. Probably he can be best helped by the type of scheme which is now being tried in Uganda, where local centres are beginning to train the rural blind for work on the land so that they can become self-supporting on small holdings."[28]

An even more basic plan for village schooling of blind Africans was visited in 1957 by the blind consultant John Wilson, in a remote part of rural Rhodesia. Thirty two blind children attended the school, built by the villagers, following an innovative, practical curriculum:

> "When they have finished this schooling, they will not be scholars, though some reach standard five in the general curriculum, but they will know every inch and every activity of their village. They will be part of their community because they have never left it."[29]

These earlier experiences have disappeared, or been dismissed by those who cannot imagine that anything worthwhile was done before they themselves arrived on stage.

4.10 The CBR field has followed some of the evolutionary path of Primary Health Care; and also that of community schools, once hailed as the cutting edge of social change. The CBR spectrum, after its heady days of pioneer enthusiasm, is now in a phase of institutionalisation, where *ideology gives way to accountancy*, and 'community participation' (or 'compliance') becomes a footnote to 'management'. That is the underlying message of the rise of *CBR operational*

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[26] C Abadie (1963) Artificial limb supply groups in the French-speaking African states. In *Disability Prevention - Rehabilitation* (q.v.) pp.401-403. JC Hill (1984) Mobile eye-care teams and rural ophthalmology in southern Africa. *S.African Med. J.* 66: 531-5. E Anderson [1967] *The Education of Physically Handicapped Blind and Deaf Children in East Africa*. London: Natl Fund for Research into Crippling Diseases. C Cusson (1976) A rehabilitation experience with Cameroon animists. In: *The Disabled in Developing Countries*. London: Commonwlth Fndtn. *Disability Prevention - Rehabilitation. Proceedings of the Ninth World Congress of the International Society for Rehabilitation of the Disabled. Copenhagen, Denmark, June 23-29, 1963*. New York: ISRD. JH Eedle (1972) *Special Education in the Developing Countries of the Commonwealth*. London: Commonwlth Secrtrt.

[27] D Glajchen (1970) Elderly patients in the Johannesburg hospital: their disability and home-care. *S.African Med. J.* 44: 118-22, based on a doctoral thesis of 1968.

[28] *Expert Committee on Medical Rehabilitation. First Report* (1958) TRS 158, Geneva: WHO, pp.47-48. *Without Holding Hands. A handbook of approaches to vocational training and rehabilitation work with the blind.* (2nd edn 1980). Bensheim: Christoffel Blinden Mission.

[29] J Wilson (1957) Blind children in rural communities. In: *Proceedings. The Second Quinquennial Conference. International Conference of Educators of Blind Youth, Oslo, August 1957.* World Council for Welfare of the Blind.

management literature.[30] CBR has also begun to be *re-professionalised*, with increased attention by WHO to training the 'mid-level'; and by UNESCO to upgrading skills of junior professionals.[31] Any CBR approach needs to balance the conflicting demands of community participation, professional standards, career hopes of poorly paid or volunteer workers, and the individual needs and contributions of disabled people and families. No CBR program is ever completely 'balanced' - the balance is always shifting (unless the program has died, and nobody has yet noticed). A WHO booklet now talks of "..an ideal situation in which a full-time mid-level rehabilitation worker is trained to work at a first referral level hospital, where rehabilitation services are provided for both in and out-patients, and to supervise the rehabilitation activities at community level." This 'ideal' is far removed from earlier institution-bashing rhetoric; possibly because of a massive lack of interest by governments in adopting CBR as it was earlier packaged.[32] Most of the possible outcomes could have been predicted by studying the earlier development of PHC, in which the false antithesis of "hospitals versus primary health care" wasted much time and energy.[33] People marching to inspiring slogans seldom wish to expose themselves to the difficulties and ambiguities apparent when studying what happened earlier.

5.0 MODELS & EVIDENCE. (2) Evidence.

5.1 The discussion above already indicates that it will be **hard to find clear, straightforward 'evidence' for or against any 'model'**, as definitions are both slippery and flexible. Using whatever definition, CBR is nowhere a *completed model* that can be fully examined. That is why, some 15 years after launching his idea of 'national CBR', Einar Helander modestly admits that **"Several decades of work will be needed to identify the appropriate ways of arriving at a system capable to deliver essential services to all those in need."**[34] CBR advocates are often tempted to claim that where there is 'success', the activities were genuine 'CBR'; but activities judged to have failed were never 'true CBR' - not set up in the correct way, not implemented with the true spirit, unfairly damaged by external factors, being judged by inappropriate criteria, or

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[30] Recent items are e.g. SP Murthy & L Gopalan (1992) *Workbook on Community Based Rehabilitation Services*, Bangalore: Karnataka Welfare Assoc. Blind; T Jönsson (1994) *OMAR in Rehabilitation. A guide on operations monitoring and analysis of results*. (Draft version), Geneva: UNDP; G Vanneste (1995) *Daily Management of CBR Fieldworkers and Supervisors*. Dar-es-Salaam. These handbooks, with their burgeoning array of forms to be filled, move onward from the sort of 'management' manual edited by A Pahwa (1990) *Manual on Community Based Rehabilitation*, Delhi: Ministry of Welfare, which largely concerns medical management of disabilities. Not all, however, attain the level of realism displayed in some ILO publications (e.g. *Guide for Community-Based Vocational Rehabilitation of Disabled People. The case of the Philippines*. Geneva: ILO, 1994).

[31] E.g. *The Education of Mid-Level Rehabilitation Workers. Recommendations from country experiences*, (1992), Geneva: WHO. *Promoting the Development of Young Children with Cerebral Palsy. A guide for mid-level rehabilitation workers*, (1993), Geneva: WHO. See also the ten UNESCO 'Guides for Special Education', claiming to be "for teachers, parents, and community workers", but clearly demanding more education than most parents in developing countries have.

[32] Education of Mid-Level, WHO, 1992, p.3. Helander, Prejudice & Dignity, p.189.

[33] *Hospitals and health for all. Report of a WHO Expert Committee*, (1987), Geneva: WHO, p.8.

[34] Helander, *Prejudice & Dignity*, p.189.

some other let-out. Vendors of snake oil have a similar range of escape clauses to appease unhappy clients who have paid their money and used the oil, but have not been cured of baldness or impotence. Must we classify CBR along with snake oil, for lack of clear definitions? A recent world conference report emphasized the need to view CBR soberly:

> "CBR is not a panacea, nor does it provide a universal template for the future. On the contrary, unrealistic and sentimental reliance on CBR can do a disservice to its aims by discounting the serious social and economic obstacles to successful implementation."[35]

5.2 *Bibliographical work.* To prepare for some advisory visits in Zambia in 1996, I began reading and listing published and unpublished material, mostly of an educational or social nature, on mental handicap and developmental delay in Zambia and neighbouring countries;[36] then included other disability categories, and background material (excluding newspaper or magazine articles). Some 930 items are now listed (see Appendix 4). This was a necessary starter for any 'appraisal of evidence'. It begins to take the shape of the *existing formal knowledge base*, i.e. what people have taken the trouble to write down about disability and responses to disability in these countries. Much of it is, in my opinion, quite weak writing, with no claim to be 'research'. Yet it is evidence of a sort - writing that seriously aims to describe and discuss the disability situation, from various points of view.[37] It also constitutes a regional roll-call of many of the participants in educational, medical and social work concerning disabilities over the past 50 years.

