

Approaches to Rehabilitation of People with Disabilities: A Review

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ABSTRACT

Traditional approaches to rehabilitation of disabled people have emphasised segregated institutional care, and have largely neglected the need both to integrate people with disabilities into their wider community, and for community attitudes themselves to be rehabilitated or changed to facilitate this integration. This paper reviews institutional and community based strategies for rehabilitation, arguing the case for a community orientation but recognising some of the difficulties of implementing this effectively in developing countries.

Introduction

Rehabilitation of people with disabilities may be summarised as meaning to integrate or re-integrate physically, sensorially, mentally and/or psychologically impaired people into as full and as normal life roles as is possible. It implies an understanding of the life role expectations of the particular individuals had they been fully able-bodied. Rehabilitation in its fullest sense necessitates, on the one hand, maximising the physical and mental fitness of individuals and their capacity to work and to enjoy life, through interventions ranging from the medical and paramedical to counselling and vocational training and job placement; and, on the other hand, promoting the accessibility and openness of the physical and social environment to people with impairments. Oliver (1983) particularly stresses the importance of the latter focus, and discusses the extent to which it has been neglected in the historical development of rehabilitation in Britain and elsewhere. Yet it is central to the concept of integration, the expressed goal of rehabilitation.

The focus of rehabilitation on the individual rather than on the wider community and the physical environment has major implications. It helps to

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keep the problems hidden from the public eye, so that policy makers, planners, politicians and others are less likely to take the needs of people with disabilities into account. Because the problem is seen to lie within the individual and in her/his limitations, the solution must also logically be sought at this level, that is, in individual adjustment, rather than in environmental accommodation or modification. We have, in effect the syndrome of blaming the victim.

In many countries it is the victims of war, and of these particularly ex-combatants, who have the highest benefits and best access to rehabilitation; ironically, wars can be seen historically to have been one of the more effective forces in improving rehabilitation policy and services in many countries, first for ex-combatants and war victims, and then for wider sections of the population. But cause of disablement, rather than simply severity of impairment, remains important with regard to access to benefits and services.

A further obvious differential is the major factor of economic privilege. The rich who can pay or have insurance cover, tend to be well provided for, regardless of the cause, nature or severity of impairment, or of sex or societal contribution of the person concerned; the poor, while at measurably greater risk of disablement in the first place, will tend to be comparatively neglected except perhaps in the most highly developed universalistic welfare programmes.

Apart from the risk of highly unequal access to services and benefits, an individual focus on rehabilitation also contributes to an emphasis on institutional as opposed to community based rehabilitation programmes. This emphasis forms the main focus of this paper.

Traditional institutional rehabilitation

Institutional services, including medical and vocational rehabilitation centres, residential homes, special schools with therapy and nursing care, sheltered workshops and day centres, to name the most salient, have formed the backbone of rehabilitation services in developed countries, supported to differing degrees by financial and material benefits, counselling and other support services in the community. However, for disabled people living at home, and for their families and friends living or working with them, access to support services may vary enormously. Many people, particularly those severely mentally handicapped, remain in long term residential care despite mounting evidence of the inadequacies of many such institutions (Thomas, 1982).

In developing countries, rehabilitation has typically developed under colonial regimes to serve primarily the colonial elite, and has consisted mainly of modern urban institutions modelled on those of the West. The rest of the population has generally had little, if any, access to rehabilitation services of

any kind, although missionaries and other concerned individuals, such as the well known Mr Jairos Jiri in Zimbabwe, have managed to provide some services on a piecemeal and often impoverished basis. Rehabilitation services developed in this way are often unable to do more than provide a very basic care service, with little effective psychological, social, educational or vocational rehabilitation, as they lack experienced and skilled personnel, facilities, equipment and money to do so, and they can in any case reach only a small proportion of the population in need. Governments face the same problems of scarce resources, and, although they racially desegregate services and provide some economic support to rehabilitation institutions in the private sector, they cannot afford to build or finance rehabilitation institutions for all the disabled in need of rehabilitation or long term care.