5.3 The formal knowledge base discussing evidence for the merits and flaws of various sorts of 'CBR' in developing countries is also quite substantial, but mostly of poor quality and with little pretence of 'research methodology'. The earliest well-documented, published formal study that I know of examined the economics of a rural blindness training project, in 1984, and gave a

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[35] *Final Report. World Conference on Special Needs Education, Salamanca, Spain, 7-10 June 1994.* Paris: UNESCO, 1995, p.45. Faced with ill-defined, floppy, socio-economic problems, biomedical researchers may be tempted to concentrate on clearcut ways of *preventing* disability. What could be simpler than preventing the disabilities caused by iodine deficiencies, using iodized salt as indicated from Boussingault's observations in 1831? In fact, this solution was kicked around the scientific world for 90 years before it became respectable. Thirty years on, David Marine, a major figures in demonstrating its respectability, admitted that the obstacles to extending goitre prevention arose mainly from three sources "(1) economic, (2) political, and (3) social", all of which were "at present beyond the authority of a Public Health Service." D Marine (1954) Endemic goitre: a problem in preventive medicine. *Annals of Internal Medicine* 41: 875-86. A further 44 years down the line, these obstacles remain active in half the world's nations. See M Miles (1998) Goitre, cretinism and iodine in South Asia: historical perspectives on a continuing scourge, *Medical History* 42: 47-67, which notes that although use of iodine began in Bengal as early as *1825*, IDD are actually increasing in Bangladesh in the 1990s. Even South Africa, with comparatively advanced monitoring capacity, only recently recognised that iodine deficiency still exists in its population, and iodized salt fails to reach a significant proportion of people. PL Joost, AJS Benadé & F Kavishe (1995) Does iodine deficiency exist in South Africa? *S. Afr. M.J.* 85: 1143-44.

[36] To the north, some modern library resources exist in Nairobi; to the south, in Johannesburg. But "Zambia and neighbours" represents 150 million people in between, most of them very poorly served by information resources.

[37] Arguments may be brought forward about the primacy of 'oral culture' in Africa. This I leave to those who know something about it. I started merely with what is publicly accessible and verifiable, i.e. written documents.

broadly positive report.[38] An earlier report (1981) on experiments in Venezuela and Mexico, starting in 1974, found positive results where Community Health Workers were given some orientation to helping disabled people, with a 'caseload' of five or six at a time, later making use of the 1979 draft of the WHO CBR manual. Without giving the survey methodology, the report suggests that

> "some 30% of disabled persons solve their problems unaided; but almost 40% of the total can be assisted through this approach [i.e. CHWs]. About 18% need help from more highly trained personnel and approximately 12% require institutional care".[39]

If this sort of modest and plausible data had characterised subsequent WHO claims, a great deal of unnecessary aggravation could have been avoided, e.g. between specialised centres and advocates of 'CBR',[40] and between WHO and ILO. In 1989 the ILO Vocational Rehabilitation section summarised thus its experience of a decade of 'CBR' efforts:

> "The existing models of community-based rehabilitation have proven to have serious shortcomings as they are professionally unsatisfactory, difficult to organise as a self-sustainable programme and not feasible without major back-up from outside the community."[41]

This critical verdict made public the longstanding unease among various UN agencies about the wilder claims for CBR; and strengthened the trend towards more serious evaluation of 'CBR', from the late 1980s onward.[42]

5.4 Helander, discussing 'Evaluation of CBR' in 1993, describes eight evaluative studies, which presumably he considers significant since his book intends to advocate CBR.[43] However, two are reported by Helander's close colleagues, and one by the director of a WHO collaborating centre, who are hardly impartial observers. One internal evaluation is given in some detail, but the reference does not appear; the other internal evaluation has been published. Another evaluation, by external observers, has no published report shown. Among the eight, the only external, independent evaluation reported in an academic journal is by Lagerkvist; and this has been

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[38] PA Berman & DG Sisler (1984) *Rehabilitation of the Rural Blind. An economic assessment of a project in the Philippines 1978-1983*. New York : Helen Keller International. (The authors were rural development economists with experience in East Asia).

[39] R Hindley-Smith (1981) *Helping Disabled People at Home: a new approach to rehabilitation*, Washington DC: PAHO. p.22.

[40] See M Miles (1985) *Where There is No Rehab Plan. A critique of the W.H.O. scheme for Community Based Rehabilitation: with suggestions for future directions*. Peshawar: Mental Health Centre; ERIC: ED267530; Palo Alto: Hesperian Foundation.

[41] W Momm & A König (1989) *From Community-Based Rehabilitation to Community-Integration Programmes. Experiences and reflections on a new concept of service provision for disabled people*. Geneva: ILO.

[42] Searching Medline recently for +community +based +rehabilitation, 1990-98, produced some 250 references in English, among which about 22 make some structured effort to evaluate aspects of community disability services in developing countries i.e. those not starting on a basis of several decades of existing nationwide health service coverage. Several derive from Southern Africa, and these presumably will be reviewed by the participants designated to do so.

[43] Helander, *Prejudice & Dignity*, pp.175-190.

severely criticised by Finkenflügel.[44] In fact, Helander does take care to review some flaws and problems in CBR, adding greatly to the credibility of his book by doing so; but his chosen formal evaluations are comparatively weak evidence, in terms of critical independence and open publication. Up to the present, the only convincing, formally published series of studies evaluating various aspects of CBR across a substantial period of time in a specific location seems to have been that by Thorburn and colleagues, as already mentioned (see footnote 7); and over a shorter period, by O'Toole and colleagues on education-based CBR in Guyana. Results in both situations have on the whole been positive. However, as a small island with a GNP of US $1,500 per capita, 90% female literacy, and child mortality rate lower than that in several European countries, the relevance of Jamaican experience to much of sub-Saharan Africa might be questioned.[45] Various guides and handbooks on CBR Evaluation are in draft or being field-tested at present, from different organisations. By 2010 a more substantial picture may emerge, from independent and rigorous published studies of a variety of approaches to CBR, and of their medium- to long-term outcomes. **In 1998, we have no clear picture.**

5.5 *Protecting the World against Evidence* The production of research data on disability services, after careful scrutiny and comparison, does not necessarily make any impact on planning that is based on 'what everyone knows'. For example, among children with impairments who get any formal education in Pakistan, in Tanzania, in Sri Lanka, and very probably in Zimbabwe, the majority get it while 'casually integrated' in ordinary schools, without planning, special efforts or additional expenditure. This was demonstrated in the 1970s and 1980s by studies in Pakistan, Tanzania,[46] and Sri Lanka. These studies made *little or no impact on policy or planning*, whether by NGOs or Government. Nobody denies that some children with impairments are found in ordinary schools. In Pakistan, a study of 103 urban and rural schools, with some 43,400 pupils, found that teachers could point out 825 (1.9%) children having some sort of impairment.[47] Why do such figures make no impact on policy or planning? The Sri Lanka study shows the mental

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[44] B Lagerkvist (1992) Community-based rehabilitation - outcome for the disabled in the Philippines and Zimbabwe. *Disability and Rehabilitation* 14: 44-50. See H Finkenflügel (ed) (1993) *The Handicapped Community*, Amsterdam, VU Press, p.147.

[45] See data in *The State of the World's Children 1998*, New York: UNICEF. The cultures, economics and geography of Guyana are also rather peculiar, though possibly of relevance to some coastal African nations. The *inspirational* effects of reportedly successful CBR work do often seem to transcend socio-economic differences; and this justifies the efforts by MJ Thorburn, B O'Toole and D Werner to develop effective communication media reaching far beyond their immediate localities. Nonetheless, it is hard to know how far inspiration can relieve the daily grind of work in conditions of severe poverty and underdevelopment.

[46] J Kisanji (1979) Incidence of handicapped children in ordinary primary schools. In: *Education and Development. Proceedings of the IYC Symposium, University of Dar-es-Salaam, Dec. 1979*. Nairobi: UNICEF.

[47] M Miles (1985) *Children with Disabilities in Ordinary Schools*. Peshawar: Mental Health Centre, for Government of Pakistan. ERIC ED265711. In the intervening years, no significant factors are known that would have reduced the proportion of disabled children casually integrated. Taking a more conservative 1% level among some 20 million Pakistani schoolchildren, there would be around 200,000 children with noticeable impairments in ordinary schools, as against a maximum of 12,000 in special schools or units. The number of children casually integrated in ordinary schools is vastly greater than the number in planned special education. (Pediatricians doing a survey could easily find 20% of schoolchildren having mild to moderate visual and hearing impairments).

compartments in which the 'received world' is kept separate from the 'world found by research'. On p.20 is the world as received from politically correct spokesmen: "Disabled children regardless of potential, are kept out of school, and are deprived of a normal developmental process". Yet on pp. 24-25, survey results show that "20.5% of school children, out of a total number of 10,105, in 34 schools are disabled", with details of their impairments, confirmed by aggregated surveys in which 4,136 (17.5%) had impairments among 23,644 school children (pp. 79-80).[48]

5.6 In most southern African countries, journal papers assert that until Independence, or even later, education for children with disabilities was provided by charitable organisations and missionaries. Everyone 'knows' this - it fits the normal picture in which 'disability' is supposed to evoke a 'charity' response. The fact that thousands of disabled children attended ordinary schools from colonial times to the present does not enter the picture - nor does the idea that maybe thousands of disabled adults attend ordinary health centres when they are ill and ordinary churches on Sundays and buy food in ordinary shops and get drunk in a perfectly normal way. The rhetoric emphasizes differences and problems. The sinful public are called on to repent and to love their neighbour and to integrate the poor rejected cripple. But if many disabled children are actually attending ordinary schools, and many disabled adults are living fairly ordinary lives in their ordinary locality, it would be useful to learn more about these situations and how they have been achieved, since an 'ordinary life' is at least an interim goal for everyone...

5.7 *Attitude-change stages* and movement are suggested in Appendix 3, among which are some hypothetical stages by which government officials get to grips with 'the disability problem'. The 'stages' have not been scientifically demonstrated - they are merely an attempt to formulate experience. Attitude change studies also suggest that people often have a complex cluster of views and feelings, parts of which may shift at different rates. For example, a Director of Social Services might respond intellectually to research evidence about mobility training for blind people, but this effect may be suppressed by an emotional reaction to the physically disabled girl begging on the pavement outside the Social Services office, and both responses may be undermined by a subconscious childhood memory of a mentally disabled person roaming about the village, whose smell was overpowering. It is a difficult area of research - but if part of the aim is to get governments to make more rational policies, we need to know more about what actually does influence the policy-makers. Activists claim that "We demonstrated, we shouted, and a month later the Government changed its policy." Scientists claim that "We submitted research evidence, and later saw it reflected in the new policy statement." Politicians claim that "We listened to all sides, then made the best policy." The senior civil servant who actually wrote the policy remembers that she drafted it several years earlier, while on study leave in Japan. She does not remember the book that influenced her...

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[48] *Prevention of Childhood Disability and Community-Based Rehabilitation of Disabled Children. Anuradhapura District*, (1987), Colombo: UNICEF. Many ablebodied and disabled children were not receiving any formal education. Among those with impairments attending school, a majority could have made more progress with a few simple changes in the teachers' style of work.

6.0 MODELS & EVIDENCE. (3) Effectiveness.

6.1 All the earlier strictures and problems apply equally to decisions about what is 'effective' in any given context, and by whom it is considered effective. Here, I will give only the example of a harassed, underpaid and overworked provincial Director of Health, Education & Welfare, faced with yet another proposed reorganisation. An 'effective' proposal, in his view, would be one that can actually be made to work *by the average and below average staff* constituting 90% of the workforce; costing no more than the present system; producing results measurable by ordinary means; that will not inflame religious teachers or other influential constituencies; that will not reinforce corruption and nepotism in staff postings; and that might deliver, within two or three years, benefits substantially outweighing the disruption involved in implementing the scheme. If no proposal meets these criteria, the Director prefers to continue the present system, whatever its flaws. Practically nothing demonstrated by NGOs has any impact at all on this Director, because NGOs run with foreign funds and other motivations which are entirely beyond what he can supply to his workforce, or demand from them. However much evidence is produced for the 'effectiveness' of such schemes when run by NGOs, government officials are unlikely to be convinced that they can be adopted as national strategies for the government workforce.

7.0 AFRICAN MODES OF RESEARCH

7.1 Are there some 'culturally African' ways of knowing, ways of gathering and sifting evidence, ways of sharing what is known and what is new, that should play some part in the disability research that this workshop hopes to promote?

a. I think there probably are some such ways.[49]

b. If so, it will be necessary for them to play a significant part if disability research is going to be effective in discovering how disabled Africans live and develop their lives amidst their communities, how communities can be supported in making necessary provisions and changes, and how African governments can be assisted to make more appropriate policies.[50]

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[49] There is, of course, published research on African cognition, by European psychologists from the 1920s through the 1980s. In this one may discern an initial scepticism and tendency towards pejorative 'racial' categorisation, followed by a slowly increasing respect and appreciation; and eventually an awareness that European methods of schooling have largely failed to build upon the strengths and goals of African cognition. (For a fascinating discussion, see R Serpell, 1993, *The Significance of Schooling. Life-Journeys in an African Society*. Cambridge UP.) The whole field is a political hot potato. The impression persists that very few African countries have found ways to develop education that is both 'modern' and based on the inheritance of cultural strengths.

[50] Even in the apparently simpler case of hearing medical symptoms cross-culturally and cross-linguistically, the practical difficulties have long been known and described in Southern Africa, see e.g. KP Mokhobo (1971) Medical history taking among the Bantu tribes of South Africa. *S.African Med. J.* 45: 111-14. Dr Mokhobo, a physician in Swaziland, remarked that "A large section of the African population is still *markedly tainted* with traditional cultural attitudes." (Emphasis added). Since 1971, the attitudes of physicians trained in European methods have progressed to the point where some would see 'traditional culture' as a feature to be worked with rather than a 'taint' to be overcome. (Even in 1903, the first issue of the *S.African Medical Record* carried a detailed description and appreciation of successful abdominal surgery by a village healer...) The cultural and linguistic difficulties involved in learning how disabled rural Africans perceive their disabilities, and aggregating such experiences to produce a public record which can be used to develop policy, will not be insignificant. The difficulties can be overcome only when sufficient motivation exists, and serious efforts are made to produce the information.

c. It will not be easy to do so, because the dominant research modalities embody particular culturally European (and perhaps inherently male?) ways of knowing, thinking and asking questions, which have often been intolerant or derisive towards other approaches. Africans may be unwilling to expose their alternative approaches, or may find difficulty in articulating them in European languages, or depicting their real strengths, in the face of the dominant modalities.[51]

I do not have clear examples to support this suggestion, and have no wish to romanticize 'Black Africans' as a kind of mysterious 'Other' having esoteric knowledge; nor to imply that Africans cannot handle European research methods. But I do think it is important to keep doors and minds open, and to leave genuine invitations, so that all ways of knowing and sifting knowledge may bring whatever they can contribute. My first experience of 'development aid' was to spend a year as a teacher in Togo, West Africa, more than 30 years ago. I was a very young man, and could hear and see some things then, which I can no longer hear or see. But I have not entirely forgotten that there is, or seems to be, something deeply important and fundamentally African that is held in common across west, east and southern Africa, and which permeates the way of being oneself and being in community - and which therefore probably affects ways of thinking and knowing. Unless some of this characteristic factor is present in the planning and exercise of disability research, the results may turn out to be unexpectedly thin, weak and ineffectual.