Economic constraints aside, the very concept of institutions caring solely for disabled people contradicts the aim of integration. The very nature of the service is one of segregation, and the real work of integration can only seriously begin at the point where rehabilitation, in this context, ends. It is not the acute medical phase of rehabilitation (which may entail hospitalisation), but long term therapy, accommodation, education, vocational training and employment that are the most critical for the successful integration of people with disabilities. In addition opportunities for social contacts and relationships, recreation and self-fulfilment are needed. If we are concerned about quality and not merely the quantity of life, then it is here ultimately that rehabilitation really succeeds or fails, and it is here that the questions of long-term institutional care or a community or home-based rehabilitation strategy become crucial.

In developed countries long term institutional care is now widely seen in a very negative light, and families who 'put away' their mentally handicapped child, for example, may feel very guilty about doing so. Studies such as that by Miller and Gwynne (1974), Shearer (1981), and many others, highlight the risks of institutionalisation, including the creation of dependency, boredom and under-achievement, low self-esteem, stigmatisation and loneliness. These problems may be lessened by a 'humanising' of institutions, making them more like a home in terms of scale, routine and regulation, and also by increasing their openness to families and the community at large — by making them less than 'total institutions' in Goffman's sense (Goffman, 1961). But such changes, particularly when they involve a genuine shift of power to disabled residents themselves, tend to be resisted by both immediate care staff, and the administrative hierarchy, despite the evident success of some such developments in both hospitals and long term residential homes for disabled people (Thomas, 1982).

In many developing countries it is commonly believed that institutions can provide better services than can home care, because they have specialist staff, specialised facilities and equipment, special education or vocational training

on the premises and so on, facilities that are scarce or non-existent in the rural areas, and in most urban areas too. Institutional care may be sought also because it removes the burden of responsibility and the stigma of disability from the family. Particularly among less educated, poor, rural families, disability can be an intolerable economic burden to the family, and the cause of severe social and family problems because of the widespread stigma attached to disability and suspicion as to its causes (WHO, 1984). For example, the birth of a disabled child in Zimbabwe may be interpreted as being due to witchcraft, to offending ancestral spirits, for example through adultery by the mother, or to some other curse.

Underlying conditions in developing countries may be seen, ironically, both to promote the appeal and to reduce the appropriateness of centralised, urban institutional rehabilitation. Most people live in rural areas, and the very lack of transport, adequate medical and nursing care, schools, time, skills, money and material resources needed for the rehabilitation of the disabled make such institutional care seem a valid solution. It resolves all these problems at once, at least temporarily. The scarcity of institutions and competition for places in the few there are may further enhance their appeal. However, at the other end of the 'rehabilitation' process, those discharged from such institutions often experience stigmatisation and rejection because of their stay there. One example of this in Zimbabwe is the dismissive reference to people who have stayed in institutions of the main organisation for mentally handicapped as 'Sascams', after the organisation's previous name. This name has become widely associated with mental handicap, and with uselessness.

In the long run, centralised institutional care is likely to fail as a rehabilitation strategy for independence and integration of the disabled into their society precisely because it separates the disabled from the family, community and normal home environment. By removing responsibility for the disabled person from the family and the community, the development of understanding of the disabled person's needs and of her/his capacity to contribute to society is inhibited. It does nothing to reduce cultural fears and beliefs about disability, nor to create a climate of acceptance for the disabled person's return — quite the contrary, the family learns to live without the disabled persons, and to take over any roles or tasks they might have performed. Removal from the family also reduces the chances of the disabled people themselves learning to cope with their normal, usually rural, environment, both in a cultural and a practical sense. Activities of daily living and those related to productive work are very different in a poor rural setting compared with a modern, urban institution. In short, long term institutional care is probably the worst possible strategy for promoting integration of the disabled into their communities. It is also, of course, prohibitively expensive as a rehabilitation strategy aiming to reach all the disabled in a developing country. For this reason also it is inappropriate. Existing institutions generally

suffer from a chronic shortage of funds, skilled personnel and equipment, and are likely to have a poor staff-rehabilitatee ratio and long waiting lists for admission. These problems are exacerbated by the difficulty of discharging people when follow up services are poor. The urban siting of most institutions also skews resources away from rural areas, thus contributing to their comparative underdevelopment.