8.0 A FEW SUGGESTIONS (mostly already outlined above)

8.1 This section is brief - because if we already knew very clearly what needed to be done and how to do it, there would be no need to hold this workshop. Further, I am merely a short-term visitor in Southern Africa, and short-term visitors very seldom understand the real social and political problems involved in getting anything done! However, a few concluding points, for those busy souls who never read more than the title and the final paragraph of any paper:

a. Information gathering, review and condensation. During and after this it may become clearer what and where are the outstanding gaps, and whether there is any sort of research capable of filling them. We should not be naive about information production and control. Throughout history, governments, professional guilds, religious teachers and other educated people, have tried to control or manipulate the circulation of information - and will continue to do so. In the traditional community, there was (in theory) a fixed amount of knowledge, handed down from generation to generation. In practice there was some slow change in the body of knowledge, some parts getting lost and other parts losing ground through externally-imposed change. We now have the colossal explosion of information and of communication media,

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[51] Some foreign anthropologists, missionaries and aid workers report that, after several years, the Africans with whom they have been living and working decided that it was time to reveal some aspects of knowledge and thought which up to then had been carefully concealed. Presumably the revelation happens only to people who have shown some respect and understanding for the surface level of local cultures, or have passed other invisible 'tests'; and who have been patient. Deliane Burck, whose report on disability and rehabilitation in Zimbabwe seems to me a model of cross-cultural sensitivity, noted (p.6) that it took a year before she could learn anything about traditional ideas, even though she knew that they existed and wished to hear them. DJ Burck (1989) *Kuoma Rupandi (The Parts are Dry). Ideas and practices concerning disability and rehabilitation in a Shona ward*. Research Report No. 36/1989. Leiden: African Studies Centre.

with enormous information power concentrated in relatively few hands, very little accountability, and no borders. If we take part in research, we take part in power games. It is better to recognise this at the start, than to be surprised by it towards the end.

b. During the gathering of information and strengthening of resources, serious attention should be given to indigenous African concepts and methods of knowing, learning, teaching and healing.

c. Disability organisations (both Of and For), as well as professional centres, should plan and work towards their own eventual disappearance. At present, they institutionalise disability information, in both a good sense and a bad sense. There is a need for information to be accumulated and refined, which the better organisations are doing. There is also a need for information to be disseminated and dispersed, as well as challenged and renewed. The ideal institution or organisation learns to do all these things, to become a multi-purpose resource centre or base; while not forgetting that ideally it should not be needed at all.[52] Members of disability organisations, and professionals and volunteers, should aim also to join one or two non-disability organisations, bringing pertinent disability information and action to farmers clubs, women's education campaigns, family planning associations, city planning watchdogs, teachers' unions, chambers of commerce, sports teams, agricultural credit cooperatives, etc.

d. Ethical review - governments and NGOs should face up to the ethical dilemmas of distribution. We can expect that finances for formal disability service development will be constrained for the foreseeable future. So when the pie is cut, will priority go to making excellent provisions for a very small number, or doing a modest job for a larger number, or spreading resources very thin in order to give a warm smile and promise to everyone? All will be attempted, as neither planners nor governments nor NGOs actually control all the available resources of knowledge and skill. There is no reason to think that elites and middle classes will suddenly behave differently from the way they always have behaved. They (we) will continue to ensure that some advanced services are available for themselves, even if they (we) have to pay for it. Politicians will give token smiles and blessings to the mass of poor and disabled people, as this is good for their personal image. Some NGOs will try to 'do the correct thing', i.e. do a better job for larger numbers, by increasing the availability of information, and strengthening the informal resources of self-help and family assistance with which the great majority of disabled people now manage their lives. Meanwhile, the people who have the know-how will continue to earn their living, and the more far-sighted or compassionate among them will get involved with schemes to do a little more for the poor. So where does ethical review come in? It is needed so that leaders and thinkers do not deceive themselves so badly. Some of this century's greatest political horrors have begun with the apparent intention of benefitting the masses; and this rhetoric has continued to the last moment when tyrannical regimes have finally crashed. Humankind has not yet finished with such games. Ethical review is very much needed.

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[52] Patrick Devlieger, scholar of African disability concepts and practices, reports that Frans Vreede once told him: "When you don't have a rehabilitation institute, try to get one; when you have a rehabilitation institute, try to get rid of it."

APPENDIX 1

TERMINOLOGIES OF DISABILITY

1. Terminology Kicked Around on the Global Street

Several contradictory forces are at work in the international uses of language, the results of which are hard to predict. The rapid rise, and lower costs, of global communications methods such as fax, email and internet has created the illusion that new ideas can be spread quickly and accurately around the world. The illusion is reinforced by the fact that millions of people learn English every year as a second, third or fourth language, to the point where they can hold simple conversations and can read quite complex documents, getting a broad impression of what the document is saying. With more time and a dictionary, they can also get a more accurate idea of what the document is about. There are two big snags: (1) people don't have 'more time'; (2) dictionaries very rarely contain the words and definitions used to communicate new ideas. So people fit the new ideas into their existing thought-patterns, as best they can, leaving out the bits which they do not understand, and knocking off any odd corners that don't seem to fit. The result may be as good as 85%, or as bad as 40% of the intended meaning. They then pass on to colleagues and students the idea they think they have received, in their own first language (which may or may not be the first language of their colleagues and students). At its best, this onward transfer process is never more than 85% accurate, and sometimes as bad as 20%. So by the time the second transfer takes place, the most difficult 30% of the new idea will certainly be lost, and often 50% or more will be lost.

Ideas spread out rapidly on the internet, but feedback to the originators is very poor, especially from regions where English is not the first language. So there is little opportunity to prevent or correct the onward transfer of information that may be less than 50% accurate. The result is that new terminology has a very short efficient and effective life - maybe six months - once it is released for global consumption. After that, intercommunication becomes much slower and less certain, because a lot of time has to be spent finding out what the other communicants mean by their terms. When terms concern anything that can be affected by local cultural factors (e.g. almost anything in the social sciences, apart from statistical theory) the gaps in meaning and understanding grow very rapidly. Of course, we are all accustomed from early childhood to working with some level of 'fuzziness' in understanding other people. We also learn how to exploit the ambiguities of language in order to trap our close relatives into agreeing with something other than what they intended. (Without some tolerance of fuzziness, cross-cultural cooperation would be almost impossible.)

One reason why English became a major language of international communication is that it is has evolved as a sloppy language, good for expressing simple thoughts and vague ideas. It has never been easy to use it for clear, precise, unambiguous communication. 'Scientific English' began to develop as Latin lost ground some 200 years ago; but 'Scientific English' is not the English that most people learn as a foreign language.

Many people feel some fear and anger at the rapid erosion of meaning in old and new terminology. There is still a widespread belief that words can be defined, meanings can be assigned to them, and that these should stay fixed and should be understood and used in the same way by all users, or at least by everyone engaged in scientific research. The idea that all words are temporary conventions, an illusion of solid ground in an ever-moving sea, is deeply threatening, especially to those who have been taught to believe that 'modern science' is the key to understanding the universe or solving the world's problems.

2. Main Current Uses of the Term 'CBR'

A. Therapy or special measures *given by families* to their disabled members in their homes, with some efforts in the neighbourhood to change public attitudes and improve access to local services e.g. schools, public buildings, leisure facilities. The efforts may be supported by a volunteer or paid worker.

B. Therapeutic, educational, vocational or social *self-help* projects run by disabled people and partners, whether in home, centre or street (with or without some external technical help).

C. An ideology whereby a nation's entire resources for medical and legal rehabilitation and social inclusion of disabled people - e.g. finance, professional skills, equipment, design, even attitudes - are centrally planned and allocated equitably across the whole population. This promotes activities as in (A) and (B), 'at the community level'; but (A) and (B) are not the whole of 'CBR', which extends to the control of resources at district, provincial and national levels. (Also sometimes known as 'Airconditioned CBR').

D. Activity of rehabilitation institutions or disability resource centres periodically take knowledge and skills to rural or deprived communities. (May be called 'Outreach Projects').

E. Externally funded program in which a network of paid and trained 'CBR fieldworkers', without a specific rehabilitation centre base but with clear management structures, ongoing inservice training, and negotiated referral contracts, undertakes the mobilisation, training and public education tasks necessary before (A), (B) and possibly (D) can practically be expected to become self-sustaining.

F. Some residential institutions caring for children with disabilities now call themselves 'CBR', on the grounds that if the children are not living with their families then they must somehow be based 'in the community'. (!)

G. A buzz-word by which well-meaning people, not actively involved in community development, soften the contrast between their own access to professional services and the access of most of humankind; and by which aid agencies and institutions can appear to adopt the latest trend, while continuing their previous patterns of expenditure and service.

3. Origin of 'Impairment-Disability-Handicap'

The triad 'Impairment-Disability-Handicap' is often assumed to originate with the WHO in the 1970s. In fact, it dates back to the 1950s. See: Maya Riviere. *Rehabilitation Codes. Classification of Impairment of Visual Function. Final Report 1968.* (Publisher and date unclear; probably published in 1970). The demand for new terminology arose through dissatisfaction among rehabilitation professionals in the 1950s. They found that the existing terminology told them something about the biomedical condition of patients' eyesight, but said nothing about the person whose eyesight had been measured. It was useless to the "non-clinical personnel responsible for social and vocational training, in terms of the implications for the person's everyday life" (p. ii).

Studies reported by Riviere originated in the early 1950s with subcommittees of the US National Committee on Vital and Health Statistics. In the 1950s, the USA had no standardised procedures or classification for professional measurement of sight or visual deficits. In 1957, Riviere and colleagues began developing "a classification for impairment of visual function differentiated from defects of vision" (p. 1). This arose because several hundred rehabilitation agency personnel having only diagnostic or employment details about the "rehabilitant", complained that they were "unable to evaluate his unimpaired assets, his education and past experience, and his potential for a future independent life. The attitudes of his family, friends, and community acquaintances were known to be critical factors in building or tearing down his morale and motivation." (p.1) Staff also complained about professional jargons causing confusion between workers from different disciplines, and problems of measuring progress in rehabilitating the rehabilitant, as they aimed to "help establish him in a satisfying independent daily life". (At this date, 'Him' was supposed to be understood to include 'Her', a convention later overturned by feminist action).

Early in 1958 one subcommittee made an adverse review of the 1955 Surgeon General's Impairment Code draft listing "injury and disease entities" etc, which "reflected current practices of identifying 'the problem' and labeling the person who might have it" (p.3), tending to "produce a stereotype of 'the blind' as a group of identical people... This negation of human variability and individuality could form no basis for a rehabilitation program" (p.4). The subcommittee that had drafted the 1955 code then let it go to oblivion. That work was taken over by Riviere's Rehabilitation Codes Advisory Committee.

However, "By that date... [i.e. early 1958] the Rehabilitation Codes Advisory Committee had already established terms of reference for their work, defining "rehabilitation," "impairment," "disability," and "handicap."" (p.8) The 1955 draft code cited above was "just the kind of labeling which the project intended to jettison, in desiring to re-orient professional attitudes and services towards individualized evaluation of the person as a human being, rather than the possessor of some detrimental condition."

'Impairment-Disability-Handicap' has had a long life of 40 years, and is still being adopted by people meeting it for the first time in 1998. Criticism has grown over the past 20 years, and some efforts have been made to introduce the diad 'Impairment-Disability'. New efforts now seem to be under way to launch '*Impairment-Activities-Participation*', in an attempt perhaps to 'accentuate the positive'. However, it has been pointed out that "impairment is still the building stone" and the new terms are "intended to be used in a primarily medical context." (A. Vreede, 1998, 'Some thoughts on definitions and a methodology of research regarding disability.' Working document for the Expert Meeting *Local concepts and beliefs regarding disability in different cultures*, May 1998, Bonn.)

SOME TYPICAL MOVEMENTS OF PEOPLE & RESOURCES IN CENTRE-BASED & COMMUNITY-BASED REHABILITATION

Many activities in both centre-based special education and rehabilitation, and 'CBR' or 'Outreach', involve movements of people and resources, which can be schematised as below, using the following abbreviations: Specialised Centre (**SpecCen**); Neighbourhood Location with disability service purpose (**NeiLoc**); Trained and Paid Worker(s) - who may be disabled or able-bodied (**Pro**); Family Member(s) (**FaM**); Child(ren) or Adult(s) with Disability seeking help (**PwD**); Community-based agent(s) - whether volunteer or paid, able-bodied or disabled (**CmtyBasAg**); Development Organisation or local branch of voluntary society working for community uplift, but not specialising in disability (**DevSoc**); Community Infrastructure e.g. ordinary school, health centre, church, mosque, village hall, market, community facilities (**CmtyInfra**).
(N.B. *Sometimes a NeiLoc takes place in CmtyInfra at a particular time of day, or on specific days of the week*).

1. Clients to SpecCen or NeiLoc

a.	PwD + FaM	->	SpecCen	for assessment, counselling etc., or for FaM to see SpecCen Pro working with PwD.
b.	PwD + FaM	->	NeiLoc	for counselling, e.g. by CmtyBasAg, monitored by SpecCen Pro.
c.	PwD ->		SpecCen or NeiLoc	regularly, e.g. for special schooling, vocational training.
d.	FaM ->		SpecCen or NeiLoc	e.g. for counselling, training to work with PwD at home.
e.	CmtyBasAg	->	SpecCen or NeiLoc	for training, to work with PwD at home or at NeiLoc, and in CmtyInfra.
f.	DevSoc or CmtyInfra	->	SpecCen or NeiLoc	e.g. for disability information or advice on working with PwD in their particular field.

2. SpecCen to Clients, usually via agent

a.	SpecCen Pro	->	Home or NeiLoc	working directly with PwD.
b.	SpecCen Pro	->	Home or NeiLoc	working with FaM or CmtyBasAg, who then works with PwD.
c.	SpecCen Pro	->	NeiLoc or CmtyInfra	training & supporting CmtyBasAg who works with PwD and/or FaM.

3. SpecCen, via CmtyInfra or DevSoc, to Clients

a.	SpecCen Pro	->	CmtyInfra or DevSoc	informing, training or working with DevSoc members or CmtyInfra Pro, e.g. teacher, health worker, religious leader, police, local councillor, journalist, who in their work may provide services to PwD, FaM or CmtyBasAg.

4. Combinations

Various other combinations of the above places, people and activities may also arise.

APPENDIX 3

PROGRESS IN DISABILITY AWARENESS *M. Miles*

The type and progress of awareness of disability varies with the experiences and viewpoint of the individual. In this article, various points of view are considered, i.e. disabled people, welfare planners, rehabilitation professionals, media practitioners, the general public. Various stages of thought are suggested below, following mainly western patterns, and in varying depths and detail.