Community based rehabilitation

The alternative strategy for rehabilitation places the primary focus on community care or family care, with institutions playing a support role rather than being the main rehabilitation resource. Community based rehabilitation has been promoted for several years by the WHO, UNICEF, the ILO and other international organisations, and it is gaining increasing acceptance by governments and NGOs in many developing countries. The WHO (1980) suggest that specialist rehabilitation institutions be used for complex medical and paramedical services for acute and special needs; for research; training; workshops for more complicated aids and appliances; coordination and planning; and bases for mobile units such as eye units, amongst other possible functions. They should be the last possible stage in a referral chain starting with families and village health workers (or equivalent), and the first stage for referral after acute, severe injury. The aim of Rehabilitation Institutions should be short term intensive care rather than long term, except in some extreme cases, and their specialist services should genuinely be available to those most in need of them.

The WHO concentrates mainly on the medical and paramedical aspects of rehabilitation, but a move away from institutional segregation is both possible and desirable for education and vocational rehabilitation as well. Disabled children can attend normal schools in the community, if they can get access to them — this means both transport to reach the school and accessible buildings. For those with special learning needs, the sensorially or mentally impaired, especially classes may be needed in some subjects, but integration in others may be feasible. Teachers in ordinary schools can be given extra training in block or day release to cope with the needs of disabled children; specially trained teachers can visit normal schools; simple aids can be developed to overcome a variety of problems. A problem-solving strategy can be adopted, with the central focus of maximising the integration of children with different disabilities into as normal an educational environment as possible, and with the aim of maximising their abilities and opportunity for normal development. Then, as Miles (1985a) describes in Pakistan, a great deal may be achieved for these children at far less cost, both economic and psychosocial, than special schools would entail.

This integrated approach may begin at pre-school, as, for example, the

Down's Children's Association of Zimbabwe is currently attempting with apparent success. It may also be extended into different forms of vocational training and work. All too often sheltered employment for disabled people fails to operate as a training ground for open employment, and becomes instead a dumping ground for many people with disabilities that need not preclude them from productive work. It is not, in fact, their physical impairment that forms the crucial barrier to open employment, but the physical and social environment — inaccessible transport and buildings; non-adapted tools and a lack of appropriate aids and appliances; and employers' prejudices and fears. In addition, underlying these immediate difficulties, the disabled person's own long term development may well have been unnecessarily stunted with respect to general education and acquirement of skills, and to self-confidence and social interaction. Self-employment and subsistence activities may likewise be problematic for reasons extraneous to the actual impairment itself. Integrated education, normal home life, integrated vocational training and strictly temporary sheltered employment may do far more to achieve the long term economic independence and social integration of disabled people than supportive but dependency creating sheltered workshops, which should be maintained exclusively for long term occupation for seriously impaired individuals, and as a very temporary measure for less seriously impaired people for specific purposes — assessment, vocational guidance, and so on.

Most importantly, vocational training must relate to the individual's needs outside the training setting, and to the opportunities that will be available. Training for its own sake, divorced from opportunities for practical application, serves no valid function. Yet in developing countries such as Zimbabwe this typifies much current practice (Dube 1986), leading to bottlenecks in sheltered workshops as rehabilitees cannot move on into open employment or to adequate subsistence activities. Removing vocational rehabilitation from a segregated setting to integrated training centres or to training in the community, focusing on the most useful skills for the disabled person, would be an extension of a practical problem-solving approach with direct, meaningful results for the disabled person. All too often the disabled people in a specialised vocational training centre have the choice of a few selected trades which they are considered to be capable of learning, and little attention is paid to the likelihood of the successful use of that trade later on. Placement officers may be employed by the centre, but the primary focus is the training programme itself, rather than job placement at the end of it. The disabled person is often left, at the end of the programme, to face unemployment, sheltered employment, or a tough struggle to survive utilising an inappropriate skill.