Disabled People

1. Acceptance of marginalised role with self-limitation and adaptation to circumstances	It's the Will of God... It's just my bad luck... We mustn't expect... You just have to accept...
2. Conscientization	It's unfair! Why can't I... If I had the chance, I could...
3. Development of group identity	We are many... We're okay! Together, we could...
4. Construction of a case	We have rights! We want our share... We have a history... They have always tried to oppress us!
5. Campaign	We demand... Help us get... Justice! Rights! Join us...
6. Token response buys off the gullible and faint-hearted	They're listening! Our representatives have gone to meet... They're going to look into it... They'll see if they can find some money... There was a piece in the newspapers... We can't expect too much...
7. Rejection of Tokenism	No Compromise! It's nothing like enough... We want a real answer... This is only the start...

8. Separation / Revolution OR	Incremental Reform
Only We know what We feel... Nobody else can speak for us... The system must be smashed and totally rebuilt... We want separate facilities... Incremental change is a sham... We must have room to live our own different life... We don't need their help...	We have to organise ourselves... We must have information... We must educate people at all levels... We need short and long-term targets... We will work with anyone heading in the same direction... Permanent change will come only as people understand for themselves... Each one has a useful contribution...

Welfare Planners

1. Ignorance	Problem not yet perceived.
2. Attention	Ah! So there is a problem!
Identification	What is it? Who are they?
Differentiation	They're different! There's something wrong with them!
Quantification	How many are there? How bad is it?
3. Accommodation	Something should be done about it!
Segregation	There should be a place for them!
Prevention	Can it be stopped?
Economisation	How much is all this going to cost?
4. Adaptation	This thing can and must be managed!
Conceptualisation Specialisation	We are examining the nature of the problem. We have found its place, and are getting familiar with it.
5. Normalisation (?)	It's not so different or unusual after all.
Integration	Maybe it can be managed in the normal health, welfare and educational provisions.
6. Optionalisation	This can be handled in many different ways, each with benefits and problems.
Individualisation	To provide several options gives the best chance of suiting individual needs.
7. Reconceptualisation	The whole thing can be seen in ways quite other than we at first thought!

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Rehab Professional

1. Me	With my training and skills, I can help the disabled... It's rewarding, when you complete a case.
2. Us	In the inter-disciplinary team, we share cases. You can learn a lot from seeing how the others approach the cases...
3. Us and clients	A good relationship is the basis for all progress... Once you know them as people, you forget they're disabled...
4. Us, our clients, and the local community	You have to think of their ordinary, everyday life... It has got to work when they're at home, with family and neighbours, round at the shops, the school, the mosque...
5. All of us together...	Really, we have all got to change our attitudes... We all need to work towards a society designed by and for all sorts of human beings...
6.. Me again...	I now see my own abilities and weaknesses in perspective... I have helped some, and been helped by many... Working together with my colleagues and clients and local communities towards a society that fits us all, I've discovered who I am...

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Media People

1. Ignorance. Labelling, stigmatising remarks.
2. Disability as "an issue", a focus, hey-look, slogan, angle.
3. Beginning to realise the complications. Consultations with Disabled People's organisations.
4. Opportunities given to people with disabilities to present their own points of view.
5. Disability as a normal 5% background, casually integrated in all programming, with periodic 'positive discrimination'.

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General Public

1. Rejection	Disabled people are a burden, a nuisance, beggars, under a curse, can be mocked.
2. Fatalism	Disability is their fate. Nothing can be done.
3. Condescension	It's not their own fault, it's God's will. They should not be mocked.
4. Pity	We should feel sorry for them, pray for them.
5. Charitable duty	It is our duty to give them alms.
6. Willing to help	We should do more than pity them and give alms. We should give them actual help.
7. Empathy	What would I find really helpful if I were in the situation of this disabled person?
8. Acceptance with dignity	There must be acceptance of disabled persons in society, and a life with human dignity.
9. Right to normal life and esteem	Acceptance must be on terms of equal value and esteem. People with disabilities must be enabled to live with a normal range of choices, and to make their contribution to the life of the community.

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Slightly revised 1997, from a paper by M. Miles originally published in the Special Education Bulletin for East & Southern Africa (UNESCO) (March 1989) Vol.7 (1) pp.15-17.

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APPENDIX 4

RESPONSES TO MENTAL RETARDATION & OTHER DISABILITIES IN ZAMBIA & NEIGHBOURS

- Angola, Botswana, D.R. Congo (formerly Zaïre), Malaŵi, Mozambique, Namibia, Tanzania, Zimbabwe.

Bibliography of published & unpublished
material (mainly non-medical & in English)
listed by first author's name, with introduction,
notes on accessibility of material, and
indexes by country and by additional authors.

M. MILES
Birmingham, UK
August 1998. Version 4.07

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Kindly send corrections and details of further relevant material to:
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1.0 INTRODUCTION

This bibliography, currently with 932 items, began with a focus on the *development of non-medical services concerned with mental retardation* (mental handicap, learning difficulties / disabilities, intellectual impairment, etc), in Zambia. As the development of *services for people with other disabilities*, and for children and language use, and developments in neighbouring countries, were pertinent to the original focus, some material on these topics was added, eventually outgrowing the initial focus. Some biomedical papers appear, mostly relating to mental retardation or goitre and cretinism and having some social content; or where a community-based program or health education activity concerned with biomedical conditions seems relevant to the development of disability awareness in communities; or where the total data listed for a country is very small. Some *historical references* to formal services from 1950 back as far as the 1850s are grouped at the end, extending across sub-Saharan Africa. The bibliography has an *index by first author under Country*, and an *index of second or additional authors*. Newspaper and magazine type of articles have mostly been excluded; so have papers purporting to be African but consisting almost entirely of accounts of European or American methods. A comprehensive bibliography would probably be twice as long, and no doubt such work should be done by someone with better access to materials in the region, and to internal papers and reports of government and UN agencies.

The region refered to as *'Zambia and Neighbours'* is not a standard one. It represents an area of some 8 million sq.km. with a population of c.150 million. (The USA is approx. 9.4 m. sq.km., 260 m. pop.; Europe, excluding the former USSR, is 5 m. sq.km., 500 m. pop.) Over 50% of the region's land and population comprises Angola, D.R. Congo and Mozambique, yet these countries provide less than 10% of the material in this bibliography, and most of the non-English material. Omitting these countries was considered, and was rejected. As they have suffered much social and economic damage during recent decades, and have comparatively weak formal services for disabled people, there is all the more need to list both internal and neighbouring knowledge and resources, and to try to overcome the language barriers.

Any information shown in square brackets [ ] has uncertain status. The publication status of some papers also remains uncertain. A few authors' names may regretably have been inverted through the compiler's lack of familiarity with African names. Some accents may have gone astray in languages other than English. The bibliography is issued as a working tool, with apologies for any flaws and with a request for corrections and for relevant additions.

1.1 Need for Listings

Society's 'responses' to mental retardation, e.g. formal efforts to prevent it or reduce its effects, to give appropriate teaching to children with learning difficulties and other disabilities, and to help them achieve more of their potential, have developed in this region mostly during the past three or four decades, with the early impetus coming from Europeans. The beginnings were uncomfortably entangled with conflicting views about the assessment of intellectual ability in Africans. A slow development took place of less culture-bound methods of assessment, along with a growing interest in indigenous approaches to child-rearing, early learning and personal relations. Efforts towards Universal Primary Education drew further attention to those children who traditionally had slipped through the net of school provisions.

Outside the region itself, there has been little awareness of the extent of these developments. Few summaries or overviews have been available internationally - the present bibliography might assist anyone wishing to fill this gap. The image of 'disability service development' in the region has largely comprised the battle against polio and eye disease, some innovative work with blind people, the Jairos Jiri movement, and rather mixed views about so-called 'Community Based Rehabilitation'. The state of play for mentally retarded people and their families has seldom achieved much publicity. Colleagues in the disability field to whom earlier drafts of this bibliography circulated were uniformly surprised at the extent of material listed from most of the countries. Though still far from a comprehensive listing, this material, and the research studies and careful thought it represents, should serve to underpin efforts to plan better services and to formulate realistic ongoing research goals.

Ideally the bibliography would include abstracts or annotation, and more information about access to material... yet to achieve this as a spare time activity during occasional trips to the region could take the compiler several years, with uncertain outcome. It was therefore decided that the present contents should be given wider circulation now, with the hope of stimulating people in the individual countries to undertake further efforts. Anyone interested in this field and region, whether as researcher, educational planner or development worker, should get a flying start in their search for formally recorded knowledge; also in awareness of the *range* of relevant material, and the *type* of documents produced by governments, UN agencies, NGOs, universities etc. For people resident outside the region, the evidence of available material may assist in acquiring travel funding so that their studies may benefit from a better acquaintance with existing work. It may also introduce to a wider audience the many writers in the region who are concerned with disability issues.

1.2 Accessibility of Materials Listed in the Bibliography

No central collection exists of disability-related materials, particularly of a non-medical nature, in sub-Saharan Africa; yet it should be possible for the determined searcher to gain access to a substantial amount of the listed material. Items fall approximately within certain categories, which can mostly be deduced from the bibliography entries:

a. Published in national or international journal..........	212	(23%)
b. Formally published by university, national or international organisation, (and/or known to be available in European/American libraries):...........................	299	(32%)
c. Goverment documents, and reports to UN bodies..........	133	(14%)
d. Unpublished European/American theses available on microfiche or by Inter-Library Loan.....................	15	(2%)
e. Unpublished theses or papers, probably accessible only by visiting the university or office of the organisation responsible for the material...........	168	(18%)
f. Other (e.g. conference papers where no published proceedings exist; short-lived local journals etc)......	105	(11%)

Accessibility will therefore depend on the researcher's location; and to some extent on the resources available to pay for mailed photocopies or fiches, and the willingness of organisations to provide them. In compiling the bibliography, university and teacher education college libraries in the capital cities of the relevant African countries were the obvious sources for unpublished theses and some formally published studies. Often there is also as much or more relevant material in departmental offices and professorial rooms, e.g. in departments of psychology and special education, as there is in the formal libraries. UNICEF offices have small electronically catalogued libraries, which contain some useful child-related disability material, e.g. government documents, research studies and reports to UN agencies. (UNICEF libraries are maintained for staff use and are not 'open to the general public'; but a bona fide researcher wishing to consult disability documents is unlikely to meet with many obstacles). Some prior correspondence, identity document, and letter of recommendation are of course advisable. The offices of national disability organisations are among the more likely sources of unpublished conference papers and other fugitive literature. Some documents may be purchased from government publication offices, or by visiting the government department that generated an unpublished document. An increasing number of authors at African universities may be contacted by email, and may wish to facilitate access to their own or their colleagues' work. Future searches on CD-Rom and online bibliographies and catalogues, using the names of authors already listed here, are likely to reveal further work that is now in the pipeline.

2.0 HISTORICAL BRIEF

No comprehensive history has yet appeared of social responses or disability service development in Africa, but the extensive references scattered by Iliffe (1987) across his history of 'The African Poor' show the possibilities. Portuguese explorers opened the first small 'hospital' in 1507 in the region that is now Mozambique (ibid., 95), which must have served some people with disabilities during two centuries of existence. Scattered notes exist on a few disabled individuals from the 1590s (Dos Santos, 1609). The first specific disability service was probably the leprosy colony near Cape Town some time before 1817 (Iliffe, 102). A leprosy settlement in Northern Rhodesia opened in 1893 (ibid, 219). There have been several centuries of potential interactions between African and European notions of welfare provision and the development of institutions.

(a) *African indigenous practices.*

The history of indigenous disability practices has attracted little research. Kisanji (1995) has developed studies of disability-related proverbs, presumably reflecting accumulated folk wisdom. Burck (1989, 60-67) cites observations of indigenous practices with disabled Africans since c. 1900, across a wide range from infanticide through to tolerance and provision of legal protection. An official study (Blindness, 1948, 7-8) endorsed positive views of traditional family and clan care. By contrast, Anderson (1967, 38-9) dismissed as "quite untrue" the view that "the handicapped child is cared for and accepted in village life" in East Africa - she attributed some of the neglect to insuperable problems faced by families (cf. Iliffe, 1987, 212). Tolerance and care towards disabled people could diminish sharply in times of famine. Latterly, more systematic anthropological studies of African disability have begun (see references in Ingstad & Whyte, 1995). Despite the apparatus of modern scholarship, such reports require critical scrutiny - trained observers still record data reinforcing their own beliefs or political stance.

A response was noted nearly fifty years ago, in terms neither of government nor NGOs but of the urban African 'almsgiving public':

> "The intermediate stage between family responsibility and the assumption by the State of responsibility for the welfare of the blind has, in the course of centuries, been reached in many parts of Colonial Africa. Its characteristic is the emergence of a class of blind beggar in the large towns, in centres of de-tribalisation and in areas where Christianity or Mohammedanism have created an almsgiving public by extolling the virtues of charity." (Blindness, 1948, 8)

Blind people organised in begging guilds were noted in Muslim regions of W. Africa and the Eastern coast, and the report described the Muslim differentiation between 'religious' and 'secular' beggars. Yet while appreciating the 'almsgiving public' as a resource, the official reporters hoped for the day when "the greater advantage of contributing to organised charities" would be perceived (ibid., 9).

Indigenous practices have also begun to be studied in the context of efforts to develop community based rehabilitation (CBR) services, intended to be built on rather idealised notions of traditional communal care. Burck (1989), for example, explored a variety of disabled Zimbabweans' actual situations, finding that some needed no help, some were beyond the help that CBR could offer, while others in between might realistically be targeted. Jackson & Mupedziswa (1988), studying people in a CBR scheme, noted a wide capacity for simultaneous multiple explanations, involving African traditional, African and Western religious, and modern scientific, beliefs about causes of disability. Kasonde-Ng'andu (1988) and Katwishi (1995) have studied the home situation and daily lives of Zambian children with special educational needs, again revealing a wide range of attitudes and dispositions on the part of their families. Robert Serpell and colleagues have produced culturally sensitive studies in Zambia over nearly 30 years, on cognitive development, learning difficulties, and aspects of CBR (see e.g. Serpell, Mariga & Harvey, 1993; Serpell, Nabuzoka & Lesi, 1989). Such studies are 'fundamental research' for developing more appropriate services.

(b) *Missions, doctors, census, law (1860s - 1950s)*

The earliest types of formal service by missionaries were with people suffering from leprosy, blindness or deafness. Some of the pre-institutional work has disappeared from the record - e.g. Moon's embossed script was used by Hoffman, an American working with a few blind people in Liberia, from 1863 until his premature death (Moon, 1877, 58-64), in the same year as "Dominican sisters pioneered schooling for the deaf and dumb" in Cape Town (Iliffe, p.102). Both preceded an Institute for Deaf and Blind opened at Worcester, S.Africa in 1881 (Wagg & Thomas, 1932, 59), which took up the Braille script, and a society for the 'feeble-minded' at Cape Town in 1908 (Dunstan, 1921). Mrs Hofmeyer taught blind people in Northern Rhodesia from 1905 onward - and Lazaro Banda, a blind man, continued the classes on her death in 1910, until the redoubtable Ellen Botes took up the task (Snelson, 1974, 72, 79-80). Blind, deaf and epileptic people were enumerated in 1930s colonial censuses, gaining a more 'official' existence (see e.g. Union of South Africa, 1937), to complement an early report on 'mental subnormality' in schools (Cape, 1932, 68-70). Some legal provisions have existed from an early date, for the protection or exclusion of disabled persons; while medical papers covering disability topics have appeared for at least 150 years. An official report Blindness in British Africa (1948) was perhaps the first extended study of the region to be published. One of its recommendations was that special classes for blind pupils be attached to mainstream primary schools, with some integrated activities (pp. 47-8).