Community based rehabilitation can potentially encompass the whole range of rehabilitation services with greater success than the expensive, segregationist strategy of institutional care. The main advantages of such an

approach may be summarised as follows:

- it is much cheaper than institutional care, and therefore has the potential to reach all disabled people, not just a select few;
- it avoids dislocating people from their communities, and the risks of institutionalisation, psychological scarring, and the creation of dependence;
- it trains people to cope directly with the environment in which they will live, using resources that are largely available locally;
- it improves detection and referral, greatly reduces problems of transport and access, allows easy supervision and follow up, and continued support for the whole family;
- it can ensure that disabled people learn useful skills that are directly applicable in their environment, thus promoting their self-sufficiency and also their capacity to contribute directly to their own society;
- it promotes community and rural development by creating jobs: rehabilitation workers can be drawn from the local community, many simple aids and appliances can be produced locally using local materials and skills as far as possible, and disabled people themselves may be trained to work for the rehabilitation of others;
- by keeping disabled people in the community it enhances family and community understanding and acceptance of disabled people, and an understanding of the causes and treatment of impairments. This will lead to better prevention of impairments, earlier detection and treatment of potentially disabling conditions, and lessened ostracism and social handicapping of impaired individuals;
- it leaves rehabilitation institutions free to concentrate on acute and severe disability or special needs requiring highly technical intervention, and on research, development, training and other functions that make rational use of specialised and scarce resources.

Thus a well developed community based rehabilitation strategy can be seen to have major benefits for people with disabilities, for their families and for the community itself. For governments with a commitment to the welfare and development of their people this approach provides the possibility of effective rehabilitation for all without the crippling expenditure of institutional care. Indeed, as reported by Rehabilitation International and a United Nations Expert Group (1981), well developed community based rehabilitation, in combination with well developed primary health care and disability prevention, is far more cost-effective than the alternative of having most disabled people not rehabilitated. This is a crucially important consideration for hard-pressed governments with many other demands on their budgets.

Of as great importance, however, is the long term conscientising effect of community based rehabilitation strategies. They hold out the possibility of challenging at source the widespread belief in the hopelessness of disablement.

The immediate family and perhaps neighbours can not only see, but also be instrumental in planning and promoting the disabled person's progress and development, thus demystifying disablement and also the rehabilitation process. If children at school learn to accept the presence of disabled counterparts, they will grow up to think of people with disabilities as part of mainstream life, rather than pariahs. Teachers, employers and other members of the wider community will also gradually learn from example and experience that disabled people do not need to be set aside, but can in fact contribute as much as anyone else to their communities, given the right support and opportunity. Indeed, employers of disabled people tend to report a greater work commitment by disabled people than the able-bodied, perhaps partly because of their great difficulty in securing employment in the first place (Lonsdale, 1984).

The very experience of disablement, and of the need to struggle to achieve the independence that most others can take for granted, may make a disabled person special in a very positive sense. Community based rehabilitation of the disabled and their integration into community life will help to alert people in general to this, and perhaps even more importantly, to the recognition that people with disabilities are normal people with a particular area of need or of functional loss. Of course, able-bodied people are also susceptible to illness and to temporary or permanent disablement themselves, and if they live to old age are highly likely to experience progressive disability. These two groups, able-bodied and disabled, actually reflect a continuum rather than discrete categories, and a person's position on the continuum is liable to change over time, even from one day to the next. When this is recognised in communities, real integration becomes much more of a possibility.

Strategies for Community Based Rehabilitation

Community Based Rehabilitation itself can take a variety of forms, but with the essential common feature that the orientation is towards the disabled persons in their community, or directed at the relationship between the two, and not at the disabled person in isolation. Work normally takes place in the person's home, or in a local setting such as a clinic, school, local meeting place or club, or perhaps in a local rehabilitation centre or village, as successfully developed in Mexico, the Project Projimo, and now being attempted at Bindura in Zimbabwe. The emphasis is on rehabilitating people in the type of environment in which they live and with which they have to cope, and to train them to do the tasks and daily living activities and work that are useful both to the disabled person and to the family — and ultimately to the community as well. In the rehabilitation village in Mexico, as reported by Sanders (1985), the mothers or other caretakers stay for a few days, weeks or even months with their disabled children, and share the learning experiences with each other.