An international meeting on rehabilitation in Africa (Disability, 1963, 394-407, listed under Levitt) reviewed efforts to date, with an emphasis on simple, low-cost prosthetics and orthotics, quickly made, easily repairable by local craftsmen. The need was recognised not only to get polio-crippled people walking, but for them to be integrated into normal patterns of agricultural employment (ibid., 403-5). Levitt (ibid., 405-6), working with cerebral palsied children, noted the need to "search for what is African and synthesise this with the contributions of developed countries." African parents began to appear as partners, learning "how to handle their children in the home as well as our treating the children at the clinic" (ibid., 406). The same meeting heard of Mr. Jairos Jiri's work, "probably the first rehabilitation effort made by an African on his own initiative" (Disability, 1963, 406-7). During the 1950s, schemes to train blind East Africans to earn their living independently as cultivators achieved notable success, reported by a blind European farmer and advisor (Mackenzie, 1960). A key factor was the constant travel of the resettlement team, headed by a blind African, visiting and encouraging the ex-trainees in their villages (Anderson, 81)

(c) *Schools and non-institutional development (1960s - 1990s)*
From the 1960s, when many countries gained independence, more extensive disability literature exists. Wilson (1963), after an official tour of work for blind people across Africa, made recommendations emphasizing independence and training for agricultural self-support, anticipating by 20 years some of the features of Community-Based Rehabilitation. Successful homecraft training for physically disabled women was also noted by the MacGregor Committee (Zambia, 1967), during a detailed study of education for disabled Zambians. In 1967, Anderson produced a similar study for Tanzania, Kenya and Uganda, while Eedle's review (1972) of Commonwealth special education included data from Uganda, Kenya, Tanzania, Zambia and Malawi. These three substantial reports described a growing number of urban special classes or 'integration units' in mainstream schools, as well as special schools and sheltered workshops, and a slow development of skills training for teachers. They also recognised that some children with mild disabilities were casually integrated without any attention being paid to them.

Anderson (p. 124) and Eedle (pp. 162-3) emphasize the role played by religious missions in developing services from the 1940s onward, while Iliffe (p. 199) notes their "entrenched position" from much earlier. Eastern and Southern African governments approved and partly supported their work, but until the late 1960s were unwilling to take the initiative or undertake more than token expenditure. The MacGregor Committee (Zambia, 1967, 4) considered the suggestion of nationalising mission-run disability work, but found it wiser that government should "rather imitate than replace" the level of "industry, dedication and, on the best stations, a sheer professional skill." However, the drawbacks of residential work with disabled children, often far removed from their families, have become clearer in recent decades. In 1976, Levitt again underlined the importance of involving families in home rehabilitation, decentralising skills, aiming for one person in each village who should be "trained to advise and instruct and publicize how to help the handicapped" (p. 48). Cecile Cusson has described the practice of attentive listening to the beliefs of families with disabled children from the interior of

Cameroon, then involving them in making assistive devices from local and imported materials. By then, more African governments had begun to budget for development of urban services, but the rural populations were still practically untouched. The situation has changed little in 1998, even though some of the pioneers' ideas were adopted in the WHO's CBR scheme.

This is only the briefest sketch of slowly developing knowledge and practice. Much of the historical data is unknown to Africans working in the disability field now. There is no central collection of relevant documents. Library services and inter-country communications are weak, and historical studies have tended to concentrate on earlier African cultures, colonial economic exploitation, and liberation struggles. Aid agencies interested in disability in Africa are usually unaware of earlier history, and may assume that 'nothing was done for disabled people' before a phase of 'institution-building' in the 1960s, which they now wish to replace with CBR schemes and 'Inclusive' measures. To see current efforts against two centuries of previous development may bring more realistic perspectives. The variety and complexity of disability-related NGOs, and the vicissitudes of their relationships with government, also have a lengthy history. This sketch can hardly elucidate the "baffling fragmentation and complexity" of welfare systems (Iliffe, 193); but may at least challenge a few of the more simplistic notions.

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** NO POLITICAL OPINION OR VIEWPOINT IS INTENDED OR IMPLIED **
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MAIN ABBREVIATIONS

Afr.	Africa, African
AJSNE	Africa J. Special Needs Education
App.	Appendix, appendices
ARJ	African Rehabilitation Journal
Assoc.	Association (of)
Bull.	Bulletin (of)
CAJM	Central African Journal of Medicine
CDC	Curriculum Development Centre
CftH	Council for the Handicapped
Ch.	Chapter
Cncl	Council
Coll.	College
Comm.	Committee
CTH	College for Teachers of the Handicapped
Cwlth	Commonwealth
Dept	Department (of)
DeS	Dar es Salaam
Dev.	Development, developmental
Disab.	Disability, disabilities
diss.	dissertation
EAMJ	East African Medical Journal
Econ.	Economic(s)
Educ.	Education
Educl	Educational
Fndn	Foundation
Gab.	Gabarone
Govt	Government (of)
GoB	Govt of Botswana
GoM	Govt of Malaŵi
GoN	Govt of Namibia
GoZ	Govt of the Republic of Zambia
GURT	Govt of United Republic of Tanzania
Handic.	Handicapped
HDRU	Human Development Research Unit
Hlth	Health
Hrr	Harare
IAS	Institute for African Studies (now Institute for Economic & Social Studies, UNZA)
IJSE	International J. Special Education
ILO	International Labour Organisation
Incl.	Includes, including
Instt.	Institute (of)
Intl	International
IJRR	International J. Rehabilitation Research
J.	Journal, Journal of
Ksa	Kinshasa
Lab.	Labour
LRR	Lands, Resettlement & Rehabilitation
Lsk	Lusaka
MMJ	Malawi Medical Journal
Med.	Medical, Medicine
Min.	Ministry, Ministry of/for
N.	Northern
n.d.	no date given
n.s.	new series
NASCOH	Natl Assoc. of Societies for Care of the Handicapped.
Natl	National
Prog.	Programme
Psychl.	Psychology
p., pp.	page, pages
q.v.	see elsewhere in this Bibliog.
RC(S)	Red Cross (Society)
Rehab.	Rehabilitation
Res.	Research
RLJ	Rhodes-Livingstone Journal
SEBESA	Special Education Bulletin for Eastern and Southern Africa
Serv.	Services
SIDA	Swedish International Development Agency
Soc.	Social
Soc.Sci.M.	Social Science & Medicine
Socy	Society
Spec. Ed.	Special Education
T&GM	Tropical & Geographical Medicine
Trng	Training
UDSM	University of Dar es Salaam
UNBO	University of Botswana
UNISE	Uganda National Institute of Special Education
UNMA	University of Malaŵi
Univ.	University (of)
Unpub.	Unpublished
UNZA	University of Zambia
UNZI	University of Zimbabwe
UP	University Press
Wdk	Windhoek
Welf.	Welfare
WHO	World Health Organisation
WTC	Without the Camp. J. Mission to Lepers
#	(not known)
§	(indicates a bibliography)
[ ]	(indicates uncertain status)

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(+ indicates further authors)

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