Simple aids and appliances and ways to achieve basic goals are developed during the stay, and there is continuing support after they return home.

This type of approach has also been developed extensively and successfully in Peshawar, Pakistan, where home based rehabilitation on the WHO model outlined below was considered inappropriate. Miles (1985b) calls this work in Peshawar 'community oriented rehabilitation', and advocates the need for flexibility of approach, using home rehabilitation, local day rehabilitation centres, special and normal schools, local rehabilitation centres with residential facilities, and so on, as appropriate. The cornerstone of his argument is that community participation is vital at all levels of rehabilitation, from the initial planning of the services required to their financing and establishment, day to day running, and future functions. In the Peshawar schemes rehabilitation was developed 'organically' with concerned people in the communities saying what their needs were and how they thought they could be met, and then being supported gradually to develop the services they requested, with some external funding and expertise, but only to a limited extent. Miles reports that much of the momentum for development of services came from the community members themselves, once people were given the possibility of doing something and they could see the achievements of other neighbouring programmes.

The model of home based care developed by WHO and UNICEF over the last few years involves training a family member or neighbour to work in the home with the disabled person, using carefully developed training manuals (WHO, 1980, 1984). There should be regular back up from trained supervisors at community worker level, village health workers or community rehabilitation workers, and a chain of referral and supervision for complex cases. Red Cross is developing this strategy in two rural areas of Zimbabwe, with their own modifications. Red Cross volunteers are the basic level motivators and trainers, backed by the Red Cross team, and by rehabilitation workers at different levels trained and employed by the Government. Zimcare, the government sponsored organisation for mentally handicapped people in Zimbabwe, also runs a highly successful home-based rehabilitation scheme using simplified training manuals developed locally.

The WHO approach has been criticised by Miles (1985) for attempting to be too universal, for taking a top-town prescriptive approach, and for lacking sensitivity and flexibility in local application, amongst other factors. Nevertheless, the original manuals have been revised (WHO, 1984), and are being further reviewed, and they may be very useful in certain circumstances — for particular families, as training manuals for trainers at different levels, or to stimulate local or national developments more suited to local circumstances.

In most community based rehabilitation schemes, one essential component is referral to more specialised treatment, assessment, training, medical or

other intervention, and provision of more complex aids and appliances if required, for example hearing aids. Community based rehabilitation schemes may be limited in their effectiveness if referral chains break down and people needing urgent or intensive treatment are overlooked. They will work most effectively where there is well developed primary health care, and a good general referral system for preventive, curative and rehabilitative treatment.

Nonetheless, as Werner (1983) emphasises, much can be achieved at grassroots level even if specialist services are unavailable or limited. For example, children with poor hearing or eyesight can be screened very simply using games involving other children, and those affected can be helped at school by being placed near the teacher and the blackboard, and by clear enunciation, even if hearing aids or glasses are not available. These children might otherwise be considered unintelligent or lazy because of their slow learning, while it is in fact due to sensory impairment, and they might well become psychologically scarred and backward over time.

Thus an imaginative use of capacities and skills in the community itself can achieve results. This is a point strongly emphasised by Werner (1983) — the need to value, respect and develop the potential already existing in the community, and to mobilise the community for its own development, rather than slipping into the common assumption that trained professionals have the monopoly of skills, knowledge and insight, and 'know what's best' for the people. Miles (1985) exemplifies this understanding and approach very convincingly.

In this context, both the identity of the medium and the form of the message itself require imagination. A recent development in some countries has been the involvement of children as assessors, monitors and rehabilitators, with positive results for common problems such as childhood malnutrition, diarrhoea and disablement (Guthrie, 1983; Werner, 1983). Guthrie is Director of the Child-to-Child Programme, one of the achievements of the 1979 International Year of the Child, which is reported to be promoting this approach in over sixty countries, and with, on early evaluation, considerable success. The Programme took as its starting point the observation that many children are looked after primarily by older siblings for much of the time. Children also learn easily, are often grouped together, as at school, and may be a highly valuable health resource if exposed to relevant concepts of health promotion, prevention of disease and disablement, care and rehabilitation. The example cited above (Werner, 1983) illustrates one possible use of children for simple screening for sensory impairment.

Disabled people may also be highly successful as rehabilitation workers, precisely because of their personal experience of disablement and its problems. In the Projimo village rehabilitation scheme cited earlier (Werner, 1983), many of the rehabilitation workers are themselves disabled, having been selected not on any remedial basis, but because they were the best applicants for the job.

Women also, through women's clubs and other organisations, may be a potent force for health promotion and rehabilitation work, particularly as their home-centered roles make them pivotal to the well-being of the whole family. Development workers at all levels have traditionally focused far more attention on men than on women, but the need for a refocus is beginning to be more clearly understood. Nevertheless, much more development in this direction is needed.

Apart from the question of who in the community should be the primary targets for training as health and rehabilitation educators and trainers, there is the question of how messages can most successfully be conveyed. Freire's work on conscientisation (Freire, 1972; Hope and Timmel, 1985) focuses on the need for active community involvement in the identification of problems, and in the learning process, through active questioning and discovery. This may include approaches such as drama to illustrate problems and possible solutions; story telling; songs; pictures; games and so on — whatever is culturally acceptable, enjoyable, interesting and challenging. The vital point is that it engages people, and that a dialogue is established in which all can contribute their ideas, experience, knowledge and skills, as a means of identifying and resolving problems.

One further aspect of the question of who initiates and promotes activities and programmes must also be considered. On one hand, people may relate best to a local person whom they respect, trust and can identify with, and who knows and identifies clearly with them — someone who is very much part of their community. On the other hand, there may be situations in which an outside expert can play a useful role in indicating the importance of something undervalued by the community. For example, Dr Laing, a community physician in Zimbabwe, has spent time personally supervising the building of ventilated pit latrines (Sanders, 1983), because, he argues, as a well-known doctor with high prestige in the community his presence lends status to the task of building such toilets, and will encourage the people to value them highly also.

Some difficulties in developing Community Based Rehabilitation

Underlying successful community based rehabilitation and primary health schemes must be a focus on community development in a much wider context, and development of the community by the community, with support but not domination from outside. Lip service is widely paid to the need for community participation, but the work of such *practitioners* as Freire, Werner, Miles and others, indicates how vital this concept really is. Nevertheless, major barriers lie in its way.

At the most general level, many governments lack a political commitment to equitable development in the first place, and those adopting ostensibly socialist policies can be seen historically to tend often towards centralism,

understanding of what is involved, and their control over the rehabilitation process. This will make it far more likely that the aid or appliance will be regularly and effectively used, and will be likely to build up a greater confidence in the family that they can do something directly to help their disabled members, or that they can help themselves. This is in itself potentially a very liberating and important consideration.

Conclusion

It would seem that some form of community based or community orientated rehabilitation is the only feasible strategy to attempt to meet both the immediate physical needs of disabled people, and the long term goal of community conscientisation about health care, prevention of impairments, rehabilitation of the disabled and their full acceptance into the community. Centralised institutional care fails to educate the community, and imposes further psychological stress and isolation on already stressed people, whilst rehabilitating them to cope with an environment different from their own. In the wider context, community based rehabilitation can be seen as part of the general aim of rural development, whereby resources of cash, materials, services, jobs, and, crucially, human potential are promoted in the rural areas. For people with disabilities it offers the possibility of real integration, and not the segregated rehabilitation of the institution. Different countries and districts need a strategy appropriate to their particular constraints and demands, and one that can be developed with flexibility to meet their particular needs in ways that are culturally acceptable and practically and economically feasible.

It is to be hoped that more developing countries will experiment with and expand community rehabilitation services, and incorporate this type of strategy as the cornerstone of national policies on rehabilitation. The potential benefits extend far beyond the immediate needs of disabled people, into the enrichment and development of the general community itself, and can be identified as incorporating both humanitarian and economic considerations.

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